‘Why I am the way I am’: A narrative analysis of the life stories of adults with a diagnosis of Asperger’s syndrome

by

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Volume I

Submitted for the degree of Doctor of Psychology (Clinical Psychology)

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January 2010

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Statement of Anonymity

Throughout this portfolio, all names and places have been replaced by pseudonyms and identifying information has been altered or omitted to preserve the confidentiality and anonymity of the service-users and research participants.
Acknowledgments

I would like to thank my family and friends for their patience and support during the demanding process of training. I would also like to thank my fellow trainees for sharing the highs and lows of this experience with me. I would also like to thank the course team and my placement supervisors and clinical tutor. In particular, I would like to thank Heather Liddiard and Vikky Petch for their guidance and encouragement. Finally, I would like to extend my appreciation to all of the service-users that I have worked with during training and have taught me most of all.
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Academic Dossier

This section contains two essays submitted over the three year course. These were related to psychological theories of and treatment of dysfunctional worry and professional issues. Three reflective accounts regarding problem based learning tasks carried out on the course are also included. Finally, summaries of two process accounts written about the case discussion groups from years one and two are presented. The full accounts are presented in Volume II of this portfolio.
Adult Mental Health Essay

How can we use psychological theory to explain 'worry'? How may we approach the treatment of dysfunctional worry? Discuss with reference to the evidence bases of the theory (ies) you present.

December 2006

Year I
Introduction
Worry is a feature of anxiety. It is an everyday phenomenon, experienced by most people. In this sense, it is ‘normal’ and does not require intervention. However, at times worry can become dysfunctional, requiring treatment. Excessive worry is the central characteristic of generalised anxiety disorder (GAD) as described in the Diagnostic and Statistical Manual for Mental Disorders, fourth edition (DSM-IV; American Psychiatric Association (APA), 2000). I was interested in this essay as a means of professional development. From both clinical and personal experience, I have noticed how widespread and debilitating worry can be across age, gender, culture, religion, educational level and psychiatric diagnosis. Indeed, Holaway et al. (2006) note that population based surveys have found equal prevalence of GAD across the life span, with lifetime prevalence rates of between 1.4 and 11.1%. However, they highlight that females appear to be more at risk with a ratio to males of approximately 2:1. I concluded that an increased understanding and awareness of this area would prove useful for my future clinical practice with a diverse range of clients.

In this essay, I attempt to explain how worry arises or is maintained using psychological theories deriving from psychodynamic and cognitive behavioural models. I concentrate on these models, as they appear to be most commonly applied in clinical practice (Leichsenring et al. 2006). I also discuss the treatment approaches for dysfunctional worry originating from these theories. Throughout, I refer to the evidence base related to these theories and their associated treatments. I draw attention to issues of contention related to the ‘evidence base’ and evidence-based practice (EBP). I also make links with current thinking within the National Health Service (NHS), considering implications for my practice. In order to provide a coherent examination of worry and dysfunctional worry, I start by considering these concepts and their definition.
What is worry? When is it dysfunctional?

Worry can be defined as verbal thought activity and sometimes imagery related to future negative events or themes that are disruptive and negative in tone (Borkovec et al. 1998). It is a common experience. In a study of worry in a non-clinical population, 38% of people reported worrying at least once per day, with average episodes lasting five to ten minutes (Tallis et al. 1994). Worry can be considered to serve an adaptive function in evolutionary terms (e.g. Nesse & Williams, 1997). It has also been found to have a role in problem solving and improved work performance by aiding planning and regulating behaviour (e.g. Perkins & Corr, 2005). Despite the prevalence and potential benefit of worry, it can be associated with impairment and dysfunction. Thompson et al. (2002) report a range of studies that demonstrate that worry leads to impaired performance and decision making on a range of tasks. The characteristics that make worry dysfunctional can be drawn from psychiatric literature.

Worry is a feature of many psychiatric diagnostic categories as outlined in DSM-IV. In particular, anxiety disorders (including social and specific phobia, obsessive compulsive disorder) and mood disorders (such as depression). As mentioned above, excessive worry is the main feature of GAD in DSM-IV. According to this diagnostic system, worry should also be unrealistic and uncontrollable, regarding multiple themes and causing significant distress or impairment. Associated features of GAD include restlessness, insomnia, fatigue, irritability, poor concentration, and muscle tension. In order to meet criteria for a diagnosis of GAD, excessive worry and three associated features need to be present for six months. Much research relating to the explanation and treatment of dysfunctional worry is associated with the literature on GAD. However, since the 1980s, worry has been viewed as a distinct phenomenon worthy of study in its own right (Borkovec et al. 1998) and interest in the subject has recently increased greatly. Whilst conducting a literature search for this essay, I noticed that there are a range of academic and self-help publications dedicated to the topic of worry (e.g. Davey & Tallis, 1994; Davey & Wells, 2006; Leahy, 2005). For the purposes of this essay, I conceptualise dysfunctional worry as excessive, negative cognitive activity regarding the future
According to the medical model, symptoms of anxiety can be treated using pharmacological interventions, such as benzodiazepines. Throughout my experience of working in the NHS, I have noticed that the most common approach to the treatment of anxiety is medication. Whilst medication can have a relatively instant impact on the overt symptoms of anxiety, they can have negative side effects. In particular, I have observed dependency on benzodiazepines frequently developing. I have formed the impression that due to this, both mental health professionals who prescribe medication and service users themselves are not always wholly comfortable with this approach. Indeed, some psychiatrists (e.g. Gelder et al. 2001) acknowledge that medication is best only used in cases where there is no response to psychological therapy or whilst the effects of psychological therapy are expected. This is reflected in the guidelines produced by the National Institute for Health and Clinical Excellence (NICE), which support the use of psychological treatments for GAD (NICE, 2004). I now describe these treatments and their theoretical underpinnings. As the earliest explanations of anxiety and worry, I begin by discussing theory and treatment from the psychodynamic perspective.

**Psychodynamic theory of anxiety & worry**

**Early psychodynamic theories**

I primarily wanted to consider psychodynamic theories of anxiety because I am relatively uninformed about this model. I viewed this as an opportunity to increase my knowledge in this area. Psychodynamic theories tend to focus on anxiety in general rather than worry specifically, so most of the discussion is related to the literature on anxiety.
There are a range of psychodynamic theories of anxiety that are based on the psychoanalytic methods and insight of analysts such as Freud and Klein. Such theorists highlight the importance of early experience and developmental factors in psychological difficulties. According to Freud’s (as cited in Trujillo, 2006) theory, anxiety (created by perceived danger) acts as a signal causing defences to be activated in order to avoid thinking about more difficult, conflicting or traumatic events or feelings. Anxiety is considered pathological when it ceases to become adaptive and becomes consciously noticeable or disruptive, which is consistent with the definition of dysfunction applied throughout this essay. According to Sullivan’s theory (as cited in Josephs, 1994), interpersonal relationships are crucial and anxiety is viewed as a means of communication of how people feel about the relationship with another. Sullivan suggests that children have primitive empathic responses that allow them to detect their parent’s feelings. For example, an insecure parent may convey anxiety to their child, who consequently experiences anxiety itself. Object relations theorists as Klein (as cited in Josephs, 1994) believed that anxiety demonstrates the fear of being unable to access the nurturing primary care giver or fear of being hurt by an antagonistic care giver. In addition, from a psychodynamic perspective, Malan (2001) notes that when individuals present to health care professionals they are given diagnoses such as ‘anxiety’. He argues that the real diagnosis should be unexpressed painful feeling. Malan (2001) talks about how ‘human beings try to avoid mental pain; how they try to control unacceptable behaviour or feelings; how sometimes what is unacceptable creeps in through the backdoor’ (pp. 5). It has been argued that psychodynamic theories should be viewed as complementary rather than conflicting, each reflecting the various aspects of the same phenomenon (Josephs, 1994).

**Psychodynamic treatment approaches to anxiety & worry**

**Traditional psychodynamic treatment**

The web-site of the mental health charity Mind states psychodynamic therapy’s ‘aim is to help you make sense of your inner world, to understand the usually unconscious
conflicts which can cause symptoms such as depression and anxiety. This is achieved by examining and linking difficulties from the past and childhood as well as the present. Traditionally, this therapy been lengthy, occurring several times a week for several years and the process of therapy is deemed to be of great importance. The therapeutic relationship is considered to be the principal mechanism of change. Specifically, the degree to which it is experienced in the same manner as past developmentally significant relationships is important. Shorter-term, more focused psychodynamic therapies were developed based on psychoanalytic insight and employing techniques derived from psychoanalysis (e.g. Malan, 1963). Trujillo (2006) claims that such approaches are applicable to the treatment of GAD. I concentrate on the approach developed by Malan (1963) as it is both well known and researched in comparison with traditional psychoanalysis.

Short-term psychodynamic treatment

Brief dynamic psychotherapy (BDP) developed by Malan (1963) aims to gain insight into unconscious conflict and then to express it. BDP lasts approximately 20 sessions and the specific date for termination of therapy is given at the start. Priority is given to thorough, systematic assessment at the beginning of therapy. This involves collection of historical and clinical data, the observation of levels of anxiety, the affect demonstrated and the use of defensive strategies towards the therapist. Therapy involves working with a carefully selected dynamic focus (unresolved interpersonal conflicts, and suppressed impulses and feelings), that is causing the client's difficulties. This is determined at the start of therapy. Therapists working within this framework employ psychoanalytic techniques organised around two conceptual triangles, the triangle or conflict and triangle of the person (Malan, 2001; see Figure 1 below). In the triangle of conflict, defences and anxieties block the expression of feelings. The triangle of the person reflects the work with conflicts in relation to the therapist and current and past people.
Selective attention and selective neglect are used throughout therapy to contain and structure what the client brings for exploration. Therapists help to access underlying impulses and feelings through clarification of defence in the triangle of conflict, by viewing the client’s story at a deeper level and providing insight. This is achieved through interpretation, which is the act of finding unconscious meaning in the material that the client brings to therapy (Leiper & Maltby, 2004). This helps the client to confront what they truly feel, learn that it is less painful than anticipated, to work through it and to use their feelings within relationships in a helpful manner. Transference is an important part of this process. It is when the client shifts emotions and fantasies related to others onto the therapist in order to reproduce past relationships in the therapeutic relationship (Leiper & Maltby, 2004). Malan (2001) suggests that the more links between the present, past and transference, the better the outcome. The aim of BDP is that effects are permanent and applicable to both current and future situations. BDP uses repeated follow-ups after the end of therapy to determine whether therapeutic changes have been sustained and if the client has improved by engaging in therapy. Individuals suitable for this approach should be motivated to change, responsive to interpretations and able to manage strong...
emotions that may be thrown up throughout the therapeutic process. I think that this approach may only applicable to a narrow group of people experiencing anxiety and worry. However, it has been praised because it allows exploration without preconceptions about the exact nature of the client’s difficulty (Clemens, 2003).

The Psychodynamic evidence base and evidence-based practice

It has been noted that in the first part of the last century, psychodynamic practice was dominated the domain of therapy (Bennett-Levy et al. 2004). However, in an influential article, Eysenck (1952) argued that there was little evidence for the psychodynamic therapies practised at the time. He claimed that in approximately 30% of neurotic disorders, clients would recover naturally without therapy. The evidence base for psychodynamic theory and practice has consisted predominantly of clients’ case histories (e.g. Malan, 1963). It can be argued that such evidence may be specific to the particular client presented and is not generalisable to the wider population. Such an approach is not always viewed as ‘scientific’ or ‘objective’ as other more systematic approaches. There is some debate regarding what constitutes legitimate evidence. With the advent of EBP, there has been increasing attention paid to practitioners looking to ‘good’ evidence to determine ‘best’ practice. Within the NHS, there is an expectation that therapy will be of high quality, evidence-based and client-centred (e.g. Department of Health, 1998; NHS Executive, 1996). Richardson (2000) highlights that there are assumptions about what constitutes acceptable evidence and differing values are assigned to different types of evidence. For example, randomised control trials (RCTs) are perceived to produce more convincing evidence than case studies. Charlton and Miles (1998) argue that this approach is problematic because certain methodological practices that place undue emphasis on the importance of information and statistics are elevated above all others. They claim that this can lead to neglect of other factors such as clinical judgement, experience and qualitative factors. Whilst working with clinicians from a range of disciplines in the NHS, I have had many discussions with colleagues regarding this issue. I have sensed some disappointment that EBP has led to quantitative approaches being favoured to the exclusion of more qualitative approaches that they feel may prove to be of most use in clinical practice. Of late, attempts have been made to study
psychodynamic theory and practice in a manner that is perceived to be more legitimate.

An example of a psychodynamic study that has used a quantitative approach is Crits-Christoph et al. (1996), who conducted an investigation into the efficacy of brief supportive-expressive psychotherapy; an approach that uses methods similar to that involved in BDP. Outcome data was collected for 26 clients with GAD, who had undergone 16 weekly sessions of therapy. The results indicated significant improvements in both anxiety and worry. More recently, Crits-Christoph et al. (2005) found evidence that brief psychodynamic psychotherapy is more efficacious than supportive counselling in the treatment of GAD. Durham et al. (1994) compared brief psychodynamic psychotherapy with other therapeutic approaches in the treatment of GAD. A sample of 45 adults with GAD received psychodynamic therapy and showed improvements at the end of therapy and no significant change at six-month follow-up. However, other studies have not had such positive outcomes. In a RCT of treatment gains at one-year follow-up, Durham et al. (1999) concluded that there was no evidence to support the use of a dynamic approach with GAD. Roth and Fonagy (1996) conducted a critical review of psychotherapy research. They concluded that due to an absence of literature in this area, they are unable to support the use of dynamic techniques alone for anxiety disorders. In contrast, a review of RCTs was conducted for short-term psychodynamic psychotherapies for common mental disorders, including anxiety (Abbass et al. 2006). The studies included outpatient adult samples and the treatments studied represented a range of psychodynamic-based models including that of Malan (1963). Anxiety ratings demonstrated moderate treatment effects compared with controls in the short, medium and long-term. However, it is acknowledged that the studies included were of variable quality and it is unclear whether the therapeutic approach employed was based on a specific brief therapy. A further limitation of these studies is that most included a majority of female participants, which means that the generalisability to males is questionable.

It appears that the evidence base for short-term psychodynamic therapies is mixed but there appears to be some support for this treatment approach. I would suggest that such shorter-term psychodynamic therapies are likely to be much more
appealing within a NHS context, where resources are limited. However, only particular clients may be suitable for this type of therapy and thus it is not widely applicable. In addition, due to insufficient evidence, it is not currently recommended in the NICE guidelines for GAD (NICE, 2004). However, Trujillo (2006) is optimistic that brief psychodynamic therapies and their research studies 'promise to restore dynamic therapies to the rank of evidence-based therapies of proven efficacy and effectiveness in the treatment of anxiety' (pp.84). At present, Cognitive Behavioural theory and therapy have enjoyed popularity in the explanation and treatment of worry.

Cognitive behavioural theories of anxiety & worry

Cognitive behavioural theories

Cognitive behavioural theories of psychological problems are the result of the integration of the principles of behavioural theory with cognitive theory (Hawton et al., 1989). Cognitive theorists propose that distortions in thoughts about the dangerousness of situations, sensations or mental events are key in anxiety disorders (Clark, 1999). In their cognitive theory of GAD, Beck et al. (1985) claim that in the case of anxiety, there may be a combination of factors that lead to the development of disorder. These may be genetic, developmental, environmental and psychological. They assert that talking about cause could be counterproductive and attempt to explain symptoms of anxiety such as worry in terms of maintaining factors such as cognitive distortions. In contrast, strictly behavioural theorists would be less interested in the cognitive process of worry. They would suggest that the physical symptoms of anxiety associated with worry are a maladaptive learned response to particular conditions. (Wolpe, 1990). Behavioural theory is based on a solid empirical foundation that has developed since the start of the last century (Hawton et al. 1989). Since Beck et al.’s. (1985) original theory of anxiety, a number of particularly salient features of worry have been identified, increasing the theoretical understanding of this concept. It is beyond the scope of this essay to include all of these here, so those that are prevalent in the literature will be discussed. For example, Wells (1995) proposes that metacognition is crucial in the explanation of worry.
Metacognitive theory

In Wells' (1995) metacognitive model (MCM) of pathological worry and GAD, two types of worry are described. Type 1 worry is concerned with worry about external daily situations/events or non-cognitive, internal physical sensations (e.g. worrying about one’s ability to perform at work or physical health). Type 2 worry is concerned with the nature and presence of worry itself. This can be both positive (e.g. it helps to prepare for threat and helps to maintain safety) and negative (e.g. it is uncontrollable or dangerous). In response to a trigger, type 1 worry is activated as a coping strategy due to positive beliefs about worry. According to this model, individuals with GAD experience a high level of type 2 worries and worrying is used as a strategy for coping with problems. It is suggested that this might have been influenced by a parent who modelled worry as a method of problem solving or from worry being positively reinforced. However, worry may become to be viewed as negative (e.g. when it begins to have a negative impact on the individual). When this occurs, three additional factors serve to increase and maintain worry. These are behavioural responses (e.g. avoidance and reassurance seeking), thought control (e.g. suppression and distraction) and emotion symptoms (e.g. anxiety, tension, panic attacks and depression).

Consistent with the MCM, there is evidence that those who report pathological worry hold both positive and negative beliefs about worry. For example, Borkovec and Roemer (1995) investigated the perceived functions of worry. They found that individuals with GAD gave higher rating for reasons for worrying than the non-anxious control group. Likewise, Wells and Carter (2001) discovered that positive beliefs about worry were endorsed more by individuals with GAD but also social phobia and depression in comparison with controls. Wells and Carter (1999) investigated the role of both type 1 and type 2 worry in pathological worry. They found that type 2 worry was associated with pathological worry independent of type 1 worry. Another influential model of worry is Borkovec et al’s. (1988) cognitive avoidance theory of worry.
Cognitive avoidance theory

Borkovec et al. (1998) argue that worry is a form of cognitive avoidance of perceived external threats in the future as well as internal unpleasant images or emotions. Worry is argued to prevent emotional processing and lead to the persistence of anxious interpretation. This theory shares some commonalities with psychodynamic theories of anxiety, as expressions of unexpressed painful emotions. It is supported by Borkovec and Roemer’s (1995) study in which distraction from more emotional topics rated highly as a reason for worry. Sibrava and Borkovec (2006) also report a number of studies in which worry has been found to suppress the physiological activity associated with anxiety. This negatively reinforces worry so that anxiety is maintained. Another cognitive theory of worry that has been highlighted as important in explaining worry is intolerance of uncertainty (IU).

Intolerance of uncertainty

In their clinical work, Dugas and colleagues identified IU as an important cognitive process involved in worry. IU is defined as a ‘cognitive bias that affects how a person perceives, interprets and responds to uncertain situations on a cognitive, emotional and behavioral level’ (Dugas et al. 2005, p.58). In particular, IU is demonstrated by the propensity to perceive uncertainty as stressful, unwelcome and unfair as well as the tendency to be unable to act in such circumstances. This theory distinguishes between worries that can be solved and those that cannot or might not even occur. In a non-clinical sample, Dugas et al. (2001) found that IU and worry were highly related. Furthermore, in an experimental study, IU was manipulated and rates of worry were higher in the higher IU group than the lower IU group (Ladouceur et al. 2000). These findings support the idea that IU plays a role in the maintenance of worry.

Overall, I consider cognitive models of worry appealing because they are supported by a firm evidence base and make logical sense to me. Indeed, it has been argued that it makes sense to focus on cognitive theories as worry is an essentially cognitive
phenomenon (MacLeod, 1994). The cognitive behavioural treatment approach has developed from cognitive theories of worry and anxiety, incorporating a range of methods based on strong theoretical and empirical underpinnings.

**Cognitive behavioural treatment approaches to anxiety & worry**

**Cognitive behavioural therapy**

Cognitive Behavioural Therapy (CBT) is the term given to talking therapies based on the idea that what we think affects both how we feel and our behaviour. It is currently a very popular treatment approach favoured by many clinicians and is the recommended psychological therapy in the NICE guidelines for GAD (NICE, 2004). *In my experience of working in the NHS, CBT is the most common treatment approach. I have found it to be acceptable to both professionals and clients. This approach incorporates interventions based on cognitive and behavioural theories.*

Behavioural theory would suggest the application of learning principles, such as observational learning (modelling) and reward for success (reinforcement) in the treatment of psychological disorders. For anxiety in particular, relaxation procedures designed to concentrate on the physiological arousal associated with anxiety are employed. Relaxation is an important component of many therapies that are cognitive-behavioural in nature (e.g. Beck *et al*. 1985). The cognitive model of therapy proposed by Beck *et al*. (1985) is a structured, problem-solving approach dealing with current difficulties. Therapy lasts between 5 and 20 sessions. Collaboration between client and therapist is key and the client is expected to perform tasks between sessions (homework). Treatment begins by providing an explanation of anxiety based on this model. Next, anxiety associated beliefs about the future; self; and the world are identified. Steps are then taken to shift unhelpful thoughts and behaviours (such as avoidance) that prevent disconfirmation of anxious cognitions. Durham *et al*. (1999) conducted an RCT investigating the efficacy of CBT for GAD based on Beck *et al*’s. (1985) approach and found that clinical results are both sustained and improved upon at one-year follow-up. The theories of worry presented above provide additional targets for intervention using CBT. As theories
have emerged, the treatment packages offered to clients have developed to incorporate these specific ideas. For example, Wells (1997) developed Metacognitive Therapy (MCT).

**Metacognitive therapy**

MCT aims to target and modify both positive and negative (type 2) metacognitive appraisals and beliefs that serve to maintain worry, as well as the associated behaviours. It is suggested that positive beliefs should be reduced because they may lead to an over-reliance of worry as a coping strategy. It is not considered necessary to tackle the specific content of type one worries or control physiological symptoms of anxiety using relaxation techniques. At the start of therapy, the model is presented, along with the individual’s case formulation to help the client understand that worry is not the actual problem but the beliefs about and behaviours associated with them. Next, direct metacognitive modification is attempted. This begins with challenging beliefs about uncontrollability by questioning the evidence for it, reviewing evidence of effective control and worry-postponement activities. Following this, danger metacognitions are modified through questioning the evidence that worry is dangerous, questioning how it works, reviewing the evidence and learning new corrective information. Behavioural experiments are also used to test negative beliefs about the danger of worrying. Behavioural experiments are organised activities that aim to gain new information to test the validity of maladaptive beliefs and develop or test more helpful beliefs (Bennett-Levy *et al.*, 2004). Following this, attempts are made to modify and weaken positive beliefs about worry, using verbal methods and behavioural experiments. The final stage of therapy is relapse prevention. Here knowledge gained is consolidated in the therapy blueprint. This contains a copy of the formulation; a summary of material covered; a record of idiosyncratic metacognitions; and evidence against them. It also includes a list of alternative coping methods when faced with stress (such as worry postponement, detached mindfulness and doing rather than thinking). Support for MCT is provided by an outcome study of 10 clients with GAD, conducted by Wells and King (2006). Large improvements at post-treatment were detected in all but one of the clients on measures of worry and anxiety. These improvements were maintained in 75% of
clients at six and 12-month follow-up. The small sample size and the absence of a control group in this study are clear limitations. However, it does provide encouraging evidence for the effectiveness of MCT that warrants further investigation.

Intolerance of uncertainty and cognitive avoidance

Ladouceur et al. (2000) propose a CBT approach for GAD incorporating components aiming to address IU and cognitive avoidance. The treatment approach follows a similar approach to that proposed by Beck et al. (1985). Clients are encouraged to develop an awareness of the inevitability of uncertainty in life and accept that increasing tolerance is possible, without the use of worry. This is achieved through behavioural experiments that involve seeking out uncertainty and learning that it is tolerable. Next, the utility of worry is evaluated by examining its costs and benefits. Steps are also taken to improve problem-solving ability. Cognitive avoidance is also tackled by using a worry diary to record worries about hypothetical situations. The core fear from these is then identified and the feared outcome is described vividly and recorded in audio form. The client then listens to this on a daily basis to process the core fear and diminish associated worry. Again, relapse prevention is the final phase of therapy. The efficacy of this approach was investigated in a RCT conducted by Ladouceur et al. (2000). It was found that compared with a waiting list control group, 26 participants with GAD had significantly lower scores on measures of anxiety and worry, with 77% no longer meeting criteria for GAD.

In my opinion, CBT appears to follow in a coherent and consistent manner from its theoretical and empirical underpinnings. In addition, it lends itself well to outcome research and therefore its use is supported by a strong evidence base. Although CBT has enjoyed popularity, there has been a recent backlash against CBT. For example, Moloney and Kelly (2004) claim that although some aspects of CBT are useful, this may only be the case for clients that are relatively privileged in socio-economic terms. They highlight that for clients in more deprived situations; the focus on challenging thoughts may be misguided, without acknowledging psychological difficulties within a social and material context.
Conclusions

In conclusion, psychological theories from psychodynamic and cognitive-behavioural perspectives are useful in explaining worry and informing the treatment of dysfunctional worry. Currently, the theories and treatments discussed have enjoyed varying degrees of support from the literature/evidence base. However, it appears that CBT has the strongest evidence base in terms of both theory and outcomes. There is not yet a coherent body of evidence concentrating on ‘worry’ per se and as evidenced in throughout this essay, there is some reliance on GAD research. In the future, I think it would be interesting to consider tackling worry specifically in a range of disorders outside of GAD.

Having, completed this essay, I feel better equipped to access relevant sources of information to inform a more accurate formulation and treatment approach. During the process of writing, I have been struck by the current focus on EBP. Although, I would not deny that practice should be informed by evidence, I am uneasy that what constitutes ‘evidence’ is currently so narrowly defined. I have also reflected that the popularity of approaches appears to be heavily influenced by the prevailing fashion of the time. Currently, CBT appears to be the most popular approach, almost to the exclusion of others. In my experience within the NHS, I have become aware that autonomous practice is constrained within this organisation. I have worked with Clinical Psychologists who prefer the psychodynamic model. However, they are unable to use this as the main treatment model due to the expectation that clinicians will be evidence-based practitioners, and follow NICE guidelines. Within adult mental health settings, this usually means practicing CBT. This limits choice for clients and places limits on the range of options mental health professionals can offer.
References


Professional Issues Essay

What are the strengths and weaknesses of multidisciplinary teams from the perspectives of staff and service users? How can you as a psychologist contribute to teams functioning optimally?

January 2008

Year III
Introduction

The term ‘multidisciplinary team’ (MDT) within the National Health Service (NHS), can be defined as groups of health and social care professionals and specialists that work together to provide services for service users in a co-ordinated manner. Within the NHS, team composition into terms of professional representation varies considerably depending on the needs and problems of its service users. For example, in mental health, teams often include members from a range of professions typically nursing, psychology, medicine, social work, and occupational therapy. Throughout the NHS, MDT working is common practice. With regards to mental health services, MDTs have a strong policy background.

The importance of multidisciplinary teams in achieving patient goals is described in NHS health care policy. Examples include the NHS Plan (Department of Health (DH), 2000) and the Mental Health Policy Implementation Guide (DH, 2001). Perhaps the most recent initiative relevant to MDT work in mental health in the NHS is the New Ways of Working Programme (NWWP), concerned with the development of mental health services. The NWWP involves representatives of carers and service users as well as the major professional bodies (e.g. the Royal College of Psychiatrists, the Royal College of Nursing and the College of Occupational Therapy). In terms of applied psychology, the British Psychological Society (BPS) and the National Institute for Mental Health in England (NIMHE) have worked together to address seven objectives in separate project groups. Of these, the work of the leadership group and MDT group are most pertinent here (BPS, 2007a, 2007b). MDT working is generally considered to be favourable and beneficial over unidisciplinary working for service users and staff (Gorman, 1998). However, it can also be problematic and a number of potential weaknesses can be identified.

Below I describe some of the strengths and weaknesses of the MDT in terms of outcome and process from service user and staff perspectives. I also outline some of the characteristics of effective teams and some ways in which applied psychologists
are in a strong position to contribute to optimal team functioning. As a Trainee Clinical Psychologist (TCP), in the process of developing skills as a scientific and reflective practitioner, I make reference to both the available literature and my personal experiences of working in teams in the NHS since being an undergraduate.\(^1\) Throughout, the focus is biased towards teams in NHS mental health services, as this is currently most relevant to me as a TCP. It has been acknowledged that in health care, there is a complexity and diversity in the cultures and ideologies of service users as well as teams, settings and the wider systems (Vetere, 2007). Therefore, not all of the points raised below are applicable to all teams, although they will have relevance to a significant number of healthcare teams. I begin by introducing some of the strengths of MDT working.

**Strengths of multidisciplinary teams**

There are a number of strengths of MDTs from the position of service users and staff (Gorman, 1998). However, due to the limited scope of this essay, I will concentrate on just a selection of the most significant strengths. Perhaps one of the most obvious features and strengths of the MDT is a wider range of knowledge, skills and abilities (KSA), which may lead to a more holistic approach.

**A more holistic approach**

It can be argued that presence of a wide range of professional groups within a MDT leads to an increase in KSA and perspectives. The enhancement of KSA in MDTs can be beneficial to service users who are more likely to receive a more holistic approach to their care or at least have choice to access a practitioner whom can offer them an approach that is acceptable and favourable to them. It is well documented that many service users have a preference for treatments other than the traditional medical model option of medication. For example, Warner *et al.* (2006) consulted service users, staff and carers about choice in mental and social health care services and found that many service users were in favour of a more holistic model and expressed a preference for alternatives to medication such as self-management.

\(^1\) For ease of reading, personal reflections are italicised.
programmes. Thus, the availability of a team member who is able to offer this has clear benefits from a service user perspective in terms of ease of access to particular skills and knowledge base. When carers were asked, they expressed a wish to be listened to and given information. They also wanted support to deal with their own stress. *This was certainly the case in my last clinical placement in adult mental health. The team that I worked in was keen to involve and support carers as far as possible. I regularly carried out carer's assessments to ascertain any needs carers had in terms of information, advice and their own stress management. The feedback that the team received from carers was extremely positive and they said that they appreciated being asked if there was anything the MDT could assist them with to ease the potential burden of the care-giving role.* In addition, increased KSA also has some clear advantages from the perspective of staff in terms of learning and development opportunities.

**Learning and development opportunities**

A major benefit of the expansion of KSA for staff is that it provides extra opportunities for learning. In a qualitative study conducted in Primary Care Mental Health Care Teams, Miller *et al.* (2005) found that MDTs present learning opportunities from others both within and between disciplines. The value of formal inter-professional education (IPE) is widely acknowledged and is now included in many professional training courses. Indeed pre and post-qualification IPE has been found useful in enabling different professions to share perspectives and gain insights into different professions and their training (Priest & Roberts, 2006). *From a personal point of view, I feel that I have learned an enormous amount from both formal and informal teaching and contacts with my colleagues/fellow students from a range of disciplines in both NHS and academic settings. I believe that my interactions with colleagues and peers have helped me to improve and develop my understanding of service users from the perspective of other disciplines.* Related to enhanced KSA, a further strength of the MDT is that by including professionals from diverse perspectives, they can lead to more holistic perspectives to approach understanding.
**Broader perspectives**

Within MDTs, members bring a range of viewpoints together. This integrated approach is often referred to as the 'biopsychosocial' model of health care. When working collaboratively, MDTs are well placed to consider a wider range of ideas that they might not have considered within a single discipline. This can lead to the challenging of perspectives, creating healthy debate and allowing the team to develop a more sophisticated understanding of service users and their systems that incorporate different information and perspectives. Indeed, Gelsthorppe (1999) argues that the main reason for a MDT should be to stimulate discussion and provide alternative viewpoints. This is of benefit to service users as it increases professionals understanding of them and hopefully leads to better quality care and decision making that incorporates an extensive range of factors. It has been found that service users value such an approach as it facilitates a wider view rather than a single interpretation of their lives and difficulties (Piippo & Aaaltonen, 2004). A broader perspective is also a strength of the MDT from the standpoint of many staff.

A wide-ranging outlook can be of huge benefit to staff in terms of personal and professional development. It allows clinicians not only to adapt their views in response to extra information but also makes them really consider their position and biases in relation to their work. *In my experience, I have found this to be especially useful as it has forced me to think about my personal and professional positions, how they are similar or different from other team members and why this might be, in a manner that does not assume any prior knowledge of psychology. In particular, my conversations with non-psychology colleagues have highlighted how much my thinking and approaches have been influenced by my academic background and professional identity. Although I have reflected on the impact of these experiences to an extent, I think that this was on a fairly superficial level and I was not aware of how powerful these influences have been.* A further strength of the MDT for service users and staff is that it can lead to sharing of workloads.
**Division of labour**

MDT working allows work to be divided between team members with varied KSA. As a result, individual staff may feel less pressured to undertake work outside of their range and level of competence (Miller *et al.*, 2005). This is positive as it would be unethical by many professional bodies for its members to operate outside of the boundaries of their capability (e.g. BPS, 2006). This enables staff to be able to practice in a safe and confident manner and protects service users from receiving poor standard health care.

Above I have presented just a few of the strengths of MDTs based on the assumption that teams are functioning optimally. As Gorman (1998) states, ‘*When it works well, multi-disciplinary working offers better treatment for patients and a better quality of working life for the practitioners*’ (p.14, emphasis added). Thus, when teams function in a dysfunctional manner, a number of weaknesses become apparent, some of which are outlined below.

**Weaknesses of multidisciplinary teams**

When MDTs do not enjoy positive processes, a number of weaknesses can be identified. For example, increased KSA may not always be advantageous in terms of outcomes. For example, Fay *et al.* (2006) argue that it an assumption that the more knowledge, skills, abilities and perspectives available to a team, then the better their outcomes and performance. They studied MDT work in NHS settings and found that multidisciplinary work is contingent on good team processes and highlight that ‘shared vision’ and frequent contacts are necessary for effective teams.

**Conflicting perspectives**

Above I highlighted that the strength of MDTs lies in their use as forums for learning and development through challenging of perspectives. However, it has been argued that increased KSA may lead to a lack of consistency between team members, so that service users and staff are provided with ambiguous or conflicting messages and
advice. In addition, the varying perspectives can also cause contention rather than debate and therefore tension. In a study of the way a MDT developed a care pathway for people with schizophrenia, Jones (2006) discovered criticism of other professionals for perceived flawed practice (for example, by questioning the evidence base of the practice and the perceived utility of interventions). In my experience, conflict and tension as a result of differing perspectives within teams is not usually discussed openly between those involved. I have noticed that it is far more likely that team members from the same discipline privately discuss differences rather than with those that the difference concerns. I have found that this can create unacknowledged strain between staff and have been concerned about the impact that this could have on both service users and staff. Alternatively, staff members have made their opposition clear by not carrying out interventions and assessments that they attribute to other professionals. I have encountered this very recently in working with direct care staff that have signalled (what I perceive to be) their lack of agreement with or commitment to psychology involvement in fairly obvious ways (like being unavailable for agreed appointments and not providing requested information needed for assessment). This may be due to lack of time and/or resources or because do not fully understand the rationale or process of assessment from a psychology viewpoint. Despite my attempts to try and understand and work with this, it has nonetheless led me to experience moments of frustration. Conversely, it has been argued that in many cases, conflict is not necessarily an outcome of the presence of varying perspectives. It may be the case that a particular model or discipline dominates a team whilst some points of view might be lost.

Medical dominance

As Gelsthorpe (1999) highlights, in reality multidisciplinary debate does not necessarily occur due to pressure to conform. He claims that the medical viewpoint usually takes precedence over that of other disciplines. This view is supported by research conducted by Atwal and Caldwell (2005), which investigated interactions between health professionals and found that medics play a more dominant role in team meetings in terms of participation and decision-making. In a similar vein, Atwal and Caldwell (2006) conducted observations and interviews of nurses and found that many felt unable to express alternative viewpoints to the medical one for
fear of ‘scape-goating’. They suggest that power and status differentials may lead to this reluctance because medical representatives are traditionally perceived to have a higher position in the team hierarchy. Likewise, Gair and Hartery (2001) investigated medical dominance in decision making in MDTs using observations and interviews. They uncovered dominance in terms of medics’ contributions to meetings and initiation of decision-making. They also found that other team members felt there could be less medical discussion. However, they also reported that contrary to their expectations, other members of the team would frequently question medics’ discharge proposals and were influential in the decision-making process. They noted that there was a high level of stability in these teams, which might have enabled non-medical team members to have the confidence to make challenges. From personal experience, medics have dominated most of the mental health teams in which I have worked. Although I have observed other professionals’ viewpoints generally being taken into account, I am not sure how much ‘real’ influence they always have. There have been a number of occasions when I have witnessed psychiatrists ‘pulling rank’ and making decisions that the entire (and not inconsiderable) teams were opposed to. In the face of much dissent, the Consultant Psychiatrists asserted their position as Responsible Medical Officer to go ahead with unpopular decisions. Such medical dominance is of central concern to both staff and service users. Not only does medical dominance act as a barrier to the provision of the more holistic approaches favoured by service users but it has been found to be associated with low patient involvement and poor patient communication. From a staff perspective, being unable to express their professional autonomy may cause dissatisfaction amongst members and prevent them from being able to contribute and function as effectively as possible within the team. As Atwal and Caldwell (2005) argue, by not expressing opinions, team members may not be contributing to sound decision-making, which is clearly to the detriment of service users. Vetere (2007) also states that, within MDTs, ‘professional differences in power and control...have not helped a mutual process of influence and cross-fertilisation of ideas for the benefit of service users’ (p. 5).
Role blurring

Gorman (1998) argues that to be successful, clear roles are required for each team member. Moller and Harber (1996) have argued that in MDTs, 'role blurring' can occur whereby a professional is unsure of their specific, unique role within a team. Increasingly, mental health professionals are becoming more generic and there is much overlap of role and responsibilities. This erosion of professional identity can lead to inter-professional rivalry. For example, Jones (2006) found evidence of dispute and competitiveness regarding who should provide certain interventions and which profession 'owns' each area of practice. He reported that ambiguity about role and function led to much protection of professional boundaries, the insistence for separate professional assessments and poor morale. This can be detrimental to staff as it causes conflict and stress thereby reducing job satisfaction. This can only have a negative knock-on effect for service users who may experience either over-assessment or a paucity of care.

With regards to role definition, I have noticed that some members of MDTs in which I have worked have welcomed greater generic work as a 'mental health professional' and are happy to perform roles and tasks that are not traditionally associated with their professional role. However, others have resisted moves towards generic working and felt that they were expected to perform jobs that they were not trained to and did not feel sufficiently competent or knowledgeable to carry out as well as their colleagues from different professional backgrounds. Contrary to this, I have noticed inter-professional rivalry developing, whereby members have become protective regarding provision of services typically linked with their profession. An additional weakness of the MDT is the general issue of poor communication and in particular confidentiality.

Communication difficulties

One of the main components of successful MDTs is good communication (Gorman, 1998). In addition, competent communication skills are identified as a core
dimension for all qualified health professionals in the NHS Knowledge and Skills Framework (DH, 2004). Poor communication can have negative consequences from the viewpoint of both service users and staff. Miller et al.'s (2005) study highlighted the importance of communication involving everyone, including different practitioners, agencies and service users. In this study, a range of interpersonal communication issues emerged within the MDT. Of these, confidentiality was a controversial issue. It was reported that different disciplines appeared to adopt quite varied ethical positions and definitions on information sharing and confidentiality which caused tension.

In terms of opinions and practice regarding confidentiality, I have noticed wide variations not only between disciplines but also within disciplines, particularly psychology. Some psychologists that I have worked with have been quite open about the work being carried out in therapy, writing up clinical notes in multidisciplinary files and giving detailed feedback at meetings. However, others have been far more cautious about disclosing the content of sessions, keeping separate notes and team feedback to a minimum. I have noticed that the latter approach has been viewed with a degree of suspicion by other members of the team who might be more inclined to disclose such information. This has had a negative impact on relationships between professional groups. However, in Miller et al.'s (2005) study, participants maintained their position for the protection of service users rather than being deliberately obstructive. Having highlighted some of the strengths and weaknesses of MDTs, I now turn to consider how Psychologists, can contribute to optimal team functioning.

**Psychologists' contribution to team functioning**

**Effective teams**

A vast research base exists related to team work effectiveness. A thorough discussion of this is beyond the scope of this essay. However, it is worth briefly considering some of the factors associated with effective team functioning. Gorman (1998) suggests five characteristics of successful teams: clear goals; defined roles; shared
responsibility for reaching goals; good communication and process between members to accomplish goals; and benefits for individuals within the team. The importance of clear and effective leadership is also highlighted (Gorman, 1998). Having considered what leads to effective team functioning, I will now consider the ways in which myself and other psychologists can contribute to optimal team functioning.

**Contribution of psychologists to optimal team functioning**

*In the past, I have considered the role of Psychologists in a MDT and thought about the ways in which they can use their unique range of clinical, academic and research knowledge and skills to contribute positively to teams in a number of ways. Psychologists can offer a broad knowledge base in terms of psychological theory as well as a range of skills in assessment, intervention and evaluation for the direct clinical benefit of clients. However, contributions are not limited to clinical practice. For example, Psychologists can provide teams with psychological viewpoints regarding wider issues than individual service user issues, such as team dynamics and the impact of organisational change. Psychologists also offer a strong background in research and knowledge and skills in the integration of theory and practice.*

The manner in which Psychologists can practice within MDTs for the benefit of service users, the public and their services are described in the BPS ‘generic professional practice guidelines’ (BPS, 2007). These make a number of recommendations about working in MDTs which would be helpful in creating effective teams and minimising some of the weaknesses of the MDT described above.

In general terms, Psychologists are directed to work respectfully and collaboratively with colleagues to develop shared goals and to be precise about their role. In order to improve understanding of service users, it is suggested that Psychologists both offer and look for discussion with other team members. Psychologists are reminded of the negative impact of inconsistent advice from different professionals and encouraged
to work towards a comprehensive, co-ordinated perspective of service users' needs and the development of effective treatment plans.

With regards to situations where conflict occurs, Psychologists are advised to draw attention to the effect that this could have on the team’s capacity to engage in effective and ethical practice and to help to resolve issues through respectful, clear communication and collaboration to resolve the matter. If no resolution is met, Psychologists are advised to seek consultation from an appropriate colleague before reporting the issue to those responsible for looking into such issues. With regards to communication, Psychologists are advised to develop explicit information sharing and confidentiality agreements whilst maintaining open communication within specified limits.

Above, I have discussed many of the ‘obvious’ ways that Psychologists can contribute to optimal team functioning for the benefit of service users and staff. However, as the NWWP gathers pace, it appears that the roles of Psychologists are set to evolve and expand. The ‘New Ways of Working for Applied Psychologists (NWWAP) working psychologically in teams’ document (BPS, 2007a) discusses ways in which Psychologists can contribute to effective team work.

**New Ways of Working for Applied Psychologists**

‘NWWAP working psychologically in teams’ (BPS, 2007a) introduces the idea that Psychology has a growing role to promote effective team work. This takes for granted that Psychologists will continue contributing in the already established ways that I highlighted above. It goes on to highlight how Psychology’s role will expand to include a range of other tasks not generally associated with Psychologists in the past.

These newer roles include a wide variety of roles and tasks, which utilise the full range of knowledge and skills available to Applied Psychologists. One such role will be increased responsibility for the design, operation and evaluation of teams. It is suggested that Psychologists can have a key role to play in teams using their research
knowledge and understanding of systemic issues to inform the design, operation and evaluation of effective teams.

Many of the new Psychology roles will require further integration of the discipline into MDTs. Increased integration of Psychology is hoped to promote individual service planning, involvement of service users and carers and reflective practice, with attention paid to the full range of areas of life. Increased integration is desirable from the perspective of service users, as long as the discipline maintains its position as a counter-balance to dominant medical models.

It is also suggested that Psychologists will have a responsibility for increasing access to a wider range of psychological therapies through service development work (e.g. group work) and supervision, support and consultation with both individual colleagues from other professional backgrounds who may be using psychological interventions (e.g. nurse therapists) and the wider system.

Another key role for psychologists that is emerging from the NWWP is that of the leadership role. This is addressed in the BPS document ‘new ways of working for Applied Psychologists in health and social care: organising, managing and leading psychological services’ (BPS, 2007b). It is argued that Psychologists possess the knowledge and some of the skills required to be effective leaders of both teams and wider systems. The NHS is a complex system, in which an appreciation of the processes of change and development within systems is important in attempting to improve effectiveness. Therefore, there appears to be an increased expectation that in the future, leadership roles at both clinical and executive level will be taken up by Psychologists.

Above I have presented some of the ideas proposed for the role of Psychologists in contributing to optimal team functioning within the ‘NWWAP working psychologically in teams’ document (BPS, 2007). However, more specific suggestions for how Psychologists and psychological models can contribute to the best possible team functioning have been suggested by many others. Due to the
restricted range of this essay and the nature of the topic, I have chosen to focus on the use of systemic thinking which seems most relevant.

The contribution of systemic thinking
Speed (2004) uses systemic ideas taken from her practice as a family therapist to suggest how team functioning can be improved, to become more collaborative rather than conflicting. Open communication, respectful working, and appreciation of both what we can learn from others and of the work that they do are put forward as helpful. It is suggested that work is best conducted whilst being mindful of the context and keeping the service user and family perspective central. She also highlights that it can be useful to team functioning to be aware of the epistemological position of colleagues and how these might differ within a team. She claims that this encourages accommodation of alternative viewpoints in a manner that permits multiple discourses rather than creates competing positions. Similarly, Vetere (2007) proposes that systemic thinking is useful to MDT practice in that it allows the incorporation of varied professional identities and approaches to understanding. Systemic network meetings and systemic consultations, which involve reframing of problems and emphasis on strengths and positives, are suggested as useful when there are difficulties with team work such as communication and liaison. From the discussion above, it should be clear that there are many ways in which both Psychologists and the use of psychological theories and models can contribute to optimal team functioning. I now go on, to draw some conclusions about MDT work.

Conclusions

To conclude, MDT work is a key process in NHS mental health services which appears to be of increasing importance due to recent initiatives such as the NWWP. MDTs are considered to have a number of strengths for both service users and staff these include providing a holistic approach and broader perspective on issues. They also add to staff learning and development and allow work to be shared amongst
team members. However, when teams are dysfunctional a range of weaknesses can be identified. For example, MDTs can lead to conflict, medical dominance, role blurring and communication difficulties.

A number of characteristics of functional teams can be identified (Gorman, 1998). It is clear from the NWWP that in the future, Applied Psychologists working in the NHS are well placed to contribute to the optimal functioning of teams over and above their direct influence in day-to-day practice in a range of areas. For example, team design and operation, supervision and consultancy and leadership.

Having reflected on my experiences of MDT working in the NHS, I would conclude that overall these experiences have been positive. However, on occasions when MDT working has presented challenges, I have learned a great deal about myself, others and the wider system. I hope that this will prove to be of benefit to both my personal and professional development. As a Psychologist, I feel that I am in a position to contribute to the optimal functioning in a range of ways both directly and indirectly. In the past, when working in a different discipline, I have felt that Psychologists can sometimes be perceived as not being as integrated into teams as others. I think that it is important that applied psychologists play a more influential role with both teams and the wider organisation. Having read through the NWWP documentation for applied psychologists, I look forward (with some trepidation) to the new and exciting challenges that face the profession within the NHS, with the expansion and development of roles.
References


Problem-Based Learning Exercise Reflective Account I

The Relationship to Change

March 2007

Year I
The problem based learning exercise

This is a reflective account of a problem-based learning (PBL) exercise that was set before starting on clinical placement. It is written in the first person for ease of description and reading. The problem set for this PBL exercise was ‘the relationship to change’. We were placed in small groups to work on a problem and produce a presentation. In this account, I will discuss my initial reactions to this exercise, the group process and the presentation. I will also reflect on the learning that has taken place throughout the exercise and in light of subsequent clinical experience on placement. I will begin by describing my first responses to the task.

Initial reactions

The PBL style of learning was novel to me and I felt apprehensive and confused by its apparent abstractness and freedom. I also felt some pressure regarding the impending group presentation. When paired with working with a group of new people, I almost dreaded working on this ‘problem’ that I didn't quite understand. I felt quite surprised by these strong emotional reactions. In order to address my concerns, I read up on PBL to try and increase my understanding of the task. Unfortunately, my reading did not ease my confusion significantly! However, I felt a sense of relief when discussing the PBL with other trainees because many seemed to be having similar reactions to varying degrees.

The group process

From the beginning, the group met, decided on tasks to be carried out outside of the group and then brought the work back to the next session for discussion. I felt this way of working encouraged equal participation of all members in the group. We
were provided with input from a facilitator (a member of the course staff) and 2 members volunteered for the roles of scribe and chair. The facilitator provided minimal input to the group but guided us when needed. At first, I found this frustrating and wanted more direction. In the first few sessions, the roles of the scribe (to take minutes) and chair (to keep the group to time and task) were clear and defined. However, as the group progressed, all group members seemed to take equal roles. From the start, I felt that the group took a respectful and collaborative approach, which had a positive impact on both its process and outcome. The group started by discussing our individual ideas about the meaning of ‘the relationship to change’. We reflected on our individual relationships with change and how they related to our professional development and presented these reflections within the group. This felt quite exposing but I felt that it gave me a better understanding of my fellow group members and stimulated discussion and ideas. Some group members felt that we were not making much headway with regards to a ‘solution’ to the problem and planning for the imminent presentation. Therefore, we decided to look at a variety of theories and models of change to explore as a group. I felt that this imposed some structure on the quite unrestrained discussions that we been engaging in. At this point, one member decided to change groups. At first I was concerned about how this might impact on the group dynamics. However, the group coped well and we were able to continue to work well together. After much discussion, we chose to focus on Prochaska and DiClemente's (1992) transtheoretical model (TTM) of change. The TTM describes five stages through which individuals progress in the process of behavioural change. The first stage is precontemplation, when the individual is not thinking about change. The second stage is contemplation when the individual is considering change. The third stage is preparation, whereby planning occurs. The forth stage is action when steps are taken to make specific behavioural changes. The final stage is maintenance when the individual works to sustain change. Within the TTM, relapse is likely when progressing through the stages to the maintenance stage. We chose this model because we thought it would be relevant to clinical practice.
Once we were on track and committed to the focus that we had agreed on, each group member took an equal share in planning and preparing for the presentation. We each wrote about one stage of the TTM for the presentation. It was interesting that when we brought our individual parts of the presentation together, they linked together almost seamlessly. I viewed this as an indication of how well we were working together and felt pleased with how much progress we had made both bonding as a group and in working towards a shared goal - the presentation.

The presentation

Our presentation was based on a popular TV show 'what not to wear', in which two forceful rich women aim to change the lives of (typically poorer) people simply by changing what they wear. I consider them to be distasteful (although to an extent entertaining) in their approach to people's difficulties. The group reflected on how insensitive they are to their 'clients' within the process of change. We mapped the TTM onto the format of this show to demonstrate the model and show how the behaviour of 'professionals' impacts on the process of change. We also incorporated ideas from the teaching in basic therapy skills. For example, Rogers (1967) proposes unconditional positive regard, empathic understanding and warmth and genuineness as fundamental in effective helping relationships (Rogers, 1967). Likewise, Burnard (1989) argues that there are several principles paramount in such relationships: the client knows what is best for them; advice is rarely helpful; listening and paying attention to the differing personal worlds of the client and helper. In our presentation, we demonstrated how not to be helpful. This meant that our helpers did not listen to the client, used their position of relative power to force their own agenda and were disrespectful, patronising and judgmental. We also included characters to represent carers. The carers differed in their level of agreement with the client regarding their needs and this had an impact on how helpful they could be to the client. For example, one carer's views matched that of the helpers and they attempted to railroad the client into relinquishing control and going along with plans that they did not agree with. This assumes a superiority of one approach over another, not taking into account
issues of difference and diversity. This can disempower the client and is unlikely to facilitate lasting change.

The presentation was considered to be a success and the feedback and comments received from observers about content and delivery was positive. I found the presentation fun and thought provoking to plan and execute. I have since considered the group process in light of clinical experience on placement.

**Re-evaluation of the group process**

Initially, the exercise set felt impossible and I felt we floundered slightly at first when deciding the way forward. In retrospect, I feel that this was necessary in order to explore the task in greater detail and bond as a group. I recently had a similar experience on my placement with a new client. During assessment, I found it challenging to ascertain precisely what her difficulties were and extended the number of assessment sessions. I spent more time reflecting on these sessions and discussing her in supervision. This led me to have moments of doubting my competency because I didn't 'get it' immediately. However, I have reflected that sometimes it takes longer than anticipated to explore a problem. As with the PBL task, I eventually developed a better understanding of the problem and had a clearer idea of how to proceed. I also developed a collaborative relationship with the client along the way.

Throughout the PBL exercise we were aware of the ethical implications of the content of our presentation. We wanted our presentation to be both humorous and engaging but there appeared to be potential for the material that we included to be interpreted as judgmental or offensive. This was something that we worked hard to avoid, so we were cautious about the language that we used. This is also something that I have become increasingly aware of throughout my clinical practice and I have
considered how the use of certain terms and words can potentially reinforce existing prejudice and inequality, even inadvertently.

The TTM has had an impact on the approach that I have since taken in clinical practice. During assessment, I have been mindful of the stage of change clients are at to establish whether therapy is appropriate. I have also used the ideas related to therapy skills to inform my practice on placement and enhance my effectiveness. I have also attempted to explore clients and their difficulties in an open manner. Theory has also proved to be a crucial component in providing a rationale and structure in my clinical work and to further enhance understanding. I found theory particularly useful with a client who identified low self-esteem as her main concern. I drew on Fennell's (1997) cognitive model of low self-esteem, which I presented to her. This allowed me to provide a formulation that incorporated her range of difficulties and helped to plan and explain the intervention.

I generally felt pleased about the manner in which we had worked together in order to achieve a positive outcome. I have thought about the way in which the roles of scribe and chair became less important as we all began more comfortable with the task and began taking an equal role in the group. I have also reconsidered the approach taken by the facilitator and feel that by being less directive, we were encouraged to collaborate, become autonomous and develop as a group naturally.

**Learning points**

I have noted a number of learning points from the PBL exercise and subsequent clinical experience. One general point is that change in approach can be uncomfortable for both practitioners and clients. It can cause strong emotional reactions and resistance. However, it can be exciting and challenging, leading to development. Another learning point is the idea that working with new people can be daunting and uncertain but is worthwhile and there is a vast amount to be learned.
from others. The potential benefits of normalising were clear to me throughout the exercise and in clinical work. I have experienced the ways in which it can be helpful and reassuring to know that others experience similar difficulties. I was also able to appreciate further the notion that theory is an important part of clinical practice. However, it has also become clear clients should not be fitted to theory, theory should be fitted to the client. In addition, I have become more aware that in order to be an ethical practitioner, it is important to be careful about the language that we use, so as not to cause even inadvertent offence or contribute to existing discrimination. Finally, in clinical practice, it is important to be aware of a client's current motivation to change and the effect of a practitioner's behaviour on change.

**Summary**

In summary, writing this account has provided me with an opportunity to reflect on change as an inevitable and universal process. The relationship to change has been highlighted as important for practitioners, clients and their carers. I will bear the TTM in mind when working with these groups in the future. Despite my initial reservations, I feel that I have derived a great deal of benefit from engaging in this PBL exercise and look forward to working in this way in the future. Not only did I increase my knowledge and understanding about issues related to the relationship to change, I developed strong relationships with other members of the group by working towards a shared goal. To conclude, I gained a great deal more from this exercise than I anticipated when it was presented. In future, I will attempt to be more open-minded and positive when new ways of learning and working are proposed by bearing the PBL experiences in mind.
References


Problem-Based Learning Exercise Reflective Account II

Child Protection, Domestic Violence, Parenting and Learning
Disabilities

March 2008

Year II
The problem based learning exercise

This is a reflective account of a problem-based learning exercise (PBL) that was set at the start of the second year of training prior to commencement of clinical placements with services for people with learning disabilities (PLD) or child and adolescent mental health services (CAMHS).

The materials provided for this exercise included a genogram and a diagram of a professional network. It was accompanied by a narrative about a couple with learning disabilities, their family, circumstances and involvement with professionals from health, social services, the legal profession and voluntary agencies. The PBL raised a number of issues related to risk, socio-economic deprivation, professional networks, parenting, domestic violence, resilience, gender scripts and conflicting perspectives. The problem was considered within existing case discussion groups (CDGs) and a presentation produced based on the work.

In this account, I will discuss my initial reactions to the exercise, the group process and the presentation. I will also reflect on learning from both the exercise and in light of subsequent clinical experience from my current learning disabilities placement. This reflective account is the second account of a PBL conducted within the CDG. Therefore, I have structured this account in a similar manner to the first in order to compare my responses, the group process and presentations between these exercises. I will start by describing my initial responses to the PBL exercise.

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2 This account is written in the first person for ease of description and reading as a reflective piece of work.
Initial reactions

This was the third PBL exercise that I had participated in and I was familiar with the group that I was working in, having participated in a CDG and PBL with them the previous year. I experienced strong emotional reactions to this task, which contrasted with those from the first exercise. Because I was familiar with the group and PBLs, I did not feel as overwhelmed and fearful as I had previously. The problem that we were presented with was very complex. However, rather than experiencing confusion, I felt positive and excited about getting started.

The group process

At the start of this exercise, the group decided when and where we were going to meet in order to produce our presentation. In contrast with the first PBL, we were able to choose when and where to meet and how often, which I preferred. During each meeting, we discussed the PBL, decided which tasks should be carried out by each group member between meetings and then emailed our contributions to each other before the next meeting. As with the first task, I think that this allowed each group member to contribute equitably. One group member volunteered to be scribe, taking minutes in meetings and later emailing them to us. The same person was scribe as in the first exercise. She appeared to be comfortable in this role. In contrast with the first PBL, we did not have input from a facilitator. I think that this gave us increased autonomy and reflected our progression through the course and professional and personal development. In addition, we did not elect a chair for the meetings. I am not sure why this was. However, I looked back on my reflections from the first exercise and noticed that as the group progressed, we took on more equal roles and the role of the chair became less defined. I wonder whether we felt more comfortable with this and did not elect a chair as a result.
In terms of our general approach, as with the first exercise, the group took a collaborative and respectful stance. However, I noticed that there was some initial apathy within the group about the value of PBLs. We acknowledged and reflected on this together in one of our CDGs. Afterwards, I noticed a far more positive and motivated feel to the meetings. In addition, I noticed that group members (myself included) were more likely to disagree and assert their own positions. Although I experienced some discomfort regarding this at the time, I was also struck by how we were able to take more risks by opposing each other. I think that this meant that we were all able to get the most out of the exercise and presentation and could feel connected to the process.

In the first meeting, we reflected on our previous presentation and discussed the ‘lessons’ that we had learned from this. Our first presentation had been humorous and entertaining. This was not considered appropriate given the subject matter of this exercise but equally we did not want to regurgitate the related legislation, policies and guidelines that we had consulted (e.g. the Children Act (2004), the white paper Valuing People (DH, 2001) and Tarleton et al., 2006). We talked generally about the problem which encompassed a wide range of important issues. We considered possible structures and formats the presentation might take. However, it was clear that this complex problem would require some unpacking before a clear way to proceed could be established. We considered how to bring the family and their relationships ‘alive’. To this end, we identified the main characters within the family and each wrote a first-person narrative for each, before sharing our accounts with each other.

In the second meeting, we reflected on the positions of family members and how they might feel ‘done to’ rather than ‘done with’. We particularly considered how the parents with learning disabilities might feel when professionals write inaccessible and complicated reports about them. We went on to consider how they might experience meetings, attended by lots professionals from a range of disciplines. We decided that a multidisciplinary and multiagency meeting might be one way of
highlighting issues raised by this PBL. We each took on a professional role and went away and researched where they might position themselves on issues, the evidence base they might draw on and the factors that that they might be most attentive to.

In the third and final meeting, we designed an overall, loose structure for the presentation to cover the viewpoints to be covered. In contrast with our first presentation, we did not write ‘scripts’ for our roles but ran through the direction of arguments within the meeting in a fairly casual manner. This demonstrated to me that as a group we felt far more able to take risks by planning less. This also might reflect general change in our approaches to clinical work, so that as confidence increases the need to prepare decreases. I now go on to describe the presentation.

The presentation

Our presentation took the form of an enacted multidisciplinary and multiagency meeting. Each group member took on a role, presenting the contribution that each profession might ‘typically’ make, whilst being mindful of the danger of reinforcing unhelpful professional stereotypes. We also attempted to allow the perspectives of the parents with learning disabilities to be heard by playing an audio-visual recording of them describing their experiences. In order to achieve this, two friends of a group member read the PBL material provided and the narratives written for each parent. A recording was then made of them discussing the situation together. During the presentation, we attempted to cover the range of themes raised by the problem and highlight how the voice of PLD could become lost in such meetings.

Re-evaluation of the group process

To begin with, the group was quite apathetic about this exercise. Although I did not feel as disinterested as other members, I could sense this and I think that it could
have had an impact on our ability to work well together. Acknowledgement of this as a group showed that we could raise such issues and discuss them in a manner that contributed to their resolution.

I didn’t fully appreciate the utility of this exercise until I started my PLD placement and experienced first-hand the pertinence of the issues raised. One client in particular that I worked with shared a number of striking similarities with the father described in the PBL (in terms of his personal circumstances and experiences of professional intervention). I think that this particular exercise was invaluable in informing my clinical work with him. I had already started to consider issues of relevance to him and in his wider networks. In particular, his experiences of attending meetings related to his parenting had been experienced as highly distressing and required addressing during therapy. Listening to this client and his story was sad and moving. However, when reflecting back on the inclusion of the parents’ narratives in our presentation, I noted that we captured similar issues and emotions that he raised. We achieved this despite being in very different positions in society (including our access to opportunities, cognitive abilities, socio-economic status and so on). This was reassuring to me entering a relatively new area on placement with PLD. I felt apprehensive about my knowledge and skills in unknown territory but this exercise increased my confidence and I didn’t feel completely uninformed. This exercise also highlighted the vast range of issues that need to be considered not only in services for PLD or CAMHS but in work with individuals and their networks in general. For example, important issues raised, such as the impact of over-assessment and unwieldy professional networks (McGaw & Newman, 2005) might be overlooked in adult mental health.

In terms of approach, I am satisfied that the group worked well in order to produce an interesting and thought-provoking presentation. I also felt that we covered as much of a complex problem as feasible in 20 minutes, without overwhelming our audience. We generally received positive comments about the content and delivery from both peers and course tutors. I feel that we were successful in giving a voice to
marginalised individuals who might be silenced when outnumbered and intimidated by relatively powerful and privileged professionals.

I have also considered how we each contributed within the group. As with the first exercise, I think that we made an equal contribution in terms of workload and in discussion. However, in retrospect I wonder whether the scribe might have felt obliged to take up the role and if it would have been fairer/more useful for another group member to take it on. Maybe in our future PBL exercise we can address this and another member can take the role?

**Learning points**

As in my previous reflective account, I can think of several learning points from this exercise and subsequent clinical experience. A major learning point is increased awareness that both individual and groups of professionals can be inadvertently unhelpful as well as helpful in their dealings with clients. Another point is that putting yourself in the position of clients can be useful as a means of increasing understanding. Having had the opportunity to practice this in a very conscious and deliberate way during the exercise has demonstrated that it is possible to imagine (albeit imperfectly) what it is like being someone in very different positions and circumstances. According to Rogerian principles, such empathic understanding is one of the core conditions of the therapeutic relationship (Rogers, 1961). Prior to this exercise and placement, I knew on an intellectual level that I was able to take another’s perspective but I was uncertain about how well I would be able to achieve this. When significant difference exists, I am now more confident that although I’ll never completely understand *exactly* how another person feels, I can do this with some accuracy.
Summary

In summary, this PBL has provided me with the opportunity to consider some important issues relevant to working with PLD and in CAMHS and how a team might approach the task of working on complex problems. Writing these reflections has led me to begin thinking about the ways in which the CDG and its approach have developed since the first account. To conclude, this account has led me to consider how this exercise has both enriched and been enriched by my subsequent clinical experience. As with the first PBL, I notice that I have gained more from it than I anticipated when first presented with it. However, in contrast with the first exercise, I think that I was far more positive and open-minded.
References


Problem-Based Learning Exercise Reflective Account III

Working with People in Later Life, their Families, and the Professional Network

February 2009

Year III
The problem based learning exercise

This is a reflective account of a problem-based learning exercise (PBL) that was set for groups of Trainee Clinical Psychologists (TCPs) in their second and third year of training to work and present together at the start of the academic year. At this time, Trainees were starting on a variety of placements with people with learning disabilities (PLD), child and adolescent mental health services (CAMHS), older adults services and advanced competencies (AC) placements.

The materials provided for this exercise included a genogram and an account of the 'problem'. The 'problem' presented was the referral of a 69-year old man to a psychology department for assessment of reported short-term memory problems and care needs. This PBL raised a number of issues including professional roles, the impact of parental divorce on adults, the relationship between mood and memory and the financial abuse of the vulnerable.

In this account, I will discuss my initial reactions to the exercise, the group process and the presentation. I will also reflect on learning from both the exercise and in light of subsequent clinical experience from my current AC placement with PLD and neuropsychological rehabilitation. This reflective account is the third account of a PBL conducted within clinical training. Therefore, it is structured in a similar manner to the first two, to allow comparison between these exercises in terms of my responses, the group process and the presentations. As my final reflective account of a PBL, I will also reflect on the learning that can be taken forward as I progress towards being qualified. I start by describing my initial responses to the PBL exercise.

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3 This account is written in the first person for ease of description and reading as a reflective piece of work.
Initial reactions

This exercise represented the forth PBL exercise that I have worked on since commencing clinical training. Looking back on my previous reflective accounts, my initial reactions regarding this exercise were quite different. In the first account, I reported apprehension and confusion regarding the PBL style of learning and working with a new group of people. In the second account, I felt more positive and looked forward to starting. On this occasion, I felt more comfortable with the PBL format and confident about the group’s ability to consider the problem and plan and present on it.

The group process

The group consisted of four second year TCPs and three third year TCPs (two males and five females). At the beginning of the exercise, we addressed practical issues such as how we would communicate (email and in face-to-face meetings) and when we would meet to plan and prepare our work. At this early stage, it was apparent that organising practical matters were fundamental to the success of the exercise as most group members had many other commitments and deadlines. I also noticed how (as with the previous exercise), the level of guidance and input from the course team was limited. I think that this reflected a reasonable and developmentally appropriate expectation that second and third year TCPs work with increased autonomy.

In terms of roles within the group, unlike previous exercises, a scribe and chair were not assigned. To begin with, I was a little concerned that there might be an expectation that third year TCPs might be perceived to be more experienced with such exercises and take the lead more than second years. However, in common with previous exercises, the group worked in a collaborative manner and contributions from group members were equal overall. In the previous PBL, I observed some initial apathy within the group. Similarly, I noticed that some group members might
be experiencing the task as an added pressure, competing with the demands of on­
going major research projects. I think that the group acknowledged this, which helped to contain the stress.

In our initial meeting, the group discussed initial thoughts and responses to the problem. I noticed that all group members (myself included), reflected far more heavily on their personal experiences (e.g. of family, parental divorce and so on) than in previous exercises. I wondered whether this might be because there was so much material in the exercise that we could relate to or whether we felt more comfortable to reflect openly and disclose personal information together. The group also shared our previous PBL experiences and presentations and thought about our aims for this exercise. One presentation I’d been involved in previously had been entertaining and humorous. Another had involved lots of ‘serious’ theory and references to research, whilst the most recent one had taken the form of an enacted multidisciplinary and multi-agency meeting. We decided that we did not want our presentation to be too ‘dry’ in terms of content and delivery but equally did not think that a very light­hearted approach would be appropriate or meaningful. At this stage, we did not discuss in great detail what format this presentation should take. This contrasts with previous PBLS when I’ve felt more pressured for the group to plan the presentation early, perhaps reflecting less anxiety with the current exercise?

As with a previous PBL, we decided to each write a narrative in the first person of family members to help us to engage further with the material. These were then shared by email and read before the next meeting, in which they were read aloud. We then considered the different positions of each family member, individual agendas and relationships. In addition, we thought about how what initially appeared to be a straightforward referral for cognitive functioning, contained many complexities. With this in mind, we began to discuss how issues (such as forgetting, intimate relationships and housekeeping standards) might be perceived differently if the referred individual had been 20 years younger. As we did this, we reflected on whether another individual in the family might have been more likely to have been
referred with a ‘problem’ instead. In subsequent meetings (we met six times in total), we decided to present the group’s work and thinking as family therapy sessions.

The presentation

The presentation that we produced took the form of two role plays of a family therapy session involving the key family members from the ‘problem’ described. The first role play demonstrated how the ‘problems’ might have been viewed and whose voices would have been privileged if all those involved were all 20 years younger. This gave us an opportunity to explore how age and expectations regarding family roles might impact on how and when individuals within families are viewed as having or being ‘problems’ that require external intervention. As we began the first role-play, we realised that the children of the named client would have been teenagers and that if they had voiced similar concerns, the ‘problems’ would have been viewed quite differently. We found ourselves viewing one of the teenage children as having difficulties coming to terms with his parents’ divorce and their subsequent relationships with new partners. In the second role-play, we enacted the circumstances with the family members being the older ages as initially presented. Here we noticed whose voices and opinions were privileged and demonstrated how the same circumstances and behaviour are viewed differently according to the ages of the players and the accompanying ideas about what is ‘appropriate’ at particular life stages. At the end, to bring the two role plays together, we presented some of the groups’ reflections regarding the problem. For example, we talked about the degree to which the exercise led us to think about and consider our personal experiences of family life and aging. In addition, we also brought in some of the theory and research relevant to our presentation. For example, ideas regarding older people being treated in a way that would be unacceptable to other groups in society (Stirling, 2004) and the application of Social Role Valorisation theory (Wolfensberger, 1983) to older adults. In terms of research, we discussed investigations regarding the impact of divorce on well-being and adjustment in adulthood (Amato & Keith, 1991; O’Connor et al., 1999)
On the basis of feedback from the audience and our own perspectives, the presentation was a success. In comparison with previous presentations, we felt less pressure to cover absolutely everything and were aware that other groups would cover different angles. Overall, I felt that we covered an adequate amount in sufficient depth given the time constraint of 20 minutes.

Re-evaluation of the group process

Generally, I think that the group worked very well together despite not knowing each other particularly well. I felt comfortable with the other group members and got the impression that this was shared by other group members as they were open in their responses to the exercise and shared their views and opinions in a frank and open manner. I think that this was facilitated by a mutual appreciation of each other’s competing demands from both the course and in our personal lives.

I feel satisfied with the approach that the group took to the exercise and feel that the contributions made by the group members were equal. In previous exercise, some group members took on particular roles and as a result, their contribution varied. However, in this exercise, I felt that group members’ contributions were far more equal and similar in nature. I wonder whether this is because it is the first time that we have worked together and had not had time to occupy particular roles within the group?

In contrast with other exercises, this particular one did not raise issues that became highly pertinent on subsequent placements as I was in a split placement working with PLDs and neuropsychological rehabilitation. However, it resonated far more with both my own and other group members’ personal experiences of issues within our own families (such as divorce, dementia, and family roles) than other exercises.
Overall, I really appreciated the chance to work with TCPs in other year groups. It not only allowed us to work together on a task and share ideas and experiences, it provided a great way to get to know each other better.

**Learning points**

As in previous PBL exercises, I learned a considerable amount from this task. Although it is yet to be directly drawn on and utilised, I believe that it will be of particular importance in my next placement in an older adult's service. A main learning point is the importance of considering the complexity of families and their histories (often spanning decades) in work with older clients. In addition, I have increased my awareness of the manner in which older people might be marginalised within their families and wider systems. It has also highlighted how my own experiences might influence my views and perspectives on issues and the need to be mindful of this. I hope that this awareness will continue to develop as I progress towards qualification as a Clinical Psychologist and throughout my career.

**Summary**

To summarise, this PBL exercise presented a problem involving a range of issues that might be of pertinence when working with older adults and their families. Writing this account and reflecting on previous accounts has enabled me to consider how my responses to these exercises has changed, how group processes have unfolded and how presentations have varied over an extended period of time as myself and my peers progress towards qualification as Clinical Psychologists. In addition, it has provided an opportunity to consider how relationships with my peers have developed on the course.
In retrospect, I have noticed how my approach towards and experiences of PBL exercises have mirrored my general state at each stage of training, beginning with anticipation and some reluctance, moving towards increasing confidence and positivity (with inevitable crises of confidence along the way!). In my first account, I wrote that I planned to be more open-minded and positive when new ways of working and learning (such as PBL exercises) are proposed. I hope that I have achieved this and continue to be to novel receptive approaches throughout my career.
References


Summary of Case Discussion Group Process Account

A reflective process account of the case discussion group in year I

September 2007

Year II
In this account, I reflected on my experiences within the case discussion group (CDG) in the first year of training. I began by situating it within the context of members undertaking year long placements in adult mental health. The account was then structured in a series of sections: the group members; the structure of the work; the contributions of group members (including myself); and the development of the group over time.

Throughout the account, I linked the CDG to other professional experiences (such as those on clinical placement), which have impacted on my experiences within the group and vice versa. I also reflected on the content and process of the group as it evolved over the year. Overall, my reflections on the group were that it had been a highly positive experience.

I concluded this account by noting how the CDG and the process of writing the account had been invaluable for both my personal and professional development by enhancing knowledge and skills relevant to clinical work, proving a supportive function and leading me to consider my reserved behaviour and contributions in specific group contexts. I also briefly considered the group in the future, with new facilitators, stating a wish for the group to continue to develop group and for member to continue to derive benefit from it.
Summary of Case Discussion Group Process Account

A reflective process account of the case discussion group in year II

July 2008

Year II
This account contained reflections on my experiences of the case discussion group (CDG) in the second year of training. I introduced the account by setting the background in terms of stage of training and group members being on placement either with People with Learning Disabilities or Children and Young People. As with the first account, I structured this account into the following sections: the group members; the structure of the work; the contributions of group members and myself; and the development of the group over time.

Throughout this account, I reflected back on the first process account of the CDG written at the end of the first year. I also linked the experiences within the CDG to other experiences related to the course. My reflections about the group remained positive and as a group we were struck by how harmoniously it functioned compared with other groups, which led us to search for conflict to no avail.

At the end of the account, I made several conclusions about the personal and professional benefits of the group and briefly considered the future of the group, looking forward to us completing our clinical training together in the coming year.
Clinical Dossier

This section contains descriptions and overviews of clinical placement experience gained in four core competencies placements and an advanced competencies placement. In addition, summaries of four clinical case reports and an oral presentation of clinical activity are presented. The full clinical case reports and documentation for the oral presentation are contained in Volume II of this portfolio. In addition, Volume II contains a full record of clinical activity, placement contracts, logbooks and evaluations.
Description and Overview of Clinical Experience
**Adult Mental Health Core Placement**

**Setting:** A Community Mental Health Team (CMHT) working with clients referred into secondary care services. The majority of the work was carried out at the CMHT base, with some opportunities for work with individuals, families and groups in day services, in-patient acute psychiatric settings and client homes.

**Models:** The main theoretical model was cognitive behavioural with some additional experience of psychodynamic and systemic psychotherapy.

**Clinical Experience:** This placement involved assessment and/or intervention with clients with a range of presenting problems including depression, social phobia, obsessive compulsive disorder (OCD), generalised anxiety disorder and psychosis. A number of assessment measures were used during this placement, including: WAIS-III-UK, NART-R, Rey Complex Figure Test, FAS, Trails, Young Schema Questionnaire, GHQ-12, Padua Inventory, OCQ, HADS, HVLT, Penn-State Worry Questionnaire, BDI-II, and BAI.

**Other Experiences:** Mood management group, presentations, teaching on family intervention for psychosis course to multidisciplinary audience, carer’s assessments, joint family intervention for psychosis work.

**People with Learning Disabilities Core Placement**

**Setting:** A joint community team for adults with learning disabilities. Clinical work was conducted in a range of settings including the team base, client’s homes, residential homes and day services.

**Models:** The main theoretical model was integrative, with additional experience of behavioural and cognitive behavioural therapy.

**Clinical Experience:** Assessment and/or intervention with clients, their families and paid/unpaid carers for a range of presenting issues including anxiety, depression, challenging behaviour, self-harm, anger, eligibility for services, dementia and autism spectrum disorders (ASDs). Assessments included the use of functional assessment procedures, observations, WAIS-III-UK, the Vineland Adaptive Behaviour Scales, the HALO, the BPVS, Oliver and Crayton Dementia Screening Test, Theory of Mind
Tests, the Guernsey Community Participation and Leisure Assessment, the Informal Test of Social Know How and the Early Signs of Dementia Checklist.

Other Experiences: Co-facilitation of a relationships and sexuality group with women with learning disabilities, presentation to local psychologists of a case to illustrate issues related to restrictive practices.

**Children and Young People Core Placement**

Setting: A Child and Adolescent Mental Health Service (CAMHS). Generally work was conducted at the CAMHS base. However, there were other chances to work with individuals at home and in schools.

Models: Mainly cognitive behavioural with the opportunity for behavioural and systemic experience.

Clinical Experience: Assessment and/or intervention with clients, their families and teachers for a variety of presenting problems. For example, simple phobias, low self-esteem, pica, encopresis, anger, self-harm, Attention Deficit Hyperactive Disorder (ADHD) and ASDs. A range of assessment measures were employed during this placement including: WISC-IV-UK, WIAT, Child Memory Scale, SDQ, HONOSCA, Connor’s Teacher and Parent Rating Scales, Social Communication Questionnaire, Social Behaviour Questionnaire, Draw a Family and Draw a Person.

Other Experiences: Case presentation to psychologists, attendance at multidisciplinary ADHD clinic, weekly attendance at the family therapy training clinic.

**Older People Core Placement**

Setting: An inpatient psychiatric ward for people over the age of 65. The majority of the work was carried out on this ward. However, there were also opportunities for working on a ward for people with dementia, in day services and in client’s homes.

Models: The main theoretical model was integrative, with some additional experiences of psychodynamic and cognitive behavioural therapy.
Clinical Experience: Assessment and/or intervention with clients with a range of presentations including depression, anxiety, psychosis, bi-polar affective disorder, dementia and challenging behaviours. Additional assessment measures employed included: the CORE; HADS; GDS; and MMSE.

Other Experiences: Co-facilitation of reflective practice group for nurses. Planning and co-facilitation of a carer’s support group and a patient discussion group. Training provided to nursing staff on life story work. Presentation about the brain made to local psychologists.

Advanced Competencies Placement—People with Learning Disabilities and Neuropsychology

Setting: This was a split placement between a community team for adults with learning disabilities and a community neuro-rehabilitation team. Work was typically carried out at the team bases. However, there were opportunities for working in day services, client’s homes and residential settings.

Models: The main model utilised was cognitive behavioural. However, subsidiary models employed were: narrative, neuropsychology models of brain-behaviour relationships and biopsychosocial models of health and disability.

Clinical Experience: Assessment and/or intervention with clients with a range of presentations including depression, psychosis, bereavement issues, memory difficulties, bi-polar affective disorder, Dysexecutive syndrome, anger, coprophagy and OCD. The assessment measures used included the WAIS-III-UK, WTAR, WMS-III, RBANS, CVLT-II, HADS, HONOos-LD, Trails, FAS and Animals, Wiegl Colour Form Sort Test, Schonell Reading Test, Hayling and Brixton Test of Dysexecutive Syndrome, Rey Complex Figure Test, BADs, Illness Perception Questionnaire, adapted BDI and BAI for people with learning disabilities.

Other Experiences: Planning and co-facilitation of a ‘managing your feelings at work’ group for young people with ASDs. A range of clinical governance projects including: a client satisfaction survey, an ethnicity audit, a consent and records keeping audit, planning and organisation of an in-service training programme.
Adult Mental Health Case Report I Summary

Cognitive behavioural therapy with a woman in her 30s presenting with social anxiety, depression and obsessive compulsive symptoms

April 2007

Year I
Referral and Presenting Problem

Carol was a white British woman in her late-thirties referred to the CMHT by her GP with social anxiety (SA), depression and obsessive-compulsive disorder (OCD). Carol reported a long history of difficulties and seeking help due to concerns regarding her children developing similar problems should hers persist.

Assessment

Information collected during assessment was drawn from clinical interviews, psychiatric notes and colleagues. Carol also completed standardised measures of anxiety, depression, social anxiety and OCD. Her scores suggested severe difficulties in every area.

Formulation

Carol's difficulties were formulated within a cognitive framework. It was hypothesised that Carol's family history of anxiety and depression may predispose her to such difficulties. General stresses and particular events triggered assumptions and beliefs leading to negative automatic thoughts. Carol's avoidance and safety behaviours decreased her difficulties in the short-term. But reinforced her anxiety, depression and negative beliefs, over the long term as there were no opportunities to disconfirm her fears. Thus, Carol's thoughts interacted with her mood and behaviour maintaining her anxiety and depression.

Intervention

I met with Carol for six intervention sessions, aiming to address her SA. The intervention was based on a cognitive model of SA (Wells & Clark, 1997), focusing on: rapport building; socialisation to the model; relaxation; and cognitive restructuring.

Outcome

Carol attended six of twelve sessions offered before discontinuing therapy. Therefore, it was not possible to determine if she had benefited. Carol's difficulties were reformulated with reference to Prochaska and DiClemente's (1992) transtheoretical model of change.
Adult Mental Health Case Report II Summary

Behaviour therapy with a man in his 20s presenting with obsessive compulsive disorder

September 2007

Year II
Referral and Presenting Problem

Toby was an Asian British man in his late twenties referred to the CMHT by his GP for OCD. He reported OCD characterised by checking behaviours, starting as a teenager.

Assessment

Information collected was drawn from clinical interviews, psychiatric notes and baseline measures of anxiety, depression and OCD, which suggested moderate to severe difficulties.

Formulation

Mowrer's (1960) two-factor theory of fear acquisition and maintenance was employed to formulate Toby’s OCD. This asserts that once fear is acquired via classical conditioning, when presented with a feared stimulus, an organism will escape or avoid, resulting in reduced anxiety (which is rewarding and thereby negatively reinforced). Subsequently, the fear response is maintained via operant conditioning. As the conditioned stimulus is not confronted, new learning about the original fear association does not occur. In Toby's case, avoidance and checking reduced his anxiety but over the long-term, maintained it. It was also hypothesised that Toby's family history of mental health problems may predispose him to such difficulties and general stresses (as well as particular cues) appeared to precipitate Toby's OCD.

Intervention

I met with Toby for twelve sessions to address his checking behaviours, using a behavioural approach: exposure and response prevention (ERP). Cognitive elements were also incorporated to address unhelpful thinking.

Outcome

Toby made significant improvements, reporting confidence in his ability to continue applying ERP to his OCD. He also reported that it was useful discussing his OCD in depth. These improvements were reflected in Toby’s scores on baseline measures.
People with Learning Disabilities Case Report Summary

A neuropsychological assessment of a male with Down’s syndrome in his late 50s, presenting with memory difficulties

April 2008

Year II
Referral and Presenting Problem

Peter was a 59-year-old man from a white British background with Down’s syndrome (DS). He was referred to psychology by his Care Manager for a baseline neuropsychological dementia assessment following two suspected seizures and memory loss.

Assessment

Information gathered for this assessment came from clinical interviews with Peter and individuals that support him as well as the following neuropsychological tests: WAIS-III-UK; British Picture Vocabulary Scale; Crayton and Oliver Dementia Screening Test; Hampshire Assessment Scale for Living with Others: Short Form; Vineland Adaptive Behaviour Scale; and the Early Signs of Dementia Checklist.

Outcome and Recommendations

A diagnosis of dementia could not be given at that time as the assessment was a baseline. Although it was difficult to compare the current IQ scores with the previous IQ, in general terms any decline in social functioning was unremarkable and no particular weaknesses were found in terms of memory.

It was recommended that follow-up assessments in the future would be required before any tentative diagnoses might be made. In addition, it was recommended that life-story work be carried out in collaboration with Peter, to act as a trigger to stimulate memories and improve mood. It might also assist carers in understanding him as an individual with a history. Peter was interested in this idea and his Support Worker keen to get involved.

Neuropsychological reports were circulated to professionals involved in Peter’s care. Peter was also provided with an accessible report summarising the outcome and recommendations of the assessment.
An eclectic intervention with a 10-year old boy presenting with anger and aggressive behaviour

September 2008

Year III
Referral and Presenting Problem

Scott was a 10-year old white British boy with a learning disability and difficulties with speech and language. He was referred to the child and adolescent mental health team for help regarding anger and physical aggression towards himself and his mother.

Assessment

Information gathered for this assessment came from clinical interviews with Scott and his parents and the use of outcome measures used within the service.

Formulation

Scott’s difficulties were formulated with reference to learning theory (in terms of modelling and positive and negative reinforcement). His specific difficulties as well as his family circumstances were hypothesised to predispose Scott to anger and aggression.

Intervention

I met with Scott for eight sessions. A creative approach was taken to this intervention, which took into account the specific needs of him and his family. In particular, communication and engagement skills were of paramount importance. The intervention was eclectic in approach, for instance incorporating behavioural ideas as well as practices from narrative therapy. Throughout the intervention, Scott’s parents were given guidance and advice and included as far as possible.

Outcome

Initial responses to the intervention were positive and parental reports suggested that Scott’s aggressive behaviour was greatly reduced. However, the summer holidays saw an increased frequency of aggressive behaviour. The intervention was ended shortly after in order to give the family an opportunity to consolidate changes they had previously made.
Advanced Competencies Case Report Summary

Behavioural assessment and management for a woman with a profound learning disability in her fifties presenting with coprophagy.

April 2009

Year III
Referral and Presenting Problem

Linda was a woman in her late 50s with a profound learning disability and cerebral palsy living in a residential care home. She was referred to the psychology department of the Community Team for People with Learning Disabilities for challenging behaviour. The behaviours of concern were faecal smearing and coprophagy.

Assessment

Information for assessment was gathered from a variety of sources including: interviews with care staff; a review of Linda’s records (including a Psychology assessment report, a Speech and Language Therapy report and a Social Work report); behaviour monitoring forms and Motivational Assessment Scales completed by staff.

Formulation

A formulation based on learning theory was presented highlighting the potential role of positive reinforcement (in the form of social contact and sensory stimulation) and negative reinforcement (in terms of removal of physical discomfort).

Intervention

The intervention consisted of the development and presentation of a psychological formulation to increase care staff understanding of this woman and a series of proactive and reactive guidelines aiming to reduce her reliance on the behaviours of concern to provide attention and stimulation and reduce the (inadvertent) reinforcement provided by social contact during the consequent personal care.

Outcome

An evaluation of this intervention was conducted. This highlighted that there was some decrease in the behaviours of concern. However, it appeared that staff had not fully understood either the formulation or the guidelines fully. As a result, further recommendations were added to resolve this and additional evaluation was planned for the future.
Case Report Summary References


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Davey. (Ed.) Phobias: A handbook of description, treatment and theory. Chichester:
Wiley.

Psychological Corporation.
Research Dossier

This section comprises the research undertaken over the three-year course. It includes: a research log checklist; a service related research project; the abstract from a group qualitative research project and the major research project.
Research Log Checklist

A summary of research activity conducted over the three years of training

July 2009

Year III
# Research Log Checklist

<table>
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<tr>
<th></th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Formulating and testing hypotheses and research questions</td>
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</tr>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and</td>
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<td></td>
<td>literature search tools</td>
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<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
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</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
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</tr>
<tr>
<td>5</td>
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<tr>
<td>6</td>
<td>Writing detailed research proposals/protocols</td>
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</tr>
<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of</td>
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</tr>
<tr>
<td></td>
<td>diversity, and structuring plans accordingly</td>
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<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
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</tr>
<tr>
<td>9</td>
<td>Obtaining appropriate supervision for research</td>
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<tr>
<td>10</td>
<td>Obtaining appropriate collaboration for research</td>
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<tr>
<td>11</td>
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<tr>
<td>12</td>
<td>Choosing appropriate design for research questions</td>
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<tr>
<td>13</td>
<td>Writing patient information and consent forms</td>
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<tr>
<td>14</td>
<td>Devising and administering questionnaires</td>
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</tr>
<tr>
<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
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</tr>
<tr>
<td>16</td>
<td>Setting up a data file</td>
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</tr>
<tr>
<td>17</td>
<td>Conducting statistical data analysis using SPSS</td>
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</tr>
<tr>
<td>18</td>
<td>Choosing appropriate statistical analyses</td>
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<td>19</td>
<td>Preparing quantitative data for analysis</td>
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<td>20</td>
<td>Choosing appropriate quantitative data analysis</td>
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</tr>
<tr>
<td>21</td>
<td>Summarising results in figures and tables</td>
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<tr>
<td>22</td>
<td>Conducting semi-structured interviews</td>
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<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods</td>
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<td>Choosing appropriate qualitative analyses</td>
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<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
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</tr>
<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
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<tr>
<td></td>
<td>Producing a written report on a research project</td>
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<td>27</td>
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<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
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<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
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<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
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Service Related Research Project

A service evaluation of family intervention for psychosis training

July 2007

Year I
Abstract

Title: A Service Evaluation of Family Intervention for Psychosis training.

Objective: To investigate post-training implementation issues experienced by those trained in Family Intervention.

Design: A questionnaire was sent to individuals who had completed Family Intervention for psychosis training.

Setting: A large NHS Mental Health Trust.

Participants: Sixteen members of multi-disciplinary staff trained in Family Intervention.

Measures: A questionnaire comprising both open and closed questions that had been employed in similar previous research into implementation of FI training, adapted from that used by Fadden (1997) in a study of Family Intervention training (based on that of Kavanagh et al. 1993).

Results: Limited impact of training on clinical work was demonstrated. The main difficulties experienced in implementing this approach were related to the issues of availability of appropriate clients, time to do family work and integration of the work with existing workload. Promotion and prioritising of the Family Intervention approach as well as support and supervision were reported to help overcome difficulties and implement family work. Overall, the training was thought to have had a positive impact on the work of those trained. Difficulties in attending supervision related to the time required attending and competing work demands. Suggestions provided to overcome these were related to the provision of local supervision and reduction of length of supervision.

Conclusions: This study has demonstrated that there are considerable difficulties in implementing Family Intervention work into routine clinical practice and considered recommendations that can be made on the basis of these findings.
Acknowledgements

Thank you to the family workers within the trust who participated in this project. Many thanks to my clinical supervisor, the Trust Lead for family work and research tutor for their support and guidance in undertaking this project. Finally, thanks to Gráinne Fadden for her permission to use the adapted questionnaire.
Introduction

Family intervention (FI) for psychosis is a collaborative approach to working with service users and carers. FI aims to build on families' existing strengths and enhance problem-solving skills whilst promoting independence, understanding of and recovery from psychosis. FI evolved from research investigating the impact of the family on the course of psychosis. It was found that level of Expressed Emotion (EE) is a risk factor for relapse (Brown, 1985) and in particular over-involvement, critical comments and hostility (Kuipers, 1992). FI aims to reduce EE (and thus relapse risk) within families. A strong and long-established evidence-base exists for the efficacy of FI for psychosis. For example, Pilling et al. (2002) conducted a meta-analysis, which supported the use of FI in reducing relapse over a range of other treatments.

FI is clearly supported by national policies and guidelines. For example, the National Service Framework for Mental Health (DoH, 1999) emphasises the importance of provision of services for the carers of users of mental health services. In addition, FI is recommended in the National Institute for Health and Clinical Excellence guidelines for schizophrenia (NICE, 2002), which state that FI should be offered to individuals with schizophrenia who have family contact.

Training in FI is provided by some NHS Trusts (e.g. Somerset and Buckinghamshire). However, it is not routinely established and where available, there is evidence of obstacles to implementation of skills (e.g. Fadden, 1997; Bailey et al. 2003). Bailey et al. (2003) report the main three problem areas in implementation as time allowed to do FI, integration with existing caseload/other responsibilities and knowledge and skills in FI. Fadden (1997) reports availability of

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4 The term 'psychosis' is used throughout for the sake of consistency. However, within the literature the term 'schizophrenia' is also used interchangeably with 'psychosis'.

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appropriate clients, engagement of clients/families and integration with existing caseload/other work responsibilities as the three greatest difficulties.

In recent years, FI training has taken place within a large Mental Health NHS Trust, delivered either as part of a Psychosocial Interventions course or a 5-day in-house course. By February 2007, 33 staff had been trained as Family Workers (FWs) for at least three months. It was intended that these skills would be incorporated into clinical practice. However, given the difficulties noted elsewhere, it was anticipated that similar issues would arise locally. However, this was yet to be explored and it was considered useful to investigate both the extent to which FI was being employed and to determine problems encountered. It was hoped that this would enable recommendations to be made to address identified difficulties.
Aims

This study aimed to investigate implementation issues experienced by those who have undertaken FI training. More specifically, to:

1. Find out how many families participants have worked with, the diagnoses of named service users receiving FI, numbers of people attending sessions and number of families that participants feel could benefit from FI.

2. Identify difficulties participants have experienced in implementing FI and the measures taken to address difficulties.

3. Explore factors that participants think have helped them to work with families.

4. Examine the impact of FI training on participants' work generally.

5. Investigate the ease of accessing FI supervision and participants’ ideas for improving attendance.
Method

Participants

At the time of the study, 33 members (12 male (36 per cent) and 21 female (64 per cent)) of current staff had completed FI training and were invited to take part in the study. Sixteen responded (response rate of 48 per cent). The participants consisted of five men (31 per cent) and eleven women (69 per cent). The occupational backgrounds of participants are presented in Table 1. Participants had completed training a mean of 8.54 months ago (range 5-13 months, SD= 3.43). One respondent had been trained for nine years and was excluded from this analysis as an outlier.

Table 1: Demographic characteristics

<table>
<thead>
<tr>
<th>Professional background</th>
<th>Total FW’S trained (%)</th>
<th>Participants (%)</th>
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</thead>
<tbody>
<tr>
<td>Nursing</td>
<td>23 (70)</td>
<td>9 (56)</td>
</tr>
<tr>
<td>Psychology</td>
<td>5 (15)</td>
<td>5 (31)</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>1 (3)</td>
<td>1 (6)</td>
</tr>
<tr>
<td>Service development</td>
<td>1 (3)</td>
<td>1 (6)</td>
</tr>
<tr>
<td>Social Work</td>
<td>2 (6)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>1 (3)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total FW’S trained (%)</th>
<th>Participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>21 (64)</td>
<td>11 (69)</td>
</tr>
<tr>
<td>Male</td>
<td>12 (36)</td>
<td>5 (31)</td>
</tr>
</tbody>
</table>

Measure

The questionnaire (See appendix A) used had been employed in similar previous research into implementation of FI training. It was adapted slightly from that used by
Fadden (1997) in a study of FI training (based on that of Kavanagh et al., 1993), in order to increase its relevance to the local context.

The questionnaire took approximately 15-30 minutes to complete and comprised both open and closed questions. Closed questions related to whether participants had worked with families since training and the number of families worked with. Participants were also asked to rate how difficult they found FI to use on a six-point scale from 0 ('not at all') to 5 ('impossible'). In addition, they were asked to rate level of difficulty experienced in 33 areas on a five-point scale from 0 ('none') to 4 ('extreme'). Other questions concerned diagnoses of named service users in families seen and the range and mean number of people attending sessions. Open questions addressed factors that helped and hindered using FI, the impact of the training on participants' work and supervision. Reliability and validity data was unavailable for this measure but its face validity appeared adequate.

**Procedure**

In January 2007, the Trust FI Lead emailed all FWs informing them about the study to prime them and encourage responses. Questionnaire follow-up was assertive to maximise response rates. Between February and May 2007, each FW was contacted on eight occasions by email and post and also accessed in person via three monthly FI supervision sessions and a skills revision workshop.

On each occasion, the questionnaire and a covering letter (see appendix B) were sent. The letter explained the study's purpose, what participation involved and assured anonymity. It was clarified that feedback would be provided to managers regarding difficulties encountered. It was crucial that FWs did not feel the purpose was to individually assess them to increase responses and encourage openness. Therefore, the letter emphasised that this was not the intention. Completed questionnaires were returned directly to the investigator via email or post.
Analysis

As the questionnaire contained a number of fixed-choice, closed questions, these were analysed after entry to Statistical Package for Social Sciences Version 14 (SPSS, Chicago, USA). Missing quantitative data were identified using a specified code. 19 per cent of data were missing from items related to difficulties implementing the approach. Three respondents stated that they felt unable to answer these items, as they were not using the approach. Next, descriptive statistics were produced. One respondent's data was identified as an outlier. This individual had trained a number of years longer and had seen a higher number of families than the rest of the sample. Therefore, this data was removed from the descriptive statistics calculated for aim one as it was anticipated that these responses would skew the results.

Open questions were analysed using thematic analysis (Braun & Clarke, 2006), a theoretically flexible approach to qualitative data analysis that involves exploring data to identify themes and patterns. Results for each aim of the study are reported separately for clarity.
Results

Aim 1: Implementation of skills since training

Nine (56 per cent) respondents reported using FI since training. The mean number of families seen per FW (employing FI) was 1.75 (range 1-2, SD= 0.46). Approximately half of families having FI had a relative with a diagnosis of psychosis, with the remaining families having a relative with a range of diagnoses but most significantly bi-polar affective disorder (see Table 2).

The mean number of people attending family sessions was 2.44 (range 2-3, SD= 0.46). The mean number of clients that respondents felt could benefit from FW on their caseload was 2.4 (range 2-6, SD= 1.84).

Table 2

Presenting problem of families offered family work

<table>
<thead>
<tr>
<th>Disorder/Presenting problem</th>
<th>No. of Families</th>
<th>% of those families seen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosis</td>
<td>12</td>
<td>48</td>
</tr>
<tr>
<td>Bi-polar</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Anxiety</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Other (Body Dysmorphic Disorder x 2, Personality Disorder x1 and undecided diagnosis x1)</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100</td>
</tr>
</tbody>
</table>
**Aim 2: Difficulty in implementing Family Intervention**

Seven FWs reported no/little difficulty using FI, three reported moderate difficulties, one reported extreme difficulty and one reported it impossible to use. The mean difficulty rating was 1.67 (range 0-5, SD= 1.5).

Participants were asked to rate their difficulties in 33 areas that could affect ease of using FI. The mean difficulties reported are listed in Table 3 (appendix C) according to level of difficulty experienced. The areas participants reported they experienced greatest difficulty in were: availability of appropriate clients; allowance of time to do FI; and integration with caseload.

When asked an open question about the difficulties/challenges experienced in using FI, four salient but linked themes could be identified, difficulties getting referrals from colleagues, the teams' mindset, competing demands in workload, and lack of confidence. Many respondents highlighted that it was difficult getting colleagues to identify appropriate families for FI. This appears to be linked with problems reported getting colleagues to value FI as integral rather than additional to their work:

> 'Lack of referrals - the team has competing issues at the forefront of its mind - family intervention is not given a high profile within the team'

(Participant 13)

> 'Getting the team to see working with carers as part of our job and not an extension'

(Participant 7)

Several respondents mentioned competing work demands as an important issue. It appeared that this inhibited their opportunity to practise their skills causing low confidence regarding their ability to do FI and deal with potential conflict in this work:
'Lack of confidence/practice/opportunities...Lack of confidence that I will be able to deal with the emotion and the family arguments that might be prompted’

(Participant 5)

In terms of attempts made to deal with these difficulties, the concepts of promotion and prioritising were identified. Many respondents dealt with the issue of no referrals by ‘selling’ the approach at individual and team level and also talked to families to introduce FI. In addition, attempts were made to deal with competing demands through promotion to managers to agree protected time.

‘Increasing awareness in team by talking in team meeting/to individual care co-ordinators, plus providing written information’

(Participant 4)

‘We have talked to the families about the potential benefits of using the approach’

(Participant 8)

‘Meeting with line and professional manager to agree protected time - emphasis on delivering NICE guidelines’

(Participant 2)

Many respondents suggested prioritising FI work as a way of overcoming challenges in its implementation, through both practical means and individual commitment:

‘Prioritise/reduce caseload’

(Participant 5)
"Giving it priority in my own mind - making my personal commitment"

(Participant 13)

Participants were asked to comment on the outcome of these attempts and the main points distinguished were related to perceived success and failure. Generally attempts to communicate with others and prioritise FI led to success in generating referrals and securing time for FI:

"Team have actually formally referred clients/families. Have worked with 2 families so far and about to start with two more"

(Participant 4)

"Am now seeing two families and have slotted into schedule"

(Participant 6)

However, other respondents reported that their attempts to communicate with families were only partially successful:

"..in both cases, either the sole-carer or service-user has made it very clear that they do not want to."

(Participant 8)

**Aim 3: Factors facilitating Family Intervention**

Respondents suggested that the approach itself; support and commitment; and supervision helped them to work with families. Many respondents suggested that aspects of FI, such as the tools used and the opportunity to include and listen to families were important in facilitating FI:
"The family seem to respond well to this specially allocated time. They feel included and listened to..." (Participant 12)

"...using the tools available, having a very structured approach, the lack of mystique or jargon around family work"

(Participant 5)

"Support of supervisor and other team members. Attendance at supervision"

(Participant 6)

**Aim 4: Impact of training on family workers' work**

Participants reported positive impacts of FI training to their work. An overarching theme of professional development was identified, with improvements across a range of domains: knowledge and understanding; skills; and collaboration.

"... has equipped me with lots of skills. Made me aware of the important role of family...it's about working together with families to deliver the best possible care."

(Participant 11)

**Aim 5: Supervision**

Two main issues emerged from responses regarding ease of accessing supervision; clashes with other commitments; and time. Many participants echoed sentiments related to difficulties in implementing FI due to other commitments:
‘Emergency/urgent visits to clients, heavy caseload..., leave’

(Participant 8)

Many respondents also highlighted that the time required attending supervision:

‘Time commitment - 3 hours plus travel time is very. long’

(Participant 6)

Suggestions for improvement included changes to supervision and; changes to existing workload. With regards to changes to supervision, local supervision, different days, shorter sessions and alternatives to meeting in person were suggested:

‘Shorter times/local supervision’

(Participant 6)

‘on-line supervision via internet...telephone supervision’

(Participant 12)

Participants also made suggestions related to their current workload:

‘Smaller caseload’

(Participant 8)
Discussion

This project aimed to examine the implementation of skills subsequent to FI training and achieved the original aims set. As with previous studies, limited impact of training on clinical work was demonstrated (e.g. Fadden, 1997), with only 56 per cent of respondents using FI and the mean number of families seen by active workers being 1.75. For example, Fadden reported 70 per cent of respondents engaging in FI, with a mean of 1.7 families (Fadden, 1997). However, a much shorter time since training had elapsed in this study compared with Fadden's (1997) study (range 9-42 months). In addition, this study demonstrated that FI is being employed with service users with a range of diagnoses other than psychosis, highlighting the applicability of these approaches to a wide range of difficulties.

With regards to specific difficulties in implementing FI, most difficulty was reported with availability of appropriate clients, allowance of time to do FI and integration with caseload. This is consistent with similar studies. For example, Fadden (1997) also found lack of availability of appropriate clients to be a primary difficulty. It is not clear why, as FI should be offered to everyone with a diagnosis of psychosis who has family contact (NICE, 2002). Fadden (1997) suggests that this might reflect an attitudinal problem about who constitutes an ‘appropriate’ client. However, in the present study, it could be related to the difficulties reported in getting referrals from colleagues rather than FWs inability to identify suitable families. Allowance of time for FI was also reported as a difficulty by Bailey et al. (2003) and integration of FI with existing caseload and work responsibilities was reported as problematic by both Fadden (1997) and Bailey et al. (2003). Respondents found prioritisation and promotion of FI to be generally effective in overcoming these difficulties and identified a range of factors that helped to use FI (the approach itself; support and commitment; and supervision).

With regards to the wider impact of FI training, the majority of respondents reported an overall positive impact on their professional development with regards to knowledge, understanding, skills and collaboration with families. Similarly, Bailey et
(2003) reported increased confidence and improvements in quality of clinical work after FI training. In contrast Fadden (1997) found that only a third of respondents felt training had improved their skills and engagement with families. With regards to supervision, time and workload constraints were reported as posing difficulties in attending. Similar problems are reported in other studies (e.g. Fadden, 1997).

Service-related implications and recommendations
This project has provided useful information that can be fed-back to emphasise specific problems concerning implementation of FI skills and to address these particular difficulties. This will assist in making the best use of training and resources within the Trust. In particular, managers will be alerted to the need to allow FWs sufficient time to engage in FI and supervision. In addition, the issue of staff commitment to the approach is important. One possible solution is to offer training and supervision to a core, committed group rather than training greater numbers who may be unable to employ these skills.

This study has also provided important information to be fed-back to existing and future FWs through supervision and training. For example, it should be made clear that support and commitment, and promoting and prioritising FI are vital to overcome barriers and implement FI.

With regards to the findings related to supervision, many of the suggestions proposed are already being put in place (such as local supervision). However, the idea of reducing the length of supervision could be considered and will be fed-back to the lead for FI.

Limitations
Despite assertive follow-up requests, the response rate (48 per cent) was poor. Therefore, it cannot be assumed that the results are an accurate representation of the experiences of all trained FWs. As Fadden (1997) argues, it is more likely that responders are using FI than non-responders. Therefore, the results may exaggerate
the extent that the skills were being employed. In addition, despite best efforts to reassure FWs, they still might have felt that they were being evaluated which could partially explain the low response rate. However, the sample was representative in terms of gender although psychologists were over-represented and nurses underrepresented.

An additional limitation is the short time gap between training and evaluation. Given the difficulties in integrating FI into existing caseloads, it is likely that FWs would need considerable time to start FI. Therefore, it is recommended that this study be replicated in the future to provide a better understanding of implementation of FI and allow fair comparison with other studies.
Conclusions

To conclude, this study has identified a range of barriers to implementing FI locally. The main issues were related to conflicting demands of work and lack of time limiting opportunities to use FI. It is imperative that these are addressed to make training worthwhile. As Fadden (1997) argues FI is effective and can reduce care costs but if training is unused, the costs (in terms of time, effort and money) may outweigh benefits.

The findings of this study were presented at a multidisciplinary academic meeting attended by mental health professionals. Feedback has also been given to the lead for FI for dissemination to managers and FWs during training and supervision.
References


Appendices
Appendix A

Questionnaire
SCHIZOPHRENIA FAMILY WORK QUESTIONNAIRE

CONFIDENTIAL: PLEASE PLACE IN A SEALED ENVELOPE AFTER COMPLETION

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NAME ................................................................ DATE

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PROFESSION .................................... TEAM/WARD/UNIT

............................................................

DATE WHEN YOU COMPLETED SCHIZOPHRENIA FAMILY WORK COURSE:...........

1. Have you been able to take on any work with families after completing using the Schizophrenia Family Work approach? YES/NO

If yes, how many families have you worked with? (Only include families that you have worked with for at least three sessions.)

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<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>More than 5</th>
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2. How difficult have you found it to use the Schizophrenia Family Work approach in your work?

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<th>0</th>
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<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>Not at all</td>
<td>A little</td>
<td>Moderately difficult</td>
<td>Very</td>
<td>Extremely</td>
<td>Impossible</td>
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3. **What have been the main difficulties or challenges in using the approach?**

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<thead>
<tr>
<th>Difficulty/Challenge</th>
<th>Attempted Solution</th>
<th>Result</th>
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4. **How have you attempted to deal with them?**

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<th>Difficulty/Challenge</th>
<th>Attempted Solution</th>
<th>Result</th>
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5. **What was the result of these attempts?**

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<tr>
<th>Difficulty/Challenge</th>
<th>Attempted Solution</th>
<th>Result</th>
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</table>
6. If you have been able to work with families, what factors helped you to do so?

Please complete this side of the page before turning over.
7. HOW MUCH DIFFICULTY HAVE YOU EXPERIENCED WITH EACH OF THE FOLLOWING?

(Please circle appropriate number)

<table>
<thead>
<tr>
<th>AMOUNT OF DIFFICULTY</th>
<th>None</th>
<th>Moderate</th>
<th>Extreme</th>
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<tr>
<td>Availability of appropriate clients</td>
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<td>2</td>
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<tr>
<td>Allowance of time from the service to do the intervention</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Availability of time in lieu or overtime for appointments</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Knowledge and skills in behavioural techniques</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Knowledge and skills in family intervention</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Clash with my preferred treatment approach</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Integration with my caseload or other responsibilities at work</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Integration with my outside interests responsibilities, e.g., my own family commitment</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Access to consultation or supervision</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Non-applicability of the programme to the needs of clients or families</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Gaps in my general clinical skills (or lack of confidence in them)</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Lack of knowledge/recognition by my colleagues of the value of family work</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Lack of support by managers for the value of the family work</td>
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<td>1</td>
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<td>Statement</td>
<td>Score</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>The use of assessment measures</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liaison with private practitioners</td>
<td>0 1 2 3 4</td>
<td></td>
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</tr>
<tr>
<td>Collaboration with my co-therapist</td>
<td>0 1 2 3 4</td>
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<td>The family intervention manual (e.g., understandable? adequate?)</td>
<td>0 1 2 3 4</td>
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<td>Time needed before the result became apparent</td>
<td>0 1 2 3 4</td>
<td></td>
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<td>Colleagues would not let me work with families they are involved with</td>
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<td>Clashes of family sessions with crises with other clients</td>
<td>0 1 2 3 4</td>
<td></td>
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</tr>
<tr>
<td>Travel to family sessions</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
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<td></td>
<td></td>
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<td>Long-term commitment to a specific client or family</td>
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<tr>
<td>Lack of progress by clients or families</td>
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<td></td>
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<td>Adequacy of the training given by the training sessions</td>
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<td></td>
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<td>Engagement of clients or families</td>
<td>0 1 2 3 4</td>
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<tr>
<td>Tailoring the programme to individual families and their needs</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Ensuring that family sessions had positive tone</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keeping to the concept that I was trying to teach</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developing specific goals for sessions</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keeping family discussion on track</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness or holidays (mine)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
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</tr>
<tr>
<td>Illness or holidays (clients or family)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Other (specify):</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8. Of those families you have worked with using Schizophrenia Family Work, what was the main presenting problem?

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>NUMBER OF FAMILIES SEEN WITH THIS PROBLEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
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<tr>
<td>Bi Polar</td>
<td></td>
</tr>
<tr>
<td>Dual Diagnosis</td>
<td></td>
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<tr>
<td>Anxiety</td>
<td></td>
</tr>
<tr>
<td>Obsessive-Compulsive disorder</td>
<td></td>
</tr>
<tr>
<td>Marital</td>
<td></td>
</tr>
<tr>
<td>Other (specify):</td>
<td></td>
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</table>
9. What was the range (smallest & largest) and average number of people attending family sessions?

<table>
<thead>
<tr>
<th>RANGE</th>
<th>AVERAGE NO. OF PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10. Have you used components of Schizophrenia Family Work with individuals? YES/NO.
    If yes, to what extent do you do so?

<p>| | |</p>
<table>
<thead>
<tr>
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<td></td>
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<tr>
<td></td>
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</tr>
</tbody>
</table>

11. Do you work with families using other family therapy models? If so, what approaches do you use?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
12. What difference has attending the Schizophrenia Family Work course made to your work?

13. Do you see families now more frequently than you did prior to attending the course?

YES/NO.

14. In your opinion, how many families on your case list could benefit from a Schizophrenia Family Work approach?

SUPERVISION

It has sometimes been difficult for people to attend supervision sessions. What factors have made it difficult for you to attend supervision sessions?
What would make it easier for you to attend?

Are there ways in which we could change the supervision sessions that would make it more likely that you would attend?
If so, please suggest.

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE.

PLEASE RETURN IT IN THE STAMPED ADDRESSED ENVELOPE PROVIDED.
Appendix B

Covering Letter
Dear name,

I am inviting you to take part in a service evaluation of the implementation of Family Intervention (FI) for psychosis training in clinical practice in XXX NHS Trust (XXX). You have been selected to participate as you have completed FI training.

Taking part involves completion of a questionnaire regarding how you have used FI skills since training, the difficulties you may have encountered and the factors that have facilitated use of FI in your practice. This questionnaire takes about fifteen minutes to complete. Please be assured that your individual responses will be completely anonymous and that the purpose of the project is to identify general patterns rather than assessment and evaluation of individuals.

This service evaluation is a partial requirement of a doctoral training programme at the University of Surrey to become a qualified Clinical Psychologist. The results will be feedback to both Family Workers and managers within XXX in order to highlight the factors that have helped and hindered carrying out FI in clinical practice.

If you decide to take part, please complete the enclosed questionnaire and return it to me in the attached stamped addressed envelope.

If you have any question or would like more information, you can contact me via email (xxx) or by leaving me a message at XXXX Community Mental Health Team (XXXXX) and I will get back to you.

Many Thanks,

XXX XXX
Trainee Clinical Psychologist
XXX CMHT
Appendix C

Table 3: Difficulties experienced by FWs in implementing FW.
Table 3

Difficulties Experienced by Family Workers in Implementing Family Work.

<table>
<thead>
<tr>
<th>Area of Difficulty</th>
<th>Mean Difficulty (SD)</th>
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<tr>
<td>Availability of appropriate clients</td>
<td>2.38 (1.04)</td>
</tr>
<tr>
<td>Allowance of time from the service to do the intervention</td>
<td>1.69 (1.38)</td>
</tr>
<tr>
<td>Integration with my caseload or other responsibilities at work</td>
<td>1.46 (1.33)</td>
</tr>
<tr>
<td>Keeping family discussion on track</td>
<td>1.00 (1.15)</td>
</tr>
<tr>
<td>Lack of knowledge/recognition by my colleagues of the value of family work</td>
<td>1.00 (1.00)</td>
</tr>
<tr>
<td>Clash of Schizophrenia Family Work sessions and other clinical needs for the clients and/or families</td>
<td>0.92 (1.03)</td>
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<tr>
<td>Knowledge and skills in family intervention</td>
<td>0.85 (0.80)</td>
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<tr>
<td>Clashes of family sessions with crises with other clients</td>
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<td>Availability of time in lieu or overtime for appointments</td>
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<tr>
<td>Knowledge and skills in behavioural techniques</td>
<td>0.77 (0.83)</td>
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<tr>
<td>Keeping to the concept that I was trying to teach</td>
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<tr>
<td>Gaps in my general clinical skills (or lack of confidence in them)</td>
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</tr>
<tr>
<td>Ensuring that family sessions had positive tone</td>
<td>0.62 (0.77)</td>
</tr>
<tr>
<td>Time needed before the result became apparent</td>
<td>0.62 (0.87)</td>
</tr>
<tr>
<td>Access to consultation or supervision</td>
<td>0.54 (0.66)</td>
</tr>
<tr>
<td>Engagement of clients or families</td>
<td>0.54 (0.78)</td>
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<tr>
<td>Tailoring the programme to individual families and their needs</td>
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<td>Non-applicability of the programme to the needs of clients or families</td>
<td>0.54 (0.88)</td>
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<tr>
<td>Clash with my preferred treatment approach</td>
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</tr>
<tr>
<td>Developing specific goals for sessions</td>
<td>0.54 (0.78)</td>
</tr>
<tr>
<td>Issue</td>
<td>Rating</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Lack of progress by clients or families</td>
<td>0.46 (0.78)</td>
</tr>
<tr>
<td>Illness or holidays (clients or family)</td>
<td>0.46 (0.66)</td>
</tr>
<tr>
<td>Illness or holidays (mine)</td>
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<td>Colleagues would not let me work with families they are involved with</td>
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<td>The use of assessment measures</td>
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<tr>
<td>Collaboration with my co-therapist</td>
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</tr>
<tr>
<td>The family intervention manual (e.g., understandable? adequate?)</td>
<td>0.31 (0.48)</td>
</tr>
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<td>Integration with my outside interests or responsibilities</td>
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</tr>
<tr>
<td>e.g., my own family commitment</td>
<td></td>
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<td>Long-term commitment to a specific client or family</td>
<td>0.31 (0.85)</td>
</tr>
<tr>
<td>Adequacy of the training given by the training sessions</td>
<td>0.31 (0.48)</td>
</tr>
<tr>
<td>Travel to family sessions</td>
<td>0.23 (0.44)</td>
</tr>
<tr>
<td>Liaison with private practitioners</td>
<td>0.15 (0.38)</td>
</tr>
</tbody>
</table>
Appendix D

Letter of confirmation of dissemination of results
27th July 2007

To whom it may concern
University of Surrey

Dear Sir/Madam

Re: Service Related Research Project

I am writing to confirm that Claire has presented the results and recommendations of her SRRP within our service. She gave a presentation at the Academic Programme at the Post Graduate Centre on Thursday 21st June as part of an hour long presentation on working with families and cares. The audience consisted of about 30 multi disciplinary professionals working in adult services in including psychiatrists, psychologists and nurses.

She has also met with Consultant Nurse and lead for the trust on Family Interventions for Psychosis to discuss how the results and recommendations will be used on a local level to improve services.

Yours sincerely

Clinical Psychologist
Abstract of Qualitative Research Project

Towards a theory of teachers' knowledge of the use of Anti-Social Behaviour Orders with children aged 10 – 16 years old

May 2007

Year I
Introduction: Anti-social behaviour orders (ASBOs) were introduced in the Crime and Disorder Act 1998 and can be imposed on anybody aged 10 years or older. Between June 2000 and December 2005, 3997 ASBOs were issued to children aged between 10 and 17 years in England and Wales. There have been some attempts to involve teachers in a wider response to anti-social behaviour, but no investigation into teachers’ knowledge of antisocial behaviour or the current measures used to address it. The present research sought to explore teachers’ knowledge.

Method: An opportunity sample of three female secondary school teachers participated in semi-structured interviews. A grounded theory approach was used to analyse the data.

Results: 12 categories were derived through the process of grounded theory, with ‘Teachers’ perceived knowledge’ as the core category. Participants did not have a strong understanding of ASBOs and their use with children but had beliefs about ASBOs and the impact they might have on the individual, the school and society. Participants indicated a desire for more knowledge.

Discussion: The results are considered in the context of existing theories about teachers’ beliefs and construction and use of knowledge. The use of grounded theory is discussed and the research is evaluated.

Conclusion: The preliminary findings suggest that teachers have limited knowledge of ASBOs, but that they may desire to learn more in order to improve the effectiveness of the use of ASBOs. Much work remains and it is hoped that the present study might initiate further interest in this area.
Major Research Project

'Why I am the way I am': A narrative analysis of the life stories of adults with a diagnosis of Asperger's syndrome

February 2010

Year III
ACKNOWLEDGEMENTS

First and foremost, I would like to express gratitude to the participants, for generously sharing their personal experiences with me. I would also like to thank the National Autistic Society staff who assisted with recruiting participants and a venue to conduct interviews.

I would also like to thank my research supervisor for her advice throughout the process. In addition, I would like to thank those that attended the narrative analysis group at the University of Surrey and provided invaluable insights and feedback.

Finally, I would like to thank my husband, family, friends and peers for their encouragement, support and understanding throughout this process.
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<td>173</td>
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<td>176</td>
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<tr>
<td>4.1.2 AS diagnosis as a release</td>
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<tr>
<td>4.1.3 AS diagnosis as a surmountable barrier</td>
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<tr>
<td>4.1.4 AS diagnosis as explanation</td>
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1 ABSTRACT

Title: 'Why I am the way I am': A narrative analysis of the life stories of adults with a diagnosis of Asperger's Syndrome (AS).

Introduction: Social interaction is crucial to development of self and identity. People diagnosed with autism spectrum disorders (ASDs), such as AS face particular challenges in this area. To date, ASD research has typically been medical and deficit-based. The need for alternative constructions of autism, incorporating the voices of people with ASDs has been highlighted. The present study explored how adults with a diagnosis of AS construct their identities through analysis of their life stories, with the aim of examining if, and how an AS diagnosis has implications for identity.


Results: Four main narrative forms emerged and are presented: AS as a source of meaning and purpose; AS diagnosis as a release; AS diagnosis as a surmountable barrier; and AS diagnosis as explanation. The narrative character, work of the narrative and narrative context (at the societal level) are explored.

Discussion: The results are considered with reference to the existing literature from within the research and AS 'community'. In addition, the study's limitations and clinical implications are discussed and ideas for future research considered.

Conclusions: These findings have enhanced the understanding of people diagnosed with AS and provided portrayals of the ways in which those diagnosed with AS construct self and identity. It is hoped that the present study might instigate further interest in this under-researched area.
2 INTRODUCTION

The present study aimed to explore identity in adults diagnosed with Autism Spectrum Disorders (ASDs), in particular those diagnosed with Asperger's Syndrome (AS). In order to provide a background and rationale for the current study, a number of issues are covered in this section: the epistemological position taken regarding self and identity; the role of social interaction in the process of identity development and implications for people with ASDs; previous relevant academic research and autobiographical material; and the applicability of narrative approaches to studying identity. Finally, the study aims are presented.

2.1 SELF, IDENTITY AND EPISTEMOLOGY

The interwoven concepts of self and identity are complex and have been characterized in a multitude of ways over time (e.g. Erikson, 1974; Tajfel & Turner, 1979). It has been noted that there are a diverse range of psychological conceptualisations of self and identity, from varied epistemological standpoints, which influence the manner in which they are theorised and researched (Crossley, 2000). Here, the main epistemological positions on self and identity are presented and the stance of the current study established.

2.1.1 Modernist positions on self and identity

Early views of self and identity derived from the modernist position have been described by Bruner (1990). From a realist perspective, self and identity have been conceptualised as concrete and fixed; as real entities, which can be defined and objectified to be studied empirically in the same manner as matter in the physical world. However, with the appearance of the 'cognitive revolution', alternative views of the self were proposed, which continue to be widespread in psychological thought.
The cognitive model highlights the crucial importance of information processing, with computational models of the mind attracting interest. Here greater emphasis is placed on matters such as ‘personal constructs’ employed by individuals to make sense of the world and self (e.g. Kelly, 1955). Such cognitive views of self do not perceive the self to be a fixed entity but still acknowledge the existence of a ‘core’ self.

### 2.1.2 Postmodern positions on self and identity

In contrast, those positioning themselves from a postmodern perspective would challenge such notions of self and identity. For example, a relativist social constructionist stance would construe self and identity as fluid and ever-changing, dependent on language and deeply embedded in the particular historical, cultural and relational context (Crossley, 2007). Thus, individuals are not viewed as having a fixed identity but ‘multiple changing identities’ (Bagatell, 2007, p.413).

There are clear limitations with both realist and relativist approaches. For instance, it can be argued that the realist, modernist position ignores the influence of important historical, cultural and relational factors. In terms of the relativist, post-modernist position, it has been asserted that in being so dynamic, the complete ‘loss’ of the individual’s experience and subjectivity is risked (Crossley, 2000). Due to these limitations, the epistemological position taken in the current study is a ‘middle’ or critical realist position (Bhaskar, 1989), placed between the two stances. This assumes that something can be discovered about the ‘reality’ of human experience beyond the interview context. However, the crucial importance of language and the fluidity of meaning making with historical, relational and cultural influences are also acknowledged.
2.2 IDENTITY, SOCIAL INTERACTION AND AUTISM

In this section, theoretical perspectives regarding identity development and the role of social interaction are presented. A description of the difficulties reported to be experienced by people diagnosed with ASD is provided and the potential implications of these difficulties for identity development are raised. Dominant and alternative perspectives regarding ASDs are also highlighted. Finally, relevant research and autobiographical material related to ASDs and identity are discussed. It is anticipated that by providing a theoretical background, the rationale for the current study will be apparent.

2.2.1 Social interaction and identity

Social interaction has been argued to be an important facet of the process of identity development. For example, Harter (1997, p.100) asserts that the 'emergence of the personal self is deeply embedded in the crucible of interpersonal relationships'. Moreover, she claims that sense of self can have a strong impact on outcomes for individuals in terms of affect and behaviour. Thus, negative social interactions (such as being ignored, rejected or denigrated) are linked with hopelessness, poor self-esteem and low mood. Taking a life-span approach, Harter (1998) also claims that the impact of others on sense of self is an on-going process.

Ideas regarding social interaction and identity are long established. For example, from a symbolic interactionist perspective (e.g. Baldwin, 1897; Cooley, 1902; Mead, 1934), development of the self is argued to occur chiefly during social processes rather than being related to individual psychology. Verbal exchanges and communication with others are deemed key to self and the attitudes of others are incorporated into one's sense of self.
2.2.2 Autism spectrum disorders

Autism is described as a ‘lifelong developmental disability’ that affects people’s ability to understand the world and others (National Autistic Society (NAS) Website, 2008). Difficulties associated with autism include differences in executive functioning (Kleinhans et al., 2005), sensory hypersensitivity (Blakemore et al., 2006) and memory (Bowler et al., 2004). Psychological issues such as worry and low mood have also been uncovered (see Ghaziuddin et al., 1998; Tantam, 2000). In addition, social issues such as employment difficulties have been found (Hurlbutt & Chalmers, 2004).

The way that ASDs have been constructed and represented has evolved considerably over time (for a comprehensive overview: see Holmer Nadesan, 2005). The first published account of ‘early infantile autism’ was written by Kanner (1943) in the United States. In the same period, the Austrian paediatrician Asperger (1944) published his thesis on children with ‘autistic psychopathy’. The patterns of features reported by both authors were strikingly similar (poor social interaction, communication difficulties and special interests). Asperger, however, described more able children with a less severe expression of Kanner’s autism. It is noted that Asperger’s work in this area was largely unrecognised for 30 years after its publication (Attwood, 1998). Later, the term ‘Asperger’s syndrome’ was coined by Wing (1981), who described children and adolescents with similar characteristics to those described by Asperger (1944). Diagnostic criteria for AS as a discrete category were first introduced by Gilberg and Gilberg (1989), and cover features including: social impairment; narrow interests; compulsive need for routines and interests; speech and language peculiarities; non-verbal communication problems and motor clumsiness.

According to current medical diagnostic systems such as DSM-IV-TR and ICD-10, people with a diagnosis of autism have a triad of impairments (in social interaction; social communication; and narrow interests and repetitive routines), which can affect individuals in a multitude of ways, with varying degrees of severity (American
As a result of this heterogeneity, autism is conceptualised as a spectrum of disorders, of which AS is one sub-group and a recent addition to diagnostic systems.

To date, research efforts in the area of ASDs have tended to be medically focused, with much investigation aiming to: identify its possible 'causes'; measure deficits and impairments; and assess interventions and 'cures' (Aylott, 2001). Although the precise aetiology for autism is yet to be established, current research suggests that an interaction of genetic, neurobiological and environmental factors appears most likely (Volkmar et al., 2004; Gupta & State, 2007; Müller, 2007; Wang et al., 2009). In addition, a highly influential cognitive model of autism proposed by Baron-Cohen (1995), focusing on 'mind-blindness' with an underlying biological pathology has achieved significant attention and directed considerable research efforts.

2.2.3 Alternative perspectives on ASD identity

As can be seen above, perspectives regarding ASDs have focused on ideas which derive from a predominantly medical model. Indeed, this approach continues to dominate the field of ASD thinking and research, which assumes the perspective of the existence of a shared, observable reality (Biklen, 2005). However, there is increased doubt regarding whether such an approach alone is sufficient. For example, Holmer Nadesan (2005) argues that although biomedical factors are important in the construction of ASDs, societal values, cultural practises and interpretative frameworks are also influential. Smukler (2005) also argues for the precedence of alternative narratives that include the viewpoints of people labelled as autistic. Furthermore, Aylott (2001) argues that the 'research agenda continues to be dominated by the medical, experimental agenda as opposed to the qualitative, social model agenda which best explains autism from a person-centred, empowering and social change perspective' (p. 169).
Thus, diagnostic categories such as ASDs may be helpfully understood as socially constructed labels with a membership of heterogeneous individuals. When writing about typical representations of autism, Smukler (2005) argues that such a ‘deficit-oriented approach is dehumanizing’, as ASDs are explained in terms of ‘deficiency’ rather than ‘difference’ in comparison with the norm (p.17). Deficit based constructions of ‘disorder’ or ‘disability’ itself may be associated with being different from a standard of normality and may lead to a negative identity (Finlay & Lyons, 2005). Likewise, Aylott (2000) argues that:

People with autism have largely experienced negative labelling because of their deficits and impairments and this then casts them into a specific social role which results in the individual fulfilling the expectations associated with that role (p. 853).

Individuals, however, may take different perspectives on the labels assigned to them and may accept or reject them along with their associated stereotypes (Finlay & Lyons, 2005). Aylott (2000) draws on Erikson’s (1974) model of identity development to highlight the importance of the achievement of a positive sense of personal identity for people with autism, with particular attention paid to sexuality and occupational identity. Furthermore, it has been argued that the inclusion of first person narratives of people with autism is crucial (Smukler, 2005).

Alternative perspectives regarding ASDs are provided not only by academics but from people with ASDs themselves. In an increasingly technological age, the internet is one source of such viewpoints and a number of ASD-related web-based organisations can be accessed. For example, ‘Aspies for Freedom’ is one such organisation which views ASDs not as a disease, necessitating a ‘cure’ but part of diversity in neurology, and ‘not negative, and...not always a disability’. As an organisation they argue against discrimination and for the rights of people on the autism spectrum and the ‘building of the autism culture’
This view implies a social model of ASDs whereby difficulties are encountered because society is structured in a way that fails to meet the needs of those diagnosed. Such a view of AS is echoed to an extent by Baron-Cohen (2000) who argued that AS is perhaps better defined as a different cognitive style rather than a deficiency. Furthermore, he argues that a small shift in this definition may mean the difference between diagnoses being received as a 'tragedy' or simply interesting information (such as handedness). He argues however, that for practical reasons a 'disability' model is necessary to ensure access to services as current legal and care frameworks only support people viewed as disabled (Baron-Cohen, 2002). Molloy and Vasil (2004) describe the tension between the different approaches as the 'double-edged sword' nature of diagnoses such as AS, which can help to provide understanding and access to services but also positions individuals as 'patients' in need of treatment with the potential for social stigma and a devalued identity.

2.2.4 Implications of ASD for identity development

People with ASDs are perceived to have particular difficulties in the domains of social interaction and communication. As such, it has been argued that for some, a sense of identity could be particularly threatened. It has been argued that it is often assumed that identity issues are not relevant to individuals with ASDs (Bagatell, 2007). Indeed, it has even been suggested that people with a diagnosis of more severe forms of ASD lack a strong sense of identity and 'provide a window into what can go terribly wrong in selfing' (McAdams, 1997, p. 59). Such a view is highly contentious. For example, Smukler (2005) would claim that rather than individuals themselves being deficient, it is the specific representations such as 'mind blindness' that imply that defining features of self and humanness are absent in people with ASDs.

Overall, there is a lack of research exploring identity in people with ASD. However, initial findings from the limited work carried out to date in this area imply that identity issues are highly relevant to people with ASDs and that its development is a complex process, with many factors likely to influence outcomes. These issues are
discussed below with reference to both the academic research base and the representations of people with ASDs.

**Research Studies**

Bagatell (2007) took a narrative approach to explore identity construction for a young man with AS. This study used a range of methodologies to collect information, including participant observation and informal conversations. The analysis illustrated the complexity of identity construction and the necessity to construct multiple identities in different contexts. This was found to be an on-going task of great significance and a source of tension leading to psychological distress.

Further relevant research was conducted by Molloy and Vasil (2004) who highlighted the importance of identity issues for six adolescents with AS using a narrative approach. In this study, autobiographical interviews were carried out with teenagers and their parents. From these, six important themes and issues were identified. The first theme was ‘diagnosis as a sense making narrative’. This suggested that for all participants, AS was an integral part of their life story and identity and provided an explanation for the experience of feeling ‘different’ from others. It is argued that this allowed a more positive self image to emerge. The second theme that emerged was ‘labelling and identity’. This was related to the degree to which participants identified with the diagnosis of AS and defined themselves in terms of the label. All participants accepted the diagnosis as valid and viewed themselves as ‘different’. However, they differed with regards to whether or not they saw themselves as ‘disabled’. Two of the six participants considered themselves ‘disabled’ and that having AS was negative and created barriers in their lives. Some participants viewed having AS as positive and highlighted the strengths that they associated with it. Other participants described attempts to disentangle which of the challenges that they faced were related to AS and which were just part of typical adolescent life. The third theme which emerged was ‘socialising and making friends’. This highlighted varying degrees of difficulties in socialising and the pressure to conform and gain social acceptance from peers. The fourth theme
described related to ‘the dilemma of schooling’. This emphasized the sense of being an ‘outsider’ or ‘not belonging’ which may occur in mainstream educational contexts, where bullying and marginalisation were common experiences. Conversely, the sense of ‘sameness’ experienced by being ‘different’ in specialised educational contexts is underscored. The fifth theme ‘family life’ draws attention to the observation that family life was not discussed in detail by the young people, although difficulties getting along with siblings and restrictions to family life due to AS were highlighted by parents. The sixth theme was called ‘rages and blues’ and highlighted the frequent experience of anger (often in retaliation to provocation at school) and low mood (often as a result of feeling like an outsider and bullying or teasing). Finally, the way in which participants viewed their futures is described. For five participants, this was focused on their career plans, highlighting the importance of anticipated future occupation for sense of identity.

Additional research related to ASDs and identity was carried out by Humphrey and Lewis (2008), in an Interpretive Phenomenological Analysis (IPA) study including 20 pupils with AS in mainstream secondary schools. The data used included semi-structured interviews, pupil diaries and drawings to investigate the views and experiences of these individuals. In this study, some pupils described themselves using a negatively imbued notion of not being ‘normal’. For others acceptance was central and for others still elements of both positions were evident. Bullying and teasing by peers, as well as anxiety and stress are highlighted as being common experiences. In addition, negotiation of difference, the importance of relationships with peers, and support and feedback in the development of a sense of self is emphasized.

Similar findings are offered by Punshon et al.’s (2009) IPA study which explored the experiences of ten adults diagnosed with AS in adulthood through semi-structured interviews. This suggested a number of important issues including negative life experiences (such as bullying), use of mental health services and a sense of difference to others. This study concluded that diagnosis with AS had a significant
influence on identity and altered beliefs about difficulties experienced. In contrast, Brownlow and O’Dell (2006) conducted research examining online discussion groups used by people with ASDs. This highlighted a rejection of the view of ASDs as disabilities and the construction of a distinct and positive ‘AS’ identity contrasted with ‘neurotypicals’ (people without a diagnosis of ASD).

Thus far, the discussion has focused on identity issues suggested by the academic research efforts of clinicians and academics. However, much is to be learned from ‘insider’ representations, of people diagnosed with ASDs. Furthermore, most of the research available has included children and young people and there appears to be a dearth of research exploring identity in adults with ASDs. In the next section, ‘insider’ representations of adults with ASDs are introduced.

Autobiographical Material

The autobiographical representations of those with ASDs take many forms and include on-line sources as well as pieces published in print-form. With regards to internet-based representations, Murray (2008) discusses the ways in which the online video posts of Amanda Baggs (a woman with autism) address the manner in which more dominant cultural narratives misrepresent ASDs. Murray highlights how Baggs proposes the concept of difference rather than deficit to be of central importance to self, taking on an advocacy role and asserting the right to be represented and understood on her own terms.

There are also an immense number of published autobiographical accounts written by people with a diagnosis on the autism spectrum (e.g. Biklen, 2005; Grandin, 1995; Holliday Willey, 1999; Mitchell, 2005; Williams, 1992; Williams, 1994; Williams, 1996; Williams, 2004). These provide further ‘insider’ representations of ASDs. Some of these highlight difficulties in identity construction. For example, in the accounts of Donna Williams (1992; 1994), the on-going and challenging nature of this process is captured in the book title ‘Nobody Nowhere’, followed by the sequel.
'Somebody Somewhere'. In contrast, Holliday Willey (1999) highlights the importance for her of 'fitting in', in her autobiography 'Pretending to be Normal'. However, the positive benefits of ASDs are also highlighted in the autobiographical accounts of people with ASDs. For example, Temple Grandin (1995, p. 208) has a positive sense of self due to her ASD. She claims that 'if the genes that cause autism...were eliminated, the world might be left to boring conformists with few creative ideas' and lists several outstanding individuals (such as Einstein, Bill Gates, Wittgenstein and Van Gogh) who have displayed traits of ASDs.

The existence of numerous autobiographies of people with ASDs, suggests a strong inclination for some individuals with ASDs to create and share their stories. Indeed, it has been argued that act of narrating is key to defining identity, an idea explored in greater detail below.

2.3 NARRATIVE AND IDENTITY

In order to clarify the rationale for a narrative approach in the current study an attempt is made to: define what is meant by narrative; describe the increased importance ascribed to narrative in the social sciences; and to demonstrate how this links with the concept of identity.

2.3.1 Narrative Psychology and identity

There is debate surrounding the exact definition of narrative. However, it can be thought of as 'talk organised around consequential events', incorporating past times and reviewing what happened to make a point (Riessman, 1993, p.3). Bruner (1986) identified several characteristics which define narrative including: a distinctive series of events, mental states and occurrences involving people as characters/actors; 'real' or fantasy content; and connections which are forged between the extraordinary and the everyday. Narratives can be thought of as not only constructed by individuals but 'situated and created within both the broader socio-cultural and more immediate
interpersonal context' (Murray, 1999, p.54). Thus, narratives are constructed not only by those telling their stories but within a social context and in collaboration with those witnessing the accounts.

The focus on narrative and story-telling in the social sciences and psychology is only a relatively recent phenomenon. Whilst interest initially started in the 1960s, the concepts received significantly increased attention since the 1980s. A number of influential publications appeared during this period (e.g. Bruner, 1990; Polkinghorne, 1988; Ricoeur, 1984; Sarbin, 1986). This has been referred to as the ‘narrative turn’ (Bruner, 1990, p.114). These books variously claimed that stories/narratives are a means by which people make sense of and bring order to an ever-changing world. Through narrative, individuals begin to describe themselves as having temporal constancy and a sense of separateness from others (Murray, 2003). In telling stories to others about one’s self and life, particular aspects are selected and connected with others with an element of order (Murray, 2003). From this perspective, narrative is the key to definition of self and identity construction (McAdams, 1993). Narrative psychology aims to explore the stories told by individuals for insight into both the identity of the teller as well as the culture in which they live (Murray, 2003). Therefore, the stories told by people with ASDs about their lives may elucidate how they view themselves and their resident culture. Narrative analysis is a popular research method employed to explore such issues.

2.3.2 Narrative analysis

‘Narrative analysis’ (NA) is an umbrella term used to describe any organized approach to examining and interpreting stories. It has been used within a range of social sciences, on the basis that personal narrative is a way in which ‘individuals construct past events and actions...to claim identities and construct lives’ (Riessman, 1993, p.2). NA was selected over other qualitative research methods such as

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6 The terms ‘story’ and ‘narrative’ are used interchangeably throughout the study.
grounded theory (Glaser & Strauss, 1967) or IPA (Smith, 1996; Smith & Osborn, 2003) because the nature of narrative as a means of identity construction renders it the natural choice for the researcher who is interested in how individuals make sense of themselves in relation to others and the wider world (Crossley, 2007). It is noted that individuals narrate particular life experiences, particularly where disruption has been experienced in order to make sense of this disruption (Riessman, 1993). Illness or disorder may constitute such a biographical disruption, which interferes with identify construction and is impacted on by cultural models of illness and disorder. Murray (1999) highlights the manner in which health and illness can be understood through narrative so that narrative reconstruction can transform the character of the meaning of the illness (e.g. from threatening to non-threatening). As a result, NA has been widely used in relation to a range of accounts of illness (e.g. Crossley, 2003; Grey, et al., 2005) and disability (Murray, 2007).

NA has also been used in other previous research specifically related to ASDs. For example, Gray (2001) used NA to explore the experiences of parents of children with autism. This suggested three narratives: ‘accommodation’ consistent with a ‘biomedical’ view of autism; ‘resistance’, associated with a more political activism stance; and ‘transcendence’, whereby religious faith was utilised to derive meaning. As described above, Bagatell (2007) also fruitfully used a narrative approach in her case-study of identity construction in a one man with AS. However, NA is yet to be employed in research with more than one adult with AS, which would allow for greater diversity and multiple perspectives in terms of findings.

In summary, NA was chosen because it appears to be of particular relevance to the study of ASDs and it is explicitly concerned with issues connected to investigation of self and identity (Lyons & Coyle, 2007). The specific narrative approach taken in this study is delineated further in the Method section below.
2.4 SUMMARY AND RATIONALE

The conceptualisation of identity varies considerably according to the epistemological standpoint taken. This study positions itself from a critical realist standpoint, a position which is placed between the extremes of modernist and post-modern social constructionist stances. Thus, identity development is viewed as a dynamic process, occurring within a social context. However, it assumes the reality of 'self' and 'identity' for individuals.

There are a number of theories which highlight the importance of social interaction in identity development. For people with ASDs, such as AS, social interaction may present particular challenges. Furthermore, it has been argued that identity issues are not relevant for people diagnosed with ASDs and medically-driven deficit focused research agendas and perspectives have continued to dominate. Despite this, a review of preliminary, qualitative research (which takes a less biomedical stance) and autobiographical material from people diagnosed with ASD suggests that identity issues are complex and highly relevant. In addition, it highlights the need for further related research and alternative constructions of identity, incorporating the range of voices of people with ASDs.

An appropriate way of including the perspectives of people diagnosed with ASDs and examining identity from a critical realist position is through narrative methods. These view the stories that people tell about their lives as a means of making sense of and finding order in the world; enabling them to begin the process of defining themselves at that moment in time; as a constant individual; and distinct from but in relation to others. Such approaches have been commonly employed in research related to illness and disability.
2.5 PRESENT STUDY AIMS

Research in the area of ASDs has typically been carried out from a realist, medical, deficit-based standpoint. The present qualitative study aimed to explore experiences from a critical realist position, incorporating the multiplicity of voices of those diagnosed with an ASD. More specifically, it aimed to explore how adults with a diagnosis of AS construct their identities through analysis of the stories that they produce about their lives. In particular, the study aimed to examine if and how being diagnosed with AS might have implications for identity. The intention was to encourage participants to tell their stories in their own way, focusing on the issues of greatest importance to them and without presupposing that AS diagnosis is central to sense of self.
3 METHOD

In this section the rationale for the approach to narrative analysis and the data source selected is presented. Following this, the main ethical issues arising in the study, the recruitment strategy employed and demographic characteristics of participants are provided. In addition, the structure and procedures followed during semi-structured interviews are delineated. Finally, a description is provided regarding the guidelines followed to evaluate this piece of research and ensure its quality and credibility.

3.1 NARRATIVE ANALYSIS

It has been noted that there is no consensus or standard set of procedures for NA (Gray, 2001). Indeed, Crossley (2007) emphasizes the nature of narrative analysis as a ‘creative art’ rather than a ‘scientific procedure reducible to specific methodological steps’ (pp. 144). However, Riessman (1993) suggests some basic steps: the telling of a narrative; transcription; reading; analysis; and representation. At each stage, the researcher must choose how to proceed. There are a variety of ways in which NA can be approached, focusing on different aspects of the narrative dependent on both practicalities and the researcher’s theoretical interests (M. Murray, personal communication, 10 October 2009). Riessman (2008) suggests three approaches to analysis of text: thematic/content-based analysis (e.g. Crossley, 2000); structural analysis (e.g. Labov & Fanshell, 1977; Mishler, 1995); and dialogic/performance-based analysis (which employs both structural and thematic analysis, considering the narrative’s purpose).

Following consultation with the research supervisor and tutors, the approach selected was that advocated by Murray (1999, 2003, 2009). This involves a series of stages, emphasising both overall structure and content, drawing on the ideas of other narrative researchers (e.g. Gergen & Gergen, 1984, 1986) and connecting personal stories with broader social representations of phenomena. Whilst Murray’s approach has been criticised for paying less attention to particular elements of narrative, such as emotional undercurrents (Hollway & Jefferson, 2000), tone, and imagery (Crossley, 2007), this potential limitation was seen as advantageous in the current
exploratory study because it did not presuppose the importance of any particular issue. In addition, it was important to the researcher to maintain participants' complete stories in a distinguishable form as well as attending to the social representations of ASDs. The approach taken in the current study is described in further detail in section 4.7 below.

A wide variety of data sources can be used when conducting an NA. For example, published text such as diary entries (e.g. Crossley, 2003), literature (e.g. Crossley & Crossley, 2001) and autobiographical and fictional narratives (e.g. Crossley, 2004). As highlighted above, a number of published autobiographical accounts, written by people with an ASD diagnosis are available (e.g. Biklen, 2005; Grandin, 1995; Holliday Willey, Mitchell, 2005; 1999; Williams, 1992; Williams, 1994; Williams, 1996; Williams, 2004). This was considered as a potential source of narratives for this study. However, the primary source of narrative tends to be interviews (e.g. Grey, et al., 2005; Murray, 2007). Moreover, it may be argued that the autobiographies selected for publication might be chosen for particular reasons to reflect certain types of story. For example, a preference for narratives related to change and development with regards to identity, will lead to the selection of progressive and ‘triumphant’ stories over others. Therefore, it was decided that interviews would be used to collect narratives for the purposes of this study.

3.2 ETHICAL ISSUES

This study was granted ethical approval by the Ethics Committee, University of Surrey in September 2008 (see Appendix i). It was not considered necessary to submit the proposal to an NHS Ethics Committee as recruitment was not through the NHS, nor was being a user of NHS services required for participation. The main ethical issues concerned: obtaining informed consent; minimising and managing the potential for risks; and confidentiality and data protection.
3.2.1 Obtaining informed consent

At each stage of the study, participants were provided with a clear and open information sheet (see Appendix ii) and consent form (see Appendix iii) outlining the nature of the study, so they could give informed consent and were prepared for the content of the interview. The information sheet and consent form stated that participation was entirely voluntary, confidentiality was assured and that if they decided not to take part or withdraw their data from the study, they were free to do so at any time. In addition, details were provided regarding what participation involved and that the researcher will require confirmation of their diagnosis. Participants were given the opportunity and indeed encouraged to ask any questions that they might have about the study. In addition, contact details for the researcher were provided should queries or concerns arise at a later date.

3.2.2 Minimising and managing potential risks

With regards to potential risks to participants, it was anticipated that there was a possible risk of participants becoming distressed due to the sensitive nature of the subject matter (e.g. potentially recalling distressing past events). If this had occurred, the researcher planned to offer affected participants advice and contact details for relevant agencies if they require additional support (e.g. to visit their GP, the numbers of telephone help-lines/charities etc).

3.2.3 Confidentiality and data protection

All data collected was made anonymous in the transcripts and final report using pseudonyms. The exact location of the groups from which some participants were drawn was not identified in the final report, to reduce the chance of identification. No personal details were stored on a computer. Digital recordings of the interviews, interview transcripts and analyses were stored on a computer in password-protected files, in a secure place. In accordance with the Data Protection Act (1998), the paper copies of data are stored in a locked cabinet in a secure place.
3.3 RECRUITMENT STRATEGY

Participants were invited to take part via the National Autistic Society (NAS), a prominent charity for people affected by ASDs. Following approval from this organisation, an advert was placed on their national website (see appendix iv). The researcher also visited a NAS user group in south east England to recruit.

3.4 PARTICIPANTS

Twenty individuals showed an interest in participating. The researcher sent them the information sheet and the consent form. Of those that expressed an interest, six individuals agreed to participate in the study. Sample sizes for interviews differ considerably in research using a narrative approach. For example, Grey, et al. (2005) had a sample size of just two, whilst Murray (2007) drew on a sample of 26 interviews that had been previously conducted for a previous study. No particular figure is suggested for narrative research in the literature. For this study, six participants was within the range of previous study sizes and represented a reasonable number to gain adequate data with which to pay sufficient account/do justice to. Of the six participants, three were recruited via the NAS website and three were recruited via a local NAS branch.

The inclusion criteria utilised was:

1. Individuals over the age of 18 years old.
2. Individuals who had received a formal ASD diagnosis (e.g. by a psychologist/psychiatrist).
3. Individuals with the ability to speak fluent English due to the interview-based nature of the study and the first language of the researcher. This was to overcome the possibility that meaning might be lost through the use of a translator (Raval & Smith, 2003).
Prior to conducting interviews, a letter was sent to a relevant health care professional to confirm participants' diagnoses (see appendix v). Participants were also asked to complete a demographics form (see appendix vi). Table 1 contains the demographic details of the study participants. The ages of participants ranged from 24 to 56 (mean age = 38.4). Five participants were single, with no children. One participant was married with three children. All participants were white British. Four participants' highest educational qualifications were City and Guilds (C & G) or National Vocational Qualifications (NVQs). One participant had no formal educational qualifications and one had O-levels. In terms of employment: three participants were in employment; one had been made redundant; one had been medically discharged (on physical health grounds) and one was unemployed. All participants had been diagnosed by a Clinical Psychologist or a Psychiatrist.

3.5 INTERVIEW STRUCTURE

A number of interview schedules have been proposed for narrative research (e.g. McAdams’ (1993) semi-structured approach to exploring personal narratives). The structure adopted during the interviews was selected by the researcher following numerous discussions between the supervisor and research tutors.

The interviews followed a life story approach as suggested by Murray (2003), with the intention of empowering and supporting participants to set the agenda and decide where they would like to start and end their narratives and what they would like to include. As a result, each interview began with an open invitation to talk about their life story, starting at whatever point in time that they wished and including the issues/experiences that they considered important. Throughout the interview, reflecting and summarising statements were made. Direct questions were asked for clarification and to check understanding or to gain further information (e.g. ‘can you tell me a bit more about that?’).
3.6 INTERVIEW PROCEDURE

Before the interview, the researcher asked participants whether they had any questions about the study and completed the demographics form. The researcher explained that the interview was an opportunity to learn about their life story and as such they did not have a particular set of 'questions' requiring 'answers' and they could select aspects of their lives that they thought important to discuss.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital</th>
<th>No. of Children</th>
<th>Status</th>
<th>Qualification</th>
<th>Diagnosis/Professional</th>
<th>Occupation</th>
<th>Highest Education</th>
<th>Residence</th>
<th>British</th>
<th>White</th>
<th>With family</th>
<th>Private?</th>
<th>Owed Home</th>
<th>Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phillip</td>
<td>47</td>
<td>Married</td>
<td>3</td>
<td>White</td>
<td>O-Levels</td>
<td>Medical retired in 2008</td>
<td>British</td>
<td>None</td>
<td>Home</td>
<td>White</td>
<td>1</td>
<td>7</td>
<td>Initially</td>
<td>Privately</td>
<td>owned</td>
</tr>
<tr>
<td>Angela</td>
<td>45</td>
<td>Single</td>
<td>None</td>
<td>White</td>
<td>None</td>
<td>Unemployed</td>
<td>British</td>
<td>None</td>
<td>Home</td>
<td>White</td>
<td>0</td>
<td>0</td>
<td>DC</td>
<td>Private</td>
<td>owned</td>
</tr>
<tr>
<td>James</td>
<td>56</td>
<td>Single</td>
<td>None</td>
<td>White</td>
<td>None</td>
<td>Unemployed</td>
<td>British</td>
<td>None</td>
<td>Home</td>
<td>White</td>
<td>0</td>
<td>0</td>
<td>DC</td>
<td>Private</td>
<td>owned</td>
</tr>
<tr>
<td>Sarah</td>
<td>24</td>
<td>Single</td>
<td>None</td>
<td>White</td>
<td>None</td>
<td>Volunteer in charity shop</td>
<td>British</td>
<td>None</td>
<td>Home</td>
<td>White</td>
<td>0</td>
<td>0</td>
<td>DC</td>
<td>Private</td>
<td>owned</td>
</tr>
<tr>
<td>Jack</td>
<td>29</td>
<td>Single</td>
<td>None</td>
<td>White</td>
<td>None</td>
<td>Volunteer in charity shop</td>
<td>British</td>
<td>None</td>
<td>Home</td>
<td>White</td>
<td>0</td>
<td>0</td>
<td>DC</td>
<td>Private</td>
<td>owned</td>
</tr>
<tr>
<td>George</td>
<td>41</td>
<td>Single</td>
<td>None</td>
<td>White</td>
<td>None</td>
<td>Administrative role in government department</td>
<td>British</td>
<td>None</td>
<td>Privately</td>
<td>White</td>
<td>0</td>
<td>0</td>
<td>DC</td>
<td>Private</td>
<td>owned</td>
</tr>
</tbody>
</table>
In terms of location, five interviews were conducted in a quiet, public setting, local to the participant (such as local libraries or community centres). Care was taken to ensure that the location was acceptable, accessible and convenient for each participant, as a sign of respect and to make participation as straightforward as possible for those taking part. One interview was carried out in the participant’s home. All interviews were digitally recorded and lasted between 45 and 90 minutes.

3.7 DATA ANALYSIS

Each interview was transcribed by the researcher to reflect both the conversational exchange and the central narrative, including pauses, interruptions and other information that appeared important (such as changes in tone and volume of voice or laughter). See appendix vii for an example of a transcribed interview.

The interviews were analysed in two main stages as described by Murray (2003, 2009). The first stage involved familiarisation with the structure and content of the narrative through careful reading and preparation of a summary (identifying the narrative’s beginning, middle and end), highlighting the main issues noted.

The second stage was interpretive, developing links between the narrative and wider theory. As a way of ‘bringing order to disorder’ in the plot (Murray, 2009, p.30), the researcher drew on the work of Gergen and Gergen (1984, 1986), identifying the main temporal form and structure within each account which indicate the sense of movement or direction through time. The three main rudimentary classifications described are ‘progressive’, ‘regressive’ and ‘stable’. Lieblich et al. (1998) reviewed Gergen and Gergen’s work and elucidate the focus of each narrative form: the progressive form focuses on advancement and success; the regressive form involves a trajectory of deterioration or decline; and the stable form entails a steady course, with no progression or regression. Gergen and Gergen (1984, 1986) also drew on the main literary narratives (i.e. comedy, tragedy, happily ever after and romantic saga) to illustrate how these basic forms can be linked. For example, the tragedy narrative would be characterised by a progressive narrative followed by a rapid regressive narrative. The opposite of the tragedy, is the comedy narrative characterised by a regressive narrative preceding a progressive narrative. The happily ever after
narrative is typified by a progressive narrative followed by a stability narrative. Finally, the romantic saga is demonstrated by a series of progressive and regressive stages, with life viewed as a series of on-going conflicts.

In the current study, the three basic forms (i.e. progressive, regressive and stable) were linked together and more multifaceted variations identified. Four basic narrative orientations were identified across the interviews. The narratives were read repeatedly with the literary genres described above kept in mind, identifying variations between the narratives. However, as Murray (2009) argues such literary genres may be a useful heuristic tool but the genres may alter in everyday narratives. Therefore, the narrative forms were generated by the researcher considering the overall essence and plot of the narrative. These forms were discussed both with the research supervisor and within a NA group to assess whether the forms generated by the researcher reflected the nature of the narratives as they read them. Therefore, they were subject to some amendment to develop the ‘fit’ between the forms and the original narratives. A description of each form is presented along with an in-depth example of each.

Throughout the interpretive phase, the researcher also recorded ideas related to: the main narrative character; the work/function of the narrative; and the narrative context (at the personal, interpersonal and societal levels), making links between the participant’s narrative about events and wider discourses which might have impacted on these (Murray, 2003; Murray, 2009). See appendix vii. for an example of the analytic process.

3.8 RESEARCH EVALUATION

Smith (2003) notes that research employing a qualitative methodology uses a different framework to quantitative research and as such cannot be evaluated according to the same principles (i.e. using concepts such as reliability, validity, representativeness and generalisability). However, a number of suggestions have been put forward as to how qualitative researchers can assess the credibility and quality of their research (e.g. Yardley, 2000; Elliott et al., 1999). In order to evaluate the current research, particular areas pertinent to NA, proposed by Elliott et al.
(1999) were selected for consideration: owning one's perspective; situating the sample; grounding in examples; providing credibility checks; coherence; accomplishing general vs. specific research tasks; and resonating with readers.

3.8.1 Owning one's perspective

The researchers' perceptions and understandings throughout the qualitative process are important. To facilitate this, the researcher reflected on her personal and professional background and considered the motivations for an interest in this area.

In terms of personal background, I am a 30 year old, married, white British female, with post-graduate education. I am aware that there were some similarities between myself and the participants (e.g. in terms of ethnicity). However, there were also significant differences (e.g. in terms of ASD diagnosis and educational level).

I have worked in the NHS for eight years and have become interested in working with marginalised groups and individuals (in particular people with learning disabilities). I am aware of the dominance and privileging of medical discourses over those with direct, lived experiences on which to draw. I hold a moral stance on this. During interviews, I attempted to retain some neutrality regarding this, to reduce my influence on the narratives. I am aware that the nature of this study indirectly provides clues about my position. Conversely, as a 'professional', it could have also been assumed that I align myself with dominant discourses. I also asked participants to 'prove' their ASD status with confirmation from a health professional. However, the nature of the study as a requirement for an academic course meant that it was important to verify that participants 'have' this entity called 'autism'. Although I hoped to provide a 'voice' for the people I interviewed, I was aware that I could not actually be the 'voice' for others. I bore in mind the important power dynamic that my role as a trainee clinical psychologist might create and attempted to keep the

For ease of reflection, the first person will be used in this section.
interviews as informal and relaxed as possible and communicate that I had no particular agenda regarding the content of the interview.

3.8.2 Situating the sample

In order to allow readers to evaluate the range of individuals to which the research findings may be applicable and relevant, the inclusion criteria for participation is stated in the methodology and basic demographic information is provided in Table 1.

3.8.3 Grounding in examples

Throughout the analysis, the main findings are supported by direct quotes taken from the interview transcripts. It was intended that this would allow the reader to judge the match between the narratives themselves and the analysis of the narrative forms as well as conceive of different meanings and understandings.

3.8.4 Providing credibility checks

In order to provide credibility checks, the interview transcripts and analysis were read by and discussed with my research supervisor. In addition, the analysis was examined during two meetings of a NA research group attended by TCPs, Research Tutors and academic members of staff at the university.

Participants were also sent a letter (see appendix ix) and copy of the draft results section, encouraging them to make comments. Three participants responded. The importance of feedback from participants in qualitative research has been highlighted by Smythe & Murray (2000). The feedback and comments from the NA group and the participants are presented as a summary in the results section.

The written feedback from participants was limited in terms of the number of responses and level of detail. The credibility checks could have been enhanced by
meeting with participants to review the narratives and draft results in greater detail. This would have facilitated fuller discussions, with the opportunity for both the researcher and participants to ask questions, check understanding, and offer comments and clarification regarding the stories and the analysis. In addition, the NA group was a useful forum for discussing this research. However, its membership consisted of a range of researchers and clinicians without specific experience within the subject area. The researcher could have sought out a Clinical Psychology colleague with extensive experience of working with adults with AS to consider the narratives and the analysis and provide comments and elaborations to the analysis. In addition to these improvements, it is important to note that Elliott et al.’s (1999) guidelines should be used with caution.

Reicher (2000) criticises these guidelines (an in particular the use of credibility checks) for encouraging ‘methodological narrowness and dogmatism’ (pp.1), arguing for different evaluation criteria for different qualitative methods. In their response to this critique, Elliott et al. (2000) reiterated that the guidelines were intended to be used as a reference point and summary rather than prescriptive. As such, this is how the credibility checks were utilised in the current study.

3.8.5 Coherence

In order to achieve coherence within the analysis, feedback was sought from the NA group and research supervisor on individual and overall analyses. In addition, direct quotations were provided from the interviews. The overall coherence of the study can also be assessed by the readers themselves.

3.8.6 Accomplishing general vs. specific research tasks

As a random sampling approach was not used, this study has limited generalisability to the wider population of adults with a diagnosis of AS. However, this was not a particular aim of this study and it would be possible to use this study as a basis for future research and make links with the existing theory and literature.
3.8.7 Resonating with readers

Using NA, results were presented by describing the narratives, with examples drawn directly from the accounts. In addition, the transcripts and analyses were shared with and discussed in a NA group and with the research supervisor. These measures ensured that the analysis was public and open for scrutiny by others.
4 RESULTS

Following familiarisation with the transcribed interviews, four main narrative forms were identified across the interviews. These narrative forms, the narrative character, the work of the narrative and the narrative context (with a focus on the societal level) follow. To enhance the readers’ understanding and illustrate points, quotations are included but edited to avoid unnecessary repetition. A summary of credibility checks concludes this section.

4.1 NARRATIVE FORMS

The four main narrative forms identified were labelled: AS as a source of meaning and purpose; AS diagnosis as a release; AS diagnosis as a surmountable barrier; and AS diagnosis as explanation. The clearest examples of each form are described below.

4.1.1 ‘That was the start of my journey’: AS as a source of meaning and purpose

Jack and George shared this narrative orientation. Their narratives were characterised by intermittent regressive forms with periods of stability, followed by a progressive form. Both participants began their narratives by describing a series of negative life events, which were later resolved through the process of increasing their understanding of AS, receiving specialist help (through the NHS and organisations such as the NAS) and making contact with other people diagnosed with ASDs. In both narratives, this process was viewed as a source of meaning and purpose for the participants, of far greater importance than diagnosis per se. This is reflected in the quote above, a comment made by Jack about making contact with the NAS. In addition, in this form a sense of agency pervades, with both participants describing pursuing future occupations incorporating an element of social campaigning and education about ASDs. In this narrative form, the AS label and occupational involvement in action related to the AS ‘movement’ is a significant component of personal identity. To highlight this narrative form, Jack’s story is briefly summarised and then presented in detail below.
Jack's story

Jack was 29 years old when he was interviewed. Whilst he received a diagnosis of AS aged 15, the diagnosis was not explained to him then. His life was described as a series of struggles and difficulties with some stability but little progression, particularly during adolescence. He talked about going to a local branch of the NAS two years previously being a turning-point whereby he received specialist support and increased his understanding of AS and consequently himself. His narrative about events since this time was more progressive and he talked about his future involving helping others with ASDs, acting as a social campaigner to increase understanding of ASDs.

Jack started his story by describing a complicated birth, which he held partially responsible for his AS. In terms of his childhood, Jack reported few childhood memories, aside from 'going on holiday...being with my sister...playing outside'. He noted that some people with ASDs have early trauma, which he had not experienced. Jack's childhood narrative suggested a somewhat stable period, giving way to a regressive form in adolescence.

When discussing school life, Jack described being bullied which he thought had led him to become a perpetrator. He talked about his awareness that he can be 'intimidating' to others and his attempts to 'clean up' his 'act' since then.

Jack talked about AS being a hidden condition and expressed a sense of having always been different. He described puberty triggering intense emotions and behaviours which worried others and professional advice being sought. Jack's diagnosis with AS was made following 'trouble at school and college', when 'nobody could really work out what was going on' and he wasn't acting 'in the norm' or a way that 'people perceive to be normal'.

*It had been going on all along my whole life...this weirdness...but I think that when I reached...puberty age...it's like your feelings come out more...it's kind of like a river all flows out rather than just bobbing along as you were...burst out of me sort of thing and all of these scenarios that I got myself into which weren't good at all...somebody eventually realised something's not quite right here...and they...sent me up to the doctor.*
Jack reported that following diagnosis, he was excluded from conversations about AS by his parents. He said this put him out ‘majorly, even to this day’ and believed that he might have ‘adapted a lot better’ if he had been more included:

I didn’t know about this condition until I was about 15, 16... even at that point my parents didn’t really talk to me about it...I always kind of wondered about myself...you know when you feel different?...it’s a kind of thread that goes through my life.

Jack talked about a period of stability in early adulthood, when he was ‘bobbing around’ for ten years, with few ‘social things’ and ‘being lazy’. He talked about his part-time supermarket job where he had worked for over a decade, describing his employers as ‘very good with disabilities’. Work acted as an ‘anchor’, providing stability throughout this time. For Jack, his occupational role was pervasive throughout his story, suggesting this was key to his identity and overall well-being. This has been found in longitudinal studies of employment and well-being (Winefield & Tiggemann, 1990).

Against a backdrop of a stable narrative, Jack also spoke about sporadic regressive periods. He talked about difficulty managing emotions and uncertainty ‘how to feel’. He described a period a few years previously, when he had been ‘quite depressed...on this pendulum’, leading him to take an overdose of painkillers. He wondered whether he had actually wanted to kill or injure himself. Consequently, he ‘didn’t even get taken into hospital’, was ‘just a bit sick for the evening’ and ‘no one even noticed’. He concluded that the incident was ‘cry for attention’ because he was ‘terrible at asking for help’. The experience of mental health problems in people with ASD has been found to be common (e.g. Ghaziuddin et al., 1998; Tantam, 2000).
In addition to experiencing psychological distress, Jack talked about other periods when he had been getting himself into ‘dangerous scenarios’ and doing things he ‘shouldn’t have been doing, acting in ways that aren’t proper...crossing lines’. He described himself during this time as ‘oblivious, not knowing what was going on’. Jack described experiencing emotional extremes such as ‘rage’ with ‘no middle point’. As a result of these difficulties, he was referred for counselling. The counsellor recommended he attend a NAS social skills group. This appears to be the key turning point in the narrative, followed by a more progressive form. He reflected back and said that he had previously not understood himself, been active or had relationships. He compared his pre-NAS and current life and self:

I never really understood myself until I...ended up here (NAS)...since I’ve come here I’ve managed to understand myself...kind of who I am...I didn’t do much. Not like now...everything is so busy...it was so frustrating...I didn’t have friends... I did basically nothing for a decade... I’m a completely different person...I used to get upset... now I’m a lot calmer.

In talking about the NAS group, Jack spoke about the ‘balance of people and staff members’ being important. He talked about the ‘tightness’ of the group as a ‘bit of a curse’ because it could be hard for new members to integrate. Jack highlighted the importance of meeting similar people with mutual experiences, likening it to the camaraderie of war veterans:

...we’ve all got the same experiences...it’s like when you go to war...veterans...you’ve got that king of shared experience...you’ve experienced many of the setbacks and happinesses that the other person that is sat next to you in the room.

Jack expressed appreciation of NAS staff as ‘mentors’ and ‘role models’ for how he would like to be himself. The significance of receiving positive feedback from others was also raised as crucial with regards to identifying himself as a ‘trusted ... and
sensible enough' individual to be selected to join important projects (such as meeting a member of the royal family to discuss ASD related issues).

As the narrative advanced and Jack considered his future, the importance of employment or engagement in meaningful activity continued to be underlined, particularly those which advance thinking about ASDs. This can be linked with the concept of ‘generativity’ proposed by Erikson’s (1974) stages of psychosocial development, in which acts leading to the growth and well-being of others are important. Jack talked about his recent involvement in a range of projects (including the current study) which had arisen due to his links with the NAS:

I’ve been presented with lots of wonderful opportunities that I wouldn’t have otherwise...I’ve met someone like you ...someone making a book...We’ve had like a think tank here. They made Rainman...into a stage play...and the director came down...and they asked us for our views and that’s a wonderful thing....If you’re making a book or a movie, the first thing you should do...go off and ask the person that’s got the condition ‘what does it feel like?’.

The on-going importance of occupation is highlighted by Jack, who reported that he had applied to work with children with autism and wanted to play a wider advocacy role:

I was very inspired to get out and do ...It’s all very well to sit around and be a talking head in parliament...but unless you get out in your communities...do things...it’s kind of useless...I want to help as many people with autism as possible...funding, social care and all that kind of thing... that’s where I see myself in twenty years, being a social campaigner...Not just helping people but kind of help understanding... the social awareness.

At this point, Jack’s story demonstrated a strong moral tone in terms of his standpoint on ASDs. He raised issues arising from a recent media story about antenatal screening for autism and his view of the future of ASDs:
It's kinda like Nazism...everyone has to be perfect, we're all the same...what's wrong with having people...who are a bit different?...this is the same with Down's syndrome years ago....'oh, it's terrible, it's the end of the world. We can't have this baby because...it's not going to be socially acceptable'. In the 80s and 90s it was like that. That's...like the autism of today. That's how I think autism will be in about 10 years...mainstream, acceptable.

He talked passionately about the need for more debate and discussion about autism and the need for faster progression in this process:

There should be more debate in general about autism...discussion forums, government ministers, people kind of asking questions...It's never going to be enough until people kind of have forums and exchange of ideas and conferences...it's progressing but not at the speed that it should be.

Jack expressed frustration about ASD organisations’ absence from debate and discussion about these issues. He expressed concern that medical technology could eliminate people with autism and the importance he placed on the universal right to life:

You could end up...wiping the whole thing out...you can't just wipe people out because they've got a.... It goes back to all the wars we fought...people have died, they died for a point. So we can live, not just these people...the norm...well, there's no such thing as normal and there never should be...everyone has a right to life. Even these people who are quite docile, they have a right to exist...even people (who) have done horrendous murders and all these things.
Throughout his story, Jack reflected back on his life and being fortunate that his immediate family were still alive. He expressed sadness regarding his grandmother’s death from Alzheimer’s disease when he was a teenager, the ‘major trauma’ in his life. Overall, he described having been ‘quite lucky’, as ‘there’s always someone worse off’ and his positivity regarding who he has become:

*I am always grateful that I ended up the way I did...I’ve been fortunate. I’ve had a kind of a normal life, not too many tragedies.*

Despite being generally positive about his current life, Jack described a sense that ‘there’s something just around the corner’ which will ‘tip’ him and a fear ‘of just going mad one day, of going completely whacko’ because of his ‘dark side’ and the ‘rage’ he ‘struggles’ to keep inside. He talked about how this could instantly undo his progress:

*I know that at any moment, there’d be a click and something would happen and that would completely ruin all my good work and my entire kind of life.*

At the end of his story, Jack’s narrative is largely progressive. He talked about his contact with the NAS being the start of his life as an on-going journey and wondered whether this was fate:

*That was start of the journey ending up here...I think ‘was that meant to happen? Was that kind of set up at that point to happen? So ...like I’d go to the doctor and he’d send me to the counsellor and then I’d get seen here?’...the journey’s not over....(it’s) going to continue but every time I come near this building ...I think ‘Is this fate?...Is someone upstairs playing chess with me?’.*
4.1.2 ‘I don’t have to live up to the expectations of other people’: AS diagnosis as a release

Angela’s story had this narrative form, which had an initially regressive structure (with periods of stability) leading to an AS diagnosis being sought and received. Following diagnosis, the narrative took on an overall stable form with progressive and regressive elements. In this form, diagnosis was construed as both a source of meaning and a release from societal demands. This sense was captured in Angela’s quote above. This form is described below.

Angela’s Story

At the time of the interview, Angela was 45 years old. She began her story by talking about her mother’s perception that there was something ‘wrong’ with her from childhood, being ‘different’ and experiencing bullying. In adulthood, Angela experienced further bullying and problems at work which she believed led to mental health difficulties. In her mid-30s, after further work difficulties, a formal diagnosis of AS was sought and received by Angela and her family. Following diagnosis, Angela’s story became more progressive. It appeared that AS diagnosis might not have purely provided Angela with meaning regarding the difficulties that she had previously faced but also empowered her to release herself from the world of work and live as she chose. Angela talked about plans for the future involving moving out of the parental home. The importance of God and faith as an additional source of meaning and purpose in her life was also highlighted. As her narrative closed, she talked about the need to focus on positives associated with AS, and the importance of the acceptance of differences by both self and others.

Angela’s narrative was initially regressive in form, with some periods of stability. She began by talking about experiencing oxygen deprivation (and consequently brain damage) during birth which she believed to be the reason for having AS. She referred to an early realisation that she was different and her mother thinking that there was
something ‘wrong’ with her. This was also picked up at nursery and school. Although she saw a child psychologist, she was not diagnosed in childhood:

_Mum did think there was something wrong and she did mention it but nobody really picked up on it....my development...was slow...she did actually take me to see a child psychologist...they just told her she was being...neurotic._

Angela described childhood as a ‘struggle’ but highlighted her mother’s role in raising her well. She described herself as ‘fortunate’ until she reached high school when she was bullied by her peers. However, her mother and best-friend helped her through this:

_I just...had to struggle...she was a lovely woman and she sort of brought me up right....school life wasn’t easy...the infants and junior school weren’t bad...in fact, autism was mentioned there and also at playgroup... I was pretty fortunate... the teachers recognised that I had special needs and they sort of treated me accordingly....The bullying started in the upper school...because I was different...But I had a best friend who always stuck up for me...and it also helped the fact that I could come home to a loving home._

Work and employment difficulties were an important feature of Angela’s narrative. She described leaving school, attending a college course (which she failed) and attending an employment programme for people with difficulties gaining work. Following this, she undertook temporary jobs. She described frequently bullying and pressure in the workplace which ‘psychologically damaged’ her. Angela said that this led her to develop a mindset that ‘anybody who made a mistake’ with her or ‘wouldn’t make allowances’ for her was ‘out to get’ her. An exception was a packing job which was successful for seven years. However, she had to leave this post following ‘a breakdown’.
Following recovery, Angela took further courses and another job where again she was ‘really badly bullied’ and got into ‘trouble’. At this point, Angela reached a ‘crisis’ point. She had not been diagnosed but told a personnel officer that she was autistic ‘as a way out’. Eventually this employment was terminated on the grounds of ill-health and Angela’s family sought a formal ASD diagnosis. She described her mother’s responses to the assessment process, in particular a questionnaire that she completed and their positive reactions to the outcome:

Mum was sent a 48-page questionnaire... she said it was the best moment of her life...
   all the problems that I’d got were in this questionnaire...They...said ‘we are diagnosing you with Asperger’s Syndrome’.... It was kind of the best day of our lives really...knowing there was a reason for why I was the way I was...I wasn’t just being awkward or stubborn or naughty.

In the above quote, it is clear that receiving the diagnosis was not only a release for Angela but her family also and provided an explanation that was morally acceptable (i.e. the difficulties were not Angela’s ‘fault’). At this point, the narrative takes on a more progressive form. Angela did not return to work due to ‘stress and pressure’. Despite the impact of being bullied and being unable to go back to full-time employment, she reported enjoying an active and satisfying life:

I keep myself fairly occupied. I do voluntary work...I’ve got a good life...I do me domestic work...and I do me computer work...which involves doing admin work for me Dad...I also manage the database of my local autistic society...in the afternoons, I do me craftwork...I’m a committed Christian and I get involved in the church and everything...I’ve made a really good life for myself.

Angela talked about experiencing further psychological issues the preceding year, when she had difficulties ‘sticking up’ for herself. This had prevented her expressing
her feelings and difficulties sleeping, leading her to make a suicide attempt. However, this episode was not interpreted by Angela in solely negative terms. She described it as a ‘wake-up call’ and being ‘better’, having learned to stand up for herself rather than ‘bottle up’ emotions.

The importance of feedback from others was raised as important by Angela. She talked about the way in which her experiences with people at church ameliorated the effects of bullying and her negative views about others:

I think at the church...the way that they have treated me, I've come to realise that not everybody is out to get me... it can take a while to realise that not everybody's gonna be a bully.

Angela talked at length about the importance of her faith, unconditional love and how the relationships with and acceptance from God and her ‘church family’ had given her life meaning and purpose and helped her to develop a more positive sense of self:

My faith is really important to me...I don't know where I'd be without God...He loves and accepts me. I don't have to try and get other people to like me or approve of me...I know that He does...that's enough for me...being part of God's family where we can love each other and help each other is really important....knowing that God loves me as I am and he's accepted...my impairment and loves me as I am.

In terms of her future, Angela’s narrative was progressive. She talked about wanting to move from her life-long parental home before her father’s death:

I have got me name on a council house waiting list and I'm waiting for a flat...I don't really want to carry on living with me Dad until he gets old and dies...it might put
extra stress on me... it would be good if I could be moved out and settled before Dad
does... die... I think he'd quite like... to see me settled.

At the narrative's close, Angela highlighted the ways in which AS is positive, focusing on strengths and acceptance of difference rather than limitations. In addition, she highlighted the vital importance of self-acceptance:

... people with Autism and Asperger's syndrome have a lot to offer society... positive
traits... none of us are perfect; we've all got our different weaknesses... if we can learn
to accept each others' differences... I have to accept the differences in... a
'neurotypical', whereas I'm 'atypical'... I don't think like you think... acknowledging
difference... You can't expect people to be what they are not... I know I don't have to
live up to the expectations of other people and if they can't take me as they find
me... it's not really my problem... the most important thing is to learn to accept
yourself. ... that's the big crunch of it... not everybody's gonna accept you.

4.1.3 'People don't always understand': AS diagnosis as a surmountable barrier

Sarah's story was characterised by this narrative structure, typified by a generally progressive form. AS (and life generally) was construed as a series of challenges successfully overcome. The narrative was progressive in spite of the diagnosis and the potential difficulties encountered. However, these difficulties were not necessary located inside the diagnosed individual but other people and wider society. Both the acknowledgement of difficulties and location in others was exemplified in the quote above, a comment made by Sarah. Her story follows below to illustrate this narrative form.

Sarah's Story

At the time of the interview, Sarah was 24 years old. She was diagnosed with and aware of AS from childhood. She attended special schools and colleges, where she learned skills and engaged in a range of activities. Sarah talked about her life post-
education, moving from supported living to independent accommodation and pursuing ambitions. Throughout her narrative, Sarah focused predominantly on positive and enjoyable events, and her special interests and activities. Throughout Sarah’s narrative, it appeared that AS is just one aspect of her and did not define her particularly. She consistently described herself in terms of positive personal attributes. Although AS and life more broadly presented her with challenges, she had successfully overcome these using her personal attributes as well as external supports and ‘gets on’ in spite of AS. The narrative ended as progressively as it began with consideration of her future hopes and aspirations.

Sarah began her story by acknowledging her difference in a sense when she said that she was diagnosed with autism as a child but that despite this, she had done lots since:

*I was first diagnosed when I was about 11 or 12 years of age, with my autism. But I’ve done a lot of good things through my young age up till now.*

She demonstrated a highly positive view of herself, talking about going to schools and colleges in childhood and adolescence, doing ‘lots of fun things’ and learning about finding jobs and living independently. She talked about her ease in doing this. The role of positive feedback in the development of a healthy sense of self was clear when she talked about the comments made by staff about her being a ‘champion’ and a ‘clever girl’:

*They said ‘you are wonderful, how you understand things quickly and work out the logistics out...follow things quickly and memorise them.*
Sarah talked about ‘one of the best things’ for her at college was travelling and going on coach trips around the UK, ‘learning the history and facts from our famous towns or stately homes and gardens’. She also talked about representing her college at conferences and acting as an ‘ambassador’, which made her feel ‘really famous’ and ‘lucky’.

When she left college, Sarah went into supported living before moving into independent accommodation. She talked about her development since this time:

*I wanted to live independently...I first went into supported living...after two years of being there... the people I was living with, they weren't as able as me...so later I moved on and this was last year...in my nice, new little place...ever since then, I've developed more good skills, freedom and learning how to run your own place, with daily activities.*

Sarah talked about her current ‘ambition’ to learn to drive. Here AS raised difficulties in pursuit of this goal. However, she viewed this as a challenge to be undertaken and achieved. In past attempts, she had been unsuccessful. She attributed this to the instructors’ inability to understand her. Sarah situated difficulties in others rather than herself and in doing so maintains a positive sense of self. This suggests an optimistic attributional style, which may be protective against psychological distress (Abramson, Seligman & Teasdale, 1978; Seligman, 1990). At the time of the interview, Sarah was learning with a ‘special’ instructor who could empathise with her:

*They had men driving that weren't able to understand me...and didn't want to take me on...and then started back with (new instructor), last year...he's a special one who helps people with disabilities...he understood how I felt...he's been very good and kind, understanding and explained things...to me.*
Sarah talked further about the positive views others held about her. She provided numerous instances of receiving encouraging remarks from others. Sarah engaged in a range of activities from which she gained pleasure and meaning. She talked about learning to use public transport and budgeting carefully when shopping and her parents commenting on her in an encouraging manner:

Another great thing I’ve been doing is learning my own ways of travelling around using trains and buses...I used to go a lot within (place far away)...they are the farthest route I’ve taken bravely...in the last year....My Mum used to say ‘where have you been today, lucky girl?...you make me so overwhelmed how much you’ve learned every week, knowing what you enjoy doing.

Sarah also talked about her interest in current affairs and documentaries as ‘fun and interesting’ and a source of information to tell her not to ‘go wrong in life and get into trouble’ and ‘what to do when you come across situations’, including those related to relationships. She said that her mother thought that she worried too much but Sarah felt that she learned from this interest and it was not a source of anxiety. This highlights the ways in which Sarah views life (including the difficulties related to AS) as a series of challenges which can be surmounted using her personal attributes (in this case as a person who seeks out information and applies it to issues which she faces). She commented on how well she manages her finances despite the global recession which was occurring at the time of the interview:

Whilst they hear all these doom and gloom stories...at least I am working hard and observing how things are going out there.

Sarah mentioned attending church since childhood as important but something she does ‘for fun’, to sing songs ‘that cheer you up’, make friends and learn about them rather than something that she ‘follows up in full’ and believes in:
I just go to enjoy mainly the singing and what they tell you and praising when
making friends and other nice, new people really.

She said that as her family do not attend church, this had caused 'disputes' and her
parents thought that as 'a few bad things occurred' through her times at church, this
might be responsible. She demonstrated the importance of asserting her
independence and identity as an individual with free-will and said that she had told
her mother that she 'can't just boss people around the older they get, once they are
adults'. Sarah explained her mother's reactions in terms of her Polish background
and the political context in which she had grown up soon after the Second World
War:

I remind myself that she might not seem as fine as she is and generally seem a bit
unhappy and cross...and didn't understand about choice and rights for young people.

Sarah talked about recent difficulties within her family and again focused on how
well she had managed these. For example, her parent's separation:

My parents were splitting up....so that was a big change I took on last year and I've
already got used to it, not...worried from it at all....so that's not changed me in
anyway.

Sarah also talked about how she had helped other family members with their
difficulties. For example, her sister, who is 'not disabled' trying to find employment
and accommodation. Sarah reflected on the economic recession and said that she had
been 'looking out for her', using skills learned from her father (an accountant) to
work out her finances. Research on helping behaviours has found associations with
well-being and implications for identity (Theurer & Wister, 2009). Sarah compared
herself with her sister who needed to ‘do things from scratch’ and not had help ‘through benefits and living allowances’. Here it is clear that having AS is viewed as an advantage over others. Sarah said that her sister appreciated her efforts and communicated this to her:

*She...likes me loads now for doing that and said ‘nice of you to offer to help me when I feel stuck’... so I’ve really been a help to my sister... looking out for her.*

Sarah also talked about her mother working too hard and attempting to help her to have ‘a bit more fun’ by encouraging her to ‘meet up and do little holidays’. She recalled previous trips they had taken together, showing her places she had visited before and sharing her knowledge. She said her mother told her that she is ‘really inspiring’ at such times. Sarah mentioned that ‘another great thing’ that she did the previous year was visiting Buckingham Palace when a relative was on the Queen’s Honours list. She talked about being ‘inspired’ by this and having a ‘real memory’ of this ‘fun day’. Again, she compared herself favourably to others, namely her sister who was unable to attend. She said that her sister had thought she was ‘lucky’ to go and see ‘such people’.

Sarah summarised the way that she is consistently described in positive terms by relatives and professionals, both in verbal and written formats:

*My family...they say ‘what’s nice about you...is you’re always full of surprises...you’ll always tell us something new that’s going on...it’s good how aware you are of things and what fun you’re getting out of yourself...Generally people say of me...is quite conscientious, diligent and clever, a very kind of sufficient and efficient girl...getting to learn lots each day, telling us new things going on...being cautious with...money.... planning well before she does things’...that’s what people would say if they ever explained me... They explain it in different ways and I’ve*
Sarah also fondly recalled her introduction three months previously to her first boyfriend on an organised holiday scheme:

*One other little surprise and this was only because (staff members)...planned this...to surprise me...I got my first boyfriend... they thought he's been lonely and she's never had someone...let's see if they meet together...one evening when we had a disco, I met (boyfriend) and he was so lovely and charming and sweet...it was amazing. We had fun together and we did a proper love impression when slow songs would come on and buy drinks for each other, celebrate in style...it was fun that night. It's a night I'll always remember.*

Sarah’s narrative ended with a discussion of her hopes and ambitions for the future. She talked about ‘still learning lots generally’ in terms of her relationship with her boyfriend and that she would eventually need to decide whether to get married. This links with the concept of ‘intimacy’ in Erickson’s (1974) stages of psychosocial development when love and relationships become significant. An additional aspiration for Sarah’s future was ‘to go abroad and really learn...what all these countries are special for’. Although there was a sense that life will inevitably throw up challenges and tests, she appeared positive about her capacity to cope. This narrative ended with a similarly progressive form as the rest of the narrative.

4.1.4 *This is a symptom of Asperger’s*: AS diagnosis as explanation

This narrative form was shared by James and Phillip. In terms of structure, this form was generally stable until a turn of negative events led to AS diagnosis and a subsequently regressive narrative. However, AS was deemed to have always been present with little attention paid to it until the downturn in events. AS does not
appear to be central to identity but drawn upon as an explanation for difficulties encountered and the sense of being unusual. This is highlighted in the quote above, variations of which were made in relation to difficulties. In order to illustrate this narrative form, James’ story is described.

James’ Story

At the time of the interview, James was 56 years old. He had been diagnosed with AS three years beforehand. He described a generally stable narrative in terms of his living and work arrangements before a negative turn of events in both domains led to his diagnosis with AS and a subsequently regressive narrative.

James began his story by saying that he was diagnosed with AS and attended NAS groups. He talked about AS not being known about when he was a teenager in the 1960s and the negative impact of others’ comments and bullying regarding being sent to an ‘educationally subnormal secondary school’.

The trouble is, in the 1960s... Asperger’s was not known... educationally subnormal school... that was what they called them... you had to be careful... people used to be very derogatory and said we’d gone to a school for nutcases... it wasn’t very funny... it was something to do with my learning difficulties.

James’ narrative focused primarily on work and his role as an employee, suggesting that his occupational role was of significant importance to him in terms of his identity. He expressed a desire to talk about ‘the happy times’, moving from London and working at a cemetery aged 18:

I will go back to what I call ‘the happy times’... when myself and my parents moved... in 1971 and in the December I started in the cemetery.
James recalled his first morning at the cemetery and meeting a particularly patient colleague who helped him. He talked about this being before his diagnosis of AS and how he might have appeared unusual to others:

*I remember...I met an elderly man...I worked with him for a time...this was a good thing because if I'd gone with one or two of the others, I might have only lasted six months...but with him, he had a lot of patience...this was long before my diagnosis of Asperger's....there was something there....I must have come over a bit funny to them but I probably didn't realise it at the time.*

He went on to talk about meeting a good friend at the same time, with whom he had remained in contact with. He talked about how they had always got on well and their friendship had been ‘bound’ by both going to ‘educationally subnormal’ schools:

...we both got to know one another...became very good friends...I used to go round to his mother's house...I went to his engagement party and ...to his wedding... We were both very good friends...we still are...I have never had a row...I've had arguments with other people...but never quite with him for some reason...we went to a similar sort of school, I think that bound the friendship...educationally subnormal school...I think that's how the friendship grew.

James spoke of his desire for independence and wanting to move out of his parents' home in his mid-twenties. At first he moved into a caravan and then the council flat where he had lived for the last 28 years. He talked about this being a ‘very settled time’. He moved from one cemetery to another in the late 1980s and had good relationships with his colleagues. He said that ‘everything was ok’ because colleagues ensured he would keep his job. He interpreted this as his AS perhaps ‘showing’:
The scenario was this: He said 'all the time I'm here, you will have a job'...there was something underlying about me somewhere in that...the Asperger's was showing somewhere but I wasn't diagnosed.

James reflected back on his less successful work experiences prior to the cemetery. He used the analogy of the musical piece Ravel's Bolero with the replication of two tunes and the gradual introduction of instruments to describe how people need to help him at work (using repetition and patience) because employers got frustrated (as illustrated in the piece by the musical crescendo building for trumpets). He described how the accommodating approach used by colleagues at the cemetery worked well as he had difficulty picking up on things outside of his particular interests. James talked about previously attributing the way he was to a 'nervous disposition' and knowing 'there was something there but couldn't...connect to'. In the following quote, the way in which James drew on AS as an explanation for his particular strengths and difficulties is clear:

I'm not very good at picking up on things but astronomy and things and grave-digging, no problem, it's weird isn't it? This is a symptom of Asperger's.

James also attributed his successful and long engagement at the cemetery to a mix of the people that he worked with, combined with his personal attributes as an employee. The role of social support in the promotion of positive mood, functioning and quality of life is highlighted, as has been found in other studies (e.g. Wang, 1998):

I found my place but it was all...behind the scenes, the people that I was with, maybe that was what it was...but I think because I was always on time and I was always reliable...they would have never got anybody to do the job properly. I think that was what a lot of it was as well...it was a mix of both really.
James talked about his diagnosis of AS coming only three years previously but talked about an awareness of being different for a long time through comparisons with others:

*I know I was weird for years...I said there was...a nervous disposition but I didn’t quite know it was that...there was something. I knew I was doing something that was out of place...I wasn’t sort of behaving like other people probably.*

He explained that it was like everyone was aware that there was ‘something’ but that ‘nobody bothered about it, everybody minded their own business, until a certain person saw it and kicked off about it.’ James talked about difficulties he had with a new colleague who disliked him. At this point, the narrative takes on a regressive form. Following these difficulties at work, James experienced mental health problems in the form of worry and low mood for which he received medication. He said that these circumstances led to him being sacked two years prior to his diagnosis with AS:

*He was...very weird character...he didn’t like me...in the end he had me thrown out of the cemetery...All sorts of mind games were going on. Like when I would put a pair of boots in ...my locker and they would mysteriously vanish...all sorts of things. He was doing these things to have me thrown out. He didn’t like me...it was dreadful...it ended up I had an anxiety state over it...and I had Prozac for a time...I think this is what led up to the diagnosis of Asperger’s.*

James also talked about more recent experiences of mental health problems following his diagnosis with AS. He talked about another stressful event two years previously, a bed bug infestation in his flat, which led him to experience paranoia and low mood and continued to affect him at the time of the interview. He attributed part of his reactions to AS:
I think it kicked off paranoia...and I haven't been quite myself ever since that happening...I do get a bit of depression now...I do have crying attacks...when things crowd into my mind and this is part I think of the Asperger’s.

James reflected back on the difficulties at work and the infestation as being the ‘first two upheavals’ in an otherwise stable life. He talked about having difficulties at the cemetery but that he continued due to his fondness for the place and because of the people there. James described that as the ‘whole story’:

I loved (the cemetery) and I know I had my ups and downs there, I really did but I rode the storm...because I loved the place, so I stayed and it was through people that I was able to stay, that’s the whole story.

James wondered what might have happened if the new colleague hadn’t arrived at work. He thought he would still be at the cemetery but conceded that (in terms of his AS diagnosis), ‘it’s got to come out sooner or later’, wondering if the difficulties at the cemetery hadn’t occurred ‘would the bed bug thing have done it?’.

The narrative’s end was less regressive than previously. The importance of employment continued to dominate and James’ future plans were related to ‘finding the right place’ to work. However, the impact of AS continued to be clear. James ended by referring to a comment made to him about AS, which he agreed with:

The lady did say to me ‘you’ve got a condition, it won’t heal. It’s not like a broken leg’...it won’t heal unfortunately.
4.2 NARRATIVE CHARACTER

In analysing narrative character, Murray (2009) highlights the importance of the extent to which the character is connected to action and how the character is defined through relationships with others. In the current study, two particular dimensions of narrative character were identified by the researcher. These were related to the impact of AS and the degree to which the character experiences control over their lives. These character dimensions are described below, with examples selected from the narratives.

4.2.1 Asperger’s Syndrome: Definition Vs. Detail

The central character in the narratives is the individual with AS telling the story. Those interviewed varied considerably in terms of the degree of importance placed on AS for identity. Individuals’ on-going social relationships and interactions with others appeared to effect whether AS (and self) were negatively, positively or neutrally valenced. This links with the long-established symbolic interactionist theories, which hold that the verbal exchanges and communications with others are central to sense of self and the attitudes of others are integrated into identity (e.g. Baldwin, 1897; Cooley, 1902; Mead, 1934).

For Jack and George, the concept of AS was a key aspect of their character and self-definition in terms of their past, present and future. This is clear from Jack’s comment that the difference associated with AS is ‘a kind of thread that goes through my life’ and George’s statement that being diagnosed was like being given the ‘answer to the universe’. Their social interactions and communications with others had been challenging and their sense of self compromised until they began establishing relationships in which they were able to receive positive feedback (for example, in ASD-related support groups). For Angela, her differences negatively impacted on how others viewed and treated her, until she developed positive relationships with God and her ‘church family’. However, for others (James and Phillip) AS played a less defining role as long as other people accommodated their ‘differences’. However, when this did not occur, AS took on a more negative
connotation. In contrast, for Sarah, AS was acknowledged in an almost ‘matter of fact’, neutral manner and the positive attitudes of others towards her were clearly incorporated into her optimistic sense of self.

4.2.2 Self-efficacy: Free-will Vs. Destiny
Internal perception of control and self-efficacy can be considered to be key elements of identity, associated with coping behaviour and psychological well-being (e.g. Bandura, 1977; 1998; Rotter, 1954). Positive social communications and a sense of being able to develop satisfying relationships have also been found to contribute to self-efficacy and buffer against stress (Bandura, 1977; 1998). The importance of these ideas was suggested in the current study’s narratives.

In the beginning of his account, Jack describes himself as ‘lucky’ not to have suffered any childhood trauma. He then speaks about his adolescent ‘self’ having little control of himself and external events, being excluded and bullied, and ‘getting in trouble at school and college’, with his emotions ‘bursting’ out of him. As his story is told, he demonstrates an increased sense of self-efficacy when he introduces his future plans, in which he hoped to make an impact on a societal as well as individual level. However, as Jack’s narrative reaches its close, the idea of destiny and fate came back to the fore, with Jack comparing himself with others, talking of having been ‘quite lucky’ and wondering about his current situation, ‘is this fate...Is someone upstairs playing chess with me?’. Murray (2009) argues that frequently in narrative, the main character can oscillate between a sense of being in control of and being controlled by events. This is clearly demonstrated in Jack’s narrative.

In contrast, Sarah’s narrative reveals a sense of very much being in control of events in her life and she demonstrates a high degree of self-efficacy. Despite describing herself as ‘lucky’ in terms of the opportunities she has been presented, she approaches potential difficulties (both practical and relational) in a considered way, collecting information and planning ahead before action. Although other people are important in this process, Sarah views herself as in ultimate control. This approach has been encouraged by those around her with positive feedback. Consequently, she experiences a high degree of self-efficacy and a sense of being in control. She makes
particular reference to this when talking about her mother not understanding about ‘choice and rights for young people’.

4.3 WORK OF THE NARRATIVE
All study participants were keen to share their stories for research purposes, requiring minimal prompting from the researcher to provide detailed narratives. In addition, five of the six participants reported attending ASD groups where they shared their experiences with others for therapeutic purposes.

It has been asserted that producing narrative can have multiple functions. One function is to organise events and experiences, give them meaning, to allow them to be understood and integrated into the broader life story (Murray, 2009). This has been described as ‘biographical work’ (Bury, 1982) and was a clear function of the current study’s narratives. An additional function of the narrative emerging from the analysis was as a form of political advocacy, drawing attention to issues of importance to those with AS. These two key aspects of the work of the narratives are described below.

4.3.1 Narrative as ‘biographical work’
The narratives demonstrated a range of experiences in attempting to integrate AS into the wider life-story. This was clearly demonstrated throughout George’s narrative whereby significant life-events were described using AS as an explanatory framework to tell an integrated story to explain how he had been, a ‘shell’ and had become, ‘a human being, the person that I’ve always wanted to be’. For Jack, George and Angela, life was a series of struggles which was interrupted by increased understanding of AS and how it relates to them. For Phillip and James, life was stable until a series of difficult events led to AS diagnosis which was used to retrospectively explain past events. In contrast, Sarah’s life (including AS) was described as a series of successfully negotiated hurdles.

Murray (2009) argues that the ‘biographical’ function of narratives can be viewed as attempts to assist in the process of organising an altered identity. Indeed for people
4.3.2 Narrative as political advocacy

In some interviews, an overt function of the act of sharing the story was related to the motivation to provide ‘insider’ perspectives on AS and to highlight issues of importance of significance at a level wider than the individual. This was clear throughout Angela, Jack, Phillip and George’s narratives. In particular, Angela’s story highlighted issues of bullying and lack of acceptance of difference in wider society. As her narrative concluded, she summarised this concisely:

*I feel that people with autism and AS have a lot to offer society...they’ve got positive traits...none of us are perfect, we’ve all got our different weaknesses...I have to accept the differences in ...a ‘neurotypical’, whereas I’m ‘atypical’*

The use of narrative as political advocacy can be linked to what Murray (2003, p. 127) describes as ‘giving witness’ or ‘coming out’ in a public domain, as a way of both questioning constraining societal narratives and generating support.

4.4 NARRATIVE CONTEXT

The present analysis concentrated on the societal context of the narrative accounts. During analysis, the significant impact of wider social representations and narratives related to ASDs (Holmer Nadesan, 2005) was apparent. The narratives connected to both what can be described as the medical and advocacy models of ASDs.

4.4.1 The medical model: ASDs as disorder

The medical model of ASDs has been argued to be currently dominant (Biklen, 2005). In the narratives (particularly those with the form ‘AS as a source of meaning and purpose’), ideas related to ASDs as disorder were apparent. In particular, Jack draws upon the medical model as a framework for explaining the ‘condition’ AS, partly as a result of birth complications and related to neurology, (‘something that’s
in your brain’). He also drew on the notion of the biological process of puberty as a trigger of powerful emotional and behavioural responses. Likewise, Angela holds the idea of a biological cause and receiving diagnosis as important. It can be argued that use of this model may serve to absolve potential ‘blame’, allowing parents and ‘sufferers’ to be morally unaccountable for behavioural issues (Holmer Nadesan, 2005). Indeed, Angela talks about being diagnosed as providing a ‘reason’ for the way she was, rather than ‘just being awkward or stubborn or naughty’.

4.4.2 The advocacy model: ASDs as qualitative difference

The advocacy model frames ASDs in terms of a way of ‘being’ and is more social in nature. It was clear in many of the narratives. Although drawing on a medical model for causal explanation, Jack rejects the medical model’s related aims for ‘treatment’ and ‘prevention’ of ASDs, favouring a social model. When talking about his adolescent behaviour, he refers to not acting in a manner that ‘people perceive to be normal’ and also suggests that ‘there’s no such thing as normal’. He also talks of screening for ASD being like ‘Nazism’, questioning whether the existence of ASD is ‘wrong’ and arguing for debate and discussion regarding such ideas.

Similar ideas were echoed in Angela’s narrative, when she highlighted ASDs as a positive difference and need for both ‘neurotypical’ and ‘atypical’ people (with ASDs) to learn to acknowledge that ‘none of us are perfect’, everyone is different and these differences should be accepted.

4.5 SUMMARY OF CREDIBILITY CHECKS

Three participants provided feedback on the draft results. Phillip said that reading it ‘was very illuminating and in a funny way comforting, knowing that despite the feelings of isolation, other people feel the same and ironically you are not alone’. Jack commented ‘that's just right, very good piece of work indeed’. Sarah commented that she found some of the language used by other participants ‘confusing’ but that she had ‘liked reading it and learnt a lot from it’. Likewise, when summaries of the analysis and draft results were shared with the NA group, the feedback was positive and the group’s members understood the analysis that had been conducted.
5 DISCUSSION

The current study explored the experiences and identity of six people with AS. In particular, it aimed to examine if and how being diagnosed with AS might have implications for identity. This section presents a summary of the main findings of the study and examines them with reference to the existing literature in terms of both the research base and the accounts of individuals with ASDs. Furthermore, some of the study's limitations and clinical implications are highlighted. Ideas for future research to extend the findings of the current study are also suggested. This section concludes with the researcher's final reflections.

5.1 SUMMARY OF ANALYSIS

This study used a life story interview approach to co-construct six narratives with adults with a diagnosis of AS. In each account, participants identified themselves as being diagnosed with AS. This was perhaps unsurprising given that participants volunteered on the basis of this diagnosis. However, participants' narratives varied in terms of the degree of importance placed on AS diagnosis for understanding self and difficulties they faced.

All participants talked about their past and present experiences, demonstrating the capacity to reflect on their life stories. They also considered their hopes and aspirations for the future and talked about themselves in terms of their relationships with family members, friends and staff. Significantly, many participants defined themselves in terms of past, current and future occupational roles whether in a paid or unpaid capacity. In addition, all participants identified and reflected on their positive as well as less helpful personal characteristics and attributes. There were additional similarities in the accounts (e.g. the experience of bullying and psychological distress). However, diversity was demonstrated in the life stories produced, which were rich, varied and distinct, with regards to the narrative form, narrative character, work of the narrative and narrative context.
5.2 NARRATIVE FORMS

The narrative forms which emerged enhance the understanding of people diagnosed with AS, providing portrayals of the ways in which people with AS construct self and identity. These narrative forms were related to recommended temporal structures (progressive, regressive and stable) of narratives (Gergen & Gergen, 1984; Gergen & Gergen, 1986). Descriptive labels were generated by the researcher for each narrative form. The forms identified in the current study were compared with those from previous research and linked with the existing narrative accounts of people diagnosed with an ASD.

5.2.1 AS as a source of meaning and purpose

With regards to the narrative form AS as a source of meaning and purpose developing an understanding of what a diagnosis of AS means and receiving information and support for this was of far greater concern than receiving a diagnosis per se. Receiving support which may be attached to such a label appears to provide a sense of meaning to explore questions such as ‘who am I?’ or ‘who was I?’ and to understand previous experiences. An additional component of this narrative is that AS provides a sense of purpose for the future, with future occupations being concerned with taking on roles which incorporate an element of social campaigning and education about ASDs which resist notions of ‘normality’ and ‘abnormality’.

This narrative form corresponds with the literature from both the academic and ASD communities. For example, it shared similarities with the narratives of some adolescents with AS in Molloy and Vasil’s (2004) research, whereby diagnosis was viewed as a sense making narrative. Diagnosis provided an explanation of difference and a sense of relief, enabling re-evaluation of their life stories. Outside of ASD-specific research, a further study that this form links with is the form of ‘disability as opportunity’ which Murray (2007) found in his study of injured fish harvesters, whereby new and alternative opportunities were explored as a result of their injuries.
5.2.2 AS diagnosis as a release

In terms of the narrative form AS diagnosis as a release, the narrative took on a stable form at the point of diagnosis with progressive elements. AS was described not only as a source of meaning but a release from societal expectations and demands and a reason for difficulties which does not blame the individual. This unmistakably connects with the findings of Punshon et al.’s (2009) study, the title of which is ‘The not guilty verdict: Psychological reactions to a diagnosis of AS in adulthood’. The occurrence of judgement and relief experienced by individuals and families both before diagnosis and as a result of diagnosis. Religious faith as a source of meaning and comfort was also important. This bears striking similarities with the narrative of ‘transcendence’ noted in Gray’s (2001) research, which highlighted the importance of meaning found through religious faith and the church as an alternative community of support (to the scientific community). The importance of religious faith was also highlighted in the autobiographical writings of people with ASDs, such as Temple Grandin (1995).

5.2.3 AS Diagnosis as a surmountable barrier

With regards to the form AS diagnosis as a surmountable barrier, AS was construed as a challenge successfully overcome. The narrative was progressive in spite of the diagnosis. This links with Murray’s (2007) form, ‘disability as a challenge’, which is to be dealt with in pragmatic terms on a daily basis. It has been noted that this narrative form is reflected in many sources from people with autism. For example, Murray (2008) draws attention to the manner in which writers with autism (such as Temple Grandin and Donna Williams), acknowledge the pressures faced as a result of ASDs but describe their success in addressing such difficulties.

5.2.4 AS Diagnosis as explanation

In terms of the form AS diagnosis as explanation, the narrative was stable until a turn of negative events led to a regressive narrative. AS diagnosis was linked retrospectively to events and regarded as always having been present but
unacknowledged directly until attention was drawn to it. In this form, AS did not appear to be central to identity but was present nonetheless. It can be hypothesised that this was related to the age at which diagnosis occurred. In this study, both individuals who fit this form did not receive a diagnosis until later in life (in their 40s and 50s). As such it is likely that they had more opportunity to develop their identities in terms of other aspects of their lives (such as employee or parent). Therefore, AS had less opportunity to be integrated into their sense of self. This narrative form was similar to that of Murray’s (2007) ‘disability as phenomenon’, characterised by a ‘controlled and distanced stance towards their disability’, in which they were able to review their past and current life from a psychological distance’ (p. 169).

5.3 NARRATIVE CHARACTER, WORK OF THE NARRATIVE AND NARRATIVE CONTEXT

5.3.1 Narrative character

In the current study, the central character in the action was the individual with AS sharing their narrative. Dimensions related to the impact of AS and fate vs. free-will were identified as important. This was also suggested in Murray’s (2009) narrative study of women diagnosed with cancer in which perceived control was recognized as an important aspect of narrative character.

5.3.2 Work of the narrative

For the present study, the work of the narrative was related to both a type of advocacy and ‘biographical work’. The keenness of participants to share their stories and narrative as a way of integrating experiences into their wider life story were also noted in Murray’s (2009) research described above.
5.3.2 Narrative context

The medical narrative suggested in the current study connects with the findings of Gray's (2001) study, in which some parents of children with ASDs held 'biomedical' views of ASDs. In particular, the narrative of 'resistance' resonates with this. In this narrative, the power of normalising discourses was opposed and the self redefined in terms of political action related to ASDs.

In terms of sources from the ASD community itself, the advocacy model assumed by organisations and individuals is widespread. In terms of individuals, Amanda Baggs is an example, of a person who takes on an advocacy role (Murray, 2008). Another advocate is Chris Mitchell, a man diagnosed with AS aged 20, who 'reinvented' himself post-diagnosis and whose objective is 'raising awareness...to promote the idea that Asperger's Syndrome is a characteristic or even a gift, depending upon how one views it, rather than a disability' (see www.chris.mitchell.org.uk. retrieved 14 June 2009; Mitchell, 2005). The title of Mitchell's (2005) autobiography is 'Glass half-empty, glass half-full: How Asperger's syndrome changed my life' and is presented in two parts, one pre-diagnosis (glass half-empty) and post-diagnosis (glass half-full) and reflects the point of diagnosis being a turning point in his story. Likewise, the sentiments of the on-line organisation 'Aspies for freedom', who 'aim to strengthen autism rights, oppose all forms of discrimination against Aspies and Auties, and work to bring the community together both online and offline' resonate with this model.

In conducting the analyses, it was interesting to note the narratives which were absent as well as those which were present. In particular, there was no narrative of 'devastation' or 'tragedy' as has been found in other research (e.g. Murray, 2007). Such narratives are widespread in the wider discourses related to ASDs. That is not to assume that such narratives are absent within the AS community and it is possible that those who had more positive narratives or had come to terms with their narratives were more likely to volunteer to participate in the current research. Nonetheless, the narratives revealed were perhaps more positive and hopeful than might have been expected from a purely biomedical or 'scientific master narrative' of disorder (Gray, 2001).
5.4 CLINICAL IMPLICATIONS

This study highlighted some implications for theory and practice. Generally, it highlighted the importance of diagnosis for identity in people diagnosed with AS and drew attention to a range of issues to consider in terms of diagnosing and working in partnership with people diagnosed with AS. The crucial role of others with ASD diagnoses was pertinent in the narrative form ‘AS as a source of meaning and purpose’.

More specifically, this study emphasized that it is not simply diagnosis and provision of appropriate support that is crucial but the process of establishing the meaning of diagnosis for individuals. In addition, the importance of supporting people with AS to hold alternative narratives about autism (which do not necessarily fit with the medical model) and the value of the promotion of alternative narratives about autism for the development of a positive sense of identity were underlined. This highlights a need for post-diagnosis support to assist diagnosed individuals and their families in this process. The role of individuals with ASD diagnoses as well as ‘professionals’ in supporting this process is suggested. In particular, Clinical Psychologists commonly provide therapy and interventions for people with ASDs. In addition, as a profession, the core purposes, philosophy and training of Clinical Psychologists are especially compatible with achieving this end due to the importance placed on an appreciation of multiple ‘models’ and approaches to understanding the full range of human experience (British Psychological Society, 2001; 2008).

Another issue is that the age at which a person first becomes aware of/is given a diagnosis appears to be of significance in terms of how central AS is to an individuals’ identity. For instance, for individuals diagnosed later in life or once they have developed numerous social roles (e.g. as a parent or spouse), an AS diagnosis may be less defining than a diagnosis received earlier in life when such roles are less likely to have been assumed. Again, Clinical Psychology is well-placed to consider
such issues, with its emphasis on: working with people from a wide range of backgrounds and age groups; and taking a life-span approach to clinical work (British Psychological Society, 2001; 2008). Ideally, this would take place in collaboration with schools and mental health and learning disability services if appropriate.

A further implication emphasised by this study is the widespread bullying, discrimination and harassment experienced in both educational and employment settings. This has implications for both schools and employers, who have a legal duty of care to ensure the well-being of pupils/employees. To support educators and employers in meeting this obligation, specialist training and support in schools and workplaces could be implemented to tackle this issue. Ideally, this would be achieved by people with ASD in collaboration with ‘professionals’ such as Clinical Psychologists. Clinical Psychology training and practice highlight the significant impact of early life and school experiences on later well-being. In addition, it includes strong components of teaching and training in disseminating psychological knowledge and skills both inside and outside of the profession, at both organisational and community levels (British Psychological Society, 2001; 2008). Indeed, it can be argued that as a profession, Clinical Psychology has greatest influence on psychological well-being by working at wider, systemic levels (British Psychological Society, 2001). Additionally, with increased focus on leadership roles, Clinical Psychologists are positioned well to provide guidance on such action (Department of Health, 2007).

The study also drew attention to the ethical implications and possible detrimental impact that research drives for screening and ‘treatment’ of ASDs may have on the identities of people with such diagnoses. For researchers, it is important to consider what message this transmits about the ‘acceptability’ of a group of people in society. For clinicians such as Clinical Psychologists, it suggests that attention should be paid to this as a potential source of distress for people with whom they work with ASDs and to be cautious about inadvertently reinforcing notions of ASDs being ‘problems’ for reduction/eradication. It also highlights that when considering diagnosing, the
potential advantages and benefits outweigh this possible drawback, so that diagnosis is not made simply for its own sake.

Finally, following the interviews all of the participants reported that they had enjoyed taking part in the research and found it a valuable experience. This suggests that allowing people with ASDs the space to think about and reflect on their life stories is a worthwhile endeavour, which clinicians such as Clinical Psychologists may be especially skilled in implementing when working with people with ASDs.

5.5 LIMITATIONS

This study has explored the complexity of self and identity in people with a diagnosis of AS and aimed to represent the perspectives of people with AS. Throughout, attempts were made to evaluate the quality and credibility of the study according to suggested criteria (i.e. Elliott et al. 1999). However, a number of limitations were identified and are highlighted below with ideas for possible ways of overcoming these.

This study was based on a small sample of white British participants at a certain period in history, within a particular cultural and social context. In addition, the stories presented only reflect the stories of those able to communicate about their lives verbally. As a result, one possible criticism is that the findings are limited in terms of generalisability to the wider population. It should be borne in mind that the aim of the study was not to represent the identities of all people with AS but to explore the identities of individuals with varied stories. Thus, the findings may be transferrable to other similar groups of people. In addition, the findings can be said to have ‘theoretical rather than empirical generalisability’ (Smith & Osborn, 2003, p. 54) by linking the findings and interpretations to the existing theory and illuminating the wider context. In this study, the findings fit well with those of previous research, as well as on a theoretical level, strengthening the case for generalisability from specific cases (Smith, 2003).
Another possible limitation is that due to the time restrictions of the study, the narratives were collected in single interviews. This might not have allowed participants to tell their story fully. In addition, participants might not have felt comfortable to share some important elements of their stories, as there was only a limited opportunity to develop rapport with the researcher. From the researcher’s perspective, it was possible to develop a reasonably collaborative relationship with participants. However, it is not clear whether this reflects the experiences of the interviewees. If the study were to be replicated, this could have been overcome by allowing longer for the relationship to develop and by conducting a series of interviews rather than single interviews, which worked well in previous research (e.g. Bagatell, 2007). Interviews could have been supplemented with additional sources of information, such as journals and art work, which have been fruitfully used in other studies (e.g. Humphrey & Lewis, 2008). Finally, a further limitation of this study is that the narrative forms presented are only likely to reflect a selection of potential forms. It would be valuable to extend this research to include more participants. This would allow additional narrative forms to be identified and provide richer detail regarding the forms identified in this study.

5.6 FUTURE RESEARCH

The current study is one of the first to explore how adults with a diagnosis of AS construct self and identity. Therefore, it would be favourable to develop these ideas further. In addition to the suggestions put forward in the limitations section, a number of additional ideas for future research may be proposed. For example, NA could also be used with specific groups of people (e.g. in terms of age, marital status, parents, socioeconomic background, ethnicity, age of diagnosis). It would also be interesting to follow up an individual’s life story over an extended period of time. The approach taken in the present study only offers a snap-shot of a narrative at one point in time and it has been argued that narrative orientations are not fixed but change over time (Murray, 2007). A longitudinal study would allow development of
the narrative and thus identity to be tracked over time with the evolution of societal narratives regarding ASDs.

**5.7 FINAL REFLECTIONS**

I made some personal reflections in the method section as part of the credibility check of 'owning one's perspective'. These highlighted some of my early ideas and concerns in the research process. In this section, I reflect on the process as it concludes.

Throughout the course of this research, I experienced mixed feelings regarding using qualitative methodology. My previous research had utilised positivist, quantitative approaches, which I was dissatisfied with in reflecting lived experience. However, as a new approach, I felt hesitation about doing NA 'right'. The advantage of NA is the freedom regarding analysis and it affords excellent opportunities to use creativity. However, this also led to moments of confusion and uncertainty.

Throughout the process I was mindful of how I represented the stories of the participants. I aimed to interpret their stories in a way that would resonate with their experiences rather than simply being a reflection of my own personal and professional biases (e.g. by particularly picking up on occupational issues and psychological distress). However, I sought and received positive feedback from participants regarding both the experience of engaging in the interviews and the results and hope that they have felt able to be frank in their comments to me. Finally, I hope that through this study, I have been able to invite readers to question some of their own assumptions and preconceptions about ASDs and identity.
6 REFERENCES


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www.aspiesforfreedom.com/

www.chris.mitchell.org.uk

www.nas.org.uk/nas/jsp/polopoly.jsp?d=225


5 APPENDICES
Appendix (i)

Letter of ethical approval
15th September 2008

Dear Claire

Reference: 249-PSY-08RS
Title of Project: A narrative analysis of the personal identity of people who have received a diagnosis of Autism Spectrum Disorder

Thank you for your submission of the above proposal.

The Faculty of Arts and Human Sciences Ethics Committee has given favourable ethical opinion.

If there are any significant changes to this proposal you may need to consider requesting scrutiny by the Faculty Ethics Committee.

Yours sincerely

Dr Mark Cropley
Appendix (ii)

Information sheet
I am inviting you to take part in a research study, the results of which will form part of a doctorate in Clinical Psychology at the University of Surrey. It is important that you understand why the research is being carried out and what participating will involve. Please read this form carefully. If you have any questions or would like more information, you can contact me by leaving a message for me at the University of Surrey (01483689441) and I will call you back or via email: cb00008@surrey.ac.uk

The purpose of this study is to find out more about the identity and life stories of people with a diagnosis of high-functioning autism or Asperger’s Syndrome from the perspective of people with these diagnoses. If you decide to take part, you will be required to complete a few brief questionnaires before taking part in an interview or series of interviews with me. This will take around an hour on each occasion but you will be welcome to terminate the interview whenever you wish. Prior to conducting the interviews, with your permission, I will need to confirm that you have a formal diagnosis of an ASD, when this was made, how and by whom by asking a health professional such as your GP/Psychiatrist/Psychologist. I will not ask them any other questions regarding your current or past medical history. I may also ask you to complete two, brief screening questionnaires for ASD to confirm your suitability for this study. Before the interviews, I will send you more information regarding the interviews. You can use this information to help you decide whether you wish to take part.

Throughout the study, your name will remain strictly confidential and you will not be identifiable in any part of the final report. Participation in this study is entirely voluntary and you will be free to withdraw from it at any time, without giving a reason.

The researcher will reimburse you for your time with a gift voucher for the sum of £10. The sum would be less, and at the discretion of the Principal Investigator, if you withdraw before completion of the study.
Any complaint or concerns about any aspects of the way you have been dealt with during the course of the study will be addressed by Dr Emma Williams, Principal Investigator on 01483 686 889 or 01483 689 434.

If you are interested in taking part in this study, please contact me via telephone at the University of Surrey on 01483 689 441 or via email: cb00008@surrey.ac.uk

Many Thanks,

Claire Binnie
Trainee Clinical Psychologist,

University of Surrey
Appendix (iii)

Consent form
Consent Form

Identity and ASD

Researcher: Claire Binnie

The purpose of this study is to explore the life stories of people who have received a diagnosis of an Autism Spectrum Disorder. The results will form part of the researcher's doctorate in Clinical Psychology at the University of Surrey.

I confirm that:

1. I, the undersigned voluntarily agree to take part in the study on Autism Spectrum Disorder and identity.

2. I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

3. I agree to comply with any instruction given to me during the study and to cooperate fully with the investigators. I shall inform them immediately if I suffer any deterioration of any kind in my health or well-being, or experience any unexpected or unusual symptoms.

4. I agree to the investigators contacting my general practitioner/another relevant health care professional about my participation in the study, and I authorise my GP to disclose details of my relevant medical history, in confidence.

5. I consent to my personal data, as outlined in the accompanying information sheet, being used for the research project detailed in the information sheet, and agree that data collected may be shared with other researchers or interested parties. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).
6. I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.

7. I acknowledge that in consideration for completing the study I shall receive a gift voucher for the sum of £10. I recognise that the sum would be less, and at the discretion of the Principal Investigator, if I withdraw before completion of the study.

8. I understand that in the event of my suffering a significant and enduring injury (including illness or disease) as a direct result of my participation in the study, compensation will be paid to me by the University subject to certain provisos and limitations. The amount of compensation will be appropriate to the nature, severity and persistence of the injury and will, in general terms, be consistent with the amount of damages commonly awarded for similar injury by an English court in cases where the liability has been admitted.

9. I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of volunteer (BLOCK CAPITALS)
Signed:
Date:

Name of researcher (BLOCK CAPITALS)
Signed
Date

If you have any questions about this research or wish to have a copy of the main findings, you can contact the researcher by leaving a telephone message via the University of Surrey (01483689441) or via email: cb00008@surrey.ac.uk
Appendix (iv)

Advert on NAS website
The personal identities of people with a diagnosis on the autism spectrum

Adults (18+) who have been formally diagnosed with Asperger's syndrome or high-functioning autism are invited to take part in this postgraduate clinical psychology study.

The purpose of this study is to find out more about the identity and life stories of people with a diagnosis of autism spectrum disorder (ASD). By using a qualitative approach, the research aims to improve understanding of the experiences of those on the autism spectrum.

If you decide to take part, you will be required to complete a few brief questionnaires before taking part in an interview, or series of interviews, with the Trainee Clinical Psychologist undertaking the study. This will take around an hour on each occasion but you will be welcome to terminate the interview whenever you wish.

Prior to conducting the interviews, with your permission, confirmation will be sought that you have a formal diagnosis of an ASD, when this was made, how and by whom. This will be done by asking a health professional such as your GP/Psychiatrist/Psychologist. No other questions regarding your current or past medical history will be asked. You may also be asked to complete two brief screening questionnaires.

Before the interviews, you will be sent a list of questions and topics that are likely to be covered in the interviews. You can use this list to decide whether you wish to take part. In addition, this list should help you to begin to think about the issues you will be asked about. The interview(s) can be conducted at a location that is convenient to you.

As a token of appreciation for participation in this study, you will receive £10 of gift vouchers.

This study ends in July 2009.

For further information, please contact:
Claire Binnie
Trainee Clinical Psychologist
Clinical Psychology
Department of Psychology
University of Surrey
Guildford
Surrey GU2 7XH

Email: cb00008@surrey.ac.uk
Appendix (v)

Letter to health professional for diagnosis confirmation
Consent form to confirm diagnosis of ASD

Dear (name of health care professional),

(Name of participant) has volunteered to participate in a research study being conducted at the University of Surrey. He/she has given his/her signed consent for you to confirm his/her diagnosis of Autism Spectrum Disorder, who made the diagnosis and how it was made. Please find enclosed his/her consent form. Please complete the form below and return to me in the enclosed stamped addressed envelope.

Many Thanks

Claire Binnie
Trainee Clinical Psychologist
University of Surrey

1. I (Health care professional’s name) confirm that (participant’s name) has a formal diagnosis of Autism Spectrum Disorder. The diagnosis was made in (year).

2. The diagnosis was made by a: GP Psychiatrist ■ Psychologist ■ Other (please specify) ■
3. The diagnosis was made using the following standardised measures:

ADI-R □ ADOS □ DISCO Other (please specify) □

Name (print)       Signature       Date

__________________  __________________  _______________
Appendix (vi)

Demographics form
Background Information

1. How old are you? _______________

2. What is your marital status?
   - Married       ☐
   - Divorced/separated ☐
   - Widowed       ☐
   - Have a partner/in a relationship ☐
   - Single        ☐

3. How would you describe your ethnicity?

   Choose one section from (a) to (e), then tick the appropriate box to indicate your cultural background.

   (a) White
      - British       ☐
      - Irish         ☐

      Any other white background, please write in below ☐

   (b) Mixed
      - White and Black Caribbean ☐
      - White and Black African ☐
      - White and Asian      ☐
Any other mixed background, please write in below □

(c) Asian or Asian British
   Indian □
   Pakistani □
   Bangladeshi □

Any other Asian background, please write in below □

(d) Black or Black British
   Caribbean □
   African □

Any other black background, please write in below □

(e) Chinese or Other ethnic group
   Chinese □

Any other, please write in below □
4. What is your highest qualification? (please tick appropriate answer)

- None □
- GSCE (s)/O Level(s)/ CSE(s) □
- A Level(s) □
- Diploma □
- Degree □
- Postgraduate degree □

5. What is your current job (or, if you are not working, what was your last job)?

__________________________________________
Appendix (vii)

Example of a transcript
George

I: So X, can you start by just telling me a bit about yourself?

GEORGE: err, right...

I: about your life, you can start where you like...

GEORGE: err, it's always felt I were missing out on something, there was something missing and I never knew exactly what it were...

I: uh huh

GEORGE: ...could never sort of put anything down to it. Obviously the ...erm... sort of like... erm... you know you have problems at work, relationships, all this sort of thing and sort of like people would say 'you don't understand, do you? You don't get it, do you?'. And they'd be talking and I'd be like 'No, I don't get it'. And one of the big things erm I learned last year was (laughs) up to 93% of all communication is non-verbal. I never knew that (laughs). So, it was a big shock to me then and I was like so that's why people...

I: So that was something new for you that you hadn't realised?

GEORGE: Yep, never realised, never knew and a lot of things from what I've learned, a lot of things that people take for granted Erm social life, interaction, communication. I have to rote-learn and I have to learn it all meself...err... once I've learned it and think about it, it clicks. Like I say, I never knew 93% of communication is non-verbal (laughs) and stuff like that comes about in job interviews when a person is sat there at a desk and they ask you a question and I answered it and I answer it and I answer if literally.
I: Right...

GEORGE: I tell them what they’ve asked and they’ll sit there staring and go ‘can you expand on that?’ and I’ll be like ‘eh?’ (laughs) and it just gets confusing and you’ll be like ‘What do you mean ‘expand on that’? I’ve just told you what you asked me!’. And they’d just stare at me (laughs). Obviously you don’t get anywhere Erm... sort of like jobs-wise Erm... I mean looking back... looking back now, what I know now, since I learned about Asperger’s and I have my assessment, diagnosis and everything else.. Erm... a lot more of my childhood makes sense...

I: Right...

GEORGE: I mean there were bullying and stuff like that and other stuff that I didn’t understand... erm... but obviously err... I think... I think maybe especially with Asperger’s I think I think erm... that as a child were all at that mature level,

I: Uh huh

GEORGE: so everybody’s immature but it’s as you grow up err...teenagers... so I got bullied a bit, some people I hung out with erm...then you start going out err...and a lot of people say ‘oh, you’re fine when you’re out’ but beer is the biggest equaliser (laughs). So have a load of beer. Everybody’s drunk. But then sort of like people start meeting people and you start wondering, you start thinking ‘what’s up with me?’

I: yeah

GEORGE: Why won’t people talk to me? You know, they stared at me. You know, you don’t pick up on any signals at all and but like I say everybody else seems to be having that inbuilt, it’s a natural thing from birth and then like because you haven’t got that, nobody tells you, so you don’t understand, so erm in a way you do miss out on a lot and a hell of a lot of stuff you do miss out on...
I: what sorts of things do you miss out on?

GEORGE: Erm, well stuff like relationships, erm, improving yourself job-wise, erm going out socialising erm a whole range of stuff that you actually want to do but you feel that there's a barrier there and you don't know what that barrier is and if you don't know what it is then you can't do nothing about it erm and so other people that are, as you say 'average', because nobody's 'normal' (laughs). So people that are average erm... sort of have that choice if they want and they can make that choice. They can say 'well, if I wanted to be sociable then I would be but I don't want to be sociable'. So they forget about it but you actually want to be sociable and when you approach people it is really really awkward, it can come across really really wrong and socially you put people off then, backing off and then I haven't got great control over me facial expressions as well, so that again... I think I'm doing one thing and apparently I'm doing another and that puts people off err talking to you and stuff like that. Err so in a way what I did erm I sort of dumbed down if you want and I tried to fit in with different groups of people err some people I still see, I still see now erm but like I say looking back, other groups of people err I tried to fit in with err I were doing it for the wrong reasons. Because you do want to be accepted err but you want everyone to accept you not just a couple of people (laughs). Erm obviously and I know it don't work like that now but you think it does. Err so sort of like and then sort of like jobs-wise, although you're intelligent it don't come out. Obviously I've got Asperger's but I've also got an assessment for dyspraxia as well and that's come about because some of the people that I've been in contact with, working in mental heath, learning disabilities, and they're sort of like saying that I could do with an assessment for dyspraxia because erm when I read stuff I'm always getting it mixed up and I'd say 'oh, it this isn’t it?’ and they’ll say ‘no, it’s this’ and you have an argument then because I’m just seeing it completely different. Erm my memory is really bad, there's all sorts of stuff, I were clumsy at school erm I think I couldn’t tie tie till I were about fourteen and didn’t learn to ride a bike till I were fifteen or some at erm it took me ages before I could tie me laces... I used to wear slip-on shoes all the time err I still can’t swim and it’s because I have a problem co-ordinating top half of me body with bottom half of me body (laughs) and I just can’t get me arms to move in one direction and my legs to do another and it just doesn’t work at all erm and sort of stuff like that people say I should get an assessment for dyspraxia as well and all this means that whilst there is intelligence in there it don’t come out...

I: Right...
GEORGE: and so like I say, ‘alright, I’m not intelligent, I’m thick’. Erm people kept telling me ‘oh, you’re stupid you. You just don’t get it, do you?’. Erm ‘don’t get what? Don’t get what?’ err and then so like jobs-wise erm you find yourself in bottom half of jobs

I: Right...

GEORGE: Erm and you feel that you can do these jobs kind of with (inaudible) the intelligence and stuff like that. But as I say, I always thought there’s a big gap between me being here and that job. So, how do I fill what is in that gap there? Erm what did I do? I left school and started as a mechanic. I think it were called YTS scheme then...

I: Youth training scheme?

GEORGE: I thought you’d be too young to remember. (laughs)

I: (laughs)

GEORGE: that’s what it were yeah (laughs) years and years ago and erm I mean sort of like in a very male dominated... if you didn’t know what you were doing you’d get a slap round the head (laughs)which they wouldn’t be able to do now. Err and even there sort of like thinking back now erm little things I did erm such as putting oil in an engine and they’d say ‘fill it up’, so I did, I did it, I filled the engine up because that’s what he’d said...

I: Right

GEORGE: ...and he says ‘No! What about the dipstick?’ . But it’s like ‘you never said the dipstick’. But then of course you’d get shouted at and go ‘oh, alright, yeah’. Err but that never worked out. I went to work in a warehouse, then I went to Gratten the catalogue company and were there fifteen years and started off in warehouse and moved on to banking which was banking cheques erm none of the jobs were anything really taxing up to that point, you know, they were easy enough and then
from there, still at Gratten I started doing management of information erm found I could use computers err started on lotus moved to excel doing spreadsheets erm and I were doing financial reports and I were doing the same things week in, week out so erm I obviously got quite good at it and then I could think of ways to improve it but then I wanted to go out... My managers says ‘go out and start asking people questions’ erm managers of areas, quite high up erm because of the communication problems obviously I ... going out asking questions... that’s all I did then. Obviously they’re quite good at communication; they pick up and think ‘I can tell him this and that’. It probably happened, I don’t know. Then I moved to another department in Gratten, err and I just reported to one person and err I’m pretty sure he’s got Asperger’s (laughs), he really has but he were an accountant so he were really good with numbers..

I: Right...

GEORGE: ...all he were interested in were numbers, so it were never a problem for him, as long as he were working he were happy. But there was certain things err where err where it were pure structure and logic I were alright but when it were abstract thinking, looking for stuff it... completely lost, I was completely lost erm although when I were lost to meself to do the work and develop me own stuff I were fine. That wasn’t a problem for me err but I only got so far in that job, this was 2001 and err I felt like I couldn’t cope anymore... so...

I: What were the reasons... you know, you said you couldn’t cope, what do you mean by kind of not being able to cope?

GEORGE: The one... I mean I think it were a build up of things, I mean it would be difficult to pinpoint things then and it would be difficult to pinpoint stuff now erm but I remember me boss says one day ‘oh, we’re gonna have to go down to London, see somebody down there’ and he says ‘so, we’re get the train’ and I thought ‘I seriously cannot cope with three hours on the train with you’ and I thought ‘I can’t do it’ and I spoke to the doctors and I told him how I felt and he’s like ‘what do you want me to do?’ and I says ‘That’s what I’ve come to you for’ (laughs)...

I: What was it... the train journey or kind of...what was it about it?
GEORGE: Being with that particular person for the three hours...

I: Right...

GEORGE: ...train journeys I'm happy with, I like train journeys but it was being with that particular person, non-stop in me ear for three hours and not being able to get away. I just thought I'm gonna...I'm gonna lose it so (laughs) so erm me doctor says I got depression and put me on some err antidepressants err the first ones he put me on, I think they were Prozac but I think they made me worse, so I went back and said 'you'd better take me off of these and gives me something better not worse' (laughs). Err so he put me on something else and that were it for 2001 and eventually I left in August 2001, took voluntary redundancy. Another thing that got me were they were desperately into... they asked me to look into cost-cutting (making redundancies) , so I'd go out take me notes and erm we had us our own marketing bit and I says it's mad making people redundant over road they've got all the equipment, they've got staff there we can save loads of money and I took it all back and I were gonna save tens of thousands of pounds and they just turns round and says 'oh no, we're gonna get all our own stuff in' and I was just do confused by that because I thought 'where's the logic in sending someone out to do all that work and then saying 'oh no it don't matter'...

I: ...and then doing something different?

GEORGE: Yes. Especially when you're supposed to be saving money, people are losing their jobs, and so you've got to pay such and such some money but you've also got to pay redundancy as well, so it just didn't make any sense at all to me erm... during that period I also went to college and got me NVQ 2, 3 and 4 in accounting and finance at Bradford College err the only I got stuck on with that were double entry book keeping, I still don't understand it to this day, it's bizarre but apparently even qualified accountants struggle with it so... part of it could be part of me and me Asperger's but maybe it's, maybe...

I: ...maybe it's just difficult? (laughs)

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GEORGE: Yeah *(laughs)*, it’s all right when there’s only so many entries but when they start adding things up, it’s like right, very confusing err *(laughs)* err it’s like, I left there and then took a month off and erm just went temping and erm I found it difficult getting a job and went round a lot of finance agencies but they were like ‘oh yeah, we’ll get back to you’, no-one ever gets back to you...

I: and what do you think that was about? You know, how difficult it was to find a job?

GEORGE: ...because of the communication, you know as I say, I’d go in and I’d be absolutely literal, erm I mean the best way...to describe it, imagine being in a nightclub and someone comes up to me and says ‘oh, are you alright?’ and I’d go ‘yeah, I’m fine’ and I’ve just answered their question but apparently they want more *(laughs)* sort of thing *(laughs)* and that’s the same in everything I did. So I went in and they said ‘have you done this?’ and I’d say ‘yes’ and they’d say ‘have you done that?’ and I’d say ‘No’ and they’d go ‘Well we can put down that you’ve done that though’ and I’d be thinking ‘but I haven’t done it’. Erm so I ended up temping at a warehouse erm and then I went out reading water meters which were a good job but they put so much pressure on you to do so many and with me being so slow with stuff, it were too much really. Err what did I do then... trying to remember... I think I did a few little odd ones just for a couple of weeks and then erm I went to Telewest which is now Virgin Media and it were basically going through a load of boxes from around the country and deciding what to keep and what not to keep and that for me were an ideal job. Although I had to report to somebody, I only saw them once a week, I were out on me own, I could work at me own pace errr nobody bothering me so in an ideal world that were probably my ideal job...

I: So without lots of colleagues and bosses and a team to contend with?

GEORGE: Yeah, yeah. No pressure or anything, as long as I did it everyone were happy with me. Erm I came down from Newcastle for a few month, I were on me own, I were doing ten twelve hour days so unfortunately that all changed. The guy I reported to leaved and went to another job, I found out the guy I had to report to would be in Sheffield then it were eventually it were moving down to Woking erm and I think they might have said ‘oh, do you want to move down to Woking?’ and I thought ‘Well no, I couldn’t afford to’. So I left there and I went to work for NHS in Bradford. Erm It’s now the X Department at x Hospital. That were only a small
team, so we all got along and we all had a good laugh. All that were doing were keying in stuff, on, for cheques to be paid to doctors and...

I: So was it like a finance department?

GEORGE: Yep, Yeah, a very small... Up to that point, every job I’d had, although it would be a large company, I’d be in a small department or on my own so I’d never had any problems and then I went to work at the tax office, and this were July 2003 err big open plan office and first it were all right learning bits and bats erm like a lot of places, they say ‘oh yeah, we’re gonna train you for two weeks and then you get trained for two days and that’s it (laughs) and kind of left (laughs). Err but a lot of it were telephone work so there’s people phoning you up saying ‘arr you sent me a demand, blah blah blah’ like that and I’m like ‘oh right, erm’ and that caused me so much problems erm I started going downhill again with depression err it really caused me a lot of problems with that and I said ‘look, I can’t cope with this sort of work, telephoning me constantly all the time’ and so in the end,. They took me off that and put me in an area where it were pushing paper but again I did virtually the same thing for eighteen months. I think people would say it were ‘soul-destroying’. You’re sat there doing the same thing and you’re thinking ‘but I can do more than this but why can’t people see that I can do more than this?’.

I: So is there a sense that throughout your jobs, you’ve done jobs that don’t require as much skill as you have, so you’re not functioning to your full potential?

GEORGE: Yeah. Erm especially at the tax office, some people were saying ‘oh, you think this job’s beneath you’. It’s not the jobs were beneath me but they weren’t within my capabilities and they were so easy I just lost concentration... I just got bored. There were nothing there, there was no challenge. Erm the phone work went and then a lot of stuff happened I got a new team leader last year, loads of changes and the problems I had, because it were a large floor, there were loads of distractions, really overwhelming, loads of people and I do have anxiety and paranoia as well err so I’m sat and there’s people behind me, you look up and think ‘are they talking about me? Are they talking about me?’. I told my boss about it and she said ‘oh no it’s not’ but she didn’t understand when I say ‘it’s all about me’, it’s because I think everybody is talking about me all the time. I didn’t know what (laughs), you think they do erm like err social chit chat and stuff like that are just non-existent. I’d go up and talk to someone for five minutes and they’d go ‘I’ve got to get on with me work’
and then five minutes later you’d see them talking to someone else for about an hour...

I: So what did you think that was about at the time?

GEORGE: I couldn’t put anything on it, you just feel isolated, like an outcast and you think ‘what’s up with me?’ but you know, like I say you don’t know what the problem is. Erm you just think ‘what’s up with me?’. Because like erm a lot of people, you have your preconceptions. I’d heard of autism but when you see it, it is usually people down at the lower end of the spectrum and they say ‘this is an autistic person’ and I say ‘if that’s an autistic person, that’s not me’ (laughs) and you don’t go any further and you feel isolated and like I’d ask about training and say ‘look, I’ve got these qualifications and you can give us a computer and that’ and they’ll go ‘oh no, we ain’t got owt in here like that’ and then later you’ll see someone using a computer and you’ll think Why have you lied to me?’ and like I put in the thing (letter), you just feel like you’ve been put in a corner and just left to rot, you know and it’s just a case of ‘oh he thinks he’s better than what he is erm we’ll just beat him down until he gives up and goes’ and stuff like that. Err and then obviously last year me head was getting in a real mess, depression, anxiety, paranoia and everything was just getting on top erm actually one of my friends, she said, because quite a few people have said I’ve got no social skills, and I’m thinking ‘I have’ (laughs) but I didn’t know what they meant and she said I might have Asperger’s and I looked it up and I actually recognised a lot of the stuff like, although I got a bit confused because I looked on different web-sites and they said different things...

I: Yeah...

GEORGE: ...Dyspraxia’s even worse, you read one thing about dyspraxia on one website, you go to another and it’s completely different and it’s like grrrrrr, so I thought ‘I’ll go and get an assessment’ (inaudible) and it’s stuff like black and white thinking, it’s either yes or no and that grey area in between is very very difficult for me erm so I went to see me doctor and think he thought I were having hallucinations or something due to me depression (laughs), do you know what I mean? And then I went to see the psychiatrist the the XXX mental health clinic. Err and they sort of like said ...oh and I wrote some stuff down, these are the problems I have , I feel I have and so he says ‘Err oh right, I’ll have a word with me boss about getting an assessment for Asperger’s’ and that were quite a long time coming and in between I discovered XXX support group and I went down there because I felt like I
needed to be somewhere I could go to talk to people and have the support and
everything else and going to xxx (support group) has been brilliant because sort of
like there are people there who do understand, who will help you and everything
else. I write a lot of stuff down because you see it’s a lot easier for me, I can sit back
and I can think to meself ‘right what have I got there? Is that the way I want to say
it?’ erm so people might look at something and think ‘oh yeah, that’s really good, it
must have taken him an hour or two well it might have taken me a week to write
(laughs)...

I: yeah...

GEORGE: ...They don’t know that and they don’t see that other side sort of thing
erm err so I mean I had loads of battles getting err assessed by social services and
I’ve only seen the (inaudible) four times ...and err

I: Who is it that you saw four times?

GEORGE: Social workers since September when they came round to assess me. She
doesn’t know anything about Asperger’s. I think she’s having problems with the fact
that err I’m improving quite quickly and I think she’s having problems with the fact
that I’m doing that I think she’s thinking ‘hold on a minute, he’s alright now’ and
he’s communicating a lot better. I don’t think she understands Asperger’s. She says
that every time, I don’t, I don’t fully understand Asperger’s, which doesn’t help but
unfortunately that’s the way XXX social services are. If I were in XXX, they
recognise Asperger’s.

I: So there are differences depending on where you live... what’s available to you?

GEORGE: Yeah yeah. Erm and so then err and then all that were really get get
getting me down errr luckily, like I say I had XXX (support group) where I could go
err I made some complaints though NHS, though PALS officer called XXX who is a
trustee of XXX (support group) and that went to the Chief Executive at NHS in
XXX. And he says they’ve gotta come out and assess me and even after that it was
quite difficult, because I phoned up my social worker and he says ‘what problems do
you have?’ and I says ‘oh stuff with money and stuff like that’ and he goes ‘oh, we

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all have stuff like that, you’re just gonna have to learn aren’t you?’ but then I sent him the stuff off, some of what I give to you and then later I got a letter back saying ‘oh yeah, you do need our help don’t you’. (laughs) Yes I (mouths swear word) well do (laughs) but then I went for the the assessment at XXX (specialist Asperger’s Service) with (Clinical Psychologist) and again this is one of them (written account of experiences/difficulties) that I created in May with about 16 categories on it and I sent her that in the post and she said because I sent her that in the post that I saved her so much time....

I: What was it that you had prepared for her?

GEORGE: It just details how I felt sort of like but by category, so I’ve got depression there, I’ve got anxiety, I’ve got paranoia, I’ve got work, all stuff like that erm and how it were affecting me at that time but as I say, she she said it really really helped her because she could read that in her own time, I mean I were still in there two hour but she says normally an assessment is about four to five hours (laughs) and she were really really nice, really brilliant and she says she says ‘Yeah, you’ve definitely got Asperger’s’, she says ‘without a doubt, you’ve got Asperger’s’ and again with XXX who’s the PALS officer that I saw again they have a social evening every Thursday at XXX (AS support organisation) and they take turns at who goes and I went one day and she says ‘Oh, can I have a chat with you?’ and I said ‘yeah’ and afterwards she said Um for the first half hour she didn’t think I has Asperger’s at all but then she said little things started to click and she says yeah after half an hour, I began to realise that yeah you have you have it and it does cause you problems and really since assessment erm for me it’s been a massive turning point err because all the questions I had, I’ve been able to think about and get an answer to erm why I am like I am , why people are like they are, erm and all these err walls, stumbling blocks, spaces, voids, whatever that I’ve had in my life, it’s like ‘oh right’! and now and now I can overcome ‘em now. Erm I feel in a lot better position to overcome ‘em . Err it were just just unbelievable sorta like like someone just give answer to universe (laughs) sorta thing so saying ‘this is how it’s done’ , it’s like ‘Oh right!’ and err and I even like got meself a book on sorta like psychology to read like a manual to life, it’s like ‘Oh right! I can fill in even more gaps now!’ err and sorta like from going from having no confidence, no, low self esteem, nothing at all and not being able to think to think clearly at all erm I’m far far more improved now and a lot of people have seen the improvement, I’m far less defensive that what I used to be because I used to be extremely defensive erm err I think I think that were one of the coping and masking strategies sorta like being defensive...
I: What sort of things would you do?

GEORGE: ...come back aggressively sort of like erm because you don’t trust people and you feel like you’re misunderstood all the time err and so you could say to me ‘go into town’ and I would be ‘why?’ but apparently the way I said it meant different things than ‘why’ *(laughs)* like that and you know you know there might be nothing in it but I’d be thinking ‘Right, what is the ulterior motive, why do they want me to go into town, what’s behind it?’ and you think like that all the time and it just really really drags you down because you don’t know who you can trust, you don’t know what you can believe and anything so when your constantly like that, you constantly analyse everything anyway err... so you constantly analyse all the time and feel misunderstood it really does really does drag drag you right down erm as I say since the assessment I’ve been able to put put work things out, sort things out in my head err... being in contact with people who are interested in Asperger’s and Autism helps as well erm and one of the other things erm I’ve found is a lot of people say I’ve got a really really good insight into it because of the way I talk about it and what I’ve wrote down people like I say people say I’ve got a really good insight into it and although I’ve got lots of passing interests in lots of things, nothing really developed err into anything erm and even though I thought ‘Oh I’ll go and work with computers’ but I always felt that even before, I looked at a job, I thought ‘I know how far I can get in this job’ and it weren’t right far, not too bad but not right far, so that’s as far as I’ll go because when they start asking questions and stuff like that I won’t be able to answer it, I won’t be quick enough. As I say, I say in the assessment me thinking is very logical, very structured and so I find anything abstract really really difficult because you can ask me an abstract question but I’m thinking one, two, three, four, five, six, seven replies and I’m thinking ‘right, which one is it, which one do they want, which is the right one?’ *(laughs)* Err... but since then sorts like I developed an interest in Asperger’s and autism erm because I’ve had loads and loads of positive feedback ... the NHS in XXX are doing and equality and human rights network thing and XXX (PALS Officer) asked me to come along. So I went along and some people there from HR came up and said, err they were asking questions, problems you were having and that and I told them about the situation at work and they says ‘Oh right, what could be done (inaudible) can’t remember exactly what I said... bit of understanding also leads to other colleagues to understand as well and sorts like I were there for about three hours and actually got more out of that in three hours, more positive feedback and felt better than I have done in five years at tax office and people there were saying the way I been tret is really bad and they shouldn’t be treating people like that but it happened and it happened in government as well. They they make the rules but they also make them to be broken *(laughs)* err and like I say it’s that thought in me head and I still writing stuff out now and I thought where where can I take this and erm I had a chat with erm XXX (pals Officer), I’ve been seeing her about once a week where she works and we just
have a chat, she’s really interested in it and erm she’s been asking sorta like you know erm we got erm... we got erm a patient who err... the one that I remember, the one that I remember is sorta like sorta like when they come in if they say ‘A’s not available, we’ll look after you today’, they’ll kick off and she says ‘what could we do to stop him kicking off?’ and I just said ‘Well, instead of saying that ‘A’s off sick’ I mean they’re not I mean they don’t really need to know because they’re not going to remember it, I mean I don’t remember it, so it’s irrelevant, just say ‘they’ve got a cold, they can’t come in today, they’re poorly. Who would you like to go with?’ and just find out who’s available...

I: ...So kind of explaining and giving a choice?

GEORGE: giving a choice because then you feel you’ve got some control and erm from my own erm experiences, it’s that lack of a feeling of control that brings up anger, frustration and everything else. If you don’t understand why, if people don’t give you choices or control, you think everybody else is getting it and I said that and she said ‘That actually does make sense because you are actually controlling the situation yourself but the person does feel that they’ve got that bit of control’ and point them in the right direction obviously, don’t just do that (makes shoving motion) erm and its stuff like that and that all got me thinking and what what I’ve done now, I’ve actually got err... I’ve done a little plan about what I could do. I spoke to XXX (Clinical Psychologist) at XXX (AS Service) and she says it’s a really good idea because the NHS are crying out for people who’ve got an insight into Asperger’s from the patient’s perspective to go out and I say I say train but I don’t mean train train but I don’t know inform or whatever, let them know what it is like from the patient’s viewpoint and it’s just crying out for that erm because it’s really difficult for a lot of people to do and not a lot wants to do it (coughs). So what I what I did was put together a plan and took it down to XXX (AS support group) and some of the guys there because I thought ‘I could do this on me own’ but it’s better erm because in the past I sorta had ideas, gone straight to it and it’s gone wrong, hadn’t asked for help, hadn’t asked for support or anything and /I thought ‘well this time, this is something I could develop and it could develop quite fast and I thought ‘I need support and like I said I could be in a room on me own and I could, people could start asking the wrong sorta questions about research and stuff like that and I can’t answer it erm and from the start and I think you need the balance between somebody that has Asperger’s but also somebody who works with people with Asperger’s, to get the balance from both sides and erm they thought they thought it were a really good idea because they’re expanding and they haven’t got anybody who goes out and does that sort of thing now, so there could also be an employment and career opportunity there. And like I say a lot of that is because the way I feel,
I’m feeling so much better and I’m getting so much good feedback from people erm you know you start thinking like that ‘I must be doing something right, there’s something there’. I mean at the tax office now, err, you’ve probably heard of Capita?

I: Yeah

GEORGE: Well, they’re sorta like supposed to assess you and I went in on Thursday to see me boss ‘cos they’re like ‘oh, when ya comin’ back?’ and and for me it were really brave to put down in writing what the problems were I had at work and what they caused me, how they made me feel erm and I’d been waiting for this appointment for two month and on Thursday I got an appointment from Capita saying ‘Oh yeah, we got you an appointment for Thursday next week’. So all of a sudden it’s gone to a high priority erm I don’t I don’t know what’s gonna ‘appcn with work, what they can do erm... I mean people ‘ave been saying ‘oh, you shouldn’t do this an’ that in this economic climate’ and all that but it’s like ‘what do I do if I’m depressed at work?’ . You know, if I’m depressed at work, I might as well be depressed on street at end of day (laughs) and stuff like that, I understand what they’re saying but I don’t think they see it from my viewpoint, that that’s not doing me any good. Erm, err, so I’m seeing them next week and sorta like take take that from there really see see what happens but I thought I thought ‘I’ve got to do it because if I don’t do it, I don’t do it now erm ten years ten years down the line I could I could be a lot worse’ because the whole thing the whole thing about this training thing as well that that I want to get across is early intervention, at the end of the day is a lot less costly to the economy than leaving it and leaving it and leaving it and suddenly people are really really depressed twenty-four seven and they need twenty-four seven help and that cost you a couple of million pound a year, so if you can see someone progressing, making improvements erm... I think it’s better to say ‘right, you are making improvements, you’ve still got a long way to go, you know, we’ll make sure you’re alright financially, you know twenty thousand pound a year for a couple of years or whatever rather than the rest of your life and costing the economy all that money. Erm I mean the other thing I want to do err I want to learn and I’ve got something inside me that I have to learn err... I’m intelligent and like I say I want to learn all the time erm and so I’m applying to go to college, which I don’t know if you know but when I were a kid you could turn up in July and just sign up for owt but now you’ve got to fill in application form in January and go for an interview and be CRB checked and god knows what else and it’s like ‘Oh, right’, all a bit of a surprise, things have changed so much. But when I go... I’ve applied to go back to college to... err.. I’m hoping to do humanities and social sciences err.... an access programme. There’s no exams, so it’s all course work. Erm... equivalent to three A-levels, plus you do English and Maths there. Erm... which is something I do
I did try doing my GCSE in English a couple of years ago but erm I got confused with some words and what they actually meant and then we started doing Macbeth and they showed us a film of Macbeth and they all had machine guns and it was even more confusing. It was like ‘what?’. It was in some warehouse and it were real strange err but then but then I didn’t understand the problems I have with my learning and then I went down there and I went through the learning disability unit and she says ‘It’s quite a good unit, you can come down any time you want, we’re always there’. I mean having that support there takes a load, takes a load off your mind. You think ‘If I have got a problem, I can get more time or err there’s somebody there to go through to go through it with me’ because there’s no exams no exams at the end of it erm it’s a two year part-time evening course, for me there’s no pressure there as well. Erm I can get into studying and I can think to meself err right, at the end of the two years ‘do I want to stop ‘ere or do I want to go on and do a degree course?’. Err and there might be exams but I’ve already done two years study so I will already be in that mode. Err and I think sorta like growing older makes a big difference when I started noticing stuff probably in me early thirties, growing older because people start having families, having kids...whereas before you were out three nights a week err... most of weekend were a blur (laughs) err... it all changes and you don’t feel, I didn’t feel any older and erm everybody else sorta like seemed to be getting older erm... somebody said I’m probably a teenager trapped in a man’s body sorta thing, which in some ways I am , I mean I mean you do get more mature, you do get better as you age but not at the same rate as other people, so that’s a big difference err... so you go home and you just get bored because there’s sorta like nothing to do. You phone someone and they’re like ‘oh I’d come out but me husband’s gone out or me wife’s gone out and I’ve got to look after the kids’ sorta thing, you know...

I: So when people are kind of settling down, you were still wanting to...

GEORGE: ...go out

I: Lead the life that you had. I guess the type of life that people might ‘traditionally’ lead in their twenties?

GEORGE: Yeah, Yeah and I mean really that’s only died down last couple of years. I mean although my brain might think it’s young, unfortunately my body isn’t (laughs). Physically, a forty year old body catches up with you in time. Erm but that don’t help with depression because you start to feel really lonely and isolated and
you feel like you can’t do anything about it and for me it’s been that feeling of not understanding and not feeling that I can do anything about it, I think that has really caused me problems err and like I say sorta like somebody tells ya what’s up with ya and why and says ‘oh there you go that’s your assessment, that’s what up with ya, you can get books about it’ and stuff like that and you think ‘hang on’. You it is literally a whole new world and it’s always like I’ve felt like I were in a long, long, dark tunnel and there’s no light at the end of it and all of a sudden now I’m out of tunnel and it’s just wide-open space and now I feel that anything is possible, which is why I’m not scared to tell work, you know the problems they caused me erm err because I feel that even in economic climate anything’s possible erm...sorta thing err. I’ve had trouble convincing some people that I’ve got Asperger’s, I mean one of me mates is very narrow-minded and when I told him err there’s about four or five of us that used to go to school together... and when I told the others, they all say that he’s got it and he’s worse than me (laughs)I didn’t think he’d like to hear it (laughs). He was saying ‘oh but we’ve all got these problems, we’re all like this, we can’t have everything’ and it’s sorta like ‘yeah, I know but’ and I don’t think he still understands it err... what was it? Trying to explain the problems that occur when you have extreme feelings and when you go from frustration to anger and there’s nothing in between and sorta like, you’ll want to lash out and do stuff like that erm... luckily for me I’ve got something in my brain that just says ‘don’t do anything ‘cos it’s wrong’ erm... you could call it a ‘moral switch’ I suppose but sorta like I know what’s wrong, so I don’t do it. I know I know it’s wrong so sorta like I’ve punched walls a couple of times and stuff like that but I mean you can’t quite grasp that, you don’t understand. You go (explosion sound) to the other extreme and this grey area in between where you could get some understanding, it’s just gone. But now I’m getting that understanding, erm of the in between bit as well. It’s still very hard to convince them. Another mate of mine, I’ve had difficulty trying to convince him because he thinks I should go back to work and that would be better for me even though I gave him a lot of the stuff I gave to work and I’m thinking ‘you’ve read it but you haven’t really understood it’. Err because at work I’d been having suicidal thoughts and it’s like go back to work and have suicidal thoughts, no-one in their right mind, even the tax office (laughs) would want anyone back at work if they’re feeling like that. So that were a bit bizarre when he said ‘Oh, I think the best thing for you to do is go back to work’. It’s like ‘no, it’s not! Making meself worse at home? No, it’s not actually; I’m feeling a lot better’. I mean err, I went down to err library in XXX yesterday and they’ve just started up an access unit for learning disabilities and all problems, stuff like that and the health and social care worker-type of person. She were really nice she were, really nice and I asked if she had owt on dyspraxia and she’d never heard of it and then we got talking and said ‘oh, er... NHS website is quite good to start with; it tells you where to go and tells you the basics about it’. So we got talking and I told her a little bit about me, I told her about XXX (AS Support group) and gave them the phone number. She’s going to get in contact with them because she says ‘we just haven’t got those services in
And like I say, as I’ve discovered, each little area is like its own little empire and they don’t talk to each other and it’s like we should all be talking to each other to share knowledge and make things better for everybody. Erm and I gave her my number as well and I said ‘you know, if you want me to come in and have a chat anytime, just give me a ring, you know you’re more than welcome, I’ll come in and have a chat’ and she said ‘you are you are actually really, really nice’ and I thought ‘that’s nice’ (laughs). All the things I’ve over the years because, again, the misunderstandings and stuff, like that and feeling isolated err, you think it’s everybody else, so you don’t like anybody else but then you think it’s yourself, so you don’t like yourself then and you think ‘oh, it must be me; I must be a bad person’.

I: Is it that kind of black and white...

GEORGE: Yeah!

I: It’s either one thing or the other...

GEORGE: Depending on what’s happened and what mood you’re in. So when it’s (inaudible) err it’s really really bad so like you know sorta like especially when I’ve had it whenever I thought it were me erm err I did attempt suicide a couple of times, sleeping tablets, it’s only one-a night, Nytol that you get from Sainsbury’s and that (laughs) you do do get right bad because you’re just like ‘It must be me, it must be me’. You can’t carry on anymore and sorta like and so like I say since October at assessment, people are saying ‘oh, you’re really nice’ and that makes you feel better and people say ‘oh, the way you say stuff, the way you explain stuff, it’s really nice, it’s really good’. So you want to help people as well. Erm, a lot of people in the same situation erm and stuff like that err and sorta like also because erm I can now see the link, and I can explain the link between having Asperger’s and having mental health problems erm because obviously you have the Asperger’s and you’ve got all your social problems, which leads you to feel depressed, then you get anxious, then you get paranoid erm I mean, I know in that assessment I’ve given you from XXX (CMHT) says oh, he’s put ‘slight paranoia’ and I thought, ‘Right, when I go down town and I think that everybody’s looking at me. That’s not ‘slight paranoia’”, it’s not in my book...erm...and that’s one of the things that I try to explain to people in that...especially going down to XXX (AS support service)err where there’s people quite far down the autistic scale erm you know and I know I’m more intelligent...or I can get my intelligence across better erm and I might be more able-bodied or
whatever erm and I can possibly do a lot more than they can but for every person that’s on that spectrum, their problems are 100%, so whether that’s one (gesturing hand low down) and that 100 (gesturing hand in the air) and your problems are at the bottom, to you they are 100% erm and again it’s it’s been difficult to get that across and for people to understand erm and I think it’s because of the way that people think about stuff and it’s the way that I thought about stuff as well so you know before because you always think with disability you’ve got to err... be seen to be doing something wrong. So if you fall over and you say ‘oh, I have problems standing up and I fall over’ or if they’re limping and things like if they’re in a wheelchair err the disabilities are easier for people who are not disabled to see and understand. And then to try and get their heads round somebody that’s got a hidden disability, it’s so confusing and what it is, it’s something as complex as Asperger’s, it’s really really hard and it’s only recently started to get an understanding of it erm...I’m think I’m the first person he’s ever had and I’ve been going to the same doctor for 25 years erm and he’s just getting his head around it now. Err...like I say he’s actually treated me a lot better now because he understands. Erm... (inaudible) one of the things I try to do now is think about what I’m saying to people and how I’m saying it and one instance of that is rather than saying ‘it’s easy for me’, I’ll say ‘It makes sense to me’ because that won’t wind people up that much (laughs). They don’t feel as if I’m being big-headed or...

I: yeah...

GEORGE: sorta like that. So, you know, I’ll say ‘Oh, that makes sense to me, does that’ and they’ll go ‘oh right, yeah’. Erm.. I’d forgotten what I were saying then (laughs)

I: I think you were saying like how when you are talking to people, you are monitoring what you are saying and what impact...or impression that can give?

GEORGE: yeah yeah

I: Is that?
GEORGE: Yeah. So sorta like I do that like I say with me doctor and he’s err he’s a lot better now and err I’ve forgotten. I do that I forget stuff (*laughs*)

I: That’s alright (*laughs*)

GEORGE: (*laughing*) err err but but that that’s an improvement I’ve made because sorta like things they said to me when I had an assessment they said I can either be as I am or you can try and fit in with the average that people perceive in society err and I’m doing that but I’m doing that at my own pace and I’m doing it for me for the right reasons, so I don’t feel I’m being forced into it, pressurised into it which like I say is a big thing for people with Asperger’s and autism, in that you often feel pressurised or made to do something that you don’t wanna do and like I say if you can look at things a little bit differently and remain in control but give that person some control back, it makes just the world of difference absolutely there’s one of the lads down at (AS Support group) XXX (person with AS) he’s ...I think he’s got Asperger’s and he’s always saying that where he is at the home where he is all the staff they don’t listen to him an make him do stuff and in a way in a way it’s a game if you imagine us playing games with kids and just thinking about what would you do if he were five year old, how would you get him to do that, so they don’t kick off (*laughs*) because no-one wants screaming kids about (*laughs*) erm and so I feel like I’ve got a lot of control back in my life and that that I can do stuff and that is in... you know I recognise now that it is up to me to do stuff because only I can make things happen...like the training thing. Whilst it’s a good idea, it’s only me that can make it happen but it’s also important for me to recognise that I don’t just ...it’s not just me on me own erm you know there’s support there. Like I say the people down at (AS support group) are so nice, they’ve always got time for a chat there’s erm, they are busy. I have to keep reminding meself they have got jobs to do (*laughs*)

I: (*laughs*)

GEORGE: well when I first went down there, I just thought everybody there was a support worker

I: Yeah
GEORGE: ...and then I found out that not everybody is a support worker err... and one of the women down there XXX, she’s financial director, XXX is an executive director, XXX... I always have to think of his name because I always called him Dave when I went there, he just looked like a ‘Dave’ to me (laughs)...

I: (laughs)

GEORGE:... so I look at him and think ‘It’s not Dave, it’s XXX’. I have to call him, remember what his name is and he’s a director. And they’re such nice people and so approachable and so you know they always say if you’ve got any problems, just come down, we’ll have a chat and see you and I’m going down there next week to fill in the disability living allowance form because I’ve got left like fifty p ha’penny but but one of the women down there, she does outreach and she’s had a lot of experience filling these in so and again so many conflicting things so like because me social worker says I’ll get it but then it’s like on what scale and somebody says like ‘ah’ erm... I shouldn’t say it (laughs) Ah.. I’ll get a car and ‘why do I need a car? I can walk and that’. ‘Oh no, all you say is just erm you get anxious, you get really anxious crossing the road and you get really paranoid going on buses and they’ll give you a car ‘Eh? What?’ (exasperated laughter) and it’s like how people think ‘oh yeah, you’re just going to try and scam the system’ but to me it’s just a bizarre system from working in government, from working in tax I would have thought that it would be so logical and so structured that it would be unbelievable but it’s the most abstract place I’ve ever worked at. They don’t have rules they have guidelines and one of my big arguments that I’ve had is that with disability attendance allowance or whatever it is erm you can get time off for appointments so I said ‘well, if somebody’s got an appointment and I get half a day and they get a day, that’s discrimination’. ‘Oh no it’s not because it’s up to the individual manager’ ‘no it’s discrimination because we work for the same place and it shouldn’t be down to an individual manager to decide’. Whether they could see it or not but to me it makes no logic to have that system where it encourages discrimination because you can treat people differently and you shouldn’t really have a situation like that at work, especially a government department and so they should have rules and they should have somebody that does decide what it is and applies it fairly across the whole of the tax office. Not just for me or a couple of others but for everybody. And like I say , I just can’t get my head around that and it’s like they’ve got guidelines and these guidelines they use them when they feel like it but when they don’t they say ‘oh no, it’s our discretion, so we can do what we want’. Well what’s the point of having guidelines then? You might as well scrap the system, have nowt and do what you want. And they don’t understand how, in my way of thinking, err yeah they have guideline but in them guidelines and within those guidelines I can operate quite
freely but I still need those guidelines so I need someone to say to me 'right this is it, these are the barriers'. So that’s the thing, I don’t understand social barriers...

I: no...

GEORGE: Like erm.. a good example of that is one of me mates one of me mates says that I’m says that I’m always invading his space and I always thought invading his space is stood right next to him but apparently you can look at someone and be invading their space. Well, I didn’t know that (laughs). No-one had told me (laughs) and it’s like ‘why did no-one tell me that you can invade someone’s space just by looking at them?’ Because I didn’t know and you know everybody takes these things for granted and you know and all these sorta social barriers they’re just not there. There’s no social barriers for me. And so you learn ‘em. I think this is another one of those things for me and so you learn ‘em but then you apply them to everybody but not everybody responds in the same way, so that just adds more to the confusion because then you don’t know where you stand because sorta like because somebody might say ‘don’t’ ohh...I can’t think of owt. Of, I don’t know ‘don’t stand within two feet of me’, so then you don’t stand within two feet of anybody and then people say , ‘oh, why don’t you come closer’ but then if he says ‘don’t stand... and you say’ and it’s little things like that, it’s so confusing when you haven’t got these...you don’t understand the social aspect of life erm and especially like I say at work erm working in what to me is just a massive unit it it just gets too much for you. Erm... I think I’ve got my point across eventually ... but erm you know even for me, being in this room is quite large. To me I mean another thing that I do erm I mentioned in my bits and bats is what I call ‘bubble world’ and so this is my world and I know there’s stuff out there but this is my world at the moment, that’s it. Nothing else in my world, it’s weird. Especially when I’ve been depressed, I can really really do that until I’ve had it sorta like just my bedroom in my house is my world and that’s it. Making everything real small, so I can cope with it. I think that’s probably why I do it because last night when I was looking at dyspraxia, it says you have problems erm problems sorta like gauging stuff and I’ve got no idea about distances erm and you come from Surrey and that to me, you might as well be from other side of world and I could drive down there. I could get down there alright but just thinking about it, it’s just other side of world. I mean Leeds to me is miles away and I’ve been there loads of times, Manchester is miles away and they are really only down the world really. Erm, I can’t estimate crowds. I remember going to err name of team err rugby team once and I went there and err my friend’s sister and she went ‘how many people do you thinks here’ and I went ‘about three thousand’ and there were nineteen thousand there. So I can’t estimate anything at all. Erm, it could be anything (laughs). Strangely, touch wood, I’m ok driving and for some reason I can
gauge a gap when I’m driving and I’ve had quite a lot of near-misses with cars but I’ve always got through gap

I: yeah

GEORGE: and I don’t know why I can do it in a car because I know, some some people with my condition have problems with driving but I don’t for whatever reason but if you, if you said to me ‘how wide is that gap?’; if the car fits through it, it’s not really relevant to me (laughs)

I: (laughs)

GEORGE: ...as long as the car gets through erm. You know it’s stuff like that erm you don’t understand why there’s so much ...err.. because I know Asperger’s in a way it’s err an umbrella term for a lot of conditions and there’s a lot of overlap err with lots of others err...and I think the main one I overlap with is dyspraxia erm so I’ve asked for an assessment for that and (inaudible, laughs). I read that, a lot of it’s relevant, so reading stuff and sometimes it’s not going, it don’t, it’s just words and it’s not going in and I start reading and I just lose concentration completely, it’s weird. Stuff like that’s weird erm. Going on about assessments, I actually had err testicular cancer when I were 21 and when I went in, they didn’t tell me this but I had err a 10% chance of survival. Got a haemoglobin count, hcg count in body and apparently a man’s not supposed to get above 8 and a woman’s gets to 80, 90 thousand when she’s pregnant and I went in and this bloke says ‘how do you know what you hcg count is?’ and I says ‘oh, I don’t’. And he says ‘oh, mines 800 and there’s a bloke over there and he’s 1600, he’s really bad, it’s really high his hcg count’ and I says ‘oh, right’...

I: Is that what pregnant women have... the hormone?

GEORGE: Yeah, yeah. I’m not... it’s so long ago now. It’s something to do...it’s because they’ve got another body inside them, it does all these things... whatever it does (laughs). And it’s sorta like (inaudible), the haemoglobin goes up through the roof but there’s a reason for it. Erm...but even then, when you’re pregnant it goes up
to 80, 90 thousand and I found out that my hcg count, when I went into hospital was 166, 500...

I: Crikey...

GEORGE: and erm I did err I did talk ... and I feel really bad now I think about it, I did talk to a load of doctors when I was there and I was like literally ‘oh, yeah’. Erm, I think erm having the Asperger’s helped so much because I didn’t realise, I didn’t understand what were going on

I: Hmm

GEORGE: So I just thought like ‘oh, I’ve got a year off work, I’ll go to hospital for a week, have some treatment, sorted’. Didn’t look at it any other way erm and it were weird. When I had that talk, when one of the doctors came to me afterwards and he says he says, you do now you had (inaudible) and I says ‘no, not really. Why?’. And he says ‘because I’ve never met anyone have an hcg count as high as yours and survive’ he says ‘people with an hcg count as high as yours never make it’ erm and I were like ‘Oh, right’. I was just off work and I went I went to hospital every week, got me arm on a drip which were annoying because it were so slow but I learnt how to speed it up even though it made me ill and I got told off for it all the time (laughs). Didn’t eat hospital food, erm it’s good for weight loss. I know it’s extreme but it is good for weight loss (laughs) because I lost loads of weight. Err you know I just got through it and sorta like, looking back, completely different now, it’s probably because I had the Asperger’s, I didn’t understand any implications about what were happening...

I: ...So it sounds like there wasn’t much of an emotional impact...

GEORGE: Oh no...

I: ...of that happening?

GEORGE: no, it were just get in and get on with it
I: Quite practical stuff to sort out?

GEORGE: Oh yeah. Yeah, like I say, got drip through quick as I can, got bored because back in those days we only had three channels (laughs). No Sky TV. That were it, it were just practical, just one of those things. Erm I had 15 chemo’s, about 120 needles stuck in me all over the place. Erm, I don’t like needles anymore (laughs). Err, erm at all erm err that were it. The regime I were on it was called ‘King’s Cross’ and at the time it were one of the two worst or extreme regimes you could go on and they had something called xxx platinum which is something they put on x in the second world war to stop rusting and I thought ‘well, I won’t rust anyway’ (laughs). And sorta like once I’d err and I mean even when I went in for like to be told that I had it, I went in, consultant there, cancer consultant there, me mum were there, me GP were there, erm support worker were there, a nurse. They were all there sat behind this table all looking really bad and they goes... err this was on a Monday...I think it were 7th October, I think it were me Mum’s birthday and they goes ‘oh, we’ve got some really bad news for you Mr XXX.’ And I says ‘oh, so what’s that?’ and they said ‘you’ve got testicular cancer and it’s quite bad. We need to get you into hospital tomorrow. It’s a rush’. And I says ‘Oh, so how much time will I get off work?’ and they went ‘Err, at least three month’ and I went ‘Oh, alright, sound’ and that were it. And they couldn’t believe it (laughs). You know they’ve probably not had that reaction before nor since. And I was like, right, get in and get on with it. Simple as. Err it was, it was a struggle because you lost a lot of strength obviously because I did lose so much weight but I mean I overcome that because err all I did was take everything really really easy, you know real slow, no rush, what’s the point? And I remember at Christmas this, this were twenty year ago and this Christmas err I developed a temperature and I only went up one degree and I were burning up. I couldn’t believe it because when you’re outside you don’t really notice one degree but the body.. Jeez I were burning up, so I had to have a blood transfusion and err and apparently I’m A plus and I got through that in record time as well. I got another telling off for that (laughs) and then somebody goes to me, the consultant comes round and goes ‘whatever you do, don’t go out, no alcohol, blah blah blah’ and all this lark. Because you have all these blood tests and if one of these blood cells is down, you’re not meant to do anything because you’re more prone to infections and like other stuff and erm, I left hospital on Christmas Eve and went straight to off licence and I got err, vodka, whiskey, Malibu and loads of beer and I spent all of Christmas absolutely hammered erm which I shouldn’t have done but I went into hospital after Christmas, had me blood tests and they says ‘your blood’s never been better’ and I was hammered all over Christmas. I couldn’t have stopped in. If I’d stopped in, I would have gone mad (laughs).Erm and it ended up I’d had 15 chemo’s. I were off work one year, one week and I came out and I just got got back
to work. Erm and one of the things erm sorta like err going to back to when I did attempt suicide, I took 24 of those Nytol other nights and like I were telling the social worker this and she goes ‘what happened?’ and I says ‘Well, I just woke up, phoned in sick and went, spent the rest of the day in bed. I went back to work next day’. And she goes ‘what, that were it, that’s alls you did?’ I goes ‘yeah, because that was what I was supposed to do’ (laughs). So that’s me, I just woke up and thought ‘get on with it’ again. Erm but that’s sorta like when my body went up in temperature by a degree, I relate that now to sorta like erm, in a way erm now, sorta like err being, sometimes you feel like you’re only one degree out from rest of society

I: Hmmm

GEORGE: ...but that one degree is just massive. And in some ways...I’ve got a friend who works with kids with autism and he says that in some ways it’s harder for me because I know there’s something there and I’m wanting to get to that but I can’t you see whereas some of the kids with autism haven’t a clue what’s there and he says they just kick off and play about, it don’t matter to them they don’t want to, there’s no desire to get there whereas for me, there’s that desire to get there but it’s that stumbling block in getting there. Err... Haven’t you got any questions? (Laughs). I told you I could talk (laughs)

I: I haven’t got any particular questions, no. Is there anything you wanted to add...or? Because you’ve kind of talked about work and how that has sort of panned out...

GEORGE: Yeah...

I: and how things have been since your thirties and getting a bit older

GEORGE: Yeah...

I: and you’ve talked about erm being unwell and having testicular cancer

GEORGE: yeah
GEORGE: Yeah, well I haven’t talked much about school. At school I did err I had one memory from school. One memory from first school, I was getting bullied in playground at four and then we moved and I went to a school called XXX and I was actually made err to write right-handed, and my hand-writing’s really err... I hold my pen really straight and my handwriting’s not that brilliant and I’ve actually put example in there (written info) for you. I was saying to XXX (Clinical Psychologist) and I wrote with my left hand and I haven’t done it for about two years and you can still read it and I wear watch on left hand and I’m not left handed and so I think I’ve sorted it out and so I think for a number of years, I had a bit of a mix up between left and right. And then through me first school and middle school, it weren’t a problem for me. I know they don’t have middle school where you come from...

I: Erm, no they don’t have middle schools where I come from

GEORGE: Erm I ask that because it weren’t for years later that I thought everyone had first, middle, upper school but apparently most schools were just first and upper and in XXX, it were just first and upper and so people that went to school in XXX had a completely different system and I’m thinking ‘oh, right’. But I went to middle school; I didn’t have any problems there. But I went to me upper school and err me first year there were alright and we moved and I think that that just completely and utterly upset me whole world and I didn’t go to school for two years. I just went back for one day in all that time, I just stopped completely and of course back in those days nothing were known about Asperger’s. We’re going back to ’81, so nothing was known about Asperger’s, dyspraxia really or dyslexia. If you behave badly, you’ve just got a behavioural problem; we don’t know what it is. So I just didn’t go to school at all for two years, which looking back was a waste but because I was other side of XXX, I were away from me friends err and everything else. I couldn’t explain it at that time but probably I could not cope with everything else and I didn’t understand why I had to be away from people and stuff like this. We moved because me Mum and Dad got a job looking after a funeral directors and they were caretakers there. Erm so that was obviously something major to me but I just couldn’t cope with it, by doing nowt by not going to school. Simple as that and up until then the work had been really easy but then err also the work got harder and they started introducing stuff like Algebra which I can’t cope with because why have letters when...
you can have numbers? Maths is numbers, letters is English and then you combine the two and it’s like completely lost. And I got moved up to English English literature class. I didn’t want to do but I got moved up because I’d done some story. Erm and then they started doing Shakespeare. That just completely threw me as well because it were so different to what used to. I was like ‘what?’ . I mean me English has always been, haven’t been too bad. I remember doing exam at upper school and it were spelling, grammar and story and story and grammar, I got 198 out of 200 and I got 3 for spelling. I got by far the highest mark that anybody’s ever got but I just can’t, couldn’t spell and I still have a lot of problems spelling now. I think there’s an overlap with dyspraxia with spelling and all these things, learning. Erm, when I went back to college, I did that because I won a competition and I just wanted to improve meself...

I: what was the competition?

GEORGE: It were one in the paper. You know, it just said ‘why do you wanna go back to college’? And I wrote something down and there were fifty places available through this government funding. And I says’oh yeah, oh you’ve got a place’. So I went there and I did me NVQ 2 in accounting and finance in April, May, June, July, four month and then I did me three and work work paid for me four. I think I think that at those times it were ’96. I think colleges were changing as well and we hadn’t got funded and erm, so more people passed the exams, the more money they got and so for the exam, it were a three hour exam, for the first hour and a half we were left to us own devices and second hour and half, they came round and told us answers (laughs). Like he goes ‘Is anybody struggling’? and so everybody put their hand up they were struggling. So he says ‘put this down, you’ll be alright with this’ because obviously because of the funding, obviously to secure funding for the year after. And it’s like ‘oh, right, this is an easy way of getting exams’ and I know, I know that it’s changed now. Back in those days, it were completely new to them so they just got funding anyway we can. Like I say before, that desire to learn has always been there but it’s always been what what do I want to learn and how can I use it err because also, if I’m gonna do something there has to be a purpose to it as well. There’s no point doing something for no reason, if you do something, there’s got to be a purpose erm and it’s like because I’ve become interested in the Asperger’s, how it’s affected me and all the really good comments I’ve got back. Err; I’ve got a book about psychology, all that teach yourself psychology. I’m reading that and I’m thinking ‘this is interesting and I can understand it’ and so I thought ‘I’ll do a course in this’, so hopefully it’ll all come together in the end, sorta thing. Like I say, one other thing I don’t think I’ve spoken about is relationships. I’ve had a couple but they don’t seem seem to work. Like people say, people that are average have problems with
relationships (*laughs*). So if you’ve got Asperger’s it’s twice as hard. But hopefully being able to understand myself and like understand a lot more about me outside world as well, and by that I mean just the world around me, how people interact with each other and stuff like that. You know people saying I’m a better person, from what me friend says, she says a lot better person, she says you can tell in me voice and hopefully, you know meet somebody and see how it goes really but sort of explain to them that I have some problems with social communication, picking up facial expressions, all this stuff that they may take for granted, you know I don’t, so they would have to talk (*laughs*), which is a bit err (inaudible). And I guess in relationships, we take things literally and in 20s, you’d read FHM, so you’d believe it (*laughs*). Apparently, it’s not true (*laughs*)

I: (*laughs*)

GEORGE: What FHM tells you about women (*laughs*). So it’s like ‘oh right’ and again it’s sorta like, going back to what I said before, you stuff and you apply it to every woman

I: Yeah

GEORGE: And sorta like you don’t understand why you don’t get the same reaction, you might even get a slap or someat like that (*laughs*) and you’re thinking ‘why, why, why?’ It’s like, it said that in magazine, to do that in magazine, it’ll be alright and you don’t find it working (*laughs*)

I: (*laughs*)

GEORGE: but now, now I understand, it’s like ‘ah, right’. So I need to try and find out. When I went down to see XXX (Clinical Psychologist) and told her, and she says you can’t say closed answers or ask closed questions, you’ve got to be open-ended. And I’m thinking ‘but I don’t do open-ended because I don’t understand it’, so you know sorta like big problem there. But er again sorta like going down to XXX (AS support group), you know there’s some people, some new people down there, you know and I’m getting more used to talking to females, I’m getting more comfortable talking to females and you know they’re saying sorta like, you know
you talk about what’s happened and they say ‘don’t worry about that, you’re nice. Don’t worry about it’. Erm, I feel, I feel now whereas before I felt like I was just a shell, I feel now like a human being. I feel now like I am the person I’ve always wanted to be. Erm and you know it’s not like I want to be an actor or a singer or something like that. I feel like I’m a person now and I’ve got a personality which I didn’t feel like I had before and because I’m being me, I think people are responding a lot better to me. Like I say, that’s the biggest thing for me from the assessment being able to find meself because I’ve got to be (inaudible) for six months to ‘find meself’. It’s like ‘bollocks’, (laughs)

I: (laughs)

GEORGE: ...you don’t have to have a free paid holiday to find yourself, don’t be ridiculous. Erm but sorta like, I don’t like using those terms, they’re a bit (inaudible) but I have found meself and I’m still finding meself. Like I say, you feel like a person and at last you’ve got a personality and you can... whereas before, I always thought like you’ve got to have excuses because you’ve got people saying ‘don’t do this’ and you’re thinking ‘why not? Why not?’ and then you feel like you’re getting tret like a child and it’s like ‘well, I am a child inside, so tough’ and I don’t feel like there’s any excuses any more for me not to be me which isn’t to say I should do owt wrong...

I: hmm

GEORGE: ...it’s no excuses to do that but I can be me, I can voice my own opinion and I can say ‘well, this is why I see it like that’ and then if people have their opinion, I actually appreciate their opinion better now than what I did before. I can understand now why they’re different and why they will have a different opinion to me you know sorta like so conversations are a lot a lot better erm sorta thing I think I can...

I: It’s alright...

GEORGE: We’ve only got ten minutes left (laughs)
I: Just out of interest, it’s not really part of the interview but I just wondered why you chose to take part in the research...

GEORGE: Erm. Because it’s something I’m interested in. All the good comments and things that people have said to me about me insight into it and erm how I can write it down, how I can talk about it and stuff like that and also erm because of whereas before, in the past, I’ve thought, I’ve thought ‘right, I’ll keep stiff to meself,’ you know I think, I think I’ve changed my thinking completely now and I’m thinking ‘if you’ve got something, use it. Don’t keep it to yourself and sorta like share it’. Because everybody is sorta trying to move towards the same goal at the end of it all. Erm and it’s like when I was talking to that woman yesterday in XXX, I said that it really annoys me in that services don’t talk to each other and don’t share information and they just want to keep it and they’re scared of sharing information and you know they shouldn’t be scared of sharing information because they might find different ways of doing stuff and be able to save money, save time and save all sorts of stuff. Erm yeah that’s why that’s why I did it because sorta like you know like I say if you’ve got something, you can help people, I mean hopefully sorta like this has helped you today and all that stuff there (paperwork) will help you as well and err sorta like it can help you in your career and you can think ‘right this is one person’s perspective on what Asperger’s is, how it’s affected them’ and you can use it in your career sort of thing.

I: Well thank you very much for taking part in the research.
Appendix (vii)

Example of analytic process
Analysis of George

1. SUMMARY

George began his account by referring to the sense he had throughout his life that there was 'something missing'. He went on to talk about his work history since leaving school and how his 'anxiety and paranoia' led him to feel like an 'outcast' at work and that people had commented on his lack of social skills. George spoke about a friend of his suggesting that he might have Asperger's syndrome. He then researched the area and waited for an assessment at a specialist AS service, when he was told by a Clinical Psychologist that he'd 'definitely got Asperger's'.

George went on to talk about his life since diagnosis as a 'massive turning point', which had led to 'improvements' on how he'd been previously (with low confidence and low self-esteem). George then talked about his plans for the future, some of which are directly linked to having AS (such as sharing his perspectives with people working in the NHS) and others which he anticipated being better able to cope with since being diagnosed (such as receiving additional support when completing college courses). George also talked about the current economic recession and the pressure to return to work from sick leave even though it made him depressed and suicidal.

He reflected back on his past behaviour and experiences (such as his reaction to being diagnosed with testicular cancer aged 21 and not having a family/going out less like other people of his age) and how being diagnosed had shed light on these, like being given 'the answer to the universe'. He spoke about attempting suicide on a few occasions and made links between his AS and having mental health problems. George talked about the confusion caused by AS being a 'hidden' disability and the choice to continue as he is or attempt to 'fit in'. He described how he has chosen to negotiate this at his own pace.

George talked about his school life briefly. He mentioned being bullied aged four and school not being a 'problem' until he was in upper school, when his family had to move for his parent's work, which 'upset his 'whole world'. This was followed by a two year absence from school. He said that he didn't understand being away from his friends and tried to cope by not going to school. He also mentioned the school work had got more difficult and he had trouble with his spelling. George talked about his desire to learn and 'improve' for a 'purpose'. He talked about his interest in AS and psychology, which he hopes to do a course in.
At the end of the account, George talked about his plans for the future in terms of finding an intimate relationship and ‘finding himself’. George reflected back on previous relationships which he said didn’t seem to ‘work’ and that he hoped his increased understanding of himself would help in future. He went on to say that he used to feel like ‘a shell’ but now feels ‘like a human being…the person that I’ve always wanted to be’.

1.1 Beginning

Although George makes reference to some of the difficulties he has experienced throughout his life, the beginning of his account predominantly focuses on his work history since leaving school and the events leading up to his recent diagnosis with Asperger’s Syndrome.

George starts his account by describing how throughout his life, he had always felt that he was missing out on something which he could not identify:

‘It’s always felt like I were missing out on something, there was something missing and I never knew exactly what it were’

He described having problems at work and in his relationships and people’s observation that he has difficulty understanding. He described ‘shock’ at finding out the previous year that much communication is non-verbal.

He described how he has to learn many things that others take for granted:

‘…a lot of the things that people take for granted…social life, interaction, communication, I have to rote-learn…once I’ve learned it and think about it, it clicks’

George goes on to describe situations in which his difficulties have become apparent in the past such as job interviews when he has answered questions literally. He talked about how since being diagnosed with Asperger’s, his childhood makes sense. He
described being bullied. He talked about how it did not appear to be a particular problem when he was a young child when ‘everybody’s immature’ but how as a teenager, he used alcohol to try and fit in and he felt different in his relationships with others and others’ apparent natural abilities:

‘Beer is the biggest equaliser...Everybody’s drunk. But then...people start meeting people and you start ...thinking ‘what’s up with me? Why won’t people talk to me?...they stared at me...you don’t pick up on signals...everybody else seems to be having that inbuilt, it’s a natural thing from birth’.

He talked about how this had led to him ‘missing out’ in terms of relationships, employment and his social life.

He described a wish to do things but feeling that there is an unknown ‘barrier’ getting in the way that other ‘average’ people don’t have, so that they have choice regarding their lives:

‘you actually want to....but you feel that there’s barrier there and you don’t know what the barrier is...people that are average...have that choice if they want and ...they can say ‘well, if I wanted to be sociable then I would be but I don’t want to be sociable’’.

George described how he wants to be sociable but that it is ‘awkward’ and he can ‘put people off’. He described how in the past, he tried to fit in with different groups of people by ‘dumbing down’ as he wanted to be accepted by them.

George went on to talk about being told he should also be assessed for dyspraxia by people working in mental health and learning disabilities. He described having a poor memory and co-ordination which has affected him since childhood, giving examples of how this had affected him:

‘...I couldn’t tie (a) tie till I were about fourteen and didn’t learn to ride a bike till I were fifteen...it took me ages before I could tie me laces...I still can’t swim’.
George talked about having intelligence but feeling as though it is not expressed. He described being called ‘stupid’ and a ‘gap’ between the jobs he has none and his capabilities:

‘Whilst there is intelligence in there, it don’t come out...people kept telling me ‘oh, you’re stupid you...’, so jobs-wise, you find yourself in bottom half...I always thought there’s a big gap between me being here (demonstrates a ‘level’ with hands) and that job (demonstrates level closer to floor with hand)’

George went on to describe his work history after leaving school, starting with work as a mechanic on a ‘male-dominated’ Youth Training Scheme. He described misunderstandings that got him into trouble during his time there, such as taking the instruction to ‘fill it up’ when putting oil in an engine literally. After this he went on to work at a Warehouse and then a catalogue company for fifteen years starting in the warehouse and moving onto banking and management of information. He talked about these jobs being unchallenging, doing the same tasks repeatedly. He said that he was good at his job and was asked by managers to go out to speak to other members of staff within the company. He said that he sensed that his communication problems might have impacted on his ability to do this job and he went onto another department where he only reported to one other person. He said that this involved working with an accountant whom he is sure has Asperger’s syndrome and that this worked well as the work was structured and logical and he was left to do his work:

‘I moved to another department...I just reported to one person and I’m pretty sure he’s got Asperger’s...but he were an accountant ...all he were interested in were numbers, so it were never a problem for him...where it were pure structure and logic I were alright but when it were abstract thinking...I was completely lost...when I were left to meself to do the work ...I were fine’

In 2001, George began feeling like he couldn’t ‘cope’ anymore. He said that he was unable to identify exactly what the reasons for this were but felt it was a ‘build up of things’. He spoke about being told he would have to go on a train journey with a colleague and that the thought of being with that individual for a long period of time, with no means of escape made him think he might ‘lose it’. He visited his GP, who told him he had depression and prescribed him antidepressants. He talked about being asked to look into ‘cost-cutting’ at work, coming up with ideas and his ideas
being ignored which seemed illogical to him. He said that he took voluntary redundancy in August 2001. He said that during the same time period he attended a local college to complete a series of NVQs in accounting and finance. George described taking a month off of work and looking for temporary work, which proved difficult as people did not get back to him. He attributed this to his communication problems, such as being literal:

'I found it difficult getting a job...they were like 'oh yeah, we'll get back to you'. No-one ever gets back to you...because of the communication...I'd be absolutely literal...someone comes up to me and says 'oh, are you alright?' and I'd go 'yeah, I'm fine'...apparently they want more'.

He went on to do a series of temporary jobs in a warehouse and then reading water meters which he liked but felt pressured in as he was slow at it. He went on to do a job working for a company which involved working solitarily only having to see his colleague infrequently, an ideal job for him:

'Although I had to report to somebody, I only saw them once a week, I were out on me own...at me own pace....nobody bothering me...that were probably my ideal job'

He talked about circumstances at work changing which would mean moving several hundred miles away. As a result, he left and began working for a finance department in a local hospital where he was happy:

'They were only a small team, so we all got along and we all had a good laugh'

He talked about always being in small departments meant that he hadn't had any problems at work until he went on to work in a large and busy open-plan office in July 2003, with little training, lots of distractions and dealing with lots of telephone calls:

'That caused me so much problems that I started going downhill again with depression...I said 'look, I can't cope with this sort of work, telephoning me constantly...'. So in the end, they...put me in an area where it were pushing paper
but ...I did virtually the same thing again for eighteen months. I think people would say it were

'soul-destroying'...you’re thinking 'but I can do more than this but why can’t people see that I can do more than this?...'I just lost concentration...I just got bored...there was no challenge...there were loads of distractions, really overwhelming, loads of people'.

George talked about having ‘anxiety and paranoia’ and how this made him think his colleagues were talking about him. He also felt that they avoided social contact with him and the impact that this had on him:

'I think everybody if talking about me all the time...I’d go up and speak to someone for five minutes and they’d go ‘I’ve got to get on with me work’ and the five minutes later you’d see them talking to someone else for about an hour...I couldn’t put anything on it. You just feel isolated, like an outcast and you think ‘what’s up with me?’.

George talked about hearing about autism but associating this with people on the ‘lower en fog the spectrum’ and he thought ‘if that’s an autistic person, that’s not me’. George talked about how last year, when he was having emotional difficulties, a friend suggested that he might have Asperger’s Syndrome and he began researching the topic:

‘me head was getting in a real mess, depression, anxiety, paranoia...actually one of my friends, she said, because quite a few people have said that I’ve no social skills...but I didn’t know what they meant...she said I might have Asperger’s and I looked it up and I recognised a lot of the stuff...although I got a bit confused because I looked on different websites and they said different things...’

George talked about visiting the doctor and being seen by a psychiatrist who referred him on for a specialist assessment for Asperger’s, which took some time to happen. In the meantime, George attended a support group for people with Asperger’s Syndrome where he has gained understanding and help:
'going to (the support group) has been brilliant because there are people there who do understand, who will help you.'

George talked about the struggle to be assessed by Social Services and the lack of understanding of Asperger's, especially as he has improved in many ways since diagnosis. He mentioned the differences in the way that Asperger's is recognised according to geographical area:

'I had loads of battles getting assessed by Social Services...She (the social worker) doesn't know anything about Asperger's. I think she's having problems with the fact that I'm improving so quickly...I think she's thinking 'hold on a minute, he's alright now and he's communicating a lot better'. I don't think she understands Asperger's. She says that every time 'I don't fully understand Asperger's', which doesn't help but unfortunately that's the way (local) Social Services are. If I were in (another area), they recognise Asperger's'.

George talked about making complaints via the local PALS service in his local NHS trust and the lack of understanding about his problems. George talked about a written account that he had produced of the difficulties that he faces which he sent to a specialist Asperger's Service prior to his assessment in order to help with the assessment. George was assessed by a Clinical Psychologist, who was understanding and confirmed that he has Asperger's:

'She were really, really nice, really brilliant and she says...’Yeah, you’ve definitely got Asperger’s’.’

1.2 Middle

The middle part of George's narrative covers the time since his diagnosis and the massive impact this has had on his life. He goes onto reflect back on his previous experiences and behaviour. He talks about how he may be able to help others, career options and his plans for the future. He also describes what it was like telling others and their reactions.
George talked about the time since assessment as a ‘massive turning point’ in terms of allowing him to think about why he the way he is, why others are the way they are and the obstacles he has faced throughout his life:

'since assessment, it's been a massive turning point, all the questions I've had, I've been able to think about and get an answer to why I am like I am, why people are like they are...and all these walls, stumbling blocks, spaces, voids, whatever that I've had in my life...and now I can overcome them...it were just...like someone give me the answer to the universe'

George spoke about how he has changed since diagnosis and has ‘improved’ from his former self:

'going from having no confidence...low self-esteem...and not being able to think clearly at all...I'm far more improved now and a lot of people have seen the improvement. I'm far less defensive...I used to come back aggressively because you don't trust people and you feel like you're misunderstood'

George talked about the importance of contact with others who are interested in Asperger’s and autism and the importance of positive feedback from others. He also spoke about his emerging interest in Asperger’s and being asked to participate in events and contribute to understanding:

'Being in contact with people who are interested in Asperger’s...people say I've got really good insight into it...I developed an interest in Asperger’s ... the NHS in (the local area) are doing an equality and human rights network thing and XXX (the PALS Officer) asked me to come along’

George talked about the importance of being provided with explanations and being given choice and a sense of control to reduce anger and frustration. He went onto talk about an idea he has to share the patient’s perspective of Asperger’s which he has to inform people working in the NHS. He has shared this with the Clinical Psychologist who assessed him as well as people at the Local Asperger’s support group. He said that he hoped to do this in conjunction with someone who works with people with Asperger’s to handle particular questions and to get a balance:
'I've done a plan about what I could do... to go out and inform...let them know what it's like from the patient's viewpoint...people could start asking the wrong questions about research and stuff like that...and from the start...I think you need the balance between somebody that has Asperger's but also somebody who works with people with Asperger's, to get the balance from both sides...so there could be an employment and career opportunity there'

George went on to talk about being invited for an assessment at work (he is currently on sick leave) and his uncertainty about his position. He talked about others' reactions to this in relation to the current economic climate (the recession) and his attitude towards it:

'People have been saying 'Oh you shouldn't do this and that, in this economic climate'...but it's like 'what do I do if I'm depressed at work?'. I understand what they are saying but I don't think they see it from my viewpoint, that it's not doing me any good.'

George talked about the cost of depression to the economy and the importance of early intervention to prevent long-term difficulties. He went on to talk about his desire to learn and application to college:

'I've got something inside me that I have to learn...I've applied to go back to college...I'm hoping to for humanities and social sciences...an access programme'.

George talked about going to college previously and experiencing confusion regarding the courses. He talked about how he did not understand his difficulties at the time and the steps he had taken to address this and how important additional support is:

'But then I didn't understand the problems I have with my learning...I went to the learning disability unit and...having that support there takes a load off your mind'

George went on to talk about the difference that growing older has also made and the differences he has noticed between his life and others' (such as other people having families and going out less). He said that although he has matured, it is not at the same rate as other people and how he is 'probably a teenager trapped in a man's
body’. He said that he noticed that this had ‘died down’ in recent years because although his brain ‘might think its young’, his body isn’t. He talked about how depressed, lonely and isolated he had been until he was diagnosed with Asperger’s:

‘It is literally like a whole new world and it’s always like I’ve felt like I were in a long, dark tunnel and there’s no light at the end of it and all of a sudden now I’m out of tunnel and it’s just wide open-space and now I feel that anything is possible’.

George went on to talk about the difficulties he has had explaining and convincing some individuals he knows that he has Asperger’s and their lack of understanding. He spoke about experiencing extreme feelings with ‘nothing in between’ and wanting to ‘lash out’ but having a ‘moral switch’ in his brain that stops him as he knows that ‘it’s wrong’.

George talked about a friend of his thinking that he should go back to work and him not understanding that he does not want to as he has suicidal thoughts when he is there. He talked again about the geographical differences in terms of services available and his view that knowledge should be shared to improve things:

‘I’ve discovered each little area is like its own empire and they don’t talk to each other to share knowledge and make things better for everybody’.

He also talked about how he had previously not liked others but then come to believe he was a ‘bad person’ over the years:

‘Over the years...the misunderstandings and stuff like that and feeling isolated...you think it’s everybody else, so you don’t like anybody else but then you think it’s yourself, so you don’t like yourself and you think ‘Oh, it must be me; I must be a bad person’.

George talked about attempting suicide on a few occasions and feeling like he could not continue:
'its really really bad so...I did attempt suicide a couple of times...you're just like 'it must be me...' ...you can't carry on anymore'.

George reflected on how receiving positive feedback since diagnosis had led him to want to help other people and how he could not make connections between having Asperger's and experiencing mental health problems:

'since...assessment, people say 'oh, the way you ...explain stuff...it's really good'. So you want to help people as well. I can now see the link between having Asperger's and having mental health problems because obviously you have the Asperger's and you've got all your social problems, which leads you to feel depressed then you get anxious then you get paranoid'.

George went on to talk about the autism spectrum and the way that for every person across the scale, their problems are '100%' to them. He spoke about how Asperger's is confusing for people to 'get their heads around' as it a 'hidden disability' in the sense that you cannot 'see 'it like you can a person who is ' in a wheelchair'. He spoke about the way that it has taken his GP of 25 years time to understand it and now treats him better as a result. George talked about being told at assessment that he can choose to continue to be as he is or attempt to 'fit in'. He described how is negotiating this choice at his own speed and of his own free-will:

'they said I can either be as I am or you can try and fit in the average that people perceive in society...I'm doing that but I'm doing it at my own pace and I'm doing it for me, for the right reasons, so I don't feel I'm being forced into it, pressurised into it, which...is a big thing for people with Asperger's...'

He went on to speak about regaining control of his life and feeling that he is responsible for what happens in his life but at the same time requires support from others:

'I feel like I've got a lot of control back in my life and that I can do stuff and...I recognise now that it's up to me to do stuff because only I can make things happen...but it's also important to recognise that ...it's not just me on me own...there's support there'.
George then talked about the support he had received at the local Asperger’s support group and the help they had given him in filling out benefits forms. He talked about the inconsistency of the benefits system and his frustration and confusion with the use of ‘guidelines’ rather than ‘rules’ and the potential for ‘discrimination’ and potential for inequality throughout the system.

He then talked about not understanding social barriers and gave the example of a friend telling him that he is ‘always invading his space’. He spoke about ‘everybody taking these things for granted’ and his need to learn them as he doesn’t ‘understand the social aspect of life’.

George then talked about living in a ‘bubble world’ whereby his current location is his entire world. He said that this is more intense when he is depressed when his bedroom in his house becomes his world. He talked about being poor at estimating distances and crowds and not understanding why this does not affect him when driving a car. He talked about Asperger’s as an ‘umbrella term for a lot of conditions’, which ‘overlaps’ with a range of other conditions such as dyspraxia.

Next George spoke about having testicular cancer aged 21, when he was told that he had a ‘10% chance of survival’. He said that he thought that having Asperger’s had helped him to get through this:

‘I think having the Asperger’s helped me so much because I didn’t realise. I didn’t understand what were going on...I just thought ‘oh, I’ve got a year off work. I’ll go to hospital for a week, have some treatment. Sorted’...it’s probably because I had the Asperger’s I didn’t understand the implications...it were just get in and get on with it’

George recalled being told that he had cancer with a number of health professionals and his mother present and his indifferent reaction to it. He described having a high temperature during his treatment and having to have a blood transfusion. He said that his temperature increased by only one degree and his disbelief that a change you wouldn’t notice outside made a huge difference in the body. He likened his reaction to having cancer to his reaction to his suicide attempts whereby he ‘just woke up,
phoned in sick...spent the rest of the day in bed’ and ‘went back to work the next
day’.

He went on to relate his increase in body temperature to how he feels in relation to
the rest of society:

‘when my body went up in temperature by a degree, I can relate to that...in a way
now...sometimes you feel you’re only one degree out from rest of society...but that
one degree is just massive’

George then talked about talking to a friend who works with children with autism
who had said that his situation can be more difficult for him because he ‘knows
there’s something there’ and he has a wish to ‘get that’ but there is a ‘stumbling
block in getting there’.

George then noticed that he had not talked much about school. He said that he
remembered being bullied in the playground when he was four before moving to
another school where he was made to write with his right hand. He said that through
his first school and middle school, ‘it were all easy, it weren’t a problem for me’. He
then went on to upper school and the first year was ‘alright’ but then the family
moved away so his parents could work as caretakers at a funeral directors. He said
this ‘completely and utterly upset me whole world’ and he attended school for only
one day in two years. He said that this was in 1981 and at the time, ‘bad’ behaviour
was put down to ‘behavioural problems’ and ‘nothing was known about Asperger’s
really, dyspraxia...or dyslexia’. He said that in retrospect this ‘was a waste’. He
described being away from his friends which he didn’t understand and that he tried to
cope with it by not going to school. He talked about school work getting harder and
his difficulty with spelling.

George went on to talk about ‘wanting to improve’ himself when he went back to
college in 1996 when he had won a competition in the paper and completed his
NVQs in accounting and finance. He talked again about his ‘desire to learn’ which
has ‘always been there’ and that there has to be a ‘purpose’. He talked about his
interest in Asperger’s and sais that he had got a book about psychology which he
finds interesting and can understands and hopes to do a course in.
In the final part of George's narrative, he talks about his plans for the future in terms of an intimate relationship and 'finding himself'.

George said that he has had some relationships but they don't seem to 'work' and having Asperger's makes it difficult. He said that he hoped that as his understanding of himself and the world around him increased he would be able to meet someone:

'I've had a couple but they don't seem to work. ...People that are average have problems with relationships...so if you've got Asperger's, it's twice as hard. But hopefully being able to understand myself and ...understand a lot more about me outside world...how people interact with each other and stuff like that...and hopefully...meet somebody and see how it goes'

George described how in the past he had relied on magazines such as FHM for information and advice about women and that this had been unsuccessful which he now understands:

'you'd read FHM, so you'd believe it (laughs)...apparently it's not true (laughs) what FHM tells you about women...you apply it to every woman and ...you don't understand why you don't get the same reaction, you might even get a slap...you don't find it working (laughs)'

George talked about getting used to talking to women more and increasing in confidence due to their positive feedback. He said that he had felt 'like a shell' previously and was becoming more like a 'human being':

'before I felt like I was just a shell. I feel now like a human being. I feel like I am the person that I've always wanted to be....it's not like I want to be an actor or a singer or something like that. I feel that I am a person now and I've got a personality...I think people are responding a lot better to me'

George talked about the assessment for Asperger's helping him to 'find himself', voice his opinions and understand differences in opinions better:
'the biggest thing for me form assessment...being able to find meself...I don’t like using those terms....but I have found meself and I’m still finding meself...you feel like a person...at last you’ve got a personality....I can voice my own opinion and ...then if people have their own opinion, I can appreciate their opinion better now than what I did before. I can understand now why they are different’

The interview ended with George being asked about why he chose to take part in the research. He talked about wanting to share his experiences, to help people (including the researcher with her career) and to provide one persons perspective on Asperger’s.

2. NARRATIVE STRUCTURE/FORM

The overall narrative structure of George’s story appears to be intermittently regressive in orientation (a life history of low self-esteem, anxiety, paranoia, suicide attempts, interpersonal problems and work problems) followed by a progressive story (post diagnosis with AS). Receiving help and increased understanding about AS gave meaning and purpose and was key to an evolving identity, which set an optimistic tone for the future (personal development/self actualisation, learning, relationships).

3. NARRATIVE CHARACTER

George’s character is central to the story. Concept of AS key to identity in terms of past, present and future. Diagnosis as ‘answer to the universe’ and key to understanding self, world and other people).

Not in control of events and self at start of narrative, using alcohol as a coping strategy, feeling like a ‘shell’, sense of being alone. Post-diagnosis experienced increased control and recognition that ‘only I can make things happen’ but also that ‘it’s not just me on me own’, other people important and can be relied upon. Links with concept of self-efficacy (Bandura, 1977; 1998).

4. WORK OF THE NARRATIVE

George was keen to share his story for research purposes. Also talked about writing his experiences down, going to support groups, sharing his experiences, thoughts and ideas with others.

Past events and reactions narrated through lens of AS (e.g. how dealt with cancer, challenges in social relationships, occupational difficulties). Links with concept of ‘biographical work’ (Bury, 1982).
Talked about wanting to be involved in training staff, wanting to share experiences as a way of helping and providing perspective on AS. Links with idea of narrative as political advocacy/'coming out' (Murray, 2003). Talked about importance of sharing common goals of increased understanding and providing help.

5. NARRATIVE CONTEXT

At the personal level of analysis, George spent a great deal of time talking about his work history, suggesting his identity as an employee was of great importance in the past. When talking about the more recent and past and his future, George talks about wanting to learn and develop as an individual but the importance of this also having a purpose is highlighted.

At the interpersonal level of analysis, George’s account emphasises how difficult his relationships and interactions with others have been throughout his life. However, there is a shift later in the account, when he reflects on how more recently (as he comes to understand himself better in terms of the AS diagnosis), he has been experiencing greater ease interpersonally, for which he has received positive feedback. This was apparent in his ease of developing a rapport with and providing a lengthy narrative to the researcher. His account looks forward into the future, suggests hopefulness that this will continue, so that he is able to ‘meet someone’ and have a successful intimate relationship.

At the societal level of analysis, George’s account reveals a number of discourses related to medical models of disability. In particular, the manner in which ‘hidden disabilities’ such as AS are difficult for society to understand. He talks about still trying to ‘fit in’ with societal expectations but as his ‘own pace’. The account also highlights societal discourses which are apparent in some magazines aimed at men about how to interact with women. These have proved unhelpful to George in trying to understand and operate within society.

6. NOTES/THOUGHTS

Identity about work and occupation to begin with, rejection of this as the most important aspect, more focus on ‘knowing’ who he ‘is’, having a personality, learning, improving, understanding.

Social rejection/bullying leading to difficulties socialising/at work and psychological distress (paranoia, anxiety, depression, suicidal thoughts and attempts). Being given positive thoughts and feedback from others important in evolving identity.
Appendix (viii)

Credibility check invitation letter
Dear (name),

Re: Research Project: Identity and ASD

Thank you very much for taking part in the above research project and for giving up your time to be interviewed. In total I interviewed six people with Asperger’s Syndrome and I felt honoured to hear such open and detailed accounts of your experiences. Following the interviews, I had lots of data to bring together and I have felt responsible for ensuring that I capture the diversity and similarities across all six accounts.

As agreed at the interview, I have attached/enclosed a draft copy of the results section for you to read through if you wish. All the names have been changed and I have given you the pseudonym of (pseudonym).

As we talked about at the interview, I would appreciate your feedback and comments on this draft version. If you have any comments that you would like to make, please email them to me/I have enclosed a stamped addressed envelope for you to do so. Please feel free to type/write your comments on the draft results section or on a separate document/piece of paper if you wish to keep the draft copy of the results section.

You do not have to make any comments if you do not wish to do so but I will try to include any suggestions made into the final report, alongside my own interpretations.

Thank you once again for your participation and time.

Yours Sincerely,

Claire Binnie
Trainee Clinical Psychologist
University of Surrey