Self-Concepts of Adults Diagnosed with Asperger’s Syndrome: An Interpretative Phenomenological Analysis

Portfolio 1

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

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July 2005
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Acknowledgements

Firstly, thank you to the participants who participated in this study and who were courageous enough to share their experiences. Thank you to the course team at the University of Surrey, in particular Mick Finlay for his extremely helpful comments and support throughout the research process. Thanks to Julie Lloyd for her help with identifying participants and for the constant stream of e-mail jokes which relieved the strain. Thank you to the staff at Godalming National Autistic Society for their support and their inspiring enthusiasm to ensure that the people with Asperger's syndrome have their voices heard. Thank you to the qualitative research group for helpful comments and sharing anxieties, and thank you to Warren Matofsky for his insights. Last but far from least, thank you to my partner, Nicky, for her unwavering support and selflessness.
Critically Discuss the Evidence Base that People with Borderline Personality Disorder Can Be Treated Effectively by General Adult Mental Health Services. What Implications Might This Have For the Provision of Services?

Introduction

One of the major obstacles for general adult mental health services in meeting the needs of those presenting with symptoms associated with Borderline Personality Disorder (BPD) has been the lack of an effective, evidence-based model of care. As well as limiting the range of services available to clients, this situation has led to staff feeling deskilled and demoralised, further marginalising sufferers through the strengthening of stereotypes of these individuals as manipulative and difficult, if not impossible to treat. Consequently, many people have been let down by the mental health system, with the practical and financial responsibility of care and/or containment left to social services, friends and relatives, general medicine and to the judicial system.

Since its inclusion in DSM-III (American Psychiatric Association, 1980) BPD has been located clearly within the domain of mental health (Paris, 2002). Blashfield (1993, cited in Links, 1998) points out that this elevated status has spurned a great deal of interest in the area of BPD treatment, with the literature on BPD doubling every eight years. This
has resulted in the emergence of a number of different therapeutic models, all of which have contributed greatly to the evidence base confirming that, with focused and individualised care, those with BPD can gain greater control over their lives. Despite increased efforts to develop more effective approaches to care and the continuing commitment of NHS staff to help clients, the support offered by general adult mental health services, with their moderate resources and training, is still of limited value to those with such complex needs. A central question is how best to implement the evidence base emerging in the literature?

The following discussion describes the development of the borderline personality disorder diagnosis, different theoretical frameworks around which new therapeutic approaches have developed and current research indicating the efficacy of these various therapeutic approaches. Also discussed are the practical difficulties in delivering a comprehensive service to this heterogeneous client group. A number of options for service delivery are explored. Throughout the discussion, the term borderline personality disorder will refer to the DSM-IV (American Psychiatric Association, 1984) definition.

**Development of Diagnosis**

The term ‘Borderline’, which developed within the psychoanalytic tradition, was first used by Stern in 1938 to describe individuals who often appeared to fall on the borders of existing psychiatric diagnostic categories (cited in Linehan, 1993). Many of the behaviours Stern described as common to this client group, such as simultaneous
idealisation and devaluation of significant others, low tolerance to stress, emotion dysregulation and psychotic features, are still recognised today as central elements in the diagnosis of BPD. Stern's definition focused on the self-destructive behaviours of these individuals and the 'faulty empathic machinery' which made interpersonal relationships chaotic and unrewarding. A shift over recent years has focused on emotional aspects of the disorder and on the interaction between the individual and environment. Specifically, the BPD population is a heterogeneous group and whilst there is no agreed cause to BPD, a 60%-80% prevalence of sexual abuse in childhood indicates that a history of trauma may be a significant contributor to the development of BPD (Murray, 1993).

The label of borderline personality disorder has stood the test of time, despite a great deal of debate as to its usefulness as a diagnostic category. A central concern is the huge overlap with other axis I and II disorders, making clear diagnosis extremely difficult. For example, Beck (1990, cited in Linehan, 1993) noted that 60% of individuals diagnosed with BPD meet the criteria for other personality disorders. As a result, authors such as Layden, Newman, Freeman and Morse (1993) suggest that it is useful to further differentiate within the diagnosis of BPD using sub-types such as Borderline-avoidant/dependent, borderline-histrionic/narcissistic and borderline antisocial/paranoid. However, whilst defending this sub-typing on the basis that BPD often coexists with other personality disorders and that individuals within sub-types can be identified by symptom constellations, they do not offer any empirical evidence for the existence of these sub-categories. Millon (1996) reported that 50% of BPD individuals also suffer from life-long affective disorders, leading him to propose the term cycloid personality to
highlight the mood instability he sees as central to the disorder. Other authors, for example Kernberg (1975, cited in Linehan, 1993), disagree with the diagnostic category of borderline personality disorder, preferring the analytically derived term 'Borderline Personality Organisation', which places emphasis on the formation of internal psychic structures. DSM-IV has adopted a descriptive approach to Borderline personality disorder based on empirical data and clinical observation, identifying 9 symptoms and behaviours associated with BPD, with a combination of any five needed for a diagnosis. These criteria include fear of abandonment, unstable pattern of interpersonal relationships, unstable sense of self, impulsivity, recurrent suicidal gestures/behaviour or self-harm, instability of mood, feelings of emptiness, difficulty controlling anger and transient psychotic states. The constellations of cognitions and behaviours, which affect many areas of an individual's life, bring a great deal of distress to sufferers. The very nature of behavioural patterns associated with BPD makes the provision of care with this client group difficult and the clinical picture is clouded further by the high level of comorbidity with substance abuse (DeJong, Van Den Brink, Harteveld and Van Der Wielen, 1993).

**Therapeutic models**

Psychoanalytic therapy was, and to a lesser degree remains the central approach to providing therapy for individuals diagnosed with BPD. As Monroe-Blum and Marziali (1995) explain, underlying assumptions within this theoretical framework developed from the idea that BPD is the result of unresolved internal conflict at specific stages in early development. These assumptions located problems within the individual and
describe an association between childhood development and a continuum of psychopathology. This traditional approach emphasised the importance of interpretation during therapy to assist in the resolution of intrapsychic conflict. Later theorists however, drawing on Bowlby’s (1969) attachment theory, object relations theory and empirical evidence suggesting that many individuals presenting with BPD have experienced a traumatic childhood, focused on actual experiences within the individual’s life that affect the development of cognitive structures. Psychoanalysis has oscillated between focusing on the use of interpretation in therapy to resolve intrapsychic conflict and more supportive therapy aimed at improving adaptive functioning (Aronson, 1989).

Despite a growing literature supporting the efficacy of psychodynamic approaches to BPD, there are only two published randomised control trials (RCT) in this area. One of the most frequently cited studies is an RCT conducted by Bateman and Fonagy (1999), which compared standard psychiatric care to a psychoanalytically oriented, partial hospitalisation treatment programme. Their results indicated that the partial hospitalisation programme resulted in a significantly greater reduction in self-mutilation, suicide attempts, state and trait anxiety, depression, interpersonal problems and global ratings. However, as Bateman and Fonagy themselves point out, it is impossible to assess which aspect of the treatment programme was most effective, as the therapeutic milieu may have had a significant impact on symptomology. Furthermore, Sanderson, Swenson and Bohus (2002) point out that the trial was actually a study of combination therapy as the clients were also using medication. Despite these limitations, the overall approach
yielded encouraging results which were maintained at 18 month follow-up (Bateman and Fonagy, 2001).

Monroe-Blum and Marziali (1995) conducted an RCT comparing group versus individual psychodynamic psychotherapy (interpersonal group psychotherapy). Whilst there were no significant differences between the two groups on outcome measures, all participants exhibited improvement in behavioural dysfunction, social adjustment, global symptoms and depression, which was maintained at 24 month follow-up. Two limitations to the study are the small sample size (22-group, 26-individual) and secondly the high drop-out rate, both of which limit the generalisability of the findings. As the authors point out, should the results be replicated with a larger sample, then IGP would prove to be a useful and cost effective approach to working with those diagnosed with BPD.

The American Psychiatric Association (APA) Practice Guidelines for the Treatment of Patients With Borderline Personality Disorder (2001) cite a number of studies highlighting the efficacy of psychodynamically oriented psychotherapy. For example, Stevenson and Meares (1992), evaluation of a psychodynamically based, partial hospitalisation treatment programme indicated significant improvement on a number of measures including self-reported symptoms, use of health services and number of recorded violent and self-harm episodes. Encouragingly, the results indicated that 30% of participants were symptom free at one-year follow-up. Due to the lack of a control group it is impossible to attribute the progress made by participants solely to the intervention described. The authors controlled for the effects of other interventions during the course
of the target treatment and patients were taken off medication through the course of the programme. Meares and Stevenson (1999, cited in APA guidelines, 2001) using the same 30 participants compared outcome with 30 patients receiving cognitive therapy and crisis intervention. Results indicated a more successful outcome for the psychodynamic treatment. However, a number of methodological issues limit interpretation of the results. For example, there is no mention of how much therapy the control group received, participants were not randomised, there was no blind outcome assessment and there was a different follow-up duration for control and treatment groups.

Stevenson and Meares (1999, cited in APA guidelines, 2001) analysed the cost-effectiveness of their psychodynamic therapy by costing all treatment received one year prior to treatment and one year after treatment. They identified a saving of 640,000 Australian dollars, which they equate to 8400 dollars per patient, per year. These savings were almost entirely due to a reduction in number of hospital days. However, as there was no control group, it is difficult to identify which aspect of the programme resulted in the changes. Developing this analysis further, Hall, Caleo, Stevenson and Meares (2001) examined the total cost of health service use plus cost of therapy compared to total health service use costs prior to therapy. They describe a net saving of 18000 Australian dollars per patient over a one-year period. They also reported that higher users prior to treatment made more significant cost reduction after therapy, whereas low service users savings were negligible.
Two studies conducted at therapeutic communities indicate positive outcomes for BPD clients participating in psychodynamic psychotherapy. At the Cassel Hospital, Chiesa and Fonagy (2000) compared a traditional one-stage programme consisting of 12-month in-patient treatment (46 participants) with a shorter two-stage programme (44 participants), which included 6-month in-patient treatment followed by 12-18 months out-patient group psychotherapy and six months of community outreach. Results indicated that participants in the two-stage model showed significantly better scores on the Social Adjustment Scale and Global Assessment scale at 12-month follow-up. The authors suggest that a shorter in-patient stay may help to focus clients and staff, hence facilitating progress over the treatment period. They further suggest that continued community support provides a smooth transition back into the community without total severance of support. Unfortunately, the participants were not randomly allocated to treatment groups and the lack of a control group limits the reliability of the results.

A second study carried out at the Cassell Hospital supports the necessity of providing community support following in-patient therapy. Chiesa, Dohroda and Longo (2000) explain that BPD clients participating in a two-stage model similar to that described by Chiesa and Fonagy (2000) were 5 times less likely than those in the one-stage model to drop out of the programme early.

Chiesa, Fonagy, Holmes, Drahorad and Harrison-Hall (2002), extending the Chiesa and Fonagy (2000) study examined health service costs by diagnosis during their comparison of three treatment approaches. These included 1) a step-down programme consisting of 6
month inpatient psychodynamic psychotherapy, followed by 6 months continuing community support; 2) 1 year in-patient psychodynamic psychotherapy and 3) General Psychiatry care in the community. Their results indicated that the Step-down programme was most cost effective, followed by the 1-year in-patient programme, with the general psychiatric care proving to be the least cost-effective. Information regarding the use of services was collected using a retrospective, self-report measure at induction and one-year follow, possibly limiting the accuracy of the results. Interestingly, the study found that a diagnosis of depression was a stronger predictor of high service use costs than BPD. When comorbidity of the two features are considered, then cost is additive, with BPD accounting for a small proportion of overall cost. Similarly, whilst acknowledging that providing care for personality disordered clients is costly to services, the authors note that level of depression and general distress is more closely related to high costs than number of personality disorder diagnoses. The study does suggest that patients returning to the community after a period of in-patient care require a high level of support in order to prevent deterioration.

Dialectical behaviour therapy (DBT) is based on a biosocial theory of BPD, which explains the development of the problem as resulting from the interaction between a) a biological disposition to react overemotionally to stressful events (poor emotion regulation) and b) experiencing an invalidating childhood environment. Invalidating refers to the way in which significant others disqualify the child’s emotions, dismissing them as inappropriate or inaccurate. Consequently, the developing individual swings between attempting to have their emotions acknowledged through extremes of emotional
expression and misunderstanding feelings resulting in an inability to trust, and repression of internal experiences. This results in intense emotional discomfort resulting from feelings of inadequacy, vulnerability, helplessness and depersonalisation. DBT, developed from cognitive-behavioural therapy by Linehan (1993), focuses on current maladaptive behaviours, cognitions and automotive reactions proposed to have been learned by individuals to cope with emotional discomfort. The model offers four modes of treatment including individual therapy, group skills training, telephone contact with the therapist and therapist consultation. Throughout therapy the relationship between therapist and client is seen as an essential tool assisting progress. The therapist aims to find a balance between accepting and validating the client's feelings whilst challenging the client in relation to maladaptive thoughts and behaviours; teaching new skills in the areas of emotion regulation, relationships and thought challenging.

The APA (2001) guidelines cite 3 randomised control trials of DBT. Linehan, Armstrong, Suarez, Allmon and Heard (1991, cited in APA guidelines, 2001) compared a 1-year DBT programme with treatment as usual (community psychiatric care) for 44 females diagnosed with BPD. Completers in the DBT group (22) exhibited fewer parasuicidal behaviours and reduced medical risk, fewer hospital admissions and fewer total days in hospital. Interestingly, all participants exhibited reduced levels of depression, suicidal ideation and helplessness, suggesting that general psychiatric care can have a positive impact on the well being of some individuals diagnosed with BPD. The second study by Linehan, Tutek, Heard and Armstrong (1994, cited in APA guidelines, 2001) indicated a greater reduction in trait anger and global symptoms in those who completed DBT when
compared to general community psychiatric care. A third significant study, considering the high rates of comorbidity with substance abuse stated above, is that by Linehan, Schmidt, Dimeff, Craft, Kanter and Comtois (1999), which compared DBT treatment with general community psychiatric care in a sample of BPD with comorbid substance abuse. Results of this study indicated more drug/alcohol free days following DBT, although there was no difference between groups on levels of parasuicidal behaviour and state anger, both of which saw a reduction in these areas. Again, the sample size was relatively small (7 DBT and 11 TAU), limiting generalizability of the results. A number of uncontrolled studies have contributed to the growing evidence base that DBT can influence a reduction in symptoms of BPD. Sanderson, Swenson and Bohus (2002) also point to the fact that the DBT approach resulted in a saving of $9000 (US), suggesting it may prove to be a cost-effective approach.

Cognitive Analytic Therapy (CAT) developed by Ryle (1997), incorporates both psychoanalytic theories of object-relations and cognitive behavioural ideas. Therapy aims to identify the limited number of dysfunctional thoughts and behaviour patterns available to the individual, which restricts them to playing out specific roles when relating to the self or others. These ‘procedures’ are hypothesised to have developed in childhood through reciprocal interaction with significant others, either in the form of contradictory, incoherent parenting or through the effects of trauma, and form the basis of personality and self-regulatory processes (Ryle, 1997). During therapy the client is encouraged to monitor unwanted emotional reactions and behaviours, their antecedents and consequences. In a collaborative process described as reformulation, client and therapist
identify ways in which the client maintains these procedures and develop more adaptive ways of thinking and behaving.

As yet there are no controlled trials demonstrating the effectiveness of the CAT approach. A study by Ryle and Golynkina (2000, cited in APA guidelines, 2001), reported a reduction in self-harming behaviour in 14 of 27 patients who completed an 18-month CAT group. There are a number of published case reports indicating the successful use of CAT. For example, Ryle (1992, cited in Mohan, 2002) described two case reports indicating the successful outcome for two suicidal males. Ryle and Beard (1993) describe a 26-session CAT intervention with a male diagnosed with BPD. The post-therapy interview indicated that the client experienced less anger, increased tolerance of others, increased self-esteem and decreased dissociation.

Manual assisted cognitive therapy (MACT), an approach that uses DBT techniques and focuses on recurrent deliberate self-harm, was also shown to be effective when compared to a treatment as usual group. An RCT by Evans et al. (1999, cited in Mohan, 2002) indicated that MACT led to greater reduction in the number and rate of paracuicidal behaviours, depressive symptoms, and the average cost of care (46% less with MACT). All participants had a diagnosis of personality disorder, but Evans et al. do not indicate how many were diagnoses with BPD.

Mohan (2002) has succinctly summarised the research literature on various drug treatments for BPD. He identified four clusters of drugs including neuroleptics, mood
stabilisers, antidepressants and opiate antagonists. Amongst neuroleptic treatments Mohan cites three studies (Goldberg et al., 1986, Montgomery and Montgomery, 1982 and Frankenburg and Zanarini, 1993) with strong methodologies showing improvement in overall symptoms, the drugs tested were Thiothixene, Flupenthixol and Clozapine respectively. Four studies describing positive effects of mood stabilisers are cited by Mohan (Links, 1990, Cowdrey and Gardner, 1988, Hollander et al., 2001 and Pinto and Akiskal, 1998) which indicated a reduction in behaviour dyscontrol and impulsivity after the use of Lithium, Carbamazepine, Divalproex Sodium and Lamotrigine respectively. In relation to antidepressants, Mohan highlights the effectiveness of Fluoxetine in reducing anger, irritability and depression, Amitriptyline in reducing depression and hostility and Phenelzine in reducing depression. Overall, there appears to be growing evidence to support the use of these various drug treatments in the treatment of BPD symptoms.

The increased interest by clinicians and researchers has undoubtedly led to a broader understanding of the etiological, developmental and treatment issues associated with BPD. Studies examining the outcome of psychodynamic, cognitive-behavioural and combination therapy with this client group suggest a high degree of efficacy for these models of care. There is evidence to suggest that the approaches indicated above may prove to be cost effective, a consideration that will be central to decisions regarding implementation of such services on a large scale. However, Marshall, Lockwood and Morris (1997), highlight the problems of conducting economic analysis alongside clinical trials following their comparison of a care coordinator approach to care management. Whilst initial results appeared to indicate a significant difference in savings between the
two approaches, the authors point out the importance of considering the confidence levels used in any analysis of cost compared to treatment efficacy, as apparent savings could disappear when this is considered. The confidence levels are affected by the level of variance in service use costs at the start of a target treatment which, for example, in the Meares and Stevenson (1999, cited in APA guidelines, 2001) study were largely due to geographical and referral differences between treatment groups. Marshall et. al. (1997) also raise the question of what exactly constitutes significant cost saving. There is a further danger of undermining the case for providing the same level of specialist care to low service users when interpreting results such as these. Service users may miss out on specialist treatment because it is not perceived as cost-effective, despite the fact that their quality of life and well being may improve dramatically due to participation in therapy.

**Options for the provision of care.**

Various therapeutic approaches have proven effective with both in-patient and outpatient samples, making the decision as to how best to implement services a difficult one. Meares and Stevenson’s (1999, cited in APA guidelines, 2001) study suggests that psychodynamic therapy may be most beneficial to higher functioning individuals, a point echoed by Paris (2002). Conversely, Links (1998) highlights the fact that cognitive behavioural and skills based programmes such as DBT appear most effective for the most severe populations, who are generally not suitable for long-term, intensive in-patient treatment. Links proposes the development of community-based, assertive outreach services for high-risk individuals, where the primary focus is on crisis management
combined with longer-term rehabilitation involving skill development and environmental change. Regardless of where the therapy is provided, the research literature appears to call for specialist services to meet this goal, at least for certain populations, since many of the models proved more efficacious than standard psychiatric care. In order to develop services to provide this requirement the NHS would require trained professionals to deliver therapy. Given the intense nature of this work, approximately 5 therapist hours per individual (Links, 1998), one option is to have dedicated specialist teams serving specified geographical areas to cover community-based clients.

As recognised in the APA treatment guidelines (2001), an essential component of care for BPD is a co-ordinated treatment effort where several professionals are involved in care delivery. In order for community care to be effective, professionals within community teams would require knowledge and skills relating to the provision of care for BPD. This would enable them to maintain continuity of care and deal most effectively with issues such as boundary violations, counter-transference reactions and the fragmentation of teams due to differential relationships between the client and various professionals. Hawkins and Sinha (1998) tested the conceptual mastery of DBT following a state department of mental health initiative training programme in DBT. Their results showed a strong correlation between training in DBT and performance on the examination, regardless of educational background. Whilst this study does not enlighten us as to the ability of mental health professionals to apply the theory to their work after such a short introduction, it does suggest that the ideas and concepts behind DBT are attainable through effective training packages. This has direct relevance to a study by Frazer (1996,
cited in Hawkins and Sinha, 1998), which showed that increased knowledge about etiology and effective treatment of BPD in mental health professionals following a four-hour workshop on the disorder was related to positive changes in staff attitudes towards BPD.

Despite the lack of empirical support for the efficacy of CAT in ameliorating symptoms of BPD, the model has been adopted by a number of professionals working in community mental health teams. For example, Dunn and Parry (1997) describe how the use of CAT diagrammatic reformulation strengthened the therapeutic alliance and increased understanding of BPD across the multidisciplinary team, thereby reducing the degree to which staff collude with, and maintain, the client's maladaptive behaviours. The article by Dunn and Parry highlights the difficulties of working with BPD in the community and proposes that it is unrealistic to think of training the majority of community based professionals to an acceptable standard in the delivery of DBT. The alternative approach, they posit, is to provide a CAT consultation service whereby clinicians are taught how to utilise CAT techniques of diagrammatic reformulation as an aid to care planning. This would require at least one professional trained in CAT who could teach the basic principles of CAT and direct clinicians in its use with their clients. If this option is to be considered in the future, more research into effective ways of providing consultation, support and supervision need to be explored.

The efficacy of various therapeutic models has been suggested by a number of trials. However, in order for care to be delivered effectively, one must consider the service
framework and professional culture in which delivery takes place. Community teams appear to have experienced difficulty in the area of co-ordinating treatment provided by multiple clinicians (Norman and Peck, 1999). Following interviews with clinical staff Norman and Peck identified a strong adherence by staff to a ‘uniprofessional culture’ due to lack of training in newly introduced working practices and mistrust of managerial solutions to inter-professional working as reasons for such difficulties. Such practical difficulties would greatly hinder the delivery of effective care to individuals with BPD. One approach, described by Ryrie, Hellard, Kearns, Robinson, Pathmanaman and O’Sullivan, (1997, cited in Norman and Peck, 1999) developed to overcome this problem is ‘zoning’. This involves a daily planning meeting that facilitates the monitoring and review of client care and enables resources to be targeted according to fluctuating levels of client need. Ryrie et al’s study also indicated that zoning promotes adherence to operational policies (including multi-disciplinary working), a forum in which staff can receive support from colleagues and the sharing of knowledge within and between disciplines. Such an approach could be useful if members of the team had received some education and/or skills training in one of the therapeutic models and could share knowledge and experiences of working with BPD clients.

Conclusion

Over the past two decades there has been a dramatic increase in the attention paid by clinicians and researchers to borderline personality disorder (Blashfield, 1993: cited in Links 1999). Whilst there is still a great deal of work to be done, outcome studies (for
example, Bateman and Fonagy, 1999, Linehan, Dimeff, Craft, Kanter and Comtois, 1999 and Monroe-Blum and Marziali, 1995) suggest that individuals with BPD can be helped to cope more effectively with their problems and lead more satisfying lives.

In relation to the provision of services, research indicates that inpatient, psychodynamically oriented therapy proves most successful with those individuals who present with low levels of disturbed behaviour (Meares and Stevenson, 1999, cited in APA guidelines, 2001). However, shorter hospital stays of approximately 6 months were more effective than year-long residential care, providing that continuing support was provided on return to the community (Chiesa and Fonagy, 2000 and Chiesa, Dohroda and Longo, 2000). For those with high-risk behaviours, cognitive behavioural approaches provide the most effective strategies for preventing self-harming behaviours and increasing adaptive functioning (Links, 1998). There are a number of studies highlighting the cost-effectiveness of both forms of therapy, however, as Marshal et.al. (1997) point out, ‘cost-effective’ needs to be clearly defined and attention paid to the difficulties in arriving at accurate figures.

A number of alternatives to providing care in the community for BPD clients have been proposed. The effectiveness of these models rests on a number of factors relating to the provision of staff training, the availability of specialist consultation and supervision, and current practices that may hinder therapeutic relationships and the delivery of suitable care plans. As a large number of people diagnosed with BPD are cared for by community mental health services, it is an area that warrants further investigation.
The methodological limitations described in studies cited in this essay indicate the need for more rigorous testing of the efficacy of therapies in order to justify their acceptance as mainstream approaches. There are also a number of gaps in our knowledge regarding effective therapeutic interventions for BPD which future research must fill. For example, little attention has been paid to gender mixes within groups. This would seem a highly relevant point considering the high percentage of sexual abuse experienced by both male and female clients diagnosed with BPD. The efficacy of therapy with learning disabled clients with a diagnosis of BPD has also yet to be established. This client group is excluded from specialist treatments such as the therapeutic community at the Cassel Hospital, who include an I.Q. of at least 90 in their inclusion criteria. Thirdly, much greater emphasis must be placed on identifying which clients benefit most from the various therapies available. The balance between cost-effectiveness and clinical effectiveness seems pertinent here: the dangers of highlighting reduced service use (and therefore overall cost) at the expense of client rated changes in well-being may well exclude a number of people who would benefit greatly from participation on treatment programmes. Finally, Considering the high levels of substance abuse among this population (DeJong, Van Den Brink, Harteveld and Van Der Wielen, 1993, Nadeau, Landry and Racine, 1999) it is also important that future research examines the efficacy of therapeutic interventions in ameliorating these problems.
References


Describe and discuss some of the issues involved in assessing consent in people with learning disabilities

Introduction

Over the past 40 years there have been a number of initiatives aimed at promoting the well-being of people with learning disabilities, culminating in the current government's white paper 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (Department of Health, 2001). At the core of each of these initiatives has been the emphasis on increasing the autonomy and individual rights of people with learning disabilities, including the right to make choices about their own lives. This has included an emphasis on gaining the consent of individuals before a particular action is taken which could have significant consequences for them. A further development was the introduction of The National Health Service and Community Care Act (HMSO, 1990) which saw the majority of people with a learning disability moved from institutionalised hospital settings where the opportunity for choice was extremely limited (Stancliffe, 1997), to community based residence. A number of authors (e.g. Whemeyer, Kelchner and Richards, 1995, Hatton and Emerson, 1995 and Wehmeyer and Bolding, 1999) have reported that community residence provide greater opportunity for decision-making than hospital settings, thus increasing individual autonomy. Examples of situations where consent might be sought include dealing with financial affairs, making a will, giving a gift, entering a contract, voting, personal relationships and medical treatment, education and employment, place of residence and care planning (Murphy and Clare, 1995). Whilst these changes are to be commended, they have also raised awareness of the need to
ensure that individuals, because of internal or external factors which might affect their ability to make decisions, are not placing themselves at risk of ill-health, abuse or misinterpretation. Consequently, the safety mechanism of assessing an individual’s ability to give consent has been the focus of much discussion over recent years.

The following essay will examine a number personal and situational factors that should be considered when assessing consent in people with a learning disability. There are numerous factors associated with assessing consent and those covered here are not presented as exhaustive. The focus will be on factors highlighted over recent years, which relate to the definition of valid consent described below. Finally, the conclusion will summarise the topics discussed, opportunities for improving assessments of consent in people with a learning disability and areas for future research.

Before exploring some of the issues associated with assessing consent in people with learning disabilities, it is important to understand what the terms consent and learning disability mean.

**Definition of Learning Disability**

There is some disagreement between classification systems on specific features of learning disability such as the relationship between I.Q. score and level of disability, and the inclusion/exclusion of specific levels of support required by an individual. However, there are three common features that all systems incorporate into their definitions. These include a significant impairment of intellectual functioning, significant impairment of adaptive/social functioning and age of onset before 18.

The definition of learning disability given by the American Association on Mental Retardation (AAMR, 1992) is used throughout this essay as it is the most comprehensive. Furthermore, The British Psychological Society (BPS, 2001) supports the AAMR’s
inclusion of levels of support required by an individual as a guide to assessing level of functioning. The AAMR define Learning disability as:

1) Substantial limitations in present functioning

2) Significant sub-average intellectual functioning (< 70) existing concurrently with related limitations in 2 or more of the following applicable adaptive skill areas:

Communication
Self care
Home living
Social skills
Community use
Self direction
Health and safety
Functional academics
Leisure and work

3) Onset before the age of 18

Sub-classification of impairment of adaptive/social functioning is divided into the following categories

Intermittent – support on an ‘as needed’ basis.
Limited – consistent and regular support, but time-limited
Extensive – supports are regular (e.g. daily) in at least some environments
Pervasive – consistent, high intensity support across all environments

*American Association on Mental Retardation (1992)*
Definitions of Consent

The Oxford Dictionary (1995) defines consent as:

"...express willingness; give permission; agree; voluntary agreement; permission; compliance...".

With the exception of ‘compliance’ (the capacity to yield under an applied force, unworthy acquiescence, Concise Oxford Dictionary, 1995) which will be discussed below, the definition implies that an individual is in agreement with another’s opinions or agrees to participate in a particular activity or procedure. This definition, however, does not taking into consideration the means by which consent is obtained or capacity of an individual to consent, therefore, within any given situation, an individual may indeed be simply complying.

In situations where the consequences of a decision can have a significant impact on the health or welfare of an individual, for example relationships, medical treatment, care provision and participation in research the term ‘valid consent’ is used. For consent to be valid the person must be:

1) Competent (have the capacity) to take a particular decision

2) Acting voluntarily

3) Provided with enough information to enable them to make the decision (informed)

4) Able to communicate a choice

*Seeking consent: working with people with learning disabilities, Department of Health (2001).*
The document goes on to define capacity as the ability to:

a) Comprehend and retain information material to the decision, especially as to the consequences of having or not having the intervention in question, and

b) Use and weigh this information in the decision-making process

The definition of capacity above is similar to that provided by the law Commission (1995), with the exception that the law commission include ‘appreciating the personal significance of treatment information’.

The complexity of these definitions reflects the difficulty in objectifying consent and ensuring the safety of individuals when decisions are made. The situation becomes more difficult when people, by definition of their long-term problems, may have limited cognitive, communication and social skills. For these reasons, it is particularly important that individuals with learning difficulties that are suspected of lacking capacity are thoroughly assessed for their ability to understand and weigh up the options, and to communicate their decisions.

**Approaches to assessing capacity to Consent**

By defining the attributes of valid consent professionals are provided with some guidance in terms of what to look for when assessing an individual, which in turn provides that individual with some level of protection from manipulation, abuse or misrepresentation. However, the above definition does not provide a standardized method of assessing capacity to consent. Until recently, the process has involved clinicians making professional judgements, with little guidance from professional or legal bodies (Arscott, 1997). Consequently, assessments were made subjectively on an instinctive or intuitive basis (Law Commission, 1991). Wong, Clare, Gunn and Holland (1999) identified three
general approaches that have been adopted by professionals when assessing capacity: *Outcome*, which uses the implied consequences of the decision making process to determine capacity. If an individual makes a decision which is contrary to convention or the views of the treatment provider they are deemed as lacking capacity. The second approach, *status/diagnosis*, is that of assuming characteristics of an individual by their membership of a particular group. In this case, the long-held assumption that the diagnosis of learning disability is synonymous with an inability to make decisions (Wehmeyer and Bolding, 1999) would lead to the conclusion that an individual with a learning disability could not be deemed to have the capacity to give informed consent. Both of these approaches lack empirical evidence and have not been supported in case law (Murphy and Clare, 1995). A third option when assessing capacity, described by Wong et al. as the most widely accepted method, is to adopt a *functional* approach. It is based on an individual’s knowledge, skills and abilities in relation to a particular decision at a particular time. For example, an individual may feel comfortable choosing the type of environment in which to work, but due to lack of knowledge or experience may not feel able to decide on whether or not to undergo a specific medical intervention. Capacity therefore, is not seen as a static characteristic; it requires periodic assessment which also accounts for the fluctuating nature of capacity (Arscott, 1997).

Wong, Clare, Gunn and Holland (1999) consider the usefulness of the outcome and status models when used in parallel with the functional model. They point to the fact that these models may raise awareness in professionals and carers of the need to consider capacity, but not to draw conclusions based solely on group membership or the complexity of the decision to be made. The importance of utilising the functional approach bears relevance when considering that the prevalence of mental health problems such as psychosis, anxiety and depression may be as high as 40% in the learning disabled population (Hatton, 2002). An individual with a dual diagnosis of learning disability and depression may not be unable to meet the demands of decision-making when unwell, and their state of mind should be considered when considering their capacity. However, this should not
exclude them from involvement in decision-making at a later date when they feel more able to participate in the process.

**Limitations to the current definition of capacity**

Despite its wide spread acceptance, the functional approach has a number of limitations when utilised with people diagnosed as having a learning disability. For example, Harris (2003) points to the fact that the definition of capacity presented in the ‘Valuing People’ document (Department of Health, 2001) on which the functional approach relies, emphasises an individual, logical process. Omitted from the description is any reference to the environment and the usefulness of others in helping an individual reach a decision. Harris states that the model of decision-making outlined above does not reflect the way in which decisions are made on a day-to-day basis and does not have any empirical basis. As such, many people with learning disabilities who have cognitive deficits that impact upon information-processing skills are placed at a disadvantage due to the emphasis on ‘intellectual capacity’ (p.19). Wehmeyer (1999) takes a similar viewpoint in his discussion on self-determination in which he identified three aspects: a) individual capacity, b) opportunity and c) supports and accommodations. He further identifies capacity as influenced both by learning and development, drawing attention to the importance of experience of decision-making in the development of specific skills required in the process.

**Factors associated with capacity**

Many individuals with learning disabilities have cognitive impairments that restrict their ability to make decisions such as memory impairment (Arscott, Dagan and Kroese, 1999) and limited problem solving skills (Wehmeyer and Kelchner, 1994). It is now recognised however, that cognitive performance on such tests is an inaccurate predictor of capacity to consent (Murphy and Clare, 1995). In support of this, Wehmeyer and Bolding (1999)
controlled for I.Q. when assessing level of problem-solving, goal setting and task performance (as measured by the Arc’s Self-determination Scale) across three settings: community based supported housing, community based residential homes and institutional settings. They found that setting, and not I.Q. was the primary factor in level of autonomy and self-determination, adding further support to the view that environment plays a primary role in an individual’s cognitive performance and self-awareness. Waldie and Mosely (1996) describe a triarchic view of intelligence, which emphasises the importance of self-esteem and self reliance as well as developmental factors associated with cognitive performance. In their study, individuals with a learning disability who scored high on a measure of low self-esteem were able to improve their performance on cognitive tasks (memory ability) when given self-enhancing feedback which, the authors point out, enhances self-esteem and therefore increases perceived level of competence to complete a task.

Hickson, Golden and Khemka (1998) highlight two other factors that impact on decision making, which questions the logical definition of capacity described above. They focus specifically on interpersonal decision-making and the influence of ‘social intelligence’ and motivation in problem solving. They draw attention to the fact that individuals with a learning disability often find it hard to consider the perspectives of others, and furthermore can lack emotional development that could limit motivation to fully consider the implications of interpersonal-interactions. Hickson et al’s study involved presenting individuals with and without a learning disability a number of vignettes depicting scenarios where a protagonist had to solve an interpersonal dilemma. Their results indicated that people with learning disabilities utilised less planning in their decision-making, were less able to fully comprehend the complexities of the social situation and were less aware of emotional consequences. Significantly, within the learning disabled group females performed better on each of these factors than the males, suggesting that gender roles could play a further part in interpersonal problem solving. These findings suggest that emotional development is an important factor to consider when, for example, assessing an individual’s capacity to consent to a sexual relationship. The degree to
which an individual considers the position of their partner and whether their partner is willing to participate in sex at a particular time needs to be considered in order to ensure that the relationship would be respectful and safe.

Khemka (2000) described the uses of training packages to enhance both cognitive and motivational aspects of decision-making in women with learning disabilities. In their study they assessed interpersonal decision-making skills pre and post training in cognitive skills or both cognitive skills and motivation. Both of these groups were compared to a control group, members of which received no training. The authors report that women who received both cognitive and motivational training improved to a significantly greater degree than either the cognitive only training group or the controls. One limitation of their study was the fact that participants were all screened for adequate communication and language skills. Therefore, the success of the training package cannot be generalised to those with limited language abilities.

Cognitive functioning then, as measured by psychometric assessments, does not accurately reflect the capacity of an individual to make a decision. At most, they provide feedback on an individual’s strengths and weaknesses, which can be used to assist carers in supporting an individual through the decision making process (Arscott, 1997). In addition to cognitive ability, factors such as self-esteem, experience in relation to a particular situation, confidence in making decisions and emotional awareness can affect outcome. Environmental factors play as significant a role as developmental factors during assessment; such factors are not fixed and may occur to a greater or lesser degree over time. The provision of support by others in coming to a decision is not included the Department of Health’s (2001) definition of capacity, but may assist individuals in making the most appropriate choice.

Comprehension of information
Wong, Clare, Gunn and Holland (1999) describe the requirement of understanding information relevant to medical treatment decision as of a low standard, explaining that only an understanding in broad terms and simple language is required. However, this may be somewhat of an oversimplification when one considers the high level of communication problems present in the learning disabilities population (Mclean, Brady and Mclean, 1996). Mclean et al. emphasise the broad range of abilities within this population, and the fact that traditional classification of mental retardation is not very predictive of communication abilities or service needs of any one individual.

Limited expressive and receptive language (Arscott, 1997) and auditory memory abilities (Broadley, McDonald and Buckley, 1995) occur to a higher degree in people with learning disabilities (particularly severe learning disabilities) than in the general population. Such disabilities can place people at an unfair disadvantage or ultimately result in them being denied the opportunity to express their wishes. A study by Arscott, Dagan and Kroese (1998) in which they assessed the ability of people with learning disabilities to consent to psychological research highlights the dangers of overestimating comprehension of information. They found that whilst most people appeared to understand the nature of the research, many had difficulty understanding the risks and benefits of participation. Arscott et. al. emphasise the need to assess comprehension when capacity is in doubt in order to ensure that information has been presented at a satisfactory level.

A number of methods of compensating for limited language abilities have been proposed in order to facilitate the decision-making process. Arscott, Dagan and Kroese (1999) described using pictures and simplified language to aid in the understanding of information presented to individuals regarding medical treatment. Similarly, March (1992) was able to use photographs successfully in assisting people with a severe learning disability to increase responsiveness to questions and intelligibility of responses. However, March states that photographs used alone do not indicate preferences and that direct observation is needed to support interpretation. These findings also have the
obvious limitation that individuals with impaired vision could not benefit from this approach. Wong, Clare, Gunn and Holland (1999) point out that familiarity of the material is important in the level of understanding an individual has. Presentation and discussion of relevant information over an extended period, with reference to their own disabilities, may enhance understanding. The Department of Health (2001) document Seeking Consent: Working With People With Learning Disabilities also suggests encouraging clients to paraphrase what has been said and to encourage them to assess whether they are able to compare alternatives.

Environmental factors affecting the comprehension of information

As well as the medium through which information is shared, Lohrmann-O’Rourke and Browder (1998) identified three other variables that can influence the outcome of preference assessment in people with severe disabilities. Context (status of the person assessing, location of assessment and method of assessment), selection response (response mode, for example initiated or passive) and response format (single choice, free selection/forced choice). Following their literature review they found that location of assessment and status of interviewer influences the preferences described by individuals. They report that research proved inconclusive as to whether being assessed by people known to the individual in a familiar environment proved more effective than being assessed in unfamiliar surroundings by unfamiliar people. Lohrmann et. al. highlight the need to pay particular attention to surroundings and compare responses to information about an individual’s previous preferences.

Limitations as a result of language and communication difficulties posses a particular problem in terms of comprehending information about a situation and communicating a decision. Whilst the ‘Valuing People’ (Department of Health, 2001) documents emphasises the need to ensure that information is presented in a suitable format, it does not provide advise on presentation or what may and may not be suitable. Often, third party opinions are sought in order to understand an individual’s preferences (Arscott,
1997). However, Ouslander, Tymchuk and Rahbar (1989) found that proxies were poor at predicting likely healthcare decisions of people with a learning disability and information provided by others should be corroborated. It is essential that an individual’s level of comprehension is assessed as part of the process of assessing consent, and that a suitable medium, whether it be speech, signing, writing, pictures or objects, is used to share information and ideas. Environment also plays a role in outcome and should be considered in order to minimise anxiety and maximise an individual’s potential.

**Voluntary decision-making**

Despite increased opportunities for decision making brought about by changes in policy and service structure, a number of authors report that people with learning disabilities living in community settings are still provided with fewer opportunities to make choices than non-learning disabled controls (Wehmeyer and Bolding, 1999, Stancliffe, 1997, Tossebro, 1995). Kishi et. al. (1988) found that the opportunities for decision making are further reduced when the decisions may impact on the long-term wellbeing of an individual or when an individual has more severe learning disabilities. Tossebro (1995) and Stancliffe (1997), found that inclusion in decision making was negatively related to size of living unit, whilst Stancliffe’s (1997) study suggested that staff presence is a further factor which limits self-directed behaviour. These restrictions present a formidable barrier to people with learning disabilities and appear to be a function of the attitudes of staff and carers as well as limited time and resources (Jenkinson, 1999). Professionals need to consider the fact that an individual may have spent many years in a long-stay hospital where opportunities for decision making were extremely limited, which could have a further impact on skills, self-esteem and motivation, all of which are essential components in decision-making (Hickson, Golden and Khemka, 1998).

**Learned helplessness**
One possible effect of being denied the opportunity to make decisions is the development of learned helplessness (Seligman, 1975), where by through repeated failure to bring about change to one’s environment an individual loses belief in their ability to control outcomes. Palmer and Wehmeyer (1998) found that adolescents with a learning disability scored considerably higher on measures of learned helplessness than non-learning disabled controls. Learned helplessness has been associated with task avoidance, (Shelvin and Klein, 1984), depression (Seligman, 1975) and reduced decision making skills (Jenkinson, 1999), consequently, the opportunity for decision making is further reduced due to the belief by others that the individual is incapable of making a decision. Individuals can become dependent on others to make decisions for them and lack the self-confidence to present preferences, even when the opportunity is provided. Given then, that many people with a learning disability lack to motivation and confidence to make decisions, how might this impact on situations when the capacity to consent is assessed?

Response biases affecting the assessment of consent

Gudjonsson (1990) defined acquiescence as the tendency to answer affirmatively to a question regardless of the content. Clare and Gudjonsson (1993) found that people with learning disabilities tend to answer in the affirmative to a question, regardless of the content. Gudjonsson (1990) also found a positive correlation between acquiescence and I.Q., suggesting that those individuals with more severe learning disabilities may be more vulnerable. In light of these findings, it is apparent that there is a danger of misinterpreting acquiescence for voluntary agreement in some individuals with a learning disability. Finlay and Lyon (2002) identified a number of factors related to acquiescence that are particularly relevant to the issue of assessing consent of those with learning disabilities. For example, where answers are not known, when questions are ambiguous, when a person has spent less time or effort in considering a question, when an individual is impulsive or exhibits a rigid thinking style, when questions are overly suggestive and when an individual has a desire to please others or conform to expectations. The issue of learned helplessness seems particularly relevant here as feeling powerless to make an
impact on one’s environment often results in low motivation to participate in the decision-making process (Shelvin and Klein, 1984).

The danger of acquiescence is most prevalent when an individual is only offered the opportunity to reply ‘yes’ or ‘no’ to a question. This is concerning as the Department of Health (2001) document Seeking Consent: Working with People With Learning Disabilities suggests providing ‘communication boards where people can indicate yes or no’ (p.7), without reference to the dangers of acquiescence. So for example, asking an individual whether they are willing to undergo surgery for an ongoing illness could result in that person agreeing to the treatment regardless of their own feeling about the procedure. In order to overcome the problem of acquiescence a number of methods have been proposed. Arscott (1997) suggests asking open-ended questions as opposed to questions requiring yes/no answers. However, Finlay and Lyon (2002) emphasise the importance of using language that the client can understand, thereby reducing ambiguity and confusion about meaning. Wehmeyer, Kelchner, and Richards (1996) take a broader view and describe the importance of developing decision-making skills (and consequently self-empowerment) with individuals over an extended period to assist them in decision-making. They point to the need to promote autonomy on a day-to-day basis within an individual’s natural environment.

Other responses biases, identified by Finlay and Lyon (2002) as occurring to a high degree in people with a learning disability, include suggestibility, defined as unquestioningly accepting the accurateness of a statement, and compliance, where by an individual agrees to a decision, regardless of whether they agree. Harrison, (2003) suggests that these biases are a result of having multiple authority figures making decisions for them. Arscott, Dagan and Kroese (1999) found that when presented with hypothetical situations related to medical procedures, a number of participants with a learning disability did not appear to appreciate that they had the option of saying no. Instead, they insisted that they would have to have the treatment no matter what they
said. This clearly illustrates the process of compliance and the impact of being denied the opportunity to make-decisions about one’s own future.

The lack of opportunity to develop confidence and skills in decision-making can place individuals in a vulnerable position when they are invited to make a choice. Consequently, as an assessing professional it is important to consider response biases when responses are given to questions or statements. In particular, care needs to be taken when selecting the way in which information is presented. When assessing an individual for consent to living arrangements, it would be unhelpful to simply ask whether they, for example, would like to live independently. One could also ask for an explanation for their particular response, such as why living in a particular place appeals to them, reverse the question or ask the individual to describe other people’s views on the subject. Finlay and Lyon (2002) also suggest providing people with the opportunity to express their ambivalence in order to avoid acquiescence.

Informed consent

How much information to provided an individual in order to ensure that a decision is informed is a complex question. Some medical procedures for example can be extremely complex and the consequences far reaching. Whilst some individuals may benefit from including all relevant information in their decision-making, for many people with a learning disability this would be overwhelming, possibly resulting in confusion and a sense of helplessness to come to a decision. Furthermore, lack of motivation due to limited experience of decision-making may render so much information useless.

Jenkinson (1999), for example, found that providing more information in the form of clarification of options and/or information regarding consequences did not improve decision making as assessed via hypothetical scenarios presented to learning disabled individuals with high levels of learned helplessness. The author suggested that, as well as the cognitive overload experienced by some participants, these individuals lacked the
motivation to seek out information relevant to the decisions and may have even lacked awareness of the need to consider and weigh options and consequences. Jenkinson highlights the danger of overloading clients with information and the need to consider individual characteristics when deciding how much information a client is expected to consider.

The issues discussed above in relation to comprehension of information are relevant here. In order to avoid overloading an individual, information could be presented over an extended period and related to specific aspects of an individual’s life. Providing such concrete examples can help to overcome difficulties with generalising information (Arscott, 1997), and give intrinsic value to the material.

Conclusion

The assessment of consent in people with learning disabilities who may have limited cognitive abilities and language skills presents an extremely difficult task to professionals where the balance between paternalism and empowerment is a primary issue. Such assessments are now recognized as involving a process, which should be conducted over an extended period in order to provide individuals with sufficient information, encouragement, training and support to make decisions. Capacity was once viewed purely in terms of an individual’s cognitive abilities. Research and experience has shown, however, that factors such as motivation (Khemka, 2000), experience (Arscott, 1997), mental health (Hatton, 2000), environment (Lohrmann-O’Rourke and Browder, 1998) and perceived level of control (Harris, 2003) are central to an individual’s ability to make decisions. Increased focus on the interactive nature of assessment highlights the need for assessors to consider communication skills, presentation of information and interpersonal processes that affect decision-making. Instead of an interrogative process where an individual is expected to prove that they have the ability to give valid consent, a supportive-unrestrictive model (Stalker and Harris, 1998) of assisting people to reach decisions provides the best balance between promoting autonomy and acting in the
client's best interests. This model emphasises professionals, carers and advocates working together to ensure that a person's best interests are met.

Whilst there is now some guidance available to professionals assessing consent, White and Steen (1996) and Hillery, Tomkin, McAuley, Keene and Staines (1998) suggest that professionals should receive formal education and training (possibly prior to qualification) in the assessment of consent. This would raise awareness of the complexities involved in assessing this particular client group and provide professionals with at least a basic level of skills and confidence.

Assessing consent in individuals with more severe disabilities, particularly where situations require an understanding of more abstract concepts has received less attention (March, 1992) and as such, highlights an area for future research. Similarly, there appears to be little mention of the impact of cultural norms on individuals from various ethnic backgrounds. Whilst a number of authors (e.g. Stalker and Harris, 1998, Harris, 2003, Hillary, Tompkin, McAuley, Keene and Staines, 1998) identify the importance of not confusing unconventional decisions with irrational decisions, little attention has been paid to the problems of acknowledging the non-Western-European views of individuals during decision-making.

References


Children Who Have Been Abused Are More Likely To Become Abusers Themselves In Adulthood. Discuss With Reference To Assessing and Intervening with Such Children

Introduction

Child abuse is by no means a new phenomenon, with many authors tracing accounts dating back some 2000 years (e.g. Corby, 2000). Despite this, it is only over the past three decades that any concerted effort has been made by researchers in both Europe and the United States to accurately identify rates of abuse, its causes and consequences. These efforts went some way to shatter firmly held social and cultural beliefs such as the idea that abuse was uncommon and usually carried out by psychopathic strangers (Browne and Finklehor, 1986). These discoveries led to a number of theories about the aetiology of abuse, one of the most widely accepted being the intergenerational transmission of abuse hypothesis. The term relates to the developmental theory that those who are abused in childhood are more likely to go on to become abusers. Despite the intuitiveness of this idea (Widom, 1989), there has been an ongoing debate as to its accuracy and usefulness, and only recently have researchers begun to examine the cycle of abuse hypothesis. This focus has been aided not only by the commitment of individuals in the field, but also by changes in social values, at least within Britain. For example, where it was previously maintained that family matters were private affairs that should not be intruded on by the state, more power has been given to government agencies to intervene in family life, particularly when there is a risk to the welfare of its members (Corby 2000). Such factors indicate that our understanding of child abuse is shaped as much by the political climate and cultural value system as by individual psychology and family dynamics. Whilst the debate around the cycles of abuse hypothesis continues, research findings in the area have informed intervention and assessment of abused children and their families.

The following essay will first focus on the argument that childhood abuse is a significant risk factor for later perpetration of child abuse, with specific emphasis on empirical
evidence and the limitations of research in this area. Following this, the evidence base will be discussed in relation to the development of effective methods of assessing and working with children who have experienced abuse and their families, with reference to theoretical models which aim to explain cycles of abuse.

**Definition of abuse**

It is necessary to first consider exactly what the term child abuse means. This has proved essential, particularly within research, where usage of the term has varied widely in relation to inclusion criteria (Oliver, 1993). As a consequence, rates of abuse vary from study to study, affecting replicability and the opportunity to compare between studies. Efforts to standardise definitions of abuse over the past three decades have led to the current definition from the Department of Health (DoH), which delineates child abuse into four categories.

Neglect:

“...persistent failure to meet a child’s basic physical and/or psychological needs, likely to result in the serious impairment of the child’s health or development...”

Sexual abuse:

“...forcing or enticing a child or young person to take part in sexual activities, whether or not the child is aware of what is happening...”

Physical abuse:

“...causing physical harm to a child...”
Emotional abuse:

"...persistent emotional ill-treatment of a child such as to cause severe and persistent adverse effects on the child's emotional development..."


Whilst this definition is now commonly used throughout Britain, it is important to recognise that research over the past three decades has not been so systematic and consistent in its definition. For example, within the literature on physical abuse, definitions range from clearly defined terms such as physical assault resulting in broken bones, to less clearly defined terms such as 'mild forms of abuse or neglect', 'excessive use of force' and 'parenting difficulties'. Widom (1989) also points to the lack of differentiation between abuse and neglect in many studies, obscuring behavioural and psychological distinctions.

**Further limitations of research**

Despite wide acceptance of the intergenerational transmission of abuse hypothesis, a number of authors (e.g. Kaufman and Zigler, 1987, Belsky, 1993) have pointed to the lack of consistent evidence across studies to fully support these claims. For example, Belsky points to a number of methodological limitations such as differential definitions of abuse, lack of randomised, controlled samples and over-reliance on self-report, retrospective data that cloud the overall picture. The use of retrospective accounts of abuse has been criticised due to the inaccuracies of self-reports resulting from distortions, inability to accurately recall the frequency or duration of abuse and the possibility that
those identified as abusers may seek lenience by claiming that they were themselves abused. However, it is common for adults abused as children to idealise their own parents (Oliver, 1993, Erdama and Caffery, 2003), suggesting that, if anything, self-reports should yield more false-negatives leading to an underestimation of the level of intergenerational transmission of abuse.

An alternative approach is the use of official legal, clinical and social services records. Whilst these provide some reliability to studies, they also confound any interpretation of general rates of abuse or rates of intergenerational transmission of abuse because only a small percentage of cases are ever brought to the attention of professionals (Corby, 2000, Oliver, 1993). The use of unrepresentative samples has been highlighted as a further criticism of research. For example, focusing specifically on males, Caucasian samples or one particular type of abuse has limited the generalisability of findings (Widom, 1989). Furthermore, Widom points to the fact that inappropriate base rates are used to compare sample rates, further confounding results.

Despite their reliance on self-report data, prospective studies are generally held to be the most robust and reliable indicators of cycles of abuse (Oliver, 1993). In such studies, parents of new born or young children report their own experiences or childhood abuse. At follow-up, the children are interviewed regarding their experience of abuse and these rates compared to those of their parents. Such studies give predictive validity to research and, when representative samples are used, provide direct support for the cycles of abuse hypothesis, without reliance on correlation data.

**Empirical support for cycles of abuse**

Whilst many early studies indicated a higher rate of childhood abuse in abusing parents compared to non-abusing control groups, the variation in methodology and definitions described above led to large discrepancies in outcome data and disagreement about the validity for the cycle of violence hypothesis. For example, in his review of the literature
Widom (1989) quoted rates between 7% and 70%. Similarly, Kaufman and Zigler (1988) concluded that unqualified acceptance of the intergenerational transmission of abuse hypothesis is unfounded. Following their own review in which they attempted to identify well defined studies, Kaufman and Zigler (1987) estimated rates of 30% (+/- 5%), concluding that whilst being abused puts one at risk for becoming abusive, the path between these two points is far from direct or inevitable (p.190). A further review by Oliver (1993) also suggested that around one third of abused children go on to become abusers whilst one third do not present any later risk. Of the remaining third, Oliver suggests that they remain at risk of becoming abusers and that this may be influenced by a number of psychological variables and external stressors.

In a more recent study Bagley, Wood and Young (1994) found that males who had experienced sexual abuse as children were significantly more likely than a control group to have interest in or actual sexual behaviour with minors. The authors used a random sample of men from the community, increasing the generalisability of their findings. Pears and Capaldi (2001) utilised a prospective, longitudinal design to investigate the relationship between parent's self-reports of child abuse and their children's reports of physical abuse, which revealed an overall rate of 23%. The authors concluded that parents who have been abused were twice as likely to go on to abuse as those parents without abuse histories. The reliability of the results was strengthened by the use of multiple sources of information about the youth's experience of abuse. Salter, McMillan, Richards, Talbot, Hodges, Bentovim, Hastings, Stevenson and Skuse (2003) focused on sexual abuse in their prospective study of 224 males who had experienced sexual abuse in childhood. At 19 years follow-up, their results indicated that 23% of sexually abused males in their study went on to become sexual abusers themselves. The limitation of this study is the lack of a non-abused control group. However, the authors qualify their design by pointing out that the focus of the study was on within-group differences. Perpetration of abuse by subjects was assessed using police and social services computer records, suggesting that their findings may have been an underestimate of the rates of offending.
Examining the cycle of abuse hypothesis has proved particularly difficult due to the nature of the problem, leading a number of researchers to question its prevalence. However, as Oliver (1993) points out, critics tend not to consider the inherent difficulties in accessing basic data relating to a topic which is, by the nature of the offence, shrouded in secrecy. Oliver emphasises the importance of inter-professional co-operation and the use of a variety of methods to gather data on child abuse. Based on a number of studies utilising various methodologies, meta-analysis has suggested a conservative rate of intergenerational abuse of around 30%, with a further 30% potentially remaining at risk of abusing, findings supported by a number of recent prospective, randomised and controlled studies.

**Consequences of child abuse**

One of the earliest models describing the effects of childhood abuse was the traumagenic dynamics model (Finklehor and Brown, 1985). The model identified four behavioural dynamics displayed in victims of childhood sexual abuse. The first, 'traumatic sexualisation', is hypothesised to result in confusion around sexual identity and promiscuous behaviour. The second dynamic of 'betrayal' leads to grief, depression and difficulties forming trusting relationships. The third dynamic is 'powerlessness'; victims of abuse overcompensate for their sense of powerlessness through the need to control, experiencing fear, anxiety and low self-efficacy. The fourth dynamic described by Finklehor and Brown is 'stigmatisation'; victims are hypothesised to experience shame and guilt as a consequence of their abuse, leading to low self-esteem and self-blame. The model was based on clinical experience rather than any specific theoretical model or empirical research. However, Oliver (1993) points to the model's common usage in the area of child abuse work and as can be seen below, accurately reflects what later research has found.

Other evidence supporting the intergenerational transmission of abuse hypothesis comes from studies examining the emotional, cognitive and behavioural consequences of child
abuse, relating these findings to research which has identified risk factors associated with adult perpetration of child abuse. In relation to the consequences of abuse, a huge array of behavioural, emotional and interpersonal problems have been identified in young children, adolescents and adults. For example, alcohol and drug abuse (Harrison, Fulkerson and Beebe, 1997, Swanston et al., 2003, Watts and Ellis, 1993), post traumatic stress disorder (PTSD) (Nelson, et al, 2002, Roth, Newman, Pelcovitz, Van der Kolk and Mandel, 1997), mental health problems including depression, anxiety, self-harm and suicide (Swanston et al., 2003, Garnefski and Arends, 1998) and sexual confusion (Swanston et al, 2003, Alexander, et al., 1998). Burgess at al. found that women sexually abused in childhood had less securely attached children in comparison to a non-abused control group, an effect that was mediated by the quality of their relationship with their partner. The authors also found that these mother-child relationships were often characterised by role-reversal and neglect. Research has also identified a relationship between child abuse and violent offending (Heyman, Slep and Smith, 2002), affect dysregulation (Cloitre, Koenen, Cohen and Hyemee, 2002) and partner violence (Lavoie et al., 2002). Avery, Hutchinson and Whitaker, (2002) found that domestic violence and sexual abuse frequently co-occur, suggesting that it is the complex interaction of a number of factors that influence the intergenerational transmission of abuse. Focusing on interactive/additive effects of early experiences of abuse, Heyman, Slep and Smith (2002) found that exposure to both inter-parental and parent-child violence increased the risk of later perpetration of child abuse and partner abuse compared to one form of family of origin violence. Heyman et al. also found that the frequency of exposure to specific forms of family of origin violence had an additive effect in that they also increased the risk of later perpetration for men and for women.

In order to address the behavioural consequences of childhood abuse, other researchers have chosen to focus on rates of abuse in offenders (adult and or adolescent). A number of studies have reported high level of abusive childhood experiences from adult sex offenders (Craissati, McLurg and Brown, 2002,) and adolescent sex offenders (Hsu and Starzinski, 1990) in comparison to rates in the general population. Davis and Leitenberg
(1987) report that sexual offending adolescents are more frequently victims of childhood physical and sexual abuse than non-sexual juvenile offenders. Lewis, Shankok and Pincus (1979) also found that 79% of juvenile sexual offenders compared to 20% of non-sexual offenders, had experienced some form of abuse in childhood. Linking these finding from research with offenders to the cycle of abuse phenomena, Salter (1988) reports that the majority of adult paedophiles report having deviant arousal in adolescents.

**External factors associated with abuse**

In one of the few studies to investigate cultural values on child abuse, Ferrari (2002) examined the impact of couples' ratings on machismo, punitiveness, valuing children, 'familism', 'nurturance scales' and vignettes depicting child maltreatment. The couples represented three culturally diverse backgrounds: African-American, Hispanic and 'European American'. The authors reported differences in ratings of the vignettes, use of verbal and physical punishment and ratings on the 'nurturance scale' between cultural groups. They also report high variance in the measures described above, pointing to the complex interaction of social beliefs and values in the cycles of abuse.

The research discussed highlights the complexity of issues around child abuse and the process through which abuse is transmitted through generations. Whilst some studies have found a direct relationship between child abuse and abusing, there appear to be a number of individual and family mediating variables which impact on the likelihood of abuse being transmitted across generations. Furthermore, abuse can change form or skip generation (Oliver 1993, p.1319), making identification more difficult. External factors such as low socio-economic status and poverty have consistently been associated with poverty (Oliver, 1993), indicating the need to consider situational factors when exploring the transmission of abuse hypothesis.

**The assessment and intervention of abuse**
Given the wide range of emotional, social and behavioural consequences of childhood abuse, and their relationship to later perpetration of abuse in adulthood, assessment and intervention of abused children must be able to address a wide range of factors. The American Psychological Association (1999) highlights a number of questions which should guide the assessment of child victims of abuse: How severely has the child's psychological well-being been affected, taking into account the child's vulnerabilities, special needs and strengths? What therapeutic interventions would be recommended to assist the child? Can the parents be successfully treated to prevent harm to the child in the future, including the parent's capacity to provide good enough care? What would be the effects of rejoining the child with/separating the child from the family? In order to answer these questions, the guidelines suggest the use of multiple methods of data gathering from multiple sources, including multi-agency records, extended family reports, parent-child interactions and clinical interviews.

There are a number of factors that may limit the practicability of this approach. For example, secrecy within the family makes it difficult to gain a clear view of frequency and duration of the abuse, who is involved and who could provide potential support to the child in the future. Whilst there are numerous assessments covering a wide range of factors related to the effects of child abuse, there are limitations when the child is very young. For example, there are currently no standardised measures for assessing the trauma symptoms of children under the age of 8 years, other than the Child Sexual Behaviour Inventory, which focuses specifically on sexual abuse (Brier, et al., 2001). Whilst standardised and normed structured interviews with caretakers exist, Briere points to the obvious limitation of using such measures with caretakers who minimise or deny the abuse. The importance of age appropriate assessment tools is highlighted by the variation in the effects of sexual abuse of children of different ages. For example, common effects of sexual abuse in pre-schoolers include internalising and externalising and sexualised behaviour. In middle childhood the symptoms are depression, suicidal ideation, PTSD, sexual anxiety and dissociation. Finally, in adolescents the consequences of sexual abuse include those described for middle childhood plus risky sexual behaviour,
substance abuse, suicide attempts, pregnancy and running away (Tyler, 2002). With younger children, general behaviour scales that assess global functioning would appear to provide the best measure of adaptation following abuse. However, they too rely on observer ratings, which are subject to situational variables, such as environmental changes often resulting from abuse discovery (Budd, Felix, LaShaunda, Naik-Polan and Floss, 2002) and assessor bias.

Assessments are also limited in that they are not generally designed to be used with children with learning disabilities, despite the fact that this group are at considerably greater risk of abuse than non-learning disabled children (Sullivan, Knutson, Scanlan and Cork, 1997). Even if this group was to be given the equal consideration by clinicians and researchers that they deserve, limited cognitive abilities in those with more severe disabilities would prove a barrier to assessing the impact of abuse.

Finally, there is an obvious cultural bias not openly discussed in the literature that has an impact on the efficacy of assessment tools. Not only the language used, but in terms of the social norms and values inherent in them. As Ferrari's (2002) study discussed above indicates, attitudes towards childcare vary across cultures, which is not considered in the development of assessment measures.

Interventions with abused children and their families.

Edgeworth and Carr (2000) identified three types of intervention typically used in child abuse cases. These include child focused interventions (individual or group psychotherapy, day-care or residential programmes), parent-focused interventions (parenting skills training, anger management) and family interventions (aimed at improving family relationships, problem solving within families, and improving access to social support).
Individual work with child victims provides the opportunity to identify specific symptoms related to the abuse and those precipitated by the family environment. The therapy process also allows intervention in a supportive environment away from the family, including the abuser(s), who may deny or minimise the abuse. Consequently, the individual can be supported in processing the abuse experience and working through issues of victimisation, which if not addressed can result in the later minimisation of abuse, self-blame, guilt and idealisation of parents, factors that have themselves been related to later abuse perpetration (Bentovim, 2002). However, research has shown that, where parents are willing to participate, their involvement in interventions is more effective than individual work in a number of areas. Kolko (1996) for example, compared the efficacy of cognitive behaviour therapy (CBT), family treatment and community treatment. Results indicated that family therapy resulted in fewer reports of parent to child physical abuse than both CBT and community treatment and that CBT and family therapy resulted in reductions in children's externalising behaviours, parental distress and child abuse potential. The focus of both the CBT and family therapy interventions was abuse-specific (for example, anger control, beliefs about violence and social skills). The approaches also combine individual skills-enhancement with family influences, which, as the authors point out, provided a broad family and social context in which to provide the treatment.

Deblinger, Steer and Lippman (1999) compared the effectiveness of CBT in treating children with PTSD following sexual abuse. The children were randomly assigned to one of four conditions, child only, non-offending mothers only, child and non-offending mother or community treatment as usual. Compared to the treatment as usual condition, CBT proved to be more effective in reducing symptoms of PTSD in those children who were included in the intervention. Including parents in the intervention led to an increase in parenting skills, parents rating their children as displaying less externalising behaviour and lower children's depression scores. The study was limited in that the majority (70%) of the child sample where white males.
Parent focused interventions have proven successful in assisting positive change in a number of areas. These include positive development of parent-child interactions, increased child empathy and less contact with services (Hornick and Clarke's, 1986), improved child-rearing practices and reduced parental anger (Whiteman, Fanshel and Grundy, 1987) and reduced abuse potential and child problem behaviours (Wolfe, Edwards, Manion and Koverola, 1988). The research on family interventions is limited in that samples may be bias in favour of those parents who are willing to accept responsibility and who are motivated to engage in treatment. Only the Wolfe et al. study report any follow-up data (at one year), limiting the reliability of the results. Despite Edgeworth and Carr's (2000) description of Elmer's (1986) successful treatment intervention for physically abused and neglected children as child-focused, the intervention actually included the promotion of parent-child interactions and individual support and training to parents, suggesting that the focus were on both the child and the parent. Whilst these studies indicate positive outcomes, Buchanan (1996) emphasises the need to identify the developmental needs of the child and incorporate these into work with parents. Buchanan also raises the question of how well skills taught to cope with particular developmental needs will be transferred across stages, suggesting that long-term work is need to ensure that positive changes are maintained.

The four studies mentioned above all incorporated a CBT or behavioural approach aimed at developing parenting and communication skills, a model that appears to dominate interventions aimed at the family. For example, of four family interventions described by Edgeworth and Carr (2000), three incorporated behavioural and problem solving techniques and the fourth social skills training and a range of group and social support. The focus on dyadic interactions between parent and child appears to address, at least indirectly, attachment issues, the importance of which is highlighted by Morton and Brown (1998), who identify a number of studies relating poor attachment styles, in both child victims and parents, to cycles of child abuse. For example, Main and Goldwyn (1984), examining the childhood attachments of abusing parents, indicate that these parents report insecure attachments with their own parents. A number of studies have
shown that secure attachment to another non-abusing carer can provide a buffer against the development of maladaptive, internalised models of relationships following abuse (Groze and Rosenthal, 1993, Egland, Jacobvitz and Sroufe, 1988), providing support to the idea that interventions should consider the family system and where possible include them in the intervention.

Based on Bowlby's (1969) attachment theory, Alexander (1992) proposed that intergenerational cycles of abuse occur as a result of poor attachment in childhood leading to the parent's diminished ability to meet both their own and their children's needs. Thus, it is the care giving relationship that is transmitted across generations rather than abusive behaviour per se. The aim of therapy focusing on attachment is to help develop new internal working models of family relationships. van Ijzendoorn, Juffer and Duyvesteyn's (1995) meta-analysis of interventions aiming to influence the attachment relationships of parents and children in abusive relationships found that less intensive interventions focusing on enhancing the parent's sensitivity to the child were more effective than in-depth treatments focusing on 'deeper' internal representations. The authors point out however, that the short follow-up period of many studies may have masked the effects of the more in-depth approaches. Van Ijzendoorn et al's findings lend support to the idea that effective interventions would focus on family dynamics and/or parenting skills rather than primarily on the victim. However, this approach is obviously limited by the degree of responsibility taken by parents, whether they acknowledge the abuse and their motivation to enter into therapeutic work. During individual work with victims of abuse, Bentovim (2002) points to the re-parenting effect of therapy and the importance of utilising the therapeutic relationship to develop trust and acceptance, thus developing more adaptive models of attachment.

There are some limitations in terms of assessment of attachments within the family. For example, the most accurate method is Ainsworth's strange situation procedure. However, this is time consuming and requires significant training. Development of useful tools to
assess attachment could be used to both identify abuse risk and to monitor the efficacy of interventions (Morton and Browne, 1998).

Crittenden (1992) also developed a model integrating abuse, attachment and coping style. The model suggests that abuse can lead to an insecure attachment style and the development of maladaptive coping strategies. These coping strategies, which may be adaptive in the abuse situation, are continued into adulthood where they are less adaptive, and are influenced by the attachment style. Shapiro and Levendosky, (1999) and Tremblay, Hebert and Piche (1999) found that internalising and externalising behaviours following abuse were mediated by the use of negative coping strategies (avoidance and cognitive coping). Furthermore, Shapiro and Levendosky's study indicated that coping style was further mediated by attachment, suggesting that both attachment and coping should be included in assessment and intervention.

The literature presented appears to suggest that interventions focus on risk reduction in families and the alleviation of symptoms. Few of the studies have focused on developing self-perception of abusers and victims, or have attempted to consider broader attitudinal factors related to abuse. Although they receive little attention in the literature, systemic approaches to family therapy has led to a focus on the deconstruction of narratives within abusing families in order to help family members understand the impact of abuse on both the parents and children (Erdama and Caffery, 2003). These include issues such as gender roles and power dynamics, often defined in terms of male dominance and ownership of women and children, which reinforce the use of violence and aggression within the home. Cultural values and norms relating to child rearing practices has also received sparse attention in the research literature on child abuse. The Violence Against Children Study Group (1999) highlight the fact that child abuse is a socially constructed narrative, within a specific historical and cultural context. Baker and Dwairy (2003) describe how in many non-western cultures where the family has greater autonomy and independence from the state, intervention by external organisations can result in family members, including the abused child experiencing shame. As a consequence the child is blamed and rejected by
the extended family who turn to support the abuser. Baker and Dwairy suggest a model of intervention that involves identifying the hierarchical structure of the family and attaining their support in providing support and direction to the family.

The studies above do not address a number of issues identified in the literature as common effects of child abuse such as drug and alcohol abuse, eating disorders and offending behaviours. Drug and alcohol abuse poses a significant problem in terms of health risks. It is also related to poor impulse control, a significant factor considering the poor affect regulation and self-harming behaviour and externalising behaviour seen in abused children. Child and family and mental health services are not generally set up to manage drug and alcohol problems, making assessment and intervention difficult within general services. Without attention to these problems, one must question the efficacy of the interventions mentioned above with such individuals. It is also worth considering the fact that drug and alcohol abuse is commonly associated with abuse perpetration (Avery, Hutchinson and Whitaker, 2002). Again the positive outcomes reported by studies do not incorporate discussion on drug and alcohol abuse in parents and therefore represent a bias group.

Conclusion

Over the past few decade research has revealed a relationship between child abuse and later abuse perpetration, supporting the intergenerational transmission of abuse hypothesis. Despite methodological limitations, a combination of study outcomes indicates a rate of approximately 30%. This relationship is mediated by a number of factors related to the child, the parent-child attachment relationship, dynamics within the family system, cultural values and norms and financial difficulties.

The complexity of the cycle of abuse process indicates the need for thorough assessments utilising a number of approaches to gain information from multiple sources. Similarly, interventions require a flexibility that takes into account the specific needs of the child
and the attitudes and motivation of the family. A number of treatments have proven to be effective in reducing negative impact on children as well as enhancing relationships within the family. However, development of both assessments and interventions appear to lack a cultural diversity and consideration of the needs of children and families with special needs.

References


Outline some of the major life transitions and their impact, faced in old age. What contributions can psychological theory and practice make to understanding and managing such transitions?

Introduction

Beginning around 1950, European and North American academic literature saw a dramatic increase in the focus on life-long development (Birren and Shaie, 2001). Professionals across disciplines have become more aware of the types of life events commonly faced by older people and the consequences of positive and negative adjustment. A number of theoretical models describing the process of change (and stability) across the life span have drawn attention to qualitative differences between younger and older generations in relation to the types of transitions faced, how these transitions are perceived and the strategies adopted to cope. Despite this long-overdue acknowledgement of the challenges faced by older people and the need to give equal consideration to their wellbeing, continuing negative stereotypes of older adults focusing on decline, physical illness and frailty (Gatz and Pearson, 1988) maintain social inequalities tantamount to agism. Such inequalities, evident for example in employment laws (McVittie, McKinlay and Widdicombe, 2003) and the provision and delivery of health care (Black, Rabins, German and Roca, 1997), present major obstacles that stand in the way of individuals successfully negotiating the transitions they face. The Department of Health (DoH) published a study in 1994 that identified a massive under-use of clinical psychology services by older adults (65+). Such an under-use of services can be accounted for to some degree by the fact that older people are less likely to rate their mental health problems as poor or very bad (Black, Rabins, German and Roca, 1997). However, Roth and Fonagy (1996) suggest a number of other factors including a reluctance on the part of psychologists to work with older people, poor identification of psychological problems experienced by older adults by primary care professionals and incorrect diagnosis of depression as dementia.
These ongoing concerns highlight the impact of social and cultural factors in the experience of old age and the need to consider them alongside more commonly recognised biological and familial factors. These issues have been taken up by researchers exploring the experiences of older adults, with greater attention being paid to the holistic nature of life-span development. In addition, clinicians have begun to incorporate the needs of older adults into existing models of therapy.

The following essay will discuss theories and empirical findings informing our general understanding of life long development, followed by an exploration of transitions faced by older adults, and possible positive and negative impacts. Finally, the essay will explore how our growing knowledge of life-long development informs clinical practice, with a focus on the use of systemic interventions by this population.

Definition of old age

Despite common usage of categorical terms such as ‘older adults/people’ and ‘the elderly’, the process of defining such terms is complicated and far from consistent across the literature. Furthermore, sub-division of later years into young-old and old-old categories reflects qualitative and quantitative differences found between these stages in life and a further complication to any simple definitions. A number of approaches have been used to define old age, for example biological/functional decline and psychosocial development, each with their own emphasis and implications for understanding development.

Biological/functionally derived definitions of old age

Whilst biological changes are an undeniable aspect of aging, defining exactly at which point within this framework one should be classified as ‘old’ has obvious problems. Research in the area of cognition offers one example of its limitations. Early research on
cognitive processes in older adults focused on functional decline, adopting a mechanistic view of human development. Whilst aging does bring about a gradual decline in some specific areas of cognitive functioning, recent studies have found that a number of functions often remain intact. For example, Balota and Duchek (1988) reported that whilst tasks requiring complex manipulation of information affect the capacity of working memory in older age subjects, primary memory (storage and retrieval of information over short periods) remains relatively intact in to old age.

Birren and Schaie (2001) also highlight the importance of considering environmental and social factors impacting on cognitive functioning. For example, external primers to aid memory is consistent well into very old age (Light and Alberson, 1989). Lack of intellectual stimulation, poor diet and the individual’s perception of aging have also been related to a decline in cognitive functioning. Furthermore, Birren and Schaie (2001) emphasise the heterogeneity of cognitive functioning across the older adult population, which precludes any overarching theory describing a lack of cognitive skills in the older population. Baltes, Staudinger and Lindenberger (1999) point out that differences in experimental assessments of cognitive functioning between older and younger adults are attenuated when knowledge-rich domains of every-day abilities such as life-planning and social cognition are taken into consideration, highlighting the need to consider qualitative as well as quantitative changes.

The importance of considering the limitations of adopting an over-simplified model of aging is highlighted by the fact that definitions often influence policy making decisions such as retirement and benefits laws. However, as Coleman and O'Hanlon (2004) points out, the reverse is also true; political decision making based on financial restrictions governing the availability of retirement benefits affect how we as a culture define old age. Chronological ‘cut-off’ ages are identified, which evolve into definitions of old age. Consequently, definitions can shift depending on economic and political need.
Many of the assumptions about decline in old age have been propagated by research utilising cross-sectional designs, the results of which are often confounded by cohort and age effects or retrospective reporting, leading to inaccurate differences between older and younger populations. Birren and Schaie (2001) highlight the need for longitudinal studies that more accurately capture stability and change across extended periods, the possible mechanisms by which change occurs and intra-individual developmental course (p.29). There are, however, limitations to longitudinal studies. Birren and Schaie explain that historical effects (for example, the population under investigation being affected by the specific events in history not experienced by others) can prevent generalisability of findings. Other factors highlighted by the authors include practice effects of repeated measuring, changes in research protocol and participant dropout. None the less, longitudinal designs provide the most accurate method of exploring development across the life span.

**Psychosocial developmental theories**

Early theorists of life span development such as Carl Jung and Erikson (1980) focused on qualitative differences between the experiences of people at different ages. Their theories paid less attention to chronological age and focused more on the type of tasks to be successful negotiated across the life span. Consequently, the focus was on development rather than decline. Jung for example emphasised the importance of a shift in thinking during mid-life from rationalism to a more emotionally-based, needs driven thinking. For Jung, individuals in later life should begin to integrate various aspects of their selves (such as masculinity and femininity) and tolerate ambivalence in their lives. Erikson divided life long development into 8 stages, with positive growth reflected in the following achievements. Developing a sense of trust in the world during infancy allows the child to develop autonomy and express creativity through their exploration of the world around them. Developing confidence in their skills the older child works hard with the belief that they can achieve goals. Through adolescence and early adulthood people develop their sense of identity and subsequently learn to integrate with the others through
intimate relationships. Middle adulthood reflects a shift in focus towards the younger generations and efforts to contribute towards their emotional and physical well-being. Finally, the task of older age adults is to reflect on their lives and develop an integrated positive self-concept, acceptance of one’s existence on a spiritual plane and an acceptance of one’s physical immortality.

Jung and Erikson challenged existing theories that saw development as reaching fruition in late childhood. They also challenge the view that individual development is independent of the environment. Erikson, for example, draws attention to the fact that interaction with others who are at different developmental stages can affect how well we negotiate our own developmental tasks. However, there are limitations to these later theories. For example, they were based on clinical observation and self-reflection as opposed to empirical investigations (Coleman and O’Hanlon, 2004). Furthermore, they tend to reflect the social and cultural norms of the time they were conceived and thus do not easily generalise to the older generations of present day. Erikson’s emphasis on increasing individuation at the expense of changes in the quality and experience of attachment across the life span has also be criticised (Franz and White, 1985), as has his perceived neglect or inaccurate portrayal of female experience (Gilligan, 1979). Finally, where Erikson explains that spiritual growth is a factor associated with later stages in his theory, commentators such as Wheeler, Ampadu and Wangari (2002) point out that this ethnocentric view does not reflect the central role of spirituality in development across the life span in, for example, African cultures.

Later theories on human development such as Levinson’s (1977) Seasons of a man’s life derived from interview data, indicated 4 specific developmental periods (eras) comprised of periods that constitute major transitions points in life. Transition from one period to the next involves reflection on previous achievements, re-establishing goals and consequently moving into a different stage of personal development. Levinson’s transition stages are strongly tied to specific chronological ages, which has been highlighted as a limitation in his theory.
Life-span psychology (LP) developed by Baltes, Reese and Lipsitt (1980), reflects a shift in developmental theory and research towards a more integrative model of human development incorporating biological, evolutionary, cultural and individual factors (Baltes, Staudinger and Lindenberger, 1999). Rather than focusing on generalisable developmental stages, the theory emphasises individual differences in aging and development. Baltes et al consider the natural changes in physical and emotional states that occur as a result of aging, but also point to the ways in which losses result in productive adaptations. Through creativity of the older person in adapting to change and by a refocusing of resources based on specific needs that change across the life span, individuals continue to develop as they age. Baltes et al. describe the main goal of LP psychology as the generation of knowledge about regularities in life span development, inter-individual differences in development and intra-individual plasticity (malleability) in development.

Transitions of later life

Santrock (2002) identifies a number of changes commonly faced in older age including loss (off family and friends), retirements, grandparenthood, second careers and creating satisfying leisure lifestyles. Pfeiffer (1977) comments on the increased risk of multiple losses of friends, family, and roles, describing this time of life as one that places considerable stress on the elderly. Supporting this view are findings of higher incidence of depression (Schwab, Holzer and Warheit, 1973, Zung and Zung, 1986, Kraaij and de Wilde, 2001) and anxiety (Hale and Cochran, 1992) in older populations. However, research suggests that this view may be inaccurate and simply reflect negative cultural beliefs about aging (Baltes, 1987, Ruth and Coleman, 2004). For example, Eaton and Kessler (1983) found no difference between older and younger populations on self-ratings of five mental health scales. As a consequences Baltes (1987) points to the danger of maintaining a view of old age as a time of increasing distress, views that we carry through into our own old age and which affect our perception of our own development.
One reason for the discrepancy in this and other areas of life span developmental research is the over use of cross-sectional studies, which are vulnerable to cohort and age effects (Ruth and Coleman, 1996). A further problem is the use of inventories that do not take into account normal developmental changes, for example depression inventories yield higher scores for older people due to individual’s problems with memory and somatic complaints that can represent normal aging (Hale and Cochran, 1992). Kraaij and de Wilde (2001) comment on the relationship between reports of childhood abuse and later life depression, highlighting the complexity of factors associated with mental health in older age. The research suggests that whilst many of the transitions faced by older adults can place considerable strain on individuals, for the majority adaptation to these transitions is successfully negotiated. However, there are a number of older adults who do not have the resources to cope or for whom previous negative experiences impact on current motivation and capacity to manage transitions.

Models of Coping

Whilst acknowledgement of the types of challenges faced by older people is invaluable, of equal importance is the identification of how older people manage change and the differences between the older and younger generations. One area of investigation that supports the need for such a differentiation is that of coping. For example, Lackovic-Gorin, Grgin, Penezic and Soric (2001) investigated the use of primary (direct cognitive or behavioural action) and secondary (reassessment of goals) coping strategies adopted by people across adulthood. The authors found that older adults (59-64) tended to use more of the secondary strategies, explaining their findings as reflecting an increasing lack of physical resources to initiate change and a greater flexibility on the part of older people in the face of impending future losses. Whilst limited by the cross-sectional methodology employed in the study, the results reflect early findings by Gutmann (1964) that older adults relied more on ‘passive’ as opposed to ‘active mastery’ as a defence against loss. Others have developed similar models of coping which also identify changes in the use of strategies with age. Brandstadter and Greve (1994) describe assimilation...
and their findings that older adults tend to draw on accommodative coping strategies. The shift may be seen, not just as a method of adapting to a lack of physical resources, but as Brandstsdter and Greve explain, as reflecting emotional maturation resulting from previous experience and adaptive change. With these findings in mind, a balanced approach to interventions with older bereaved people is needed; practical support in addition to emotionally rewarding relationships are essential to adjustment. For example, McAvay, Seeman and Rodin (1996) found that low instrumental support was related to a reduction in activities of daily living in older bereaved people, emphasising the need for relationships based on practical support.

Emphasising that aging can be defined in terms of both losses and gains, Baltes and Baltes (1990) have developed a model of adaptation in older age within the Life Psychology framework. The model, known as SOC describes three primary strategies adopted by older adults in response to change: selection (of interests and commitments), optimisation (modification of the environment and/or one’s behaviour to secure positive outcomes) and compensation (the use of alternative means to reach a desired goal). Baltes et al.’s model can be applied to findings in research into the effects of widowhood in older age. Research on spousal death in younger populations emphasises the importance of large network size for positive adjustment, however, research has found that social support networks tend to decrease with age, suggesting that older people would be at greater risk following this event. This view is supported by McWhirter (1990) who found that loss of a spouse in older age is related to loneliness, which the author explains as a consequence of reduced social networks and increased isolation. The SOC model provides a more adaptive explanation of reduced networks. Lang and Baltes (1997) explain reduced social networks as the choice of older adults to spend less time with people and to focus on a few emotionally supportive contacts. This selective strategy helps to minimise unhelpful or even over-protective interactions. A similar view comes from socio-emotional selectivity theory (Carstensen, 1991), which states that as individuals grow older they select and invest in those relationships from which they
receive the most emotional reward. In line with these findings, interventions focusing on utilising existing support networks as opposed to encouraging the development of many sources of social support would be most effective when the bereaved is an older adult.

Whilst the SOC models provides a more positive focus on the adaptive coping resources of older adults, there is a danger of overlooking the difficulties faced after such an event and the capacity of some to draw on effective strategies. Brady (2003) and Kraaij and de Wilde (2001) for example, highlight the implications of previous trauma on the development of post traumatic stress disorder (PTSD) symptoms following the loss. There is a need for specific interventions to consider such distress, which are seldom discussed within the general literature on loss in older age. Other factors may also impact on the surviving adult's well-being and need to be considered alongside the application of the SOC model. Reich, Zautra and Guamaccia (1989), for example, found that physically disabled bereaved older adults reported higher levels of anxiety, less of a sense of well-being and more distress than non-disabled bereaved older adults. The authors suggest that greater dependence on the lost spouse may have resulted in poorer adjustment following the loss and reduced ability to remain in contact with social networks. Whilst the literature on older adults continually emphasises the need to consider the physical well-being of clients, there appears to be little research into the psychological factors that affect those suffering from a physical disability in relation to adjustment following loss.

A further danger of generalising theories such as SOC is to ignore gender difference in emotional processing, which may impact on contact with and/or perceived support from social networks. For example, Guinther, Segal and Bogaards (2003) found that whilst emotional disclosure following spousal bereavement benefited both older males and females, the process of changes differed between the two groups. Whilst females exhibited an initial high level of negative effect followed by a steady decrease in symptoms, males initially presented with lower levels of negative emotion followed by an upsurge in negative thoughts. How these differential processes interact with issues such as satisfaction with social support networks and choice of coping strategies may
provide greater insights into the most effective interventions. Considering the differential coping strategies adopted by individuals of different ages, it would be useful to consider how these differing approaches help or hinder families in transition and the processes through which such differences are negotiated.

The SOC model describes the process of adaptation in terms of individual choice within the boundaries of cultural norms and the limits imposed by the specific situation. The model appears to focus less on how such strategies and skills develop across the life span or the mechanisms by which selective strategies are chosen. Erikson’s (1950) theory explains that successful resolution of psychosocial conflicts in one stage of life leads to the acquisition of resources to be used in coping with future conflicts. By exploring with clients their previous transitions and the positive/negative experiences the therapist can gain some sense of the resources an individual has accumulated across life experiences and why particular aspects of adaptation to the current challenge may be more difficult. Rennemark and Hagberg (1997) for example, found that satisfaction with current social networks was related to positive evaluations of generativity periods in their sample of 247 older people (71 years old). However, the authors highlight the fact that where as for males, satisfaction with later generativity period was more strongly related to current positive social networks, for females this was more strongly related to the earlier generativity period. A further finding of the study was the strong relationship between sense of coherence and satisfaction with previous life stages. The authors relate sense of coherence with Erikson's view that present life quality is associated with integration of experiences over the course of life. Successfully integrating past experiences assists in negotiating the eighth stage of life (integrity v’s despair), which Erikson described as leading to wisdom and acceptance of the life one has lived. One limitation of the research however was the use of retrospective reports. Furthermore, as the study utilised a cross-sectional sample, one must be careful in generalising the findings. Despite these limitations the study highlights the importance of considering the person within the context of their lived experiences.
Reminiscence

The example above highlights the importance of exploring past experiences in order to understand the client in context. It also provides the basis for reminiscence work which, individually or in groups, has been used to help individuals to reflect on past experiences and, where necessary, to re-author stories that sustain negative views of self or maladaptive coping strategies (Coleman, 1974). The efficacy of reminiscence or life review work is disputed. After reviewing the literature Parker (1995) concluded that studies were methodologically weak and that the findings were difficult to compare because of differences among study variables and study designs. Coleman and O’Hanlon (2004) highlight the fact that depending on the use of reminiscence, such an approach can have positive or negative effects. For example when used to ruminate or reflect guilty feelings and regrets (P.69) the outcome can be negative, whereas reflections that help to integrate a person’s past can assist in the process of self-acceptance and developing wisdom (Erikson, 1950). The reminiscence approach bears many similarities to narrative therapy described by White and Epston (1991). It provides the opportunity for an individual to re-author their lives and explore positive experiences that may have been overshadowed or ignored. It is interesting to note that narrative therapy has gained in appeal over the past decade and is used with clients of all ages, suggesting that forms of life review are useful across ages. Furthermore, such work with younger clients is not seen as a form of natural disengagement, but as a possibility for personal growth.

Fitting therapeutic interventions to older clients

Efficacy studies report positive outcomes for the majority of models generally used across the NHS (Roth and Fonagy, 1996), challenging previously held stereotypes that older generations are unable to benefit from psychological intervention. Kennedy and Tanenbaum (2000), following their review of the efficacy of psychosocial interventions with older adults suggest that interventions need to be tailored to meet the specific needs of this population. Adaptations include consideration of physical illness, awareness of the
cognitive capacities of older people and recognition of the value of family and friends. The above research and theoretical development on coping and adaptation indicate the need for clinicians to be aware of how individual needs change with age and how this affects the choice of strategies utilized to cope with transitions.

A further area that has received less attention in the literature is the position of the therapist and their impact on the therapeutic process with older clients. Katz and Genevay (1987) identified 6 countertransference issues that are commonly experienced by professionals working with older adults, including denial, fear of growing old, fear of dying, anger, the need for professional omnipotence and the need to be needed.

**Family therapy**

One of the most salient issues in research on transitions faced by older people is the impact of role loss. For example, loss of spouse often brings with it the need to adopt roles the dead partner previously held (domestic chores, maintaining social relationships). Similarly, retirement, whether forced or through choice results in many changes in roles such as professional, manager, friend and colleague, which likely to have been a central part of a person’s life for many years and for many will have become a part of their personal identity. Adaptation can be difficult where individuals lack skills to accommodate such changes or where the environment inhibits successful adaptation.

The inclusion of the wider system in work with older adults brings into focus the impact of events such as retirement on the whole family as opposed to the individual. For example, reduced income can impose added stresses on the family, along with difficulty negotiating household chores and difficulty learning to share physical and emotional space (Carter and McGoldrick, 1989). Emphasising this point, Lo and Brown (1999) describe how successful adaptation to retirement is related to pre-retirement preparation and that this relationship is strengthened when other members of the family system are involved. Following transitions such as loss, retirement or illness older people often turn to members of their extended family for support. The quality of support they receive may
depend on the quality of relationships before the transition and therefore expectations of care may come at a cost of increased hostility and even elder abuse (Carter and McGoldrick, 1989). Change in roles may be too difficult for some to negotiate, for example, the child who has been overly dependant will find it hard to adopt the caring role. Likewise, the parent may find it difficult to accept help despite increasing needs. Tsai and Lopez (1997) point to the role of culture in how families adapt to events such as retirement. In Chinese families children are expected to become the main carers and providers for older family members following retirement. However, western culture’s focus on individuality and the resultant disintegration of the nuclear family make fulfilling traditional roles difficult. Younger generations who have adopted western ideas may come into conflict with aging parents who they see as being ill-prepared for retirement and placing an unfair burden on them.

Following a review of current interventions used with older clients Kennedy and Tanenbaum (2000) offered a number of suggested adaptations including the recognition of the role of family members and caregivers. Despite their suggestions regarding the important role of family and friends in the well-being of older people, there appears to be limited literature on the use of systemic work with older people referred to psychological services. Leff (1998) found that family therapy was both more accepted and more efficacious than medication in the treatment of depression in a sample including older adults up to the age of 85. Sukosky (1994) incorporated life review work into family therapy with older adults and reported positive effects in the form of shared understanding regarding past experiences and insights into future goals. In relation to illness and later life adaptation, Cooklin (1998) reports on the positive effects of family work where an older parent is diagnosed with dementia.

Within the family therapy field, models of family functioning have evolved that include a life-long perspective. Cater and McGoldrick (1989) discuss their family life cycle approach to work with families. They identify the central underlying process to be negotiated within family life as “...the expansion, contraction and realignment of the
relationship system to support the entry, exit and development of family members in a functional way...” (p.34). Similar to Erikson, the authors highlight the fact that the system often comprises a number of generations, the members of which will be faced with their own developmental tasks simultaneously. Furthermore, it is often at times of transition that difficulties arise, difficulties that can be compounded by earlier unresolved family conflicts or stressful events. Inclusion of the wider system provides a basis for rallying support and considering the rippling effects of transition on others in the system which, if gone unnoticed, could lead to ongoing adjustment difficulties.

In order to assist families manage later life stages it is necessary to consider previous patterns of family functioning, in particular, established patterns used to negotiate (successfully or unsuccessfully) previous family transition phases. This includes the rules by which families are guided and the cultural norms shaping family behaviour (Carter McGoldrick, 1989). The structural composition of the family (for example are there clear generational boundaries, are relationships disengaged or enmeshed) is a further focus of family work with older families. Families that lack the skill or safety to be flexible are likely to experience intense anxiety during developmental transitions (Qualls, 1999). The goal of therapy is to help the system rearrange its self in order to accommodate change.

Despite the development of family life cycle models and an increase in the application of family therapy to the problems faced by older adults, Carter and McGoldrick (1989) suggest that current approaches to family work tend to be anchored in the early stages of the family life cycle such as coping with the birth of children. The authors highlight the need for further research into the efficacy of family interventions in later transitional stages. Both Individual and family systems developmental theories have failed to encompass minority groups such as homosexuals into research and practice. Tasker and McCann (1999) highlight two transitional processes: self-definition (as a gay person) and ‘coming out’. As the authors point out, both processes involve possible alienation from a community and involve considerable stress for both individuals and friends and families. The current debate on the legality of same sex marriage highlights the significant impact
social values play on gay relationships and their developmental course, indicating the need for further research into the transitions faced by this group.

Conclusion

Over the past few decades increasing attention has been paid to development across the life span, challenging stereotypes of older people as frail and the concept of aging as one of decline. Adopting a more holistic perspective, authors such as Baltes (1987) have highlighted the flexible and adaptive capacities of older people, which enable them to successfully negotiate transitions in later life by redirecting goals and efforts to accommodate biological, environmental and psychological changes. However, theories utilised in clinical practice incorporate historical and cultural biases that stand in the way of fully incorporating diversity into work with older people (Wheeler, Ampadu and Wangari, 2002).

Such findings inform interventions with older clients by highlighting how specific strategies such as accommodation and selection of goals can be developed during therapy rather than seen as a process of disengagement or as a sign that primary coping resources need to be developed. Interventions also provide the opportunity for clients to reflect on experiences, draw on positive achievements and challenge dominant narratives that restrict growth.

There appears to be a lack of research with specific populations including people with learning disabilities and those in non-traditional family systems such as gay couples. Further research on the effects of therapist attitudes towards their own aging would also benefit the field.

References


Department of Health (DoH) published a study in 1994


Adult Mental Health Placement Summary

During this placement I worked as part of a Community Mental Health Team located in a suburban area where there were few opportunities to work with people from minority racial and cultural backgrounds.

Clients presented with a broad range of mental health problems including depression, obsessive compulsive disorder, anxiety, agoraphobia and anorexia. As this was my first placement the main pressures came from attempting to focus on both my interpersonal and basic therapeutic skills, whilst trying to get to grips with more technical aspects of clinical work. I mainly used a cognitive-behavioural model during interventions. However, I was able to employ some solution focused strategies with one client.

I worked with clients ranging in age from 18 to 52, which gave me good experience of how different age groups have different expectations of therapy and the different levels of motivation that accompanied these attitudes. Older clients were more motivated to engage and complete homework tasks. However, They also tended to be more ‘passive’ during our interactions, which demanded greater emphasis on allowing them to explore their own goals and preferred outcomes.

I found the work frustrating at times in the sense that the opportunity to work with wider systems or to work with clients in their own homes did not arise. Whilst I did have conversations with clients about the social and professional networks they were involved with, working with clients alone often seemed limiting.
Learning Disabilities Placement Summary

During the course of the placement I worked with clients who had varying levels of learning difficulties. The problems they presented with often related to the way in which carers responded to client’s behaviour and/or failed to identify the communicative nature of behaviours. As such, much of my work involved working with staff and parents struggling to cope with what they saw as clients being difficult or manipulative. I found that utilising a Cognitive Analytic Therapy (CAT) model that focused on reciprocal relationships extremely helpful in sharing ideas with staff and carers. This helped to avoid blaming whilst acknowledging the interpersonal contexts in which behaviours occurred.

Co-facilitating a ‘Feelings’ group with clients attending a day centre provided a great opportunity to step outside of the behavioural framework that is often emphasised in work with people with learning difficulties. The clients appeared to gain a great deal from exploring their emotional experiences and learning to recognise non-verbal social cues.

I also had the opportunity to draw on Cognitive-behavioural models when working with one particular client. This experience was useful in learning to adapt models to the functional level and needs of the client.

One particularly difficult case related to a woman who’s children were on the at risk register following physical and sexual abuse by her and her ex-partner. The team had to make a decision as to whether she was capable of looking after the children herself. Unfortunately her children were taken into care and I continued working with her to help her manage this distressing situation.
This was my first experience of working with children and families. The placement, a psychology service focusing specifically on children with developmental difficulties and their families provided the opportunity to develop my knowledge and skills working with people diagnosed with Asperger’s syndrome, learning disabilities and physical disabilities such as Cerebral Palsy. In addition, I worked with children referred with mental health problems including Obsessive Compulsive Disorder and depression, and behavioural problems.

One of the most prominent learning experiences for me was my growing awareness that many of the difficulties children presented with were inseparable from the way in which parents interacted with their children or the way in which schools and other organisations organised themselves around problems. A number of interventions that began as work with children developed into work with parents, providing them with a space to explore their own difficulties.

Over the course of the placement I developed skills working with individual children and working systemically with families. One of these interventions involved a step-family, which provided valuable insights into how differing attitudes and beliefs influence family functioning and the difficulties of working through any conflicting beliefs systems.
Specialist Child and Family Placement Summary

My placement with a Community Mental Health Team for Children and Families brought me into contact with clients presenting with a range of emotional and behavioural difficulties. These included obsessive compulsive disorders, depression and anger management. The issue of mental health and stigma made became particularly salient here, as many of the children talked about their concerns about peers or siblings finding out about ‘their problems’.

During interventions I drew on behavioural, cognitive, narrative and systemic models to guide our work. I found the narrative model particularly useful in helping the children to develop some control over difficulties and in developing therapeutic alliances.

The most difficult aspect of the placement for me was working with adolescent boys. I found them difficult to engage and felt that a number of issues, such as my representation of a father figure to the children made the work challenging, particularly as many of the children had difficult relationships with their own fathers.

During the placement I was a member of a reflecting team working with a number of families. This was really useful experience in terms of observing therapists working to maintain neutrality in their work and the importance of an outside view to reflect on where families and therapists become stuck. I also observed situations where social narratives such as gender roles and generational assumptions brought conflict to families. Communication between family members was often multi-layered with members of different generations using discourse embedded in different narratives.
Older People Placement Summary

My placement at a Community Mental Health Team for the Elderly brought varied work in terms of location where therapy took place, client’s presenting difficulties and the pace of the work.

Presenting problems included Post Traumatic Stress Disorder, anxiety and depression, schizophrenia and bereavement. Reflecting on the work I think that I held the most inaccurate stereotypes about this client group before beginning the placement. I expected the pace of the work to be much slower than with children or adult. However, I met some extremely energetic and motivated people during my work.

The stigma attached to mental health problems in older populations proved to be a barrier to some of the interventions I engaged in and as such I focused a great deal on normalising experiences and helping clients to challenge stereotypes of ‘mentally ill people’. Stereotypes about professional/patient relationships also played a big part in how therapy developed, with many clients presenting as more ‘passive’ in the therapeutic relationship.

Working with clients in their own homes changed the dynamic of therapy and I felt allowed a strong therapeutic alliance to develop. However, it was also more difficult to maintain boundaries, or at least to feel comfortable as a therapist with the changing boundaries in that location.
Adult Mental Health Case Report Summary

Cognitive-behavioural assessment and intervention with a 35 year old female presenting with symptoms of depression

Reason for referral

Ms. Phelps, a white, English woman described low mood and suicidal ideation. She had attended self-esteem and craft groups with little effect. Her Beck Depression Inventory (BDI-II) score was 16 on initial assessment.

Initial assessment

Ms. Phelps explained that her mood became low following the break-up of her marriage one year previous. She described her self as ‘a weak person’, ‘a failure’ and ‘a nobody’. She identified a number of ongoing stressors that contributed to her current difficulties. These included financial problems, a physical injury the previous year and a lack of perceived family support. She had a four-year old daughter with whom she reported a good relationship.

Family background

Ms. Phelps explained that she thought her two younger brothers received more support from their mother. She also described a distant relationship with her parents. She believed that there was a family tradition of giving more care to male children and expecting females to be independent.

Intervention
Ms. Phelps attended ten fortnightly sessions which focused on reducing frustration, increasing self-worth, being more active and coping with work stress effectively. Ms. Phelps engaged well with the cognitive-behavioural model and despite initial difficulties identifying negative automatic thoughts developed adaptive skills of challenging these thoughts which in turn led to more adaptive behaviours.

**Outcome**

Ms. Phelps' score on the BDI-II fell at 9 on the final session. She also reported being more open about her feelings to her new partner and had been able to leave the work firm she had been having problems with and find a new job.
Learning Disabilities Case Report Summary

Extended assessment of a 54-year old woman with Down’s syndrome and learning difficulties presenting with emotional instability and a decline in global functioning

Reason for referral

Jill had been referred to the psychology department following reports by staff at her care home of increased agitation, screaming, refusing to climb stairs, reduced appetite and disturbed sleep.

Assessment

Two unstructured interviews were conducted with Jill’s carers. In addition, a number of psychometric measures were utilised to assess Jill’s current level of cognitive functioning including the Assessment of Cognitive Deterioration in People with learning Disabilities, Early Signs of Dementia Check List (ESDCL) and the Hampshire Social Services Staff Support Levels Inventory (HALO). Direct observations of Jill’s behaviour at home were also made to inform the assessment.

Formulation

Comparison of Jill’s current scores with previous scores indicated an increased need for staff support, with an accelerated increase over the past few months.

In terms of cognitive performance, although no direct comparison could be made between current and previous assessments due to the tests used, Jill appeared to display a general decline over the past three years.
Jill Exhibited a number of behaviours associated with Alzheimer’s disease including loss of appetite, cognitive decline, mood disturbance reduced motor speed and apathy. Her presentation also indicated depression and anxiety.

**Intervention**

Laminated picture booklets were made to assist Jill and staff in communication, as her scores on visual memory were a strength in relation to other cognitive domains. Jill was also referred for multi-sensory therapy to help reduce anxiety and reduce aggressive outbursts. A reassessment of her cognitive and adaptive functioning was recommended in 12 months.
Case report Summary

Narrative Therapy with a Four-Year-Old Male Presenting with Social and Communication Problems and Aggressive Behaviour

Reason for referral

Jonathon was a four year old Afro-Caribbean/British male with Cerebral Palsy, referred to the psychology department following suggestions that he exhibited difficulties with communication and social interaction, poor understanding of danger and aggressive behaviour towards his mother. Previous professionals suggested an autistic spectrum disorder.

Family background

Jonathon lived at home with his mother and 9 year old sister. His parents had split up two years previous and his father had left the family home. Previously his mother and father argued a great deal and they disagreed over care and boundary setting with Jonathon. His parent’s relationship had become less strained over the previous year.

Initial assessment

Jonathon and his Mother attended two assessment sessions. Jonathon interacted little with the therapist but mother and son exhibited a warm and reciprocal relationship. Jonathon’s mother complained of feeling out of control regarding her son’s behaviour. One dominant narrative identified during assessment was that the problems were developmental and genetic. This story had been reinforced by frequent contact with mental health professionals who suggested disorders such as Asperger’s syndrome. As a consequence, a further story of Jonathon’s mother as helpless to do anything dominated the way she
understood the problems. On a continuum we developed to indicate how ‘balanced’ she saw her parenting skills, she saw her self as swinging between being too soft and too strict.

**Intervention**

Whilst Jonathon and his mother’s attendance at sessions was not consistent, throughout the work we were able to identify a number of situations where Jonathon’s mother had shown a great deal of strength and skills in providing a safe and nurturing environment for her children. For example, following the break-up of her marriage. We were also able to highlight reactions to Jonathon’s behaviour that she found help to reduce his challenging behaviour.

The work helped Jonathon’s mother challenge the dominant narrative of her self as helpless to do anything about her son’s ‘developmental problems’ and to re-story her experience in terms of a mother who was able to manage her children’s behaviour effectively.

**Outcome**

In terms of outcome, Jonathon’s mother reported that as a family they had started talking more. She described her interactions with her son as more ‘balanced’ in terms of her parenting style and thought that she did not swing as much in terms of providing safe boundaries as she had previously thought.
Child and Family Case Report Summary

Group Intervention with children aged 9-11 of divorced parents

Referrals to the group

Following assessments sessions with mothers and children separately and a joint assessment session, 5 children participated in the group. All children (four girls and one boy) exhibited emotional or behavioural problems associated with their parent’s divorce.

Intervention

A combination of cognitive-behaviour and psychodynamic models and theories were utilised to guide the content and structure of the group. The group met weekly for six weeks. The group aimed to focus on the following areas. Providing a space for children to talk about their experience of divorce, to feel supported by facilitators and peers in their experiences, to develop a number of cognitive-behavioural strategies to manage difficulties and to provide positive experiences of adult male/female relationships as modelled by the male and female group facilitators.

Outcome

All group members completed the Children’s Beliefs About Parental Divorce Scale (CBPDS) and The Strengths and Difficulties Questionnaire (SDQ). They also identified 5 problem areas at the beginning and end of the group. Group member’s parents also completed pre and post questionnaires about their children’s well-being. Pre and post scores differed dramatically across group members, with the majority showing no change, one showing positive change and one group member showing an increased in self-perceived problems. Reports from parents indicated greater perceived confidence
across three of the group. Importantly, the mothers interviewed post group reported considerably greater insight into how their own behaviours contributed to their children’s difficulties.
Older Adult Case Report Summary

Systemic intervention with a 69-year old woman coping with multiple losses

Reason for referral

Kate was referred to the psychology department following concerns about her low mood. She declined to take psychiatric medication and therefore psychological input was suggested.

Initial assessment

Kate explained that she had lost her son one year ago, her husband one year ago. In addition, following long-term difficulties in her relationship with her daughter, they no longer kept in touch. She had limited mobility due to her weight, her diabetes and other physical problems. Kate explained that she had not coped well since the loss of her husband and that the loss of her son exasperated her sense of loneliness and helplessness. Gendered family themes of women as passive and reliant on men for emotional support were identified, as well as themes of daughters having to be independent from their mothers.

Intervention

Kate and I explored a number of family stories and the way in which they had influenced the way she perceived her self. These discussions were interwoven with conversations about loss and adjustment, family expectations and Kate’s own abilities that had been over-shadowed by illness narratives.

Outcomes
Exploring family narratives about gender roles helped Kate to consider alternative perspective on her own capacity to cope with difficulties. She also found it beneficial to explore specific relationships with her husband, son and daughter. In line with models of grief, Kate was able to transform and internalise new relationships with the deceased that she found comforting and supportive.
An Investigation into Client Drop-Out from an Adult Outpatient Psychology Service

Abstract

Objective: The aim of the present study was to explain why some adult clients drop out (unplanned termination of therapy by the client) of a community-based outpatient psychology service.

Methods: Client contact records for the psychology service for the period November 2001 to January 2003 were used to compare the 67 clients who had completed therapy with the 26 who dropped out of therapy and 10 clients who did not show up. Questionnaires assessing reasons for drop out were completed by 11 of the 26 clients who dropped out.

Results: The audit of contact records revealed no significant differences between completers and those dropping out on age at time of referral, client’s sex and distance from client’s home to the team base. The most common reasons given for dropping out in the questionnaire related to practical issues (inadequate transport), difficulty talking about problems, a lack of identified progress and the feeling that the client was wasting the therapists time.

Discussion: Whilst the present location experiences lower drop out rates than those described by previous research, this study indicates that service access, referral procedures and client expectations may impact on client’s decisions to terminate therapy. Recommendations for service development are discussed.

Prior to conducting this project the nature of the study was discussed with the placement supervisor who agreed that no ethical approval need be sought (see appendix 1).
Introduction

The psychology service to which this study relates is part of a community mental health team in the South East of England comprising one full-time clinical psychologist. The clinical psychologist expressed some concern over perceived high client drop out rates and requested that research be conducted.

Concerns over client drop out have been echoed in the research literature which suggests rates in the U.K. between 35% (Madden and Hinks, 1984) and 40% (Trepak, 1986), with rates in the United States appearing even higher (Hughes, 1995). A meta-analysis by Wierzbicki and Pekarik (1993) of studies published over the past three decades indicated a mean rate of 46.8%. Differences in observed rates can be accounted for to some extent by the different client groups (adults, children and families or a combination of the three) included in studies. Further difficulties in interpretation arise due to the use of different definitions of drop out (Renk and Dinger, 2002). A number of authors have used duration-based definitions, for example, discontinuation after the first session or termination within the context of different phases of therapy. An alternative approach found to be more reliable (Pekarik, 1983) is to use therapist definitions.

Despite these limitations, a number of studies indicate that early termination is related to poorer outcome. For example, Shapiro et al (1994) found that clients with more severe depression showed greater improvement after 16 sessions than after 8 sessions. Similar results were found by Garfield (1994), who suggested that clients who terminate therapy early may not have completed the changes for which they entered therapy, and may not experience a reduction in symptoms. It is not known how well these findings generalize to other mental health problems and, as Pekarik's (1992) study showed, many early terminators classify themselves as 'completers', reporting associated high levels of improvement.

In addition, drop out has also been shown to have a negative impact on the clinician. For example, Hill, Nut-Williams, Heaton, Thompson and Rhodes (1996) reported that...
therapists described feeling frustrated, angry, disappointed and questioning of their self-efficacy. A later study by Tweed and Salter (2000) found that clinicians often experienced self-blame and anxiety following early termination by clients.

Three approaches have previously been employed to identify factors affecting client drop out. The first involves examining client demographic variables for common factors. Whilst such data suggests that drop-outs are a relatively heterogeneous group (Pekarik, 1992), a number of studies consistently found that low socio-economic status (e.g. Trepak, 1986), ethnicity (e.g. Sue, McKinnen, Allen and Hall, 1974) and low level of education (e.g. Weighill, Hodge and Peck, 1983) predicted drop out. Trepak (1986) also found that drop out referrals tended to come from professionals who were less familiar with the psychology service.

Investigations of clients’ reasons for drop out have generally involved the client completing a postal questionnaire. Studies indicate three broad categories into which responses equally fall, including “dissatisfaction with treatment”, “problem improvement” and “environmental obstacles” (Pekarik, 1983, Pekarik, 1992 and Garfield 1994). Pekarik and Finney-Owen (1987) suggested that a fourth category, ‘resistance’, could make interpretation of responses more comprehensive. However, Todd, Deane and Bragdon (2003) did not find support for this.

A third method involves comparing client and therapist reasons for drop out. Findings appear contradictory in that whilst some therapist tend to endorse more negative terms such as client resistance (Lane 1984), others are more likely than clients to attribute ‘improvement’ as a reason for drop out (e.g. Pekarik and Finney-Owen, 1987). In Pekarik’s (1992) study, similar differences were observed between client and therapist reasons; whilst therapists tended to perceive all drop-outs as ‘failures’, many of the drop out clients reported greater problem improvement than ongoing cases. The study also found that outcome and satisfaction measures were not highly correlated, suggesting that negative experiences by clients do not always indicate a negative outcome.
Research questions

The present study utilised client demographic variables and questionnaire responses relating to reasons for drop out in order to examine three questions. 1) Do client drop out rates differ significantly from the average drop out rate cited in Wierzbicki and Pekarik (1993). 2) Can drop-outs be distinguished from 'completers' on specific demographic variables. 3) What specific reasons do the present client group cite for dropping out of therapy. Clients who did not attend any appointments were also included in the present study. Previous research has reported rates for this group of 17% (Trepak, 1986 and Madden and Hinks, 1984).

Design

A non-experimental, independent-groups design was employed to investigate differences between clients who complete therapy, those who did not show up and those who dropped out. A questionnaire was also used to investigate reasons for dropping out of therapy.

Participants

Referral audit

Data relating to all clients referred to the psychology service between November 2001 and January 2003 were obtained from computer-based records. A total of 103 cases were identified and categorized as 'completers' (n=67), 'no shows' (n=10), and 'drop-outs' (n=26) (see procedure section for a definition of these terms).
Questionnaires

26 questionnaires assessing reasons for terminating therapy were sent to clients identified as drop-outs. Due to the low participant numbers involved, no differentiation was made between early and late drop-outs (Hynan, 1990).

Procedure

Referral audit

Clients identified from the database were categorized into three groups. 1) Completers - clients who had completed treatment and been discharged from the psychology service. 2) No shows - clients who had been offered an appointment, but failed to show. 3) Drop-outs - clients who had attended at least one session with the psychologist, then failed to attend any further arranged appointments, despite prompting via a letter. The clinical psychologist was also consulted to ensure that those cases identified in the data as drop-outs met with her agreement. This method of clinician definition was employed due to difficulties inherent in using treatment duration or number of sessions attended to define drop out (Wierzbicki and Pekarik, 1993). A total of 4 discrepancies between computer records and therapist explanations of why therapy ended were excluded from the study.

Following categorisation of clients, information was gathered from both computer records and case files for analysis (details of data collected are provided in the measures section below).

Questionnaire

Those clients who met the criteria for drop-out were sent a 14-item questionnaire assessing their reasons for dropping out (see appendix 2). A letter explaining the nature of the study accompanied the questionnaire. The letter also assured participants of their
anonymity and provided a contact number should they have had any concerns or questions about the study (see appendix 3).

Three weeks after the initial postal questionnaire a reminder letter including a second copy of the questionnaire was sent to all clients who dropped out, requesting that they complete and return the questionnaire if they had not yet done so (see appendix 4). A stamped, addressed envelope was provided to all participants during both of these phases.

**Measures**

**Referral audit**

The following data were collected from computer records for each case:

1) Age at date of referral (in years).

2) Sex (male or female).

3) Whether the client dropped out, recorded as “yes” or “no”.

4) Shortest distance between the client’s home and the community team base (in miles, using AA ‘route finder’).

Information relating to primary diagnosis was collected from case files for each participant identified as dropping out. The total number of sessions attended by completers was also recorded.
**Questionnaire**

The questionnaire consisted of 14 statements relating to reasons why people decide to leave therapy. Participants were asked to rate on a five-point Likert scale ranging from "strongly disagree" to "strongly agree", the degree to which each statement described their reasons for leaving therapy. Participants were also provided the opportunity to add their comments relating to each item and to offer any general comments about the psychology service.

The development of items was guided by previous studies (Pekarik, 1983; Pekarik 1992 and Garfield, 1963). Following initial scale development the clinical psychologist was consulted for her opinion of the validity of the items.

**Results**

Referral audit

Of the 103 cases, 26 (25.2%) ‘dropped out’ of therapy, whilst 10 (9.7%) did not show up for any appointment. A binomial test was conducted in order to compare drop out rates in the present study with that of 46.8% reported by Wierzbicki and Pekarik (1993). The binomial test was chosen as it includes a continuity correction procedure for two category variables (Green and Salkind, 2003). Results indicated that the current rates were significantly lower than previously reported levels $\chi^2(1,93) = 0.44$, $p = 0.002$ ($p$ adjusted for one-tailed calculation). $N$ (completers) = 67, $N$ (drop-outs) = 26. In order to compare the three groups in terms of age of clients and traveling distance, Kruskal Wallace tests were conducted. Non-parametric tests were used due to the difference in numbers between groups. The results are shown in table one below. No significant difference was found between the three groups.
Table 1: Comparison of age and distance from client's home to the psychology service across the three groups

<table>
<thead>
<tr>
<th></th>
<th>Dropped out (n=26)</th>
<th>Completed treatment (n=67)</th>
<th>No show (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (Years)</strong></td>
<td>n=26</td>
<td>n=67</td>
<td>n=10</td>
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<tr>
<td>Mean</td>
<td>34.6</td>
<td>38.8</td>
<td>35.4</td>
</tr>
<tr>
<td>S.D.</td>
<td>9.9</td>
<td>12.2</td>
<td>5.7</td>
</tr>
<tr>
<td>Range</td>
<td>19-57</td>
<td>19-65</td>
<td>28-44</td>
</tr>
<tr>
<td>df</td>
<td>2</td>
<td>Ns</td>
<td>Ns</td>
</tr>
<tr>
<td>$\chi^2$</td>
<td>1.423</td>
<td>Ns</td>
<td>Ns</td>
</tr>
<tr>
<td>$\rho$</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Distance (Miles)</strong></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Mean</td>
<td>4.1</td>
<td>4.4</td>
<td>3.7</td>
</tr>
<tr>
<td>S.D.</td>
<td>1.9</td>
<td>1.5</td>
<td>1.6</td>
</tr>
<tr>
<td>Range</td>
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<tr>
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</tr>
<tr>
<td>$\rho$</td>
<td>Ns</td>
<td></td>
<td>Ns</td>
</tr>
</tbody>
</table>

Table 1: Comparison of clients who completed treatment, dropped out or never attended on measures of age and distance from home to psychology service.

A Chi-squared test was conducted in order to compare the distribution of males and females across the three groups. Table 2 below shows the distribution of sex across the three groups. Results indicated no significant relationship between client's sex and group membership. Pearson's $\chi^2 (2,103) = 1.932$, $p = 0.243$ ns.

Table 2: Distribution of males and females across the three groups

<table>
<thead>
<tr>
<th></th>
<th>Completers</th>
<th>Drop-outs</th>
<th>No-shows</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Males</strong></td>
<td>21</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td><strong>Females</strong></td>
<td>46</td>
<td>15</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 2 shows the distribution of males and females across the three groups.

The mean number of sessions attended prior to drop out was 6.5 ($n = 17$, s.d = 5.4), 76.5% attended 7 or fewer appointments before dropping out. In relation to diagnosis of those who dropped out, the highest frequencies were depression (47.8%), panic attacks (13%) and drug and alcohol problems (8.7%).
Questionnaire measures

Eleven useable questionnaires were returned (42.3%). Table 3 below indicates the means, standard deviations and total scores for the 14 items. The final two columns indicate the number of 'strongly disagree' (0) / 'disagree' (1) and 'agree' (3) / 'strongly agree' (4) response to each item.

Table 3: Means, standard deviations, total number of responses to each statement

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Total</th>
<th>Number of 0 and 1 responses</th>
<th>Number of 3 and 4 responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>It took too long to get there</td>
<td>1.6</td>
<td>1.6</td>
<td>7</td>
<td>18</td>
<td>4</td>
</tr>
<tr>
<td>Public transport was inadequate</td>
<td>1.8</td>
<td>1.7</td>
<td>20</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>I found it difficult to balance other commitments</td>
<td>1.5</td>
<td>1.3</td>
<td>16</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>I forgot about appointments</td>
<td>1.1</td>
<td>1.5</td>
<td>12</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Problem improvement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapy had helped enough</td>
<td>1.1</td>
<td>0.8</td>
<td>12</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Problems went away by themselves</td>
<td>0.5</td>
<td>0.7</td>
<td>6</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>I did not think that my problems were serious enough to see a psychologist</td>
<td>1.2</td>
<td>1</td>
<td>13</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Appointment times were not flexible enough</td>
<td>0.7</td>
<td>0.6</td>
<td>8</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>I did not like the psychologist</td>
<td>0.8</td>
<td>1.4</td>
<td>9</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>I did not like the style of therapy offered</td>
<td>1.6</td>
<td>1.2</td>
<td>18</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>I wanted to talk to a male therapist</td>
<td>0.3</td>
<td>0.5</td>
<td>3</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Therapy was not helping me with my problems</td>
<td>1.8</td>
<td>1.3</td>
<td>20</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>I found it difficult to talk about my problems</td>
<td>1.5</td>
<td>1.5</td>
<td>17</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>I felt that I was wasting the therapist's time</td>
<td>1.8</td>
<td>1.2</td>
<td>20</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
‘Practical issues’ received 13 agree/strongly agree responses, ‘problem improved’ received 1 agree/strongly agree response, whilst ‘dissatisfaction with the therapist/therapy’ received 9 agree/strongly agree responses. Therefore, for this population, practical issues and dissatisfaction proved to be the most important factors in clients’ decisions to drop out of therapy.

Statements relating to transport received 8 agree/strongly agree responses. Each of the following statements received 4 agree or strongly agree responses: I found it difficult to talk about my problems; I felt that I was wasting the therapist’s time; I did not like the style of therapy; Therapy was not helping. Three clients reported that forgetting their appointments resulted in drop out. None of the participants reported the fact that their problems had improved or that therapy had helped enough as reasons for dropping out.

Discussion

The present study aimed to a) compare drop out rates at the present location with those described in the literature, b) examine characteristics of drop-outs compared to those who complete therapy and c) identify client reasons for dropping out. Findings of the study were fed back to the CMHT (see appendix 5).

Despite concerns regarding drop out from therapy in the present location, this study indicates that rates are significantly lower than the average rate of 47% quoted by Wierzbicki and Pekarik (1993). Such concern appears to be common place amongst clinicians (Tweed and Salter, 2000) and without reference to rates in other services, it is easy to see how clinicians could become demoralised.

The current emphasis on clinical effectiveness and the scientist-practitioner model may serve to strengthen the view of the clinical psychologist as the ‘all-knowing expert’ and increase the pressure to ‘get it right’ (Pilgrim and Treacher, 1992). Consequently, the
importance of assessing drop out rates both to provide feedback to clinicians and to develop service delivery is emphasised by these findings.

Consistent with previous studies, no differences in terms of age, sex or distance to travel was found between those who completed therapy, dropped out or did not attend. However, the small sample sizes used here may have obscured any real difference. Due to lack of available data, factors previously associated with client drop out including socio-economic status (e.g. Trepak, 1986), ethnicity (Sue, McKinnen, Allen and Hall, 1974) and education level (Weighill, Hodge and Peck, 1983) were not included in the study. Such information would have provided a more comprehensive view of drop out patterns.

Clients identified as drop-outs attended an average of 6.5 sessions, which is comparable to the average attendance of 6-8 sessions at community mental health centres reported by Garfield (1994). Significantly, it did not differ from the mean number of sessions attended by completers (6.5), supporting the view that therapy duration is an unreliable method of identifying drop out. 48% of drop-outs here had a primary diagnosis of depression. In light of previous findings that the best outcome for severe depression followed 16 sessions, information regarding severity of symptoms would have been useful in examining the impact of drop out on specific groups of clients.

Contrary to previous findings (e.g. Pekarik, 1992), responses to the questionnaire were not evenly distributed across the three hypothesised categories. Rather, the majority of reasons were evenly distributed between ‘practical issues’ and ‘dissatisfaction with therapy/therapist’. Whilst this may simply reflect the idiosyncrasies of the present population, an alternative explanation is that these results reflect a bias in who responded; those who were dissatisfied with the service may have felt more compelled to complete the questionnaire than did those who experienced a reduction in problem severity.
Of those who did respond, the relatively high rate of ‘practical issues’ associated with drop out reflects 8 negative responses to statements relating to transport, suggesting access to the team may cause difficulty to some clients. This appears to contradict findings from the referral audit, which indicated that distance to travel was not a significant factor in drop out. However, it is possible that, regardless of distance, some clients find it difficult to negotiate public transport, thus influencing their decision to terminate therapy.

Four clients reported that their decision to drop out was influenced by the style of therapy offered. It is difficult to draw any conclusions about these findings as none of the participants provided comments to explain their response. However, Todd, Deane and Bragdon (2003) comment on the fact that expectations of therapy have a strong impact on an individual’s views of the therapy process and goals. Similarly, having found considerable differences between client and therapist reasons for drop out, Hunsley, Aubry and Verstervelt (1999) recommend that research on client drop out should be related to the broader literature on both client and therapist expectations about therapy.

Again, without explanatory comments, it is difficult to draw conclusions about the fact that seven clients felt that they were wasting the therapist’s time. It would be useful for future research to investigate exactly how this statement relates to the client’s experience of therapy. If, for example, these responses related to client characteristics such as minimising problems, then clinicians would be able to identify this as an early predictor of drop out and provide the opportunity for clients to discuss their views on the legitimacy of their problems.

Relatively high response rates to the statement ‘I found it difficult to talk about my problems’ may support previous findings by Pekarik and Finney-Owen (1987) that client resistance constitutes a fourth general category of reasons for drop out. Further research could aim to delineate factors associated with this response and the degree to which it relates to both client and therapist characteristics.
Limitations of present study

Due to the low numbers involved in this study it is difficult to draw firm conclusions or generalise findings. Furthermore, the study was limited in terms of available client data and therefore the breadth of investigation.

In relation to questionnaire responses, the time between drop out and questionnaire completion varied considerably between participants (1 year to 2 months), possibly decreasing the reliability of some participants' recall of experiences during therapy.

A number of statements in the questionnaire, such as 'I felt that I was wasting the therapists time', are too general for specific conclusions to be drawn about how the process of therapy contributes to clients dropping out.

Recommendations

Providing prospective clients with an information leaflet may help them to develop more realistic expectations of therapy. Webster (1992), for example, found that providing an information leaflet reduced apprehension and consequently drop out rates. This effect increases when the information leaflet is sent with an opportunity to opt in/out form (Keen, Blakey and Peaker, 1996). A pre-assessment questionnaire providing clients with an opportunity to describe problems and identify goals would help client and therapist work towards shared therapeutic aims.

The level of knowledge referrers have of the service has also been shown to have an impact on drop out rate (Trepak, 1986). One option for the present location is to provide information about the psychology service to other professionals; this would assist them in their decision to refer, and help them to inform prospective clients about the service.
If a more comprehensive analysis of drop out in the present location was to be conducted then it would be useful to develop a system to record details such as socio-economic status, ethnicity, education level and symptom severity for future investigation.

In relation to access to the service, providing clients with information on routes and timetables for local public transport services may improve accessibility of the service.

Finally, in order to assist clients in providing accurate reflections of their experience of therapy, questionnaires could be sent out after a short, predetermined period following drop out.

References


Appendix 1

Ethics scrutiny form signed by placement supervisor
The nature of the proposed project is such that I am satisfied that it will not require scrutiny by the trust's ethical committee.

Name of Supervisor: Jean Foley
Signature of Supervisor: Jean Foley

Name of Trainee: Philip Anderson

Title of SRRP: An Investigation Into Client Drop Out From an Adult Out-patient Psychology Service

Date: 28/03/03
Appendix 2

Questionnaire sent to participants identified as drop-outs
Reasons for Discontinuing Psychology Sessions

Below are a number of statements about why people end therapy early.

Please indicate how much each statement applies to you by circling one of the numbers to the right of each statement. The numbers range from 0 (strongly disagree) to 4 (strongly agree).

We have provided a space below each statement where you can add your own comments. You can also add any other general comments you have about the psychology service at the end of the questionnaire.

Thank you very much for your time.

Date of Birth..../..../....  Sex M / F  Car owner at time of using psychology service Y / N

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It took too long to get there</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Comments:</td>
<td></td>
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<td></td>
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<tr>
<td>2. Public Transport was inadequate</td>
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<tr>
<td>Comments:</td>
<td></td>
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<tr>
<td>3. I found it difficult to balance other commitments (e.g. children, work)</td>
<td></td>
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<tr>
<td>Comments:</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>4. The appointment times were not flexible enough</td>
<td></td>
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<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5. I found it difficult to talk about my problems</td>
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<tr>
<td>Comments:</td>
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<tr>
<td>6. I wanted to talk to a male therapist</td>
<td></td>
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</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please turn over...
<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Undecided</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. I did not need to see the therapist any more – therapy had helped enough</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. My problems went away by themselves</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I did not think that my problems were serious enough to see a psychologist</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I did not like the psychologist</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I did not like the style of therapy offered</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Therapy was not helping me with my problems</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I felt that I was wasting the therapist’s time</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I forgot about my appointments</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do you have any other comments about the psychology service: 

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
Appendix 3

Letter accompanying first mailshot of questionnaires
Dear Ms./Mr...

As you know, ....... Community Mental Health Team provides a psychology service to individuals who feel that they might benefit from this type of support.

In order to find out how effective the psychology service is in meeting your needs, I have been asked to conduct research into the reasons why some people do not continue with their psychology appointments.

....... records indicate that you had at least one appointment with the psychologist then decided, or where not able to continue with your appointments. It would help us a great deal if you could tell us about your experience of ......... Psychology Service and the reason why you stopped attending.

As with many people, you may have stopped attending then restarted your sessions at a later date and may currently be seeing the psychologist. We would still like you to complete the questionnaire, as we are interested in why it is that people stop attending in the first place.

The research is completely confidential. None of the staff involved in your care at ....... will see your answers and your participation will in no way affect your current or future care.

I would appreciate it if you could spend 5-10 minutes completing the enclosed questionnaire, which asks about your reasons for discontinuing attendance with the psychologist. The questions do not ask for any personal information or about the reason for your referral. A pre-paid envelope is provided for return of the completed questionnaire.

If you have any questions about the research project please feel free to contact me, in confidence, on the number above.

Kind regards

Yours Sincerely

Trainee Clinical Psychologist.
Appendix 4

Letter accompanying second mailshot of questionnaires
Dear...........

We recently sent you a questionnaire about the reasons why some people decide to stop attending psychology sessions at ...... Community Mental Health Team.

The research, which is completely confidential, is design to help us improve the psychology service. Therefore your experience of the service is great value to us.

If you have already completed the questionnaire and returned it to us then please accept our appreciation and disregard this letter.

If you have not yet filled in the questionnaire, a similar one is enclosed for you to complete and return in the pre paid envelope provided. We would be most grateful for your help.

Kind regards

Yours sincerely

Trainee Clinical Psychologist.
Appendix 5

Letter confirming feedback of research findings to Community Mental Health Team
Our Ref: JE/MD1907

DATE 19th July 2005

TO WHOM IT MAY CONCERN

This is to confirm that Phillip Anderson has fed back his small-scale research project on:

**NON ATTENDANCE**

to Conifers Mental Health Team members.

Signed

Jean Eley
Clinical Chartered Psychologist
The Impact of Receiving a Diagnosis of Asperger’s Syndrome on the Self-concepts of Adults: An Interpretative Phenomenological Analysis

Abstract

Previous research has provided contradictory findings regarding the capacity of adults with a diagnosis of Asperger’s syndrome to reflect on and express their inner experiences. This has led to the proposal that only those people functioning at the higher end of the autistic spectrum have the rich and complex self-concepts associated with development in those without the diagnosis. There has been little research into the ways in which receiving the psychiatric diagnosis of Asperger’s syndrome impacts on the self-concepts of those so labelled. The present qualitative study explores this issue via the self-descriptions of eight adults with the diagnosis.

Analysis of interview data revealed that participants were able to provide rich descriptions of their inner experiences, which included thoughts, feelings and interpersonal experiences. In relation to diagnosis, participants expressed ambivalence about receiving a label of Asperger’s syndrome. This was accounted for by a number of factors including mixed messages from professionals during diagnosis, lack of follow-up support in understanding and coming to terms with the diagnosis and efforts to externalise problems in order to increase a sense of mastery over them. The majority of participants were aware of negative social attitudes towards psychiatric labels. However, such descriptions did not necessarily become salient features of participant’s self-concepts. Participants were active in rejecting negative stereotypes they saw as inappropriate and in fact described themselves in terms of characteristics that are counter-intuitive to the diagnostic descriptions used to diagnose Asperger’s syndrome.
1. Introduction

1.1 Definitions of the self-concept

Dominant personality models of the self-concept generally conceive of the self as a relatively stable cognitive representation or schema (for example, Markus, 1990, Costa and Macrae, 1992). However, even within these self-schema theories, the introduction of concepts such as a working self-concept (Markus and Wurf, 1987), which describes the varying accessibility of self-aspects that surround a more stable core self, allow for some fluidity (although the core self is seen as unchanged by social circumstances). Within this tradition, Onorato and Turner (2004), for example, describe the self-categorisation model. The authors draw on research by Kuhn and McPartland (1954) and McGuire and McGuire (1988) which they say demonstrates that social identity, consisting of comparisons between the self and others, is often more salient than any personal notion of self. They do, however, acknowledge that broad categories such as ‘British’ and ‘female’, held in long-term memory stores, are used as more stable self-referent dimensions.

Thoits (1983) emphasises that people have multiple social identities. She employs a social-interactionist perspective in the development of her arguments, drawing on the theory of Mead (1934) to propose that individuals develop social selves based on the roles and categories ascribed to them by specific others and society in general. Incorporating these roles into one’s identity provides a sense of meaningful existence and purposeful behaviour. Thoits points to a number of studies suggesting that those who hold fewer social roles are at greater risk of developing psychological problems (Grove, 1980, Link, 1984). Thoits’ (1983) own investigation of the relationship between social identities and well-being also indicated that a greater number of social identities correlated with less psychological distress.

More recent theorising, influenced by the postmodern tradition, has further challenged the view that the self is stable, referring instead to a relational self. Rather than being a
fixed, internal entity, the self is described as a 'self-in-action’ (Flaskas, 1999), which is constantly being created and recreated in social interaction. Particular attention is paid to the role of language in the construction of these self-narratives. Anderson (1997), for example, describes how the self is a created concept, constructed through language in relationships. Taking constructionist notions of language to their logical extreme, authors such as Gergen (1994), argue that we can only ever know our selves through language, which is it’s self a constructed tool embedded in a specific historical and social context. The self, then, becomes bounded by the language available and therefore by current definitions of what it means to be human (p.211). Whilst this radical view of conceptions of self assists us in acknowledging the fluidity of identity and the influence of broader cultural factors on the way in which we think of our selves, Flaskas (1999) has highlighted a possible limitation in this theorising. She suggests that as well as the constructed narratives we have about our selves, it is also helpful to make space for elements of our experience, which are not, or cannot always be put into words. Flaskas draws on the notions of pre-linguistic experiences of the infant in early attachment relationships (Stern, 1995) where the infant must have some sense of self in order to set out on the path of trying to symbolise experience through language. Flaskas suggests that narratives are one way of coming to knowing our selves, but emphasises the importance of acknowledging the experiencing self, which often exists outside the bounds of language.

I have chosen to draw on Thoit’s notion of social roles and Flaskas’ ideas regarding both the continually reconstructed narratives of self and the experiential, often emotional self, which is less tethered by language. This fits with my own notions of a fluid self. Whilst not wishing to present to the reader the idea that these models are an accurate or true reflection of a self-concept, they have influenced the way in which I have presented and discussed the present study.
1.2 Asperger's syndrome - historical overview

The symptoms commonly associated with Asperger’s syndrome were first described by the Austrian paediatrician Hans Asperger (1944), who identified a group of children he saw as withdrawing into their own psychotic world. The children presented with specific difficulties in the areas of social interaction, communication and idiosyncratic patterns of interest, for example, memorising bus and train timetables. Asperger also commented on the children’s poor co-ordination and motor clumsiness. He considered the problems an indication of an underlying personality disorder and used the term Autistic Psychopathy.

Working independently from Asperger, Leo Kanner (1943) described a similar group of children exhibiting a triad of impairments including qualitative impairment in social interaction, qualitative impairment in communication and restrictive, repetitive and stereotyped behaviours, interests and activities. Kanner used the term ‘early infantile autism’ following Eugene Beuler’s use of autism in the early 1900’s to describe individuals who exhibited disturbances of contact with the social world.

Lorna Wing (1981) brought the descriptions provided by Kanner and Asperger to the attention of the English speaking world. Wing suggested the term ‘autistic spectrum disorder’ (ASD) to describe the variability in a ‘triad of impairments’ including social interaction, communication and imagination, evident across individuals. Wing introduced the term Asperger’s syndrome, referring to a group of individuals functioning at the higher end of the spectrum who exhibit specific difficulties with speech, non-verbal communication, social interaction, motor co-ordination and idiosyncratic interests, but who did not meet the criteria for autism.

Since the introduction of the term there has been constant debate as to whether Asperger’s syndrome is a condition distinct from autism, or whether it describes individuals functioning at the higher end of an ‘autistic spectrum’, as Wing (1981) proposed. Research by Tantum (1988) focused on specific characteristics of Asperger’s syndrome and autism,
emphasising various differences between the two. Tantum highlighted the lack of delay in language or cognitive development in Asperger’s syndrome often evident in more impaired individuals. These differences were supported in the field trials of the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (1994) (DSM-IV), which found enough information to include Asperger’s syndrome as a discreet category belonging to the Pervasive Developmental Disorders (PDD). DSM-IV uses the same core criteria of impairments in social interaction, communication and restricted and stereotyped patterns of behaviour, interests and activities, highlighting lack of delayed speech and age appropriate cognitive abilities as the defining features differentiating Asperger’s syndrome from autism. The International Classification of Diseases and Related Health Problems, 10th edition (ICD-10) (World Health organisation, 1995) has taken a similar stance and now provides differential diagnostic criteria for autism and Asperger’s syndrome.

A criticism of the diagnostic criteria described above relates to the findings of Wing (1981) and Gillberg (2002), who reported identifying a number of adults with Asperger’s who also exhibited delayed speech development as children. A more general criticism is the fact that the definitions are based on research focusing on children. Because specific symptoms often decline with age, for example, repetitive behaviours and a focus on fine detail in the environment, the criteria are not useful for diagnosis in adult populations. This is particularly relevant as 46% of people with Asperger’s syndrome are diagnosed after the age of 16 (Tantum, 2003). In light of these diagnostic difficulties, Olly and Gutentag (1999) highlight a general agreement amongst professionals that the differential diagnosis of ASD’s is a daunting challenge characterised by subjective professional judgement. As a consequence people are often misdiagnosed with other mental health problems or receive no diagnosis at all (Barnard, et. al., 2001).

Despite the difference in focus across the various diagnostic criteria, all converge on identifying the central features of Autistic Spectrum Disorders as difficulties in communication, social interaction and imagination/stereotyped thoughts and behaviours. In the present study the definitions of Autism and Asperger’s syndrome provided in DSM-IV
have been used. However, in line with suggestions by Klin, Pauls, Schultz and Volkman (2005), emphasis is given to the narrative text accompanying the diagnostic criteria describing features that are not seen as essential for a diagnosis. This allows for a greater distinction between different manifestations of difficulties and a greater differentiation between Autism and Asperger’s syndrome. For example, differentiating between individuals who isolate themselves and those who actively seek social interaction, but in a socially insensitive manner. Furthermore, in terms of language, distinctions can be made between those who’s language is delayed, echolalic or stereotyped (typical of autism) and those who’s language is developed but pragmatic in use (typical of people with Asperger’s syndrome).

1.3 Theoretical models of Asperger’s syndrome

Whilst a number of models have been proposed only three will be described here. Theory of Mind (Baron-Cohen, 1993, Frith, 1989) and Socio-Affective (Hobson, 1989, 1994) models were chosen as they reflect two main distinctions in theorising about the aetiology of autistic spectrum disorders; those that focus on affect and interpersonal-relational factors and those that emphasise cognitive deficits. A model describing relationships between early attachment experiences and the development of self/other awareness (Fonagy and Target, 1997) will also be described. Whilst Fonagy and Target do not make particular reference to Autistic Spectrum Disorders, their model provides insight into possible internal mechanism and external social contingencies impacting on the development of children’s ability to consider their own and other’s mental states.

1.3.1 Theory of mind

One of the most commonly cited models is the Theory of Mind model (Baron-Cohen, 1993, Frith, 1989). Theory of Mind (ToM) refers to the ability to attribute mental states to self and others in order to predict and explain behaviour. Children generally acquire the explicit ability to understand that others have beliefs about the world and intentions that
influence their behaviour from around the age of four years (Perner, 1990). Baron-Cohen, Leslie and Frith (1985) propose that it is a lack of, or a delay in the development of this ability to read other’s minds that underlies the problems experienced by children with ASD’s. The model also proposes that ToM deficits stem from neurological impairments in discreet areas of the brain (frontal lobes) with specific roles in ToM functioning.

Evidence supporting the ToM model comes from studies assessing children’s ability to attribute false beliefs to others, where children with ASD perform poorly in comparison to ‘normally developing’ controls (Baron-Cohen, Leslie and Frith, 1985). Even those who do pass these simple tests are found to be impaired on more complex ‘second order’ tests examining beliefs about beliefs (Baron-Cohen, 1989). Social withdrawal is seen as a consequence of this lack of ability to explain the behaviour of others in relation to their mental states; the behaviour of others appears unpredictable, making social interaction confusing and stressful. In addition, Baron-Cohen suggests that lacking theory of mind would explain the limited motivation to communicate identified in people with ASD’s. Without awareness of the knowledge that others posses, it is difficult to know what information is required during communication.

The strength of the Theory of Mind hypothesis has been undermined to some degree by findings that a minority of individuals with high functioning autism or Asperger’s syndrome are able to succeed on even advanced theory of mind tests (Bowler, 1992, Happe, 1994, Ozonoff, Pennington and Rogers, 1991). However, Frith, Happe and Siddons (1994) suggest that passing theory of mind tests in controlled conditions does not mean that individuals can cope with the subtle nuances of everyday interactions. Consequently, they suggest that people with Asperger’s syndrome appear slow to respond in social interactions, as they attempt to ‘compute’ the correct meanings conveyed by other’s body language, often with limited success. A further limitation of the model is the fact that ToM deficits are also exhibited by children with Attention Deficit Hyperactivity Disorders (Gillberg, 2002), indicating that this difficulty alone is not sufficient to identify individuals with ASD’s or to explain all the problems they present.
1.3.2 Theory of Mind and Self-concepts

The Theory of Mind model of Autistic Spectrum Disorders described above focuses on the lack of awareness of other people as centres of their own experience, possessing thoughts and emotions that guide their behaviour. The ToM model goes further in suggesting that this lack of awareness of intention and motivation extends to the individual’s self-perception. The model suggests that people with ASD’s, whilst they may be able to experience their own mental states, are often unable to reflect on them and are unaware of their own intentions and goals. Frith and Happe (1999) suggest that people with ASD’s interpret their internal experiences as newly processed perceptual information and are not able, or are limited in their capacity to differentiate between what is for example, a memory, an ongoing thought or an attitude. A study by Philips (1993) investigated this idea through the use of a target-shooting task. Philips asked normally developing children and children with autism who were all aged 5, which targets they were going to shoot at, knowing that there was a reward behind one of them. After shooting they were asked again which target they aimed at. Normally developing children usually replied that they had aimed, for example, at the blue target, but hit the red by mistake, even when the blue target led to the reward. Those children diagnosed with autism, however, commonly stated that they meant to hit the blue, even if they had been aiming for the red target. Philips interpreted these findings as suggesting that the children with autism were unable to differentiate between the outcome of their actions with own intentions. Hurlburt, Happe and Frith (1994) propose that because the ability to read one’s own and other’s minds appear at the same time developmentally (Gopnik and Meltzoff, 1994), they may share neurological and cognitive mechanisms.

1.3.3 Socio-Affective Model of autistic spectrum disorders

Hobson (1989, 1993) provided an alternative explanation for the central features of ASD’s, proposing that symptoms are best viewed as resulting primarily from a deficit in the individual’s ‘inborn capacity’ to form affective relationships, which in turn are a result of
an underlying neurological impairment. The model, in contrast to the cognitive model described above, focuses on the interpersonal-developmental nature of self/other awareness. Evidence supporting the innate capacity to attune to the emotional states of others is drawn from studies indicating that infants, from around the age of 7 weeks, engage in ‘protoconversations’ (Bateson, 1979), or preverbal interactions with caregivers. These interactions are seen not just as imitation of the mother’s behaviour by the child, but as a mutually led communication in which the child can be seen to regulate the mother’s behaviour and vice versa. On occasion, the infant attempts a complex set of expressive movements suggesting more than the expression of a single emotional state. These utterances are interpreted as the child offering a message about its feelings and also can be seen as the infant responding to the perceived emotional state of the caregiver (Stern, 1974 and Trevarthen and Hubley 1978). At this stage the child does not have a concept of others with emotional states, but is naturally attuned to behaviours that reflect non-verbal communication of the caregiver’s internal emotional state.

In the first few months of life the infant tunes in to the emotional expressions of caregivers through the perception of their non-verbal communication and begins to learn that these expressions relate to specific events in the environment, including the self. At approximately 8 months the child uses ‘social referencing’ to guide her/his behaviour. For example, Sorce, Emde, Campos and Klinnert (1985) found that when a visual cliff was placed between an infant and a toy the child responded to the emotional expressions of the mother to determine whether it ‘crossed’ the cliff. Hobson (1989) suggests that through having their own affective response to the environment changed as a result of another’s emotional response to the same stimuli, the infant learns that objects or events can have an affective meaning for others that differ from their own affective attitudes towards the same stimuli. This relational triangle (Hobson, 1989) represents the first step in the infant learning that other people have minds that adopt a position with regard to the world.

Hobson proposes that the infant, through the process of affectively attuning to those in their social world and recognising at a pre-verbal, non-conceptual level that others are
'centres of their own experience' (p.169), begins to recognise themselves as an object towards which others hold affective attitudes. The child then begins to adopt an objective or decentred view of themselves, a process of self-reflection through the eyes of another. Internalising the emotional communicative behaviours of others towards the self is seen as the first step in the process of self-reflection. Having developed the capacity to self-reflect (primarily on their emotional experience) the child then begins to project their own internal states onto others. Only through having the experience of reflecting on a self does the child begin to understand that others can also reflect on their own internal experiences; the child develops a concept of others as thinking, feeling people.

Hobson proposed that children on the autistic spectrum lack or are slow to develop the innate motivation to receive the affective communications of others. As a consequence, their capacity to perceive of themselves, and consequently others, as thinking, feeling people is restricted. Continuing with this hypothesis, Hobson further suggests that the self-concepts of such individuals will be limited to physical characteristics rather than psychological states including thoughts and feelings.

A further point needs to be made regarding the reference to other developmental process occurring in the infant that Hobson (1989) describes as necessary for the process of developing a concept of minds. Firstly, Hobson draws attention to the increasingly sophisticated cognitive structures of the infant's developing brain (involving for example, memory), which allows the process of internalising information from the social environment and forming cognitive structures that represent the interaction between the child and the outside world. Secondly, Hobson highlights the role of language development in the formation of complex self-concepts. However, he does not elaborate on how language influences and shapes the content and structure of the self-concepts of children. Neisser (1997, p.16) elaborates further on this issue, proposing that the self develops within a specific cultural context and that shared understandings of human nature, transmitted through language and other symbols, are internalised by the developing infant, which in turn influences how we learn about our selves.
1.3.4 Early Attachment experiences and the development of self/other awareness

Fonagy and Target (1997) have also turned their focus on the influence of early infant/caregiver relationships on the capacity to develop awareness of one’s own and other’s mental states. The authors draw on attachment theory (Bowlby, 1992), which aims to describe the quality of infant/caregiver interactions by categorising them at the broadest level, as either secure or insecure attachments. Bowlby initially suggested that the level of parental sensitivity to an infant’s emotional states would influence the child’s ability to develop and utilise an understanding of the caregiver’s perspective. Developing this idea further, Fonagy (2001) proposes that Interpersonal Interpretive Mechanism (IIM) that underlies our ability to develop an awareness of our own and others attitudes and intentions. IIM’s are described as “a collection of neurocognitive mechanisms that are naturally selected to evolve under the influence of early social interactions” (Fonagy, 2001 – p.226). Like Hobson’s model, it emphasises the role of early emotional experiences involved in the child’s developing awareness of their own and other’s mental states. However, Fonagy and Target (1997) give even greater emphasis to the relationship between biological preparedness and the child’s experience of early attachment relationships.

Fonagy (2001) further draws on the model of ‘psychofeedback’ proposed by Gergely and Watson (1999) to explain the relationship between early relationships and development of mentalising abilities. The psychofeedback model describes how the child’s metarepresentational system is initiated in the first months of life by an internalisation of the caregiver’s empathic mirroring of its own emotions. The caregiver’s empathic response is recognised by the child as an organiser of their emotional state, which is the bedrock of the intimate connection between attachment and self-regulation. Through this process, the child is developing an awareness of its own internal states. Over time, emotional experience takes on a functional role for the child, for example, acting as a trigger or
inhibitor of behaviour. A central difference between the psychofeedback and socio-affective models is Gergely’s (2001) suggestion that this move to a functional awareness is triggered at around the age of 3 months by a switch in the child’s innate capacity to recognise cause and effect relationships to detect social contingencies. Following this switch, the child’s focuses on the interaction between it’s own emotional states and the responses of caregivers. Finally, reflective awareness develops where the child can reflect on their emotional state before it results in an action response.

Fonagy (2001) explains that this process of the child developing an awareness of their own internal states is an intermediary step in them understanding that other’s also have psychological experiences. Fonagy and Target (1997) describe a number of studies that show a positive relationship between early infant-child relationships and later ToM ability. For example, a study by Bretherton and Beeghley (1992) indicated a positive relationship between sensitive care-giving and parental openness to emotional expression and children’s later performance on ToM tasks. In terms of self-reflective ability, Main and Kaplan (1991) found that children observed in secure attachments with their mothers at 12 months exhibited increased presence of self-talk as toddlers and greater spontaneous self-reflective remarks at 6 years.

Fonagy (2001) does not comment specifically on the relationship between the model described above and ASD’s. However, he does suggests that if the mechanisms underlying attachment (IIM’s) are weaker either because of attachment experience or biological problems, individuals will not develop as strong an ability to differentiate between themselves and others. In extreme cases, the lack of an interpretive mechanism that sustains social relations functions so poorly that the capacity to arrive at representations of the mind states of others independent of those of the self are profoundly compromised. Given the focus on the inter-relationship between biological and experiential factors, one could assume from the model that the ability to develop even the most limited level of self/other awareness in those infants who have biological abnormalities would be attenuated by the responses of others in their early environment.
1.4 Autistic Spectrum Disorders and self-awareness

The cognitive and socio-affective models described above share the view that features central to ASD stem from neurological impairments that underlie the lack of ability to ascribe mental states to one's self and others. Hobson's (1989) model however, places greater emphasis on the role of emotional relatedness as an underlying problem resulting in ToM deficits. The Socio-affective model also deviates from the cognitive model in that it pays particular attention to the way in which awareness of the self as a thinking, feeling person affects one's capacity to develop a coherent concept of others. Fonagy and Target (1997) move further away from a purely cognitive explanation of mentalising capacities and emphasise the interrelationship between biological factors and early attachment experience.

Initial support for the lack of awareness in people diagnosed with an ASD comes from studies exploring the affective experiences of autistic children. Hobson’s (1986) own research highlighted difficulties with recognising and expressing own emotions exhibited by children on the autistic spectrum. Further support comes from a study by Dawson and McKissick (1984) in which he interviewed parents of 93 individuals with high-functioning autism in order to explore how their children thought about their difficulties. The results indicated that whilst 35 of the 93 young persons reported a sense of difference, only 11 reported worrying about it. Dawson explains the results as supporting the view that people with ASD’s have limited capacity to self-reflect and are limited in their capacity to identify and express their own emotional experiences. Whilst the large sample size of the study supports the generalisability of the findings, the fact that observer reports were used weakens their validity.

More recent support for the lack of self-awareness in people with ASD’s comes from a study by Lee and Hobson (1998), who compared the self-concepts of 12 children with and without a diagnosis of autism, using Damon and Harts (1988) semi-structured self-understanding interview. The instrument is based on a multidimensional model of self-
understanding in which they delineate the physical, active, psychological and social selves. In addition, Damon and Hart identify four levels of self-knowledge relevant to each of the above domains. These include 1) Categorical identifications - characteristics of the self are important in and of themselves, without any underlying significance 2) Self/other comparisons 3) Interpersonal relationships and 4) Plans and goals - the self is organised around personal moral and belief systems. These levels reflect four developmental levels of self-reasoning, with plans and goals representing the most conceptually advanced. Based on the socio-affective theory described above, the authors hypothesised that autistic children would be less psychological and social in their self-descriptions. The authors report that these predictions were supported by their results. In addition, those socially related reflections autistic children did make were at a ‘lower level’ than the non-autistic controls; whilst the children exhibited some degree of social awareness (‘I am good’ or ‘I am nice’), they did not acknowledge other people in their self-descriptions. In relation to the psychological category, Lee and Hobson found no difference between groups in terms of number of statements used to describe the self. However, the autistic children’s responses were predominantly made of physical/material preference statements, whereas those of non-autistic children included a greater number of social likes and dislikes. There were no differences in the number of emotional self-statements. However, the authors suggest that emotional responses of non-autistic children were more varied and less ‘restricted’ than emotional descriptions given by the autistic children. Whilst the research described above provides illuminating insights into the way that people with autism describe themselves, it provides little insight into how these people feel about themselves.

Damon and Hart’s (1988) schedule focuses on conceptualisations of the self in terms of characteristics, but has only one question that addresses self-evaluation, a factor commonly related to self-esteem.

Whilst the studies above provide valuable insights into the self-reflective capacities of younger people diagnosed with ASD’s, they provide limited understanding of how adults with a specific diagnosis of Asperger’s syndrome experience their inner worlds. This is particularly important given findings that many of the diagnostic features of Asperger’s
syndrome disappear or diminish with age (Tantum, 2003) and the fact that people with Asperger's often develop insight into their difficulties around adolescence/early adulthood (Hill, Berthoz and Frith, 2004). There are only a few efforts to explore this area - these are described below.

1.5 Self-awareness in adults with Asperger's syndrome

In order to test the relationship between ToM and self-perception Hurlburt, Happe and Frith (1994) used the 'descriptive experience sampling method', in which the three adults with Asperger's syndrome wore a device that produced a bleep, signalling the participants to write down details of their experience at that moment. The study found that the majority of reported experience consisted of visual images and a paucity of other types of thinking such as inner verbal experience, unsymbolised thinking and emotions frequently reported by a control group of adults. In addition, the two participants who scored highest on the ToM tasks also found the self-reflective task easier to engage in, which, the authors highlight, suggests that self-reflective capacity is linked to the ability to attribute mental states to others. Whilst the authors highlight the fact that 'self-reflective' abilities vary greatly across the spectrum, they suggest throughout the article that individuals with Asperger's syndrome who have a well-developed capacity for self-reflection are a 'talented minority'. This, they suggest, provides support for the hypothesis of a paucity of an introspective psychological self in higher-functioning autistic people.

Accessing thoughts at specific periods in time, however, does not necessarily equate with how individuals think about themselves and their experiences generally. The results could also be explained as participants finding it easier to express their inner experiences in visual form.

A further source of information about the inner experiences of people with Asperger's syndrome comes from the autobiographical writings of people with the diagnosis. Happe (1991) analysed the writings of three adults with Asperger's syndrome and reported that a
common feature of the material was a limited insight into their own emotions and thought processes. Despite being able to reflect on their own and other’s behaviour, they lacked the awareness of mental states (thoughts and feelings). Again, just because people chose to express themselves in their autobiographical accounts in terms of behaviours does not mean they were unable to reflect on emotional experiences.

Focusing specifically on the idea that people with Asperger’s syndrome have difficulty processing their own and others emotions, Hill, Berthoz and Frith (2004) assessed the cognitive processing of emotions of 27 high-functioning adults with ASD’s. Thirty-five adults without a diagnosis and 49 relatives of individuals with ASD were also included as control groups. The authors utilised the TAS-20, a 20 item self-report scale measuring three components of emotional processing including identifying feelings, describing feelings and externally oriented thinking. The authors also assessed levels of depression using the Beck Depression Inventory (BDI-II) (Beck, Steer and Garbin 1988). Results indicated that 13 of the 27 adults with ASD fell within the severely impaired category for emotional processing difficulties compared with none of the controls and only one of the relatives. Furthermore, adults with ASD scored significantly higher on all three emotional expression difficulty sub-components. The adults with ASD exhibited significantly higher scores on the BDI-II. However, the differences in emotional processing remained significant even when depression scores were controlled. The authors concluded that although the individuals with ASD had some insight into their own and other’s minds, they showed difficulty in identifying and describing feelings. They also concluded that through compensatory learning from experience, the adults with ASD slowly acquire an explicit ToM and consequently developed increasing awareness of their difficulty fitting in, which may have explained to some degree the significantly higher depression scores in the ASD group. The authors did not however, control for anxiety, a common experience of people with Asperger’s syndrome, which may have influenced their ability on the emotion recognition and expression tasks.
Robert, Jones and Huws (2001), following their qualitative study of the experiences of people with autistic spectrum disorders posted on the internet, challenge the prevailing view about ASD and emotions. Roberts et. al. found that the material they analysed implied that emotional issues are important to people with ASD and that the prevailing emotions evident in the writings they analysed included frustration, depression and fear/apprehension. Robert et. al. warn against making generalised assumptions about deficits in emotional processing and the importance of drawing on first hand accounts from people with ASD. Unfortunately, Roberts et al’s study was limited in sample size (5) and therefore their own participants may not have been very representative of the adult ASD population.

In an unpublished paper by Mavrapoulou (1995), the author examined how children and adults with ‘mild autistic disability’ (AS) think about themselves. Mavrapoulou utilised Damon and Hart’s (1988) semi-structured self-understanding interview to compare children identified as having ‘autistic tendencies’, children with moderate learning difficulties (MLD) and seven adults with Asperger’s syndrome. Mavropoulou found that there were no differences across groups in terms of physical and active self-descriptions. However, whereas only one of the AS children referred to their social selves, this was done by 7 of the MLD children and five of the six adults with Asperger’s syndrome. In addition to these findings, Mavropoulou also found that children with MLD and the adults with Asperger’s made social comparisons based on a range of physical, social and active features, whereas children with ASD found it more difficult to compare themselves beyond their physical features. These results support Tantum’s (2003) findings that as people with Asperger’s syndrome get older their self-concepts become more complex, with for example, social and emotional aspects of themselves becoming more salient. The study is limited in that no comparison was made with ‘normal’ adult controls, limiting the degree to which the self-concepts of adults with Asperger’s syndrome can be viewed in relation to normal adult self-concept development. A further limitation is that Damon and Hart’s (1988) interview schedule was designed specifically for use with children. In addition, the
fact that the children assessed were identified as having ‘autistic tendencies’ and had not received a specific ASD diagnosis also limits the reliability of the findings.

A further study by Hurlburt and Chalmers (2002) highlights the importance of adopting qualitative approaches in studies aimed at understanding the experiences of people with ASD’s. The authors report on interviews with three adults with high functioning autism that span over a 9-month period. Interviews were analysed using an open coding procedure where recurring themes were identified across the three participant’s interviews. Throughout the interviews participants were able to provide rich descriptions of their experiences, which included insightful reflections related to their thoughts and feelings about having an autistic spectrum disorder. For example, one of the participants commented on her experience of starting a social skills group:

“When it came to trying to figure out these social problems I felt isolated and alone. I was a little envious of neurotypicals’ ease in socialising...” (p.109).

Overall, the studies described above which have aimed to explore the inner worlds of people diagnosed with ASD’s suggests that those categorised as having ‘higher functioning’ disorders such as Asperger’s syndrome do develop some capacity for self-reflection and with this comes a more complex self-concept that includes thoughts and feelings. However, the majority of studies also support the view that even adults with Asperger’s syndrome will be limited in their ability to self-reflect and to access and express their own thoughts and feelings.

1.6 Stigma and identity

One question posed by the above findings is how receiving a label of Asperger’s syndrome would impact on the identities of people with limited self-awareness and limited opportunity for identification with meaningful social roles. The relationship between psychiatric diagnosis and stigma has been well-documented (Farina and Ring, 1965, Wahl,
However, if people with Asperger’s syndrome have limited self-concepts, we need to understand whether this would result in the label, and thus stigma, dominating self-descriptions, or whether limited self-concepts would serve as a protection against the effects of stigma. A great deal of research effort has been applied to investigating the impact of psychiatric diagnosis on identity and self-esteem. A number of studies have suggested a negative outcome in terms of self-concepts, self-esteem and social functioning. An overview of some of the main findings from the literature of stigma and mental illness are presented below.

1.6.1 Modified Labelling Theory

Over the last decade a prominent area of investigation has been the way in which membership of a stigmatised group, such as those with a psychiatric diagnosis, affects self-concepts, self-esteem and social functioning. Scheff’s (1966) Labelling Theory of mental illness proposes that individuals internalise society’s assumptions and expectations regarding mentally ill people even before experiencing mental health problems themselves. When their behaviour is perceived by others as falling outside of culturally defined norms and labelled as mental illness, the internalised assumptions and expectations take on personal relevance, guiding self-perceptions and behaviours. As a consequence, the individual adopts behaviours prescribed by the label, fulfilling the role of ‘mental health patient’. A number of criticisms have been raised against the model, most notably by Gove (1970) who, after reviewing the literature, concluded that individuals with a psychiatric diagnosis report very few experiences of direct discrimination and that the labelling process is a consequence of deviant behaviour rather than the cause.

Link (1982) developed Scheff’s original theory, arguing that by focusing on the impact of labelling on illness aetiology, other important influences are overlooked. Link’s Modified Labelling Theory (MLT) proposed that, through the mechanisms of discrimination, expectations of rejection and internalising of negative views of their abilities, practical aspects of an individual’s life would be negatively affected. He points to research by
Farina, Gliha, Boudreau, Allen and Sherman (1971), which showed that individuals who were told that others believed they had a mental illness behaved differently during a conversation with a stooge in comparison to a control group who were not told this. This was despite the fact that no such information about them had been given to the stooges. Link also refers to previous studies linking psychiatric status with self-concepts of labelled individuals. Becker (1963) for example, suggests that labels and the assumptions encapsulated within them become a central feature of a person’s self-concept. The longer a person holds this stigmatised status, the more likely the label becomes a ‘master status’, where by the individual reorganises their views of themselves in terms of the deficits defined by the label (Jones, et. al., 1984).

Link’s (1982) own research highlighted the impact of labelling on life opportunities, showing that those with a psychiatric label have lower income and work status, regardless of symptom severity (Link, 1982). A further study by Link (1987) showed that those who have received a psychiatric label scored higher on a self-report scale measuring ‘demoralisation’, which included questions relating to self-esteem, helplessness-hopelessness, confused thinking and sadness. Link concluded that in addition to direct discrimination, the negative stereotypes associated with mental illness learned throughout an individual’s life are applied to the self, leading to a sense of demoralisation and expectations of rejection. Consequently, problems associated with employment, self-esteem and income result.

Extending MLT, Link et. al. (1989) and Link, Miroznik and Cullen (1991) suggested that people labelled with psychiatric illness also adopt specific and often unhelpful coping strategies to manage the expected reactions from others. These included secrecy (concealing a history of treatment), withdrawal (avoiding potentially threatening situations) and education (attempting to teach others in order to forstall the negative stereotypes). Link’s first study showed that those psychiatric patients who feared rejection the most and who endorsed the strategy of withdrawal have insular support networks. In the second study Link et. al. examined the effectiveness of these coping strategies in a
group of psychiatric patients. Their results were interpreted as indicating that none of the three strategies were useful in ameliorating the negative consequences of unemployment and demoralisation that had previously been related to perceived stigma. In fact, the study indicated that the strategies had a negative effect, increasing the likelihood of unemployment and demoralisation.

A limitation in the ability of Link’s theory to explain the effects of stigma on well-being is the fact that individuals differ in the degree to which they are aware of stigma attached to their in-group. Thus, people differ in the degree to which they are affected by negative stereotyping (Pinel, 1999). Even those who are aware are not necessarily in agreement with the stereotypes and may not regard them as self-descriptive (Bem, 1981). Camp Finlay and Lyons (2002) support this point following their study of the degree to which ten women diagnosed with chronic mental health problems were aware of social stigma and the degree to which the associated negative stereotypes became salient aspect of the women’s self-descriptions. Camp et. al. found that the women rejected unfavourable representations when they were perceived as unrealistic or negative, or when the women thought that their symptoms did not fit with the diagnostic criteria. The authors emphasise the importance of considering the individual’s own understanding of social categories and the implications for their self-concepts.

1.7 Proposed positive outcomes of receiving a psychiatric diagnosis

A general criticism of MLT is that through the process of being labelled mentally ill people receive appropriate professional input, which has significant benefits in terms of symptom management and reduction. Miles (1987) also points to other benefits such as reducing ambiguity, shame, anger and guilt that individuals with psychiatric problems often experience. The psychiatric rehabilitation literature in general emphasises the importance of accepting the diagnosis so that appropriate services can be accessed (McEvoy, 1986). Kravetz, Faust and David (2000), however, criticise previous research finding a positive relationship between acceptance of a psychiatric label and well-being. The authors note
that across previous research various definitions of acceptance have been used (such as self-labelling, acceptance of disability and insight) and in response to these methodological limitations developed a multifaceted measure of the degree to which forty adults diagnosed with chronic mental illness self-label. Results of the study indicated that participants who described their problems in terms generally associated with their diagnosis reported higher levels of physical discomfort and symptomology, lower level of emotional and economic security and lower levels of social satisfaction. A further finding of the study was that perceived control over symptoms was independent of acceptance of a psychiatric label, suggesting that people can develop mastery over symptoms without acceptance of a psychiatric label.

1.7.1 Relationship between health service use and stigma on well-being

In order to explore the relationship between stigma and received services, Rosenfield (1997) assessed the relationship between quality of life, expectations of stigma, self-esteem, sense of mastery over symptoms and received psychiatric rehabilitation services. Participants included 157 patients with chronic mental health problem attending a community-based rehabilitation service. The results of the study indicated that approximately half of the participants believed that mental patients are stigmatised. Those that did believe stigma existed reported significantly lower life satisfaction. Expectations of stigma were also related to lower self-esteem and decreased sense of mastery. In terms of services received, Rosenfield found that the rehabilitation program was related to an increased overall satisfaction with life and that this was mediated by self-esteem and a sense of mastery. Level of perceived stigma, however, had a significant impact on the positive outcome of services. Rosenfield concludes that both stigma and services received impact on quality of life, sense of mastery and self-esteem, but in different directions. She goes on to highlight the importance of providing effective services that enhance empowerment and access to social and financial resources. Rosenfield’s findings are particularly relevant in light of Barnard, et. al’s. (2001) finding that there is a severe shortage of appropriate services for people with autistic spectrum disorders. Those at the
higher end of the spectrum are at an even greatest risk due to their ‘high functioning’ described in diagnostic criteria, as this now excludes them from Learning Disability services where the majority of support has come from.

1.8 Managing identity

There appears to be some evidence supporting a relationship between membership of a stigmatised group and negative impact on self-perception. However, other studies have found that labelled individuals do not necessarily apply negative stereotypes to the self and can adopt a number of strategies to protect and enhance identities (see Crocker and Major, 1989 for a review of the stigma and coping literature). Quadango and Antonio (1975) explored the impact of a psychiatric diagnosis on self-descriptions of people with a broad range of psychiatric diagnosis. The authors found that mental health patients who accepted their psychiatric diagnosis do not necessarily succumb to negative self-evaluations, often applying stereotyped views about the mentally ill to others, but not to themselves. Harter (1986) has argued that the negative impact of criticism or external feedback is dependent on the centrality of the dimension to the self-concept. The degree to which an individual’s self-esteem will suffer as a result of stereotypes depends on the degree to which the individual values that property. In relation to this, Taylor and Brown (1988) and Harter (1986) found that people tend to value those things they perceive themselves as good at and are thus able to avoid negative self-appraisals by dismissing dimensions they do not see as intrinsically important.

1.8.1 Social comparison theory

A further strategy for enhancing self-esteem is described by Festinger’s (1954) Social Comparison Theory. The original theory proposed that people choose those perceived as similar to oneself with which to make comparisons and evaluations of their own attributes, abilities and opinions. The theory was developed further by researchers investigating the ways in which people make social comparisons in order to maintain self-esteem. A
number of studies have shown that rather than selecting others perceived as similar to the self, people chose a variety of target others for comparison. In addition, these comparisons can be upward (with those seen as better off), downward (with those seen as worse off) or lateral (with those seen as similar to one's self) (Wheeler, 1966). Taylor and Lobel (1989) also found that the direction of comparisons depends on its intended purpose. The authors describe how in their study of individuals with cancer (a group previously shown to be stigmatised) participants made downward comparisons with less fortunate others in order to enhance self-esteem and upward comparisons in order to affiliate oneself with those perceived as in a better position. This latter process helped to increase motivation and hope.

As well as providing insights into the mechanism adopted by people in order to maintain a positive self-image, research on social comparisons has challenged the prediction of labelling theory that internalised stereotypes related to the stigmatising label take centre stage in the individual's identity. For example, a study by Finlay and Lyons (2000) exploring the social comparisons made by people with learning difficulties found that participants chose multiple dimensions other than those related to their status as people learning difficulties. Fine and Asch (1988) highlight the danger of assuming that issues perceived as important to researchers take as prominent a role in how individuals see themselves.

1.9 Current research aims

The research described above indicates that labelling people with a psychiatric diagnosis can have negative effects on identity and on financial and social opportunities. However, labels and stereotyped attributes associated with them do not always become a central part of the labelled individual's identity and people receiving diagnosis often adopt a number of strategies to protect self-esteem and maintain a positive self-concept. A review of the literature did not reveal any previous research into the effects of diagnosis on the lives of people with Asperger's syndrome. In light of research suggesting that people with
Asperger's syndrome have limited self-concepts, the question arises as to how receiving a diagnosis would affect identity and other areas of every-day functioning. In addition, if such individuals are aware of the sigma attached to the 'label' of Asperger's syndrome, do they have the cognitive flexibility to adopt the strategies described above in order to protect themselves from the negative effects of stigma?

The current study aimed to explore these issues by focusing on the following questions.

1) How do people diagnosed with Asperger's syndrome describe themselves?
2) How do people diagnosed with Asperger's syndrome relate to their diagnosis?
3) Do people diagnosed with Asperger's syndrome experience the label as stigmatising and if so how does this impact on their lives?

1.10 Qualitative approach

In the current study Interpretative Phenomenological Analysis (IPA) (Smith, 2003) was chosen as the most appropriate methodology based on the following factors. Firstly, qualitative research, as opposed to quantitative methods, is indicated where there is little previous research in a specific area (Turpin, et. al., 1997). Despite previous research efforts exploring the degree to which people diagnosed with Asperger's syndrome have the capacity to reflect on their own mental states, little has been done in the way of exploring self-concepts or the way in which receiving the diagnosis impacts on how people view themselves. Secondly, IPA focuses on “the content of consciousness and the individual’s experience of the world” (Willig, 2001, p.52). Rather than aiming to uncover an objective view of the world, IPA attempts to understand meaning making in context. This is particularly relevant in relation to ideas of self-concepts and psychiatric labelling where previous research has shown that, rather than passively accepting diagnostic labels, people actively engage in constructing meanings around mental health, identity and diagnosis (Finlay and Lyons, 2000, Quandango and Antonio, 1975, Harter, 1986).
Qualitative methodologies provide a useful strategy to gather rich information from participants based on their own interpretation of events or situations. IPA’s specific focus on phenomenology assists in steering the researcher away from drawing over-generalised conclusions from data or from describing findings in terms of truths or realities. However, there are a number of limitations of IPA that should be considered by the reader. Firstly, despite it’s recognition of the fact that the research is influenced by their own motivations and assumptions, IPA places little emphasis on the specific ways in which these biases can influence interpretation of findings or useful ways to discuss and explore them. In order to address this issue, the quality checks described by Elliot, Fischer and Rennie’s (1999) described below were incorporated into the research process. Secondly, due to the small, generally homogenous participant groups used in IPA, the opportunity for transferability of findings to other groups is limited. Thirdly, unlike quantitative methodologies, IPA relies heavily on the interviewing techniques of the researcher, and the ability of participants to express themselves in that particular setting. Fourthly, an underlying assumption of IPA is that the descriptions of experience provided by participants equate with their actual experience of the event or situation in question. Authors such as Potter (1996) highlight the boundaries placed on the expression of experience by language, which is its self shaped by historical and cultural factors. Given this point, a method such as Discourse Analysis would have provided the opportunity to explore the way in which participants used language to construct their accounts of themselves and to consider what roles these constructed realities may perform. A second methodology that may have proven a useful tool in exploring self-concepts in relation to diagnosis is Narrative Analysis (Crossley, 2000), which pays particular attention to the way in which individuals draw on culturally sanctioned ways of thinking and being to construct stories of themselves and their experiences. However, IPA allows for a greater identification of themes across a group of individuals.
2. Method

2.1 Recruitment strategy

Participants were recruited via local NHS Adult Mental Health and Learning Disability services, and a local National Autistic Society social skills group for people with Asperger’s syndrome. Participants were recruited from a suburban area in Southeast England. The researcher contacted a number of teams inquiring whether any professionals worked with individual’s with Asperger’s syndrome and those who responded affirmatively were sent a copy of the information sheet to pass on to clients (see appendix 1). After gaining approval from staff running the NAS social skills group, the researcher met with people attending the group at the NAS centre. Members of the group were told about the research project and given a copy of the research information sheet further outlining the nature and aims of the study. Group members were informed that volunteers could contact the researcher on the number provided on the information sheet. Ten people at the NAS centre approached the researcher directly following the presentation, indicating that they were interested in participating. The researcher met with each individual separately in order to assess their suitability (see criteria below). In addition, staff running the group were approached and asked for their opinion regarding suitability and risk. All ten people were assessed as suitable to take part. Of these, two people did not contact the researcher to arrange an interview and one further participant was later unable to take part. Only one participant was recruited via an NHS professional. The individual was given an information sheet and he chose to contact the researcher, whereby an interview was arranged. Of the eight people who took part in the study, one person was interviewed at the researcher’s university as requested, whilst the other seven were interviewed in their own homes.
2.2 Participants

Seven men and one woman diagnosed with Asperger's syndrome were recruited for this study. Whilst the number of participants is limited, the use of qualitative methodology ensured that data generated is rich in descriptions of experience. Conrad (1990) differentiates between quantitative and qualitative research in terms of generalisability, suggesting that with qualitative studies the work should be measured by the applicability of the concepts rather than looking at sample size and statistical power. For example, how does the concept of 'control' identified in this study help to provide some insight into the impact of diagnosis on self-descriptions? A number of studies utilising IPA exist in the literature with similar participant numbers. For example, Osborne and Smith, (1998) who incorporated 9 participants and Smith (1998), who used for participants. The inclusion criteria used in this study are highlighted below (see appendix 2 for a further discussion of inclusion criteria).

1. Adult (18 years or over) with a formal diagnosis of Asperger's syndrome. For the purpose of this study, the term Asperger's syndrome is used in relation to the definition provided in the DSM-IV. Whilst there are limitations in the use of these criterion, as described above, emphasis is placed on the non-essential features described in the accompanying narrative text of the DSM-IV, which recognises the motivation to socialise and difficulties with language exhibited by many people with Asperger's syndrome.

2. Awareness of their diagnosis

3. Sufficient expressive and receptive language skills to take part in an interview

4. English as a first language
5. Have the capacity to understand the nature and purpose of the research project and to give informed consent to participate.

Demographic details of those who participated in the study are shown in table 2. Below. Seven of the participants were male and one female. Ages ranged from 24 to 58 (mean age = 33). Age diagnosed ranged from 14 to 47 (mean age of diagnosis = 27). Participant's names have been changed to maintain anonymity.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Age diagnosed</th>
<th>Sex</th>
<th>Ethnic origin</th>
<th>Employed</th>
<th>Married</th>
</tr>
</thead>
<tbody>
<tr>
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<td>21</td>
<td>Male</td>
<td>White/British</td>
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<td>No</td>
</tr>
<tr>
<td>Fred</td>
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<td>14</td>
<td>Male</td>
<td>White/British</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Gary</td>
<td>58</td>
<td>47</td>
<td>Male</td>
<td>White/British</td>
<td>Yes (PT)</td>
<td>No</td>
</tr>
<tr>
<td>Harry</td>
<td>35</td>
<td>33</td>
<td>Male</td>
<td>White/British</td>
<td>Yes (FT)</td>
<td>No</td>
</tr>
<tr>
<td>Andrew</td>
<td>31</td>
<td>30</td>
<td>Male</td>
<td>White/British</td>
<td>Yes (FT)</td>
<td>No</td>
</tr>
<tr>
<td>Brian</td>
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<td>24</td>
<td>Male</td>
<td>Middle-Eastern</td>
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<td>No</td>
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<tr>
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<td>White/British</td>
<td>Yes (PT)</td>
<td>No</td>
</tr>
<tr>
<td>Dean</td>
<td>33</td>
<td>24</td>
<td>Male</td>
<td>White/British</td>
<td>Yes (FT)</td>
<td>No</td>
</tr>
</tbody>
</table>

2.3 Interview procedure

Prior to interviewing all participants were asked to sign a consent form (see appendix 3) relating to their participation in the study and agreement to have the interviews recorded. A semi-structured interview (see appendix 4) was utilised, which lasted between 30 and 90
minutes. All interviews were audio tape-recorded. The semi-structured questionnaire provided a framework for the interview. Although participants were free to talk about topics as they arose, questions were used as prompts and as a funnel to maintain some structure in the interview.

It is worth commenting on the experience of conducting interviews in order to consider how my approach was influenced by my previous experience (clinical, personal and with academic literature). Previous writings have consistently reported a high level of anxiety experienced by people with Asperger’s syndrome. As such I was anxious myself to help participants feel as comfortable as possible. During interviews I was aware of my anxiety, which usually dissipated as interviews progressed. However, with a number of participants I found the whole interview process anxiety provoking. I often inappropriately located the cause of this anxiety within the interviewee (or at least as a result of their difficulties with communication). It wasn’t until I thought about how anxious I was about the research process and the need to ‘pass’ the course that I realised a lot of the anxiety in fact came from me. Reflecting further I noticed that there were a number of other factors that were influencing the interview process. These included: 1) My need to be seen as a ‘good’ professional who was on the side of the participants; 2) My need to be seen as a ‘good researcher’ by the course and my self and 3) the need to feel like an able clinician utilising my skills effectively. Having identified these stressors, I was able to manage my anxiety more effectively during the proceeding interviews. Rather than battling to get as much information as possible, I acknowledged that having worked to build a rapport and make the process as informal and supportive as possible, when people ran out of things to say this was probably a good indicator that they had said all they wished to say. The experience was a good example of how my own needs influenced the interaction and how my reliance on theory unwittingly allowed me to project my discomfort onto others.

My own interests influenced the way in which I conducted the interview. For example, whilst giving participants some freedom to talk about issues they thought important, I tended to focus in on issues I thought were related to self-descriptions, the impact of
diagnosis and areas where participants appeared to make social comparisons. As a result, I am sure that a great deal of valuable information was not paid the attention some participants may have liked.

Despite my efforts to use open-ended questions and to avoid influencing the responses of participants, the fact that were aware of my position as a trainee clinical psychologist is likely to have influenced how they interacted with me. In particular, many of the participants had negative experiences with health care professionals (and psychologists in particular) which may have led to a defensive stance. However, I did not pick up on this during interviews and hopefully the fact that participants felt comfortable enough to criticise other professionals was an indication that my professional position did not restrict their responses, at least on this issue.

It is also possible that my connection with clinical psychology created an imbalance of power in my relationship with participants. That is, most of the participants had been reliant at some point on professionals for receiving support, getting their diagnosis and gaining some insight into what Asperger’s syndrome meant. Traditional patient/professional role may have been enacted during interviews with some participants, although I made efforts to stress how my role as a researcher differed from that of the professionals they see in relation to their diagnosis.

2.4 Interview schedule

The initial interview schedule (see appendix 4) was constructed following consultation with the researcher’s clinical and academic supervisors. A number of texts providing guidance on the construction of semi-structured interviews (Willig, 1999, Charmaz, 1995) were also consulted. Arriving at these research questions was quite a complicated process that is worth reflecting on. Initially, the research was to focus specifically on social comparisons made by people with Asperger’s syndrome as a way of exploring how such individuals construct their identities. However, during the first pilot interview the
interviewee spent a lot of time talking about the process of getting a diagnosis and coming to terms with it. I incorporated questions on this topic into the interview schedule and used them in the second interview, which appeared to reveal a great deal about how the participant’s self-concepts had changed since diagnosis. The process facilitated a move from research based on theory and researcher experiences to a project drawing on participant’s experiences in guiding the focus of the study.

The developed interview began by asking participants to describe themselves. For example, ‘what makes you unique?’ and ‘what are you good at/not so good at?’ Then questions relating to their experience of being diagnosed were asked. For example, ‘did receiving your diagnosis change how you saw yourself?’ and ‘How do you feel about yourself now that you have a diagnosis of Asperger’s syndrome?’ Finally, questions relating to perceptions of stigma were asked. These included questions such as ‘What do you think the general public think of Asperger’s syndrome?’ and ‘Do you feel comfortable telling people about your diagnosis?’

2.5 Analysis of data

Data was analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1996). IPA draws on the philosophical tradition of phenomenology, which proposes that all experience of the external world is subject to transformation via the beliefs, ideas, motivations and judgements of the perceiver (Willig, 1991). Consequently, perception is a constructive process within each individual. The aim of IPA, then, is to focus on the way in which participants experience the world rather than to explore any notion of an objective reality. Drawing on social-constructionist perspectives, IPA also acknowledges that any information provided by participants will itself be interpreted by the researcher based on their own assumptions, beliefs and goals. A key assumption of IPA is that the language used by participants is an accurate representation of their inner experiences. IPA has been used mainly in health related research, although some studies have utilised the method to explore experiences related to psychiatric labelling and perception of stigma (Knight,
Wykes and Hayward, 2003). One limitation of IPA highlighted by Willig (1991) is the fact that participants need to be able to articulate their experiences clearly in order for meaningful themes to be identified. This limitation was considered in relation to the current research participants, as social interaction can cause a high level of distress in this group as well as the fact that people with Asperger’s syndrome have, by definition, difficulty with expressive language. However, a number of previous studies have indicated the capacity of people with AS to report experiences effectively during interviews (Hurlburt, Happe and Frith, 1994, Marapovoulou, 1995, Robert, et. al., 2001), suggesting that semi-structured interviews would be an appropriate method of gathering information.

Analysis of transcripts involved an idiographic approach, which is recommended for sample sizes smaller than 15 (Smith, 2003). Each interview recording was typed verbatim. Individual transcripts were initially read a number of times during which broad, unfocused notes were made. These broad points were drawn up into a table, integrated, and the emerging themes used to construct a table of ‘master themes’ that were seen to reflect experiences across the group as a whole. A research group consisting of myself, three trainee clinical psychologists and a research tutor then read one of the transcripts. Each member of the group provided their perspective of significant points within the text. These were compared with the themes I had identified as part of the process of triangulation (Elliott, Fischer and Rennie, 1999). My research supervisor then checked the table of themes to ensure that they were grounded in the text. An example of one transcript is provided in appendix 5.

2.6 Research quality checks

Elliot, Fischer and Rennie’s (1999), following an analysis of existing principles of good practice in qualitative research, highlight seven quality measure guidelines as part of their evolving guidelines. Four of the seven principles are addressed below. I perceive the remaining three principles, coherence, accomplishing general and specific tasks and
resonating with the reader as points to be assessed by readers themselves who have not been involved with the research process.

2.6.1 Owning one’s perspective

Above I have commented on factors that I was able to identify as having a particular impact on the research process and reflections on my experience of conducting the research. The aim of including these comments and reflections is to provide some context to the research in terms of the researchers background, so that readers can assess for themselves where biases and personal motives may have influenced the process, for better or for worse (Finlay and Gough, 2003). Below is a broader reflection on my own cultural and professional background and my initial interest in exploring this area.

This study was conducted as part of the course requirement of the University of Surrey Doctorate in Clinical Psychology. I am a white, British male who has spent over 8 years working as a ‘health care provider’ in the National Health Service. I am interested in the area of self-concepts, how these are constructed socially and their impact on the well-being of individuals. I have worked with both adults and children diagnosed with autistic spectrum disorders who had varying degrees of difficulty associated with their diagnosis. During my early experiences working with these individuals I had paid little attention to how they thought about themselves. However, working with one particular adult with Asperger’s syndrome who functioned well in the community inspired me to question the degree to which higher-functioning individuals perceived of themselves and in particular what it was like to be labelled with Asperger’s syndrome. My own attitudes towards psychiatric labels are ambivalent. I believe that both the public and professionals working in the health service apply negative stereotypes to the people so labelled. However, I have found that many people diagnosed have reported positive repercussions such as gaining insight into their difficulties, feeling less responsible and receiving support.
2.6.2 Situating the sample

Elliot et. al. (1999) highlight the importance of describing participants and their life circumstances in some detail so that readers can assess for themselves the applicability of the findings. Demographic details are provided in table one and further personal details are drawn out in the examples taken from interviewee texts. However, anonymity has been maintained by ensuring that participants cannot be identified by such information.

2.6.3 Grounding in examples

Examples of comments made by participants have been included to allow the reader to assess the fit between the data and the researcher’s interpretations (Elliot et. al., 1999).

2.6.4 Providing credibility checks

Credibility checks aim to prevent idiosyncratic interpretation by the researcher and provide some credibility for the analysis (Elliot et. al., 1999). This requirement was fulfilled by having one of the texts read by members of a research group and incorporating feedback into the final analysis. In addition, my research supervisor also read through two transcripts and following this we discussed my interpretations. Finally, my research supervisor read a draft copy of the final report, ensuring that identified themes were grounded in the data.

3. Analysis of themes

3.1 Organisation of themes

The following section provides a description of the main themes and sub-themes that emerged from interviews with participants. The section begins with an overview of the way in which participants described themselves as children, adolescents and young adults, prior to receiving their diagnosis of Asperger’s syndrome, and the factors they highlighted
as having a significant impact on their self-perceptions. The second theme relates to the process of receiving a diagnosis and the positive and negative impact this had on participants’ lives. The main concern of this theme is the way in which being labelled with Asperger’s syndrome affected self-descriptions. The third theme explores the complexity of self-descriptions and the degree to which a diagnostic label becomes central to the way in which participants describe themselves. Finally, the theme of managing identity highlights the various ways in which participants maintain a positive self-image. Table 1 below gives an overview of the main themes and sub-themes discussed.

Table 1: Main themes and Sub-themes identified from interviews*. 

| 3.2 Self-descriptions prior to diagnosis |
| 3.3 Positive and negative impact of diagnosis |
| 3.3.1 Initial negative impact of diagnosis on self-perception |
| 3.3.2 Challenging negative self-definitions |
| 3.3.3 Further developing a social (looking-glass) self |
| 3.3.4 Increased sense of control |
| 3.3.5 Mixed messages from professionals affecting adaptation to diagnosis |
| 3.4 Asperger’s syndrome as only one aspect of identity |
| 3.5 Managing identity |
| 3.5.1 Secrecy |
| 3.5.2 Educating others about Asperger’s syndrome |
| 3.5.3 Managing stigma |
| 3.5.4 Out-group Lateral comparisons (normalising) |
| 3.5.5 In-group downward comparisons (minimising) |

*Main themes are shown in bold.

Descriptions of experiences both prior to and following diagnosis of Asperger’s syndrome given by participants included rich accounts of inner experiences with reference to
thoughts, feelings, actions and behaviours. In contrast to the findings of previous research (for example, Hurlburt, Happe and Frith, 1994, Happe, 1991) suggesting a limited capacity to reflect on and describe emotional states, many responses from participants included descriptions of feelings. Whilst this could be explained as a reflection of their current capacity to reflect on and describe such vivid inner experiences, a number of the quotes highlighted below suggest that many of the participants had this ability as children and adolescents.

3.2 Self-descriptions prior to diagnosis

Before exploring how participants described themselves following diagnosis it is useful to look at self-descriptions prior to this, as it provides a point of comparison with current self-definitions and a degree of insight into how sensitive participants are to the labels given by others. The descriptions provided highlight an important theme of feeling different from others. This sense of difference was traced back to childhood by all of the participants, who also commented that they did not understand why they were different. Participants frequently referred to the social comparisons they made as children and adolescents. These comparisons were made in relation to behaviour, such as not going to friend’s houses after school as other children did, emotions, such as being more sensitive to the environment than peers and academic achievement.

Recognising difference appeared to have left many of the participants confused as to its cause. However, others in their social networks provided various descriptions and explanations, which were often negative, derogatory and centred within a deficit framework. They included descriptions such as the person being thick, a naughty child and being mentally ill. These negative labels from others also placed responsibility for the difficulties firmly within the participants and often led to a sense of inferiority. These explanatory terms became salient aspects of participant’s self-descriptions. Claire described how for many years she had put herself down and made negative comparisons with those around her, in particular her brothers. Her sense of things being ‘wrong’ related
to both her actions in the world and a more general feeling about herself. The negative sense of being different appeared, at least in part, to have come from the comments of others in her family network, rather than being purely the result of self-other comparisons. Other's comments had an obvious impact on Claire's emotional well-being at the time and resulted in her questioning her own abilities. The responsibility for failure was placed on her, without acknowledging the role others played in undermining her confidence. In response to the question 'Did you feel you had problems before you were diagnosed?' she replied:

"Yeah, I did feel different. I didn't know why, I just thought, everything, when I grew up I just thought I was different; my brothers were much better than me and I just felt apart... so with mum saying that's wrong, this is wrong, the other's wrong, you shouldn't do that, you should do this, you're stupid, blah de blah, I did feel very bad... My GCSE's weren't as good as they could have been... 'cause I didn't believe in myself. I didn't think I could do it, I thought I was thick (laughs)... The only opinion that I ever had was that I'm not good at this, I'm thinking, I'm not very intelligent, I'm really bad at that. I was really, really negative... "

Mike's description of his difficulties at school indicate how the reactions of other's to his behaviour and the resulting labels he received located the problems firmly within him. He was seen as a disruptive child who caused problems for others in the class. He appeared to retain this perception of himself as a problematic child, as his current explanation for these childhood difficulties included a sense of responsibility:

"I kept attention seeking I did... I kept disrupting the class... I just kept upsetting my parents and... attention seeking"

From an early age Gary's peers had been critical about his behaviour and described him as someone who was mentally ill. For Gary, the experience of being labelled as different and being treated negatively in his early relationships provided a model that guided his
perception of, and behaviour in, later relationships. He saw both himself and others as responsible for negative reactions of others and appears to have internalised expectations of rejection, not purely as a consequence of labelling, as Link (1984) describes, but also as a result of previous rejection:

"...Even at school the kids thought I was a bit strange...you know, 'you should be in a mental home or something'. You take it as part of...life. You think if people are rude to you, you think it's you...the people who treat me bad, you develop a different method. In other words, I think it's normal for people to be rude to me. You always put it down to any infinite number of reasons, like...I'm ugly, people are just nasty...""

Harry described how he turned feeling different as a child into a more positive self-evaluation. He recalled how he often felt ‘insecure and emotionally I felt inadequate’. However, he also acknowledged that in order to protect himself he would elevate his own position in relation to his peers:

"Not appreciating the positive side of other people around me. But I was quietly pretty arrogant I think...kind of ironic really, feeling inadequate, being aware you feel inadequate...I think that was really to ...compensate for some of the problems by saying, oh, you know, you're different because you're better or something..."

3.3 Positive and negative impact of diagnosis

One of the participants read about the symptoms of Asperger’s in a newspaper, whilst one other heard about the symptoms from a friend that had recently been diagnosed. Both of these participants described recognising the symptoms in themselves and set out on the task of getting a diagnosis. The other six participants were encouraged to see a health professional by friends or family for other problems, which included depression (2) and difficulty chatting/relating to people (4).
Receiving a diagnosis had a number of consequences for participants. Some described positive changes, such as providing an alternative explanation for their problems and reducing the sense of responsibility and blame. However, participants also highlighted a number of negative consequences such as feeling inferior and the shock of having previous ideas about the cause of their difficulties challenged. The participants also described a number of factors influencing the degree to which they were willing to accept their diagnosis, including the attitudes of professionals they came into contact with, age at diagnosis and the degree to which the symptoms described in diagnostic manuals fitted with their own experiences.

An important context in which the following comments from participants should be considered is the fact that six of them described having received psychiatric diagnoses other than Asperger's syndrome in the past. Only three participants felt that previous diagnosis had been accurate and of these three, all thought that the diagnosis had been secondary to other difficulties that had not been recognised. Six participants reported feeling angry on receiving their diagnosis of Asperger's syndrome, reflecting on what they perceived as missed opportunities. They all felt that if they had been diagnosed earlier they could have received more support and achieved more socially and academically.

3.3.1 Initial negative impact of diagnosis on self-perceptions

Only one of the participants in this study reported rejecting the diagnosis of Asperger's when they were first diagnosed. Fred, who was the youngest (and diagnosed at the youngest age - 14), explained that his age played a significant part in how he reacted. Being told that he had a neurological condition that was implicated in many areas of his life was something that he could not relate to and resulted in him rejecting the diagnosis. It had a particular impact because prior to the diagnosis he had argued with his parents about his behaviour, believing that he was normal and it was they who had the problem. Whilst Fred described his reaction as a result of his age, it could also be considered in relation the
ToM model; difficulties accepting the diagnosis may reflect his limited capacity for self-reflection, making the diagnosis seem less relevant to his own experiences:

"I was too young to understand about Asperger's, that's the point... I was too young to comprehend it, take it all in and I didn't believe at first that it was anything so I didn't see there being anything wrong..."

For the other seven participants, diagnosis allowed them to reframe past difficulties and challenge prior derogatory descriptions used by others and themselves. The label of Asperger's syndrome appeared to serve as a concrete explanation that more accurately described their inner experiences. However, reaching this point involved going through a process of having to cope with the initial shock of receiving a diagnosis. Despite feeling 'different' and being acutely aware of the difficulties they experienced, relating Asperger's syndrome to themselves was a difficult process and presented a variety of challenges, impacting on their identity, previously held assumptions about their difficulties and their hopes for the future.

Dean was one of the two participants who found out about the symptoms associated with Asperger's from sources other than professionals. He read an article about Asperger's which described it as 'the triad of impairments'. Reading the diagnostic criteria resulted in increased social awareness, which resulted in Dean making negative comparisons between himself and a more 'able' group of people without Asperger's syndrome. His reactions indicate that for him, at this early stage at least, Asperger's syndrome related to being inadequate. His response appeared to be related to the way Asperger's was presented in the article as opposed to any stereotyped assumptions being applied to himself.

"...the short-term it's negative cause you're suddenly more conscious of what the differences are... I suppose It's a bit of a shock really... sort of seeing it as though you're sort of inferior in a way"
For the six participants who had not specifically sought a diagnosis of Asperger’s syndrome, receiving the diagnosis from professionals was equally distressing. Ewan’s ambivalence reflected the fact that on one hand the diagnosis helped him to understand difficulties in his childhood ‘it was a good thing it was... (I understood) why I was distracted at school’. On the other hand, it left him thinking that the diagnosis represented a permanent problem, which shattered the belief he held that things would naturally improve with time. His recollections indicate that initially the diagnosis took some control away from him and led to the assumption that he would not be able to move forward in his life:

“It was a bad thing for me it was because I thought it would disrupt my life... I thought I wouldn’t be able to make friends... I wanted to harm myself... I was relieved in a way, sometimes I wasn’t relieved, mixed feelings, yes”

Harry described how, initially, the concept of having Asperger’s was difficult to accommodate because his own explanations had been so different. He already had a framework for understanding his sense of difference and the difficulties he experienced. Being given an alternative explanation was traumatic. Significantly, he made specific reference to the emotional impact of being diagnosed:

“It was a bit of a bolt, yeah it was. It was completely different, I’d made this assumption, I’d decided it was encephalitis and my response to it. So it was completely a bolt out of the blue and I really felt a bit numb from it and I didn’t know how to deal with it at first...”

3.3.2 Challenging negative self-definitions

Six of the participants reported that having been given a diagnosis they engaged in a process of reframing their past. Specifically, they drew on the symptom definition provided by professionals to explain problems in their past that they had previously been confused about or that had caused them distress. Through this process the participants were
able to challenge alternative negative ideas they or others held about their behaviour, which in turn led to more positive self-definitions. However, this process of reviewing the past also proved to be difficult, as for some it also involved having to ‘face up to’ behaviours that they would now consider unacceptable or inappropriate.

In light of her diagnosis, Claire was able to challenge the negative perception of herself as “thick” and see herself as having greater potential in terms of academic ability. She was also able to place some of the responsibility for her difficulties in the hands of others, suggesting that she could have achieved more if she had received the right level of support. “Basically, If I’d been diagnosed earlier and given the help I think I could have gone to university”. Having challenged previous negative self-perceptions, she was more able to accept her self. Her ideal and actual selves appear to be more aligned, reducing the need she had before diagnosis to strive to be a different person:

“I think I’m at the image I’d wanted to be before I was diagnosed. If I hadn’t have been diagnosed I wouldn’t have felt this way. It was just a dream that I could never get to. But now I don’t actually think about how I would like to be, I accept myself...what I’m becoming and how I’m growing”

For Andrew, the diagnosis provided a more coherent framework in which to consider his past and current difficulties. Whilst from childhood he was aware of being “slow to develop in the area of relationships”, his social experiences at university had been positive and as a result he did not consider that his behaviour had any major impact on himself or others. When he began his current course, which required a lot of self reflection and empathising with others, staff on the course made general comments about his interactions that left him confused as to their nature and powerless to do anything about it. Asperger’s syndrome appeared a more logical explanation that he felt more comfortable with:

“well the label was helpful because it was a lot more intelligible than what the ... staff had been saying ever since my first year here, which is that ‘well, you look like a nice guy but...
there’s something wrong with your being’. ‘I said my what?’, they said ‘your being’. I said ‘oh, can you explain that to me?’ They couldn’t, I said ‘what do you want me to do about it?’ they didn’t know…”

Claire described a similar experience of being able to piece together past experiences, which results in a less fragmented and more coherent understanding. The diagnosis also provided greater insight into her social interactions, particularly how her behaviour influenced others:

“Well, as an adult finding out, it put things together. I realised things, realised why people acted differently around me…”

For the majority of participants, receiving the diagnosis provided a more acceptable explanation of why things had been difficult in the past. However, the process of reflecting on the past was itself difficult for some. Gary, for example, described having flashbacks and moments of realisation which he finds distressing. He made reference to the emotional reactions he experienced when he was younger, and the fact that reflecting on those experiences includes a re-experiencing of the emotions, which became a salient aspect of his self-awareness:

“…suddenly you get a flash-back to something else, you’re in this room and you get a flash-back to the 1960’s and someone telling you to (go away) and suddenly that feeling comes back and it’s bad for a couple of days…”

3.3.3 Further developing a social (looking-glass) self

Three participants described developing insight into how others might view them. Descriptions of Asperger’s syndrome commonly claim that as people with the diagnosis get older they often develop an increasing awareness of themselves and others, suggesting an increased ToM (Tantum, 2003). However, little attention is paid to the mechanisms that can precipitate this. Andrew, Claire and Dean described three different events (diagnosis
and family support, social skills training and experiences at work) that they saw as increasing awareness of how others perceived them. In these examples we can see evidence of ToM as participants learn to cope with how their behaviour affects other people.

Andrew explained that staff on his course had made general comments about there being something wrong with his “being” that confused him. He also commented that during a group discussion as part of his course he was made aware of the fact that other people “might be uncomfortable in my presence for reasons that I’ve not come across before”. The discovery appears to have been quite uncomfortable for Andrew, but he was able to use this feedback by trying to understand how others perceive him. His comment also suggests some degree of defensiveness, as he made reference to other’s ‘prejudices’ in the way they interpret his behaviour:

“I hope I will be more sensitive to other people cause I hope I should learn a bit about what ever non-verbal cues that, sort of the way other people think that I’m not picking up at the moment. Particularly things that I don’t realise that people react to me because of certain worries or prejudices they have or the ways they interpret my behaviour”

Claire’s comment below also suggests that she was trying to focus more on how others interpret her behaviour during social interactions, which she explained was a result of getting her diagnosis of Asperger’s syndrome and through talking to her family about her difficulties in social interactions. Like Andrew above, there is a sense of vulnerability in her comment as she suggested that part of the reason it was important to develop an awareness of others was to protect herself from being taken advantage of:

“...I realised things, realised why people acted differently around me. Because I wasn’t really acting cautiously and people would think that I’m easy to walk all over...whereas now I ain’t got no worries about that what so ever...because I know that people do judge me...”
For Dean, getting a diagnosis of Asperger’s made him more aware of the ‘differences’ he had previously experienced. In reaction to this, he makes a concerted effort to try and understand how others may be thinking. This appeared to be part of a process of pre-empting negative appraisals from them, although he is careful to point out that being perceived as difficult is a perception others might have, rather than making a generalised statement about how he thinks everybody perceives him:

“I try rationalise other people’s behaviour or things they say and I think sometimes, I think ‘oh maybe they can’t be bothered or maybe they don’t want to deal with someone they might see as being difficult, so I try to think of it in how they would feel a bit”

3.3.4 Increased sense of control

Gaining a sense of control over problems was one of the most important positive changes participants commented on. This appeared to be related less to receiving the diagnosis per se than to the possibility of change provided by the support received from the groups they attended. This support offered a way of understanding both what Asperger’s meant generally and how it related to them individually. It allowed people to see not only a triad of impairments, but also the positive attributes they posses. For example, Brian described how understanding the diagnosis led to a better self-understanding and a platform from which to develop his skills and abilities:

“...I know what I have, I can build on, I know what my strengths are. I can understand my self better...what my weaknesses are, I know what I can improve myself on, things like communication for example”

Claire commented on how her diagnosis provided an explanation of why she felt different. The idea of difference had been central to all participants’ concepts of themselves growing up and this was usually accompanied by negative connotations of being less able or less
worthy than others. However, the diagnosis helped Claire to reframe ‘difference’ as something more tangible and also as something that could be controlled. This played a significant role in increasing her self-confidence:

"...I’m more confident now, erm, I know I’m different for a reason, not because I’m odd. I’m different and there are ways to deal with that difference... It’s a better way of being different and there are ways to overcome the reading of body language and the tones of voice and things like that..."

Fred also reported on the positive effects of feeling more in control of his problems. He implied that accepting the diagnosis was a process that was helped by learning about Asperger’s and consequently himself. Receiving the diagnosis had an initially negative impact that was overcome by developing an understanding of the symptoms and the knowledge that he could develop specific skills. Central to this potential for change was the support he received:

"...well, I used to (get depressed) but now I’ve come to, I’ve learned about it, I feel better about it now that I’m used to it because I understand it better... but I feel better now and at (NAS) I feel happier because they do understand about it and I’ve made a lot of progress in sort of tackling Asperger’s, finding ways of coping...

Whilst feeling more in control was described as a positive aspect of receiving support, for some of the participants the control issue was a double-edged sword. Claire, for example, explained that she felt she had to be on her guard all the time in order to control her behaviour:

"But when Asperger’s kicks in I’m rude, I’m insensitive to other people and I can be horrible, really horrible... sometimes I can’t control my self, I can other times, when I constantly think about it”
3.3.5 Mixed messages from professional affecting adaptation to diagnosis

Despite the fact that only one of the participants rejected the diagnosis when it was first given to them, three participants commented on how experiences with professionals had a continuing impact on coming to terms with and accepting the diagnosis. Because different professionals held different views about the validity of the Asperger’s syndrome diagnosis or different approaches to making a diagnosis, participants were often left confused as to whether they actually had Asperger’s or not. Experiences of professionals varied greatly across participants. However, five of them commented on negative experiences including professionals differing in their view as to whether they had Asperger’s syndrome, different views as to the benefit of getting a diagnosis and one professional who discounted the diagnosis outright. The experiences left some of the participant feeling angry and confused.

Dean described going to a number of professionals who either dismissed the diagnosis out of hand or made him feel like they didn’t believe him when he explained to them that he thought he might have it. He left professionals feeling confused about Asperger’s syndrome, but retained his belief that it accurately described his experience and consequently continued seeking a diagnosis:

“...I went to see a psychiatrist and he was basically, he was coming up to retirement and he basically thought anything that had been discovered in the last 20 years or so didn’t exist... one thing he said to me, ‘oh, this is a load of rubbish, it’s come over from America... so that was a bit of a waste of time... well I did walk away feeling confused...”

Gary explained that psychiatrists and GP’s had consistently told him there was nothing wrong with him. As a consequence, he remained unsure about his diagnosis and sceptical in his views towards health care professionals in general:

“...She’s (GP) the one told me there’s nothing wrong with me... Now you get very suspicious, now you see why I’m not always a happy bundle of joy to the mental health
people...you've had doctors telling me there's nothing wrong with me so you've been in denial of a problem...You're never sure whether you're Asperger's or not...”

Brian explained that the professionals he saw differed in their opinion as to whether he had Asperger's. Those that agreed he did were of different opinions as to whether he should bother to get the diagnosis. This left him confused as to whether he does actually have Asperger's syndrome:

“...and the diagnosis, I'm not happy about it. One of my GP’s said you don’t need to get a diagnosis you see... well, one of them said I went to see a psychologist, she goes I don't think you've got Asperger's yeah, but I'm not 100% sure, or something related yeah. One of the GP’s says there's no point in going for it. Other GP’s recommend you go, that I should go and get a diagnosis”

3.4 Asperger’s as only one aspect of identity

Implicit within Link's (1982) Modified Labelling Theory is the assumption that negative social attitudes towards stigmatised groups are internalised and become self-relevant following diagnosis. Consequently, the individual's identity becomes engulfed by the psychiatric patient role (Schur, 1966). In contrast, various studies (Finlay and Lyons, 2000, Finlay, Dinos and Lyons, 2001, Crocker and Major, 1989, Tyler and Lobel, 1989) indicate that people in stigmatised groups have complex identities and often adopt a number of strategies to protect themselves from becoming defined solely in terms of the stigmatising label. People diagnosed with ASD's are generally believed to have limited self-concepts and find social situations difficult without formally proscribed roles to adopt. As such it is difficult to know how receiving a label would impact on self-descriptions.

In the present study, participants appeared to contextualise their difficulties, with Asperger's becoming more or less salient to their self-descriptions depending on the nature of the discussion. As described above, where the diagnosis provided a useful framework
for understanding problems and options for overcoming specific difficulties, participants more readily associated with it. However, all but one of the participants asserted that having Asperger’s does not mean that this is the only way they define themselves. For example, whilst Brian found it difficult to draw a division between ‘himself’ and Asperger’s, engaging in this process itself indicates that the diagnosis is only a part of how he saw himself:

“I don’t know how much of it is Asperger’s and how much is not because it’s all psychological isn’t it? What I’m saying, not all of it, my life, is ruined by Asperger’s. Your experiences and your genes that influence you and how you are, that have got nothing to do with Asperger’s... how good a person you are is how, how you act. Asperger’s doesn’t make you a better or a worse person...”

Brian’s cultural identity was central to his understanding of himself and whilst he could relate to his diagnosis on some level, it was important for him to emphasis that he should not be considered the same as everyone else with Asperger’s, which helped to maintain his sense of individuality.

“It’s difficult for me ‘cause there’s nobody from my background... with Asperger’s I can’t think of anyone who’s like me. It’s hard to find someone in this country with my background, Asperger’s and things... culture and social background, education, especially cultural or social background... I haven’t met anyone non-white with Asperger’s...”

Whilst Dean appeared to accept the diagnosis and talked about how it helped to explain his previous sense of feeling ‘detached’, he also explained that Asperger’s is not always salient in how he thinks about himself. The extract below also suggests that when he does think about having Asperger’s it automatically implies a sense of inferiority. Therefore not thinking about himself within that framework would serve the purpose of maintaining a more positive self-view:
Interviewer: "Did it affect how you thought about yourself, thinking you might have Asperger's?"

Dean: "I think it might have done at the time, to begin with... sort of seeing it as though you're inferior in a way"

Interviewer: "In what way do you think?"

Dean: "just socially I suppose"

Interviewer: "Where do you think you got that (message) from then?"

Dean: "I don't know, I suppose it was from reading the article and relating it to my own experiences".

Interviewer: "Do you still think the same way sometimes?"

Dean: "Sometimes yeah... I don't think it all the time 'cause I'm not thinking all the time, 'oh, I'm someone with Asperger's syndrome... just a person I suppose, rather than a person with Asperger's syndrome... I don't constantly think about it".

Significantly, Dean made a similar comment to Brian above about feeling confused as to whether his actions are related to 'himself' or the Asperger's: "Yeah I do get that sometimes, is it Asperger's or is it me?"

Claire appeared to separate Asperger's from positive aspects of herself, which helped her to maintain a positive self-image. Her description below suggests that she sees Asperger's as something that takes over her 'normal' personality and behaviour to the point where she feels out of control and depends on others to manage things. Her description suggested that her own emotional state acts as a trigger for Asperger's syndrome to 'kick in':
"...but when the Asperger's syndrome kicks in, I'm rude, I'm insensitive to other people and I can be horrible, really horrible. When I'm under stress and whatever, erm, and if there's no one to calm me down then I can't help what comes out of my mouth. I'm really horrible when I'm angry (laughs) and upset, so that's the complete opposite to what I am normally."

Gary offered a vivid description of Asperger's, using the analogy of a machine with a loose part inside causing problems. He explained that Asperger's is not always central to how he sees himself, suggesting that the 'machine fault' does not always impact on how he 'operates'. He appeared to contextualise his difficulties in that it only becomes relevant when it affects how he functions:

"...when you walk down the road you don't think you're Asperger's, you just, you're walking down the road. The Asperger's is like a loose wheel nut, or there's something wrong, it's not something you're conscious of, you understand? You're not conscious you got Asperger's until things, until after things have gone wrong (laughs)..."

Whilst the analogy used above suggests that Asperger's is a problem Gary sees as internal to himself, he also described it as something separate from himself that causes the problems in his life. This allows him to feel less responsible for past difficulties:

"...people have said after the Asperger's, after the diagnosis, I got a lot better... coz you always feel everything goes, is something different, everything is wrong for a different reason. Then you realise there's one causation and it's not you... it's the diagnosis...you realise it's one reason, which is Asperger's, so you don't feel so bad"

Fred, who was diagnosed younger than any of the other participants, was the only one who appeared to describe Asperger's as a central aspect of his identity. As he was the youngest when diagnosed, it may reflect the fact that at an earlier age a diagnosis becomes more
central to one’s self-concept. However, as Fred was the participant with the most positive outlook towards Asperger’s syndrome, it may also reflect the fact that he felt less threatened by his diagnosis. When asked if there was a side to him apart from Asperger’s he replied: “No, no, I don’t think there is anything else, it’s just I’m more able with Asperger’s I think, but I know I have it.”

Not only were participants able to differentiate Asperger’s syndrome from self-descriptions to some degree, they were also able to provide self-descriptions that included characteristics which are the antithesis of the way in which diagnostic criteria portray people with this diagnosis. Four participants described themselves in terms of positive social traits including ‘being friendly’, ‘affectionate’, ‘kind’, ‘a good listener’, ‘thoughtful’, ‘caring and honest’. It was also interesting that five of the participants made frequent reference to their job roles, which appeared to play a significant part in how they viewed themselves.

3.5 Managing identity

The comments described above in relation to self-descriptions prior to and following diagnosis reflect how many of the participants viewed themselves negatively, either as a result of derogatory comments about their behaviour or through comparing themselves less favourably with others. However, the majority (7) of participants were also able to offer positive self-descriptions, indicating that any negative ideas related to Asperger’s syndrome, such as it being a collection of deficits, did not dominate the way they viewed themselves. Participants were also able to describe a number of ways in which they were able to maintain a positive self-image. These included specific strategies to overcome the stigmatising effects of psychiatric labelling, as well as more general activities, such as making self-enhancing social comparisons.
3.5.1 Managing stigma

Asperger's syndrome is a relatively new addition to both the DSM-IV and ICD-10. It is difficult to predict, therefore, how stigmatising being a member of this particular group is. A review of the literature revealed no existing studies exploring social attitudes towards the syndrome or research into the possible effects of stigma on those given the diagnosis. In order to explore the latter issue, the participants in this study were asked what they thought the general public's perception of Asperger's syndrome was and whether such attitudes would influence how others behaved towards them. Responses differed greatly across participants; Four participants expressed the belief that people tended to be negatively biased towards people with Asperger's syndrome, seeing it as a disability, whilst others thought that general attitudes towards the diagnosis would be positive. The differences in opinion appear to be based on previous experience of discrimination as well as internalised social attitudes towards those perceived as different.

The following comment from Brian arose following a discussion of his experiences applying for jobs and feeling that, having disclosed his diagnosis in the past to potential employers, he was discriminated against. Ironically, he described the people who he felt discriminate against him as rigid in their thinking. His concerns about being stigmatised related to the idea that people generally hold negative assumptions about anyone perceived as being 'different', as well as his belief that people perceive Asperger's syndrome as a disability, and thus negatively.

"They tend to see things in white and black with no grays in between... it's the people that you experience who view Asperger's badly, they think that if you've got it then you must be maybe not good at communication, er, stupid or maybe they don't understand. They think it's a disability, so they turn you down you see... but I should be encouraged by actually admitting you have it. But I think the chances are it's not good to admit it because if you see someone who's different, er, that deviates from the normal person, they think it's not good"
Gary thought that people would be scared of those with Asperger’s syndrome, again due to a lack of understanding. He also thought that they would ‘relate it to mental illness’ and think people with Asperger’s syndrome were ‘nutters’. He also suggested that people might think of Asperger’s syndrome in terms of a disability, which Gary felt was negative. Harry believed that others would feel ‘very uncomfortable’ about Asperger’s syndrome because they know so little about it and because of its relationship to autism: ‘The connection with autism I think as well, I think people have a problem with it’. Dean held a similar view, believing that some people might find talking about Asperger’s syndrome ‘difficult to deal with and they don’t know how to deal with it themselves’.

Whilst not all participants held the view that society in general holds negative views about Asperger’s syndrome, a number of participants highlighted various ways in which they try to manage their identity during social interactions. These strategies were analysed within the framework proposed by Link (1989), who suggested that people in stigmatised groups adopt one of three coping strategies; educating others about their condition, isolating one’s self and secrecy (hiding the diagnosis from others). In the present study however, the only strategies described by participants were secrecy and educating others. However, as mentioned above, it is difficult to differentiate between isolating as a strategy to avoid stigma and social isolation as a consequence of difficulties with interpersonal interactions or the negative responses of others.

### 3.5.2 Secrecy

Three participants described trying to hide their Asperger’s when with others who do not know about their diagnosis. Stigma theories suggest that strategies to hide membership of a stigmatised group serve the purpose of protecting the individual from being stereotyped and rejected by others. This matches the reasons why Brian tries to hide the fact that he has Asperger’s syndrome. He believes that others will view it as a learning disability and reject him. As a result he does not tell people about his diagnosis. When asked if he told people about his diagnosis he replied:
"...I did, but I don’t say it because it’s negative... (people) tend to see things as erm, either black or white with no grays in between... they think that if you’ve got it you must be may be not good at communicating, stupid or maybe they don’t understand, they think it’s a disability..."

Harry explained that he does not always tell people about Asperger’s because he feels ‘ashamed’. It is difficult to know whether this sense of shame relates to how other’s see him, or whether it reflects a comparison between how he would like to be and how he actually sees himself. However, the fact that he also commented on the negative assumptions some people hold about Asperger’s suggests that his feelings are the result of thinking others will judge him negatively. Significantly, shame is one emotion that ToM models of autistic spectrum disorders predict people with the condition would not feel.

"Ewan explained that initially he did not tell people he came into contact with about his diagnosis because he ‘worried what people might think’. Whilst he does tell more people now he still is unsure of how they will react and described how telling people was still difficult for me”

3.5.3 Educating others about Asperger’s

Claire, who was unsure about whether others would hold negative views about Aspeger’s, was the only participant who described using the strategy of educating people about her Asperger’s. She did this in two ways, firstly to challenge any negative comments about Asperger’s and secondly, to pre-empt any negative appraisal from new acquaintances. She believed that others knowing about the diagnosis would stop them holding as negative a view about her should they simply perceive her as ‘different’. She described an episode at work where one of her colleges did make jokes about her Asperger’s. She chose to confront the person and explained what her diagnosis meant. Having explained to the
person, they appeared ‘interested’ in what she had to say, suggesting that Claire saw it as a helpful strategy.

In terms of pre-empting negative appraisals, Claire described how she protected herself from possible negative judgements from people she does not know by telling them about her Asperger’s at the beginning of their interaction. Despite its usefulness in the past, however, Claire’s use of education as a strategy to manage negative interactions has reduced over time. This may reflect the fact that friends have told her others will use it against her. “We go out with my friend and her friend and then going home the other night her friend said to her, well, why does she do that, she was a bit strange… So that’s why I tell people, I just tell people what they need to know”. In addition, she also comments that because she now has a close group of trusted friends she does not need to tell everyone. Having close social support increases self-esteem and may provide an alternative source of protection against negative comments:

“I tell less and less people now, only the people I think need to know, the people I spend most time with, actually everyone I’m close to I suppose”

3.6 Social comparisons

Social comparisons can serve a number of functions such as enhancing self-esteem and increasing motivation and hope (Taylor and Lobel, 1989). Consequently, the direction of comparison (upward, downward and lateral) is determined by the situation and the goal of the individual. In the present study, only downward (four participants) and lateral comparisons (four participants) were identified. In-group* comparisons (comparison with others diagnosed with autistic Spectrum Disorders) were downward, in that they were made against people seen as less able than themselves on all but one occasion. Out-group comparison, however, were lateral (identifying similarities between self and others not included in the perceiver’s stigmatised group), and appeared to serve the purpose of normalising participant’s experiences.
3.6.1 Lateral comparisons (Normalising)

Wheeler (1966) described lateral comparisons as a strategy to identify one’s self with those perceived as similar on a specific dimension. Four of the participants made spontaneous social comparisons with a majority out-group of people without Asperger’s syndrome. In line with Wheeler’s comments, these comparisons appeared to serve the purpose of normalising negative experiences, such as difficulties in social interactions or negative mood states.

Claire described how even on a good day she sometimes ‘wishes she was normal, or neuro-typical’. However, she then went on to talk about how through her experiences at work and the social comparisons she made there, she felt more normal. These comparisons normalise her experiences and reduce her sense of difference.

"Actually I do think that everyone has a problem in some way. And I have actually learnt that recently, because the assistant manager that like to see things through, that sometimes I have a problem with at work, who’s lovely out of work, she’s normal but she finds it hard to do things...”

Brian explained that he thought his problems might not be related to Asperger’s syndrome. Rather, they might be normal difficulties faced by other people without a diagnosis. His comments may reflect his ambivalence about his diagnosis resulting from the confusing messages he received from professionals regarding whether they thought he had Asperger’s. However, he was one of the participants that believed people generally stereotype those perceived as ‘different’. As such his strategy of normalising his experience may serve to protect against negative self-evaluation.

"One thought I had, maybe it’s not Asperger’s... I had the idea that I lose it when it comes bad and everyone has that"
Fred normalises his experiences by pointing out his view that ‘we’re all different’. His comment serves to dissolve the socially proscribed boundary between people with characteristic associated with Asperger’s syndrome and others who think and behaviour in their own unique ways. Gary described meetings he attended with parish counsellors during which he surprised himself at how well he conducted conversations and emphasised the fact that ‘most people wouldn’t cope with it would they’. Gary’s description highlights the fact that he viewed his abilities in that situation as above the level of the general public and so is able to identify with a skilled group of people without Asperger’s syndrome.

3.6.2 In-group downward comparisons (Minimising)

Five participants made social comparisons with others diagnosed with Asperger’s Syndrome. These comparisons are ‘downward’ in that they focus on others having more difficulties than themselves. The comparisons made here all relate to Asperger’s syndrome and the symptoms defined in diagnostic criteria. Rather than indicating that this is a salient feature of participants’ identities that they commonly compare themselves with others on, it may reflect the fact that interviews talked explicitly about their diagnosis and thus it is within this context that this dimension becomes salient. Whilst group membership provided the opportunity to make self-enhancing comparisons, none of the participants used group membership as a way of identifying positively with Asperger’s syndrome.

Andrew described himself in comparison to the other member of the Asperger’s group he attends. Through these comparisons he was able to reflect on the level of difficulties he and others present with, which he interpreted as him being more ‘normal’. He appeared to distance himself from the label of Asperger’s by identifying with those functioning at the highest level in the group, whose difficulties may be less immediately noticeable.

*Note – The terms ‘in-group and ‘out-group’ are used here as analysis categories. It is important to bear in mind, however, that the participants themselves may not necessarily view this as an in-group or out-group.
"...to see the mix of people in the Asperger’s group, half of them I would label as people with problems, half of them I would say, ‘mm, ordinary person’. And I see myself as in, what I would label an ordinary person, which perhaps really means people like me..."

Brian, as well as making out-group comparisons to normalise his experiences, also made comparisons with others with Asperger’s to highlight the fact that he sees it as only a small part of his difficulties:

"...Asperger’s is very mild in my case, I, it’s not, it’s not that bad in my case you see, I went to university, I left home you know. I, it’s not that bad. But there are other people that are much worse than me..."

Claire drew on a gendered framework to make comparisons with others in the Asperger’s group, as she was the only female attending. She highlighted differences in communication and also referred to differences between the genders generally.

"Some of them talk slower, whereas I can be quite a fast speaker, erm, and my words flow... may be that’s the reason why girls are harder to diagnose than boys..."

Fred also focused on communication skills to highlight the difference between himself and others that attend the Asperger’s group when asked how he functioned in comparison to other people with Asperger’s.

"...there are people at the drop-in who you could tell that they did have Asperger’s ‘cause they were showing signs of having it. Like there was this (guy) who I’m friends with who goes...and he wouldn’t listen to (the group facilitators)...talking in long monologues and that was like Asperger’s"
4. Discussion

The present study explored the way in which people diagnosed with Asperger’s syndrome related to their diagnosis, the degree to which the diagnosis had become a salient part of their identity, the degree to which they believed that Asperger’s syndrome represented a stigmatising label and the ways in which participants managed awareness of stigma.

4.1 Summary of analysis

The participants in this study described complex inner lives. The majority frequently made reference to emotional experiences, their own thoughts about themselves and their social worlds. Within this complex framework of self-understanding, participants were able to give rich accounts of their experiences both prior to and following diagnosis. They all described an awareness of feeling different from others from an early age. In addition, people in their social worlds often gave negative and derogatory labels to describe and explain their behaviour. These labels frequently became salient in terms of how participants described themselves, which led to negative self-evaluations.

Receiving a diagnosis of Asperger’s syndrome had both positive and negative consequences for participants. For some, receiving a diagnosis initially caused discomfort and reduced the sense of control they had over their difficulties. However, all participants explained that giving a name to their difficulties allowed them to challenge the negative views of themselves given by others. This resulted in them feeling less responsibility for previous problems.

For the majority of participants, the diagnosis in itself did not provide any further opportunity for managing difficulties and the majority appeared to view Asperger’s negatively. However, the support received from charitable organisations provided an opportunity for participants to understand the diagnosis, how it applied to their own experiences and an opportunity for skills building. As a consequence, most of the
participants reported an increased sense of control over their lives and an increased understanding of themselves.

Half of the participants thought that people generally would hold negative views about Asperger's syndrome, although most could not identify what these would be. Of those that could, the most commonly stated was the belief that they would be seen as stupid or thick. As a consequence, people utilised a number of strategies including keeping their diagnosis a secret to maintain a positive self-image. In addition, the social comparisons described by participants also helped to maintain a positive self-image.

4.2 Rich descriptions of inner experiences

The self-descriptions provided by participants in this study contradict many previous findings suggesting that people with Asperger's syndrome have a limited capacity to reflect on their thoughts and feelings (Lee and Hobson, 1998; Hill, Berthoz, Frith, 2004; Happe, 1991). The small number of participants here limits the generalisability of the findings. However, they do suggest that whilst people with Asperger's syndrome may represent a group who find self-reflection and self-understanding a difficult process, the descriptions often used in the academic literature inaccurately present such people as rather two dimensional. This point was made recently in The New Scientist (2005) by a self-proclaimed "proud Aspie" responding to comments by Temple Grandin who stated that "(autistic people) don't have complex emotions such as shame or guilt". The respondent asserts that "the idea we don't feel guilt makes no sense to me" (p. 22).

Tantum (2003) highlights the fact that it was the parents of people with ASD who initially challenged the idea that all people on the spectrum lacked self-awareness. Many parents rejected the diagnostic definitions in DSM-IV and ICD-10, developing their own functional description of Asperger's syndrome, which included an ability they recognised in many of their (adult) children to reflect on their own emotions and thoughts. There are a number of factors that may account for the discrepancy between previous studies and the
current findings. Firstly, many previous studies were carried out with children who may not have developed the capacity to self-reflect. Consequently, the applicability of these findings to adult populations is inappropriate. Secondly, most studies reflect descriptions given using unnaturalistic methods such as writing down thoughts when prompted by a bleep, which may influence the information presented by participants. Only Robert, Jones and Huws (2001), who found that people with Asperger’s syndrome did in fact have the capacity to reflect on emotional experiences, used extracts from writings by people with Asperger’s syndrome that were produced under more normal situations (written on the internet). In the present study, whilst participants were asked specific questions about themselves, the interviews were kept informal and participants were allowed to lead the conversation to some degree in directions they thought relevant. This appeared to allow them to feel more comfortable reflecting on their experiences and more able to relate their inner experiences. Thirdly, as the participants in this study had all attended a social skills group and/or structured support schemes focusing specifically on the needs of people with Asperger’s syndrome, such support may have assisted with the development of self-reflective skills. However, a number of the participants were able to clearly describe the emotional impact of events prior to and during the diagnosis process, suggesting some degree of emotional awareness relatively early on in their lives. Fourthly, the participants were a self-selected sample and therefore may represent a group more comfortable with interview-type questions, although this does not necessarily indicate greater ability to self-reflect than those who did not volunteer to take part in the study.

Overall, the descriptions provided by participants support the findings of a number of authors (Tantum, 2003, Roberts, et. al., 2001, Mavorapoulou, 1995) that some people with Asperger’s syndrome do have the capacity to reflect on their own inner worlds, which are complex and emotionally rich.
4.3 Effects of diagnosis on self-descriptions

Participants had complex and dynamic relationships with their diagnosis of Asperger’s syndrome. The way in which they related to and described themselves in terms of Asperger’s syndrome changed over time and across situations. In some cases, ambivalence about their diagnosis was apparent across sentences; some participants attempted to both reject the diagnosis and embrace it to describe their difficulties. Denial of an illness label is often seen as a ‘lack of insight’ and an indicator of the degree of illness (Estroff, Laithcotte, Illingworth and Johnstone, 1991). Whilst participants may have had difficulty adjusting to the label, it may also reflect the complex way in which individuals manage their identity across situations. People were active in choosing when and how to disclose their diagnosis and often commented that Asperger’s syndrome was only a part of how they thought about themselves. This suggests that rather than passively accepting the diagnosis and its meanings as defined by professionals, they were active in giving meaning to their difficulties whilst maintaining a sense of identity other than as a member of a group of people with Asperger’s syndrome. The fact that half of the participants identified stigma attached to the Asperger’s label suggests that choosing when and to whom they disclosed their diagnosis may have been a strategy to protect against stereotypes. This point is discussed below. The contextual nature participants relationship with their diagnosis could also relate to the fluidity of the self and the role of cultural factors, mediated through language, in constructing an individual’s sense of identity (Flaskas, 1999). For example, whilst meeting with care professionals where notions of disability and difference are reinforced, participant’s sense of themselves become shaped by the culturally sanctioned view that difference equates to less worthy and efforts to achieve normality are rewarded. On the other hand, where participants reported feeling a connection to other people with Asperger’s syndrome who saw their way of being as normal in its self, identity was something that was acceptable and positive.

The majority of participants reported negative reactions immediately following diagnosis (or self-labelling). The shock of receiving the label related to the way in which it
challenged assumptions people held about themselves and their difficulties, the fact that they were forced to think about themselves within a deficit framework and a belief that their problems were permanent and insurmountable. In some cases this resulted in negative self-judgements such as feeling inferior and in one case thoughts of self-harming. The diagnostic criteria used by professionals describing Asperger’s syndrome frame the construct as a collection of impairments, which immediately forces individuals into a ‘less able’ minority group. Estroff, et. al. (1991) highlight the fact that around the time of initial diagnosis people are most vulnerable as their self-concepts are challenged and the psychiatric label is ‘stamped on people’s identities’. Often during the diagnostic process no attention is given to the positive qualities associated with Asperger’s syndrome or the positive attributes held by individuals. In addition, no support was provided to participants in this study immediately following diagnosis in order to help them adjust. Hayward and Bright (1997) discuss the impact of diagnosis and how it can have a negative affect on identity, highlighting the importance of providing support that addresses issues of self-image.

Despite the initial negative impact, following diagnosis all of the participants reported a sense of relief in being able to identify a known cause for their problems. The label appeared to legitimise functional or social difficulties for which they had no previous explanation, or for which others had applied derogatory and denigrating labels. This echoes findings by Charmaz (1991) and Murphy (1992) who noted that receiving a diagnostic label often allows people to better understand their own functioning. Miles (1987) also highlighted the positive implications of receiving a diagnosis as including the reduction of ambiguity, shame, anger and guilt. By re-evaluating past and present problems, participants were able to challenge self-blaming narratives and construct a more acceptable understanding of themselves.

Part of this process involved making a distinction between themselves and the diagnosis. This seemed particularly important in maintaining a positive self-image. Asperger’s syndrome was often seen as a negative thing external to the individual’s identity that
impacted on participant’s lives and which they had to control. Olney and Kim (2001) found similar strategies of coping in their study of the way in which people with cognitive disabilities integrate their diagnostic label into self-descriptions. Estroff, et. al. (1991) suggest that this form of self-presentation, whilst not addressing labelling directly, locates the problem in relation to the self and is not a process of denying difficulties. Engagement in this process by participants also highlights the complexity of their inner lives and the active way in which participants attempt to manage their identity. This externalising process increased positive self-evaluations by reducing feelings of responsibility. However, it did not in itself increase a sense of mastery over difficulties. In fact, the opposite tended to occur during the initial period after diagnosis. That is, participants actually felt less in control because they did not receive enough information about Asperger’s syndrome to fully understand it or how it related to their own lives. Putting a name to their difficulties alone was not enough to feel in control.

A further factor that prevented participants developing a sense of understanding about how Asperger’s related to their difficulties was the differing attitudes of professionals during the diagnosis process. A number of people reported feeling confused as to whether they actually had Asperger’s syndrome because of the contradictory messages given by health professionals. This finding supports the comments by Olly and Gutentag (1999), that diagnosis of autistic spectrum disorders is a daunting challenge to professionals who rely on subjective clinical judgement. For some of the participants, this sense of confusion about Asperger’s syndrome continued despite having received the diagnosis a number of years previously. When participants did receive support, their sense of mastery over their difficulties increased dramatically. The positive relationship between received services and mastery has been identified previously (Rosenfield, 1997). Rosenfield described how clients with psychiatric diagnoses attending a community rehabilitation service reported increased mastery, sense of empowerment, self-esteem and quality of life. In the present study, increased sense of control over problems appeared to have a direct impact on self-perception; participants described understanding themselves more and being more aware of both their strengths and weaknesses.
There did not appear to be any relationship between time since diagnosis and greater acceptance of Asperger's syndrome. In fact, the only two participants to make positive statements about their diagnosis had been diagnosed most recently. In the majority of cases Asperger's syndrome was seen as something negative that had to be controlled. Whilst this may reflect the negative impact people's difficulties have on their lives, it may also reflect the fact that Asperger's syndrome is generally described as a developmental disability characterised by a triad of impairments. In addition, the majority of therapeutic interventions developed for delivery with Asperger's syndrome clients focus on managing deficits and aiming to achieve 'normal' functioning (Barnard, et. al., 2001). As the two most recently diagnosed participants were the most accepting and positive about it, their experiences of being diagnosed may have been different to those diagnosed years previously. More is being learned about Asperger's syndrome and it is possible that professionals are more confident in their ability to diagnosis. Age at diagnosis may also play a significant role in attitudes towards Asperger's syndrome and the self. The youngest participant (who was also diagnosed at the youngest age) had the most positive comments to make about his Asperger's syndrome, which he was more comfortable 'owning'. Older participants, with a number of pre-existing narratives about their experiences that they have invested in emotionally, socially and cognitively, may have had greater difficulty adjusting to a new descriptive and explanatory label describing their experiences.

4.4 Stigma awareness

The fact that participants could describe rich inner experiences suggests that they would be as vulnerable to the effects of stigma as any other adult group. This was supported by comments made by half of the participants in this study who thought that the public would hold generally negative views about Asperger's syndrome. Whilst most participants struggled to explain exactly what they thought others believed about the diagnosis, two participants thought that they would be seen as intellectually impaired. Baron-Cohen also points out that society generally views people who are 'lower functioning' as having a
disability in the form of ‘retardation’, which may go some way to explain the comments found here. Link’s (1984) Modified Labelling Theory would explain this as reflecting how the participants had internalised social assumptions and expectations about people with Asperger’s syndrome resulting in the expectation of rejection. However, because Asperger’s syndrome is a relatively new and unknown diagnostic category, it is difficult to make any comment about how the public generally would consider the syndrome. The belief held by participants that others will view Asperger’s negatively may reflect more general, internalised socially proscribed beliefs regarding others who appear different in some way to accepted norms (Scheff, 1966). This is supported by comments from two participants who believed that being ‘different’ was enough to be rejected by others.

Perception of stigma may also be related to participants’ experiences of labels in the past. Prior to diagnosis, all participants had received formal and informal negative labels such as mentally ill or stupid, which they associated with being ‘different’. The diagnosis of Asperger’s syndrome (and the use of terms such as neuro-typical/atypical) specifically highlights impairments in normal functioning and therefore by definition emphasises differences between groups. This emphasis on difference may trigger the negative association of being labelled and rejected or treated as less able in the past. Authors such as Baron-Cohen (2002) have highlighted the dangers of characterising people with ASD’s as impaired and instead suggests that seeing such people as simply ‘different’ is less judgmental. However, the descriptions of experiences described here suggest that the whole idea of being different is something that in itself causes considerable distress and needs to be considered carefully when applied to people for whom being different has negative connotations.

Modified Labelling Theory also proposes that negative beliefs and assumptions about marginalised groups are internalised once a person becomes a member of that group and become a central aspect of their identity. However, the results of this study indicate that participants chose a number of dimensions on which to describe themselves, which often did not include being a person with Asperger’s syndrome. The self-descriptions offered
reflected positive self-concepts that often included attributes such as friendly, chatty and a good listener, which theories and diagnostic categories describing Asperger's syndrome class as deficient in this population. For example, drawing on DSM-IV criteria, Baron-Cohen suggests that people with Asperger's syndrome could accurately be described as people who 'are immersed in the world of things rather than people' (p.2), which can be seen as a different way of being rather than a disability. However, his argument is based on the diagnostic criteria for Asperger's syndrome, which, as mentioned above, is based on childhood presentations and does not take into account the fact that many of the characteristics present in childhood disappear as people move into adolescence and adulthood. In fact, adults with Asperger's syndrome do want friends, the difficulty is in not knowing how to go about being a friend or receiving friendship (Tantum, 2003, Barnard, 2001). This supports suggestions by Fine and Asch (1988) that researchers should beware of presuming that individuals in a minority group will necessarily only see themselves in relation to their stigmatised group identity.

4.5 Managing identity

Participants chose a number of strategies to manage their identities during social interactions. Link, Miroznik and Cullen (1989) proposed three strategies that are commonly adopted by those in stigmatised groups including education, isolation and secrecy. Due to the nature of the difficulties experienced by people with Asperger's syndrome, it is difficult to assess whether people adopted isolation as a strategy or whether it relates to specific difficulties socialising. However, in this study, none of the participants spontaneously talked about isolating themselves from others to avoid negative reactions. Only one of the participants chose to educate others about her diagnosis. This was used in two ways; to pre-empt and avoid negative appraisals based on the belief that others would find her 'odd', and to inform others about Asperger's syndrome. Whereas Link, Miroznik and Cullen (1991) found this strategy to be counter-productive, the participant in this study found that using education to pre-empt negative appraisal was successful initially as it provided her with the confidence to socialise. Educating others about Asperger's syndrome
also proved to be successful in that it stopped negative comments from others who previously did not understand what the term meant. However, she was warned off from using this strategy by a friend who thought that it would result in less favourable reactions from others, which may explain why she changed her strategy to selectively disclosing about her diagnosis.

In line with Link et. al.’s (1989) proposed strategy of secrecy, three participants described keeping their Asperger’s syndrome from others through fear of negative reactions or evaluations. Furthermore, those who felt that they had not received enough support to understand their diagnosis were more likely to continue keeping their diagnosis a secret. These findings could be interpreted as participants lacking the knowledge about AS and thus confidence to explain the diagnosis to others. However, this strategy appeared to change over time; rather than keeping their diagnosis from everyone, some of the participants began selectively revealing and concealing their diagnosis (Goffman, 1963). The change in strategy appeared to reflect people becoming more comfortable with their diagnosis and developing a social network with a few trusted friends with whom they felt more secure disclosing their diagnosis to. This suggests that support provides not only the opportunity to develop a sense of mastery over difficulties, but helps individuals develop more constructive strategies such as identifying safe relationships within which they can talk about their problems.

A number of authors (Fine and Asch, 1988, Olney and Kim, 2001) highlight the importance of considering how the meaning of disability changes over time for people. Rather than seeing people as passive victims, their relationship with their difficulties should be seen as dynamic, thus coping strategies initially adopted after diagnosis are not necessarily the ones people use after a number of years. One must also consider the environmental factors impacting on this process. As mentioned above, support played a role in the type of strategies adopted, partly through helping develop greater understanding and acceptance of difficulties. Support also provided the opportunity to develop specific coping strategies to deal with the social and functional difficulties associated with
Asperger’s syndrome, helping to manage symptoms and to develop supportive social networks.

4.6 Social comparisons

The social comparisons made by participants indicated that to some degree the label of Asperger’s syndrome was integrated into their self-descriptions. In order to manage identity, participants engaged in a number of social comparisons, which included downward and lateral comparisons. Downward comparisons were made with other people with Asperger’s syndrome or autism. This does not necessarily reflect the salience of the diagnosis to the self-descriptions of participants however, because these comparisons were pre-empted by the researcher who asked how they saw themselves in relation to others who attended their support group. However, in this context, participants were able to highlight their perceived higher levels of functioning than others in the group in order to maintain an image of themselves as ‘high functioning’ people with Asperger’s syndrome. Overall, affiliation with this in-group provided the opportunity to differentiate themselves from those they saw as ‘lower-functioning’.

Lateral comparisons made by three participants were all made spontaneously with out-group members of the majority group (people without Asperger’s syndrome). Through this process, participants strove to normalise their experiences and to assert the similarities between themselves and those without Asperger’s syndrome. Two participants emphasised that people without Asperger’s syndrome also experienced problems in their day to day lives whilst one other participant emphasised the fact that ‘we’re all different’ (interview 1, line 108). This last point has relevance when the idea of an autistic spectrum is considered. Generally, the spectrum is seen as being made up of a minority group of people with specific difficulties. However, an alternative approach is to consider the spectrum as representing the broad range of difficulties we all face. That is, abilities such as empathising, reading body language and self-reflection should be represented on a
continuum on which we all fall rather than creating a sub-group of people that we can exclude ourselves from.

The interpretation of conversations with participants highlighting the contextual nature of their self-concepts draws parallels with work exploring identity with various social groups. For example, Heiman and Kariv (2002), following interviews with students in higher education who present with learning disabilities, found that participants utilised various coping mechanisms to adapt to educational obstacles, and through this process their self-concepts changed and developed into more positive self-perceptions. Focusing specifically on people diagnosed with ‘cognitive disability’ (including Tourette syndrome, Brain injury and Tardive Dyskinesia), Olney and Kim interviewed several adults about how they coped with receiving their diagnosis. The authors report that participant’s self-concepts changed over time as they worked to incorporate their disabilities into their self-concepts. This process involved participants adopting multiple perspective, which proved to be an ongoing and active process, influenced by a number of internal and external factors such as cultural beliefs about ‘normality’.

4.7 Clinical implications

A major problem highlighted by the current research project is the fact that professionals involved in the process of diagnosing Asperger’s syndrome are usually at odds with each other regarding inclusion criteria and the benefits of giving a diagnosis generally. This, as indicated above, causes particular difficulty for people in terms of the stress of going through the diagnostic process, in their ability to come to terms with and adapt to a diagnosis, and ultimately in accessing appropriate support structures. A great deal more research needs to focus on clarifying diagnostic criteria and in particular, providing useful criteria for use with adult populations.

The lack of support described by participants reinforces the findings of a study by the NAS (2001). The NAS found that since the government’s white paper outlining the development
of health services (DoH, 2001), no specific service or professional group have responsibility for the care of people with Asperger’s syndrome. Participants in the present study often managed for up to one year without any specific support from health services, a period during which people felt depressed. If diagnoses are to be made, then appropriate professional support needs to be made available. Services need to consider a number of factors in relation to the needs of people diagnosed with Asperger’s syndrome:

1) Support in managing the initial impact of receiving a diagnosis

2) Professional support providing information and education about Asperger’s syndrome

3) Individualised care focused on helping people relate the diagnosis to their personal experiences and which focuses on identity and self-esteem.

4) Practical support and education in relation to developing specific social and living skills.

5) Providing the opportunity for people diagnosed with Asperger’s syndrome to explore their beliefs about stigma, taking into consideration previous experiences of being labelled, both formally in terms of mental health diagnosis and informally by members of social networks.

6) Adopting a psycho-social model of Asperger’s syndrome (Tantum, 2003), which focuses on the impact of other’s attitudes and reactions to people with specific difficulties, as opposed to placing responsibility for difficulties solely within the individual.

7) Providing public with information about autistic spectrum disorders
8) Increasing focus on strengths and skills of the individual following diagnosis.

4.8 Limitations of current research

The are a number of factors that limit the generalisability of the current research project. Firstly, as participants were volunteers, they may not be representative of other people diagnosed with Asperger's syndrome. For example, they may have felt more comfortable with the interview process, they may have represented a specific group with greater self-reflective capacity and they may have developed a relationship with their diagnosis that they felt more comfortable talking about. Secondly, only one of the participants was female. This is particularly relevant in light of Faherty's (2004) article describing the differences between men and women with the diagnosis. A female member of the Asperger's support group Faherty runs commented that women with Asperger's syndrome also face 'problems of society's expectations of women'. The third limitation of the present study relates to the fact that only one member was from a minority cultural group (Middle-Eastern/Muslim). Focusing specifically on autism, Dyches et. al. (2004) highlight the lack of research examining the relationship between diagnostic categories and racial/cultural background, or between cultural/racial identity and adaptation to a diagnosis of autism by clients and their families. These issues would appear as relevant to research on Asperger's syndrome as autism. Thus the findings of the present study may not generalise clearly to people of different ethnic and religious backgrounds.

4.9 Suggestions for future research

Given the rich and complex inner lives of the participants here, it would be of use to explore further the way in which people with Asperger's syndrome construct their identity and what external factors help or hinder the development of a positive self image. Further exploration of factors that relate to the development of self-reflective and ToM capacities as children and adolescents develop would also provide some insights into how clinical input could be best timed to support growing self-awareness and which models would be
most effective. Longitudinal studies tracking change in self-reflective capacities of individuals or cross-sectional studies comparing different age cohorts are two options for exploring this issue.

There is little empirical evidence on the efficacy of specific therapeutic interventions with people diagnosed with Asperger’s syndrome (Hare, Jones and Paine, 1999), and the majority of studies that have indicated positive outcomes have focused specifically on Cognitive Behavioural Therapy and skills-based interventions. However, a few clinicians have adopted approaches that focus more on the individual’s self-perception such as Personal Construct Therapy (Hare et al., 1999) and psychodynamic psychotherapy (Schwartz, 2002). Further research exploring the most effective ways of helping people adapt to receiving the label in terms of exploring identities and managing stigma would be fruitful. Given that participants in this study frequently externalised Asperger’s syndrome in order to develop some degree of mastery, approaches such as narrative therapy (White and Epstein, 1990), which encourages the externalisation of problems, may prove a useful intervention.

The purpose of this study was to explore the self-definitions of people diagnosed with Asperger’s syndrome and how these individuals related to their diagnosis. Therefore, limited attention has been paid to the impact of social networks and family on developing identity. This is an area where future research could hopefully provide some insights into the type of support that best helps friends and carers to promote positive identity in those diagnosed.

The use of qualitative methods in this research project proved fruitful in providing the opportunity for people with Asperger’s syndrome the opportunity to have their voices heard and in providing a medium through which to explore the impact of diagnosis on notions of self. However, the use of quantitative methods in future research would provide greater opportunity to explore experiences in a greater number of participants, thus allowing for more generalisation of findings. For example, a great deal of research has
indicated a relationship between adults’ perceptions of their own childhood attachments to caregivers and their current relationship quality. It would be useful to explore the way in which people with Asperger’s syndrome describe their early attachments, and whether these change in light of receiving a diagnosis.

4.10 Reflection on the impact of the project on the self-concept of the researcher

Having engaged in the process of talking to people about their ‘self-concepts’ and exploring notions of the self presented in the literature, I have taken the time to reflect on how this process has influenced my own self-perceptions. The first point that comes to mind is the way in which the cultural norms in terms of language influence how I define myself, both in and out of work. In terms of work, terms such as professional, therapist, and Clinician carry certain values. I feel it is important to explore these assumptions and how they have influenced my identity. In relation to this, the process of self-reflection has highlighted the fact that other’s (clients and peers) are influenced by the same social rules, influencing how they think about and behave towards me, thus possibly reinforcing my self-concept.

Reading the work of Flaskas (1999) made me aware of my own need for a sense of individuality and the fact that his is likely to have an effect on what I expect to find when people talk about themselves. It also brings into focus the need for me to capture those times when my own assumption about a self influence the questions I ask of clients (or participants). I have also developed a growing sense of the way in which my interactions with others impacts not just on how I feel about my self, but on the different person I can be around different people and in different roles. Flaskas’ theorising helps one to feel that this is acceptable and even normal, rather than indicating a ‘weak’ self. Flaskas’ comments attempting to explore the paradox between stable and flexible selves also highlights the danger in psychology generally of shutting down avenues of thought about the self in an attempt to challenge existing theoretical notions of identity.
My reading and conversations with the participants who kindly agreed to take part in this study has also led me to think about how there may be times when people’s experience of being themselves is in contradiction to the culturally proscribed ways they ‘should be’. I have begun to ask my self more often if how I feel is ‘normal’, and more importantly what role normal plays for society. Hopefully this will influence my clinical work in helping me to think with others about how they respond to such dilemmas, should they be aware of them, and how highlighting such situations could be used to help clients challenge repressing stories about themselves. Of particular importance is the possible contradictions experienced by people from different cultural backgrounds in relation to their self-concepts and ways of being proscribed by British culture.

4.11 Impact of the researcher’s self-concept on the research

Considering my comments on my own views about my self, it is useful to consider how this influenced the way in which the project was conducted. Reviewing the questions asked highlights for me the way in which they initially guided participants to think of themselves in a unitary way. For example, asking people what type of person they are could be seen as placed emphasis on static characteristics. This could well reflect my own need, described above, to have some sense of individuality, which, in my own culture, often comes from the belief that a healthy person is one who has stable characteristics. However, as interviews progressed, I recognised that participants highlighted the contextual nature of how they thought about themselves, which influenced me to ask questions based more on experience than on characteristics.

Choosing to interview participants from mainly one location was made on the basis of practical limitations and accessibility. However, my own need to find ways in which people could challenge notions of self and identity could also have played a part in this selection process. For example, interviewing participants with more limited language and/or self-reflective skills may have yielded different outcomes, possible indicating that some people are more vulnerable to playing out proscribed roles. It is important that future
research plays a part in extending these finding by exploring the self-concepts of people with varying levels of difficulties and from different backgrounds.

References


Appendix 1

Participant Information Sheet
Participant Information Sheet

Research Title: The Impact of Diagnosis on the Self-concepts of Adults with Asperger’s Syndrome

Researcher: Philip Anderson, Trainee Clinical psychologist, University of Surrey

LREC reference number: 04/Q1908/62

I would like to invite you to take part in a study exploring the ways in which people with Asperger’s Syndrome think about themselves and their experiences. You have been asked to take part because you have a diagnosis of Asperger’s syndrome. Whilst I am interested in hearing your views, the research is voluntary and you do not have to take part. The information below is there to help you decide if you would like to participate.

What is the study about?

A great deal has been learned about the ways in which Asperger’s syndrome affects the lives of people with the diagnosis. However, we know very little about how having the diagnosis influences the way people think about themselves. This study aims to provide the opportunity for people with Asperger’s syndrome to talk about their own views and experiences.

What is the study for?

The study is part of my clinical psychology doctoral course at the University of Surrey. I have chosen this topic because of my interest in autistic spectrum disorders and how people with these diagnoses manage their everyday lives.

The study will help us to understand the experiences of people with Asperger’s syndrome by giving individuals with the diagnosis the opportunity to express their views. This will help carers and professionals provide better support.

Will I be paid for my time?

Yes, each participant will receive ten pounds for their time following the interview.

What will I have to do?

The study involves taking part in an interview during which you will be asked to talk about your experiences. The interview will last between half an hour and one hour, depending on how much you want to say. The conversation will be recorded on audiotape. Recording our conversation will ensure that your responses are recorded accurately.

Is the information I give confidential?

Yes, nobody else will hear the tape and all the information used during the write up of the study will by anonymous. People’s names are removed so that they cannot be identified.

Can I bring someone along to the interview for support?

Yes, I recommend that participants have someone they know attend the interview with them, for example, a friend, relative or professional involved in your care.
What happens to the information?

A copy of the research will be held at the University of Surrey library. Parts of the study may also be published in academic journals. Any information will be anonymous. At the end of the study all information on the tape will be erased.

What do I do if I want to take part?

If you would like to take part in this project you can contact me on the number below to discuss the study further. By calling you have not committed to taking part in the study.

Contact details: Philip Anderson. Tel. or

Alternatively, you can give your name and contact number to the professional who told you about the study and I will contact you.

Thank you for taking the time to read this information sheet.
Appendix 2

Inclusion Criteria.
1) Age: Adults over the age of eighteen with a diagnosis of Asperger's syndrome. The lower age limit was chosen due previous findings indicating that symptom profiles of adults with Asperger's syndrome differ from those of children with the diagnosis and that differences generally begin to occur around adolescence. (Tantum, 2003, Wing, 1981, Gillberg, 2002). Whilst it is acknowledged here that chronological age does not necessarily equate with developmental level in terms of core features of Asperger's syndrome, selecting an adult population provides the most appropriate method of comparing current findings with previous research.

2) Diagnosis: There are a number of diagnostic criteria and assessment tools available to guide professionals in the diagnosis of Asperger's syndrome. Unfortunately, it was not possible to identify individuals who had been diagnosed using the same criteria or assessment measures. A broader criteria of having received a diagnosis of Asperger's syndrome was chosen as it reflects the current clinical situation and therefore is probably quite representative of the general population of adults with Asperger's syndrome.

3) Language skills: Due to the interview style adopted during this study, a further requirement for inclusion was that participants had sufficient expressive and receptive language skills. This was not assessed formally. However, staff working with potential participants were asked to give their impressions of clients' ability to understand and utilise language.

4) Risk assessment: Staff were also consulted prior to inclusion regarding the current mental health status of clients and the risk of an interview causing undue stress. Staff were asked if any potential participants were currently experiencing mental/physical health problems, life changes or other stresses that would make it inappropriate and or unethical for them to take part in the interviews.
5) Availability of support prior to, during and after the interview: The current researcher also met with all potential participants prior to inclusion in the study to assess people’s suitability for participation and any risk to their own or other’s health. In addition, participants were asked to identify a family member, friend or professional they felt they could talk to should they find the interview stressful. As all of the participants were currently attending a social skills course run by the National Autistic Society, staff running the course also agreed to provide support to any participant who required it prior to or following interview.
Appendix 3

Participant Consent Form
Consent Form

Research Title: Identity and Self-concepts of Adults Diagnosed with Asperger’s Syndrome

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LREC reference number: 04/Q1908/62

If you have any concerns or feel unsure about the study then you should ask the researcher to explain things more clearly, or talk to someone you know well about your decision.

Please initial box

1) I confirm that I have read and understood the information sheet and have had the opportunity to ask questions about the research project.

2) I understand that my participation in this study is voluntary and that I can withdraw at any time, without any of my rights being affected.

3) I agree that the interview can be tape-recorded. I also understand that any information I give will be confidential and that the tape will be erased at the end of the study.

4) I agree to take part in this study

Name of participant Signature Date

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

Signature of researcher Signature Date

............................... ............................... .........
Appendix 4

Semi-structured Interview
Interview Schedule

1) What type of person are you/how would you describe yourself?

2) What makes you unique?

3) What made you the way you are?

4) How do you think other people see you?

5) In what ways if any have you changed in the last 5 years?

6) How do you know you have changed?

7) In what ways if any have you stayed the same in the past 5 years?

8) How do you know you have stayed the same?

9) Do you think you will be the same/different in 5 years time?

10) In what ways are you similar/different to the people at?

11) When did you get your diagnosis of Asperger’s syndrome?

12) Did getting your diagnosis change anything for you?

13) Do you see yourself as the same or different since getting your diagnosis?

14) Do you tell people about your Asperger’s syndrome?
15) How do you think the general public see Asperger' syndrome or people with the diagnosis?
Appendix 5

Participant Transcript
The Impact of Diagnosis on Self-concepts of Adults with Asperger’s Syndrome

Interview 3 Transcript: Claire, age 25

1 I - First off then, I just wanted to ask you what type of person you are.

2 P – Erm, what type of person I am? Can I take as long as I want?

3 I – Yeah, of course you can, yes definitely.

4 P – Good or bad (laughs)?

5 I – You choose. What ever, it can be both or either.

6 P – Erm, I’m affectionate to people I know. Only affectionate to my mother at times.

7 I – Mm.

8 P – Erm, maybe that’s because she loves affection, I don’t know. Erm, with people that I don’t know, with everything that I’ve been through, erm, I tend to be more wary.

9 1 – Right.

10 P – Until I get to know them, whereas in the past I was extremely friendly straight away and then I’d find out they weren’t particularly nice, and then I’d think, oh dear, and get hurt. So if I get to know someone nice, slowly and chose, instead of telling them all about me at first...

11 I – Mm.

12 P - ..If I get to know and feel comfortable with them first, then tell them things about myself, then I won’t get hurt.
17 I – Right. OK. So when you say everything that’s happened to you, do you mean your past experiences in relationships?

19 P – Yeah, before I found out I had Asperger’s, yeah.

20 I – OK. So that changed something for you then? You learnt something when...

21 P – Yeah.

22 I – How did it change? I’m just, I’m writing things down here just to remind me of the things you said so I don’t miss it out.

24 P – Mm.

25 I – Erm, you were telling me about how you changed since your diagnosis, and how you relate to other people, and I was just wondering how getting the diagnosis influenced that.

27 P – Well, as an adult finding out, it put things together. I realised things, realised why people acted differently around me.

29 I – Mm.

30 P – Because, I wasn’t really acting maybe cautiously, and people would think that I’m easy to walk all over, erm, whereas now I ain’t got no, no worries about that what so ever. Erm, Because I know that people do judge, so, with the fact that I know about myself now, I’m not going to go into a friendship or spending time with somebody whether it’s work or what ever, a colleague or friendship, without being careful.

35 I – Mm.

36 P – ..Am I making sense?

37 I – Yeah, yeah. It’s sound like you...

38 P – Because...(pause)
...Like you've learned something about yourself...

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P - Yeah...

---

...and what you've learnt helped you understand why things might have been difficult before.

P - Yeah.

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I - Can you remember what your worries used to be before you had the diagnosis?

P - (Pause) Er, I'd meet someone, and then, by the time I'd finished they'd know all about me, and I'd hardly know about them.

I - Mm.

P - and I'd think to myself, this is a bit odd. And then they would either talk to me in the future or not. So, I then realised that maybe this was the wrong way of going about it, and I'd, through talking to my family and my mom and, people don't usually do that. So that's why I changed to talking a little, and more slowly over days, and then (pause)...

I - Mm, mm.

P - which is better.

I - So you...

P - And it's more two sided rather than one sided. Which is good.

I - I see. Mm. So you don't open up and tell everybody everything straight away?

P - Mm, and they can't judge me (laughs).

I - Right.

P - Like, if you let things slowly, when you get to know someone, talk about your self slowly, then they're more likely to accept you.
I – OK.

P – That's what I think.

I – That's interesting. How do you think that happens, have you thought about that?

P – Because they've got time to go away and think about whatever you said to them, and come back and carry on the conversation and it's not all done on one big flow (laughs).

I – Right.

P – (Laughs) one big go.

I – Right, not to overwhelming?

P – Yeah.

I – Yeah, yeah, OK. And you said you, your family's helped you out there?

P – Yeah.

I – Initially I thought it was when you had, when you got your diagnosis?

P – Mm.

I – ...then you understood. But it seems, but I wonder if it was before..

P – It's both, my family and the diagnosis.

I – Right. OK. Can I ask you, it's quite hard to do I suppose, but trying to think about how you used to see your self before you got the diagnosis. Has it changed the way you view your self since you got the diagnosis?

P – Yeah.
In, in what way?

I'm more confident now, erm, I know that I'm different for a reason not because I'm odd (laughs), and I'm not actually odd, I'm different and there are ways to deal with that difference.

Mm.

...to fit into life.

Did you used to think you were an odd person?

Yeah, I did feel different. I didn't know why. I just thought, everything, when I grew up I just thought I was different; my brothers were much better than me, and (pause) I just, I just felt apart, do you know what I mean?

different and apart in terms of being able to connect to other people?

Well obviously the way an Aspergic acts is different to somebody who can actually see and has learnt things growing up, cause it's not obvious to them, where as an Aspergic person needs to be told, to understand and they carry on.

Mm.

But, so with my mum saying that's wrong, this is wrong, the other's wrong, you shouldn't do that, you shouldn't do this, your stupid, blah de blah, I did feel very bad.

Mm. Is that the response you used to get from your Mam? Did she used to say that?

Mm.

So it sounds as though she didn't understand either.

Mm.

That must have been pretty painful?
101 I – What effect did all that have on you?

102 P – Erm, My GCSE’s weren’t as good as they could have been.

103 I – Why was that?

104 P – Cause I didn’t believe in my self. I didn’t think I could do it, I thought I was thick (laughs). So I tried my best but I had to retake them, and, I, basically, if I’d been diagnosed earlier and given the help I think I could have gone to university. The only opinion that I ever had was that I’m not good at this, I’m think, I’m not very intelligence, I’m really bad at that. I was really, really negative.

108 I – Right.

109 P – But I’m going to go to college now, which is good.

110 I – Good. Have you got plans for that in the near future?

111 P – Yeah. September.

112 I – Oh, fantastic. Where are you going?

113 P – Sheffield college, I’m going to learn how to be a nail technician.

114 I – So you’re moving away from home?

115 P – Yeah.

116 I – Exciting. Wow. And that’s because you’ve got the confidence to do that now.

117 P – Yeah.

118 I – I was going to ask you something there, but it’s gone now.

119 P – Sorry.
120 I – No, no it’s fine, erm, I suppose it was that thing you were talking about feeling apart.

121 P – Mm.

122 I – and you asked me if I understood it and maybe I don’t actually understand it quite so well and I
123 wonder if you could explain a little bit.

124 P – Feeling apart, I mean, I felt not involved, like a cast-out. At school as well, as well as in my family,
125 and felt a cast-out in my family and since I was 22, I’m 24 now.

126 I – Mm.

127 P – And, I may get a bit emotional, and…

128 I - If there’s anything that you’re not comfortable talking about you know it’s fine, just let me know.

129 P – Mm. And, I don’t know which bit do I talk about. We’re talking about feeling apart, an out-cast.
130 Erm, I was very lonely..

131 I – Mm.

132 P – Extremely lonely. I didn’t know what I wanted to do with my life. My parents would tell me off
133 about that and obviously because they want the best, wanted the best for me.

134 I – mm.

135 P – Erm, and the confidence thing as well. And I did turn to drink…

136 I – Mm.

137 P – And that was the end of my 20’s, when I was, at the end of my 22\textsuperscript{nd} year when I woke up and
138 thought this is not what I want.

139 I – Mm.
140 P - I had no friends, I was drinking 2-3 bottles of wine a day...

141 I - Mm.

142 P - On my own in my flat.

143 I - Mm.

144 P - I'd had fights when I was living at home with my family, physical fight fights, and in the end basically I wanted to go out and my parents were worried to let me out, and I didn't know why I had such a pull to go out and get away. I wanted to go down the pub and I wanted to get drunk. I wanted to drown my sorrows, I wanted to be stupid and not care.

148 I - Mm.

149 P - But I woke up, obviously, one night and I was all alone and the friends that I'd made were completely wrong and I thought this is not right. And I, I had been attacked a few times from a female friend and my house had been smashed, smashed up the door had been smashed. And I thought to my self, I had a glass of wine in my hand and that's all I ever did. And I, I noticed my self drinking in the morning and I just thought it's not right, I've got a problem, and I admitted it. So I phoned AA, joined AA, and for five months I went to AA. I didn't do the program properly...

155 I - Mm.

156 P - But, me just being there and just listening got me away from it. And then I got, Had counselling, and that's when I was diagnosed, Last year. And I felt really angry, and then I felt relieved. Whereas my Mum, she felt really relieved at first and then really angry (laughs).

159 I - Oh, right, the other way round?

160 P - Yeah.

161 I - Ok.
And I didn’t actually think there was a problem with me. I thought at that point it was a problem with my Mum (laughs), because in the end I felt so much anger towards my Mother, because everything that she said, that everything I did was wrong, so basically I would go to counseling and I was basically telling the counselor that it’s my Mum, she does this she won’t let me do that, she won’t let me do the other. But then in the end with my mum talking she said she’s actually got a disability, a difficulty or whatever you want to call it, and erm, I was just really angry because no one had found out about it before.

when I was a child. But I did go to seventeen schools, cause my dad works for Shell.

And, erm, I have actually been thinking about, a lot about my past, in the last two months.

And my parents knew then, they noticed something in me, and they thought oh, she’s OK, she’s just gone to another school.

... And my parents knew then, they noticed something in me, and they thought oh, she’s OK, she’s just gone to another school.

Did you change schools because of your Dad’s job, or for other reasons as well?

‘Cause of my Dad’s job.

So, I quit school when I was 19, and, I’ve only just got it together. 19, 20, 21, 22, 23, 24, 6 years later I’m better. Mentally as well. And I went through some things, ‘cause my Mum said you’ve got to clear out some of your files. ‘cause obviously when you’re moving and I’d moved a lot over the last 4 years, 19 to 23, and I went through my things. And I went through an old folder from
186 when I had counseling, and my mum was trying to talk to me, and I said, Mum, I'm not going to listen
187 to you because I’m actually reading something, and it, about my past, and I really can’t talk right now.
188 And I basically read it and I was so messed up, I couldn’t believe it, I knew I was messed up at the
189 time, but I was mentally I was not in any...(laughs)

190 I – Mm.

191 P – And erm, I, I’m really shaking now because, it’s not been nice..

192 I – Mm.

193 P – And, when I left school and not being able, for a girl, this is something really serious. And I know
194 it’s extremely hard to diagnose in girls, but, when I left school I had a death threat..

195 I – Mm.

196 P – I had a stalker for months.

197 I – Mm.

198 P – And it’s obviously contributed to my mental state.

199 I – Mm.

200 P – And I’ve had so many jobs, and I’ve been out of jobs for so long, long periods of time where I’ve
201 been on the dole.

202 I – Mm.

203 P – And, erm, that’s not good, obviously not good for my self-esteem.

204 I – Mm.

205 P – So, what I’m trying to say is, erm (pause), I don’t want any other females to go through what I’ve
206 been through (starts to cry).
207 I – Are you OK carrying on or do you want me to stop the tape?

208 – I’m OK.

209 - Do you think, growing up as a girl in this country with all the expectations that are put on a girl, that
210 - had an impact on trying to understand who you were?

211 P – Well I didn’t actually grow up in this country, I grew up all over the world.

212 I – Oh, right. OK.

213 P – ‘cause my Dad was always travelling. So, but I think if I had stayed in one place I would have had
214 more chance of being diagnosed earlier.

(brother enters the room)

215 I – Sorry.

216 P – And erm…

217 I – Do you want to keep going or stop it?

218 P – Stop it for a bit.

(stopped tape)

219 I – You forget about it (the tape) quite quickly don’t you when it’s on.

220 P – Mm. So when I first got diagnosed, I was on anti-depressants.

221 I – What did it mean, ‘cause I suppose when you get diagnosed you don’t know what Asperger’s is. Or
222 maybe you did, maybe you’d read about it or…

224 P – No, I had no idea.
I – So somebody, did they tell you it was Asperger’s or did they tell you they weren’t sure what it was but it was something, or...?

P – Erm, it was definitely diag, er diagnosed Asperger’s.

I – I’ve been going to Asperger’s groups and everything ties up. Like facial expressions and not reading people properly.

I – Right.

P – And getting into situations I’d rather not be in.

I – Right.

P – So since I’ve been to the meetings and talked about it, learned about it, and I went to a seminar actually on, (name of facilitator) don’t know if you’ve heard of her, ...... something. Anyway, she erm, got diagnosed in her 30’s...

I – Right.

P - ...and she wrote a book on it, ‘Self-help For Adults With Asperger’s Syndrome’.

I – Right. OK. I think I’ve heard of it.

P - Yeah. And erm, I read that, and that helped, and, what am I trying to say?

I – You were talking about erm...

P – I’ve done this twice today (laughs).

I – When you got the diagnosis and what you thought about it. So I suppose what you were telling me is now you relate...

P – I’m still studying it.

I – Yeah, so reading a book by somebody who had it, helped you?
246 P - Yeah.

247 I - Because you could relate to some of those things?

248 P - Yeah and just obviously reading about it and going to the coffee mornings and going to groups and talking and (group leader)’s great, and (other facilitator)’s great. And Just basically sorting it all out in my head, you know. As in you know it’s a better way of being a different way, and there are ways to overcome the reading of body language and the tones of voice and things like that, and (pause) what else, there are still some things that I need to learn. And I know that...

253 I - Mm.

254 P - There are some things, but I’m getting there slowly.

255 I - Mm.

256 P - But fast as well. Fast compared to when I first got diagnosed.

257 I - Mm.

258 P - ‘Cause now, erm, I’ve been all right for 5 months now. So that’s good. And erm, they’re very supportive, the first job I had at Christmas was a Christmas job, and I told them. But, I, it was obviously my first job with it, and I did feel a bit worried about, and communication (?) my Mum and my boyfriend with work.

262 I - Mm.

263 P - But now, I’m a lot better, even though I don’t know when I’ve got the message across to my manager that I’m not what, I’m not happy about my hours.

265 I - Mm.

266 P - ‘Cause I’m not happy about my hours at the moment.

267 I - Right.
Erm, But I understand from his point of view that it's hard to get, fit everyone in, and one person stays off on different days.

Mm.

But I do, do the communicating right, which is good.

Right.

And my performance at work, I've got employability in Guildford, well she helps people with a learning disability in the work place, help them to keep there jobs so she helped me in work. So we all have meetings at work, erm, and we, er, and that's very helpful, and basically I do get told straight away (laughs) for instance. My manager today was in because all the assistant managers, had the area managers training them today and they were all upstairs. All the assistant managers in the area came to our café, because, above the café, erm, there's a big enough room, erm, for everyone.

Mm.

And she said to me, Claire, you've got to be on your best behaviour because (manager's) here.

(laughs)

(laughs).

And I just smiled at him, so it's good. So Instead of, in the past I'd just get sacked.

What does that mean, best behaviour, why do you think they said that?

Because if I get stressed...I can't control it at work. If I feel under pressure, erm, they are very good there, they tell me, they can see I'm getting under pressure from a customer

Mm.

...and upset or what ever, erm, they say it's OK, it really doesn't matter. It's alright, we'll sort it out.

Mm.
290 P - ..and that just really makes me feel better.

291 I - Mm.

292 P - then I just carry on the day as normal.

293 I - Mm.

294 P - So it's a lot better knowing rather than not knowing, cause work can deal with it with me and I can
295 get training. They know that if I don't get something straight away they just have to tell me again and
296 again until I get it and once I've got it I've got it and I'm really good.

297 I - So people are being more patient with you?

298 P - Yeah.

299 I - And when they say you have to be on your best behaviour...

300 P - Yeah.

301 I - What do you do then to be on your best behaviour?

302 P - What did I do today? Just kept myself busy and kept out of the way. I think what I did was keep
303 out the way of customers that I felt that might be a bit iffy. If they would complain I kept out of their
304 way.

305 I - Mm.

306 P - (?) serve them there wasn't a big thing with me trying to hide it.

307 I - Trying to hide...?

308 P - Hide my reaction to situations.

309 I - Right.
310 P – Erm, because when I first started work I was very rude (laughs).

311 I – Mm.

312 P – Which is not good. Erm, but now, I’ve been told I’m not allowed to swear so I don’t.

313 I – Mm.

314 P – and if I do (?) like poo, but another word.

315 I – Mm.

316 P – Erm, and I had a cry once at work and they were really really nice about it, they said we all cry. So that made me feel really good.

318 I – Mm, mm.

319 P – To know that even the assistant manager cries. (laughs). Even the assistant manager cries. So, yeah, so.

321 I – Mm.

322 P – It’s actually quite good working there and my, a new colleague of mine actually pointed that out, that with complaints all the time and customers not being brilliant all the time, it’s actually good for me to control the way I respond.

325 I – Mm.

326 P – And it, and it is good. Erm, like it’s less noticeable, or I walk away or do something else, and has that affected being at home? I think it has, my Mum, the other day, she said something about, she’s always going on, well occasionally, it’s less and less now, but she said my organisation was bad and it’s because of my Asperger’s Syndrome. And instead of yelling at her I walked out of the room.

330 I – Mm.
331 P – With a not very happy face on. Which is a lot better than you know, over-reacting.

332 I – So you think you’ve learnt that at work?

333 P – Yeah.

334 I – And you developed your skills and you’ve brought it home and you use it quite a lot now generally.

335 P – Yeah.

336 I – When you were talking about work I was thinking about what you said before when you were younger, about not feeling a part of things…

338 P – Mm.

339 I – …Or feeling apart from them…

340 P – Mm.

341 I – and when you were talking about work it sounds as if you feel part of something now, especially when people say, Oh, I get like that, and I do that…

343 P – Yeah, Yeah.

344 I – cause they’re saying well you’re normal. You know, we all do that too.

345 P – Yeah.

346 I – and that must be really nice for you I imagine?

347 P – Mm.

348 I – How does that make you feel about your self?

349 P – Erm, well obviously I’m human, I react the same way that other human beings do…
350 I – Mm.

351 P – …but the only difference is, are the obvious ones where I don’t read people properly, and I need to
352 learn how to, well I know all about how to deal with unhappy situations. Erm, that’s very different to,
353 whereas other people could deal with it better.

354 I – I noticed that, I was saying a positive thing…

355 P – Mm.

356 I – That some things gone well for you and you agreed with that and then said ‘but’, I get this wrong
357 and this wrong.

358 P – Did I?

359 I – Yeah. And I just wondered if, if, do you spend a lot of time about getting it wrong, or trying to get it
360 right? Or, what do you think?

361 P – I get very angry with my self at work if I’ve got something wrong, if I’ve done something wrong
362 then I do. Quietly get very angry, ‘cause I want to get everything right, ‘cause I spent so long doing
363 everything wrong and feeling wrong and taking the blame and feeling inferior, I want to be right, I
364 want to be praised I want to be told it’s OK, You Know?

365 I – Mm.

366 P – So, have I answered the question?

367 I – Yeah. I think you are, yeah. Erm, I was going to sort of add a bit on the end to it. Are there times
368 when, are there lots of times when you just don’t worry so much and you don’t think about Asperger’s
369 and you just do things naturally and then afterwards you just think, Oh, I did that alright? Or, is it quite
370 constantly on your mind about having to get it right?

371 P – It depends who…

372 I – Do you see what I’m getting at?
373 P - ...I'm working with. And how like, Mm, there's two assistant managers, one's absolutely lovely, and the other one...

375 I - Isn't?

376 P - But she's lovely out of work I found out. She's a lovely person out of work. It's just in work we clash a bit. And I've also found out from my manager, that she has, he said it was something similar to me, I can't (?) It's just the way she's made. Because she's got lots on her mind and she's not happy at the moment.

380 I - Mm.

381 P - When she's doing one thing she doesn't like to be interrupted, so it's good to know. So, erm, what was I saying?

383 I - So we were talking about, you were telling me,

384 P - ?

385 I - ...It's alright, You were telling me how, you think differently when there's different people around.

386 P - yeah, so I think that (pause), when I'm working with..., when I'm working with her I feel, OK, I might do something wrong in her eyes and it's going to, it's, it's, it's going to it might cause a situation.

389 I - Mm.

390 P - Erm, so I do think about myself. On the days that she's working.

391 I - Right.

392 P - But when the person I get on with really well, the other assistant manager's working, then I can go a whole day thinking, erm, I'm OK, everything's fine, everyone likes me, I like everyone here, it's a lovely day, there's no problems and it's going to be OK. But there are still times when I do feel, Oh, I wish I was normal, even on a happy day at work.
Mm. And what does normal mean?

A neuro-typical mind (laughs)

A neuro-typical mind?

Do you know what it means?

I've heard it, What does it mean from your point of view.

Non-autistic, the way society, erm, distinguishes between different brains (laughs).

Right.

So that's a sort of normal brain, not a different brain, 'cause I've got a different brain.

Right.

'cause I don't understand everything, things are harder for me.

Mm. And you talk about society. It's a big one that isn't it? It's hard to, it's hard to have a conversation about I think sometimes, 'cause it's hard to see how influences us. And you lived in different cultures and societies...

Mm.

...Do you think that has an impact on how people behave and what they do?

Mm.

In their day to day lives?

Mm.

Can you give an example?
P – Society expects people, in work, to be able to be flexible, to be understanding, to be hard working, to be determined, to be willing, to be, you know, all the good things, erm, and I think, actually I do think everyone has a problem in some way. And I have actually learnt that recently, because the assistant manager that likes to see things through, that sometimes I have a problem with at work, who’s lovely out of work, she’s normal, but she finds it hard to do things...

I – Mm.

P – ...as well, and she’s trying really hard to do her job and, you know.

I – So you’re, am I right in saying...

P – Society expects you to be something and everyone’s trying to live up to that. People who have it even harder, who are Aspergic, or autistic, it is really hard.

I – Yeah.

P – Yeah.

I – What about expectations of women? Being a man I can guess what it’s like but I think it’s different for men and women, and you were telling me about how you are different from the men in the Asperger’s group. Can you say more about what the difference is? I know it’s hard to put your finger on sometimes.

P – Some of them talk slower, where as I can be quite a fast speaker, erm, and my words flow, erm, maybe that’s the reason why girls are harder to diagnose than boys, but I don’t know. Erm, I seem, I don’t know if it’s the way I’ve been brought up and may be a bit of my personality, but I’m very chatty in group, erm, I tend to but in (laughs).

I – Right.

P – But I have to control that, and even in class or what ever, I do have to control that ‘cause obviously I’ve done Spanish and French and at school I was butting in. Be quieter. So I have to control my self more.

I – And is your personality something different from Asperger’s?
440 P – Erm, affectionate, I’m kind, I’m thoughtful, when I feel relaxed with the person.

441 I – Mm.

442 P – Or a group of people. Erm, I’m jealous, Friendly, affectionate, determined…

443 I – Mm.

444 P – I’m very capable…

445 I – Mm.

446 P – Erm, I’ve got two arms, two legs, a brain (laughs)…so..

447 I – When you were saying, it’s really nice to hear you say all those things, positive qualities, and that must sort of reflect you self-esteem.

449 P – But when Asperger’s syndrome kicks in, I’m rude, I’m insensitive to other people, and I can be horrible, really horrible. When I’m under stress and what ever, erm, and if no one’s calmed me down then I can’t help what comes out of my mouth. I (?) calm down.

452 I – Right.

453 P – I think (?) why have I done that?

454 I – So the other woman at work, who you were telling me about, when she gets under pressure and stressed, she’s quite difficult. Is there a difference between you doing it and her doing it?

456 P – (pause). Well she doesn’t swear. So, but she has thumped her hand down on the table, on the till, it was quite scary (laughs). But that was a situation and she was not happy that day or what ever. And erm, but I actually, when I was in a mood with her on the day I went into, I went in front of the (?), Anna was working and I said, She’s a shit manager, (laughs). And then… said, I’m not involved, I’m nothing to do with this, I’m not involved at all, I’m not into this bitchiness. And then later on I calmed
down and ....was there, I said I’m really sorry I said that and I’m really sorry you had to hear that and I’m really horrible when I’m angry (laughs), and upset, so that’s the complete opposite to what I am normally.

I – Mm.

P – I think that’s maybe frustration and, I don’t know.

I – Mm.

P – laughs, So it’s weird, so (pause) er, ask me another question.

I – I was just thinking about what you were saying about, it’s the idea about not being in control of things, Asperger’s, sounds like Asperger’s to you means not being in control, when it comes in?

P – Mm.

I – It takes over in a way? Is that true?

P – Yeah.

I – Is that what it feels like to you, or is that not the right description, the way I’ve just put it?

P – Well, sometimes I can’t control my self, I can other times, when I constantly think about it. If something’s happened, there was another situation at work and I asked the customers to read, to go slow with me, with writing up the menu, writing up the order…

I – Mm, yeah.

P - ...I said can you go a bit slower please? So I turned to, that was the customer on the left, turned to the one on the right and she said (says very slowly) shall I go really slowly for you then? I said actually I have a learning difficulty, and she said Oh, right (laughs)

I – Laughs.

P – And I walked away and I told my manager what had happened and they said just don’t worry about
483 it. Don’t worry about it. And, erm, I then went back and they ended up, erm, she ended up being really nice and saying please and thank you...

485 I – Mm.

486 P – Went back again and said I insist, let me pay the bill, and then she left me a tip, I can’t remember how big the tip was, but her personality really changed.

488 I – Mm.

488 P – But that was me dealing with it the best, on a good day that was being my best. On other days I would have got upset and just maybe gone (mimics crying) and walked away (laughs). That’s a bad day. But obviously I can’t do that at work, so I’ve got to deal with each situation as they come up. So,

492 I – Quite clever of you to do that I think. Or quite brave?

493 P – What?

494 I – To actually stand up for your self. And not be put down by her.

495 P – Thank you.

496 I – OK. Right, I wonder if you can tell me Unity, what makes you unique?

497 P – You can ask my boyfriend, I think he knows me better than I know my self. Erm, unique? (pause) erm, (long pause). If someone needs help, I’ll do anything to help them. My friend was in a very tricky situation and I got them out of it, no matter what I felt, I got them out of it. Her and her daughter, I’m going to go and see them this weekend actually and they are safe now. She had a violent ex-partner and I just didn’t think selfishly, I just thought I’m going to get you out of here, and I did it.

502 I – Mm.

503 P – And, I left work ‘cause (boyfriend) was diagnosed with abnormal cells. I will go to the end of the earth for someone that I care about basically.

505 I – Mm.
P - And whether I get sacked or not, that can be dealt with afterwards. But if I care about someone and they need me and I can help them, then I will help them. And I suppose that's what makes me unique. 'cause most people won't do that, I don't know, tell me is that normal or what?

I - Well, the important thing is how you see yourself and it sounds like that's a really important quality to you, that you know you've got. And that, well I just wonder how you think other people would describe you. How do you think other people that know you would describe you?

P - (Manager) always describes me as lovely. My friends, she always says I'm lovely. Well my manager from...nick-named me 'fluff'. And I said to......what do you actually think 'fluff' means and she thought about it and she said I think it means, and it actually suits you, means your fluffy and nice and companionable and affectionate.

I - Wow.

P - Just a really nice person, when you're happy. So, that was really nice to hear. So, yeah I'm nick-named fluff at work (laughs).

I - I wanted to ask you about when you tell people about Asperger's. Do you tell everyone, friend's and family now?

P - Erm, my Mum's told the family. But I do tell colleagues, I want them all to know at work, erm, and some friends. I've told, I tell less and less people now. I only tell the people that I think need to know.

I - Right. And why has that reduced?

P - (pause) because before I used to be so lonely, I've actually got a good select group of friends now and not just acquaintances, 'cause I used to know loads of people, but I don't now. So now I only tell people that I think need to know.

I - Right.

P - I spend most time with, Actually everyone I'm close to I suppose. My two friends know, my boyfriend knows, my family knows. Erm, but when I'm going out for a drink with a friend and she brought a friend a long, then I do mention something, but only very briefly, 'cause I don't know erm
I'm going to see them again or, just say I have a learning difficulty, I might not be able to understand what you are saying. I might believe you when you're not telling the truth and joking around, but I'm not odd, I just might not be able to tell. You might say something and I might not react, so the way you'd think I would react. So I do tell them to make them aware. Instead of them, we go out, with my friend and her friend and then going home the other night, her friend said to her, well, why does she do that? She was a bit strange.

Has that happened.

The girl did say that, because before I was diagnosed, ....knows someone in ....that I used to know, and ....and I went to ...., for a drink and, erm, when I went to the loo, it was a friend, an old friend of mine's ex-boyfriend, said to....what are you hanging around with her for she's strange.

Mm.

And I was quite angry, but .....’s response was, because she's a nice girl. And, that did hurt. So basically that's why I do tell people, I just tell people what they need to know.

Yeah.

They don't need to know then I don't tell them.

Right.

What do you think people think of that, when you tell them. Do you think it influences how people think about you, how they see you?

I've have this discussion with (boyfriend), 'cause ....got the intelligence, overly high intelligence, he's got an intelligence of 167.

Right. Wow. Is he diagnosed with Asperger's?

No. But he has and IQ of 167. And erm, he, finds life hard because he has a difference, and we did talk about this a lot, and he says you don't need to tell anyone, erm, everyone, because, they're going to judge you and they treat you differently. So it's a hard one, I've had quite a few conversations about
it and I’ve got really quite upset, because, his is intelligence and his is something else that makes him
different.

I – Right.

But he chooses not to tell people about it. But I’m, I think I need to in some cases, but not always.
So,

I – Why does it upset you when he says that you don’t need to tell everybody about it?

Because he says people aren’t going to treat me normally and look for differences and take the
mick out of me behind my back.

I – Right.

But I don’t know. So, erm, there was a girl at work who works one shift a week with me, but we do
come into contact with each other for a bout an hour or so, and she said you’ve got to tell me about
your asparagus disease (laughs) and I told … and he said she’s taking the piss out of you. And I said
it’s not a disease and you make me sound like a vegetable.

And what did she say

She said, Oh, then she said well tell me what it is, so I told her, and went into it, she was quite
interested, I haven’t seen her since.

I was just wondering if she’s embarrassed about it.

Why.

Rather than taking the mickey out of you, well I mean if people don’t understand something it can
be quite scary. Quite intimidating if you don’t know what it is, what it means, somebody says they
have something and you don’t know what it means and you don’t know how to ask them about it. It’s
just a different view, an idea. But it’s interesting what you say about, it sounds as though you think
long and hard about what you should and shouldn’t tell people.

Yeah, I do.
579 I – and you’re changing all the time and developing in how you manage the whole thing.

580 P – Yeah.

581 I – I’m just checking to make sure I’ve asked all the questions I planned to.

(stopped tape while client leaves room).

582 I – Do you think that women with Asperger’s have it easier or harder than men with Asperger’s?

583 P – Similar to do women have it easier in life than men, isn’t it.

584 I – In what way?

585 P – Erm, (pause) I don’t know to be honest.

586 I – Do you think society expects different things from women, compared to men, things that you are 587 supposed to live up to and achieve?

588 P – Well I think, to be a more equal society, so whether or not I’m a boy or a girl who is not doing well 589 in their life or who has problems or what ever it goes the same way, they say you lazy bugger, and 590 what were you trying to ask? Well the same thing, well women are prettier, so, because women are 591 prettier they can get by, do you know what you mean. So whether women have Asperger’s or not, 592 (pause)

593 I – So it sounds like how women look is an important thing?

594 P – Erm, it’s important for men as well, but for women more, but at the end of the day it’s down to 595 how far you go and how much you achieve. It’s down to mentality and determination and attitude, and 596 all those things.

597 I – Mm.

598 P – What’s the word I’m looking for, attitude, it’s all about attitude. There’s this guy who comes into 599 work and I’m talk to him a lot because he’s out of work and I know what it’s like to be out of work,
and I think to my self, I used to be like him, and the more I see him the more angry I get. I do.

I – Why is that?

P - because he thinks he’s looking for work but he’s not, he’s just having a coffee. I used to go sit in the pub and chat up the barman. And I just don’t like to see anyone else do the same thing that I did.

I – Right.

P – And he’s doing exactly the same thing. I think I’ve digressed again haven’t I?

I – That’s alright. So you mentioned work as well and the expectation that women work the same as men now. So that’s an expectation that you have to live up to now, And I was wondering, before you got your diagnosis of Asperger’s, whether or not you were living up to your expectations of being a woman? Or the expectations that other people have.

P - I was living up to what everyone else thought I should be. And the people I was with. I wasn’t listening to how my family wanted me to be and all the good ways of being and good ways of going about things, I was listening to drunken people. Erm, So, I did, before I was diagnose, I did used to, not that I, I didn’t think for my self at all, I didn’t know what was right or wrong, I just looked to everyone else and did what everyone else did. I used to be a follower. But now, I do exactly what I want. If I don’t want to have a drink when I go out with my work friends I won’t have a drink.

I – Right.

P – I’m much more of an individual than I ever was. And I do believe in my thoughts and my opinions a lot more, erm, so I’d listen to everyone else. I would listen them to them, but now I don’t, I listen to my family.

I – Right.

P – And now I think about my self. What I think as well, which is a lot better.

I – How would you like to be. Do you have an ideal image of how you would like to be?

P – Erm, Erm, I think I’m at the image I’d wanted to be before I was diagnosed now. I didn’t think I
would have ever got there before I was diagnosed. If I hadn't have been diagnosed I wouldn't have felt this way. It was just a dream that I couldn't ever get to. Erm, but now I don't actually think about how I would like to be I accept my self how I'm growing and how I, what I’m becoming, and how I'm improving. Erm...

I - I'm not saying that you have to have that. And it's really nice to hear that there isn't this massive gap between what you want to be and how you see your self. It sound like you are there and you are happy being it?

P - Yeah. I still, when I go to group (Aspergers) I do pick up things that I need to work out, like eyes. I'm not very good at reading eyes.

I - Mm.

P - I can read the mouth quite well. But eyes, I'm not very good at, erm, there are things that I don't know, and there are things that I need to improve on. But I feel that I'm, I don't know how far I am, getting there, I really don't. But I know I've improved, and as for my image, well I want to be the best I can be. I want to be the best sister, I want to be the best daughter, friend. Erm, but I can't, I don't have an image now I suppose, because I don't know what else there is to learn. Does that make sense. I know what there is to learn like eye contact, but there are other things.

I - So it's like, before when you weren't happy with who you were you wanted to be something different.

P - Yeah.

I - So it was easy for you to something different to go towards.

I - Well, obviously I don't want to be a waitress all my life, and that's why I'm going to college. Erm, But I can't really focus on those things until I'm actually there. Where as in the past I had all the time in the world to dream about what I wanted to do.

I - Right.

P - But now I've got to focus on everyday living and getting by and making my family happy and
707 paying back my debt I owe. The present is something is something I need to focus on. So Just doing
708 the present, living the present, I'm actually improving. Actually doing things and thinking Yeah, I can
709 do that I can actually do money. I can pay back my Dad and pay my rent and I can organise travel.
710 Erm, and just constantly doing things, that I used to hate train drivers, I used to hate, erm, ticket men.
711 But now every time I do it I'm a lot better now. And I know I've always got someone on the other end
712 of the phone. If I don't understand why and I'm about to throw a big tantrum and \( \text{I keep it to a} \)
713 minimum. I can actually get the guard on my side and say look can you please speak to my partner on
714 the phone, because I don't understand the situation properly. And they do talk to him and then it was
715 really bizarre, because it was so simple, but because I'd been fined before and for not having the right
716 ticket it I got all upset. All it was I had to pay £2.50 for the underground because it wasn't on the ticket,
717 and, but basically I didn't understand that, so as soon as they phoned..(boyfriend) he spoke
718 to... (boyfriend), (boyfriend came on the phone, but actually I already understood with him telling
719 (boyfriend), telling someone else the problem. Instead of telling me when I'm upset and it not going in,
720 it should have gone in but it didn't go in. Once he told somebody else it went in and I took it out of my
721 purse and it was alright. And (boyfriend) said do you understand and I said yes and said thanks by now
722 (laughs). A real learning experience for me. So, yeah.

723 I – Did you know (boyfriend before you were diagnosed?

724 P – No.

725 I - So it's you family who have known you since before you were diagnosed. Do they behave
726 differently towards you now do you think?

727 P – Yes. (brother) is a teacher and he because he's always going on at me for this that and the other, I
728 sometimes think that he's getting at me. So, I need to know about pitch and tone, I think it's on in the
729 group next week which will be really good. Erm, I was having dinner, and he said thank you for getting
730 my tea and making my tea, and I said stop taking the mick out of me. This is in front of my whole
731 family cause he keeps doing that to me. And he said Asperger's people are supposed to be thanked and
732 rewarded for good things that happen, and I thought what a childish thing, but I didn't say that and
733 thought oh. So because basically because he, I now know why he does it, because he teaches he knows
734 how to be with children so he's applying it to me even though I'm an adult.

735 I – Right.
P - so, erm, I'm not going to get like that anymore. Erm, my Dad, is more understanding. Erm, My mum, well everyone is a lot better. Yeah.

I - And that's not just because you've changed? Do you think that them learning about the Asperger's has made them change the way they behave towards you.

P - Yeah, yes. But my mum said, to a friend of hers, I've never had such a good relationship with my daughter, ever. And that was good to hear.

I - Mm.

P - So, erm, things are changing. But my family has found it hard as well, but they find it easier obviously because I responding well to them.

I - Well, we've being talking for a long time and I think I've asked all the questions I wanted to. Thank you for taking part. Is there anything you wanted to add?

P - No.
<table>
<thead>
<tr>
<th>Research experience</th>
<th>How skill/experience acquired</th>
<th>Date skill/experience acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literature search</td>
<td>Conducted a literature search of a) social comparisons b) Autistic Spectrum Disorders c) Self-concepts d) Asperger’s syndrome and self-concepts.</td>
<td>April 2003, Year 1</td>
</tr>
<tr>
<td>Formulated a specific research question</td>
<td>Following review of the literature developed research question: How do people diagnosed with Asperger’s syndrome compare themselves to people without the diagnosis? Approached potential supervisor and discussed research proposal.</td>
<td>June 2003, Year 1</td>
</tr>
<tr>
<td>Wrote brief research proposal.</td>
<td>Outlined focus on adults with Asperger’s syndrome and the lack of previous research exploring self-concepts of this client group. Discuss pros and cons of qualitative and quantitative research methodologies.</td>
<td>July 2003, Year 1</td>
</tr>
<tr>
<td>Wrote detailed research proposal submitted to course.</td>
<td>Following discussions with supervisor research questions broadened to encompass exploration of specific self-descriptions of people with Asperger’s syndrome as well as exploration of social comparisons.</td>
<td>August 2003, Year 1</td>
</tr>
<tr>
<td>Approached potential external (field) supervisors.</td>
<td>Identified clinician with experience of working with this client group to provide support regarding interview process who agreed to provide supervision.</td>
<td>August 2004, year 2</td>
</tr>
<tr>
<td>Participant information sheet and consent forms written.</td>
<td>In liaison with supervisor ensuring that aims of study and expectations of researcher clearly presented. Consent forms to cover interview, tape recording interview.</td>
<td>September 2003, Year 1</td>
</tr>
<tr>
<td>Judge ethical issues, alter research appropriately. Write ethics application form and submit to appropriate LREC.</td>
<td>Specific consideration given to support of participants during and after interviews. Use of appropriate language and interviewing style to accommodate client’s needs.</td>
<td>September 2003, Year 1</td>
</tr>
<tr>
<td>Approval obtained from LREC</td>
<td>LREC suggest changes regarding support of clients following interviews. Changes incorporated into research plan. Ethics</td>
<td>July 2004, Year 2</td>
</tr>
<tr>
<td>Activity</td>
<td>Details</td>
<td>Date and Year</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Approach clinicians and send copy of information sheet. Contact local National Autistic Society groups.</td>
<td>Limited response form NHS professionals due to limited services for people with Asperger's syndrome. Attended NAS social skills group to recruit.</td>
<td>August-September 2004, Year 2</td>
</tr>
<tr>
<td>Present MRP to years 1 and 2</td>
<td>Feedback on presentation style and clarity of description of study</td>
<td>September 2004, Year 3</td>
</tr>
<tr>
<td>Begin interviews with clients.</td>
<td>Two pilot interviews conducted and questionnaire developed in line with participant comments. Initial analysis of qualitative data and identification of emerging themes. Greater focus on diagnosis and impact on self-descriptions.</td>
<td>October 2004, Year 3</td>
</tr>
<tr>
<td>Carried out literature search</td>
<td>Mental health and stigma, mental health and identity, coping with stigma</td>
<td>October 2004, Year 3</td>
</tr>
<tr>
<td>Carry out remaining interviews.</td>
<td>8 participants interviewed.</td>
<td>October 2004 – April 2005, Year 3</td>
</tr>
<tr>
<td>Meet with qualitative research group</td>
<td>Feedback provided from group on themes of study. Ideas incorporated into analysis.</td>
<td>April 2005, Year 3</td>
</tr>
<tr>
<td>Analysis of qualitative data</td>
<td>Main themes of interviews identified and table of themes drawn up. Themes and examples from text looked over by research supervisor.</td>
<td>June 2005, Year 3</td>
</tr>
<tr>
<td>Submit draft of introduction and method sections.</td>
<td>Feedback from supervisor and further consultation with literature on qualitative research methods.</td>
<td>June 2005, Year 3</td>
</tr>
<tr>
<td>Submit draft of MRP</td>
<td>Feedback from supervisor and discussion about content of MRP</td>
<td>June 2005, Year 3</td>
</tr>
<tr>
<td>Research experience</td>
<td>How skill/experience acquired</td>
<td>Date skill/experience acquired</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------</td>
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<tr>
<td>Discussed potential research projects in line with service need with placement supervisor.</td>
<td>Exploration of feasibility in terms of time constraints and ethic considerations.</td>
<td>December 2002, Year 1</td>
</tr>
<tr>
<td>Identified research topic and discussed with placement supervisor.</td>
<td>Identified most feasible and useful study.</td>
<td>December 2002, Year 1</td>
</tr>
<tr>
<td>Conducted initial literature review and identified appropriate methodology.</td>
<td>Literature search using search terms: psychology Non-attendance, DNA, Therapy dropout.</td>
<td>December 2002, Year 1</td>
</tr>
<tr>
<td>Wrote draft research proposal and submitted to course</td>
<td>Developed methodology and research questions based on service need and previous literature.</td>
<td>December 2002, Year 1</td>
</tr>
<tr>
<td>Developed questionnaire</td>
<td>Identifying supervisors concerns, possible limitations of the services and themes identified in previous research.</td>
<td>January 2003, Year 1</td>
</tr>
<tr>
<td>Questionnaire feedback from supervisor</td>
<td>Following consultation amendments made to questionnaire and final version produced. Development of introductory letters.</td>
<td>February 2003, Year 1</td>
</tr>
<tr>
<td>Identification of potential participants</td>
<td>Examination of service client records identifying those who had ‘dropped out’ of therapy. Using therapist definitions of those who had dropped out (as described in the literature). Clients identified.</td>
<td>February 2003, Year 1</td>
</tr>
<tr>
<td>Sent out first mail-shot of letters and questionnaires.</td>
<td>Letters and questionnaires sent to clients identified from records.</td>
<td>February 2003, Year 1</td>
</tr>
<tr>
<td>Data collection</td>
<td>Returned questionnaires</td>
<td>February 2003 – May 2003, Year 1</td>
</tr>
<tr>
<td>Analysis of data</td>
<td>Use of appropriate statistical methods to analyse data</td>
<td>May 2003, Year 1</td>
</tr>
<tr>
<td>Discuss findings with supervisor.</td>
<td>Identify relevant issues for feedback to CMHT</td>
<td>May 2003, Year 1</td>
</tr>
<tr>
<td>Hand in SRRP to course</td>
<td>Completed write-up of study</td>
<td>June 2003, Year 1</td>
</tr>
<tr>
<td>Feedback SRRP to CMHT</td>
<td>Presentation and discussion of results with team</td>
<td>August 2003, Year 1</td>
</tr>
</tbody>
</table>