

**HOW IS COUNSELLING EXPERIENCED BY PEOPLE WITH ASPERGER'S
SYNDROME?:**

A QUALITATIVE STUDY

STEPHANIE WILSON

A thesis submitted in partial fulfilment of the requirements of the University of
the West of England, Bristol for the award of Professional Doctorate in
Counselling Psychology

Department of Health and Social Sciences, Faculty of Health and Applied
Sciences, University of the West of England, Bristol.

October 2016

CONTENTS

	Abstract	4
1.0	Introduction	6
1.1	What is Asperger’s Syndrome (AS)?	6
1.2	Terminology	9
1.3	Assessment and Diagnosis of AS	10
1.4	Lived Experiences of AS	12
1.5	Critiques of the Diagnosis of AS	15
1.6	Theories of Causation	17
1.7	AS in a Counselling Context	18
1.8	The Therapeutic Relationship	24
1.9	The Aims of the Current Research	26
2.0	Methodology	27
2.1	Research Design	27
2.2	Analysis	32
2.3	Personal Reflections	34
3.0	Analysis	35
3.1	Overarching Theme 1: Being ‘Aspie’: Belonging and not Belonging; “I’m Happy to Know my Place in the World”	37
3.2	Overarching Theme 2: Why Traditional Counselling does not Work for Me; “How Could She Help Me if She Didn’t Understand Me?”	45
3.3	Overarching Theme 3: The Importance of the Therapeutic Relationship to Counselling	58
3.4	Overarching Theme 4: What is Wanted from Therapy: Practical Strategies and Interventions	66
4.0	Discussion	71
4.1	Key Research Findings	71
4.2	Implication for Practice	80
4.3	Reflections on the Research Interview	87

4.4	Evaluation of the Research	89
4.5	Recommendations for Future Research	90
4.6	Conclusions	92
5.0	References	93
	Appendices	114
	Journal Article	122

ABSTRACT

Introduction: People with Asperger's syndrome (AS) are known to have high incidences of anxiety and depression, meaning they sometimes seek counselling. The majority of authors writing about counselling for people with AS write from either psychodynamic or cognitive perspectives, advocating those approaches. Traditional counselling is based on communicating and exploring emotions but this is problematic for people with AS because of the core traits of difficulties with, socialising and communication, and the associated traits of difficulties with sensory processing and emotional processing. For this reason adaptations are suggested by some therapists, for example, use of visuals, use of clear language, and psycho-education around recognising their own and others' emotions. There are some outcome studies and single case studies of therapy where the client has AS, however, the opinions and experiences of individuals with AS have yet to be researched so the views of the client group are unknown. Clinicians and clients will benefit from the views of the client group being included in the literature base, particularly as therapists who do not have AS will not necessarily understand the experiences of people with AS. As well as this, there is currently a focus in much of the counselling literature on practical tools and adaptations (such as use of visuals) and an absence of discussion of the therapeutic relationship, something that is key for counselling psychologists. This research aimed to explore and report the counselling experiences of people with AS, including their views of the therapeutic relationship. The intention is for clinicians to be better informed about what people with AS do and do not want from counselling psychology interventions.

Methodology: Thirteen semi structured interviews were conducted with adults (nine women) recruited from online groups for people with AS. Interviews were carried out via Email (eleven), *Skype* (one), and face-to-face (one) to explore their experiences of counselling. Methodological recommendations for conducting interviews with people with AS are discussed (e.g. minimising use of non-literal language). The transcripts were analysed using thematic analysis so that common themes relevant to the research aims could be reported.

Results: A thematic analysis of the data identified four overarching themes. 1) Being 'Aspie': Belonging and not belonging. This captured the participants' developing self-identity, from their experiences of being excluded by their peers and being regarded as different and strange, to their

relief at being diagnosed and finding like minded people. 2) Why Traditional Counselling does not Work for Me. This theme reported the areas of AS that participants wanted therapists to know about (e.g. emotions, communication, sensory issues). 3) The Importance of the Therapeutic Relationship to Counselling. This concerns the participants' desire for a respectful relationship with a therapist who listens to and understands them. 4) What is Wanted from Therapy: Practical Strategies and Interventions. The final theme briefly outlines participant feedback about specific practical strategies or interventions.

Discussion: The findings provided important insights into the wants and needs of participants including the attitude they wanted from therapists, and what they wished therapists knew about AS. It is recommended that those working with this client group educate themselves about the traits of AS, and that they pay attention to their attitude and to the relationship between themselves and their client. Further discussion points are raised such as the applications of relational therapy, and the different presentation in women and men.

1.0 INTRODUCTION

Overview

There is a higher than average prevalence of depression, anxiety, and relationship difficulties amongst individuals diagnosed with Asperger's syndrome (Aston, 2003; Ghaziuddin, Weidmer-Mikhail and Ghaziuddin, 1998; Kim, Szatmari, Bryson, Streiner, and Wilson, 2000; Wing, 1981). However, little is known about how counselling is experienced with this population. There have been case studies of therapeutic work with this population (Alvarez, 1992; Briggs, 2005; Bromfield, 2000, 2010; Miller, 2008; Pozzi, 2003; Shuttleworth, 1999) and some studies exploring interventions aiming to improve mood (anxiety, happiness, anger, Sofronoff, Attwood, and Hinton, 2005; Sofronoff and Hinton, 2007). However, the counselling experiences of this population have only been heard in a handful of primarily autobiographical accounts (Aston, 2003; Gerland, 1999) and never through systematic research seeking to elicit and explore experiences of therapy. The present study aims to explore these experiences to contribute to understanding of the wants and needs of people with AS seeking therapy.

This introduction outlines characteristics of AS to give an understanding of what AS is; it lists diagnostic definitions; and it reports on therapeutically relevant theories of causation (biological and psychodynamic theories).

1.1 What is Asperger's Syndrome?

Asperger's syndrome (AS) was first described in 1944 by Austrian paediatrician Hans Asperger, who was studying institutionalised children. His work was unknown in Britain until psychiatrist and physician Lorna Wing coined the term "Asperger's syndrome" in her 1981 paper. AS is a developmental disorder characterised mainly by difficulties with socialisation, language differences, struggles with understanding emotions and by a need for environments and interactions to be predictable (known as a need for sameness; Gillberg, 1991). Conceptualisation of the diagnosis has changed since AS was merged with the autism spectrum disorders (ASDs) in the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM; APA, 2013) rather than being classified as a separate syndrome. The criteria listed in DSM-5 are: persistent deficits in social communication and interaction (such as deficits in social-emotional

reciprocity, deficits in nonverbal communications, deficits in developing and understanding relationships); and restricted or repetitive patterns of behaviour, interests or activities (such as repetitive motor movements and speech, insistence on sameness in routines, restricted interests, hyper- or hyporeactivity to sensory input).

All diagnostic criteria state that to some degree the person with AS will have difficulty recognising the emotions of others, as well as with recognising, coping with, and communicating their own emotions (APA, 1994; Attwood, 2015; Gillberg and Gillberg, 1989; Szatmari, Bartolucci, and Bremner, 1989; World Health Organisation (WHO, 1992). People with AS generally have no difficulties with recognising happy and sad, and many can recognise other emotions (Adolphs, Sears and Piven, 2001; Robel, Ennouri, Piana, Vaivre-Douret, Perier et al. 2004) however, recognition can be impaired in demanding everyday situations (Koning and Magill-Evans, 2001). As well as these traits, people with AS are described as having difficulties with sensory processing (Romano, 2011): “in a crowded store, for instance, my brain seems to want to process what each person is saying, causing my mind to become dazed” (Hawthorne, 2002, quoted in Bogdashina, 2005). Sensations may also be experienced with a great intensity and lead to overload:

“All auditory input was magnified in volume and echoed very painfully in my ears. Everything my hands and feet touched felt like flames.” (McKean, 2015)

AS and intellectual disability are not linked (autistic traits are found in people of average intelligence, Rutter, 2005b). The DSM IV (APA, 1994) criteria for AS specifies “no clinically significant general delay in language” and “no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills...”. It is not an intellectual, but a social disability that impacts on daily living, as Jim Sinclair describes:

“It's hard for me to tell when someone is lying. [...] I have to use cognitive strategies to make up for some basic instincts that I don't have. In the social area, as with everything else, there are a lot of things that I don't understand unless someone explains them to me” (Sinclair, 1992:302).

AS is also characterised by an impaired Theory of Mind (ToM; Baron-Cohen, Leslie and Frith, 1985; Baron-Cohen, Wheelwright, Hill, Raste and Plumb, 2001b; Baron-Cohen, Wheelwright, Stone and

Rutherford, 1999b; Happé, 1994). ToM is required for understanding that other people have independent thoughts, beliefs, desires and intentions, and that these are not always communicated to others; TOM enables individuals to understand and predict the behaviours of others (Frith, Morton, and Leslie, 1991; cf. Hobson, 1990, 1991). Impaired ToM can lead to social faux pas (Baron-Cohen, O’Riordan, Stone, Jones, and Plaisted, 1999a). It is theorised that this impairment contributes to the impaired social communication traits of AS, including the tendency to make literal interpretations of language (Happé, 1994; Kaland, Møller-Nielsen, Callesen, Mortensen, Gottlieb and Smith, 2002; Martin and McDonald, 2004).

Another proposed characteristic of AS is ‘weak central coherence’. Central coherence is the ability to see the whole picture, to summarise the overall story or message of something without necessarily recalling the detail (Frith and Happé, 1994). Individuals with AS tend instead to excel at identifying and recalling fine details; rather than the overall gist of something. Frith and Happé (1994) theorised that central coherence accounts for some traits of AS (restricted and intense interests, desire for sameness, excellent rote memory, detail focus). It can also mean that meanings beyond the literal, such as irony, are not grasped; subtext or overarching themes can also be lost (Martin and McDonald, 2004). Donna Williams (1996: 33) explains what this is like for her:

“My ability to interpret what I saw was impaired because I took each fragment in without understanding its meaning in the context of its surroundings. I’d see the nostril but lose the concept of the nose [...]”.

A final proposed characteristic is deficit in executive function (Ozonoff, South, and Miller, 2000). These result from impairment in the frontal lobe areas of the brain that govern flexible behaviour, planning, modifying behaviour according to feedback, switching between behaviours, and changing habitual but no longer adaptive behaviours (Frith, 2004; Hill, 2004; Medical Research Council (MRC), 2001). In reviewing the literature, Hill (2004) concluded that there is clear evidence for the theory of an executive function deficit, however, there is debate about what elements are typical of autism spectrum conditions (ASC). Evidence is also reviewed by Frith (2004).

The prevalence of autism has been estimated at 1.16% (Baird, Simonoff, Pickles, Chandler, Loucas

et al., 2006), 1.57% (Baron-Cohen, Scott, Allison, Williams, Bolton, et al., 2009), or 0.6% of under 8 year olds (Medical Research Council, 2001). The numbers diagnosed were 3 to 4 times higher in 2003 than in the 1970s (Fombonne, 2003), although the reasons for this are unclear, it is possible that the previous lower rates reflect missed diagnoses because professionals lacked knowledge of AS. Having briefly described the traits and prevalence of AS, I will now explain some key terminology used in this thesis, including the terms 'high functioning autism' (HFA), 'disorder', and 'neurotypical'.

1.2 Terminology

The terms AS and HFA were both first used in 1981 in Britain (Demayer, Hingtgen and Jackson, 1981; Wing, 1981) and refer to a similar presentation of social and communication traits. There has been some debate about what distinguishes the two (Klin, Volkmar, Sparrow, Cicchetti and Rourke, 1995; Manjivino and Prior, 1999; Miller and Ozonoff, 2000). Age of language development is the key marker but the majority of evidence shows that there is no clinical difference between the two diagnoses (Dissanayake, 2004). Prior to 2013 the diagnoses of AS and HFA were distinct in DSM-IV because AS was not categorised as an ASC (APA, 1994) and therefore the current report includes some research on HFA, and some authors use the terms interchangeably.

The lack of distinction between AS and HFA has, in part, led to the removal of AS as a separate diagnosis from DSM-5 and its merger into “autism spectrum disorders” (ASDs; APA, 2013: 42). Because this change occurred in 2013 and the participants in this research were all diagnosed with AS prior to this I primarily refer to AS rather than ASDs in this thesis, but this research is also applicable to those now being diagnosed with as ASD who might previously have been diagnosed as having AS.

The APA's Diagnostic and Statistical Manual uses the language “disorders”. Some authors have spoken out against that type of language being used because it frames autism as being a defect to be corrected (Baron-Cohen et al., 2009; Lawson, 2015). The term autism spectrum condition (ASC) is favoured by some who feel that 'disorder' is a derogatory term (e.g. Williams, 2006, who has AS); for this reason I will use the term ASC unless I am directly quoting an author who has used the term 'disorder'.

There has been some debate over the language used to refer to people with AS. Many of the AS and autism societies currently use 'person-first' language on their websites (i.e. 'person with autism'; e.g. Autistic Society, 2012; National Autistic Society, 2012). Recent research shows that there is no consensus within the autistic community (autistic people, their families, professionals working with people with AS) about what language should be used when talking about autism (Kenny, Hattersley, Molins, Buckley, Povey, and Pellicano, 2015). For example, Sainsbury (2001: 11), who has AS, states her objection to people-first language saying that: "we are not people who 'just happen to have' Autism; it is not an appendage that can be separated from who we are as people, nor is it something shameful that has to be reduced to a sub-clause". There are also websites with large memberships (e.g. 23,000 members of Aspies for Freedom, 2012) where members favour the term 'aspie' (e.g. WrongPlanet, 2012; Aspies, 2012; Aspiescentral, 2012). Because there is no consensus on appropriate terminology I will use person-first language in this thesis. I do not use 'Aspie' because it is a term that people with AS have developed to name themselves, rather than a term to be assigned by researchers.

I use the term Neurotypical (NT) to describe people of average social and emotional intelligence who do not have AS. It is a term used frequently by people with AS on forums and in books to refer to people without AS (Ford, 2010). I use it throughout to refer to those without AS because it is free of the negative connotations of 'normal'; it is a term embraced by people with AS; and is clearer than saying 'people without AS'.

I use the terms counselling, therapy, talking therapy, psychological therapy and psychotherapy with some interchangeability. Although I asked about counselling, participants also described experiences with non-counsellors to give insights into their wants and needs. Furthermore, as a counselling psychology trainee my focus is broad, and my results are relevant to any professional working with this client group. This means that I often use the more generic term of 'professionals' or 'mental health professionals' when reporting the views of the interviewees.

1.3 Assessment and Diagnosis of AS

There is no biological test for AS; identification and assessment of the condition is based on observation, history taking, and interview with an experienced clinician. The National Institute for Clinical Excellence (NICE, 2012) produced guidelines entitled 'Autism: recognition, referral,

diagnosis and management of adults on the autism spectrum’, to clarify what clinicians should look for when assessing people for AS. These are listed in Box 1.

Box 1: ‘Identification and initial assessment of possible autism’ (NICE 2012: 16)

Consider assessment for possible autism when a person has:

One or more of the following:

- persistent difficulties in social interaction
- persistent difficulties in social communication
- stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, and

One or more of the following:

- problems in obtaining or sustaining employment or education
- difficulties in initiating or sustaining social relationships
- previous or current contact with mental health or learning disability services
- a history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or mental disorder.

The first section covers the key areas known as the 'triad of impairments' (Wing, 1981b):

“difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests” (NICE, 2012: 18).

The NICE guidelines suggest that where an adult does not have a moderate or severe learning disability the Autism-Spectrum Quotient – 10 items (AQ-10 in Allison, Auyeung and Baron-Cohen, 2012) can be used as a further assessment. This list of 10 items in Table 1 gives a useful indication of the kinds of traits that are commonly seen in people with AS. Some traits are expected to be positive (present) and some negative (absent) in AS. I have annotated the table with these for clarity.

Table 1: Traits of AS according to the AQ-10

Skill area	Example of trait
Attention to Detail	<i>1.</i> I often notice small sounds when others do not. [positive]

Attention Switching	<p>2. I usually concentrate more on the whole picture, rather than the small details. [negative]</p> <p>3. I find it easy to do more than one thing at once. [negative]</p> <p>4. If there is an interruption, I can switch back to what I was doing very quickly. [negative]</p>
Communication	<p>5. I find it easy to 'read between the lines' when someone is talking to me. [negative]</p> <p>6. I know how to tell if someone listening to me is getting bored. [negative]</p>
Imagination	<p>7. When I'm reading a story I find it difficult to work out the characters' intentions. [positive]</p> <p>8. I like to collect information about collections of things (e.g. types of car, types of bird, types of train, types of plant etc). [positive]</p>
Social	<p>9. I find it easy to work out what someone is thinking or feeling just by looking at their face. [negative]</p> <p>10. I find it difficult to work out people's intentions. [positive]</p>

The NICE guidelines suggest that a person with 6 or more of these 10 traits should then be offered a comprehensive assessment. Having outlined the assessment criteria for AS, I will now cover the lived experiences of AS, as described by people with AS.

1.4 Lived Experiences of AS

Descriptions of how some traits are experienced by people with AS were given above (e.g. sensory sensitivity). There have also been several studies interviewing people with AS about their

experiences, I will briefly summarise these below to give a more general account of the lived experience of AS, such as the attitudes of people with AS towards AS. In her (2006:1) doctoral thesis "Living with Asperger's Syndrome – the phenomenon of 'not quite fitting in'", Portway interviewed 18 adults (18-35 years old) about their experiences of AS. She reported that the non-obvious nature of AS was central to experiences because participants 'looked normal' but behaved differently. Participants expressed 'feeling different' from others, "and had difficulty identifying a sense of 'self' in relation to others" (2006:7). In their (2009:265) paper "the 'not guilty verdict'", Punshon, Skirrow and Murphy (2009) interviewed 10 adults with AS about their experiences of being diagnosed in adulthood. Their participants reported negative life events, primarily because of feeling isolated and alone prior to diagnosis, and of being misdiagnosed and experiencing failed interventions that reinforced their feeling of being different. Another theme participants reported was that they were aware of what made them stand out from other people, and many tried to mask those aspects of themselves. This masking caused them great stress. The participants also shared that being diagnosed helped them in various ways, including allowing them to understand themselves and to access support. They described being positive about AS, but aware of their difficulties.

In her unpublished doctoral thesis Romano (2011) interviewed five adult women with AS about their experiences of having AS. Her participants reported a process of trying to fit in socially by finding people who were similar to them in some way, and of experiencing social alienation and being vulnerable to manipulation. Participants were also positive about traits of AS. A major theme of her research was the desire to be understood by the rest of society, including professionals, something that the current research hopes to improve at least within the therapy room. The final study I review here is Cousins' (2002) unpublished doctoral research into people with AS' experiences of diagnosis. She interviewed eight adults from online support groups and reported a number of themes, these were: "being an outsider" (p57; including being blamed and being aware of being different from NT people); "in search of explanation" (p60; including being misdiagnosed); "revelation" (p61; including relief and the sense of fitting in; most participants identified AS before professionals did and saw the diagnosis as important); changing self identity; and understanding themselves and NT people. Cousins also reported participants' experience that in trying to fit in with people with AS they sometimes felt pressured to let go of 'pretending to be normal', and to embrace being Aspie.

Having discussed the diagnostic features of AS, and the lived experiences of people with AS, I will now address the different presentation in men and women.

Women with AS

There is a growing movement advocating awareness of the differences in how AS presents in men and women (Marshall, 2013; Simone, 2015; Yaul-Smith, 2008) and arguing that professionals need to be better educated because AS is harder to recognise in females than males (MRC, 2001). Historically the literature on ASCs is dominated by studies of men with AS, this includes Kanner's 1971 work, and Hans Asperger's case studies (4 boys, no girls; 1944). This male focus is self-perpetuating because girls and women being misdiagnosed or not being referred for assessment results in their exclusion from statistics and research (Ehlers and Gillberg, 1993; Wing, 1981). The AS stereotype reflects how men express AS, so it is orientated to technical hobbies and collection of facts about things like trains; however, girls will also pursue hobbies with "abnormal" (APA, 2013: 50) intensity but often in different domains than found in boys (horses, animals, classic literature), and this intensity is a marker of AS (Gould and Ashton-Smith, 2011). Yaul-Smith (2008: 30) explained that AS traits are also framed differently when they appear in women rather than in men. Traits that are regarded as markers of the diagnosis in men such as insistence on routine or social isolation are dismissed and labelled "shy", "catty", or "fussy" in women.

A key difference between males and females with AS is that women and girls are also more likely than men and boys to conceal their AS traits by imitating those around them (Attwood, 2007). It is not clear if this is due to the different cultural pressures on women and men, or if there are biological reasons for the difference in presentation. As well as this Nichols, Moravcik and Tetenbaum (2009) noted that because girls are often more able than boys functioning at the same level to answer questions about social situations, this makes diagnosing females with AS more challenging for clinicians. However, the speed with which these answers are given tends to be slow because the information is being processed, rather than coming intuitively; girls are using their intellect rather than social intuition, and are also likely to struggle to use the same skills in the real world (Koning and Magill-Evans, 2001). The DSM-IV (APA, 2013:57) highlights that diagnosed "females tend to be more likely to show accompanying intellectual disability, suggesting that girls without accompanying intellectual impairments or language delays may go unrecognised, perhaps because of subtler manifestation of social and communication difficulties." Having discussed AS in

women and outlined the features of AS I will now give an overview of critiques of the diagnosis.

1.5 Critiques of the Diagnosis of AS

The clinical conceptualisation of AS is not uncontested. One debate is whether ASC, including AS, is a coherent syndrome “comprising of a close-knit grouping of clinical features that regularly co-occur” (Hobson, 2014: 6), or whether the traits can be identified independently of one another and in varying degrees. Happé, Ronald, and Plomin (2006: 1218) state: “twin data suggest largely non-overlapping genes acting on each of these traits”, and that at the cognitive level, “attempts at a single explanation for the symptoms of autism have failed”. They suggest that the triad of impairments would be better studied individually, rather than together as a triad. This argument does not undermine the usefulness of ASC as a diagnosis that describes a “constellation of clinical features that tend to appear together” (Hobson, 2014: 6). However, the implication is that a person could have significant difficulties in one area of the triad but would currently not be diagnosed and offered appropriate support. Furthermore, there are different views on whether AS is a categorical (yes or no) diagnosis, or whether it exists on a continuum where traits vary in strength. Mild traits are also found in the non-AS population (Baron-Cohen et al., 2001a). Because there is evidence that AS exists on a continuum, the diagnosis has been criticised for being ill-defined and too easy to wrongly apply, particularly to boys (Tamimi, 2004). As noted above, there is no biological test for ASCs, and the process of diagnosis is subjective (there is no definitive test). Psychiatrist Tamimi (2004: 226) argued there is a risk of many children growing up “unnecessarily convinced that they are somehow deficient and incapable” (Tamimi, Gardner, and McCabe, 2011). However, without diagnosis there is a risk that support and adaptations will not be offered and children with AS will be expected to cope in non-adapted learning environments (e.g. without sensory breaks, or visually supported lessons). Furthermore, if the process of diagnosis also focused on the positives of AS, such negativity might be avoided.

The diagnostic criteria of the DSM focus on deficits because if the individual is not having any difficulties a diagnosis would be unnecessary; diagnosis and interventions are not required simply because something is unusual (e.g. musical talent), they are intended to reduce the distress of the individual (APA, 2013). However, AS is not only defined by deficits; autistic traits, as measured by the Autism-Spectrum Quotient (AQ), are associated with skills in mathematics and science (Baron-

Cohen, Wheelwright, Skinner, Martin and Clubley, 2001a; James, 2010); autism occurs more often in the families of physicists, engineers, and mathematicians (Baron-Cohen, Bolton, Wheelwright, Scahill, Short, et al., 1998), and is also associated with creative thinking (Best, Arora, Porter, and Doherty, 2015). There are arguments that AS should be considered in terms of positive attributes including cognitive skills, and social skills, such as being trustworthy and honest (see Attwood and Gray, 1999). There is a risk of harm to the diagnosed individual and their family if the positive aspects of AS are not highlighted and only the negative aspect are examined (Hodge, 2005).

As well as arguments for shifting the focus of AS away from deficits and towards looking at the strengths and potential benefits, some authors make the argument that AS should be thought of as a difference, rather than a disability, and therefore not a deficit to be corrected (Baron-Cohen, 2000). Furthermore, that disability/difference should be acknowledged and supported without conceptualising a person as being defined only by their difficulties and therefore as worse than others (see Brisenden, 1986). However, there are difficulties associated with AS traits that should be understood so that “disabling barriers” (Barton, 1998: 60) can be removed (e.g. accepting a need for sensory breaks when someone with AS is overwhelmed). Donna Williams (2006), who has AS, notes that not all suffering associated with AS is caused by society failing to accept natural diversity; some difficulties would remain even if the person with AS was surrounded only by others with AS, and therefore the diagnosis can be helpful.

Social Construction Theories of AS

As well as the critique that the definition of AS is not well defined, some also argue that AS is a socially constructed diagnosis that pathologises natural variations (Tamimi et al., 2011). Tamimi et al. (2011) highlight the ratio of males to females diagnosed with AS, saying more boys than girls are diagnosed because boys' behaviours are more often deemed socially unacceptable and in need of controlling. As well as those critiquing the diagnosis of AS, others have critiqued the discriminatory attitude some people have to differences such as AS. Hodge (2012) criticises ableist attitudes. He describes the processes through which a notion of 'normal as best' prevails, and those that are not deemed normal are sidelined (see Campbell, 2008, and Davis, 2000, for more on ableism). The result is a framing of certain types of people as being better than others and the yardstick by which others are judged. Hodge (2012) reported ableism displayed in case studies

about people with ASCs, highlighting therapists who talk about disability as a personal tragedy (Fonseca, de Barros and de Almeida, 2001), and those that are working from the perspective that disability is located in the individual (an individual model of disability), rather than being affected by environment (social model; see Runswick-Cole, 2008, and Shakespeare, 1998 for more). Therapists are at risk of being ableist. However, this risk can be reduced by allowing the individual client to guide what is and is not wanted in therapy. This is a clear rationale for the importance of research seeking the views of people with AS. Others have argued that in 'disability' the problem is not the 'deficit' but the environment (Marks, 1999). In the case of AS social intolerance does cause difficulty (e.g. bullying), however, as stated by Williams (2006), who has AS, social intolerance is not the whole picture.

1.6 Theories of Causation

The major competing theories of causation are the biological explanation that AS is neurological and largely genetic, and the theory that AS is caused by environmental factors such as very early relational deprivation or abuse. As these theories are relevant to how interventions are conceptualised I will briefly outline them below.

Biological Theories of Causation

Biological research is primarily around ASC rather than AS specifically. The neurobiological and genetic basis of autism is currently widely recognised (Medical Research Council, 2001; NICE, 2012b), with estimates of genetic inheritance reported at between 40 and 90% (Hallmayer, Cleveland, Torres, Phillips, Cohen, et al., 2011). The remainder is likely to be due to interactions between genes and the environment, for example, the non-genetic influence of parents conceiving at an old age (see Rutter, 2000, 2005 for comprehensive reviews of biological and neurological theories and evidence for the aetiology of ASCs). Researchers claim to have had some success in finding neurological bases for the core traits of AS (social, communication, and repetition; see Di Martino, Ross, Uddin, Sklar, Castellanos and Milham, 2009; Nicki-Jockschat, Habel, Michel, Manning, Laird, et al., 2012, for reviews of the evidence; cf. Tamimi, 2011). Evidence of differences in physical brain characteristics are limited by the low number of ASC brains available to studies for post-mortem examination, and by the difficulty with assigning causality to differences found (MRC, 2001). Key evidence for the biological view comes from the link between ASC and epilepsy. By

adulthood approximately one third of individuals with ASCs have developed epilepsy, which is suggestive of congenital brain differences (Volkmar and Nelson, 1990; Mannion and Leader, 2014). Some are critical of the biological evidence. Tamimi (2011) argues that no biological evidence explains the high ratio of males to females, that much of the evidence is related to general learning difficulties rather than the specifics of ASCs, and that neuroimaging studies have not been successfully replicated. Furthermore, much of the evidence relates to severe autism, rather than AS (Tamimi et al., 2011).

Environmental Theories of Causation

In contrast to biological theories of the aetiology of AS, some psychodynamic therapists have theorised that autism is caused by disturbances in early relationships (Bettelheim, 1967 cited in Mesibov, Adams, and Schopler, 2000; Tustin, 1981). Therefore some psychodynamic theorists approach treatment of the traits of AS using psychodynamic therapy. The psychodynamic view that early relationships are responsible for the development of ASCs has been criticised by Gerland (1999), who has AS. Many psychodynamic writers now state that theories about AS and autism have changed (Mesibov et al., 2000): “[...] early psychoanalytic interest in autism centered around the notion that experience might play a role in pathogenesis. A large body of data suggest this is not the case; rather the condition appears to be the result of genetic and other neurobiological factors” (Volkmar, 2000: 660). Some psychodynamic theorists cite neurological factors as important in the aetiology of AS, but suggest certain traits arise when people with AS use protective strategies to guard against “a world experienced as overwhelming”. For example, because of neurologically based difficulties reading the intentions of others, people with AS have a strong preference for predictable routines (Cohler and Weiner, 2011:209). In this way genetic factors also have an indirect environmental effect.

1.7 AS in a Counselling Context

Having outlined characteristics of AS, including traits, diagnostics, and aetiology, I will now move on to discussing AS in the context of counselling.

Why do People with AS Present for Counselling?

It is important to understand the reasons why people with AS come for counselling so that

counsellors can understand what these individuals will want to achieve in counselling. Evidence suggests that depression and anxiety is common in those with AS (Department of Health, 2001) and that the prevalence is higher amongst those with AS than in the general population (Farrugia and Hudson, 2006; Ghaziuddin et al., 1998; Kim et al., 2000; Wing 1981). Kim et al. (2000) found that in their sample of 9-14 year olds, with AS (19) or HFA (40), anxiety levels were significantly greater than in the control sample. Farrugia and Hudson (2006) assessed the anxiety levels of 29 12-16 year olds with AS. They found levels were comparable with the anxiety in 34 adolescents with anxiety disorders, and were higher than their 30 non-clinical controls. Ghaziuddin et al. (1998) assessed 35 adolescents with AS, they diagnosed 13 of the 35 with depression, and of those over 13 years of age 8 out of 15 were diagnosed with depression (see Kim et al., 2000, for a more detailed review of the evidence base on depression and anxiety in people with AS). People with AS have also reported that they are stressed by having to hide aspects of their AS in order to fit in with NT society (Portway, 2006; Punshon et al. 2009). Yaul-Smith (2008:31) has also described the “exhaustion” and mental health difficulties experienced by women who are trying to fit in by copying the behaviour of NT people. Difficulties with anger management in relationships have also been reported (Aston, 2003), however, this was not a systematic study of a representative AS population. It appears that people with AS are more likely to present with anxiety and depression, and for this reason they may be referred for counselling.

Counselling Approaches for People with AS

As well as high levels of anxiety and depression, people with AS also attend counselling for the same range of reasons that bring people without AS to counselling: social and relationship issues, eating disorders, loneliness, self-image, bullying, discrimination, past trauma (Anderson and Morris, 2006; Craig and Boardman, 2007). This thesis concerns counselling for presenting issues of that nature. Some treatment approaches, particularly early psychodynamic approaches (Mesibov et al., 2000) have targeted treating the ASC. This was because of their conceptualisation that early relational environments caused the ASC and therefore therapy focused on the ASC itself. However, this type of therapy is generally no longer advocated by psychodynamic therapists (Bromfield, 2010; Mesibov et al., 2000; Shapiro, 2000). I will now review the main counselling approaches before moving on to consider the relevance of the therapeutic relationship in work with people with AS.

Counselling is typically concerned with exploring thoughts and feelings. However, the core traits of AS are related to social understanding, emotions, communication, and a desire for predictable environments, therefore, it is important that therapists understand these traits. For example, a therapist who does not understand the social communication difficulties such as the theory of mind deficit, might wrongly assume that they share an understanding of what is expected in therapy. I will now give an overview of the recommendations and adaptations that have been suggested by therapists and psychologists working with people with AS.

Some therapists have proposed cognitive behavioural therapy (CBT) approaches specifically tailored for people with AS. Some traits of AS, such as communication difficulties, could increase the risk of mental health problems as these can lead to relationship and employment difficulties. CBT for people with AS seeks to reduce the negative impact of those traits (Donoghue, Stallard and Kucia, 2011; Gaus, 2007, 2011). The key focus of CBT, according to psychologists and counsellors Paxton and Estay, 2007, and clinical psychologist Attwood, 2007, is to improve emotional literacy by helping the client both to recognise 'grey areas' of emotion and to communicate those emotions. Some adaptations are listed below, but for more details on CBT approaches for people with AS see Gaus, 2011, 2007; Anderson and Morris, 2006. Also see Donoghue et al. (2011) for a review of studies of CBT for children with AS which show generally positive outcomes. However, while these results appear positive, as yet no research has been conducted to explore whether people with AS have found CBT interventions helpful, or explored the influence of the therapeutic relationship in therapy; as such these findings do not represent the opinions and experiences of the client group involved.

Psychodynamic approaches focus on linking significant past relationships and life events with a person's current patterns of thoughts and feelings to make sense of current difficulties (Milton, Polmear, and Fabricius, 2006). Psychodynamic therapy can be abstract, working with metaphor and thoughts and feelings that have become unconscious, but are having a negative impact on the individual. Psychodynamic therapists also work with the transference relationship, which is explained below. Various authors have suggested that psychodynamic psychotherapy is of limited use for people with AS (Riddle, 1987; Jacobsen, 2004; and Gerland, 1999); Jacobsen stated that: "Psychoanalytic theories do not generally help us understand these patients, although they may help us understand our own reactions" (2004: 568). Working with the abstract can be problematic

for clients with a deficit in theory of mind, and prefer literal thinking. In typical children (for example) pretend play can give insights about the inner world and relationships whereas in AS the play is more likely to be based on learnt facts or stories. However, modern psychoanalysts increasingly make recommendations for adaptations that account for traits of AS (e.g. Bromfield, 2010; Gerland, 1999; Palombo, 2002; Shapiro, 2000). Jacobsen (2004) cautions against the use of symbolic interpretations of language, Bromfield (2000) recommends engaging with the individual's interests, being prepared for the slowness of pace, and being aware of client difficulties in understanding the perspectives of others. Cohler and Weiner (2011) suggest that psychodynamic psychotherapy is valuable for helping people with AS deal with their feelings of isolation and alienation from others, and for helping them to understand the minds of others. Other psychodynamic practitioners, while cautioning against working in traditional ways, have also made suggestions on working with psychodynamic ideas. Palombo (2002, discussing children with non-verbal learning disabilities) proposed that disorders of the self, often presenting as low self-esteem, depression, anxiety, or difficulties in affect regulation, can be understood psychodynamically. He viewed these issues as stemming from the intense shame felt by individuals who are smart but unable to demonstrate their abilities on account of neuropsychological deficits. The goals of therapy are to engage in an experience that replicates an old pattern of interaction but creates new, more beneficial patterns, and to create a new narrative with the child that helps them to understand their strengths and weaknesses in a more compassionate light. Palombo (2002: 150) stated that "If the therapist has no knowledge of learning disorders, he may grasp intuitively the source of some of the child's struggles but will not understand their origins as related to neuropsychological deficits." Similarly, Shapiro (2000) urges an understanding of the neurological basis of autism, and cautions against traditional psychodynamic interpretations. He highlighted the role of the therapist as maintaining the humane quality of the therapeutic relationship, with the therapist being available to both contain the emotions and reflect on social skills with an eye toward better adaptation.

As well as CBT and psychodynamic approaches there may be other approaches that are helpful for people with AS, such as humanistic approaches (Rogers, 1992a), however, theorists from these approaches have not written about working with people with AS. Theorists from various approaches have made suggestions for AS specific approaches to counselling, these include:

- Use of written and visual material to adapt to a predominately visual thinking style (Anderson and Morris, 2006; Donoghue, Stallard and Kucia, 2011; Paxton and Estay, 2007; Sofronoff et al., 2005, 2007; Sze and Wood, 2007)
- Emphasis on emotional and social psycho-education (Anderson and Morris, 2006; Cardaciotto and Herbert, 2004; Gaus, 2011; Paxton and Estay, 2007; Sofronoff et al., 2005, 2007)
 - Improving emotional literacy by helping clients recognise 'grey areas' of emotions (rather than just the extremes; Paxton and Estay, 2007; Attwood, 2007)
- Use of literal language to adapt to difficulties with metaphorical, abstract, and implied meaning (Anderson and Morris, 2006; Donoghue et al., 2011; Gaus, 2011; Jacobsen, 2004; Paxton and Estay, 2007; Shuttleworth, 1999; Sze and Wood, 2007)
- A more directive approach (Anderson and Morris, 2006; Donoghue et al., 2011; Reaven and Hepburn, 2003; Sofronoff et al., 2005, 2007)
- Adjusting to the pace of processing and communication (Bromfield, 2000; Gaus, 2011)
- Explicit and clear boundaries and goals (Donoghue et al., 2011; Gaus, 2011)
- Computerised CBT to adapt to non-verbal communication difficulties and a preference for written, rather than spoken language (Donoghue et al., 2011)

Working within any therapeutic approach without understanding AS could potentially result in harm to clients. Any therapist is likely to leave clients feeling misunderstood if they do not understand AS. Despite various recommendations, there has been no systematic qualitative

research on how adults with AS experience the counselling process, or what they find helpful or unhelpful in counselling. Therefore, it is necessary to investigate the experiences of people with AS to establish what their wants, needs, and experiences are with counselling and adaptations to counselling. I will now review the non-research literature on the experiences of people with AS who have had counselling.

Lived Experiences of AS and Counselling

The British Psychological Society (BPS, 2015) stresses the importance of practitioners understanding the diverse life experiences of those they work with, and the need to challenge the views of people who pathologise on the basis of disability and difference. For these reasons it is vital that counselling psychologists understand and respect the views and experiences of clients with AS. People with AS have expressed their views on counselling in a handful of studies and autobiographies, I will now summarise those reports.

People with AS have described their negative experiences of being misunderstood by therapists. Aston (2003) reported that 40% of the couples (at least one with AS) they interviewed had experienced therapy with counsellors who did not understand AS, saying that this had been unsatisfactory. Beth Adler (2006:165) also described a negative experience of group counselling in which her sensory sensitivity to sound was seen as inappropriate because she had covered her ears, her response was approached without understanding, and she was permanently removed from the group. Psychodynamic therapy was criticised by Gerland (1999), who wrote her critique in response to the publication of 'encounters of autistic states', a book about Frances Tustin's psychodynamic work with people with autism. She wrote that "I myself have been through 4 years of psychodynamic therapy, where I was constantly misunderstood and misinterpreted on the basis of psychodynamic theories and ideas" (p310). She recommended that therapy be focused on "feelings, thoughts and actions on a more concrete level" (p311). Wenn Lawson (2015) has also described an instance of being misunderstood by a clinician who did not understand that she had answered literally a question about hearing voices. The clinician did not understanding that Wenn did not grasp the unspoken meaning of hearing voices, and wrongly diagnosed her as psychotic.

As part of Cousins' (2002) study on experiences of late diagnosis participants did share that their difficulties had been minimised or dismissed by therapists, however, there have been no studies

focused on exploring the counselling experiences of people with AS. Several authors with AS advocate the need for researchers to ask about and understand their experiences (Morris, 1999; O'Neill, 1999, both cited in Cousins, 2002). Furthermore, many studies have shown that NT clients and counsellors' views on therapy are different (see reviews by Henkelman and Paulson, 2006; Manthei, 2007) and therefore asking clients about their experiences is valuable. Having outlined people with AS' accounts of having therapy, I will now discuss the relationship in therapy, and people with AS' descriptions of the importance of relationships to them.

1.8 The Therapeutic Relationship

People with AS can find socialising difficult, and can find displays of affection overwhelming (Attwood, 2012). This contributes to the misconception that people with ASC prefer their own company and do not want friendships (national autistic society, NAS, 2016); such misconceptions could influence therapists' use of the relationship in therapy. Some people with AS have expressed that they are happier without intimate relationships (Grandin, 1995; McIlwee Myers, 2006), however, many people with AS have stated that relationships are important to them (Aston, 2003; Jackson, 2002; Willey, 1999). Therefore it may be that the therapeutic relationship is important to people with AS, but no research has explored this with the client group, something the current research seeks to address. I discuss the therapeutic relationship below, before outlining people with AS' views on relationships in general.

The therapeutic relationship is key in therapeutic approaches such as psychodynamic therapy (Kohut, 1971, 1977, 1984), in person-centred therapy (Rogers, 1992a; 1992b), and in relational models (Kahn, 1991; Loewenthal and Samuels, 2004). It does not have prominence in CBT approaches for AS. A good therapeutic relationship has consistently been found to be associated with better outcomes with NT clients (Duncan, 2012; Norcross, 2002; Steering Committee, 2002), regardless of the therapist's orientation (Norcross and Wampold, 2011). Gelso and Carter (1994), writing about therapy generally, have described the therapeutic relationship as consisting of three related elements. These components are the working alliance, the transference, and the real relationship (Gelso and Carter, 1994).

1. The working relationship is the degree of agreement over the goals and tasks of therapy, with degrees of agreement being a factor in the outcomes of therapy (Duncan, 2012;

Hovarth and Bedi, 2002; Horvath and Symonds, 1991).

2. The transference relationship captures those thoughts, behaviours and feelings that are artifacts of previous relationships that are transferred onto the therapist, but rightfully 'belong' to another relationship (Gelso and Hayes, 1998). Working therapeutically with the transference means exploring the origins of these thoughts and feelings in order to bring them into consciousness and thus increase understanding and control over them.
3. Finally, the real relationship captures a genuineness (Rowan and Jacobs, 2002) of connection, and a realness between the client and therapist that is undistorted by transference (Gelso and Carter, 1994). The real relationship is key to the processes of person-centred, Rogerian therapy (as noted above; Rogers, 1992b), and to Kohut's approach, in which the therapeutic use of transference occurs within an empathic relationship (Kohut, 1981). Components of the real relationship have been found to be important to clients who express a preference for therapists who are genuine, empathic (Horvath and Luborsky, 1993), and similar to them (Manthei, 2007; Vera, Speight, Mildner and Carlson, 1999).

Carl Rogers (1992a) outlined the processes of therapy with constant reference to the importance of the nature of the relationship. He stated that the core conditions of offering genuineness (an honesty about what is being felt), empathy (trying to understand the client's perspective), and unconditional positive regard (being like the parent who 'prizes' the child) was sufficient for treating clients.

Some theorists have made recommendations related to the relationship in therapy with people with AS. Hare and Flood (2001) stated that explicit agreement on the goals of therapy would be more appropriate than making an empathic therapeutic relationship the basis of the work. Some therapists state that the attitude of the therapist is important to the therapeutic relationship and success of the therapy (Bromfield, 2000, 2010; Gaus, 2007). g Jacobsen (2004) wrote that in therapy with children with AS the task is to understand the meanings and experiences of the other person, and Shuttleworth (1999) stressed the need for acceptance and understanding. However, it is not known how people with AS experience such approaches to the relationship in therapy.

Although no research has asked people with AS about their counselling experiences or views on the therapeutic relationship, people with AS have written about their wants and needs from relationships more generally. They have expressed the importance of relationships in their daily life (Aston, 2003; Jackson, 2002; Willey, 1999): “I wanted to be wanted. It's interesting, fun and exciting to be around someone” (Hendrickx, 2008: 19). They have also stated a need for relationships with people who accept them for who they are, care about them (Willey, 1999), make concessions to them, understand them (Jackson, 2002), does not try to change them, and listens to them (Jackson, 2002; Willey, 1999). Furthermore, there are websites such as 'Aspie Affection' (2012) and a *Facebook* group called 'Aspie Friends' (2016), which suggests a desire for some kind of friendships even if they are online rather than in person.

1.9 The Aims of the Current Research

People with AS have traits that may make traditional approaches to counselling inappropriate, for example, difficulties in reading the emotions of others might make non-verbal methods of expressing empathy unhelpful. For this reason, as outlined above, some theorists have made specific recommendations regarding counselling people with AS, such as avoiding non-literal language. Although some individuals with AS have written about their counselling experiences, no systematic studies have gathered and represented the views and experiences of clients with AS and therefore the views of this client group are not represented in the clinical literature. The present research seeks to explore the helpful and unhelpful experiences of counselling that are particular to this client group in order to provide general recommendations for therapists working with people with AS. Having outlined the background literature and the rationale and aims for the study I now move on to outlining the methodology, before reporting the analysis, and finally moving on to the discussion of findings.

2.0 METHODOLOGY

2.1 Research Design

Thirteen adults (18 years+) with a diagnosis of AS who had had some experience of counselling participated in semi-structured interviews focusing on exploring the positive and negative aspects of these experiences. Most interviews were conducted via email, although participants were given a choice of being interviewed face-to-face, or using synchronous or asynchronous online interviewing. The research was conducted within a broadly experiential framework and the data were analysed using inductive Thematic Analysis (TA; Braun and Clarke, 2013). A qualitative approach was chosen because the present study aimed to explore the participants' subjective experiences of therapy. Similarly, interview is an appropriate method for gathering rich data about participants' experiences (Braun and Clarke, 2013).

Recruitment and Sampling

Thirteen adults (aged 18-years or older), with AS, who had experienced counselling (for any issue or duration), were recruited via online social networks for people with AS (groups like 'Aspergers Support Network' [sic] on *Facebook*). Other recruitment strategies were also tried but were unsuccessful. Permission was granted by website administrators to post a recruitment notice on several websites and *Facebook* groups. The notice provided my contact details, and information about the study (Appendix 1). Potential participants who made contact were sent the information sheet (Appendix 2). Participants were given a week to read the information sheet before I sent the consent (Appendix 3) and demographics forms and I asked them if they were still interested in taking part.

Thirteen was deemed an adequate sample size to identify both common themes and differences amongst participants, in line with guidance on TA research (Braun and Clarke, 2013). The sampling strategy was 'purposive', with a specific population being targeted (Patton, 2002). Participants needed to be 18-years or older, have had some experience of counselling, be fluent in English, and be capable of understanding the information sheet. Participants also needed to have a diagnosis of AS. Cousins' (2002) research on experiences of having AS was criticised for not detailing the

process of participants' diagnosis or requiring proof of diagnosis (Punshon, Skirrow and Murphy, 2009). To be respectful I did not request proof. However, participants were asked about the process of their diagnosis and who gave the final diagnosis as evidence that they had received a formal diagnosis. In Punshon et al.'s (2009) study of diagnosis experiences, individuals who were actively psychotic, or currently involved in forensic services were excluded. I was not recruiting from a clinical population and excluding participants who have had mental health problems would arguably exclude anyone who has received therapy. Instead, I outlined the risks of taking part (possible distress from discussing past therapy). I strongly encouraged participants not to take part if they did not have support available. I encouraged them to talk to trusted people about their decision to take part. I also provided information about sources of support (e.g. National Autistic Society).

Data Collection

Adapting research procedures to the needs of individual participants has been advocated by Elliott, Fischer and Rennie (1999). For this reason I offered participants a choice of interview methods, including asynchronous email interviews, synchronous online interviews, and *Skype* interviews (see Appendix 4 for methods chosen). Face-to-face interviews are typically perceived as the 'gold standard' of interview research, and virtual interviews merely substitutes for when face-to-face interviewing is not possible (Novick, 2008). However, qualitative researchers have demonstrated that virtual interviews can also provide rich data (Bjerk, 2010; Madge and O'Conner, 2002; McCoyd and Kerson, 2006). Advantages and disadvantages have been found to using online interviews. On the negative side researchers have warned that rapport and a non-judgemental spontaneous environment may be more difficult to build (Beck, 2010; Madge and O'Conner, 2002); and have warned of potential technical problems (McCoyd and Kerson, 2006). There are also concerns over the lack of non-verbal cues (Bjerke, 2010) and direct observation of emotion (McCoyd and Kerson, 2006); however, these apply less to people with AS who may have a preference for online communication that removes non-verbal communication (Anderson and Morris, 2006; Dekker, 1999; Hare and Flood, 2001). Researchers have also cited ways in which virtual interviews improve the richness of data gathered, and have practical benefits. Beck (2010) reported the benefit of participants making sense of it all, being empowered, feeling listened to, acknowledged, and that interviews provide a voice. Others cited the possibility of promoting more honest responses

(Madge and O'Conner, 2002) and less social pressure (McCoyd and Kerson, 2006). Several researchers have also described the general benefits of having ready transcribed interviews (in typed interviews) (Beck, 2010; McCoyd and Kerson, 2006); of geographical freedom; and the ability for thoughtful follow up and clarifications (Bjerke, 2010).

Participant Demographics

I now outline a summary of key demographics of the 13 participants¹: The average age was 31-years (with a range of 20-44-years). There were four men and nine women. Six were in paid employment, two in voluntary employment, and two unemployed. Eight were heterosexual, three bisexual, and one gay. Eleven were white and one Asian American. Seven labelled themselves as middle class, and four as lower or working class. Six replied that they considered themselves to have a disability other than AS. Six lived in their own house, one in a student house, one in supported housing, and one in their own apartment with state welfare support. Regarding therapeutic approach experienced, seven participants gave no answer to the question, three said CBT, and three said 'talking'. Four participants were in the UK, four in the USA, two in Canada, one in Switzerland, one in Germany, and one in New Zealand. There were also a broad range of presenting issues such as depression and anxiety, that are listed in Appendix 5.

A demographics question was asked on disability, however, because both mental health difficulties and AS could be considered a disability it was unclear what participants meant by their answers (Table 1). For clarity I asked "Other than Asperger's, do you consider yourself to have a disability?". Because this wording implied that I viewed AS a disability, the last three participants were given an altered question: "Do you consider yourself to have a disability? Not including AS (if you consider that a disability)". I considered the problem of asking a differently worded question to be less important than the possible offence and damage to rapport I could be causing.

1 One participant did not return demographic information, although some data was gleamed from the interview itself. Furthermore, some participants did not respond to all questions. For this reason not all responses total 13.

Table 1: Disability demographics

Pseudonym	Response to question
<u>Other than Asperger's, do you consider yourself to have a disability?</u>	
Mike	Yes
Dawn	No
Annie	Yes
Rea	"Not sure I'd call AS a 'disability'; either way my family has a history of depression and other stuff I occasionally show, if that counts?"
Elizabeth	No
Aggie	"No – and I don't consider it a disability"
Grace	No demographics returned
Stella	Yes
Cali	Yes
Unisonic	No
<u>"Do you consider yourself to have a disability? Not including AS (if you consider that a disability)"</u>	
John	Yes
James	No
Virginia	No

I will now outline the interview procedures that were adopted, including those specific to people with AS.

Interview Procedures and Technique

The interviews were semi-structured, with a list prompting pre-interview procedures (e.g. welcoming, reminding of confidentiality), and closing procedures (e.g. thanking, informing of next steps). Potential prompts had been noted prior to interviews, these all intended to elicit responses on the topic of participant experiences of counselling (e.g. what did you find helpful in counselling? If you were beginning with a counsellor what would you want from them?). However, there was

no interview schedule, prompts were not required in all interviews, and including a list of prompts within the appendices would give a false impression that the interviews were structured using a schedule. To invite participants to talk about what was important to them the interview began with an open question about the broad topic area (Merton, Fiske and Kendall, 1990): "Can you tell me about your experiences of counselling?" This question was also used in order to gauge the participant's ability to respond to this type of question (the success of using open or closed questions is discussed below). When responses were very short, I stated that it was okay to give much longer answers if the participants wanted to. The interview also ended with a broad question inviting the participant to add anything else they had not already shared. The majority of responses were long (from few sentences to several pages) and relevant enough that I could respond with follow up questions to clarify my understanding and encourage participants to expand on their answers. I typically asked between 1 and 10 questions in each email, including clarifying and follow up questions.

Generic prompts designed to elicit further information and encourage disclosure were used (e.g., "Can you tell me more about that?"). If participants were unable to respond to this style of broad question and follow up questions then increasingly closed questions were used (Booth and Booth, 1996). Once the initial responses of the participant had been explored as much as I thought was helpful, I asked some more specific questions based on my literature search and areas raised by other participants that had not already been addressed (e.g. use of medication or thoughts on online therapy). At the end of the interview I thanked each person and asked if they had any follow up questions, and participants were invited to contact me if they had any questions in the future (until I finish my thesis). Many participants also said I would be welcome to contact them with any other questions, and said they would be interested in reading anything that is published.

The real time interviews (face-to-face and *Skype*) lasted between 70 and 90 minutes. The email interviews were without time limit and most exchanges continued over several weeks. One continued over several months because the interviewee moved house halfway through and needed to put the interview on hold. One interview also included data from a brief email exchange (initiated by the participant) following the interview to clarify some points. There was no other follow up contact once interviews had come to an end. However, all participants were contacted at the write up stage and invited to provide pseudonyms (all but one participant did

this).

Ethics

Ethical approval was awarded by the UWE Faculty of Health and Social Sciences research ethics committee. It was considered that care was needed to ensure that participants with AS fully understood the nature of the research and what exactly would happen and why (Macdonald, Sinason, and Hollins, 2003). Participants were given a week to consider the information sheet before being asked to give consent, and they were encouraged to consult with a trusted individual about whether to take part. The information sheet (Appendix 2) was written to be accessible to someone with difficulties with non-literal language. The right to withdraw from the research during the interview was stressed. I will now outline the methods of analysis that were used.

2.2 Analysis

Three methods of analysis were given serious consideration, interpretive phenomenological analysis (IPA), grounded theory (GT), and TA. GT was disregarded because it aims to create an overarching theory and to explore psychological processes, which was not my aim (Charmaz, 2008). IPA was disregarded because it focuses on themes across data but also has an ideographic focus that was not appropriate for my aims. Furthermore, IPA requires both latent and semantic analysis; latent analysis (the 'heuristics of suspicion', Smith, Flowers and Larkin, 2009) was not appropriate for my aim to stay faithful to the words of the participants, rather than put my own interpretive frame on the data. TA allowed me to meet my primary aim of analysing and reporting the patterns in the data to show the common themes raised by my interviewees. TA allows flexibility in the coding of data and therefore allowed me the freedom to produce a faithful representation of what participants stated they had experienced (Braun and Clarke, 2006). Furthermore, TA is not attached to one epistemological school of thought so this allowed me the freedom to use an experiential/critical realist approach to TA. This treats the language of participants as providing a window into their experiences and meanings (Braun and Clarke, 2006), but it remains aware of the contextual nature of the data gathered from participants. This approach was used because this client group's views on what is helpful and unhelpful in therapy had not been represented before, therefore it was important to listen to the voices of people with AS (Gerland, 1999). Because of the exploratory nature of the research question, the analysis was

inductive. The analysis was guided by Braun and Clarke's (2006:35) six phases of TA, see Table 2:

Table 2: Braun and Clarke's phases of Thematic Analysis

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

TA is a flexible process, and these stages are intended as a guide to analysis, rather than as rigid instructions (Braun and Clarke, 2013). For this reason my own analysis varied slightly from these six stages, however, the stages are representative of the essence of my approach to analysis. In

addition to these steps, my analysis was checked by my supervisors, who, read 2 or 3 interview transcripts, and the code and theme development. Therefore they were able to give feedback about the appropriateness of the developed themes, and would have been able to suggest changes.

2.3 Personal Reflections

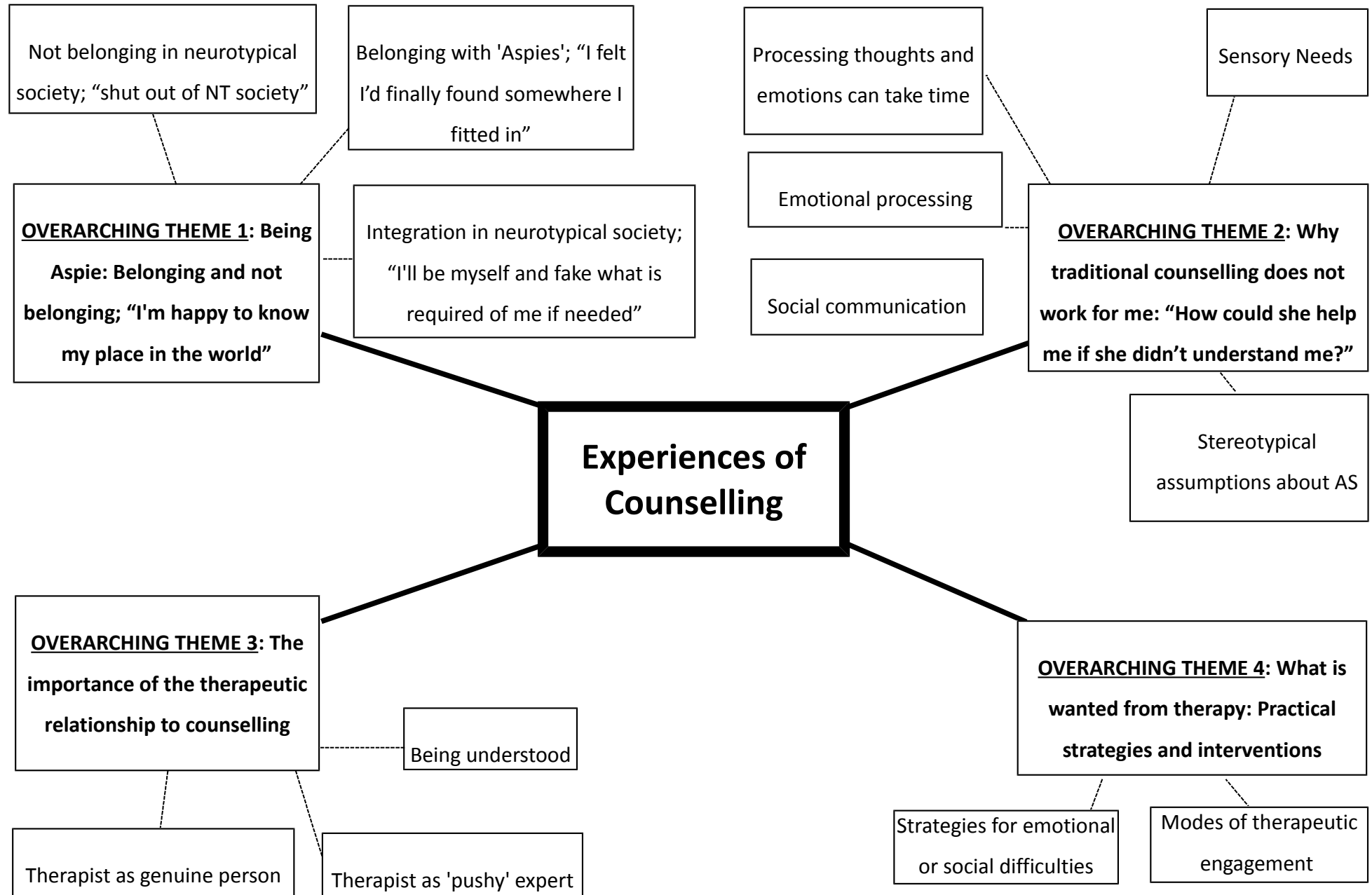
I chose to focus on AS and counselling because of my experience of working with people with AS in a teaching and psycho-education capacity. I wanted to work more productively in a counselling psychology role, but the literature has very little to say about what this group find helpful in therapy or about working with the relationship with sensitivity to the needs of people with AS. In my own practice with teenagers with AS my clients often want to know how to make friends and keep friends; how to socialise with others. In my work I frequently use the ideas of speech and language pathologist Michelle Garcia Winner, who writes about the need to help people to think about what those around them are thinking, and why they are thinking it (Winner, 2011). The adaptations and approaches described by cognitive psychologists (Attwood, 2007) are closest to my own thoughts. The main difference is that I place higher emphasis on the use of the relationship in counselling than the cognitive behavioural therapists have done in their papers. This may guide my questions and analysis towards a more sympathetic evaluation of these approaches.

In terms of working with neuro-typical (NT) people, I have been trained to work in an integrative model with a relational core. I see the therapist's role as encouraging clients to explore the reasons why their current thoughts and behaviours once kept them safe, and to have compassion for themselves when they conceptualise their current difficulties and their origins. I am influenced by psychodynamic ideas about working with the therapeutic relationship (including transference) to explore relationship patterns and their origins. I also see value in Carl Rogers' (1992a; 1992b) ideas of providing warmth and empathy, Heinz Kohut's (1981) emphasis on empathy, and Michael Kahn's (1991) position of integrating the two ideas of working with the relationship and providing warmth and empathy. This could impact on data collection because my training values the relationship in therapy, and could therefore guide both collection and analysis towards the value of the relationship.

3.0 Analysis

My thematic analysis produced four overarching themes (see Figure 1). Theme one concerns participants' experiences, prior to diagnosis, of being perceived as different, as well as the relief felt at being diagnosed. It does not directly address the research question, but provides important context for participants' needs in therapy (theme two and three). The second overarching theme outlines the AS traits participants require professionals to understand prior to working together. The third theme captures the participants' experiences of good and bad relationships with professionals, and their desire to work with professionals who are respectful, take them seriously, and really listen to what they are saying. The fourth and final theme outlines the more practical elements of therapist approaches that participants said they would benefit from. These include being offered social and emotional coping strategies and psycho-education. The four overarching themes are presented below, each overarching theme has several related themes nested underneath them.

Figure 1: Thematic Map



3.1 Overarching Theme 1: Being Aspie: Belonging and not Belonging; “I'm Happy to Know my Place in the World”

The overarching theme captures participants' experiences of feeling different from neurotypical (NT) people whilst feeling like they fit in with other 'Aspies'. In theme one (Not Belonging in NT Society; “shut out of NT society”) participants described their childhood experiences of feeling like they did not fit in with those around them: of being bullied, ridiculed and outcast by their school peers; of knowing that their parents thought something was wrong with them; and of having mental health professionals try to 'fix' them. After these early experiences, the second theme (Belonging with 'Aspies'; “I felt I'd finally found somewhere I fitted in”) reflects the enormous relief felt when participants were diagnosed with AS. The third and final theme of Integration in neurotypical society; “I'll be myself and fake what is required of me if needed” describes the dilemma of trying to fit in with NT society without hiding their true selves. Participants found NT people to be ignorant about AS and intolerant of difference. Subsequently in order to live alongside NT people they employed methods to conceal their AS traits, which caused them great stress. Overarching theme one provides the context for the therapy needs participants describe in overarching themes two and three, for example, having been misunderstood during childhood it was important to participants that therapists did not repeat this experience.

Not Belonging in Neurotypical Society: “Shut Out of NT Society”

Many participants reported early experiences of not belonging with peers and of family members thinking there was something wrong with them. Prior to receiving an AS diagnosis concerned parents pursued assessments and interventions, leading participants to suspect that there was “something wrong with [them]” (Rea). Virginia described the impact of this:

“I realised that my parents had shuttled me from one type of mental health professional after another [...]. Nothing drives home the idea that you're crazy like that”.

“[My mother] pretty much claimed that I am nuts. She didn't exactly use those words, but the way [my parents] tried to 'make me better' or control me at home pretty much suggested it.” (Rea)

This sense that others thought that something was wrong with them has not been reported in other studies focused on experiences of AS, which typically report distress at being different (e.g. Portway, 2006).

Participants described how they found assessments and interventions with professionals distressing and confusing. In addition, they added to the feeling of being somehow defective. Grace, for example, had speech and language therapy and “didn't like it being called speech and language therapy as I thought this implied I didn't talk properly”. These assessments and interventions added to participants' questions of who they 'belonged' with; and for many this was people with mental health problems and people who needed to be 'fixed' or changed in some way. Many participants began seeking answers for themselves. Mike researched “various conditions that might cause [his] problems and happened across Asperger's”, he raised the issue with the therapist he was seeing at the time and was eventually diagnosed. Rea became frustrated with being misunderstood: “Eventually I got to the point of [being] sick of always having people tell me 'something is wrong with me' or 'that I am mental' and I did research; then accidentally stumbled over Aspi [sic] material”.

Childhood bullying was a key experience for many participants. Partly as a result of not being diagnosed, participants had no access to help with understanding the social world or support with bullying (which is endemic for people with AS, Little, 2002). Annie described a process of “mourning that child who felt so isolated, misunderstood, anxious, ridiculed, bullied” and “who was unable to stop the bullying”, and her anger “at the school staff who didn't protect [her]”. This demonstrates both the degree of suffering and the lack of support experienced by people with AS. The experience of bullying also strengthened the feeling that there was something wrong; that they did not belong with and were not accepted by those around them (school peers, family, mental health professionals). High rates of bullying have been reported in the literature (Asperger, 1944; Little, 2002; Portway, 2006; Punshon et al, 2009; Wainscot, Naylor, Sutcliffe, Tantam, and Williams, 2008). This includes reports of peers provoking children with AS to engage in inappropriate behaviour (Simpson and Myles, 1998) and children rarely being invited to their peers' parties (Wainscot et al., 2008). Individuals reported that bullying continued beyond teenage years (Portway, 2006). A number of authors have suggested that social communication difficulties mean the intentions of others are not always understood, leaving a person naïve, and vulnerable

to those with negative intentions (Blacher and Lauderdale, 2008; Church, Alisanski and Amanullah, 2000; Simpson and Myles, 1998; Sofronoff et al., 2011; Yau-Smith, 2008). This suggests that accurate diagnosis and appropriate support could therefore reduce the incidence of bullying and associated negative psychosocial effects (see Aalsma and Brown, 2008; Baumeister and Leary, 1995; Blacher and Lauderdale, 2008; Leary, 1990; Portway, 2006; Punshon, et al., 2009).

The theme of not belonging supports findings from other studies and autobiographies (Cousins, 2002; Griffith, Totsika, Nash and Hastings, 2011; Jones, Zahl and Huws, 2001; Portway, 2006; Punshon et al, 2009; Williams, 1996). Portway (2006) also points out that the titles of many autobiographies in this field capture the feeling of not belonging or fitting: “Nobody Nowhere” (Williams, 1996), “An Anthropologist on Mars” (Sacks, 1995), “A Real Person” (Gerland, 1997), “Pretending to be Normal” (Willey, 1999), “Freaks, Geeks and Asperger Syndrome” (Jackson, 2003), and “Women from Another Planet” (Miller, 2003). Furthermore, the experience of being excluded by peers was reported in other studies interviewing people with AS (Cousins, 2002; Jones, Zahl and Huws, 2001; Portway, 2006; Pushton, Skirrow and Murphy, 2009). My research shows that some people having these experiences later seek counselling, although the nature of that relationship is unclear; it may not be that these experiences directly lead to a later need for counselling. Having grown up experiencing being excluded from NT society, participants were relieved to be diagnosed and find that there were people they fitted in with. I now outline the theme Belonging with 'Aspies'.

Belonging with 'Aspies': “I Felt I’d Finally Found Somewhere I Fitted in”

'Belonging with 'Aspies' describes how after the confusion of not fitting in with NT people, the diagnosis of AS came as a huge relief; participants described embracing the diagnosis. It legitimised experiences previously dismissed as madness or weirdness as well as providing membership of a group which they could be proud to be a part of.

Having grown up “feeling like a minority, that as a general rule, people [wouldn't] understand [them], or like [them]” (Annie), they felt “shut out of NT society” (Virginia). Participants were relieved to find people who understood them and this created a sense of relief and belonging. Rea explained: “I started to make Aspi friends and would often find myself saying 'I feel like **** right now'” (Rea); there was a level of “natural understanding” between people with AS that was often

absent with others. Having been diagnosed Annie said: “I'm happy to know my place in the world, and to know a lot of other cool people on the spectrum, so in fact I'm kind of honoured to have AS!” Annie described her fear of not being diagnosed: “I badly wanted 'in' to this Aspie 'club' because I felt I'd finally found somewhere I fitted in – and yet I was aware that if they said I *didn't* have it, then what would that mean?” This emphasises the importance of finding a group of people to 'belong' to. Having lived an “entire life” “spent wondering why [they] felt like the jigsaw piece from another puzzle, mixed up in the wrong box” (Annie) or being seen as “some broken person who would never be able to achieve” anything (Rea), the diagnosis allowed participants to make sense of themselves:

“The most help came from learning what of my traits were features of my Aspergers and were shared traits of a minority people. That helped me to reframe them from 'weird, wrong' to 'differently normal.' That was reinforced by going to a meet-up group for adult Aspies & experiencing truly fitting in for the first time, as well as experiencing seeing NT people standing out like sore thumbs as the minority people against the AS majority. That flipped my perspective and helped me see myself as 'different, not less.' (Virginia)

Similarly, Cousins quoted one participant in her study as stating that they viewed AS as a “difference of mind not deficit” (2002: 73). Traits, such as preferring immersion in hobbies to time with friends labelled as dysfunctional by parents during childhood, started to make sense in the context of AS and as such were re-framed and validated. Rea explained that: “It seriously meant that stuff just works different for me.” Because NT people had been unable to understand what the participants thought and felt, many participants had had their experiences dismissed as wrong or weird. After this, receiving the diagnosis was like “getting a vocabulary for your experiences and an external validation of what you experienced all your life” (Mike). Participants could start to make sense of why they seemed to think and feel differently from everyone else: “My inner turmoil and questions about why I was different and felt different were legitimized” (Aggie). Unisonic explained that he “used to feel bad about not having a full compliment of feelings as others do” but said that “finding out that I was an Aspie has helped me get over some of those feelings.”

The diagnosis also opened up access to blogs and articles that discussed the positive traits of AS,

such as honesty and attention to detail. Participants could finally make sense of their lives because they had a framework for understanding themselves, rather than struggling to make themselves fit. Discovering AS could provide answers to many questions: “I bought [the book] 'Aspergirls' and set out with the intention of highlighting everything I felt applied to me. Practically the entire book was highlighted. I wept with relief” (Annie). None of the participants reported unhappiness at receiving the diagnosis; it appeared to be greeted with relief because as Grace said: “my whole life made sense”. Participants also felt the freedom to 'be themselves', something also found by Cousins (2002); Yauell-Smith (who has AS) stated that gaining a diagnosis was “almost like having a license to be me” (2008: 31). Participants were positive about learning more about AS, which supports the suggestion that psycho-education about AS could be helpful for people who have just been diagnosed (Finn, 2006). The diagnosis offered an additional re-frame: “IT WASN'T MY FAULT!” (Annie). Many participants had been labelled negatively by others; this could now be countered:

“[it meant] that I wasn't just 'mental' or somehow 'high maintenance', 'confusing' or...you name it, really. Any of the stuff people had thrown at my head in the past years” (Rea).

This was also reported by Cousins (2002), and by Punshon et al. in their 2009 paper 'The not guilty verdict', who likened the process of feeling outcast and discovering the diagnosis to the process of 'coming out' as lesbian, gay, or bisexual.

As part of forming a positive identity participants made negative comparisons with NTs, towards whom there was a sense of anger. Participants perceived NT traits as undesirable in comparison to AS traits: “all they did was get drunk, black out and make overly stupid sexual jokes” (Rea). NT lives were described as “not fun at all” and perceived as complicated. Participants also talked about the undesirability of being 'normal', defining this as a lack of individuality and an inability to question the 'normal' ways of doing things:

“I don't want to be normal because most 'normal' people are lemmings. They aren't independent enough in their mind or self-esteem to forge their own path [...]it's a boring, cookie-cutter life” (Aggie).

The positive re-framing of their experience allowed participants to develop a sense of pride in their

AS identity; they described their traits and skills positively and identified traits which they believed to be unique. Virginia described “hyperfocus as a gift and one of the blessings of [her] Aspergers”, and Aggie stated that “we all have some sort of super power. It kind of goes with being autistic and genius within a limited field”. Participants were also generally positive about the influence of AS on society because it “make[s] the world a more diverse place” (James), and so counters the lack of diversity perceived in NT people. “People with Asperger's are the 'next evolution' of the human race [because they] can accept all and any differences in others; be honest; not play (mind) games; help others, but still not to the point of forgetting about their own self”. This process of characterising NTs in an undesirable light supports Portway's finding (2006: 124) that AS individuals did not want to be 'normal' because they saw normal people as “sheep”. Romano (2011) also identified (p148) the theme “the virtues of AS”; her participants identified positive aspects of having AS. Cousins (2002) noted how AS individuals felt that problems were caused because differences were devalued or stigmatised by NT people (also stated by Lawson, 1998).

Integration in Neurotypical Society: “I'll be Myself and Fake what is Required of me if Needed”

This theme captures participants' need to balance fitting into NT society whilst still retaining pride in their identity as someone with AS; this balance seemed difficult to achieve: “NT people DO definitely have a tendency to act extremely inappropriate around stuff that is 'not normal'”. (Rea)

Participants felt that it was primarily NT individuals' difficulties with difference that caused their problems. Some NTs also used the labels autism or AS in a derogatory way to describe “weird” behaviour:

“A lot of my fellow Aspis [sic] kinda struggle with that. Just being an outcast and all that. [...] I read comments like earlier on YouTube, where an NT tried to insult somebody acting a bit weird with 'Control your autism'...yeah, I really get why we're in such cast-off places” (Rea).

Rea also described how she does not see herself as “suffering” from AS, instead: “the only thing that makes me suffer is people being stupid about it, but that's not a symptom or effect caused by my Aspi per se”. Mike stated that “It's really only a 'disability' because we live in a world that is getting more and more social”. This supports the ideas of Tamimi, Gardner and McCabe (2011) who argue that the label of AS unnecessarily pathologises normal variations in humans. There are

some traits, such as sensory sensitivity, which do cause stress regardless of the reactions of NT people, but participants stated that the intolerance and inflexibility of NT people worsened the impact of such traits.

Some participants responded to the diagnosis by no longer pretending to be 'normal': "I told my therapist that if anything, should I get a diagnosis, I will become more not less autistic, i.e. pretend less to be someone I'm not" (Mike). This is supported by Portway's (2006) participants, who also reported being more openly Aspie in response to the diagnosis. Participants were aware that some AS traits (like atypical facial expressions or eye contact) made some other people uncomfortable and they often wanted to avoid being a source of discomfort for others. For many participants this meant hiding traits and 'playing normal' so they could 'fit in' despite wanting to 'be themselves'. Annie expressed this dilemma:

"On the whole though, I like having AS. What I struggle with is the way society responds to my AS. I know that people were looking at me strangely, but I didn't care. [...] I don't mind letting my aspie-ness out these days, people *should* be exposed to it, or how will they learn to accept it? Having said that, there are other times when I desperately wish that I could rely on myself to behave 'normally'."

Some participants felt that the alternative to fitting in was withdrawing.

"For me, learning how to play normal is essential for being a functional part of society. Learning social rules, human interaction, etc. even fake, is necessary for me as I don't wish to live in a cave by myself [...] I want to work, make money, etc. so I'll be myself and fake what is required of me if needed". (Unisonic)

Fitting in involved an attempt to "wear that neurotypical mask, get by un-noticed" (Annie), similarly, Aggie "developed coping mechanisms" in order "to get along with the rest of the world". A common strategy was pretending to be someone else, as Aggie explained: "sometimes I think I should win the Academy Award for acting because today a stranger would think I'm 'normal' and by outward appearances I am".

Participants reported two aspects of 'playing normal': pretending not to be anxious or stressed,

and concealing AS traits, many of which predominate during times of stress. Elizabeth described this difficulty: “I do get sick of acting normal sometimes. Most of the time I don't think about it, but when I get particularly stressed and I just want to be me, other people seem to be shocked or annoyed”. Frith (2004: 683) also noted how “The appearance of normality is deceptive...and breaks down when novel or stressful situations arise”. Participants described how their ability to hide behind a 'mask' was developed throughout childhood, in order to survive the effects of bullying. For example, Annie reported that:

“I think my ability to do this – appear 'normal' on the surface, whilst underneath feeling horrific, was really honed during the years of being bullied. [...] This 'on-the-surface' numbing, in order to cope and get through each, neurotypical day, I think is very dangerous to [A]spies, and leads to depression, low self-esteem [...]”.

Virginia similarly noted that: “I learned masking as a strategy, as many undiagnosed AS girls do, and the acting classes I took in high school helped that greatly.” Although 'playing normal' reduced some problems, suppressing aspects of the self was experienced as stressful, difficult, damaging and exhausting; the degree of suffering that continued behind the mask was intense: “the sheer effort of trying to appear 'normal' and functional, plaster that 'neurotypical mask' on my face, having no-one to talk to, was just exhausting”. (Annie)

“I've only been able to 'blend in' because I have been able to create this mask, still suffering behind it because it's unnatural to act 'normal'. My real self wants to act 'Aspie'.”
(Cali)

Participants wanted to show their authentic selves and felt the strain of having to suppress themselves. Virginia said: “it has been a huge problem for me and has led to some serious psychological problems in my later life [...] people often wondered if I had Dissociative Identity Disorder”. Aside from the exhaustion and stress caused by such extensive self-regulation, there was some sadness because participants were not able to be openly proud of how they were, Aggie explained:

“Let's take Superman. He can't be Superman all the time. Sometimes he's Clark Kent so he can be accepted and fit in to society. No one, but a choice few, knows his REAL identity.

Clark Kent keeps chugging along, but don't you think Superman wants to be out? Isn't that a little sad that he can't be considered normal? Wouldn't there be a certain amount of sadness every day if this was your dual life?"

A similar theme was also reported by Cousin's (2002: 66) participants who observed how fitting in with 'Aspies' meant they were pressured to let go of 'playing normal'. This pressure was not reported by my participants, who instead reported pressure from NTs to let go of their Aspie identity (also in Portway, 2006). Desire not to mask AS traits was also reported by Thompson (2008).

In summary, this overarching theme has explored how participants formed positive self-identities as people with AS despite what they perceived as the intolerance and ignorance of some NT people. Having felt outcast from NT society they found belonging with other 'Aspies', but participants had to balance their desire to reject being 'normal', with the need to 'play normal' to fit in with NT society. This overarching theme also provides the context for the wants and needs that are expressed in overarching themes two and three. Having been misunderstood and labelled as weird during childhood, participants did not want these experiences to be repeated in therapy. These needs are expressed in overarching theme two, which captures the ways that standard therapy did not work for participants, and what they wanted therapists to know about AS.

3.2 Overarching Theme 2: Why Traditional Counselling Does Not Work For Me:

"How Could She Help Me if She Didn't Understand Me?"

Participants wanted to feel that they were understood by therapeutic professionals and wanted therapists to understand what adjustments might be needed. James felt that if his therapist could not understand AS then there would be no benefit to working together:

"[...] I almost felt like, well, what's the point in being here? If you're not going to understand the context of which I'm talking to you, and the fact that you may have to look beyond the end of your nose to understand what I'm saying. [...] I just wanted that level of understanding I suppose."

"While I can appreciate traditional therapy I don't think it always works for me given the way

I sense and perceive the world. So it would be nice to work with someone who really understands ASD” (Unisonic).

Cali suggested that therapists should “do a little bit of research before meeting with the person just so they [at] least start to understand them”. Participants were misunderstood when AS traits were interpreted in traditional ways: in terms of individual biographies, rather than in the context of AS traits. Unisonic explained: “if the root of the problem is being on the spectrum then it is easier to see how the other things developed over time. For example, I love routine [...]”. He explained that a need for routine can be wrongly interpreted as ‘co-dependency’ when it involves certain people: “so from a non-spectrum perspective you could say I’m co-dependent. From a spectrum perspective that’s not the case”. Concerns were expressed that therapists working without knowledge of AS would do people harm:

“[...] unless you’ve taken some serious time to look into AS, and explore how and why conventional counselling might not always be as helpful for people with AS, then just don’t bother - you’ll do more harm than good.” (Annie)

James experienced high anxiety as a result of “being in the room with [...] people who didn’t understand [...] pressing all the little autism buttons without realising that they [were] doing it”.

Participants were generally accepting of therapists who were working hard to understand AS, however, they did not want to have to explain everything about AS during the sessions. As Annie explained:

“I don’t think she understood me, and I had to explain a lot of what I meant about my AS [...], which was draining for me, and frustrating. How could she help me if she didn’t understand me?”

Another impact of professionals lacking knowledge was that some were experienced as dismissive, mocking, or patronising regarding the AS diagnosis, something that repeated early experiences (overarching theme one):

“[there was] a complete refusal to believe the diagnosis because I don’t look or act like a

classic autistic and unwillingness to take into account what I tell her my autism-related problems are.” (Mike)

“I upright told him that I had been diagnosed with Asperger's. He laughed at me and said I didn't, just brushing it off. He also denied things my Asperger therapist had told me, saying it 'wasn't true'.” (Cali)

Annie spent two sessions “describing the frustration [she] felt surrounding a particular stim” before discovering that her therapist did not know what “stimming²” was, and therefore that much of the previous sessions had not been understood. Aside from 'stimming', participants shared examples of traits they wished their therapists (and other professionals) had knowledge of:

A) Social Communication Difficulties

As explained above, social communication difficulties reflect differences in intuitive understanding of inferred and non-verbal communications, and associated difficulties in working out the agendas, expectations, judgements, desires, unspoken intentions, thoughts and feelings of others. These difficulties meant that participants experienced discomfort and anxiety due to being unsure about what was expected of them during a session; some felt that providing an explanation of what happens during a counselling session could reduce their anxiety; “rules of counselling would've been great” (Elizabeth). James described how he would have “a silent meltdown” in the absence of “very simple explanations for very simple things”. Elizabeth initially assumed that she needed to ask for practical solutions to problems or she would be “wasting [her therapist's] time and the university's money”. She later realised that it was “Ok just to talk and someone listen”. People with AS have been found to prefer clear, 'scientific', logical, concrete and explicit language generally (Weiss and Lunskey, 2010), and explicit and directly expressed rules in all areas (Reaven and Hepburn, 2003). Participants described a number of specific problematic issues related to social communication in therapy.

2 Stimming (or self-stimulatory behaviour) is something that can be experienced by people with Asperger's; it is very often associated with heightened emotions, a well-known example is hand flapping (Attwood, 2007)

A1) The use of Broad Questions

While broad questions were not impossible for participants, they reported that these sometimes caused confusion as the scope and intention was not inherently obvious. Aggie explained that: “Non-specific questions drive me crazy because I don’t know what’s expected of me”. Participants described how, in the absence of clear guidance, they would try to “guess [their] way around the question [and] hope [they] stumble upon what they're looking for” (James), but this strategy often lead to anxiety. Realising that the 'wrong' answer has been given could make the participants feel inadequate and ashamed:

“Too broad of a question and I don't know how to answer it. If I take my best guess at what the asker wants, I inevitably end up being told 'Okay but what I meant was...' and that can trigger an anxiety attack and self-recrimination, I screwed that up, I did it wrong, now they think I'm a moron or something.” (Virginia)

A2) The use of Non-literal Communication

Participants had a strong preference for literal language so that they did not have to work out a possible subtext.

“Personally, I can understand metaphors and think I catch most subtext, but I still prefer literal language and use it myself” (Mike).

“I've been trying to understand since god knows how long why they can't just keep it simple and actually say the things they mean; as opposed to playing games and hinting or guessing [...]. Communication is a real problem for people, I noticed.” (Rea)

Even when non-literal communication such as metaphor is understood, it is still time consuming to process and can therefore be tiring:

“I'm a literal thinker about 100% of the time. Over the years I've learned to manually process the fact that people aren't always being literal. However, my first thought on a matter is literal. If someone uses a saying like, 'I'll be a monkey's uncle' I will literally visualize a

monkey with this person. Though I understand they don't mean to say they literally are related to monkey.” (Unisonic)

Participants wanted therapists to understand that as someone with AS they were far more likely to speak in an honest, literal, and direct way and therefore non-literal interpretations were unhelpful: “People OFTEN over analyse me and just assume things or jump to conclusions. [...] I always encourage them to ask if something isn't clear” (Rea). This is a further example of the early experiences of being misunderstood being repeated; therapists would make biographical interpretations of participants' thoughts and feelings, and this was unwanted:

“[...] she should take what I'm saying at face value rather than trying to find hidden meanings and assume that I don't tell her everything. Someone on the spectrum is just much more likely to tell you the truth right away. Therapists aren't used to that, it seems.” (Mike)

Participants preferred open discussion to ensure that there was mutual understanding in the relationship, rather than assumptions. Rea explained that she is “always very upfront and honest”, and wanted people to avoid making assumptions, “but it doesn't usually work. I feel like therapists are sometimes just as bad (or worse); which is why I generally don't like them.” Similarly, Aggie suggested checking meanings are understood: “Especially the 'do you understand what I'm talking about?' question. And then you, as a therapist must follow up with, 'explain back to me how you translated what I just said.'”.

A3) The use of Silence

Silence can be a feature of traditional therapy (Hill, Thompson and Ladany, 2003). Also related to social communication difficulties, participants shared that silences without explanation could be bewildering because the 'rules' or expectations are unknown and there is no way to work this out. Silences can leave people with a feeling of discomfort because it can be experienced as breaking the expected rules of interaction:

“I don't know. It's very uncomfortable. I feel like they are violating rules of conversation. If I'm with someone expecting a conversation I don't know what to do if there isn't one. It can make [me] anxious and actually at times can make me feel physically uncomfortable. Most

of the time I feel that if the other is silent then I have to keep talking. That if they are silent then there must be more I am expected to say. That can be exasperating. What's worse is silence mixed in with a neutral look on the face.” (Unisonic)

The feeling of knowing there is something expected of them and feeling like a rule had been broken was very stressful:

“if I'm too anxious to open my mouth and [...] my head is screaming [...] what on earth do you want from me? You're just sitting there looking at me, I know you want something but what you want I cannot give you, without you doing a little bit more here. And I, it was, it was one of the things that absolutely it made me feel very uncomfortable, and it drove me crazy.” (James)

Silence in therapy was not necessarily unhelpful for all participants. However, when the reasons for silence were not explained, or when the client had no chance to discuss it some participants just sat, silently suffering and unable to speak out, hiding their distress.

A4) The use of Hypothetical Examples

Participants reported finding it difficult to work with hypothetical or imaginary examples; if the situation being discussed was not factually accurate then this was perceived to be unhelpful. As Stella explained: “The way I concentrate only on my present moment makes me unable to understand hypothesis”. Virginia's therapist attempted an approach of re-framing a traumatic event in third person, but this did not help Virginia: “I think I'm too pragmatic for that to work”. As well as difficulties re-framing a past event, working with imagery caused misunderstandings between therapist and client:

“I've found that I have a very hard, if not [im]possible, time coming up with something that I haven't already experienced. So some therapy always tends to involve some sort of imagination exercise that I would take very literally. I think it created an instance of misunderstanding because I was drawing on something I've experienced though may not have directly involved me.” (Unisonic)

B) Difficulties in Recognising, Processing and Communicating Emotions

Participants struggled with expressing emotions in therapy. Participants described how they did not instinctively and automatically feel and label their emotions, were sometimes overwhelmed by their emotions, and experienced difficulties in communicating their emotions.

Participants wanted therapists to understand their emotional processing, and alexithymia; the inability to identify or describe emotions (Taylor, Bagby and Parker, 1997). John explained that “dealing with emotions is something I don't do as I don't recognise any very well [dealing with] emotions in therapy doesn't work for me, it's [...] extremely foreign to me”. Unisonic described having to intellectually process what his bodily feelings indicated about the emotions he was experiencing: “How I understand it is that for most people it just happens intuitively [...] whereas I have to stop, think, and process it.” Furthermore, “I have a very hard time explaining how I feel. I don't always have words nor the awareness to describe them.” (Unisonic).

Many participants also experienced their emotions as overwhelming: “talking about emotions, for me at least, would be a hard thing to do. Because most of the time I feel like I turn off my emotions because they're too overstimulating” (Cali). James described how “there are times when the emotion is so overpowering [...] [it's] the puppet master” and how he felt “out of control because the emotions and the feelings are so strong”. Participants reported that at times they needed to be alone in order to process their emotions, rather than share them with others:

“The closest thing I can think of to that was a bad break-up I had about 6 years ago, but I spent a lot of time by myself, distracting myself by doing things. And I wasn't diagnosed then either. I think I'd want a lot of time by myself probably. I can't say what I'd want in terms of people support, I can't picture it.”

Virginia experienced difficulties with therapists who could not explain how talking about emotions would help her, and could not understand that she was not being helped by their approach. She found that as a result of this “therapies collapsed, the therapists would give up [...] and label me as resistant or non-compliant.”

As a result of differences in processing emotions participants reported that therapists sometimes

misinterpreted their facial expressions: “When [my therapist] thinks she can read something on my face (reactions, things she thinks I'm thinking about) and tells me so she's usually wrong” (Mike). Unisonic described being “pretty stoic on the outside”; consequently his mannerisms and facial expressions did not demonstrate how he was feeling. Many participants were seen as being unemotional or indifferent due to these differences in non-verbal communication. Stella suggested that: “the counsellor has to believe that the patient is very sensitive even if there is no emotion on his face”. Virginia described a facial expression she gets when she knows something bad is going to happen to her and she won't be able to do anything to stop it, “it's an expression that NT people almost universally interpret as a satisfied smile, like I'm glad that something bad is happening”. Mike said people misunderstand him because he tends to look “stern and displeased most of the time, regardless of what I am actually thinking or feeling”. This supports the early findings of Hans Asperger (1944) who observed, in his case studies of children, that they had few facial expressions and their emotional world was difficult to understand.

Due to these misunderstandings participants described how they try to adopt appropriate facial expressions; this becomes particularly difficult when under stress. Aggie described how she had to smile when working in retail: “crook mouth up, show a little teeth, crinkle eyes, scrunch face to show my dimple. And when they leave I have to remind myself to relax my face”. Similarly, Virginia described how she learned to “police [her] face very carefully” but that this is difficult because what her face feels like to her and what “shows on the outside are two very different things”.

“I'm mindful I try to show some expression when I talk. A lot of it is learned though there is a bit that is genuine. When I'm stressed or anxious though it is hard to tell. They usually think there's nothing wrong because I 'look' calm.” (Unisonic)

Participants also identified difficulties with reading the emotions of others, making communication more difficult to manage: “there can be this total obliviousness to other people's feelings, [but] not because I'm selfish or because I don't care, just because it doesn't register” (James). This can cause offence when it appears that the emotions of others are being ignored. There is also a risk of misreading expressions and becoming anxious when interactions go wrong as a result:

“I interpret expressions of puzzlement, disbelief, bafflement, worry, anxiety, apprehension, all of those I interpret as angry expressions, blaming expressions. [...] This is an issue in therapy if the therapist is baffled by something I've said, and I interpret it as I said something wrong.” (Virginia)

This was also reported by people with AS in the literature. Jackson explained: “I used to laugh when someone cried because I thought that other person was laughing.” (2002: 20).

Many participants expressed a preference for intellectual and logical approaches to therapy and a need for facts when exploring and understanding themselves and others. John said: “I prefer the intellectual and practical, I simply don't do emotions”. Similarly, Elizabeth wanted an intellectual focus in therapy: “practical and intellectual things did help - before I got diagnosed I didn't really talk about my feelings, so at that point I wasn't interested with anything else!” Virginia also described telling her therapist: “Okay, so I feel this, what about it? What now? I'm still feeling it, what do I do about it?”. Even when working with an issue of trauma participants stated that what they found most beneficial was talking at an intellectual level. James described how his therapist: “gave me not just words, but [also] the reasoning that my logical mind craves”. Virginia described a positive experience in therapy when a therapist adapted to her preference for logic by asking her “‘what did you think when it occurred' or 'what did you do in response'”, rather than asking about feelings.

C) Processing Thoughts and Emotions can Take Time

At times difficulties with communicating were related to anxiety, but specifically anxiety around communication rather than anxiety relating to the subject being spoken about. Unisonic explained that “the biggest unhelpful thing I think is misunderstanding my difficulties with speaking and thinking that some subject might be bothering more than it is.”

Participants wanted therapists to understand that communicating and processing thoughts and feelings can take a long time. As Annie said “If you don't 'feel' it, it doesn't have any value for you [...] and with me, things can take a loooooong time to sink in and mean something to me”, so therapists need to be patient. Similarly, Unisonic explained how his emotions need to be thought about and processed, which can take “a day or two to fully process, sometimes a week”. As

reported in overarching theme one, some participants grew up struggling to understand those around them, Aggie said: “I've always felt like I was playing catch-up in class” when the pace of work was dictated by others. Rea had experienced the impatience of others: “you really have to TAKE THE TIME to help us understand. Because we generally want to, but people often get tired of explaining way too easily, because it may take a while until we get it”. Pace of therapy was mentioned by the majority of participants, John also stressed that it is: “important to be able to allow me time to process what's going on”. Patience and care was needed from therapists who respected their pace. Participants shared it would be counterproductive to be made to talk about something they were not ready to talk about:

“[...] I don't think I would feel comfortable with an impatient [counsellor]!! I don't think I could bear it. It would make me feel inferior, or not able to go at the pace of normal people, if I was being too slow... Or if there was an issue that I didn't want to talk about until I felt comfortable, I wouldn't like being pushed at all, otherwise I would just close off completely and never discuss it with them.” (Elizabeth)

Participants wanted professionals to be aware that as with feelings, ideas take time to be processed and change is often a source of great anxiety. Participants had difficulties working with therapists who did not understand this:

“There were so many times she didn't understand things that were an issue for me. First of all, my triggers to anxiety were things like change and dating, etc. [...] She pretty much told me to like it. [...] Or she would say 'The more you're in public, the more you'll get over your fear of people and socializing.' She was very wrong! I spent my whole life thinking I was normal and tried to socialize because people told me to and not once did I ever enjoy it or 'get used to it'.” (Cali)

Forcing or pushing a new idea was experienced as unhelpful, as Annie said: “I find it much easier to accept an idea if I'm left to consider it for a while, rather than have someone tell me it's a good idea”.

Difficulty with change impacted upon how the endings of therapy relationships are experienced:

"I abhor, loathe and detest change... unless it's instigated by me and is under my control. And I think that's a major problem in this 'short term' counselling thing (6-12 sessions) – the whole thing is one big transition." (Annie)

Participants reported feeling "abandoned" (Annie) when relationships with therapists came to an end: "I felt abandoned, even if nothing could be done about it. I felt a lot of loneliness" (Stella). Similarly, James felt that a bad ending with one of his therapists had ruined his memory of the whole relationship: "all I took away from that relationship and those sessions in the end was this massive feeling of failure". The ending of therapy was difficult for some people even when it was planned and agreed with:

"You get used to talking to someone and having that outlet so changing it can feel like 'breaking up'. Even if it is the best thing it can still be hard. It's a mournful process."
(Unisonic)

Abrupt therapeutic endings were particularly difficult. Dawn reflected on therapy that was terminated suddenly and without warning, stating: "that actually really hurts". However, while many participants reported difficulties with endings, Elizabeth observed:

"I think my endings with counsellors/helpers so far have been planned and so I've known they were coming, but generally I don't see people like that as people to bond with, so I guess I don't [bond with them]".

D) Sensory Needs

Some participants struggled to access therapy if they were overstimulated by sensory noise:

"[the psychiatrist] had me waiting in a busy corridor for twenty-five minutes while I had to listen to consultations going on in three rooms around me (not loud enough to hear what was said exactly, but definitely loud enough to cause sensory overload)." (Mike)

Participants described having sensory issues with the therapy room itself, with rooms being distracting (sounds, sights, smells): "[...] a friendly office can always help too. Nothing too

distracting [...] but not just an empty broom closet either. [...] Nothing that smells somehow overwhelming etc” (Rea). Both individual differences and variations in sensory needs from day to day were reported: “hugs are good and pats on the back. But only if you have asked the individual. Some people don't like it or sometimes they also have certain DAYS where they don't like it” (Rea).

Participants also explained that sensory issues are a source of great stress in daily life, increasing their already heightened baseline anxiety. “[...] everything affects my emotions. Being sensory just living can be an assault on the sense which can tax me, irritate me, sadden me, etc.” (Unisonic). If sensory issues are not properly acknowledged this can lead to professionals searching for irrelevant reasons for anxiety or anger. Unisonic described how this caused problems in therapy:

“It was common to be misunderstood. I could be anxious but have no idea why. Knowing what I know today I would be able to answer something like 'I went to the store and it was too bright/loud' and that caused me to be anxious. In the past I would try to logically figure out why I would be anxious along with prompting from the therapist which would result in made up sources.”

Another sensory issue raised by many participants was their difficulty with eye contact, particularly when they were feeling anxious. While a lack of eye contact might show discomfort with the therapist or the material, it was also reported as being generally difficult: “eye contact is something I can do but not very well and if I feel uncomfortable whether it's family, or the counsellor, or whoever, I choose not to make it” (John). The participants reported their awareness of social rules around eye contact:

“NT people get really bothered about eye contact and AS people can't seem to get it right. We either give too little or too much. [full eye contact] intimidates NT people. But if we don't make eye contact, NT people think we're not being completely truthful or are dodging an issue.” (Virginia)

Because of the risk of misunderstandings, participants suggested that therapists need to understand eye contact and need to check out their understanding with each individual:

“I'd want them to say at the beginning that it is Ok with them for me to not look them in the

eye. When I talk about feelings, I feel uncomfortable [and] I find it extremely difficult to look people in the eye. (I'm normally Ok at it). It would be a big relief to not have to worry about this particular social norm!" (Elizabeth)

E) Stereotypical Assumptions About AS

There was great variety in what interviewees said about their wants and needs in therapy, and participants were frustrated by therapists who did not try to get to know them as an individual and made assumptions without checking that they were correct: "Gain an understanding of the individual. Honestly – I don't think there is a blanket feel good therapy. It is very individual." (Aggie). Similarly, Unisonic said: "Being aware of what being on the spectrum means. There is no one size fits all with this one. There is high functioning, low functioning, sensory, defiant, etc."

Some of the women raised the issue of differences between men and women and stated that the common representations of AS (and autism) in academia and the media are men:

"I think if a counsellor was aware of AS, it'd probably be the stereotypical 'male' AS – reciting bus timetables, obsessing over trains, co-morbidity of OCD, computer game nerds etc... basically, Sheldon from *The Big Bang Theory*³. [...] he's a long way from what I experience." (Annie)

Similarly, Virginia was aware that knowledge of AS in women was extremely limited when she was seeking diagnosis: "It was long before Asperger's was known over here (it only hit the books in America in 1994 and then only as a 'boys' disorder.')." Some participants thought this lack of knowledge of women with AS had impacted how long it took them to be diagnosed. Annie said "all the literature highlights the high prevalence in boys! Until I heard the name 'Rudy Simone'⁴, I had never heard of the idea of Asperger's manifesting differently in girls." Annie also felt that her therapy would have benefited from her therapists understanding the differences:

"People need to know about how it can manifest in FEMALES! [...] I actually think that it

3 The Big Bang Theory is a US sitcom, the lead character (Sheldon) unofficially has AS.

4 Rudy Simone (2015) writes about Aspergers and women.

would help me gel with a lot more female counsellors. [If a counsellor has] educated herself about this curious creature that is the female aspie.”

This supports the evidence outlined in the introduction (p14) that the male centric nature of the diagnosis causes difficulties when women are seeking help (Gould and Ashton-Smith, 2011; Marshall, 2013; Simone, 2015; Yaul-Smith, 2008).

Finally, participants expressed a desire not to be patronised or work with therapists who assumed they needed to be 'fixed':

“We shouldn't be treated like we're 'sick' or like 'we need help' or 'people are just trying to help us', but instead people should treat us normally. [...] I also always cringe so hard when people say 'illness' to my Aspi. I don't feel ill. I feel fine, actually. Geez. 'Oh, you are suffering from Aspi'...Uhm...I am not 'suffering', no. The only thing that makes me suffer is people being stupid about it, but that's not a symptom or effect caused by my Aspi per se.”
(Rea)

Similarly, Aggie described her frustration with the negative assumptions that some therapists made about her because of her AS: “[therapists] THINK they know why I'm broken but I'm NOT broken.” Regarding negative attitudes she said:

“Here are some assumptions. Autism/Asperger's = retarded, low IQ, selfish, non-empathetic, unfeeling, unable to hold a meaningful job, incapable of having a rich and happy life. I resent any kind of pity or feeling that I'm being pitied because I am stronger and think more deeply than anyone could possibly know.”

Manthei (2007) also found that NT people liked to be treated as intelligent, not as fragile, failures or unable to cope. I now outline overarching theme three.

3.3 Overarching Theme 3: The Importance of the Therapeutic Relationship to Counselling

For the majority of participants the of approach and intervention used was important, but the

relationship with the therapists was crucial. Having been misunderstood and not listened to during childhood (overarching theme one), participants did not want these experiences to be repeated by therapists. This overarching theme consists of three themes: the importance of an authentic therapist; being understood; and therapist as 'pushy expert'.

The Importance of an Authentic Therapist

Participants shared that it was important for therapists and professionals to be authentic, human, and genuine in their relationships with their clients. Participants also appreciated self-disclosure, particularly if they had shared interests. James explained:

“I liked that because [...] you don't feel like you're throwing words at a brick wall. [...] She opened her world up a little bit to me as, I suppose as much as a professional could do. God I really appreciated that [...] knowing that actually I was speaking to somebody who had a mutual love of animals. [...] And it just makes [...] a person human.” (James)

“I would like to know that I have something in common with my therapist. It would almost be like a water cooler conversation to make everyone at ease before you talk about the real stuff”.

(Aggie) Although participants valued having interests in common, Annie warned that this should not be false and therapists should not ignore the existence of differences. Annie explained that “It's a balancing act between recognising how aspies differ from NT's, but also finding enough common ground to work together and create a respectful, two-way relationship.”

Another form of connection was humour: “We laugh at times and I find it healthy. [...] I think it means we [know] each other well enough to have this sense of humour at times.” (Stella).

Participants reported that they did not want to work with someone cold or robotic, James said that humour “makes you human and it makes you accessible. [It] opens all sorts of doors in my mind, and when it comes to serious things”.

Participants wanted to work with a therapist who genuinely cared about them: “My Art therapist supported me when I was really low in mood and felt like no one cared and that I was going to be stuck in Hospital forever and that no college would ever have me etc. She was a really genuine person.” (Grace). And similarly Stella shared a helpful moment in her therapy:

“I have been crying almost the whole time and felt it was useless time. My therapist answered back 'it can make the difference in your life knowing that someone really cares about you. I care about you and I am sorry you're sad'.”

Some participants reported that they were aware when professionals were 'fake': “if I perceive falseness, I cannot stand it” (Annie), and James remarked “I'd look into this person's eyes, you know as I was talking, and I could see that this person cared”. This is also true of NT clients and their counsellors (Yardley, 1990).

Being Understood

As well as wanting therapists to be authentic and genuine, participants wanted to feel understood. Many participants grew up feeling like outsiders and being misunderstood, this meant that finding a therapist they connected with, and who understood them was important. As Cali explained: “Having connection in therapy definitely is the biggest thing for me because I'm always so surrounded by people who don't understand or don't want to understand.”

Participants described their frustration when therapists and professionals did not 'get' them. Rea stated that it would be discouraging if a therapist misunderstood, she would be thinking “This person doesn't get me, what's the point?” Annie described a difficult session with a therapist she normally worked well with: “one session I just got really irritated by whatever he said, felt like he, and no one else, understood, and eventually I stomped out”. Feeling that their views were being heard and understood was important. Feeling dismissed and misunderstood evoked similar experiences from childhood. Rea for example, stated that: “[Mum] also never took me seriously on anything”. As well as family and friends, participants experienced professionals who dismissed their views because they had AS, Mike explained: “My impression is that they think I'm just being 'difficult' because of Asperger's.” And Virginia stated: “For me, it's also important that my experience not be diminished because of my Asperger's”. Half of Cousins' (2002) participants reported that their difficulties had been minimised or dismissed by therapists. Furthermore, participants did not want therapists to repeat their past experiences of being blamed for being difficult:

“Of course a lot of people [...] (mostly the ones who thought 'something was wrong with

me') would say that it's just an excuse. [...] You could bring them 10 different diagnosis papers from 10 different professionals and they'd still claim 'it's just an excuse'." Rea

Participants wanted their experiences to be heard and understood. Cali explained that: "as an Aspie it's hard to connect with people so making sure you're wanting to understand and connect and not contradict what we say to be true helps us to trust you." Having had their experiences dismissed, participants reported valuing therapists who understood them and made them feel validated. Annie explained that her therapist had acknowledged and accepted her experiences and needs:

"My sister always said I was attention-seeking when I self-harmed, and when I broached this with the counsellor, she said 'So what if you are? Maybe you need attention', and I suddenly realised that yes, I had been silently begging for attention, mainly from my Mum, ever since I could remember. [...] The counsellor acknowledged that need, which felt really good. And fascinating. And horrifically sad, all in one. [...] I had never considered it to be a legitimate emotional need, and that it could be acceptable to feel that way."

Participants wanted to be understood and wanted to know that therapists were fully listening to what they were saying. Annie described her first experience of counselling: "Maybe the very act of talking was cathartic, I don't know. It was the first time I felt like I was really being listened to". Conversely, participants felt frustrated when professionals were not listening: "One therapist was always so tired during our sessions that I had caught him several times nearly falling asleep" (Aggie).

Therapist as 'Pushy' Expert

This theme captures participants' reports of working with therapists and professionals who did not have a respectful and collaborative approach to the relationship, did not demonstrate the 'core conditions' (Rogers, 1992a) and adopted an expert role.

One element of this theme was that participants wanted professionals to be open-minded, rather than be 'expert'. Annie described a good experience with her therapist:

“She'd basically be very supportive, open-minded, interested and would just 'diagnose' to point out possible solutions, but not to stick me into some drawer. [...] I always hate when they [...] get so stuck on their opinion that - no matter what you say or do - you are basically this 'nutcase' or 'solved case'.”

Rea also explained her experience of professionals in the 'expert' role who were not open to listening to her:

“'[P]rofessionals' treating you like 'Case Study #2876347' is really hurtful. [...] they don't ever think that 'we' would notice [...] (we're 'mental' and 'something is wrong with us' after all, right?) [...]. We notice. And that's when that person really loses trust and you sit there, wondering 'what you're doing here' if they already 'figured you out' [...]. It's always better to feel like you're talking to an equal (a very curious one) than some...god-like creature.”

Donna Williams (1996; who has AS) recommends a balance between textbook knowledge of AS, and getting to know the individual person. Similarly, Hodge (2012) suggests that being curious and wanting to understand the other person is something that should apply to counsellors.

Some participants experienced professionals making assumptions and being unwilling to accept that those assumptions were incorrect:

“[The military psychologist] listened to what I had to say and didn't try to change my mind. Like if I said I didn't want to make friends she accepted that. Whereas, other therapists took that statement as 'Oh, you're shy.' Or 'Oh, you have low self esteem and you're afraid to make friends.' When that wasn't the case at all, even when I tried correcting them!” (Cali)

Participants also wanted flexibility about what was done in therapy, rather than for a therapist to insist on an approach. Virginia stated that:

“Trust is critical. I must feel safe enough to be comfortable saying when something isn't working for me, and the therapist must respect that I know my own experience AND be flexible enough to try something else.”

Some therapists were not willing or able to listen to what participants said they wanted. Cali stated that: “Honestly I haven't found anything helpful so far. Every therapist seems to have a different opinion and they are all very stubborn (very by the book).” Similarly, Mike wanting to work at an intellectual rather than emotional level:

“She wants me to become more emotional and therefore is reluctant to engage me at an intellectual level. Consequently, neither an emotional nor an intellectual alliance is formed. I feel that the lack of an alliance is at least one reason why we don't make any real 'progress'.”

Participants described their frustration when professionals reached 'expert' conclusions without really understanding or respecting them. Aggie described her psychiatrist:

“He was the WORST! [...] I never got the impression he was actually LISTENING to a word I said. After a 45 minute session [...] he basically stroked his academic whiskers, said I was depressed and angry and prescribed antidepressants. I never returned.”

Related to the wish that therapists listen to what is being said was the desire for therapists to be respectful with challenges; participants did not want to be pushed into talking about things that they were not ready to explore. Grace described a negative experience with a school therapist because “he was too intrusive too soon and kept on and on and the same thing all the time”. Annie described the frustration of working with a therapist who gave her strategies (graded exposure related to social anxiety) without really listening to her needs and understanding her as an individual: “I couldn't make him see that I could and would do everything on the list, but that I'd feel horrendous afterwards. [...] he acted like I was cured!” Participants wanted therapists to listen to their individual experiences and felt hurt, angry, and judged when they were not being listened to, understood or accepted, but instead were being labelled as different and wrong:

“I am fine with people 'figuring me out' but when it's for condemning or judging in a negative way, that's not cool. [...] It's probably why I also always felt like therapists were weird. I mean the way they talk down on you would have you think that they're these perfect people (otherwise how or why would they judge you like that?), but they're not.” (Rea)

Participants also reported discomfort when therapists or other professionals appeared to be analysing them without sharing what was being thought.

Grace described an unhelpful experience: “She kept giving that gaze that psychiatrists give me, the one that implies that there is something seriously wrong with you.” Similarly, James explained his reaction to a child psychologist who told him he was attention seeking: “I'd sort of get up, throw my chair to the floor and walk out because I couldn't deal with the way he was communicating with me, [in] an antagonistic and negative way.”

Another element captured by the “therapist as 'pushy' expert” theme was that participants reported dissatisfaction when they felt forced into therapy or into certain approaches to therapy. As Grace explained: “I think that feeling forced into therapy is detrimental to the whole therapy process. You have got to want to open up and get help otherwise it won't work.” Participants reported childhood experiences of mandatory therapy where they were not listened to, something Virginia described as “a form of mental abuse”. Furthermore there was little explanation provided at the time of what the professionals were doing: “I didn't understand why he [mental health professional] was saying all these things, it wasn't explained in a way which I could understand” (James). Grace also described the daunting nature of some settings for example having “chairs around a table and random CAMHS people” (Child and Adolescent Mental Health Services). There was a sense of anger because their views were not heard, as Rea stressed: “Though, to make sure, the arrangements were not made FOR my mother. They were usually FROM my mother. I was the only person not being asked, is what I am saying”. Similarly, referring to therapy as an adult, Aggie explained that she would be waiting the therapist to make a mistake: “Seeking permission is the best way because you are allowing your client time to make a decision on whether or not they're going to work with you. They will be judging you and waiting for you to fail.” Related to wanting control over choosing a therapist, was the desire for control over what subjects were talked about.

The majority of participants wanted therapists to fully explain the rationale for the therapeutic approach adopted and to discuss with them what might be most helpful. Annie suggested explaining an approach, like mindfulness, so that they can decide whether or not it might be helpful:

“You'd have to suggest it in a way that would make sense to them. [...] And then I'd step back and let them research it and decide whether or not it's for them. I find it much easier to accept an idea if I'm left to consider it for a while, rather than have someone tell me it's a good idea.”

Rea stated that: “We need to understand the WHY, otherwise it won't work. Otherwise we might just say 'Yeah okay' without really meaning it [...] and then everybody will be disappointed and it just falls back on us, because 'we're unreliable'.” Related to this, participants stressed that they wanted therapists to take the time to make sure they understand each other. Stella said: “We do take the time to explain to each other what is needed. This is so important if I want to improve ... I must understand what he says to me.” Similarly, Aggie suggested checking meanings are understood: “Especially the 'do you understand what I'm talking about?' question. And then you, as a therapist must follow up with, 'explain back to me how you translated what I just said.'”.

The final aspect of having a collaborative respectful relationship captured in this theme was being able to trust the professional to maintain confidentiality and have the participant's best interests in mind. Grace, for example, said her art therapist “seemed more interested in reporting back to CAMHS doctors” than helping her, and Annie said:

“Yeah, I like direct people, who lay their cards on the table. I'd hate to really open up to someone, feel that they understood, then find out that they've recommended I be sectioned or something. Trust is a very important issue.”

People wanted their therapist to be honest and not talk to others without their knowledge. Elizabeth stated: “it's nice to talk to someone [...] and not worrying that they'll go gossiping to other people”. Several participants experienced breeches of trust, Grace said: “When I had therapy at boarding school, what I had said travelled to people who it didn't concern and that made me angry”.

Overarching theme three captures the type of relationship and attitude the participants wanted from therapists, and how this relates to the early experiences described in overarching theme one. I will now outline the final overarching theme which concerns participants' experiences of practical strategies and interventions, such as being offered strategies for coping with emotions.

3.4 Overarching Theme 4: What is Wanted from Therapy: Practical Strategies and Interventions

Theme three captured the importance of the therapeutic relationship. It also reported that any strategies or approaches would only be useful if suggested respectfully within a trusting relationship. Participants also had ideas about strategies and practical approaches they had found helpful, and what they might want in future therapy. Theme four captures these ideas. It includes being offered strategies for emotional or social difficulties, psycho-education around social and emotional issues, and preferences for the delivery of therapy, such as online rather than face-to-face.

Strategies for Emotional or Social Difficulties

Participants found advice on strategies to cope with emotions and socialising were helpful. Aggie said: "I guess for me therapy was more a quest for knowledge to help myself and find NEW or BETTER coping mechanisms." Some wanted directive advice: "I explain the difficulties of [the] previous week & how I struggled with it & she gives me advice on dealing & managing it". (John) This need for guidance on practical coping strategies for socialising supports the advice of Ramsey et al. who suggest therapists offer specific advice and a relationship in which socialising can be practised (Ramsay, Brodtkin, Cohen, Listerud, Rostain and Ekman, 2005).

Some participants explained that they wanted practical strategies because they wanted to know *how* to cope better with social or emotional difficulties. Virginia stressed that she wanted to know "what to DO" about being depressed, she explained:

"Most of the Aspies I've met have been problem-solving types of people, so when we have a problem, we want to solve it. It doesn't help me to hear 'You have to learn to fit in with people' and not follow up with HOW to learn to fit in."

Rea also stressed that she wanted to know what to do: "I always hate when people tell me 'You'll be fine' or 'It'll pass' or something like that, because I already KNOW that myself, but the question I always have is HOW." However, participants stressed that everyone with AS has different needs (see above). Grace, Annie, and Virginia all reported finding 'mantras' helped them to cope with

their emotions. Grace described having affirmations written in her hospital bedroom and said: “These helped me believe that better things were to come”; and Virginia said “[...] even if I can’t identify what I’m feeling. I can use the generic 'Even though I have this feeling, I deeply and completely accept myself,' and it is effective.” As well as mantras, some participants stated that breathing (Elizabeth) and calming strategies (Dawn, Stella) had been helpful, and Grace described how she made a “tool box” of different strategies to help her stop “hair pulling”. If offered respectfully, and explained fully, strategies and coping skills were welcomed by many participants.

Some participants wanted specific strategies for managing social situations. Annie explained how “having key phrases in my head helps in vulnerable situations, like 'I’m sorry, I don’t want to talk about that right now’” was helpful. As well as having strategies to reduce social vulnerability, some participants wanted to be helped to 'fit in'. Dawn said: “psychologists could focus on ways of fitting in. [...] I would have had more friends if I had realised how to become more interested in things other kids were doing.” However, some participants had mixed feelings because they did not always want to hide who they really were:

“I think that it is good to have a therapist who gives advice and teaches strategies....or maybe just someone who can teach us how to cope because I feel like strategies are just a way to put a mask on us.”(Cali)

Some participants found it helpful to be given social information (psycho-education), such as what body language or facial expressions communicate:

“ALL people on the autism scale would benefit from the 'psycho-education stuff.' I am still meeting adults (in their 40s and older) who are SHOCKED by simple recommendations that make their lives easier.” (Aggie)

Similarly, Stella said she was helped to understand that she could appear rude in emails and that “there is good and bad in everyone”. Unisonic said:

“On my own I can figure some things out over time. In a way I'm kind of still a big kid. I recently picked up the idea that because a person misbehaves in one way that doesn't mean they are that in total.”

Virginia also reported that it helped to learn about the motivations of NT people; she said: “that explained so much of why I have so much trouble fitting in with NT people.”

As well as some social psycho-education, some also wanted to learn more about emotions. Stella remarked: “As an Aspie, I don’t perceive people’s emotions and he helped me to recognize them”. Other participants reported wanting help with recognising their own emotions:

“Having awareness of the emotional effects beyond just the 'feeling' of it. For example, I learned certain physical responses I have to anxiety or depression. So it's a manual process but I know if I have these other sensations then I must be feeling a certain way.” (Unisonic)

Participants also reported wanting help to identify what triggers their emotions. Aggie said: “Having someone who has observed you and can see the outward triggers and essentially pull you to safety before the tantrum or anxiety happens would be SO beneficial.”

Most participants did not want either all practical strategies or all active listening from their therapists, generally a mixture of both was preferred. Elizabeth explained: “Usually when I'm under a lot of stress [...] I want logical and practical solutions suggested to me, but when I'm not under much stress it's more to offload which makes me feel better.” I now discuss participant preferences for certain modes of therapeutic engagement, such as online.

Modes of Therapeutic Engagement

Participants shared that communicating through speech was difficult at times and many suggested that writing could help. Dawn stated that therapists should try “providing opportunities for written expression [...] when speech is just too painful”. Similarly, Elizabeth said that when she is “stressed” her words get “stuck” and she cannot say what she wants to say, sometimes becoming “unable to speak”, but that this can be overcome by writing instead. Writing things down allowed people more time to process their thoughts and feelings. Elizabeth said: she has “more time to think about what [she] actually want[s] to say”. Most participants noted a preference for participating in an email interview because it allowed them time to think and process and they felt that they were more articulate in writing:

“In person I don't sound so astute. There are times where I can be non-verbal but I do force myself to communicate. I recall a time where I wrote my father a letter before he passed away. It was the first time he ever communicated back to me on the level of as adult. It surprised him that I could be so thoughtful and articulate. [...] It's too much sometimes to convey what I can write verbally.” (Unisonic)

Participants reported that writing also had the benefit of allowing them to reflect on past events, and find solutions to problems. Writing was also an effective way of managing the difficulties with processing described above. Rea said writing often helped her to “figure things out [...] because it's like a mirror as well; much like a therapist should be”. Writing things down outside of sessions was helpful for some participants.

Many interviewees talked about the potential of online therapy for accommodating some of their difficulties with face to face therapy, such as processing speed and reading non-verbal communications as described above:

“I think it's an excellent idea. Many of us do struggle with words, especially when we're 'on the spot', and do better with text. Online also gives us an added layer of shielding; we don't have to worry about eye contact or policing our facial expressions or trying to read the other person's facial expressions.” (Virginia)

Cali also saw benefits: “Online counselling would be awesome! There are so many times when I've been able to 'speak' through my writing.” Some people did prefer to see therapists face to face, but the majority spoke of the benefits of online therapy and preferred an Email based interview to a live chat or *Skype* interview.

The final approach that was mentioned by a large number of participants was medication. Although one person stated that medication had eventually helped them, most participants had unhelpful experiences. Aggie felt strongly that she did not want to suppress her grief with medication. She said: “It's been nearly 4 years since my dad died and I know I am depressed but I'm working through it because I OWN it and I don't want some therapist slapping on a band-aid to make me feel better.” Annie also stated that medication could cover up aspects of AS, she said:

“We, as a society, are too keen to offer medication, I think. I also think that I would have got my AS diagnosis sooner if I hadn’t been medicated so much, because I wonder if they help to cover up the AS symptoms? For example, being medicated can help me actually cope with the socialising experience. I still meltdown afterwards [...]”

In sum, some participants did have definite ideas about what they wanted to be done in counselling: some wanted coping strategies, some social strategies and advice, and some emotional education, some favoured online counselling, and some participants had negative views of medication. There was no consensus on these practical aspects, however, the data suggests that participants wanted professionals to listen to them and offer suggestions respectfully, rather than insist on a certain approach.

4.0 DISCUSSION

In this section I summarise the participants' 'story' and outline the key findings of the study and how they relate to the existing literature. I then discuss implications for practice. I reflect on the use of interview in the study, give methodological recommendations for researchers interviewing people with AS, and evaluate the strengths and limitations of the study. Finally, I provide recommendations for future research.

4.1 Key Research Findings

The four themes outlined above capture the story of how participants came to be seeking counselling and what they wanted and needed as a result of both their difficult life experiences, and their needs associated with AS. Theme one illustrates participants' traumatic relational experiences involving a sense of being excluded, judged, misunderstood, dismissed and bullied. These early experiences go some way towards explaining the relief participants felt at being diagnosed with AS; diagnosis made sense of their experiences as well as providing them with a sense of belonging with others like them. These experiences also provide counselling psychologists with a significant context for participants' needs in therapy; understandably participants did not want negative relational experiences to be repeated in therapy. Participants wanted therapists to be understanding, accepting, validating, genuine, open-minded, to listen, and to work collaboratively without being 'pushy' or judgemental. Participants also wanted therapists to avoid repeating their experiences of being misunderstood by people without knowledge of AS. They wanted therapists to understand that standard approaches to counselling did not work for them so they needed therapists to understand the traits of AS so that they could benefit from therapy without being misunderstood. They offered specific ideas of what they wanted from therapy, such as practical strategies and approaches.

The life experiences of participants contextualise why it is important that therapists understand traits of AS clients, and their therapy relationship needs. Theme one (Being Aspie: belonging and not belonging) will therefore be discussed alongside themes two (Why traditional counselling does not work for me) and three (The importance of the therapeutic relationship). I will now outline the key findings from themes two, three and four (What is wanted from therapy: practical strategies

and interventions), and contextualise them in the literature.

Theme Two: Why Traditional Counselling Does Not Work for Me

Participants found therapy unhelpful when they felt that their therapist did not understand AS. Participants reported childhood experiences of being blamed for causing problems because people did not understand AS, something also reported by Punshon et al. in their 2009 paper 'the not guilty verdict' (also see Cousins, 2002). Some participants reported this being repeated by therapists, with therapy being terminated by professionals as a result of ignorance (e.g. participants were accused of non-compliance because they did not engage with emotions in expected ways). This was also experienced by Beth Adler (2006: 165), who reported being asked to leave a therapy group because she was "behaving inappropriately". Furthermore, this supports the findings of Aston (2003) who reported that 40% of the couples (at least one with AS) they interviewed were dissatisfied with counselling, primarily due to a lack of understanding of AS. Gerland (1999) has also written of her difficulties with therapists. She explained that some therapists see ASC as a "state of mind" (p309), rather than as a syndrome made up of specific criteria, and that this had caused her to be "constantly misunderstood and misinterpreted" (p310) during four years of therapy. She stressed that therapy that is not developed with ASC in mind will do harm to people with ASC. My participants wanted therapists to educate themselves about AS traits. They felt that the key areas of misunderstanding were social communication, emotions, processing time, and sensory issues.

Social communication difficulties are characterised by weaknesses in intuitive understanding of the intentions of others (agendas, expectations, thoughts and feelings). Participants described how their difficulties with subtext led to misunderstandings when their therapists assumed a shared understanding. What participants wanted was clarity. Many therapists write about interventions that directly target social communication issues in order to increase awareness of the thoughts of others, and to decrease the social difficulties experienced by people with AS (Anderson and Morris, 2006; Jacobsen, 2003; Gaus, 2011; Ramsay, et al. 2005). This shows that these therapists have understanding of social communication issues and suggests they adapt their practice to avoid anxiety and confusion, although this is not stated. However, Gaus, 2011, in her book on CBT for people with Asperger's, does stress that confusion can be caused by therapists if social communication difficulties are not understood, but she is unusual in explicitly stating this.

Specific areas raised by my participants were use of broad questions, use of silences, and use of non-literal language. Silence was problematic. There are a number of theories that advocate the use of silence as part of the therapeutic process to facilitate reflection and to convey empathy, respect and support (Hill et al., 2003). Therapists in Hill et al.'s research generally reported sensitivity to (NT) client reactions when using silence and did not use this intervention until a good therapeutic relationship was established. Participants in the current study reported that silence was not used sensitively enough by the therapists they had encountered and this led to confusion and anxiety. Specific difficulties with silences are not discussed in the current therapy literature on ASC, therefore this is an important contribution. Difficulties with broad questions are observed in Ramsay et al.'s (2005) paper. They suggest giving more direct, specific questions, offering examples, or in some cases, writing questions down. They also suggest giving fuller explanations of practical elements of what will happen in therapy and why, in order to reduce anxiety and the pressure on clients to work out what the rules are.

A further difficulty was caused by non-literal language. It is not unusual for NT people, including therapists, to use metaphor or other non-literal language to explore concepts, particularly when exploring painful issues. However participants in this study stated a preference for literal language. Participants reported frustration when therapists appeared to focus on unconscious psychological processes rather than taking what they said literally. Wenn Lawson, who has ASC (2015) described being assessed by a clinician who asked her 'do you sometimes hear the voices of people you cannot see?' For Lawson, the literal answer was 'yes' (e.g. I can hear people's voices when I speak to them on the telephone), this response was misunderstood by the clinician and Lawson was medically treated for psychosis for 20 years. Although this is an extreme example, participants did experience both being misunderstood by therapists, and not understanding the non-literal language of therapists. This finding supports the advice of Gaus, a CBT practitioner, (2007: 73), who recommends using "word-perfect accuracy" with clients with AS to reduce confusion and frustration. Jacobsen, a psychotherapist, (2004) also recommends that non-literal interpretations are approached with care, and Ramsay et al. (2005) caution that statements made by clients are likely to be literal, not figurative, and also that clients will often take therapists literally. This is the first research to find that people with AS report difficult experiences with non-literal language in therapy.

As reported by participants, AS is associated both with some degree of difficulty recognising the emotions of others, and with recognising, coping with, and communicating emotions (APA, 1994; WHO, 1992; Gillberg and Gillberg, 1989; Szatmari et al., 1989). Clinicians have also reported that people with AS have difficulty with recognising and expressing their own emotions (Aston, 2003; Paxton and Estay, 2007; Hill, Berthoz and Frith, 2004), and with recognising the emotions of others (Blair, 2003; Davies, Bishop, Manstead, Tantam, 1994; Lindner and Rosén, 2006).

Exploration and communication of emotions is central to counselling, although it is understood that some emotions will be difficult to access. Emotions were experienced as overwhelming for many participants, which supports the findings of Romano (2011), whose participants also talked about becoming overwhelmed by the emotions of others. This meant some had a very narrow tolerance for working with emotional material; they would quickly become overwhelmed and unable to cope. Practitioners have suggested psycho-education approaches for helping people with AS to cope with their emotions, and to better understand them (Gaus, 2011; Jacobsen, 2003; Paxton and Estay, 2007; Ramsay et al, 2005). This shows that these therapists were aware of the emotional difficulties of people with AS, something that my participants saw as important. Participants described a strong preference for working intellectually because emotional processing did not help them reach therapy goals. This preference for intellectual processing was also reported by the women with AS in Romano's (2011) research about experiences of living with AS. Wing (1981) also suggested that therapy should utilise the preference of logicity to effect therapeutic change, rather than a more traditional emotional focus.

Participants were aware that they took longer than NTs to process and articulate thoughts and emotions, and to understand unspoken communications of others (Kaland, Møller-Nielsen, Callesen, Mortensen, Gottlieb and Smith, 2002; Koning and Magill-Evans, 2001). Participants explained that when professionals were not respectful of differences with processing speed the relationship suffered. This supports the writing of Gaus (2007), who stressed the need for giving extra processing time in CBT interventions, explaining that clients may appear not to have heard a question or comment, when in fact they are still processing their thoughts. She described how a therapist who does not give sufficient time and instead repeats a question will cause the client to stop processing their answer, and start their thought process from the beginning again. Many participants expressed a preference for written rather than spoken communication, feeling that

this provided both more processing time and the opportunity to articulate their experience. Some felt that therapists might wrongly assume that this preference reflected an avoidance of emotionally difficult content. This is the first research that represents the experiences and preferences of people with AS regarding processing time in therapy. Similarly, resistance to change, or a need for the familiar, has long been identified as a trait of AS individuals (Gillberg, 1991). Participants stated that they needed time to process the idea of change. They described misunderstandings when therapists believed they were being non-compliant, when actually they had felt pressured and needed more time to consider new ideas. One aspect of change that participants found hard was the end of therapy. It is acknowledged that endings can raise painful feelings for clients (Murdin, 2000). Participants explained that endings could be difficult and that they preferred considerable warning so they could come to terms with the idea of the relationship ending. Participants described feelings of abandonment, disappointment, loneliness, and hurt when ending. Some also described how a badly handled ending to therapy could undermine any good work that had previously been done. While a preference for repetition is reported in the clinical literature, specific needs around the endings of therapy have not been reported by either people with AS or by clinicians. Therefore this finding adds to current knowledge about what is needed in therapy.

Sensory overload affected many areas of participants' lives (also reported by Romano, 2011), including therapy sessions, and they wanted professionals to be aware of the extent of this so they understood their stress levels. Participants described being misunderstood by therapists who would come to different conclusions about why they were stressed, or would fail to make adjustments to the therapy space to reduce sensory demands. Gaus (2007) stated the need to make therapy environments meet the sensory needs of clients in order that the environment does not stress and distract them. Jacobsen (2003) also talked about the sensory needs of children in her book 'Asperger Syndrome and Psychotherapy'. She advocates the involvement of specialist occupational therapists who can assess and adjust environments to suit people with AS. The need to understand the sensory-based stress triggers of people with AS has been stated by practitioners working in education with people with AS (Attwood, 2007), but is not widely discussed in therapy specific AS literature. As such this is an important addition to that literature. Related to sensory needs, are difficulties with eye contact. Therapists might reasonably interpret a person's eye contact as revealing something about their thoughts and feelings. Some people with AS and ASCs

have described their intense discomfort with eye contact (see Robinson, 2007). Participants reported occasional difficulty, however, this was not universally reported by participants in this study and likewise only one of Romano's (2011) participants described this. Some participants explained that people's expectations and interpretations of eye contact could lead to misunderstandings because it was not necessarily related to current thoughts and feelings about the material or the therapist. This also raises the issue of stereotypes about AS. Participants remarked that having an inability to make eye contact was a common myth about AS, and therapist assumptions based on this caused further confusion and frustration.

Participants' disliked being negatively stereotyped as people who need to be fixed or helped. Participants were generally positive about their experiences of AS, several remarking that AS is an improvement on being NT in many ways, a finding which supports the views reported in other studies (Cousins, 2002; Romano, 2011; Punshon et al, 2009). They were proud of AS and did not want to be seen as broken. Although, other researchers have found that *some* viewed the diagnosis negatively for at least some amount of time, showing the variety of experiences (Pushton et al., 2009; Attwood, 2007).

Theme Three: The Importance of the Therapeutic Relationship to Counselling

Having felt dismissed, forced into mental health interventions, and frequently misunderstood, participants needed a therapeutic relationship that did not repeat these experiences. The key areas that were important to participants were: having a therapist who is genuine; being understood by the therapist; and not working with a 'pushy' expert.

Many participants had experienced relationships with people with whom they had little connection, and did not experience as caring for them (theme one). Participants did not want their therapeutic relationship to repeat these negative relational experiences. They wanted a therapist with whom they could experience a genuine relationship, they wanted to know that the therapist cared about them, and they wanted to feel a connection by finding things in common such as humour, and shared hobbies and interests. Several watched mental health professional for signs that they were false and did not really care, something also true of NT clients and their counsellors (Hill et al., 1993; Yardley, 1990, cited in Manthei, 2007). Therapist self-disclosure was favoured because this increased the feeling of connection and trust (also recommended by Ramsay

et al., 2005). This is not particular to people with AS: NTs had better relationships with counsellors who demonstrated a similarity to them (Manthei, 2007; Vera, Speight, Mildner and Carlson, 1999).

Participants also stressed the need to be understood by their therapist. Having repeatedly experienced feeling dismissed and misunderstood by others, as other researchers have found (Punshon et al, 2009; Cousins, 2002), participants did not want these experiences to be repeated by their therapists. Participants wanted therapists to be interested in them and curious about their experiences. This finding supports Williams (1996; a writer with AS) who suggested that professionals get to know the individual with AS, as well as understanding AS generally.

Furthermore, interviewing women with AS about their life experiences, Romano (2011: 146) observed that participants wanted 'deeper understanding', characterised by the 'underlying outcry for participants to be understood by the rest of society'. Although not specifically speaking about therapy, this further supports the finding that there is a need to be understood. What participants wanted was to feel validated and heard, regrettably, many reported dismissive therapists who did not take their concerns seriously. Half of Cousins' (2002) participants also reported that their difficulties had been minimised or dismissed by therapists, suggesting this was not unique to my study.

The finding of a need for an understanding and genuine relationship is supported by the writing of people with AS. Although not related to the therapy relationship, people with AS have expressed that relationships are important to them in their lives, sharing that they needed relationships with people who accept them for who they are, care about them, are loyal to them, understand them, and listen to them (Aston, 2003; Hendrickx, 2008; Jackson, 2002; Willey, 1999). Furthermore, in their paper on the difficulties of the therapeutic relationship, Ramsay et al. (2005) state that in their experience people with AS appreciate people who 'stick by them' and make an effort to understand their problems. The views of people with AS on their needs from the therapeutic relationship have not previously been reported so this is an important finding. It supports the view of Rogers (1992a), that the therapist should offer the client the three core conditions of genuineness, empathy, and unconditional positive regard.

Participants wanted therapists to work collaboratively and respectfully. However many had encountered professionals with fixed ideas about therapy and about the participant; professionals

who adopted an expert view and did not listen, and who would make the participant feel judged, analysed and criticised. These attitudes were damaging to the working alliance, which is also important for NT people (Bordin, 1979, cited by Werbart et al, 2014). Prior to diagnosis, participants reported being seen as abnormal and being forced to see mental health professionals without being consulted about the processes or being given any explanations. Aston (2003) also found that clients with AS preferred interventions to be explained, and Manthei (2007) found that NT clients wanted to be better informed so that they could decide what happens in therapy. Discussing therapy preferences with the client has also been found to improve the therapeutic alliance and lead to more positive outcomes in NT clients (Swift and Derthick, 2013). Anderson and Morris (2006), writing about CBT and AS, also recommend that goal setting be a collaborative and open process so that expectations can be managed from the outset and realistic therapy goals agreed.

The participants needs from the therapeutic relationship can also be understood within the context of relational therapy. Kohut theorised that individuals have three core developmental needs that need to be met by 'self-objects' (people or other objects who provide psychologically sustaining functions). Needs that were frustrated in the early lives of participants. These core needs are the need for mirroring (a need to feel understood and approved of by others); the need to idealize (a need to feel that there is something or someone greater to comfort and inspire); and the need for kinship (a need for others who are like us in some way; Kohut, 1971, 1977, 1984; Lynch, 2005). Kahn (1991) integrated Kohut's theories with those of Carl Rogers, who theorised that people need to be accepted, understood, and prized for who they are. The frustration of these needs may explain why therapists who participants felt had failed to provide a good relationship were experienced negatively and why participants wanted to work with therapists who they could experience a connection with, and feel understood by. A relational framework is of relevance for counselling psychologists and expands on the currently CBT dominated literature by demonstrating the relevance of relational work and the importance of the therapeutic relationship for individuals with AS.

Having summarised the literature that is of relevance to themes two and three, I will now describe the key findings of the final theme regarding practical strategies and interventions.

Theme Four: What is Wanted in Therapy: Practical Strategies and Interventions

Participants talked about the interventions that would and would not benefit them. Many wanted psycho-education around social and emotional areas, and many wanted to be advised what to *do* and why so they had practical or intellectual methods to attempt. Descriptions of psycho-educative interventions for people with AS are numerous. Anderson and Morris (2006) describe a CBT type intervention to improve the affective understanding of people with AS (and therefore lessen the social and emotional impact of weaknesses in that area). Gaus (2007; a CBT practitioner), Jacobsen (2003) and Ramsay et al. (2005) (psychotherapists) advocate psycho-education in social and emotional areas and recommend strategies for people with AS who want to work on these areas. Ramsay et al. (2005) states that their clients ask for advice of this type, and appreciate strategies. My results indicate such approaches would be appreciated. A lack of strategies was frustrating for some participants, and is also found unhelpful by some NT clients (Boyhan, 1996, cited in Manthei, 2007). Some participants wanted social strategies that allowed them to get by in NT society. However, one narrative of theme one was that participants wanted to be themselves, but found they had to 'play normal' in order to be accepted, something also reported by the participants in Portway (2006) and Pushton et al.'s studies (2009). Participants reported the stress caused when having to hide aspects of themselves to fit in with NT society, because they wanted to be themselves. This stress was also reported in other studies (Portway, 2006; Punshon et al., 2009), and by Yauill-Smith (2008:31) who has AS, and wrote about the "exhaustion" and mental health difficulties experienced by women who are trying to fit in. As with theme one, in therapy there may be a balance between learning strategies to fit in, and taking pride in being true to themselves.

Although specific approaches were not the focus of my analysis the two areas of online therapy and medication were discussed frequently enough by different participants that they warrant mentioning. The vast majority of participants were in favour of online therapy because it is a context in which skills with reading body language and facial expressions are not required and written words rather than spoken communication is used (Anderson and Morris, 2006; Dekker, 1999; Hare and Flood, 2001). The majority had had negative experiences with medication.

4.2 Implications for Practice

The following section on implications for practice outlines how the key findings can impact the therapeutic work of professionals. It is important for therapists to be informed about how to work with diverse client groups who may have experiences that cannot be assumed to be understood by people outside of that group (Griner and Smith, 2006). The implications for practice seek to draw on the voices of the participants in order to provide recommendations for practice that meet the participants' needs. Current NICE guidelines for “management of adults on the autism spectrum” (p1), while not directly advising on counselling, includes a section on “experience of care”, and seeks to promote best clinical practice for psychological and psychosocial interventions (NICE, 2012: 55). I will outline recommendations derived from the results of the current research, and where these fit with the NICE guidelines (2012). See box 2 for an overview of implications for practice:

Box 2: Implications for Practice

- Why standard counselling techniques do not work for people with AS
 1. Be aware of social communication needs
 2. Be aware of emotional processing differences
 3. Be aware of processing speed of thoughts and feelings
 4. Be aware of sensory needs
 5. Be aware of differences between men and women with AS
- The importance of the therapeutic relationship to counselling
 1. Be aware that clients want a connection with therapists who are genuine, and caring
 2. Be aware that clients need to be understood and listened to, not dismissed
 3. Be aware that clients want to work collaboratively and not with pushy, 'expert' therapists
- Practical strategies and interventions
 1. Be aware that clients may want to be offered practical strategies and interventions
 2. Be aware that caution is needed when offering social skills strategies

There were a number of recommendations regarding traits of AS that participants wanted therapists to understand so that they could work with them without misunderstandings occurring. These were in the areas of social communication, emotional processing, processing time, and sensory needs. The NICE guidelines (2012) recommends that those working with adults with Aspergers should have a good understanding of the nature of autism and it's impact on individuals. Unlike the current report, NICE do not currently specify the features of autism that professionals would benefit from understanding (social communication etc.), although they do state that interventions should be delivered in environments that take account of sensory sensitivities.

Social Communication

Participants wanted therapists to understand social communication difficulties. They wanted practitioners to be clear with their expectations and with what they were communicating because participants were not always able to gather this information by 'reading between the lines'.

Broad questions could be difficult for people with AS, but participants certainly did not find them impossible to answer or suggest they should *never* be used. Difficulties arose when the questioner assumed a shared understanding of the boundaries of the answer and therefore expectations remained unspoken. The participants in my study suggested that therapists sensitively check understanding, or ask questions with the context more explicitly explained. Similarly, therapists' use of silence was reported as anxiety provoking and unhelpful for participants. This study suggests that silence should not be used unless participants understand the purpose of that silence. Participants suggested that they would prefer that the 'rules' of silence in therapy were explained and that they were invited to feed back about how they experience its use. With all the social communication needs, but also generally, what participants wanted from therapists was explanations of processes and checking out that things are being understood.

Non-literal language could be difficult and cause misunderstandings. Participants did not suggest that non-literal language never be used, but they did want therapists to be sensitive to the added demands of such language and that misunderstandings might occur. Participants also reported difficulties when working with hypothetical or imaginary examples and that therapists assumed they were being unnecessarily pedantic when correcting aspects of hypothetical examples. Therapists may need to avoid use of hypotheticals because they are unlikely to achieve what is

expected. Participants also described difficulties when therapists did not take them literally (e.g. when subtext was assumed), and they were misinterpreted, and confusion was caused. Participants wanted therapists to listen at a literal level, and to be open and transparent with interpretations they do make so that inaccurate ideas can be corrected. Therapists who encounter 'resistance' to interpretations should consider that from an AS perspective non-literal interpretations may not be relevant (although there are individual variations.)

Emotional Processing

Participants wanted therapists to understand how they processed and experienced emotions. Therapists should be aware that people with AS might find it difficult to recognise and communicate their own emotions, and that the grey areas between no emotion and extreme emotion are particularly difficult to sense.

Participants wanted therapists to understand that their facial expressions often did not match their internal thoughts or feelings and that this could add to feelings of being misunderstood. For some this will be an area they want to work on, others will not, but professionals need to know that relying on facial expressions for emotional information might cause problems. Again, therapists who are expecting NT interactions may misinterpret tone, expressions, and difficulties accessing emotions. Participants also wanted therapists to understand that they could not always read the therapist's non-verbal communications so could miss attempts to convey warmth and encouragement. It is preferable for therapists to express their thoughts and feelings without reliance on non-verbal signs, which might be missed, or to check understanding with the individual. Some clients may want to work on recognising non-verbal cues, some will not. Furthermore, participants wanted therapists to know that they preferred working in intellectual ways (to emotional processing) and that they could be helped by being given a logical way to understand themselves or past trauma. Participants talked about wanting practical ways to help them with negative feelings; they wanted to be told what actions to take and why.

Processing Time

Participants wanted therapists to understand that they might need more processing time than their therapist expects. They also wanted therapists to understand what might help them to

process and communicate their thoughts.

Participants wanted therapists to know that they were often more able to express themselves in writing than in spoken communication, and that their inability to speak was not always indicative of difficult material. The participants in my study made several suggestions of what might help them if they are having difficulty with spoken communication (opportunities for written expression; a therapist giving prompts or asking them to explain in a different way). Participants were clear that silence from the therapist was very unlikely to help them to express themselves.

Participants wanted therapists to understand that they might take longer than expected to process their thoughts and feelings. Therapists who do not understand this might be confused by the apparent slowness of responses, or by unexpected responses if someone has not reached the expected conclusions. Professionals should provide plenty of time for information to be processed and communicated, particularly if the content is emotionally or socially orientated. Participants also wanted therapists to know that they might take longer than expected to consider new information, perhaps even days or weeks. Therapists working overtly with identifying and challenging thought patterns will need to work more slowly than they might generally anticipate or they will meet 'resistance'. Resistance should not necessarily be viewed as a disinterest in or a refusal to commit to therapy.

Participants wanted therapists to understand that the end of a therapy relationship could cause distress and should be sensitively handled. Care with endings and transitions should apply in all therapy and much has been written about the need for sensitivity and exploration in NT therapy (Murdin, 2000). However, acknowledging that all clients require endings to be approached with care is not sufficient and could be construed as dismissive of the degree of distress that change can cause people with AS. For a therapist to say 'endings are important for all clients' risks the kind of dismissiveness that Yauill-Smith (2008: 31) describes; the "we're all like that sometimes" type of dismissiveness.

Sensory Needs

Participants wanted therapists to understand that their anxiety and stress levels were often affected by sensory stimuli that therapists might not expect to cause such difficulties. Some

participants wanted to work on identifying their sensory-based stress triggers so that they could limit their exposure to such stimuli and understand what had caused their stress. Some therapists may need to alter their waiting rooms or their therapy space to reduce such stresses. Participants also wanted therapists to understand that their patterns of eye contact were not always related to current thoughts and feelings about the material being discussed. It is important that therapists do not ascribe the 'normal' meanings to avoidance of eye contact, or to intense eye contact because this will create misunderstandings. Participants also expressed a desire for it to be acceptable not to follow 'normal' social rules regarding eye contact.

Women with AS

Even with a diagnosis, women reported that some professionals did not understand their experiences because most were unfamiliar with the presentation in women. Where necessary, those working with women with AS should seek to educate themselves further about the specifics of AS in women. For example, women with AS are more likely to imitate the social behaviours of those around them, masking some traits of AS (Attwood, 2007); “Girls are often more aware of and feel a need to interact socially” (Gould and Ashton-Smith, 2011:35). This ability to 'play normal' and give the 'right' answers adds to difficulties in diagnosis, and may be related to the themes of wanting help with social skills and the descriptions of trying to wear a mask to fit in (play normal). Although both points were also mentioned by the men in my study.

Having described recommendations relating to AS traits traditional counselling, I will now outline recommendations under the heading of the importance of the therapeutic relationship to counselling. These will follow the three key themes of the importance of an authentic relationship, being understood, and therapist as 'pushy' expert.

The Therapeutic Relationship in Counselling

Therapists should be aware that the attitude of the therapist was crucial to the relationship and to the success of the therapy, and that participants reported specific positive and negative experiences regarding aspects of therapeutic relationships. Some of these needs can be understood in the context of past relationship experiences that had been difficult for them and which they did not want repeated in therapy.

Therapists should be aware that participants needed a connection with their therapists and they wanted them to be authentic, genuine, and 'human'. One implication of this is managing self-disclosure, something that participants reported finding helpful. Participants expressed their view that therapist self-disclosure improved trust and connection. However, caution should be used. Manthei (2007) found that inappropriate self-disclosures were unhelpful and unwanted (Hill and Knox, 2002). Also, relational perspectives suggest care should be taken with self-disclosure. Kahn (1991) recognised that it can make the therapist seem more human, and Kohut (1981) was clear that unnecessarily avoiding self-disclosure could leave the client feeling rejected. Self-disclosure needs to be balanced with maintaining enough ambiguity to work within the transference relationship. For example, if a client asks if the therapist understands AS the therapist could first explore the client's concerns that they will be misunderstood, and their history of being misunderstood. However, participants were clear that therapy processes should be explained, and they would not want to feel dismissed, therefore care should be taken in ensuring the working relationship is stable. Therapists should also be aware that participants had a strong desire to be understood and accepted. It is important that therapists try to understand the individual life stories and needs of clients. Therapists should not be dismissive of experiences; participants wanted to feel validated by therapists.

Therapists should be aware that participants did not want to work with those who behaved like experts who 'knew best', but wanted to work with therapists who were respectful of their views and of their individual needs. Some clients might want therapists to take control and give expert instruction; most of 'my' participants did not want this; most wanted relationships to be collaborative (for professionals to listen and remain open minded). It is important for therapists to pay attention to whether the patient's needs and expectations are being met by the therapeutic approach, and if not to allow an open conversation about any incompatibilities. Participants wanted therapists to have an understanding of AS, however, they did not want therapists to make assumptions without getting to know them individually. Participants were clear that they did not want to work with someone who treated them like they were a text book case study and did not attempt to get to know them.

The importance of a good therapeutic relationship is also best practice according to the NICE guidelines on working with adults on the autism spectrum (NICE, 2012: 11): "the importance of

organising care in order to support and encourage a good therapeutic relationship is as important as the specific treatments offered.” Something supported by the current research. Furthermore, in support of the current research, the NICE guidelines also encourage a respectful and collaborative approach as best practice. The guidelines recommend professionals: “work in partnership” and “offer support and care respectfully” (NICE, 2012: 72).

What is Wanted in Therapy: Practical Strategies and Interventions

Therapists should be aware that participants wanted practical strategies and interventions. However, strategies must be *offered* and *explained*. Furthermore, participants described sometimes wanting active listening without practical strategies, and at other times wanting concrete advice or information. It is recommended that discussion of goals and approaches is encouraged and ongoing. Participants also expressed a desire for help with social skills to understand and fit in with the NT world to some extent (see theme four). Caution and self-examination is required when giving strategies around 'playing normal' because there is a risk of being influenced by ableism; a risk of endorsing the notion that normal is better than Aspie and therefore being more normal and less Aspie is an appropriate aim. There is a need to discuss with the individual how to balance the desire to have the strategies to fit in, with the risk of ableism, and the dangers of mental health issues if encouraged to conceal parts of themselves.

Ableism and respect for diversity is also an important consideration for counselling psychology. The British Psychological Society (BPS, 2015) states in its practice guidelines that practitioners must “make themselves knowledgeable about the diverse life experiences of the clients they work with” and “challenge the views of people who pathologise on the basis of such aspects as sexual orientation, disability [...]”. Practitioners should therefore respect the client’s views on AS; this respect was not always experienced by participants. Participants were generally positive about their experiences of AS. They described their frustration with therapists who thought AS was something to be corrected, and with therapists who were patronising towards them because of assumptions about their AS (e.g. that they are 'damaged' or 'stupid' or need to be fixed). These experiences suggest that some therapists may have been influenced by negative social constructions of individuals with AS; an example of ableism (Hodge, 2012). Having experienced being judged as 'crazy', 'weird', and 'different' during childhood, then learning about AS and

finding pride in the diagnosis, participants did not want negative judgements to be repeated by therapists. A further aspect of working with diversity is the need to acknowledge differences and not shut down exploration by going too far in highlighting similarities and shared experiences. There is a risk of being unintentionally dismissive of a person's experiences. Yauill-Smith (2008), who has AS, wrote: "[...] even now, I sense people questioning and passing judgement on whether I have a disability or not remarking: 'we're all like that sometimes'". It is an important part of counselling psychology's ethos that difference is respected, and this was not always experienced by my participants.

Having discussed specific implications for therapists I will now discuss my reflections on interviewing people with AS.

4.3 Reflections on the Research Interview

There are currently no specific recommendations for interviewing people with AS but as with therapy, some characteristics of AS (communication, emotional and social literacy) could mean that standard interview approaches do not fit this participant group. The areas of interview type (online/face-to-face), use of broad questions, time for processing, and need for clarity are discussed. After this I will reflect on my use of language in describing traits of AS.

I would recommend that online asynchronous interviews are offered as part of a range of possible methods because these were often favoured by participants. Seven participants stated their preference for written over spoken language because it helped them to understand the questions, allowed thinking and processing time, and increased their ability to express themselves. Three participants favoured synchronous spoken interviews (face to face or *Skype*), showing it is preferable to offer a choice. It has also been suggested that online interviews allow participants to feel heard (Beck, 2010), this idea was supported by feedback from my participants. Some researchers have suggested potential limitations of online interviews. First, that rapport and trust are hard to build (Beck, 2010; Madge and O'Conner, 2002), however, my experience was that rapport was easily built with most participants; many stated that they enjoyed sharing their experiences with someone who was genuinely interested. Second, while the lack of non-verbal cues is seen as problematic by some researchers (Bjerke, 2010; McCoyd and Kerson, 2006) participants in this study were generally unconcerned due to their difficulties in reading these, and

in being read by others. I found it was easy to substitute non-verbal communication using emoticons, or to directly ask about the feelings associated with a topic.

As well as a preference for written asynchronous online interviews, participants also expressed preferences about how interviewers asked questions and explained the interview process. Below I explain participant feedback, and my own experiences regarding how to make interviews clear and understandable for participants with AS.

I would recommend that broad questions are only asked with sensitivity to the possibility that interviewees might be unsure what is expected of them. I began with an open question in order to gauge the individual's ability to answer such a question, and to allow the participant to share things I had not already thought of. Eleven of the thirteen participants gave generally full and informative answers, however, several participants responded in ways that suggested the scope of the question was concerning:

"Can you tell me something about your experience of counselling?" [Me]

"Well as you say it is very broad this question, I will say something random!" [Grace]

I tried to explain my reasons for asking questions, for example if the context was that a previous participant had raised something then I stated this. In the later interviews I explained my reasons for asking a broad opening question, I also tried to explain the reasons for asking clarifying questions which might seem obvious (and therefore suggest that I was failing to understand their perspective). As reported in the analysis, participants had a preference for expectations and sub-text to be made explicit. I would also recommend that interviewers respectfully check that questions and answers are being understood (by both themselves and the interviewee). To do this I sometimes asked for examples, and I tried to be open about what my interpretations were (e.g. "so tell me if I've got this wrong, but...".) In terms of the interview, no one expressed a dislike of being asked to clarify and generally responded with more information.

I would recommend that non-literal language is used only with sensitivity to the potential confusion it can cause. Participants fed back that literal language was preferable. When I was not careful with what I was writing there could be misunderstandings, for example when asking about what kinds of things happened in therapy I asked:

"What did the chatting look like etc?" [Me]

"Well it was me and her and her sat in comfy chairs at a little round table in a really interesting room with random arty pictures on the walls." [Grace]

Without understanding that my question was unclear to Grace I might have interpreted her response as rude. The desire for uncomplicated questions was feed back by one participant when I asked more than one question in a sentence. That added to the amount of re-reading required to understand what I was asking. It is not that people with AS are not capable of understanding complex questions, but it is important to consider reasonable adjustments to reduce the effort required in responding.

I would recommend that the interviewer adopts a curious and respectful approach to encourage the interviewee to feel comfortable with sharing their experiences (DiCicco-Bloom and Crabtree, 2006, writing about NT people). As with therapy, some adaptations are advisable when interviewing people with AS. Having described these, I will now comment on my use of language in describing traits of AS.

My own use of language in interviews and the report is relevant to ableism. I have sometimes referred to areas of 'weakness' or 'difficulty', rather than areas of 'diversity'. This could imply a belief that people with AS are inferior to NT people. That is not my intention; my choice of language is generally reflective of my participants' language. My position is that AS is an example of neuro-diversity and is not something to be corrected, however, there are areas that cause individuals difficulties and those areas should be acknowledged (e.g. pain from sensory hypersensitivity). I will now discuss evaluations of the research.

4.4 Evaluation of the Research

As a piece of qualitative research the notion of generalisability is not relevant as qualitative research does not aim to be generalisable. Furthermore, while some quantitative research seeks to have a sample large and diverse enough to be statistically generalisable to larger populations, qualitative research does not. However, what is relevant is the notion of transferability (Braun and Clarke, 2012; Lincoln and Guba, 1985). Transferability means considering the other areas in which the results may be relevant, and demands thought about the relationship the results have to the

characteristics of the sample. Furthermore, Lincoln and Guba (1985) stressed that the *reader* is responsible for assessing whether the circumstances and context of the original study make the results relevant for their own needs. With this in mind, below I further unpack the sample characteristics, for example the higher number of women than men, the recruitment from support groups, and the fact that most participants were diagnosed with AS later than average. Each participant was motivated enough to give detailed and personal answers, primarily because of an interest in the research area; all the participants were members of online AS groups. Furthermore, ten participants came from an online group which may have had its own culture of shared ideas (e.g. strong on advocacy) and this may have influenced the data (e.g. towards themes of advocacy). It is also possible that people who seek out online groups are more likely than others to have 'stories' around wanting to find somewhere to fit in, or wanting to be listened to. Cousins (2002) interviewed adults who were part of online groups about being diagnosed during adulthood. She recognised the potential influence of common views being shared within these groups. It is possible that those diagnosed at a younger age would have a different relationship with the diagnosis, perhaps one less characterised by relief, however, none of the recommendations for practice are obviously influenced by the late diagnosis age of participants.

The average age of diagnosis of AS is eleven, with autism diagnosed at five (Howlin and Moore, 1997), however, only three of my participants were diagnosed before the age of twenty. Many participants' social difficulties were significant enough that they became a target for bullying, and for mental health intervention. Late diagnosis may also be related to the gender of participants, girls with AS have been found to be diagnosed later, often in their 30s and 40s (Gould and Ashton-Smith, 2011; Marshall, 2013). I interviewed four men and nine women. The ratio in my study is unusual in AS and could have impacted the analysis if women have different experiences to men. For example, women may have greater difficulties in being diagnosed and experience more dismissiveness from professionals, although, this was also reported by male participants, and by Cousin's (2002) participants (four men, four women). I will now outline recommendations for future research.

4.5 Recommendations for Future Research

Although specific therapeutic modalities were not the focus of my analysis, online therapy was perceived positively by participants because it is a context in which skills with reading body

language and facial expressions are not required and written words rather than spoken communication is used (see Dekker, 1999). Only one participant had experienced online therapy and although they were positive about it, more research is required into AS clients experience of online therapy. This could be approached as a qualitative interview to explore the experiences of people who have had online therapy, or this could be carried out as a quantitative study of outcomes following online therapy compared to face-to-face therapy.

There is a growing literature on the differences in the experiences of men and women with AS, and the importance of professionals recognising those differences. In this research, women talked about having difficulties in therapy because the male presentation of AS dominated therapists' understandings. This meant that women were likely to be misunderstood both by those with no knowledge of AS, and by those with knowledge only of the male presentation of AS. For this reason, further research could seek to interview just women, or just men so that their different therapy experiences and needs can be more clearly understood.

The process of gaining a diagnosis is important for counselling psychologists to consider because they are likely to work with clients who are yet to be diagnosed. Participants reported having difficulties being referred, and pursuing this while professionals were dismissive about the possibility of AS, it is important that counselling psychologists avoid adding to these difficulties (something also stated in the NICE guidelines for people with autism: NICE, 2012). Similarly, Cousins (2002) found that 75% of her participants actively sought the AS diagnosis, because professionals themselves did not (also see Romano, 2011; Howlin and Moore, 1997). Research is needed into which professionals are first contacted so that education can be targeted at those groups and mis-diagnosis reduced. This was also raised by Lorna Wing (2005, cited by Portway, 2006) who wrote that "In the UK there is still a dearth of information and knowledge among professionals such as health visitors, social workers and GPs." My participants generally reported that GPs were their first contact point and that they often had insufficient knowledge to know that a referral to a specialist team would be appropriate. It would be beneficial to investigate which professionals are involved in the process of diagnosis and delayed diagnosis in order to understand where further education is required.

Finally, while my research did not target specific approaches, my analysis suggests that understanding the relationship in therapy could help therapists to understand what people with AS

value in the therapy relationship. It would be important to explore the experiences of people who were in different types of therapy, including relational therapy. In this way the importance of the therapeutic relationship to people with AS could be further explored, and recommendations for practice made more strongly.

4.6 Conclusions

The aims of my research were to explore the counselling experiences of people with AS in the hope that practice could be improved where necessary. The analysis has implications for those working with people with AS, both as counsellors, and also in other professional roles. It was evident that participants had had negative experiences with counsellors who did not have enough knowledge of the traits of AS to effectively adjust their standard approaches. Participants became anxious and frustrated when therapists did not adjust to their difficulties with reading subtext, and did not explain the expectations they had at certain moments in therapy. For example, broad questions, silences, and non-literal language left participants unsure of what was expected of them and lead to confusion and distress. It was also evident that participants had worked with therapists who did not meet their relational needs. Having had negative relationship experiences in the past with people who did not understand them, or listen to them, participants wanted to work with therapists who did meet their needs of being heard and understood. Furthermore, it was important to participants that they worked with therapists who would work collaboratively, respecting their views on what should happen in therapy, rather than leaving them feeling forced into working in certain ways. The interview process also led to recommendations about adjustments that can be made when interviewing people with AS. These included being careful with use of broad questions, with clarity of explanation, and with conveying a curious and respectful attitude. The negative experiences shared by participants often included a perception that they had worked with practitioners who were not respectful, and did not have the required knowledge and attitude to work effectively with people with AS. It is hoped that by adding the voice of this client group to the literature base, the needs of people with Asperger's can be better met by therapists.

5.0 REFERENCES

- Aalsma, M. & Brown, J. (2008) What is Bullying? *Journal of Adolescent Health*, 43: 101-102
- Adler, B. (2006) No! You Don't Understand! In Ariel, C. N. & Naseef, R. A. (Eds) *Voices From the Spectrum* (pp. 204-207). London: Jessica Kingsley Publishers
- Adolphs, R., Sears, L. & Piven, J. (2001) Abnormal Processing of Social Information from Faces in Autism, *Journal of Cognitive Neuroscience*, 13 (2): 232-40
- Allison, C., Auyeung, B. & Baron-Cohen, S. (2012) Towards Brief “Red Flags” for Autism Screening: The Short Autism Spectrum Quotient and the Short Quantitative Checklist in 1,000 Cases and 3,000 Controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51 (2): 202-212
- Alvarez, A. (1992) *Live Company: Psychoanalytic Psychotherapy with Autistic, Borderline, Deprived and Abused Children*. New York: Brunner-Routledge
- American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders (4th edn)*. Washington, DC: American Psychiatric Association
- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders (5th edn)*. Washington, DC: American Psychiatric Association
- Anderson, S. & Morris, J. (2006) Cognitive Behaviour Therapy for People with Asperger Syndrome. *Behavioural and Cognitive Psychotherapy*, 34 (3):293-303
- Asperger, H. (1944) Autistic Psychopathy in Childhood (U. Frith, trans.) In Frith, U. *Autism and Asperger Syndrome* (pp. 37-92). Cambridge: Cambridge University Press
- Aspie Affection (2012) Aspie Affection. Retrieved June 14, 2012, from www.aspieaffection.com
- Aspies (2012) Aspies. Retrieved 14 June, 2012, from www.aspies.co.uk

Aspiescentral (2012) Aspie Central. Retrieved 14 June, 2012, from www.aspiescentral.com

Aspies for Freedom (2012) Aspies for Freedom. Retrieved 14 June, 2012, from www.aspiesforfreedom.com

Aspie Friends (2016) Aspie Friends [facebook]. Retrieved 7th October, 2016 from <https://www.facebook.com/AspieFriends/?fref=ts>

Aston, M. C. (2003) *Aspergers in Love: Couple Relationships and Family Affairs*. London: Jessica Kingsley Publishers

Attwood, T. (2007) *The Complete Guide to Asperger's Syndrome*. Jessica Kingsley Publishers: London

Attwood, T. (2012) Relationship Problems of Adults with Asperger's. Retrieved 21 March, 2016, from http://www.mindsandhearts.net/images/newsletter/April2012/The_Relationship_Problems_of_Adults_with_Aspengers_Syndrome.pdf

Attwood, T. (2015, May) ASD and mental health: differential diagnosis and treatment and why it matters. *Presentation at the national autistic society autism and mental health conference, London.*

Attwood, T. & Gray, C. (1999) The Discovery of "Aspie" Criteria. Retrieved 21 August, 2015, from <http://xminds.timberlakepublishing.com/files/Aspie%20Criteria%20by%20Attwood.pdf>

Autistic Society: Greater Manchester Area (2012) Retrieved June 14, 2012, from <http://www.asgma.org.uk/>

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. & Charman, T. (2006) Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368: 210-215

Baron-Cohen, S. (2000). Is Asperger Syndrome/High Functioning Autism Necessarily a Disability? *Development and Psychopathology*, 12, 489–500

Baron-Cohen, S., Bolton, P., Wheelwright, S., Scahill, V., Short, L., Mead, G. & Smith, A. (1998) Autism Occurs More Often in Families of Physicists, Engineers, and Mathematicians. *Autism*, 2:296-301

Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E. & Brayne, C. (2009) Prevalence of Autism-Spectrum Conditions: UK School-Based Population Study. *The British Journal of Psychiatry*, 194(6): 500-509

Baron-Cohen, S., Leslie, A. M. & Frith, U. (1985) Does the Autistic Child Have a “Theory of Mind”? *Cognition*. 21 (1): 37-46

Baron-Cohen, S., O’Riordan, M., Stone, V., Jones, R. & Plaisted, K. (1999a) Recognition of Faux Pas by Normally Developing Children and Children with Asperger Syndrome or High-Functioning Autism. *Journal of Autism and Developmental Disorders*, 29: 407-418

Baron-Cohen, S., Wheelwright, S., Hill, J., Raste, Y. & Plumb, I. (2001b) The “Reading the Mind in the Eyes” Test Revised Version: a Study with Normal Adults, and Adults with Asperger Syndrome or High-Functioning Autism. *Journal of Child Psychology and Psychiatry* 42(2): 241-251

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J. & Clubley, E. (2001a) The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/High-Functioning Autism, Males and Females, Scientists and Mathematicians. *Journal of Autism and Developmental Disorders*, 31(1): 5-17

Baron-Cohen, S., Wheelwright, S., Stone, V. & Rutherford, M. (1999b) A Mathematician, a Physicist and a Computer Scientist with Asperger Syndrome: Performance on Psychology and Folk Physics Tests. *Neurocase* 5: 475-483

Barton, L. (1998) Sociology, disability studies and education: some observations. In Shakespeare, T. (Ed) *The disability reader: Social science perspectives*. (pp. 20-27). London: Continuum

Baumeister, R. F. & Leary, M. R. (1995) The Need to Belong: Desire for Interpersonal Attachments

as a Fundamental Human Motivation. *Psychological Bulletin*, 117 (3): 497-529

Beck, C. T. (2010) Benefits of Participating in Internet interviews: Women Helping Women. *Qualitative Health Research*. 15 (3): 411-422

Best, C, Arora, S, Porter, F & Doherty, M. (2015) The Relationship Between Subthreshold Autistic Traits, Ambiguous Figure Perception and Divergent Thinking. *Journal of Autism and Developmental Disorders*, DOI 10.1007/s10803-015-2518-2 [retrieved 24/08/2015]

Bjerke, T. N. (2010) When My Eyes Bring Pain to My Soul, and Visa Versa: Facing Preconceptions in Email and Face-to-face Interviews. *Qualitative Health Research*. 20 (12): 1717-1724

Blacher, J. & Lauderdale, S. (2008) Children with Asperger Syndrome and Bullying: "Don't laugh at Me, Don't Call Me Names." *Exceptional Parent*, 35(8): 62-63

Blair, R. J. R. (2003) Facial Expressions, Their Communicatory Functions and Neuro-cognitive Substrates, *Philosophical Transactions of the Royal Society B*, 358: 561–572

Bogdashina, O. (2005) Communication Issues in Autism and Asperger Syndrome: Do We Speak the Same Language? London: Jessica Kingsley Publishers

Booth, T. & Booth, W. (1996) Sounds of Silence: Narrative Research with Inarticulate Subjects. *Disability & Society*, 11 (1): 55-69

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2):77-101

Braun, V. & Clarke, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. London: Sage

Briggs (2005) A Little Boy's Use of His Male Child Psychotherapist to Help Him Understand a Painful Conundrum? *Journal of child psychotherapy*, 31(3): 352-367

Brisenden, S. (1986) Independent Living and the Medical Model of Disability. In Shakespeare, T.

(Ed.) *The Disability Reader: Social Science Perspectives*. (pp. 20-27) London: Continuum

British Psychological Society (2015) *Professional Practice Guidelines*. Leicester: British Psychological Society

Bromfield (2000). It's a Tortoise Race: Long-term Psycho-dynamic Therapy with a High-functioning Autistic Adolescent. *Psychoanalytic Inquiry*, 20: 732-745

Bromfield (2010) *Doing Therapy with Children and Adolescents with Asperger's Syndrome*. New Jersey: John Wiley and Sons

Campbell, F. K. (2008) Exploring Internalized Ableism Using Critical Race Theory. *Disability & Society*, 23 (2): 151- 162

Cardaciotto, L. & Herbert, J. D. (2004). Cognitive Behavior Therapy for Social Anxiety in the Context of Asperger's Syndrome: A Single-subject Report. *Cognitive and Behavioral Practice*, 11(1): 75-81

Carrington, S., Papinczak, T. & Templeton, E. (2003) A Phenomenological Study: The Social World of Five Adolescents Who Have Asperger's Syndrome. *Australian Journal of learning Disabilities*, 8(3): 15-21.

Carter, S. (2009) Bullying of Students with Asperger Syndrome. *Issues in Comprehensive Pediatric Nursing*, 32: 145–154

Cohler, B. J. & Weiner, T. (2011) The Inner Fortress: Symptom and Meaning in Asperger's Syndrome, *Psychoanalytic Inquiry*, 31 (3): 208-221

Cousins, E. (2002) Exploring the Experience of a Late Diagnosis of Asperger Syndrome and High-Functioning Autism: A review of Relevant Theory, Research and Methodology. (Unpublished doctoral thesis, University of Exeter, UK)

Charmaz, K. (2008) Grounded Theory as Emergent Method. In Hesse-Biber, S. N. & Leavy, P. [Eds] *Handbook of Emergent Methods* (pp. 155-172). New York: The Guilford Press

Church, C., Alisanski, S. & Amanullah, S. (2000) The Social, Behavioural and Academic Experiences of Children With Asperger Disorder. *Focus on Autism and other Developmental Disabilities*, 15: 12-20

Craig, T. K. J. & Boardman, A. P. (2007) ABC of Mental Health. Common Mental Health Problems in Primary Care. *British Medical Journal*, 314: 1609-1612

Davies, S., Bishop, D., Manstead, A. S. R. & Tantam, D. (1994) Face Perception in Children with Autism and Asperger's Syndrome, *Journal of Child Psychology and Psychiatry*, 35(6): 1033–57

Davis, L. J. (2000) Bending Over Backwards: Disability, Narcissism, and the Law. *Berkeley Journal of Employment and Labor Law*, 21: 193-212

Dekker, M. (1999). On Our Own Terms: Emerging Autistic Culture. *Paper presented at the Autism99 Internet Conference, November, Shirley Foundation and National Autistic Society, UK*. Retrieved 20th October, 2015 from <http://www.autscape.org/2015/programme/handouts/Autistic-Culture-07-Oct-1999.pdf>

Demayer, M., Hingtgen, J. & Jackson, N. H. (1981) Infantile Autism Reviewed: A Decade of Research. *Schizophrenia Bulletin*, 7(3): 388-451

Department of Health (2001) *White Paper: Valuing People: A New Strategy for Learning Disability*. Retrieved 6th June, 2012 from <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.htm>

DiCicco-Bloom, B. & Crabtree, B.F. (2006) The qualitative research interview. *Medical Education*, 40(4): 314-321

Di Martino, A., Ross, K., Uddin, L. Q., Sklar, A. B., Castellanos, F. X. & Milham, M. P. (2009) Functional Brain Correlates of Social and Nonsocial Processes in Autism Spectrum Disorders: An Activation Likelihood Estimation Meta-Analysis. *Biological Psychiatry*, 65: 63–74

Dissanayake, C. (2004) Change in Behavioural Symptoms in Children with High Functioning Autism and Asperger Syndrome: Evidence for One Disorder. *Australian Journal of Early Childhood*, 29: 48-57

- Donoghue, K., Stallard, P. & Kucia, J. (2011) The Clinical Practice of Cognitive Behavioural Therapy for Children and Young People with a Diagnosis of Asperger's Syndrome. *Clinical Child Psychology and Psychiatry*, 16 (1): 80-102
- Duncan, B. L. (2012) The Partners for Change Outcome Management System (PCOMS):The Heart and Soul of Change Project. *Canadian Psychology*, 53 (2): 93–104
- Ehlers, S. & Gillberg, C. (1993) The Epidemiology of Asperger Syndrome. A Total Population Study. *Journal of Child Psychology and Psychiatry*, 34 (8): 1327-1350
- Elliott, R., Fischer, C. & Rennie, D. (1999) Evolving Guidelines for Publication of Qualitative Research Studies in Psychology and Related Fields. *British Journal of Clinical Psychology*. 38: 215-229
- Farrugia, S. & Hudson, J. (2006) Anxiety in Adolescents With Asperger Syndrome: Negative Thoughts, Behavioral Problems, and Life Interference. *Focus on Autism and Other Developmental Disabilities*, 21 (1): 25-35
- Finn, R. (2006) Melt(d)ing Down. In Ariel, C. N. & Naseef, R. A. (Eds) *Voices From the Spectrum* (pp. 175-177). London: Jessica Kingsley Publishers
- Fommbonne E. (2003) The Prevalence of Autism. *Journal of the American Medical Association*, 289 (1): 87–89
- Fonseca, V. R. J. R. M., de Barros, I. G. & de Almeida, O. M. P. (2001). Three ways of understanding Ida. *Journal of Child Psychotherapy*, 27(2): 139- 157
- Ford, I. (2010) *A Field Guide to Earthlings: An Autistic/ Asperger View of Neurotypical Behavior*. Albuquerque, New Mexico: Ian Ford Software Corporation
- Frith, U. (2004) Emanuel Miller lecture: Confusions and Controversies About Asperger Syndromes. *UK Journal of Child Psychology and Psychiatry*, 45 (4): 672-686
- Frith, U. & Happé, F. (1994) Autism: Beyond 'Theory of Mind'. *Cognition*, 50: 115–32.

Frith, U., Morton, J. & Leslie, A. M. (1991) The Cognitive Basis of a Biological Disorder: Autism. *Trends in Neurosciences*, 14(10): 433-438

Gaus, V. (2007) *Cognitive-Behavioural Therapy for Adult Asperger Syndrome*. London: The Guildford Press

Gaus, V. (2011) Adult Asperger Syndrome and the Utility of Cognitive Behavioral Therapy. *Journal of Contemporary Psychotherapy*, 41 (1): 47-56

Gelso, C. J. & Carter, J. A. (1994) Components of the Psychotherapy Relationship: Their Interaction and Unfolding During Treatment. *Journal of Counseling Psychology*, 41(3): 296-306

Gelso, C. J. & Hayes, J. A. (1998) *The Psychotherapy Relationship: Theory, Research, and Practice*. UK: John Wiley and Sons Inc.

Gerland, G. (1997) *A Real Person: Life on the outside*. London: Souvenir Press

Gerland, G. (1999) Letter to the Editors: Autism and Psychodynamic Theories. *Autism*. 3 (3): 309-311

Ghaziuddin, M., Weidmer-Mikhail, E. & Ghaziuddin, N. (1998) Comorbidity of Asperger Syndrome: a preliminary report. *Journal of Intellectual Disability Research*. 42 (4): 279-283

Gillberg, C. (1991) Clinical and Neurobiological Aspects of Asperger Syndrome in Six Family Studies. In U. Frith (Ed) *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press

Gillberg, I. C. & Gillberg, C. (1989) Asperger Syndrome-Some Epidemiological Considerations: A Research Note. *Journal of Child Psychology and Psychiatry*, 30(4): 631-638

Gould, J. & Ashton-Smith, J. (2011) Missed Diagnosis or Misdiagnosis? Girls and Women on the Autism Spectrum. *Good Autism Practice*, 12(1): 34-41

Grandin, T. (1995) *Thinking in Pictures and Other Reports From My Life with Autism*. New York: Doubleday.

Griffith, G., Totsika, V., Nash, S. & Hastings, R. (2011) 'I Just Don't Fit in Anywhere': Support Experiences and Future Support Needs of Individuals with Asperger Syndrome in Middle Adulthood. *Autism*, 16(5): 532-546

Griner, D. & Smith, T. (2006) Culturally Adapted Mental Health Interventions: A Meta-Analytic Review. *Psychotherapy: Theory, Research, Practice, Training*, 43(4): 531-548

Hallmayer, J., Cleveland, S., Torres, A., Phillips, J., Cohen, B., Torigoe, T., Miller, J., Fedele, A., Collins, J., Smith, K., Lotspeich, L., Croen, L. A., Ozonoff, S., Lajonchere, C., Grether, J. K. & Risch, N. (2011) Genetic Heritability and Shared Environmental Factors Among Twin Pairs With Autism. *Arch Gen Psychiatry*. 11: 1095-1102. doi:10.1001/archgenpsychiatry.2011.76.

Happé, F. (1994) An Advanced Test of Theory of Mind: Understanding of Story Characters' Thoughts and Feelings by Able Autistic, Mentally Handicapped, and Normal Children and Adults. *Journal of Autism and Developmental Disorders*, 24 (2): 129-153

Happé, F., Ronald, A. & Plomin, R. (2006) Time to Give up on a Single Explanation for Autism. *Nature Neuroscience*, 9(10): 1218-1220

Hare, D. J. & Flood, A. (2001) Approaching Work with People with a Diagnosis of Asperger's Syndrome: Some Notes for the Perplexed. *Clinical Psychology Forum*, 147: 11-17

Hendrickx, S. (2008) *Love, Sex and Long-term Relationships. What People with Asperger Syndrome Really Want*. London: Jessica Kingsley Publishers

Henkelman, J. & Paulson, B. (2006) The Client as Expert: Researching Hindering Experiences in Counselling. *Counselling Psychology Quarterly*, 19(2): 139-150. DOI:10.1080/09515070600788303

Hill, C. E. & Knox, S. (2002). Self-disclosure. In J. C. Norcross (Ed.), *Psychotherapy Relationships That Work* (pp. 255–266). London: Oxford University Press.

Hill, C. E., Thompson, B. J., Cogar, M. C. & Denman, III, D. W. (1993) Beneath the Surface of Long-term Therapy: Therapist and Client Report of Their Own and Each Other's Covert Processes. *Journal of Counseling Psychology*, 40(3): 278–287

- Hill, C., Thompson, B & Ladany, N. (2003) The Therapist Use of Silence in Therapy: a Survey. *Journal of Clinical Psychology*, 59(4): 513-524
- Hill, E. L. (2004) Evaluating the Theory of Executive Dysfunction in Autism. *Developmental Review*, 24: 189-233
- Hill, E., Berthoz, S. & Frith, U. (2004) Brief Report: Cognitive Processing of Own Emotions in Individuals with Autistic Spectrum Disorder and in Their Relatives. *Journal of Autism and Developmental Disorders*, 34 (2): 229-235
- Hobson, R. P. (1990) On Acquiring Knowledge About People and the Capacity to Pretend: Response to Leslie. *Psychological Review*, 97(1): 114-121
- Hobson, R. P. (1991) Against the Theory of 'Theory of Mind'. *British Journal of Developmental Psychology*, 9: 33-51
- Hobson, R. P. (2014) The Coherence of Autism. *Autism*, 18(1): 6-16.
- Hodge, N. (2005) Reflections on Diagnosing Autism Spectrum Disorders. *Disability & Society*, 20(3): 345-349
- Hodge, N. (2012) Counselling, Autism and the Problem of Empathy. *British Journal of Guidance & Counselling*, 41 (2): 105-116
- Horvath, A., O. & Bedi, R. P. (2002) The Alliance. In Norcross, J., C. (Ed.). *Psychotherapy Relationships That Work* (pp. 267-283). London: Oxford University Press
- Horvath, A. O. & Luborsky, L. (1993) The Role of the Therapeutic Alliance in Psychotherapy. *Journal of Consulting and Clinical Psychology*, 61(4): 561-573
- Horvath, A. O. & Symonds, B. D. (1991) Relations Between Working Alliance and Outcome in Psychotherapy. A Meta-analysis. *Journal of Counselling Psychology*, 38: 139-149
- Howlin, P. & Moore, A. (1997) Diagnosis in Autism. *Autism*, 1 (2), 135-162

- Jackson, N. (2002) *Standing Down Falling Up: AS from the Inside Out*. Bristol: Lucky Duck Publishing
- Jackson, L. (2003) *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence*. London: Jessica Kingsley Publishers
- Jacobsen, P. (2003) *Asperger Syndrome and Psychotherapy*. New York: Jessica Kingsley Publishers
- Jacobsen, P. (2004) A Brief Overview of the Principles of Psychotherapy with Asperger's Syndrome. *Clinical Child Psychology and Psychiatry*, 9(4): 567-578
- James, I. (2010) Autism and Mathematical Talent. *The Mathematical Intelligencer*, 32(1): 56-58
- Johnston, L. & Dallos, R. (2014) Introduction to Formulation. In Johnston, L. & Dallos, R. (Eds.) *Formulation in Psychology and Psychotherapy, Second Edition*. (pp. 1-16) London: Routledge Ltd
- Jones, R. S. P., Zahl, A. & Huws, J. C. (2001) First-hand Accounts of Emotional Experiences in Autism: A Qualitative Analysis. *Disability & Society*, 16 (3): 393-401, DOI: 10.1080/09687590120045950
- Kahn, M. (1991) *Between Therapist and Client*. USA: Holt
- Kaland, N., Møller-Nielsen, A., Callesen, K., Mortensen, E. L., Gottlieb, D. & Smith, L. (2002) A New 'Advanced' Test of Theory of Mind: Evidence From Children and Adolescents with Asperger Syndrome. *Journal of Child Psychology and Psychiatry*, 43 (4): 517–528
- Kanner, L. (c1971) Follow-up Study of Eleven Autistic Children Originally Reported in 1943. *Acta Paedopsychiatrica*, 35: 100-136
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. & Pellicano, E. (2015) Which Terms Should be Used to Describe Autism? Perspectives from the UK Autism Community. *Autism, ONLINE* Downloaded July 23, 2015 from aut.sagepub.com
- Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L. & Wilson, F. J. (2000). The Prevalence of Anxiety and Mood Problems Among Children with Autism and Asperger Syndrome. *Autism*, 4: 117–132

Klin, A., Volkmar, F., Sparrow, S., Cicchetti, D. & Rourke, B. (1995) Validity and Neuropsychological Characterisation of Asperger Syndrome: Convergence with Nonverbal Learning Disabilities Syndrome. *Journal of Child Psychology and Psychiatry*, 36: 1127-1140

Kohut, H. (1971) *The Analysis of the Self*. New York: International Universities Press.

Kohut, H. (1977) *The Restoration of the Self*. New York: International Universities Press.

Kohut, H. (1981) (2010) On Empathy. *International Journal of Psychoanalytic Self Psychology*, 5:2, 122-131

Kohut, H. (1984) *How Does Analysis Cure?* Chicago: University of Chicago Press.

Koning, C. & Magill-Evans, J. (2001) Social and Language Skills in Adolescent Boys With Asperger Syndrome, *Autism*, 5(1): 23-36

Lawson, W. (1998) *Life Behind Glass: A Personal Account of Autism Spectrum Disorder*. London: Jessica Kingsley Publications

Lawson, W. (2015, May) *Gender and Gender Dysphoria in ASC: Across the Spectrum and Lifespan*. Presentation at the National Autistic Society Autism and Mental Health Conference, London

Leary, M. R. (1990) Responses to Social Exclusion: Social Anxiety, Jealousy, Loneliness, Depression, and Low Self-Esteem. *Journal of Social and Clinical Psychology*, 9 (2):221-229

Lincoln, Y. S & Guba, E. G. (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage

Lindner, J. L. & Rosén, L. A. (2006) Decoding of Emotion Through Facial Expression, Prosody and Verbal Content in Children and Adolescents with Asperger's Syndrome. *Journal of Autism and Developmental Disorders*, 36: 769–777

Little, L. (2002) Middle-class Mothers' Perceptions of Peer and Sibling Victimization Among Children with Asperger's Syndrome and Nonverbal Learning Disorders. *Issues in Comprehensive Pediatric Nursing*, 24: 43–57

Loewenthal, D. & Samuels, A (2004) *Relational Psychotherapy, Psychoanalysis and Counselling: Appraisals and Reappraisals*. London: Routledge Ltd

Lynch, G. (2005) The Application of Self-psychology to Short-term Counselling. *Psychodynamic Practice*, 4 (4): 473-485

Macdonald, J. Sinason, V. & Hollins, S. (2003) An Interview Study of People with Learning Disabilities' Experience of, and Satisfaction with, Group Analytic Therapy. *Psychology and Psychotherapy: Theory, Research and Practice*, 76, 433-453

Madge, C. & O'Conner, H. (2002) On-line with E-mums: Exploring the Internet as a Medium for Research. *Area*. 34 (1): 92-102

Manjivinoa, J. & Prior, M. (1999) Neuropsychological Profiles of Children with Asperger Syndrome and Autism. *Autism* 3: 327-356

Mannion, A & Leader, G. (2014) Epilepsy in Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 8: 354-361

Manthei, R. J. (2007) Clients Talk About Their Experience of the Process of Counselling, *Counselling Psychology Quarterly*, 20, 1: 1-26

Marks, D. (1999) *Disability: Controversial Debates and Psychosocial Perspectives*. London: Routledge

Marshall, T. (2013) Flying Under the Radar: Girls and Women with Aspergers Syndrome. Retrieved 24 August, 2015 from <https://taniaannmarshall.wordpress.com/2013/03/09/flying-under-the-radar-girls-and-women-with-aspergers-syndrome/>

Martin, I. & McDonald, S. (2004) An Exploration of Causes of Non-literal Language Problems in Individuals with Asperger Syndrome. *Journal of Autism and Developmental Disorders*. 34(3): 311-328

McCoyd, J. L. M. & Kerson, T. (2006) Conducting Intensive Interviews Using Email: A Serendipitous

Comparative Opportunity. *Qualitative Social Work*. 5: 389

McKean, T. (2015) One Explanation Of Sensory Overload. Retrieved 8th Jan, 2015 from <http://www.thomasamckean.com/gallery/albums/writings/Overload.pdf>

McIlwee Myers, J. (2006) Dating, Relationships and Marriage in Asperger's and Girls p106-145, Arlington, Texas, Future Horizons Inc.

Medical Research Council (MRC) (2001) Review of Autism Research: Epidemiology and Causes. London: Medical Research Council. Retrieved 24th August, 2015 from <http://www.mrc.ac.uk/news/publications/autism-research-review/>

Merton, R. K., Fiske, M. & Kendall, P. L. (1990) *The Focused Interview: a Manual of Problems and Procedures*. (2nd edition). London: Collier MacMillan

Mesibov, G., Adams, L. & Schopler, E. (2000) Autism: A Brief History. *Psychoanalytic Inquiry*, 20(5): 637-647

Miller, K. M. (ed) (2003) *Women From Another Planet Bloomington*. IN: 1st Books

Miller (2008) A Kaleidoscope of Themes: Intensive Psychotherapy with a Girl on the Autistic Spectrum. *Journal of Child Psychotherapy*, 34 (3): 384-399

Miller, J. N. & Ozonoff, S. (2000) The External Validity of Asperger Disorder: Lack of Evidence from the Domain of Neuropsychology. *Journal of Abnormal Psychology* 109: 227-238

Milton, J, Polmear, C. & Fabricius, J. (2006) *A Short Introduction to Psychoanalysis*. London: Sage Publications

Morris, B.(1999) New Light and Insight on an Old Matter. Paper Presented at the Autism99 Internet Conference, November, Shirley Foundation and National Autistic Society, UK. Cited in Cousins, E. (2002) Exploring the Experience of a Late Diagnosis of Asperger Syndrome and High-Functioning Autism: A review of Relevant Theory, Research and Methodology. (Unpublished doctoral thesis, University of Exeter, UK)

Murdin, L. (2000) *How Much is Enough? Endings in Psychotherapy and Counselling*, London: Routledge

National Autistic Society (2012) *What is Asperger Syndrome?* Retrieved 6th June, 2012 from www.autism.org.uk

National Autistic Society (2016) *Myths, facts and Statistics*. Retrieved 22 March, 2016 from <http://www.autism.org.uk/About/What-is/Myths-facts-stats>

NICE (2012) *Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autistic Spectrum*. National Institute for Health and Clinical Excellence. Retrieved 24th August, 2015 from <http://www.nice.org.uk/guidance/cg142>

NICE (2012b) *The NICE guideline on recognition, referral, diagnosis and management of adults on the autism spectrum*. The British Psychological Society and The Royal College of Psychiatrists

Nichols, S., Moravcik, G. M. & Tetenbaum, S. P. (2009) *Girls Growing Up on the Autism Spectrum* London: Jessica Kingsley.

Nicki-Jockschat, T., Habel, U., Michel, T. M., Manning, J., Laird, A. R., Fox, P. T., Schneider, F. & Eickhoff, S. B. (2012) Brain Structure Anomalies in Autism Spectrum Disorder—A Meta-analysis of VBM Studies Using Anatomic Likelihood Estimation. *Human Brain Mapping* 33: 1470–1489

Norcross, J. C. (2002). Empirically Supported Therapy Relationships. In Norcross, J. C. (Ed.). *Psychotherapy relationships that work*. New York: Oxford University Press

Norcross, J. C. & Wampold B. E. (2011) Evidence-Based Therapy Relationships: Research Conclusions and Clinical Practices. *Psychotherapy*, 48 (1): 98–102

Novick, G. (2008) Is There a Bias Against Telephone Interviews in Qualitative Research? *Research in Nursing & Health*, 31: 391-398

O'Neill, J. L. (1999) *Through the Eyes of Aliens. A Book About Autistic People*. London: Jessica Kingsley. Cited in Cousins, E. (2002) Exploring the Experience of a Late Diagnosis of Asperger Syndrome

and High-Functioning Autism: A review of Relevant Theory, Research and Methodology. (Unpublished doctoral thesis, University of Exeter, UK)

Ozonoff, S., South, M. & Miller, J. N. (2000) DSM-IV-defined Asperger Syndrome: Cognitive, Behavioral and Early History Differentiation From High-functioning Autism. *Autism*, 4(1): 29-46

Palmobo, J. (2002) The Therapeutic Process With Children With Learning Disorders. *Psychoanalytic Social Work*, 8 (3-4): 143-168

Patton, M. Q. (2002) *Qualitative Evaluation and Research Methods* (3rd ed.). Thousand Oaks, CA: Sage

Paxton, K. & Estay, I. A. (2007) *Counselling People on the Autism Spectrum: A Practical Manual*. London: Jessica Kingsley

Portway, S. M. (2006) Living With Asperger's Syndrome-the Phenomenon of "Not Quite Fitting in". (Unpublished doctoral thesis, St. Bartholomew's School of Nursing and Midwifery, UK)

Pozzi (2003) The Use of Observation in the Psychoanalytic Treatment of a 12 Year Old Boy With AS. *International Journal of Psychoanalysis*, 84 (5): 1333-1349

Punshon, C., Skirrow, P. & Murphy, G. (2009) The 'Not Guilty Verdict': Psychological Reactions to a Diagnosis of Asperger Syndrome in Adulthood. *Autism*, 13(3):265-283

Ramsay, J., Brodtkin, E., Cohen, M., Listerud, J., Rostain, A. & Ekman, E. (2005) "Better Strangers": Using the Relationship in Psychotherapy for Adult Patients with Asperger Syndrome. *Psychotherapy: Theory, Research, Practice, Training*, 42(4):483-493

Reaven, J. & Hepburn, S. (2003) Cognitive-Behavioural Treatment of Obsessive-Compulsive Disorder in a Child With Asperger Syndrome: a Case Report. *Autism*, 7: 145-164

Riddle, M. A. (1987) Individual and Parental Psychotherapy in Autism. In D. J. Cohen & A. Donnellan (Eds.) *Handbook of Autism and Pervasive Developmental Disorders*, 1st edition (pp. 528-544). New York: Wiley

Robel, L., Ennouri, K., Piana, H., Vaivre-Douret, L., Perier, A., Flament, M. F. & Mouren-Siméoni, M. C. (2004) Discrimination of Face Identities and Expressions in Children with Autism: Same or Different?' *European Child and Adolescent Psychiatry*, 13: 227–33

Robinson, J. E. (2007) *Look Me in the Eye*. Three Rivers Press

Rogers, C. R. (1992a) The Processes of Therapy. *Journal of Consulting and Clinical Psychology*, 60 (2): 163-164. [Reprint of 1940 original from *Journal of Consulting Psychology*, 4: 161-164]

Rogers, C. R. (1992b) The Necessary and Sufficient Conditions of Therapeutic Personality Change. *Journal of Consulting and Clinical Psychology*, 60 (6): 827-832. [Reprint of 1957 original from *Journal of Consulting Psychology*, 21: 95-103]

Romano, G. M. (2011) Experiences of Adult Women With Asperger Syndrome: an Interpretive Phenomenological Approach. (Unpublished doctoral thesis, University of Surrey, UK)

Rowan, J. & Jacobs, M. (2002) *The Therapist's Use of Self*. Maidenhead: Open University Press

Runswick-Cole, K. (2008). Between a Rock and a Hard Place: Parents' Attitudes to the Inclusion of Children With Special Educational Needs in Mainstream and Special Schools. *British Journal of Special Education*, 35: 173- 180

Rutter, M. (2000) Genetic Studies of Autism: From the 1970s into the Millennium. *Journal of Abnormal Child Psychology*, 28 (1): 3-14

Rutter, M. (2005b) Incidence of Autism Spectrum Disorders: Changes Over Time and Their Meaning. *Acta Paediatrica*, 94: 2–15

Rutter, M. (2005) Aetiology of Autism: Findings and Questions. *Journal of Intellectual Disability Research*, 49(4): 231-238

Sacks, O. (1995) *An Anthropologist on Mars*. London: Macmillan Press

Sainsbury, C. (2001) *Martian in the Playground*. *Understanding the Schoolchild with Asperger's*

Syndrome. London: The Book Factory.

Shakespeare, T. [Ed] (1998) *Disability Reader: Social Science Perspectives*. London: Continuum

Shapiro, T. (2000) Autism and the Psychoanalyst. *Psychoanalytic Inquiry*, 20 (5): 648-659

Shuttleworth (1999) The Suffering of Asperger Children and the Challenge They Present to Psychoanalytic Thinking. *Journal of Child Psychotherapy*, 25(2): 239-265

Simone, R. (2015) <http://www.rudysimone.net/> [Retrieved 21/08/2015]

Simpson, R. & Myles, B. (1998) Aggression Among Children and Youth Who Have Asperger's Syndrome: A Different Population Requiring Different Strategies. *Preventing School Failure*, 42(4): 149-15

Sinclair, J. (1992) Bridging the Gaps: An Inside-out View of Autism. In Schopler, E & Mesibov, G. B. [Eds.] *High-Functioning individuals with Autism*. New York: Plenum Press

Smith, J. A, Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage

Sofronoff, K., Attwood, T. & Hinton, S. (2005) A Randomised Controlled Trial of a CBT Intervention for Anxiety in Children With Asperger Syndrome. *Journal of Child Psychology and Psychiatry*, 46(11): 1152-1160

Sofronoff, K. & Hinton, S. (2007) A Randomised Controlled Trial of a Cognitive Behavioural Intervention for Anger Management in Children Diagnosed With Asperger Syndrome. *Journal of Autism and Developmental Disorder*, 37: 1203-1214

Steering Committee (2002) Empirically Supported Therapy Relationships: Conclusions and Recommendations of the Division 29 Task Force. In Norcross, J. C. (Ed.). *Psychotherapy relationships that work* (pp. 441-446) New York: Oxford University Press.

Swift, J. K. & Derthick, A. O. (2013) Increasing Hope by Addressing Clients' Outcome Expectations.

Psychotherapy, 50: 284–287

Szatmari, P., Bartolucci, G. & Bremner, R. (1989) Asperger's Syndrome and Autism: Comparisons on Early History and Outcome, *Developmental Medicine and Child Neurology*, 31: 709–20

Sze, K. M. & Wood, J. J. (2007) CB Treatment of Comorbid Anxiety Disorders and Social Difficulties in Children With HFA: A Case Report. *Journal of Contemporary Psychotherapy*, 37(3): 133-143

Tamimi, S. (2004) Current Epidemic has Social Context. *British Medical Journal*, 328: (7433) 226

Tamimi, S. (2011) Autism is Not a Scientifically Valid or Clinically Useful Diagnosis. *BMJ (Clinical research ed.)* 343 (162): [10.1136/bmj.d5105](https://doi.org/10.1136/bmj.d5105)

Tamimi, S., Gardner, N. & McCabe, B. (2011) *The Myth of Autism*. Hampshire: Palgrave Macmillan

Taylor, G. J., Bagby, R. M. & Parker, J. D. A. (1997) *Disorders of Affect Regulation: Alexithymia in Medical and Psychiatric Illness*, Cambridge: Cambridge University Press

Thompson, B. (2008) *Counselling for Asperger Couples*. London: Jessica Kingsley Publishers.

Tustin, F. (1981). *Autistic States in Children*. Boston: Routledge.

Vera, E. M., Speight, S. L., Mildner, C. & Carlson, H. (1999) Clients' Perceptions and Evaluations of Similarities to and Differences from Their Counselors. *Journal of Counseling Psychology*, 46: 277-283

Volkmar, F. (2000) Understanding Autism: Implications for Psychoanalysis. *Psychoanalytic Inquiry*, 20, 660-674.

Volkmar, F. R. & Nelson, D. S. (1990) Seizure disorders in autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 1: 127–129.

Wainscot, J. J., Naylor, P., Sutcliffe, P., Tantam, D. & Williams, J. V. (2008) Relationship With Peers and Use of the School Environment of Mainstream Secondary School Pupils With Asperger

Syndrome (High-functioning autism): A Case-control Study. *International Journal of Psychology and Psychological Therapy*, 8{1}: 25-38

Weiss, J. A. & Lunsy, Y. (2010) Group Cognitive Behaviour Therapy for Adults With Asperger Syndrome and Anxiety or Mood Disorder: A Case Series. *Clinical Psychology and Psychotherapy*, 17: 438-446

Werbart, A., Below, C., Brun, J. & Gunnarsdottir, H. (2014) "Spinning One's Wheels": Nonimproved Patients View Their Psychotherapy, *Psychotherapy Research*, DOI: 10.1080/10503307.2014.989291

Willy, L. (1999) *Pretending to be Normal. Living With Asperger's Syndrome*. London: Jessica Kingsley Publishers

Williams, D. (1996) *Nobody Nowhere: The Remarkable Autobiography of an Autistic Girl*. London: Jessica Kingsley Publishers

Williams, D. (2006) Culture, Conditions, and Personhood: A Response to the Cure Debate on Autism. In Ariel, C. N & Naseef, R. A. (Eds.) *Voices from the Spectrum* (204-207). London: Jessica Kingsley Publishers

Wing, L. (1981) Asperger's Syndrome: A Clinical Account. *Psychological Medicine*, 11: 115–119

Wing, L. (1981b) Language, Social, and Cognitive Impairments in Autism and Severe Mental Retardation. *Journal of Autism and Developmental Disorders*, 11(1): 31-44

Winner, M. G. (2011) *Social Thinking Worksheets for Tweens and Teens: Learning to Read Between the Social Lines*. San Jose, CA: Think Social Publishing

Winner, M. G. (2015) Social thinking. Retrieved 24 August 2015 from <http://www.socialthinking.com/>

World Health Organisation (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva: World Health Organization

WrongPlanet (2012) Wrong Planet. Retrieved 12 February, 2012 from
<http://www.wrongplanet.net/>

Yardley, K. M. (1990) Psychotherapy Process and Research: Missing Persons and Missing Values.
Counselling Psychology Quarterly, 3(1): 43–55

Yaul-Smith, D. (2008) Girls on the Spectrum. *Communication*, Spring: 30-31

APPENDICES

Appendix 1: Call for participants posted on Aspergers Syndrome Awareness Worldwide

Hello everyone,

I'm a trainee counselling psychologist at UWE, Bristol. I'm researching the experiences of people with Aspergers who have received counselling in the hope that I can learn more about what is helpful or unhelpful so that counsellors can improve the way counsellors they work with clients with Asperger's.

I need to interview people who have a diagnosis of Aspergers, are over the age of 18, and have had any number of counselling sessions, about any issue.

The interviews can take place either face-to-face or online (using email, instant messaging etc.).

If you would like more information please email me: Stephanie.Wilson@live.uwe.ac.uk,

Thanks, and happy new year to you all!

Appendix 2: Information Sheet

Participant Information Sheet

How is counselling experienced by clients with Asperger's Syndrome?

You are being invited to take part in a research study; you will need to understand why the research is being done and what will happen. This information should help you to decide whether or not you want to take part. Before you decide please read the information carefully and talk about it to others if you want to. Please email me <Stephanie.Wilson@live.uwe.ac.uk> and ask me if there is anything that is not clear of if you would like more information.

Who are the researchers?

My name is Steph Wilson and I am a trainee counselling psychologist in my fifth year of study at the University of the West of England. This research is part of my training. My research is supervised by Victoria Clarke, an Associate Professor, and Andrea Halewood, a Senior Lecturer in Counselling Psychology.

What is the research about?

The purpose of this study is to ask people with Asperger's what their experiences of counselling have been. By doing this, I hope to learn about how counsellors can work more effectively with people with Asperger's.

Who is eligible to participate?

You are eligible to participate if you have a diagnosis of Asperger's, and you have had experience of counselling either in the past or are currently undergoing counselling. This counselling could have been about any issue, it doesn't have to have been about Asperger's. You will need to be over 18 years old. I will be interviewing 10 to 15 people in total who fit this description.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form to show that you understand the information on this sheet and consent to take part in the study.

If you say you will take part you can still change your mind and withdraw from the study without giving a reason. However, once my thesis has been submitted it will not be possible for your material to be removed. Therefore, if you wish to have your data removed from the study you are strongly advised to contact me within one month of your interview. You will need to keep note of your ID number so that your data can be removed.

You can also change your mind and stop the interview at any time, or decline to answer any question, without giving a reason.

After receiving this information sheet I suggest you wait a week before you decide whether to take part. You are strongly advised to show this information to another trusted person so that you can discuss your decision with them. A week after emailing you this sheet, I will contact you by email to invite you to take part; the decision to take part is entirely up to you. If I do not hear from you, or you do not wish to take part, I won't make any further contact.

What does participation involve?

If you decide to take part you will be asked to read and sign the consent form below. At the start of the interview you will be asked for some general information about yourself (such as age, employment). This allows me to understand who might be helped by the information provided, for example, if I have interviewed 10 men and no women then I wouldn't be able to use my analysis to inform counsellors about the experiences of women with Asperger's, because I haven't interviewed any.

Participation involves you taking part in an interview with me about your experiences of counselling. What the interview covers will depend in part on what your experiences have been, but my questions will be about the kinds of things your counsellor did, what things you found helpful or unhelpful, what you might want from a counsellor if you were to have counselling again, and general questions about your experience of counselling.

Some of your experiences might be very personal; you don't have to say anything you don't want to and you can decline to answer any questions without giving a reason.

You will be invited to choose between talking to me face to face at a location convenient to you, or talking via the internet. If you choose to meet face to face we can then arrange a location such as your own home, a private room in your place of work, or at the University of West of England (Bristol). Because my research is self-funded, face to face interviews need to be conducted in a location that is not too far from Bristol.

If you choose to be interviewed via the internet we will arrange a time that is suitable for you to have a text based conversation. This could take place via instant messaging such as Gmail chat, or a similar form of instant messaging which you have access to (for example, Yahoo Messenger! or MSN Messenger). You could also choose to be interviewed over email, or skype. Interviews can either be 'instant', or take place over several hours or days to allow time to think about responses. Please allow about 2 hours for the interview.

I will audio record your interview if we meet face to face or will save the text of our interview if we talk over the internet. This will help me to analyse the information without the risk of missing any important detail.

What are the possible risks of taking part?

It is possible that you may find talking about your experiences upsetting; you can stop the interview at any time if this is the case. While I can provide you with information about accessing support if you feel upset after the interview, you are strongly advised not to take part if you don't have people in your life who can support you.

If you tell me about a counsellor who you think you want to make a complaint about I will provide you with information about exactly how you can do that. I will not do this on your behalf.

What are the possible benefits of taking part?

You might benefit from having an opportunity to talk about your experiences. You will also be

contributing to efforts to improve the standard of counselling for people with Aspergers.

What happens if I'm upset by the interview?

If you have been upset by any part of the interview you are advised to read the information below about agencies which provide emotional support and information.

If you are unhappy about something to do with this study and you want to discuss this you can contact one of my supervisors, Andrea Halewood or Victoria Clarke (see below).

Will my taking part in this study be anonymous?

All the information you provide will be made anonymous and labelled with the ID number on your sheet or a pseudonym (a fake name); your real name won't be used. Any references to place or people's names which could identify you will be removed or changed so that it is unlikely that anyone will recognise you from what is published. Your data will be stored securely under password if it is digital information, and in a locked location if the interview was recorded on a Dictaphone.

What will happen to the results of the research study?

The results will be submitted as part of my training. I hope to publish the results of this study in a journal so that other academics and counsellors can read and learn from it.

Who can I contact if I have been upset by discussing my experiences

The National Autistic Society has a list of counsellors who have experience working with clients with Asperger's.

Tel: 0808 800 4104 (open 10.00am-4.00pm, Monday-Friday)

Text: 07903 200 200

Email enquiry service: visit www.autism.org.uk/enquiry and complete the online form

The following website lists counselling services in the Bristol area:

<http://www.pmhbristol.nhs.uk/Counselling.htm>

The Bristol Mind website lists sources of support for young people in the Bristol area:

<http://www.bristolmind.org.uk/mental-health-resources/young-people>

Who can I contact if I want to make a complaint about a counsellor?

Witness (formerly POPAN) are an organisation who provide support and advice to people who feel they have been mistreated by professionals, including counsellors.

[Helpline: 0845 4500300](tel:08454500300)

[Email: info@popan.org.uk](mailto:info@popan.org.uk)

Website: <http://www.popan.org.uk>

Contact for further information

Steph Wilson, c/o Victoria Clarke, Department of Health and Social Sciences, Faculty of Life and Health Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY

Email :stephanie.wilson@live.uwe.ac.uk

You can also contact Victoria Clarke or Andrea Halewood at the same university address or by

Email: 'Victoria.clarke@uwe.ac.uk'; 'Andrea.halewood@uwe.ac.uk'

Thank you for taking the time to read this information sheet

This research has been approved by the Faculty of Health and Life Sciences Faculty Research Ethics Committee (FREC)

Appendix 3: Consent form

How is counselling experienced by clients with Asperger's Syndrome?

Consent Form

Thank you for agreeing to take part in this research on the counselling experiences of people with Asperger's. Before you begin the study I'd like to emphasize that:

- your participation is entirely voluntary
- you are free to refuse to answer any question
- you are free to withdraw at any time (within the limits specified on the information sheet)

Please sign this form to show that you have read the contents of this form and of the participant information sheet and you consent to participate in the research:

_____ (Signed)

_____ (Printed)

_____ (Date)

This research has been approved by the Faculty of Health and Life Sciences Faculty Research Ethics Committee (FREC)

Appendix 4: Interview methods chosen by participants

Type of interview	Participants
Asynchronous typed (using website)	1
Face to face (Participant's home)	1
Skype with video (audio taped)	1
Email (Asynchronous)	The 10 others

Appendix 5: Issues Leading Participants to Counselling

<u>Summary of Presenting Issues</u>
Trauma (childhood abuse at school and at home; being bullied; abuse from ex-partner; domestic abuse between parents; PTSD; childhood sexual abuse; abusive father)
Social (unemployment; being sacked; wanting assimilation into society)
Anorexia; bulimia; eating disorder-not otherwise specified (ED-NOS)
Depression (suicide attempt; self-harm; bereavement)
Anxiety (panic attacks; phobia)
Trichotillomania
Insomnia
Anger management
Problems related to AS
Self-identity

JOURNAL ARTICLE

Article to be submitted to 'Autism', published by SAGE, in association with the National Autistic Society.

Word Count (excluding references and abstract): 5525

Ethical approval was granted on 26th September 2013 by the University of the West of England research ethics committee (UWE REC REF No: HLS/13/04/63).

Original Article

What do people with Asperger's Syndrome say they want from their counsellors?: A qualitative analysis

Stephanie F Wilson

Department of Health and Social Sciences, Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK

Victoria Clarke⁵

Department of Health and Social Sciences, Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK

Andrea Halewood

Department of Health and Social Sciences, Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK

5 Corresponding author

Steph Wilson: 03503102

Abstract

Introduction: People with Asperger's Syndrome (AS) are known to have high incidences of anxiety and depression that could result in them seeking counselling. At present there are some recommendations regarding counselling for people with AS, such as using literal language. However, no research has directly asked people with AS about their experiences of counselling.

Methodology: Thirteen adults (9 women and 4 men) recruited from online AS groups and social networks participated in face to face, email or video-calling (*Skype*) interviews. The interview transcripts were analysed using thematic analysis.

Results: Four overarching themes were reported in the full thesis, one of which is summarised here. The theme of 'wanting therapists to understand AS' outlines the traits of AS that participants thought were relevant to the counselling process and wanted therapists to understand. These included emotional processing, sensory processing, language processing, and pace.

Discussion: Recommendations are made regarding the desired knowledge of those wanting to work productively with people with AS.

Keywords

Autism, therapy, counselling psychology, thematic analysis, qualitative research.

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

Introduction

People with Asperger's Syndrome (AS) have a higher than average prevalence of depression, anxiety, and relationship difficulties (Ghaziuddin, Weidmer-Mikhail and Ghaziuddin, 1998; Kim, Szatmari, Bryson, Streiner and Wilson, 2000; Wing, 1981; Aston, 2003), this may mean they will benefit from counselling for these (and other) issues. This is not a report on interventions that

seek to 'cure' AS; it concerns therapy when a person with AS is experiencing distress in their lives.

There have been case studies of therapy work with this client group (Alvarez, 1992; Briggs, 2005; Bromfield, 2000, 2010; Miller, 2008; Pozzi, 2003; Shuttlesworth, 1999) and some studies of changes to mood (anxiety, happiness, anger) following psycho-education (Sofronoff, Attwood & Hinton, 2005; Sofronoff and Hinton, 2007). The literature is broadly split into two groups of theorists: theorists who are knowledgeable about AS traits and suggest adaptations based on these in order to provide psycho-education, but tend to say little or nothing about the value of the relationship in therapy work (Attwood, 2007; Paxton and Estay, 2007); and theorists who are trained in relational approaches to counselling but have little knowledge of how to adapt their work to AS traits. Bromfield (2010) does write from a psychodynamic viewpoint yet stated that traditional counselling approaches are not helpful to people with AS. More research is needed to improve therapy for people with AS.

AS traits may mean that counselling methods require adaptations to meet the needs of this client group. AS is characterised by difficulties in socialisation; by language differences; by struggles with understanding emotions (their own and others); and by a need for sameness (Gillberg, 1991). It was anticipated that counselling approaches that rely on exploration of emotions, interpretations around metaphor, and generally use of verbal communication could be experienced with some difficulty by people with AS. However, the experiences of this client group have only been heard in a handful of papers, primarily autobiographical (Gerland, 1999; Aston, 2003) but never through systematic research seeking to elicit and explore those clients' experiences of therapy. The present study aims to represent these experiences to contribute to understanding of the wants and needs of clients with Asperger's who are seeking therapy. This was explored from a counselling psychology perspective with the anticipation that combining an understanding of both Aspergers traits, and the therapeutic relationship could usefully bridge some gaps in the literature.

Methodology

Thirteen adults (18 years+) with a diagnosis of Aspergers who had had some experience of counselling or therapy took part in semi-structured interviews to collect data about these experiences. Most interviews were conducted via email (10), although participants were given a choice of being interviewed face-to-face (1), or using synchronous (Skype, 1) or asynchronous

online interviewing (1). The real time interviews lasted for 1-2 hours and the asynchronous interviews anything from days to weeks. The research was conducted within a broadly experiential framework and the data were analysed using inductive Thematic Analysis. Various ethical considerations were made; most notably the importance of ensuring participants fully understood the process of the interview, including right to withdraw and the aims of the research.

Analysis

Of the four themes reported in the full thesis, only one theme is reported here, the theme: 'wanting therapists to understand Aspergers', it outlines the traits of Aspergers that participants said they would need professionals to understand if they were going to work together (sensory issues, emotional processing differences etc.).

'Wanting therapists to understand Aspergers'

Participants wanted therapists to understand traits of Aspergers so that their experiences were understood; so that therapists understood what adjustments might be needed; and so that therapists understood they might not be helped "in traditional ways" ('Cali'⁶). For example, 'Unisonic' experienced difficulties when therapists explored childhood experiences for causes of anxiety and anger rather than understanding these in the context of Aspergers. Some participants were clear that therapists needed knowledge of Aspergers:

"[...] Unless you've taken some serious time to look into AS, and explore how and why conventional counselling might not always be as helpful for people with AS, then just don't bother - you'll do more harm than good." ('Annie')

A lack of understanding caused problems when therapists did not seem to adapt their practices: "[there is] a complete refusal to believe the diagnosis because I don't look or act like a classic autistic and unwillingness to take into account what I tell her my autism-related problems are" ('Mike').

Participants shared examples of traits they wished their therapists (and other professionals) had knowledge of. These included social communication differences, emotional processing differences,

6 All participants chose pseudonyms, with the exception of 'Mike', for whom I chose a pseudonym

cognitive and language processing differences, and sensory sensitivities. I will now list the areas which were raised by several participants.

A) Social communication difficulties

Social communication difficulties cause issues in intuitive understanding of inferred and non-verbal social communications, and associated difficulties in working out the agendas, expectations, judgements, desires, unspoken intentions, thoughts and feelings of others. Participants named a number of issues related to social communication which caused difficulties in therapy.

A1) Avoid broad questions

Broad questions were not impossible for participants, and I used open/broad questions at times during my interviews, however, participants reported that they sometimes caused confusion. 'Aggie' explained that: "Non-specific questions drive me crazy because I don't know what's expected of me". Open questions can cause difficulties because it is not inherently obvious what the scope of such questions are; 'Unisonic' recalled that: "a question like 'so what's bothering you today?' could get an answer that is a litany of all [the] woes that I can recall". Attempts to answer broad questions lead to anxiety and shame when trying to work out what answer was expected:

"Too broad of a question and I don't know how to answer it. If I take my best guess at what the asker wants, I inevitably end up being told 'Okay but what I meant was...' and that can trigger an anxiety attack and self-recrimination, I screwed that up, I did it wrong, now they think I'm a moron or something." ('Virginia')

A2) Use literal communication

Participants had a strong preference for literal language so that they did not have to work out subtext. 'Mike' described how a therapist not adapting to his needs made therapy unworkable: "In any event, her communication style combined with my autistic need for clear, precise and literal information was just never going to work out". Even when non-literal communication such as metaphor is understood, it is still time consuming to process and can add to the tiring nature of spoken communication in therapy:

"I'm a literal thinker about 100% of the time. Over the years I've learned to manually process

the fact that people aren't always being literal. However, my first thought on a matter is literal. If someone uses a saying like, 'I'll be a monkey's uncle' I will literally visualize a monkey with this person. Though I understand they don't mean to say they literally are related to a monkey." ('Unisonic')

A3) Don't overanalyse

Participants wanted therapists to understand that as someone with Aspergers they were far more likely to speak in an honest, literal, and direct way, and therefore non-literal interpretations were unhelpful. Several participants experienced being overanalysed by therapists. 'Rea' described how she was asked to draw a tree by her art therapist, but that she had not learnt how to draw a tree yet: "so I made this stump and then attached the branches on top; which - I am pretty sure – they [wrongly] read as 'me being closed-up'." 'Mike' shared his advice to therapists:

"[...] she should take what I'm saying at face value rather than trying to find hidden meanings and assume that I don't tell her everything. Someone on the spectrum is just much more likely to tell you the truth right away. Therapists aren't used to that, it seems."

Participants preferred open discussion to ensure that there was mutual understanding in the relationship, rather than assumptions or confusion. 'Stella' explained her good experience with her therapist: "We do take the time to explain to each other what is needed. This is so important if I want to improve ... I must understand what he says to me."

A4) Avoid silence or explain its purpose

Silence can be a feature of traditional therapy (Hill, Thompson and Ladany, 2003). As with broad questions, participants shared that silences without explanation could be bewildering because the 'rules' or expectations are unknown and there is no way to work out what they were meant to do. Silences can leave people with a feeling of discomfort because it can be experienced as "violating rules of conversation" ('Unisonic'). The feeling of knowing there was something expected of them and feeling like a rule was being broken was very stressful:

"if I'm too anxious to open my mouth and [...] my head is screaming [...] what on earth do you want from me? You're just sitting there looking at me, I know you want something but what you want I cannot give you, without you doing a little bit more here. And I, it was, it

was one of the things that absolutely it made me feel very uncomfortable, and it drove me crazy." ('James')

Silence in therapy was not necessarily unhelpful for all participants. However, when the reasons for silence were not explained, or when the client had no chance to discuss it some participants just sat, silently suffering and unable to speak out, hiding their distress.

A5) Discuss the expectations of counselling

The participants reported that they experienced discomfort and anxiety when they were unsure what was expected of them during a session. Participants thought that having an explanation of what commonly happens during a counselling session and why this happens could reduce their anxiety. 'Elizabeth' said that "rules of counselling would've been great". The absence of explanations caused some participants anxiety, for example, 'James' said he: "needed [the professional] to tell me what was Ok and what wasn't Ok so I could [...] define the rules of the room". As well as causing anxiety, for 'Elizabeth' the lack of discussion meant she made the assumption that she needed to come to sessions asking for practical solutions to problems or she would be "wasting [her therapist's] time and the university's money".

A6) Avoid hypothetical examples

Participants reported finding it difficult to work with hypothetical or imaginary examples, so often if the situation being discussed was not factually accurate then the discussion was not helpful.

'Annie' described how this caused problems for her in therapy:

"There was a lot of 'Well I wouldn't be in the staff room at that time because I take my tea and go down to the classroom...', [...] It's possible they thought I was deliberately trying to waste their time, but honestly, unless a situation is 100% real to me, I struggle to relate to it."

As well as this, working with imagery could cause misunderstandings between therapist and client:

"I've found that I have a very hard, if not [im]possible, time coming up with something that I haven't already experienced. [Working with imagery could have] created an instance of misunderstanding because I was drawing on something I've experienced though may not have directly involved me." ('Unisonic')

B) Emotional processing differences

Many participants described difficulty, for example, 'Elizabeth' said “When I talk about feelings, I feel uncomfortable”. Participants wanted therapists to know the following points about how their emotions are experienced differently.

B1) Difficulties in recognising and communicating emotions

Participants described difficulties, 'Virginia' explained that “the biggest issue is that most therapies concentrate on identifying and resolving emotions”. Similarly 'John' described the difficulty: “dealing with emotions is something I don't do as I don't recognise any very well [dealing with] emotions in therapy doesn't work for me, it's [...] extremely foreign to me”. 'Unisonic' described having to intellectually process what his bodily feelings meant about what emotions he was experiencing: “How I understand it is that for most people it just happens intuitively [...] whereas I have to stop, think, and process it. Sometimes the feeling takes a day or two to fully process. Sometimes a week.” Participants wanted therapists to understand these differences in identifying emotions and also in communicating those emotions and feelings to somebody else. 'Unisonic' described this: “I have a very hard time explaining how I feel. I don't always have words nor the awareness to describe them.”

B2) Emotions can be experienced as overwhelming

As well as having difficulty identifying their emotions, many participants also experienced their emotions as overwhelming. 'Cali' explained: “talking about emotions, for me at least, would be a hard thing to do. Because most of the time I feel like I turn off my emotions because they're too overstimulating.” Participants reported that at times they needed to be alone in order to process their emotions, rather than to share them with a therapist. 'Elizabeth' shared her thoughts on her needs following a bereavement:

“The closest thing I can think of to that was a bad break-up I had about 6 years ago, but I spent a lot of time by myself, distracting myself by doing things. And I wasn't diagnosed then either. I think I'd want a lot of time by myself probably. I can't say what I'd want in terms of people support, I can't picture it.”

B3) Therapists can misunderstand the facial expressions of people with AS

Participants reported that therapists sometimes misinterpreted their emotions because of differences in facial expressions: “When [my therapist] thinks she can read something on my face (reactions, things she thinks I'm thinking about) and tells me so she's usually wrong” ('Mike'). 'Stella' had found this problematic and said that she would want therapists to know what is happening on the inside is not the same as what is showing on the outside: “the counsellor has to believe that the patient is very sensitive even if there is no emotion on his face”. Similarly, some participants reported that their facial expressions do not always match how they are feeling and so people can misunderstand them. 'Virginia' described a facial expression she gets when she knows something bad is going to happen to her and she won't be able to do anything to stop it: “it's an expression that NT⁷ people almost universally interpret as a satisfied smile, like I'm glad that something bad is happening”.

B4) Participants facial expressions have to be policed

Some participants described how they try and make the socially expected facial expressions, but that they need to think about it mechanically and when they are stressed they cannot always maintain the expected face. 'Aggie' described how she had to smile when working in retail: “crook mouth up, show a little teeth, crinkle eyes, scrunch face to show my dimple. And when they leave I have to remind myself to relax my face”. Similarly, 'Virginia' said she has learned to “police [her] face very carefully” but that this is difficult because what her face feels like to her and what “shows on the outside are two very different things”. This added to the confusion of others because at times of stress it was hard to keep facial expressions consistent with what is being felt on the inside.

B5) Difficulties reading others' facial expressions

Not only do therapists have difficulty interpreting their client's facial expressions, but participants also had difficulty reading the emotions of others, which made communication more difficult to manage. 'John' shared that he “never recognised anyone's facial emotions”. This can cause problems in relationships if the other party does not realise why their feelings are seemingly being ignored. Not knowing what others are feeling (or thinking) makes it hard to react to people in the way that they would want or expect, which can cause difficulties in relationships and can also be

7 NT is short for Neuro-typical, a term used by some people with Aspergers to describe those without Aspergers.

misinterpreted by professionals:

“I took a facial expression recognition test once and discovered that I interpret expressions of puzzlement, disbelief, bafflement, worry, anxiety, apprehension, all of those I interpret as angry expressions, blaming expressions. It's no wonder I've gone through life thinking everyone is angry at me. This is an issue in therapy if the therapist is baffled by something I've said, and I interpret it as I said something wrong.” ('Virginia')

B6) Preference for intellectual over emotional processing

As a result of the way that emotions are processed, experienced, and communicated, many participants expressed a preference for intellectual and logical approaches to therapy and a need for facts when exploring and understanding themselves and others. 'John' said: “I prefer the intellectual and practical, I simply don't do emotions”. Even when working with an issue of trauma participants stated that what they found most beneficial was talking at an intellectual level. 'James' described the benefit of understanding abuse from his Dad because his therapist: “gave me not just words, but [also] the reasoning that my logical mind craves”. 'Virginia' described how the standard therapeutic approach of working with feelings does not work for her, and as a result she would tell a therapist: “Okay, so I feel this, what about it? What now? I'm still feeling it, what do I do about it?”, but therapists found this hard to understand and the therapy would collapse.

C) Processing thoughts and emotions can take time

As well as the difficulties participants experienced with identifying and recognising emotions in ways that were expected by neuro-typical therapists, participants also described how they can have difficulties processing and expressing their thoughts, particularly in spoken communication.

C1) Spoken communication can be difficult

Spoken communication was difficult for many participants, especially when what was being said required thought. 'Elizabeth' described her difficulties with explaining symptoms to her GP. Despite being sure of everything she wanted to say beforehand she said: “when I was sitting there, I got a kind of stage-fright, and wasn't able to describe my symptoms properly, and also forgot half of them. I felt stupid and really embarrassed.” At times difficulties with communicating were related to anxiety around communication rather than anxiety relating to the subject matter.

'Unisonic' explained that "the biggest unhelpful thing I think is misunderstanding my difficulties with speaking and thinking that some subject might be bothering more than it is." Participants talked about ways the therapist could help their client to express themselves. 'Rea' suggested that the therapist could invite the "person to explain 'around it', by using similar or other words, so they can both figure out whatever it is the Aspi⁸ [sic] wanted to say", or they could "help with brainstorming or [...] aid with finishing thoughts" if someone is struggling.

C2) Therapists need to be patient with processing speed

Participants wanted therapists to understand their issues with communicating and processing thoughts and feelings, and to be patient and sensitive to their pace. 'John' stressed that it is: "important to be able to allow me time to process what's going on". Thoughts and feelings can take a long time to process, as 'Annie' said "If you don't 'feel' it, it doesn't have any value for you [...] and with me, things can take a loooooong time to sink in and mean something to me", so therapists need to be patient. 'Rea' had experienced people in her life not being willing to take the time to help her to understand things: "you really have to TAKE THE TIME to help us understand. Because we generally want to, but people often get tired of explaining way too easily, because it may take a while until we get it".

C3) Change can be stressful

Related to awareness of pace, participants wanted professionals to be aware that ideas take time to be processed and change is often a source of great anxiety and cannot simply be forced. Participants had difficulties working with therapists and professionals who did not understand this. 'Mike' described the frustration of working with a dietician who did not accept his difficulties with change: "I couldn't make her understand that someone on the spectrum can't just change their eating habits (or anything for that matter) from one moment to the next". Forcing or pushing a new idea was experienced as unhelpful, as 'Annie' said: "I find it much easier to accept an idea if I'm left to consider it for a while, rather than have someone tell me it's a good idea".

C4) Endings in therapy are hard

Having difficulty with change also impacts upon how the endings of therapy relationships are

⁸ 'Aspie' is a term adopted by many people with Asperger's

experienced; some participants described endings as painful. 'Annie' said:

“I abhor, loathe and detest change... unless it's instigated by me and is under my control. And I think that's a major problem in this 'short term' counselling thing (6-12 sessions) – the whole thing is one big transition, you don't have time to achieve much because you're aware it's ending soon.”

The ending of therapy was difficult for some people even when it was planned and agreed with; 'Unisonic' said: “You get used to talking to someone and having that outlet so changing it can feel like 'breaking up'. Even if it is the best thing it can still be hard. It's a mournful process.”

Participants reported suffering particularly when therapy was ended without enough warning or time to process it. 'Dawn' talked about the hurt of sudden endings, she explained: “that actually really hurts”. Several people described the benefit of having enough warning when an ending is going to occur; 'Virginia' stated that: “I've had many bad endings where I was deemed non-compliant and I was ejected. But I've also had 'positive' endings where the therapist declared me to be functional.” Although many participants reported difficulties with endings, not everyone did; 'Elizabeth' stated: “I think my endings with counsellors/helpers so far have been planned and so I've known they were coming, but generally I don't see people like that as people to bond with, so I guess I don't [bond with them]”.

D) Miscellaneous

D1) Sensory needs should be understood

Participants wanted their therapists to know about the impact of sensory issues so they could make adaptations to the setting (when needed). Some participants struggled to access therapy if they were overstimulated by sensory noise:

“[the psychiatrist] had me waiting in a busy corridor for twenty-five minutes while I had to listen to consultations going on in three rooms around me (not loud enough to hear what was said exactly, but definitely loud enough to cause sensory overload).” ('Mike')

Participants explained that the same issues apply to the therapy rooms itself, if the room is distracting (sounds, sights, smells) then the work will be compromised. Furthermore, there will be both individual differences and variations from day to day. For example, 'Rea' stated that “hugs are

good and pats on the back. But only if you have asked the individual. Some people don't like it or sometimes they also have certain DAYS where they don't like it".

Participants also explained that sensory issues are a source of great stress and anxiety in people's day to day lives, increasing the strain of daily living and adding to a heightened base line anxiety level. For example, 'Annie' described her struggles with Christmas day because of "small talk, sensory over-stimulation, unfamiliar environment, [...] volume on TV, 3 hyped up kids etc etc." 'Unisonic' described how not understanding sensory issues caused problems in therapy:

"It was common to be misunderstood. I could be anxious but have no idea why. Knowing what I know today I would be able to answer something like 'I went to the store and it was too bright/loud' and that caused me to be anxious. In the past I would try to logically figure out why I would be anxious along with prompting from the therapist which would result in made up sources."

D2) Eye contact is hard

Another issue which was raised by many participants was their difficulty with eye contact, particularly when they were stressed. While sometimes a lack of eye contact might show discomfort, it was reported as also being generally difficult: "eye contact is something I can do but not very well and if I feel uncomfortable whether it's family, or the counsellor, or whoever, I choose not to make it" ('John'). The participants also reported their awareness of social rules around eye contact:

"NT people get really bothered about eye contact and AS⁹ people can't seem to get it right. We either give too little or too much. [full eye contact] intimidates NT people. But if we don't make eye contact, NT people think we're not being completely truthful or are dodging an issue." ('Virginia')

D3) Women and men show Aspergers differently

Some of the women in this study raised the issue of differences between men and women and stated that the common representations of Aspergers (and autism) in academia and the media are

9 Aspergers Syndrome.

men. 'Annie' felt that her therapy would have benefited from her therapists understanding the differences:

“People need to know about how it can manifest in FEMALES! I know, this is my 'thing', my 'cause', my 'soap-box topic', but I actually think that it would help me gel with a lot more female counsellors. [If a counsellor has] educated herself about this curious creature that is the female aspie.”

D4) Treat everyone as an individual

It was important to the interviewees that people with Asperger's are thought of as individuals, rather than as everybody with Asperger's being seen as the same. 'Mike' felt strongly that people should understand the variety within the population: “As they say, if you've met one person with Asperger's, you've met one person with Asperger's. People on the spectrum have different capabilities and needs.” Participants were frustrated by therapists who did not try to get to know them as an individual and made assumptions without checking that they were correct. There was great variety in what interviewees said about their wants and needs in therapy, and they felt it was important for therapists to avoid approaching clients homogeneously: “Gain an understanding of the individual. Honestly – I don't think there is a blanket feel good therapy. It is very individual.” ('Aggie').

D5) “Don't be patronising”

The final element mentioned by participants, is the desire not to be patronised by professionals who make assumptions about Asperger's. For example, 'Mike' said: “don't be patronizing either - we're autistic, not dumb”. As well as this, a few participants reported that some professionals and non-professionals viewed Asperger's as an illness, and this was not welcome. 'Rea' stated that:

“We shouldn't be treated like we're 'sick' or like 'we need help' or 'people are just trying to help us', but instead people should treat us normally. [...] I also always cringe so hard when people say 'illness' to my Aspi. I don't feel ill. I feel fine, actually. Geez. 'Oh, you are suffering from Aspi'...Uhm...I am not 'suffering', no. The only thing that makes me suffer is people being stupid about it, but that's not a symptom or effect caused by my Aspi per se.”

Overall the theme reported here captures how important it was to participants that professionals

had a good understanding of how people with Asperger's might be different from their other clients. It shows that when professionals did not have knowledge of Asperger's, misunderstandings could happen and participants could be affected negatively.

Discussion

The discussion of the above analysis takes the form of recommendations for practice. In order to work effectively with people with Asperger's it is necessary to have an understanding of how the world is experienced by those people, without this understanding there is a risk that clients will be viewed only through a neuro-typical frame of reference and therefore misunderstood.

Professionals should educate themselves about the key area of social communication difficulties (Michelle Garcia Winner's website, 2015, and Tony Attwood's 2007 book are useful resources).

Avoid broad questions: Broad questions are not impossible for people with Asperger's to understand, and I used them throughout my interviews. However, therapists should be aware that use of broad questions can add to cognitive strain on a person because they might not intuitively know what type of response is expected.

Use literal language: As with broad questions, understanding non-literal language is not impossible for people with Asperger's, and many people with Asperger's will use metaphor themselves. However, decoding the intended meaning from a non-literal phrase can slow down processing and cause misunderstandings so therapists should be aware of this.

Don't overanalyse: Some therapy approaches developed for neuro-typical people use interpretations to explore the historical basis of current issues. It has been suggested that this is of limited use for people with Asperger's (Jacobsen, 2003) who are likely to be frustrated by such interventions.

Avoid silence or explain its purpose: Psychodynamic therapists tend to use silence to facilitate reflection, and humanistic therapists to convey empathy, respect and support (Hill et al, 2003). Therapists should not assume that these rationales are known and they should be aware that without explanation silence it is likely to cause confusion and anxiety.

Discuss the expectations of counselling: People with Asperger's may have a preference for clearly

expressed rules of counselling (Reaven and Hepburn, 2003). Without the expectations and rationale of counselling being explained people might be left anxious or unwilling to continue with counselling.

Avoid hypotheticals: People with AS do not typically work with imagination in the ways that therapists might expect. Resistance to use of hypotheticals, or pedantic corrections of non-factual statements should not be interpreted as resistance to the therapy or confrontation.

Therapists should educate themselves about the ways that people with AS experience emotions, particularly if they are therapists who are used to working with neuro-typical clients with neuro-typical ways of processing emotions.

1. Recognising and communicating emotions: Therapists should know that people with AS might find it difficult to recognise their own emotions, and that even if they can be recognised they might struggle to communicate them.
2. Emotions can be overwhelming: Therapists must understand that for some people with AS there is a small window of tolerance in which emotions are recognised without becoming overwhelming. Care should be taken.
3. Therapists may misunderstand facial expressions: Therapists should be aware that the facial expressions of people with AS do not always match the thoughts and emotions they are experiencing. People can be experiencing great distress but show little or no facial expression to suggest this.
4. People with AS may misunderstand facial expressions: Reading facial expressions is a core difficulty (Wing, 1981). Therapists should not assume that their facial expressions are being read as intended, they should not be surprised if their expressions are not reacted to in the expected way.
5. Preference for intellectual over emotional processing: People with AS may benefit more from using their intellectual strengths rather than trying to work with emotions. Therapists should expect to explain their approaches, rather than assume a shared belief that talking about emotions is helpful.

Processing thoughts and emotions can take time so professionals should be respectful of the pace required by a person; they should be patient if processes take longer than they might expect.

1. Spoken communication can be difficult: Therapists should not equate spoken articulateness with other cognitive abilities. Many people with AS will find written communication a lot easier than spoken. Difficulties speaking should not be assumed to relate to the nature of the topic being explored.
2. Change can be stressful: Resistance to change, or a need for sameness, has long been identified as a trait of AS (Gillberg, 1991). Therapists should expect change to cause discomfort and should approach change and new ideas with patience. This includes endings, which may be experienced as difficult.

There are many other traits of AS and experiences that should be understood from the point of view of the individual if someone wants to work productively with someone with AS.

1. Sensory needs: People with AS may be either hypersensitive or hyposensitive to some sensory stimuli, meaning they might be stressed in situations that neurotypical people would not expect. Therapists should understand that adaptations may be needed, and that emotions can be impacted.
2. Eye contact is hard: Therapists should be aware that eye contact can be difficult for people with AS and that avoidance of eye contact does not necessarily mean that a topic is difficult or that the person is being rude.
3. Sex differences: Therapists working with women with AS must educate themselves about how AS is experienced by women (Simone, 2015). Making assumptions based on a stereotypical male presentation may cause women to be misunderstood.
4. Don't be patronising: Participants spoke negatively of therapeutic experiences where they felt they were being treated as though they were stupid, needed to be fixed, or were inferior.
5. Treat everyone as an individual: While being educated about AS is important, professionals must also understand that everyone has their own experiences and background which

must also be heard.

Conclusion

Professionals who work with people with AS may benefit from educating themselves about the traits and experiences of that client group in order to work effectively. Therapists and counsellors should be aware of the particular traits that are likely to be relevant to the process of therapy.

References

Alvarez, A. (1992) *Live Company: Psychoanalytic Psychotherapy with Autistic, Borderline, Deprived and Abused Children*. New York: Brunner-Routledge

Aston, M, C. (2003) *Aspergers in Love: Couple Relationships and Family Affairs*. London: Jessica Kingsley Publishers

Attwood, T. (2007) *The Complete Guide to Asperger's Syndrome*. Jessica Kingsley Publishers: London

Briggs, A. (2005) A little Boy's Use of His Male Child Psychotherapist to Help Him Understand a Painful Conundrum? *Journal of Child Psychotherapy*, 31(3), 352-367

Bromfield, R. (2000). It's a Tortoise Race: Long-Term psycho-dynamic therapy with a high-functioning Autistic adolescent. *Psychoanalytic Inquiry*, 20: 732-745

Bromfield, R. (2010) *Doing Therapy With Children and Adolescents with Asperger's Syndrome*. John Wiley and Sons: New Jersey

Gerland, G. (1999) Letter to the Editors: Autism and Psychodynamic Theories. *Autism*. 3 (3): 309-311

Ghaziuddin, M., Weidmer-Mikhail, E. & Ghaziuddin, N. (1998) Comorbidity of Asperger Syndrome: a preliminary report. *Journal of Intellectual Disability Research*. 42 (4): 279-283

Gillberg, C. (1991) Clinical and Neurobiological Aspects of Asperger Syndrome in Six Family Studies.

In U. Frith (ed) *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press

Hill, C., Thompson, B. and Ladany, N. (2003) The Therapist Use of Silence in Therapy: a Survey. *Journal of Clinical Psychology*, 59(4): 513-524

Jacobsen, P. (2003) *Asperger Syndrome and Psychotherapy*. New York: Jessica Kingsley Publishers

Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L. and Wilson, F. J. (2000). The Prevalence of Anxiety and Mood Problems Among Children With Autism and Asperger Syndrome. *Autism*, 4: 117–132

Miller, B. (2008) A Kaleidoscope of Themes: Intensive Psychotherapy With a Girl on the Autistic Spectrum. *Journal of Child Psychotherapy*, 34 (3), 384-399

Paxton, K. and Estay, I. A. (2007) *Counselling People on the Autism Spectrum: A Practical Manual*. London: Jessica Kingsley

Pozzi, M. E. (2003) The Use of Observation in the Psychoanalytic Treatment of a 12 Year Old Boy With AS. *International Journal of Psychoanalysis*, 84 (5), 1333-1349

Reaven, J. and Hepburn, S. (2003). Cognitive-Behavioural Treatment of Obsessive-Compulsive Disorder in a Child With Asperger syndrome: a case report. *Autism*, 7, 145–164

Shuttleworth, J. (1999) The Suffering of Asperger Children and the Challenge They Present to Psychoanalytic Thinking. *Journal of Child Psychotherapy*. 25(2): 239-265

Simone, R. (2015) <http://www.rudysimone.net/> [Retrieved 21/08/2015]

Sofronoff, K., Attwood, T. & Hinton, S. (2005) A Randomised Controlled Trial of a CBT Intervention for Anxiety in Children With Asperger Syndrome. *Journal of Child Psychology and Psychiatry*. 46(11): 1152-1160

Sofronoff, K. & Hinton, S. (2007) A Randomised Controlled Trial of a Cognitive Behavioural Intervention for Anger Management in Children Diagnosed With Asperger Syndrome. *Journal of*

Autism and Developmental Disorder. 37: 1203-1214

Wing, L. (1981) Asperger's Syndrome: a Clinical Account. *Psychological Medicine*, 11: 115–119

Winner, M. G. (2015) <http://www.socialthinking.com/> [Retrieved 03/11/2015]