Portfolio: Volume One

- Doctoral Thesis -

A mixed methods exploration of the sense of self among people diagnosed with Asperger syndrome in adulthood

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This research study would not have been possible without the contributions of the participants. I would like to dedicate this thesis to them to show my appreciation.

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Abstract

Asperger syndrome is a relatively recent diagnostic classification. Several factors, including a high prevalence of mental illness, mean receiving a diagnosis in adulthood is a very unique experience but remarkably there is little literature about the impact on individuals. Instead the dominance of the medical/psychiatric paradigm pervades and limits understanding and possibilities. The main implication is a lack of clarity about what support services are needed and effective, and as such the needs of this population are often overlooked.

This is the first study to explore the sense of self among a sample of males and females diagnosed with Asperger syndrome in adulthood using social constructionist and constructivist ideas. It was interested in whether personal construal of the self before diagnosis and self after diagnosis were differentiated. Given the importance in the development of self-concept of discriminations between the self and others, the research also sought to explore how people diagnosed with Asperger syndrome in adulthood construe other people with and without Asperger syndrome.

Using the repertory grid and other techniques from Personal Construct Psychology (Kelly, 1955) in combination with a semi-structured interview, this study presents a novel exploration of idiosyncrasies and commonalities across a demographically diverse sample of eight participants. An extended analysis of a unique subsample of women diagnosed aged 50 years and over was undertaken. Both cognitively complex and simple construct systems were found across the sample. Findings indicated the self before diagnosis was construed critically and was more elaborated than the self after diagnosis. Several participants had a reduced sense of self following diagnosis. The diagnosis offered an explanation of symptoms but for some participants these symptoms were a way of life and accommodating the new label with the existing view of self posed challenges. An overarching and striking theme was the sense of difference felt by participants before *and* after diagnosis.

This study offers a fresh insight into a virtually unexplored population which, through dissemination, may influence the way clinical psychologists and other practitioners work to support adults diagnosed with Asperger syndrome. Recommendations for clinical practice included approaches that target the need for individuality, commonality and sociality, and should be gender-specific where possible. Such approaches might elaborate multiple aspects of self, the diagnosis and related dilemmas. They should support people to widen their perceptual field to alternative ways of construing and explore change. The mixed method approach was assessed to be a strength of the study and a number of recommendations for future research are presented.

Chapter 1: Introduction

The research aimed to explore the sense of self among people diagnosed with Asperger Syndrome (AS) in adulthood. Using a Personal Construct Psychology (PCP) (Kelly, 1955) perspective, the alternative selves were explored, including the self before and after diagnosis and the ideal self. The research was also interested in how participants construed other people with and without AS, and how this compared to their construal of self.

This introductory chapter will start by defining the terminology and narrowing the subject focus within the broader Autism Spectrum Disorders (ASD) research context. A number of theoretical explanations for AS will be critiqued, and key PCP concepts will be given. The concepts of self and identity as they relate to the subject will be presented. There is a paucity of research into the experience of people diagnosed with AS in adulthood, so the author has drawn on the more substantial, but still limited, literature on adults living with AS diagnosed in childhood and adolescence. The literature search strategy can be found in Appendix 1. The chapter will conclude with a presentation of the rationale and research questions.

Asperger Syndrome

Prevalence & Impact

In the UK prevalence of ASD among adults (over 16 years old) is approximately 1% of the population with 1.8% of males and 0.8% of females (Brugha et al., 2012). Given half of people with ASD have intelligence within the average range (Fombonne et al., 2011), we can estimate approximately 0.5% or almost 350,000 people might have AS. (It is possible that this figure is higher because this study excluded people living in institutions.) Despite this significant population research to understand and develop services for AS is underfunded (Tantam, 2014). Access to services is often equated with intellectual ability and so people with AS are often overlooked in the community (National Audit Office, 2009). It is estimated that as many as 50 per cent of people with AS reach adulthood without ever being assessed or supported by professionals (Szatmari, Archer, Fisman, Streiner & Wilson, 1995).

Psychiatric definition

Hans Asperger first described ‘autistic psychopathy’, later known as AS, in 1944. Children with AS were said to have normal intelligence and language development alongside impairment in reciprocal social interaction and behavioural peculiarities, which persist into adulthood. Almost four decades later, Wing’s (1981) description of the clinical manifestations of ‘AS’ in speech, social interactions, motor coordination and unusual interests led to its inclusion as a pervasive developmental disorder or Autistic Spectrum Disorder (ASD) (Wing, 1991). Owing to assumptions regarding the neurological influences on ASDs, psychiatry generally refers to those without ASD as being neurologically typical or neurotypical (NT).

The term ‘AS’ originated within a nomothetic, medical/psychiatric paradigm, as a disorder related to a wider collection of pervasive developmental disorders sharing the ‘triad of impairments’ (Wing & Gould, 1979). This means adults are likely to have difficulties with communication, social interaction and flexibility of thinking and/or behaviours. It is generally accepted that pervasive developmental disorders fall along a spectrum or continuum of symptom severity (Wing, 1991) with those diagnosed with AS thought to be less functionally impaired. The distinction between subcategories is still hotly debated (Matson, Nebel-Schwalm, & Matson, 2007; Tantam, 1988) despite advances in neuroimaging and neurological assessment. Though findings are inconsistent in regard to distinguishing biological markers for AS and other subcategories, the medical model of AS maintains its fierce dominance.

According to the World Health Organisation’s (WHO, 1992) International Classification of Diseases tenth edition (ICD-10) used in the United Kingdom (UK), AS is a pervasive developmental disorder. This view was shared by the American Psychiatric Association’s (APA; 1994) Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) until 2013 when the ‘triad of impairments’ was reconfigured (see Figure 1.1) and the AS subcategory removed from the DSM-5 (APA, 2013). Due to fears about the implication of losing the AS diagnostic category, a new category of social (pragmatic) communication disorder was introduced (Tantam, 2014). This change raises important questions in relation to the reliance on and validity of diagnostic criteria, which are beyond the remit of this thesis.

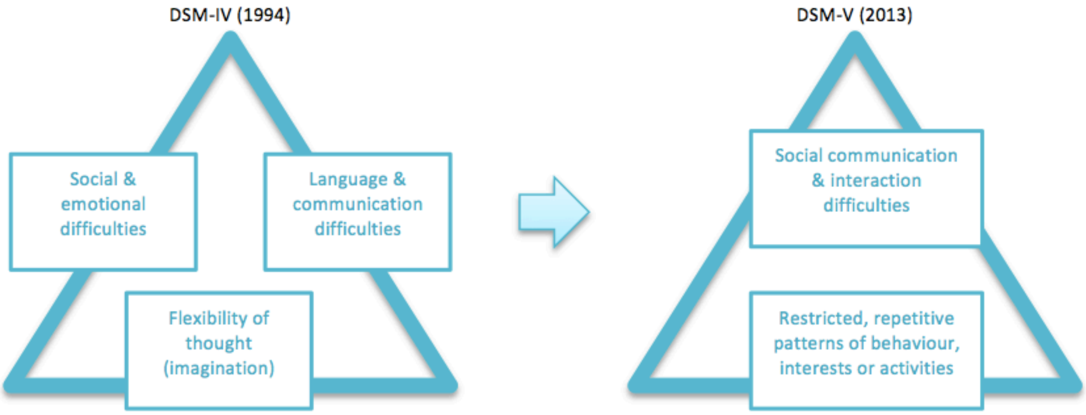


Figure 1.1 Diagram illustrating the changes to DSM criteria

Symptoms in adulthood

It is widely acknowledged that adults vary in their reported symptoms and experiences, which are rather more complex due to the significant demands of adulthood such as employment and relational expectations (Howlin, 2000). The literature is scattered with attempts to categorise and quantitatively measure these symptoms and experiences, often concluding with limitations and recommendations for further exploration and development of tools. Aside from these inadequacies a number of themes have been identified and are presented below.

Social and emotional communication difficulties are most written about in the literature because of their pervasive impact on an individual's life. For example, adults with AS can experience difficulties with pragmatic language (Loukusa & Moilanen, 2009) which impact on their ability to provide the right information at the right time, use social niceties, read nonverbal cues and interpret information literally. In the day-to-day situations of adult life (work, family, friends) people can feel overwhelmed by social demands, particularly when social cues might be ambivalent and fast responses are required (Barnhill, 2007). Adults with AS might also find it difficult to identify and express emotions in the ways that NT others might (Berney, 2004). In such circumstances adults may detach from or avoid social situations, the implication of which is limited social interactions and isolation (Griffith, Totsika, Nash & Hastings, 2012), and exhaustion from the efforts they have to take to develop greater social and self-awareness (Müller, Schuler & Yates, 2008). Females can experience stronger feelings of isolation as their so-called 'unusual social and emotional communications' defy gender expectations (Faherty, 2006; Davidson, 2007).

Restricted, repetitive patterns of behaviour, interests or activities (APA, 2013) are another symptom discussed in the literature. In adults with AS it can refer to the preference for predictability, particularly of the external environment and routines (Soderstrom, Rastam & Gillberg, 2002). Many adults with AS are said to have 'special interests' which may seem unusual because of their subject matter or the intensity at which they pursue them. These preferences and interests become problematic when they interfere with daily life. The literature suggests females may have fewer and/or less unusual special interests than males (van Wijngaarden-Cremers et al., 2014). Several studies have focussed on difficulties experienced in the workplace (Barnhill, 2007; Howlin, Alcock & Burkin, 2005; Hurlbutt & Chalmers, 2004) for example, when days are unpredictable or disrupted. Tantam (2014) suggests part of the reason people with AS experience problems in the workplace is due to executive functioning difficulties affecting planning, persisting with frustrating tasks, and ability to switch between tasks.

Diagnosis in adulthood

Typically ASDs are diagnosed in childhood. However, several important developments account for the later diagnosis of AS. Firstly, AS was not discussed in the English literature until 1979 and brought to attention until the 1990's by Uta Frith (1991), thus ruling out its application to a large proportion of adults while they were children. The implication is steadily increasing diagnosis of adults of all ages. Research, though scant, has begun to explore the experience of young adults (Jennes-Coussens, Magill-Evans & Koning, 2006) and those in 'middle adulthood' (Griffith et al., 2012) as more people are diagnosed. Data on older adults diagnosed with AS remains a weakness (Happe & Charlton, 2012; Perkins & Berkman, 2012), particularly given the aging population in the UK. While the symptoms associated with AS are pervasive, the literature on ASDs has indicated changes at different ages. Perkins and Berkman (2012) propose self-awareness, knowledge of social etiquette and accumulated knowledge from experiences and coping may be significant influences on the symptom trajectory of people with ASD.

The second explanation for late diagnosis is the relatively recent recognition that AS can be present without intellectual impairment (Baird et al., 2006). Although average or above intelligence and good language skills are thought to be protective factors in terms of outcomes in adulthood (Howlin, Goode, Hutton & Rutter, 2004) they obscure difficulties and so diagnosis occurs much later than other ASDs (Barnhill, 2007; Howlin, 2000). The literature indicates a variety of reasons why intellectual and language strengths are outweighed by difficulties and an assessment is considered (Guerts & Jansen, 2012). These include difficulties adapting to a new situation or social challenge (e.g. changing jobs) (Tantam, 2000b); and psychological distress (Abel & Hare, 2005; Hofvander et al., 2009) such as depression (Stewart, Barnard, Pearson, Hasan & O'Brien, 2006), anxiety (Hare et al., 2014), bipolar disorder (Vannucchi et al., 2014) and suicidal ideation (Paquette-Smith, Weiss & Lunsky, 2014; Spencer et al., 2011).

Thirdly, over time diagnostic criteria have become more inclusive (Guerts & Jansen, 2012). This means adults who now fit diagnostic criteria might have experienced misdiagnosis or an alternative explanation for their difficulties (e.g. 'oddness'). Ryan (1992; p.907) reported characteristics including "eccentricities, emotional lability, anxiety, poor social functioning, repetitive behaviours and fixed habits can mimic other illness, including schizophrenia spectrum illness, bipolar disorder, anxiety disorders and obsessive compulsive disorder". Furthermore, with the most common comorbid disorder, depression, estimated to be prevalent in around 37 per cent of adults with AS (Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998) the picture becomes more complex. The diagnosis of depression may be obscured by symptoms typically associated with AS, including social withdrawal and unusual sleep or appetite routines. Furthermore, many symptoms commonly associated with AS change with mood (Stewart et al., 2006).

A final issue raised by Tantam (2014) is in relation to the apparent sex differences in prevalence and age at diagnosis. He queries the extent to which fewer numbers of diagnosed women, who are apparently diagnosed later than men, reflect their greater ability, or willingness to fit in, and the greater willingness of men to adopt and defend eccentricity. Baron-Cohen and Wheelwright (2003; p.510) found that "women [with ASD] are more likely to enjoy close, empathetic supportive friendships, to like and be interested in people; to enjoy interaction with others for its own sake; and to consider friendships important". The gap between societal expectations and personal abilities is said to be greater for women with AS than for men owing to more pressure to present a strong social identity. Women may also encounter difficulties in forming friendships because female relationships frequently rely on nuanced emotional and social exchanges whereas male friendships tend to be more activity focussed (Zaks, 2006). Furthermore, Davidson's (2007) paper on the exclusion and "alienation" of women with AS highlights the impending threats they face in coming to terms and living with the diagnosis.

Women in general (with and without AS) are more likely to internalise frustration or distress whereas men tend to externalize their difficult feelings. Although not validated by scientific research, anecdotal evidence suggests that women with AS may experience more severe and frequent comorbid mood disorders because they internalize feelings of frustration and failure. This may mean women are mis/undiagnosed for longer (Faherty, 2006; Davidson, 2007).

The situation in the UK is that adults continue to be diagnosed with AS for the reasons above. However, a literature search on the experiences of people diagnosed with AS in adulthood is limited to two studies in the UK and five studies in the USA. The two UK studies focus on the experience of diagnosis (Punshon, Skirrow & Murphy, 2009) and the applicability of existing psychological models of receiving a medical diagnosis; and support experiences and future support needs of adults diagnosed with AS (Griffith et al., 2012). The USA studies focussed on issues relating to negotiating social experiences and employment (Hurlbutt & Chambers, 2004; Müller, Schuler, Burton & Yates, 2003; Müller et al., 2008).

Psychological support for adults with AS

A major implication of the dearth of research into this population is the lack of knowledge about how best to offer support (Department of Health, 2010; DOH). Much of the literature reported thus far indicates a significant need and the National Institute for Health and Care Excellence (NICE, 2012) guidelines propose psychosocial interventions to support adults and their families with difficulties associated with the AS diagnosis and comorbid mental health difficulties. However, often adults diagnosed with AS fall between service provisions (National Audit Office, 2009) as mainstream community mental health systems claim not to be expert, while services specialising in ASD are often not commissioned to provide services to people who do not have intellectual impairments. In this respect it seems the dominant psychiatric/medical paradigm has limited the possibilities.

Theoretical Approaches to AS

Attempts have been made to understand ASD from a range of theoretical positions and these have been applied to AS, the most influential or novel of which are presented below.

Understanding ASD has been the focus of cognitive researchers and theorists and the basis for cognitive skills interventions, albeit with conflicting results. The three most influential theories are the “Theory of Mind” (TOM) account (Baron-Cohen, Leslie, & Frith, 1985; Lombardo & Baron-Cohen, 2010), the theory of “executive dysfunction” (Ozonoff, Rogers & Pennington, 1991; Rumsey & Hamburger, 1988), and the “central coherence theory” (Frith, 1989; Happé & Frith, 2006). TOM proposes that people with AS have a reduced ability to recognise and link their own and other people’s mental states to responses or actions. The theory of executive dysfunction posits that AS symptoms are a consequence of impairments in executive functions, including planning, inhibition, flexibility, and working memory. Central coherence theory suggests that people with AS have an inability to construct higher meanings from a set of details, or take a broad perspective. It is generally accepted that none of the theories (or their modifications) can explain all difficulties associated with AS, but that each has the capacity to account for a wide range of atypical behaviors common to AS (Happé & Ronald, 2008).

An alternative paradigm, which deconstructs diagnosis and its discursive practices, is social constructionism (Burr, 1995, 2003; Foucault, 1977; Gergen, 1985). From a social constructionist perspective, meaning and experience are socially produced and reproduced, rather than inhering within individuals (Burr, 1995, 2003). Molloy and Vasil (2002) proposed a social constructionist perspective on AS, critically asserting psychiatric diagnosis as merely an explanatory mechanism for defining individuals which negatively impacts on their individuality and limits the expectations others have of them. The social constructionist model instead locates difficulties with fit or flexibility of the social and/or cultural context in which the person with AS lives.

From this perspective, a diagnosis of AS does not represent objective truth or reality about an individual. Instead the act of observing differences (or symptoms) changes them. People then use language, or diagnostic labels to agree on what constitutes reality. Gergen, Hoffman and Anderson (1996; p.5) suggest that, “diagnoses, official and unofficial, often concretize identities that limit people; they create black boxes with few, obscure exits; and they form obstacles to more viable and liberating self definitions”. This means that a diagnosis of AS is not only descriptive but powerfully organizes peoples’ lives, bringing forth pathology, creating problem-saturated identities and potentially constructing careers as patients (Bagatell, 2007; Molloy & Vasil, 2002).

Evidence drawn from the literature on the experience of adults with ASD more generally lends itself well to a social constructionist perspective. The eminent author Frith (2004) emphasized the importance of environmental support for adults with AS, insofar as difficulties might even be hidden when good support is available. Often challenges arise however with unexpected situations, for example at work (Hurlbutt & Chalmers, 2004; Tantam, 2000a & b), which make it difficult for adults with AS to negotiate. The result, not of their diagnosis per se but rather the misfit of the environment, is that social and emotional situations are difficult and unsatisfying, and the person may be left feeling anxious, unconfident and depressed.

Constructivism is the final paradigm considered to offer an alternative perspective on AS, with a particular focus on personal construct psychology (PCP; Kelly, 1955). Generally speaking, a criticism of social constructionism is its neglect of human agency and assumption of passivity. Constructivism is concerned with the unique and active ways that people make sense of their lived experiences (Neimeyer, 1999) and offers a more holistic view than other psychological approaches. The literature shows one paper in which PCP methods were proposed as a useful clinical tool for adults with AS (Hare, Jones & Paine, 1999). In addition a small number of articles have used PCP to conceptualise the experiences of children (Procter, 2001) and adolescents (Cridland, Caputi, Jones & Magee, 2014) with ASD and their parents (Sharma, Winter & McCarthy, 2013). PCP offers an opportunity to move away from the dominant medical discourse and explore the shades of grey in the way people with AS (and other ASDs) experience the world. In doing so it recognises and values the uniqueness and complexity of AS (Procter, 2001), giving voice to those who might otherwise be undervalued or unheard.

Personal Construct Psychology

Rather than attempting to discount other paradigms or theoretical approaches, George Kelly (1955) coined ‘constructive alternativism’, the view that there are multiple ways of construing the world. Kelly viewed people as ‘naïve scientists’, actively classifying, categorizing and theorizing about their world. Individuals are said to construct their own set of personal theories to help make the world more predictable. These personal theories are organised in construct systems of an unlimited number of ‘constructs’. Personal constructs may be highly idiosyncratic or widely shared, and may vary in terms of how central or important they are in construing one’s life (Winter, 1992). Construct systems function like a kaleidoscope through which individuals view, give meaning to, or construe the world around them. Just as the view through a kaleidoscope changes continuously with new colours and shapes, an individual goes through a process of adapting (and retaining) their construct system as experiences influence their interpretations. Kelly (1955) referred to this process as the ‘experience cycle’.

Cognitive complexity (Bieri et al., 1966; p.185) refers to the “tendency to construe social behaviour in a multi-dimensional way, such that a more cognitively complex individual has available a more versatile system for perceiving the behaviour of others than does a less cognitively complex person.” Adams-Webber (1969) explored whether relatively cognitively complex people exhibit more skill than cognitively simple people at inferring the personal constructs of others in social situations. He found that cognitively complex people had a more varied view of how characteristics can interact whereas a cognitively simplistic person had a more stereotyped view of people in terms of qualities.

Constructs can be tight, which leads to unvarying predictions or loose, which leads to varying predictions that retain their identity. For a person to develop new constructs they require first loose construing then tighter construing, a process Kelly (1955) termed the ‘creativity cycle’. When a person’s construing is predominantly tight their thinking will be concrete and lacking in new ideas (Bannister & Fransella, 1986). Such individuals tend to be characterised by a range of interpersonal difficulties, which include impairments in predicting the construing of others, integrating conflicting information about other people and communication skills. Thus they also have restricted options available to them. People who have tight construct systems are likely to be especially vulnerable to invalidation since their construct systems will be brittle and prone to collapse.

PCP is founded on Kelly’s (1955; *p.46*) fundamental postulate, that “a person’s processes are chanellized by the ways in which he anticipates events”. This basic assumption was elaborated with eleven corollaries, which Cridland et al. (2014) have applied to adolescents with high functioning autism and may well apply to adults with AS. Corollaries that may be particularly pertinent to understanding the experience of adults diagnosed with AS will be described below.

The *individuality corollary*, for example, states that people are unique in their construal of events owing to their own past experiences. This corollary is likely to be very important for people diagnosed with AS in view of the complex nature of their difficulties and previous experiences.

A flexible thinking style allows for reflection, revision and elaboration of constructs through a process of validation and invalidation. Kelly (1955) described the *experience corollary* to encompass this “trial and error” learning, and viewed it as central to the development of coherent personal constructs. New experiences alter our future anticipations of events. This style of reflection is likely to be difficult for people with AS, given the tendency for less flexible thinking styles. The difficulties adults have reported in employment (Hurlbutt & Chalmers, 2004; Müller et al., 2003; Müller et al., 2008), and with significant life changes might be helpfully understood from this perspective.

The *commonality corollary* states that people have shared constructs. One might consider diagnostic criteria used in psychiatry (and psychology) as an example of common construing of deviance from the norm. The commonality corollary reminds us that people share the desire for acceptance despite their different ways of perceiving and experiencing the world. It is likely this is an important corollary to consider when newly diagnosed adults begin to negotiate the label of AS and their sense of belonging to one group or another.

Finally the *sociality corollary* posits that relating is based on the construing of another person's construction processes. Poor sociality or limited ability to understand another person's perspective has been shown to be associated with problems associated with ASD (Procter, 2001). Thomas (1979, cited in Winter, 1992, p.8) elaborated this corollary with the *social-awareness corollary*, proposing that the way a person construes their construction of social interactions will determine their ability to consciously influence social interactions. No research has explored this in relation to AS but it is possible a person's awareness of their construction of social interactions might be influenced by the meaning they make of their diagnosis, and therefore may play an important role in negotiating social interactions.

Emotions in PCP

Kelly (1955) put forward a unique interpretation of emotional phenomena (Katz, 1984). In his focus primarily on negative emotions, Kelly (1955) formulated that emotions are the symptoms of characteristic vicissitudes of construction. Invalidation or disruption of constructs is thought to lead to negative emotional states. Other PCP theorists such as McCoy (1977) have related positive emotions to validation of construing. Understanding the meaning an individual attributes to the AS diagnosis is key in understanding their responses to it and so several PCP emotions will be outlined below.

Kelly was eager to differentiate aggression from hostility (Butt, 2008). Kellyan *aggression* refers to the state in which a person widens their perceptual field or elaborates their construing. It is characteristic of areas in which a person has interest or confidence. AS diagnostic criteria concerned with special interests might be understood in this way. By contrast *hostility* occurs when a person's construct system is in need of revision but they are reluctant to do so. Instead the hostile person clings to the structure of their construct system in spite of its invalidation, often requiring manipulation of the world to extort evidence for their construing. AS diagnostic criteria concerned with flexibility of thought might represent a form of hostility in which a person is less able to incorporate new information into their construct system and instead persists with a response that is inappropriate or unsuccessful.

Kellyan *anxiety* results when the person's constructs do not enable them to make meaning of an event. In such circumstances an individual's assumptive world is likely to be shaken. Given that a central feature of AS is difficulty understanding social situations, it is reasonable to assume that individuals with AS might interpret social situations as beyond the *'range of convenience'* of their construct system, and consequently the experience of anxiety. In adulthood it is generally expected that one is able to manage significantly complex situations at work or in relationships. The more situations a person finds themselves in, the increased likelihood that situations might be outside the range of convenience and lead to anxiety.

Certain emotions are associated with more significant disruptions to construct systems. This follows from the *organisation corollary*, in which Kelly (1955) stated that personal construct systems are hierarchically organised. *Superordinate* constructs, for example, are higher order constructs, which subsume lower order *subordinate constructs. Core* constructs are also higher order constructs governing a person's maintenance processes. Transitions of these constructs are likely to be subject to emotions such as *threat* and *guilt*. Kellyan *threat* is the awareness of an imminent comprehensive change in one's core constructs, and *guilt* is the awareness of dislodgement of the self from one's core role structure. No literature has explored the impact of a diagnosis of AS on the sense of self, yet Griffith et al. (2012) and Punshon et al. (2009) point to significant changes to the process of sense-making and feelings of belonging in their participants. Turpin, Dallos, Owen and Thomas (2009), using PCP methodology, found a medical diagnosis of cancer posed a threat to individuals' sense of self. It seems possible therefore that people diagnosed with AS in adulthood, when core constructs may be well established, might experience *threat* and/or *guilt.* Understanding these experiences is likely to have useful implications for clinical practice.

Concepts of 'self'

The self, what it is and how it develops, has long been the subject of study for philosophers and psychologists, and the wealth of literature is too large to consider in this thesis. This introduction will instead cover some pertinent points as they relate to the focus of this research.

Leary and Tangney (2011) identified several ways that the term *self* is used within the social sciences. In this research the self was understood as the 'experiencing subject', which is defined as the psychological process responsible for self-awareness and self-knowledge; and the 'self as beliefs about oneself', which refers to the thoughts and feelings people have about themselves. The self is referred to in different ways in the literature (e.g. identity, self-concept, sense of self) but in this study they were understood as synonymous.

Theoretical approaches to self

Developmental approaches suggest that the self becomes increasingly detailed and complex over time and experiences. Early theorists liked Erikson (1968, 1974, 1982) believed identity was fixed and that individuals progress through defined stages of identity development. Erikson's (1968, 1974, 1982) psychosocial development theory proposed that individuals experience crises and conflicts at different times in their life and resolution of these was necessary for progression to the next stage. Marcia (1966) suggested the choices about personal and social traits were important for determining identity. Critiques of these theories suggest they lack clarity about the definition and progression through the stages (Miller, 2002). Furthermore, Pasupathi and Hoyt (2009) suggest they underestimate the importance of micro rather than macro level processes. These theories did not consider identity to be a fluid process that is driven by an individual's personal context.

Social constructionist thinking acknowledges the interweaving of self and society and has explored the origins of dominant personal constructions of the self. Mead (1934; *p.63*) wrote, "selves can only exist in definite relationships to other selves". From this perspective individuals can have multiple changing identities that are expressed in specific, but fluid, social relationships. Foucault (1977, 1980) later emphasised discourse and power relationships, suggesting that dominant discourses and labels are imposed or 'inscribed' on people. Bruner (1990) suggested the self as situated within cultural and historical contexts and Gergen (2009) proposed that individuals are social constructs that emerge from relationships and their social context. From these perspectives the self is a product of a person's social interactions, context, and the current and historical narratives available (Elliot, 2005).

The social constructionist approach is coherent with a narrative conceptualisation of identity. Narrative theories propose identity as a process rather than a construct that fixed and inflexible. De Fina, Schiffrin and Bamberg (2006) emphasized four aspects of the social constructionist perspective of identity as a process. This process takes place in concrete and specific interactional occasions; produces constellations of identities instead of individual immovable constructs; grows from social interactions rather than from within individuals; and needs discussion for it to be revised and altered as necessary.

Narrative theories of identity development have focused on how life events are understood and evaluated (Bruner, 2004). It is how a person makes sense of their experiences that influences identity (Kirkman, 2002). The stories a person tells about himself or herself are what constitute identity. Riessman (2002) suggested that constructing a narrative about one's life allows for continuity over time and serves to represent past and future selves. This begins in childhood and continues throughout a person's life. Narrative theories also view the self as defined by and dependent cultural and societal contexts (Atkins, 2004).

Constructivist understanding of self shares the view of the self as a process which changes over time and experience. PCP theorists have had much to say on the self but using a 'credulous attitude', and in so doing, taking an individual's view of him or herself at face value (Winter, 2013). According to PCP, a person's identity consists predominantly of core constructs. Kelly (1955; *p.432*) defined these as those constructs that "govern people's maintenance processes – that is those by which they maintain their identities and existence". Core constructs are therefore essential for understanding our sense of self (Butler, 2006). Core constructs are developed as part of a sense-making process, which helps people to anticipate themselves. Core constructs are considered to be the most complex superordinate constructs in a person's construct system (Butler, 2006). This complexity arises because core constructs are developed and influenced by lower order constructs.

Unlike lower order constructs, core constructs appear to remain consistent so that individuals can maintain a core belief about themselves, an attribute that is supported by the relatively low awareness people often have of them (Leitner & Thomas, 2003). However, at a meta-level, Thomas' (1979, cited in Winter, 1992, p.8) *self-awareness corollary* proposed that the way a person construes their own construct system influences the view they have of themselves.

It is assumed that core constructs are few in number (Rowe, 2003) but it is likely that a person's self is maintained through more than one core construct and the variety of roles a person adopts may serve to validate different constructs at different times. The counter to this is that identity may be destabilised by invalidation if the various roles (e.g. family member, friend, work colleague) are not easily assimilated. In his *fragmentation* corollary, Kelly (1955; *p.58*) suggested, "a person may successively employ a variety of construction subsystems which are inferentially incompatible with each other". Roles that interfere with each other are likely to become conflicting. This may be relevant in the instance where a person is labelled by a diagnosis or symptom, which is incompatible with the way they construe themselves.

Kelly (1955) proposed that the process by which we make sense of our identity evolve out of discriminations between self and others. Socially dependent common factors underlying core constructs have been theoretically (Rowe, 2003) and empirically (Butler, 2006) proposed. Rowe (2003) proposed the common dimension of core constructs of 'self-liking', whereby a persons' perception of self is developed from the reactions of others. Butler (2006) proposed 'relatedness' as a common factor of core construing, describing the ways our core constructs are embedded in our relationships with others.

Fay Fransella was a PCP theorist who was interested in meaning and significance of symptoms to a person's construal of self. Fransella (2005; *p.99*) wrote, *"*all ways of behaving that a person has adopted over many years becomes a part of their 'self' construing". In this sense symptoms can become a 'way of life' (Fransella, 1970). In her work with people who stutter, she found that becoming a fluent speaker was relatively meaningless to the person who stutters. Therefore, although they may not like being a stutterer, the symptom of stuttering was preferred over not stuttering because it was a more effective predictor for their own and others' responses. In relation to an appropriate intervention, Fransella (1972) hypothesised that changing from stuttering to fluency was related to the meaningfulness of being a fluent person. Evesham and Fransella (1985) found interventions, which actively modified a person's construal of self to show less improvement than a speech modification technique but a lower relapse rate. This suggests active modification of a person's construal of self was an important and effective approach to supporting people to reduce negative symptoms. This theory may also be relevant to the experience of people who are diagnosed with AS as adults, and presumably had lifetime experiences of difficulties.

The self and AS

There is a longstanding tradition for considering ASD as disorders of self and self-understanding, perhaps a reflection of the word 'autism' rooted in the Greek word 'autos' meaning self. Several authors have written specifically about identity formation in ASD (Aylott, 2000; Bagatell, 2007; Brownlow, 2010). Each suggest difficulties associated with ASD can be exacerbated by feelings of difference from others and a lack of belonging. They recommend support approaches, which facilitate the development of a positive sense of self and identity. However, the self has rarely been clearly defined and consequently research findings have often been at cross-purposes with each other (Zahavi, 2010). In addition, the self has rarely been explored among people with an AS diagnosis (Molloy & Vasil, 2004), much less for those diagnosed in adulthood.

A small body of research has explored self-understanding and the development of self during adolescence; particularly in view that this is a key period of identity development. In adolescence, social life is complex as a person attempts to establish oneself as a unique individual by drawing upon existing, recognizable cultural categories. For individuals with AS, who may find initiating and maintaining friendships difficult, the challenge of constructing a social identity is made even more complex (Bagatell, 2007). Problems in developing an effective sense of self in adolescence and young adulthood have been linked with serious mental health problems (Paradise and Kerr, 2002). Therefore, an underdeveloped personal identity may be a contributory factor to the mental health difficulties found across the lifespan of people with AS (Happe & Charlton, 2012).

Self-understanding in people with AS has been found to differ from a matched NT sample (Jackson, Skirrow & Hare, 2012). When considering the self, people with AS placed a greater emphasis on the present moment rather than the broader context of their lives; expressed a more permanent sense of self; and found physical aspects of self to be important. The authors hypothesise in this and a later paper (Skirrow, Jackson, Perry & Hare, 2014) that people use routines and repetitive behaviours to bridge the anxiety experienced as a consequence of internal self-discontinuity.

Rationale

At present, the paucity of research into the experience of people diagnosed with AS in adulthood, in particular the impact of a diagnosis on the sense of self, continues to be a blind spot for how best to support them socially and psychologically. Prevalence estimates combined with an aging population in the UK highlight the real and growing need for a better understanding of the experiences and needs of this specific population. While the

UK government seeks to increase understanding, provide appropriate assessment and therapeutic services and improve the lived experience of people with AS through its autism strategy (DOH, 2010), it is predominantly influenced by psychiatric and positivist discourses around diagnosis. In summary, the dominance of these discourses dictates the diagnosis as problem-saturated and permanently located within the individual and provides a narrow focus for understanding and opportunities for effective support. In the author's opinion, such a narrow focus appears at odds with the general consensus that the experience of adults with AS is highly complex and idiosyncratic. For example, adults have areas of strength as well as difficulty and both appear to be influenced by factors within and beyond the individual (Barnhill, 2007; Howlin, 2000).

While diagnosis may be important, there is a need to understand the meaning of AS and the experience of receiving the label for the individual. Little is known about the experience of people diagnosed with AS in adulthood, much less directly from them. This is surprising given the often very articulate and eloquent characteristics of people with this diagnosis. People with AS themselves have the potential to have a powerful voice in how society conceives of what AS is and what it means to live with it (Bagatell, 2010) and it is research such as this which can mobilise that powerful voice.

The recent findings of quantitative research (Jackson et al., 2012; Skirrow et al., 2014) offer some insight into self-understanding in adults with AS. However, it seems researchers' attempts to categorise and quantify the complex phenomena of AS and the self offer limited clarity or clinical applicability. By comparison, qualitative studies have attended to the individual nature of AS in adulthood and provided more specific ideas for social and psychological intervention. Punshon et al. (2009) suggest the meaning making processes to make sense of the diagnosis and its implications for the sense of self are likely to be areas which clinical psychologists and other professionals may be able to support.

This person-centred research study aimed to build upon previous UK-based studies exploring the experience of an AS diagnosis in adulthood (Punshon et al., 2009) and the need for support (Griffith et al., 2012). It aimed to provide clinically applicable findings that would offer ideas for supporting adults with AS socially and psychologically (Tantam, 2014). The specific focus on the sense of self of people receiving a diagnosis of AS in adulthood aimed to address significant gaps in existing research. PCP theory and a mixed-method research design offered a rigorous perspective from which to explore the sense of self among a group of people diagnosed with AS in adulthood so as to honour both individual idiosyncrasies and shared experiences.

Aim

The overall research aim was to explore the how people diagnosed with AS in adulthood construe the self. It was interested in whether personal construal of the self before

diagnosis and self after diagnosis were differentiated and in what ways. Exploration of the ideal self in relation to construal of self before and after diagnosis would establish the preferred construal of self. Given the importance in the development of self-concept of discriminations between the self and others, the research also sought to explore how people diagnosed with AS in adulthood construe other people with and without AS. Using a PCP approach, this study would value the unique experiences of individuals while also providing a novel exploration of themes across an otherwise under-researched population.
The main research questions were:

- How do people diagnosed with AS during adulthood construe the self?
- In what ways, if any, is the self before and self after diagnosis construed differently?
- How does the construal of the self before and self after diagnosis compare with the ideal self, and does this indicate any preference for having the diagnosis or not?
- How do people diagnosed with AS during adulthood construe other people with and without AS, and in what ways is this similar or different to the way they construe themselves?
- What are the clinical implications for understanding how the self is construed for individuals diagnosed with AS in adulthood?

Chapter 2: Method

2.1 Design

The research aimed to explore issues related to the self in people with AS. The phenomena of AS and the self are highly complex, thus requiring a methodological approach that facilitates exploration at more than one level (Monrad, 2013). Therefore a mixed quantitative and qualitative design was adopted. Although debates about the compatibility of different theoretical approaches to research continue, there is wider acceptance of the value of combining methodologies across a range of disciplines (Cresswell, Klassen, Plano Clark & Smith, 2011; Morgan, 2014; Tashakkori & Teddlie, 2010). When the specific strengths of quantitative and qualitative approaches are combined they can, in the best cases, be complementary and help to avoid the biases inherent in each approach (Johnson, Onwuegbuzie, & Turner, 2007). Using quantitative and qualitative approaches can provide different perspectives of the same phenomena and as such offers more and richer evidence (Cresswell et al., 2011).

'Repertory grids' (Kelly, 1955) provided an original mixed-method approach to identify idiosyncratic patterns (Winter, 2012) and structures of the self. The combination of repertory grids and semi-structured interviews has been used to triangulate data in other studies (Gerrish, Neimeyer & Bailey, 2014; Turpin et al., 2009). Therefore a semi-structured interview which was thematically analysed (Braun & Clarke, 2006) enabled further qualitative exploration of the perspectives of participants. A sequential design was adopted (Harrits, 2011; Morgan, 2014), beginning with repertory grid interviews, the analysis of which informed the semi-structured interview schedules for selected participants.

Epistemological stance

Malterud (2001) highlighted the significance of a researcher's background and epistemological stance in their decisions of what to investigate, the choice of methods, the findings considered most important and the conclusions drawn. As this study has used a mixed methodology it was important to acknowledge the author's position to ensure validity of the findings of the study. The author's interest in the topic was initiated by her work with a man in a forensic setting, who had received a diagnosis of AS. The therapeutic task was to explore the meaning of the diagnosis, which led to many discussions about his understanding of himself in the past, present and future. In addition, the aims for the autism strategy (DOH, 2010) in the UK welcomed new research to enhance understanding of the needs of adults with ASD and influence the political agenda and service provision.

The author adopted a social constructionist stance that challenges the notions of certainty and objective truth. Instead the stance encourages a critical stance towards the "taken-for-granted world" (Gergen, 1985, p.267), which was in line with her personal epistemology.

Repertory Grids (Kelly, 1955)

Repertory grids were chosen for this study as an effective method for investigating subjective experiences, particularly in relation to topics that are not easily defined or articulated (Burr, King & Butt, 2012). They are less prone to researcher bias than interviews or questionnaires, instead accessing information about personal experience directly from the participant.

Kelly (1955) suggests that personal construct systems are unique and so methods which position people as experts on their own experience should be employed to explore them. The repertory grid technique offered an opportunity for capturing how people view themselves. The technique does not force a response on the individual as a questionnaire might, but provides a reflective, collaborative interview structure (Pollock, 1989) as a unique way of exploring idiosyncratic and shared frames of reference (Pope & Shaw, 1981). The process of constructing and reflecting upon repertory grids is a useful way of equalizing the playing field between researcher and participant; a means of honouring the expertise of both parties; and a way of valuing multiple and alternative constructions which emerge (Hermans, 1997).

More specifically, Hare et al. (1999) found the repertory grid a useful technique for people with AS, who tended to be interested in number, order and sequence; had a preference for relatively formal structures and interactions; and needed flexibility within a set structure. They found the aspects of the procedure that required participants to refer to their own and other's mental states made the process slow but not insurmountable.

A number of studies have attempted to capture the reliability and validity of repertory grid measures (Feixas, Moliner, Montes, Mari & Neimeyer, 1992; Smith, 2000). Overall, repertory grids have been found to provide consistent information (Caputi, Viney, Walker & Crittenden, 2011). Caputi et al. (2011) expect the stability of constructs will vary at certain times in a person's life such as during psychotherapy. In terms of validity, correlations among measures have provided evidence for their distinctiveness, as well as supporting the concurrent validity of measures. Feixas et al. (1992) found conceptually related measures tended to converge, and conceptually distinct measures showed little relationship.

Repertory grids are not without their weaknesses. As stated above PCP assumes that people learn and develop from experience, and therefore their constructs may change over time, which can make replication of findings difficult. In addition, repertory grids do not necessarily explain contextual factors that may influence a participant's response at a particular time. Further limitations arise when the meanings of bipolar constructs appear to be contested, or aggregation of similar constructs from multiple individuals threatens to distort the collective analysis (Katz, 1984). In this research study a follow-up interview offered an opportunity to explore construct meanings with participants to avoid researcher bias in analysis.

Semi-structured interviews

Interviews are one of the most common methods in qualitative research to elicit perceptions, feelings and experiences from the perspective of the participant. Semi-structured interviews provide sufficient structure to allow the participant to set the agenda, and highlight issues important to them, while still addressing the information needed to answer the research questions.

When considering the most appropriate qualitative method to further explore the repertory grid data, a number of options including in-depth interviews were considered. A semi-structured interview, guided by the ABC method (Tschudi, 1977; Tschudi & Winter, 2012), offered a particularly useful method for exploring a subset of participants' views on AS as these related to their repertory grids and sense of self.

Analysis of the repertory grids informed the semi-structured interview schedule. The ABC method allowed exploration of what AS meant for the individual and their sense of self, the advantages and disadvantages associated with their diagnosis, and ideas to reduce difficulties.

Advice for employers interviewing people with AS suggested open-ended questions may be difficult to respond to (National Autistic Society, 2013). The semi-structured interview enabled the researcher to cover material appropriate to addressing the research question but offered a degree of flexibility in how questions and prompts were used.

2.2 Participants

Context

Participants were recruited from a voluntary sector support group for adults with AS living in the Greater London area. Members did not need a diagnosis of AS to attend; it comprised a mix of people seeking assessment and those formally and self-diagnosed. The support group provided opportunities for peer support and socializing, and information from professionals on a range of issues relating to AS. Monthly meetings were held at a community venue and members paid £2 to attend. The group comprised approximately 50 men and women, aged 18 and over.

The researcher was cognizant that recruiting from this group would potentially make for a biased sample since members of this self-selecting group had identified with AS in some way.

Purposive sampling approach

Purposive sampling was adopted. Maxwell (1997, p.235) defined purposive sampling as an approach in which "particular settings, persons or events are deliberately selected for the important information they can provide". This study was interested in the experiences of people diagnosed with AS in adulthood from a broad perspective, and so a purposive sampling protocol was defined for the first phase of the study. A purposive subsample of the original sample was later selected for further exploration in the second phase of the study.

Sampling protocol

Diagnosis

The specific aim of the current research was to explore whether construal of the self differed before and after a diagnosis of AS. Therefore people in the process of assessment were excluded from the study.

Participants were eligible if they had received a formal diagnosis of AS from a qualified mental health professional. Those with a diagnosis other than AS were excluded from participation, even when individuals identified more closely with AS than their actual diagnosis.

The sampling protocol did not limit the length of time since diagnosis for phase one. Gathering the experiences of participants with a range of time since their diagnosis offered a unique opportunity for reflection on the self before and after diagnosis using repertory grids.

Participants for phase two of the study were required to be less than three years from their diagnosis, in order to control for the recall bias inherent in retrospective reports of self before diagnosis.

Language

The mixed method approach relied heavily on language and was particularly appropriate for participants with AS (Gillberg & Ehlers, 1998). Participants were required to have English as a first language. This decision was made in the context of this being a time-limited piece of research. The researcher acknowledged this as a possible area for expansion of this research.

Sex

A sample which was closely representative of a 2.5:1 male to female ratio reported by previous research (Baron-Cohen & Wheelwright, 2004) was selected for phase one of data collection. Based on the findings of the repertory grid analysis a unique subsample of three females was selected for the phase two interview because they were closely matched on a number of other demographic characteristics yet the findings from their repertory grids were varied.

Age

Participants needed to have been assessed after their eighteenth birthday and a representative sample of ages across the lifespan was recruited in the first phase of data collection.

A subsample of female participants aged fifty and over were selected for the second phase of the study to address the identified gap in knowledge about this age group (Griffith et al., 2012; Happe & Charlton, 2012; Tantam, 2014) and to reduce confounding variation.

Recruitment Procedure

The research was outlined at one of the monthly meetings of the support group. Members were invited to express an interest in participation by leaving their name, contact details and preferred method of communication with the researcher. Interested participants were contacted by email and telephone, given a more detailed explanation of what the research would involve and invited to ask any questions.

A brief screening tool was used to assess fulfillment of inclusion criteria and to meet the purposive sampling strategy. Potential participants were sent the information sheet and consent form via email or post following the initial screening phone call. A follow-up call was offered to answer any further questions, confirm participation and arrange an appointment for the structured repertory grid interview.

Sample

Overall, thirteen people expressed an interest in participating. Eight people met the sampling criteria and were selected. Five participants did not meet one or more inclusion criteria; being still in the process of assessment (n=3); having a diagnosis other than AS (n=1); being diagnosed during childhood (n=1); and/or not having English as a first language (n=1). Eight people aged between 28-66 years of age consented to participate in phase one of the study, five of which were male and three female.

2.3 Measures

Demographic data

Demographic data was collected about age, sex, ethnicity, level of education and occupation. In addition, information was gathered in relation to the diagnosis of AS and other mental health difficulties: reason for adult assessment, age at assessment and diagnosis, type and location of assessment, assessments in childhood, and mental health history.

Measurement of Psychological Wellbeing

The General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988) is a widely used screening device for identifying minor psychiatric disorders in the general population. The

12-item questionnaire assesses an adult's ability to carry out normal functions and the appearance of new and distressing phenomena. Research indicates good validity and reliability (Goldberg & Williams, 1988). Its application in survey research including the Health Survey for England and Living in Britain Survey offered the possibility of comparing participant results to normative data. Hu, Stewart-Brown, Twigg, & Weich (2007) suggest it can also be used to identify positive wellbeing, although Hankins (2008) highlights the potential for response bias on the negatively phrased items. On balance, the GHQ-12's brevity and simplicity was a key factor for its use in combination with more time intensive measures.

Phase 1: Structured Repertory Grid Interview

The structured repertory grid interview aimed to explore participants' construal of elements using elicited personal constructs. The procedure was informed by previous research (Hare et al., 1999), which deemed it appropriate to ask people with AS to think about different self, social self and other elements.

This interview comprised four stages (Jankowicz, 2004). Firstly, participants were informed of the topic area by the information sheet and conversations with the researcher. Secondly, participants were presented with twelve elements (below) determined by the researcher in relation to the research question and were invited to compare and contrast elements systematically with each other to elicit constructs. Finally, participants were required to rate each element (self and others) against the different constructs generated (Winter, 1992).

Grid Elements

To preserve the validity of the grid design, care was taken to choose homogenous elements for inclusion. Elements needed to be within participants' capacity to understand and *range of convenience* (Fransella, Bell & Bannister, 2004). The elements were correspondent with the main research questions and the area and population of study. Elements pertaining to the self at different time points, the self as viewed by others (social-self) and other relevant people were important and relevant for this study.

The following elements were provided by the researcher on individual flashcards:

- Self before a diagnosis of AS
- Self after diagnosis of AS
- Self now
- Ideal self
- Self in one year's time
- Self as someone with a diagnosis of AS perceives me
- Self as a Neurotypical person (without AS) perceives me

- A person I know who has AS
- A person I know who has AS (different to previous)
- A person I know who is Neurotypical (without AS or other ASD)
- A person I know who is Neurotypical (without AS or other ASD)

Participants were shown each element card. For the self and social-self elements they were permitted to write brief notes and for the non-self elements were asked to name a person who fulfilled each role. If they were not able to identify someone they knew personally, they were asked to think about the type of person who they thought best fitted the role.

Elicitation of constructs

Elicitation of personally relevant constructs was felt to be important in understanding individuals' personal meanings so the researcher attempted to elicit ten or more constructs using either triad or dyad combinations. The researcher provided the construct of "Asperger Syndrome - Neurotypical" to enable a comparison across the sample.

To increase the replicability of this research in the future, an elicitation protocol was established:

- Elements most relevant to the research question were prioritised (e.g. self before and after diagnosis, ideal self, other elements with and without AS).
- Each element appeared in a triad or dyad combination at least once.
- Triad elicitation was attempted in the first instance.
- If participants found triadic elicitation too difficult, dyadic elicitation was implemented.
- Participants were invited to choose their preferred elicitation approach.
- Previous research had found people with AS varied in the number of constructs they could elicit (Hare et al., 1999) and the priority here was to keep people engaged with the task so the elicitation process was ended either when people had difficulty finding new constructs with dyad or triads, or expressed a preference to finish.

In all instances, Kelly's (1955) original triad elicitation method was attempted with participants. However, only two participants utilized this method to complete elicitation. This involved showing three element cards and asking, *'In which important way are two of these alike and different from the third?'* The response was recorded as the emergent pole and the implicit pole was elicited by asking, *'Can you think of a phrase or word to describe the opposite of (emergent construct pole)?'*

The triads were presented sequentially by changing only one element at a time, as recommended by Kelly (1955). To ensure the personal relevance of elicited constructs, at least one ‘self’ element was retained in each presentation.

Epting, Schuman and Nickeson (1971) proposed that more explicit contrast poles could be obtained using only two elements at a time. This procedure involved presenting the participant with pairs of elements and asking ‘*In what way are these alike or different?’* If a similarity was offered, it was used as the emergent pole and then the participant was asked, ‘*Can you think of a phrase or word to describe the opposite of (emergent pole)?’* If a difference was offered, the descriptions of difference were used to form the bipolar construct. This was the preferred method of elicitation for participants in this study.

Rating of elements along constructs

Participants rated elements on a 7-point scale for each of the elicited constructs. Emergent poles were rated as seven and contrasting implicit poles were rated as one. A printed Likert scale was provided and the participant’s construct poles were written on separate cards and placed at the appropriate ends of the scale as a visual aid for this.

Phase 2: Semi-structured follow-up interview

A follow-up interview was carried out with three participants who were demographically similar in terms of close proximity to diagnosis, sex and age so that the similarities and differences between their repertory grids could be explored and compared as a group.

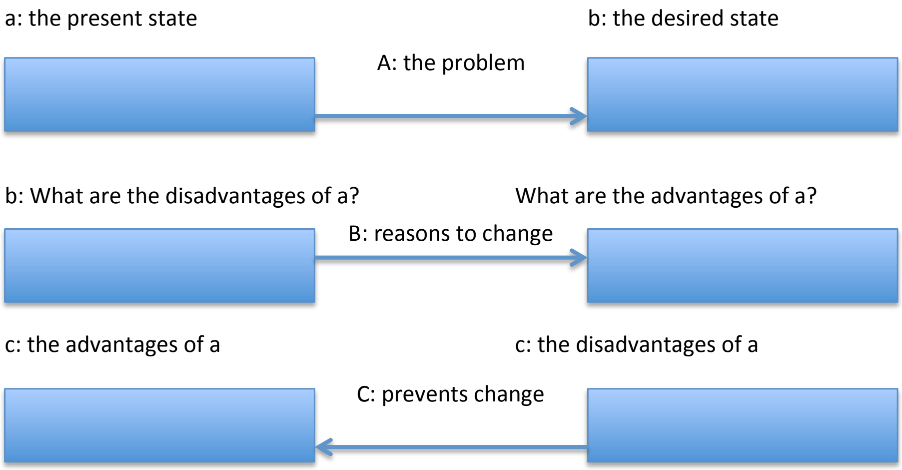


Figure 2.3.1: Illustration of Tschudi’s (1977) ABC Model

ABC Method (Tschudi, 1977)

This method devised was used to explore the advantages and disadvantages of AS and being neurotypical. The model, illustrated in Figure 2.3.1, provided a useful framework for exploring the factors influencing whether participants’ construal of self may or may not have changed following their diagnosis. Two further questions were added to the original method:

- What might need to happen for you to achieve the desired state?
- What might be the advantages or disadvantages of a position in the middle of AS and being neurotypical?

These questions were informed by the repertory grid interviews, in which participants gave accounts of what movement towards a construct pole might require. For some participants the ideal self was positioned in the middle of AS and being neurotypical.

Interview Schedule

The interview schedule (see Appendix 2) was devised to allow a degree of methodological triangulation (Mason, 2002). The initial part of the interview was used to share a summary of the individual's repertory grid and the principal component analysis of this. Participants were invited to comment on the findings, explaining or justifying as appropriate. A range of open-ended questions with possible prompts and closed questions were prepared. An iterative approach meant the schedule could be adapted to suit individual participant responses.

Questions relating to the summary were adapted from Fransella et al. (2004) and Jankowicz (2004). Questions sought to clarify advantages and disadvantages of having AS or being neurotypical, the characteristics of either and how participants felt they fitted the description of AS. They were tailored to each individual but aimed to explore the impact of an AS diagnosis, the experience of the diagnostic process on the sense of self, relationships and quality of life. They also explored the nature of support (if any) received by the individual and what would have been beneficial for them. Additional questions and prompts, influenced by the literature review, were used to further explore the main research questions and the semi-structured format gave participants opportunities to raise issues important to them.

2.4 Ethical considerations

Ethical approval

The University of Hertfordshire Ethics Committee with Delegated Authority (ECDA) for Health and Human Sciences granted ethical approval (See Appendix 3).

Informed consent

Informed consent was gained using the ECDA approved participant information sheet and consent form (See Appendix 4). Information sheets were distributed following the initial point of contact and reviewed via telephone conversation and at the start of the first interview. Participants were invited to ask questions and reminded of their capacity to withdraw from the study at any time without giving an explanation and without any risk of impacting on current or future services. Participants were asked to read the consent form and sign to give their consent. The consent process was repeated for participants who took part in a phase two interview. They were advised that the findings of the study would be published as part of the researcher's doctoral thesis and that presentations and articles would follow, but confidentiality and anonymity would be maintained at all times.

Managing distress

The following procedures were planned to manage potential distress that participants might experience when talking about their self-concepts and diagnosis-related experiences. Interviews were held at a location of the participant's choosing (e.g. home, workplace or private room arranged by the researcher). Participants were reminded that they did not have to answer any questions that they did not wish to answer, and that they could stop the interview and take a break at any point. If a participant showed any sign of distress the researcher would draw on her clinical experience of working with people who are distressed and use person-centred clinical skills to be empathic, listen and contain the participant's distress. Participants would be reassured that they did not have to continue with the interview and signposted to appropriate services as necessary.

Post interview, participants were offered a debriefing telephone call or email conversation at their request. All participants were sent an email or letter thanking them for their participation and given contact details should they wish to speak to the researcher.

Confidentiality

Confidentiality was protected using anonymous identification codes on all data records and pseudonyms used during analysis and reporting. All data was password-protected and stored in accordance with data protection legislation.

2.5 Procedure

In order to optimize the convenience and comfort of participants, they chose the initial method of contact (email or telephone) and a convenient location (e.g. home, work or private room arranged by the researcher) to be interviewed over one, two or three 90-minute sessions. Figure 2.5.1 illustrates the different phases of the research process.

During Phase 2, principal component analysis plots (see below) were presented to participants and an individualized semi-structured interview was undertaken to explore what sense participants made of the grids and explore the research questions using an alternative methodology. The approach of combining repertory grids and semi-structured interviews had been found to offer a degree of triangulation in other studies (Smith, 1990, 1994; Turpin et al., 2009).

The interviews were recorded with the participants' permission and were transcribed verbatim. Brief field notes were taken during the interview to record external factors impacting on the interview as well as inconsistencies. This allowed the researcher to adjust the approach for subsequent interviewees.

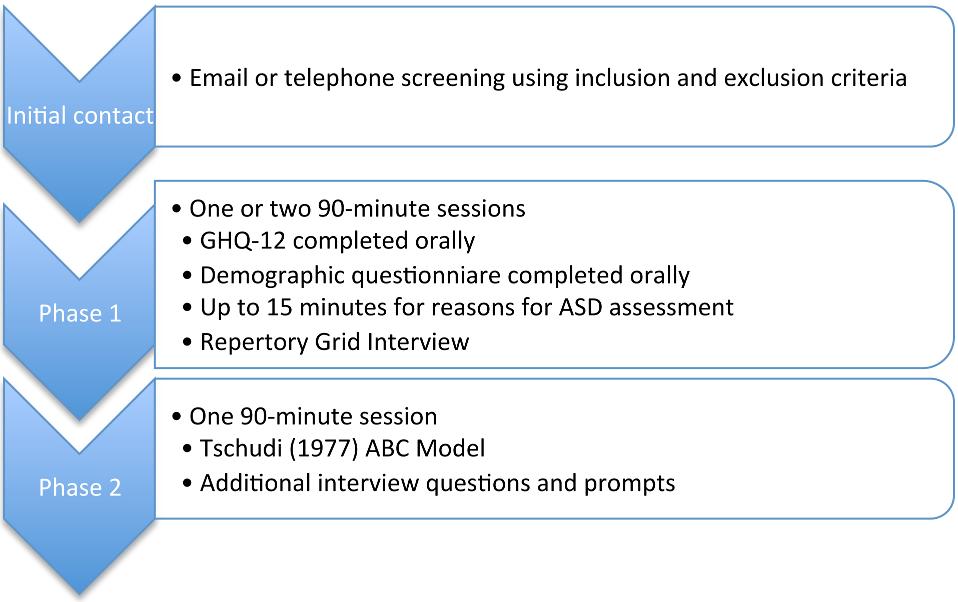


Figure 2.5.1: Illustration of research procedure

2.6 Analysis Overview

Findings from the demographic questionnaire provided a descriptive profile of participants across the domains of personal characteristics and AS diagnosis. Findings from the GHQ-12 (Goldberg & Williams, 1988) were used to provide descriptive data of the sample's characteristics regarding emotional wellbeing.

Content analysis of repertory grid constructs

The content analysis of constructs in the repertory grids was informed by Feixas, Geldschläger and Neimeyer's (2002) Classification System for Personal Constructs (CSPC). The CSPC has been applied, either fully or partially, in several repertory grid studies including research into element role titles (Haritos, Gindidis, Doan, & Bell, 2004), self-concept (Compañ et al., 2011) and depressed people (Montesano et al., 2014).

The CSPC recommended bipolar constructs be coded as complete meaning dimensions rather than coding two construct poles separately as Landfield's (1971) classification system had done. Green (2002) acknowledges there are benefits of both approaches however. The CSPC provided a six-category coding system, with 45 sub-categories relevant primarily for psychological constructs. Major categories were hierarchically organised so each construct would be allocated to the highest order category applicable. Three categories found to have lower inter-rater reliability by the CSPC creators were relevant and so included in this research study. This was not found to lower the overall reliability.

The CSPC's application in this research study enabled the author to categorise and explore the types of constructs elicited by individuals and across the sample. The content analyses were considered at a group level for the grid constructs, and the content of the constructs defining ‘self before diagnosis’, ‘self after diagnosis’, ‘self now’ and ‘ideal self’ elements (using extreme ratings of either 1 or 2, or 6 or 7) were compared.

Two raters coded grid constructs independently. Discrepancies were typically associated with the use of subcategories and were resolved through discussion. The raw percentage agreement was 80%, which gave a high level of inter-rater reliability (Cohen’s kappa = 0.81; Cohen, 1960) according to Landis and Koch’s (1977) interpretation of kappa scores. This was close to Feixas et al.’s (2002) study, which found 87% inter-rater reliability (Cohen’s kappa = 0.89).

Analysis of raw grid data

Each participant’s raw grid scores were examined using the Jankowicz (2004) ‘eyeball analysis’ to consider how the participant construed the self before and after diagnosis, now and ideally. Extreme ratings of 1 and 2, or 6 and 7 were viewed as defining constructs (Fernandes, 2007).

Analysis of grid data using Idiogrid version 2.4 (Grice, 2008)

All repertory grids were analysed individually using Idiogrid (Grice, 2008), a grid analysis software package. Slater (1977) analyses were conducted on each grid to produce the following measures.

Correlations between constructs

Correlations between the provided construct ‘AS-Neurotypical’ and other grid constructs were calculated using Pearson’s r for each participant. Dancey and Reidy’s (2004) categorization was used to assess the strength of correlations. Constructs correlating most highly (r=0.7-0.8) with the ‘AS’ construct were considered to indicate the meaning of AS for the participant.

Distances between elements

Distances between elements were reviewed using the standardized Element Euclidean Distances (Grice, 2006). This would indicate whether the participant construed elements similarly or not. The following pairs of elements were of particular interest;

- Self before diagnosis/Self after diagnosis
- Self before diagnosis/Self now
- Self before diagnosis/Ideal self
- Self after diagnosis/Self now
- Self after diagnosis/Ideal self
- Person with AS/Self now
- Person with AS/Ideal self
- Neurotypical person/Self now
- Neurotypical person/Ideal self

The distance between pairs of elements indicated how similarly or differently the participant construed them. A distance of less than 0.5 implies that the elements are very similar and a distance of more than 1.5 indicates that the elements are very different (Winter, 1992). A distance of 1 is the expected value for the distance between elements. The distance between self now and ideal self was used as a measure of self-esteem with a smaller distance reflecting a high self-esteem.

Measure of elaboration: sum of squares

The sum of squares accounted for by each element, and these scores as a percentage of the total sum of squares, showed the meaningfulness of elements to the participant (Winter, 1992). A high score was taken to indicate an element was relevant, while a low score indicated mid-point ratings on most constructs. The percentages total sum of squares of elements self before diagnosis, self after diagnosis, self now and ideal self were compared for each participant.

Principal component analysis: percentage variance accounted for by principal components

The percentage of variance accounted for by the first principal component was used as a measure of cognitive complexity (Winter, 1992). High percentages of variance demonstrated a more simple or one-dimensional type of construing, which are properties of a tight construct system. Lower scores indicate greater differentiation or complexity and reflect looser construing. A tentative approach was taken to interpreting these findings when repertory grids were small.

Superordinate constructs

The constructs loading most highly on the first principal component were viewed as being superordinate constructs within the participant's construct system (Winter, 1992). Both the terms core construct and superordinate construct were used synonymously, as they referred to stable, higher-order constructs that relate to a person's identity.

Principal component analysis plot

The principal component analysis provided a two dimensional plot for each participant. These plots illustrate the relationship between the participant's elements and constructs and are based on the loadings of each element and construct on the first two components (Watson & Winter, 2000). The constructs (as they are accounted for by component one and two) are shown as vectors on the plot and the elements are shown as points on the plot. Generally, elements that are plotted in the same quadrant are construed similarly, whereas those plotted in diagonally opposite quadrants are least similar to each other. The elements that are close to the origin of the plot are less significant to the participant, while the elements that are furthest from the origin are construed most extremely (Grice, 2006; Watson & Winter, 2000).

Implicative dilemma analysis

Implicative dilemmas (Hinkle, 1965, cited by Winter, 1992, p.23) are composed of two types of construct; *discrepant* constructs, which indicate some dissatisfaction; and *congruent* constructs, which reveal personal qualities a person would not like to change at all (Montesano at al., 2014). Unlike discrepant constructs, congruent constructs are assets of one's personal identity and therefore their change can be experienced as threatening (Fernandes, 2007). They were therefore an important consideration for this research study.

Both construct types were identified by comparing repertory grid ratings of self now and ideal self; a difference greater than three points was indicative of a discrepant construct and a difference less than two points is indicative of a congruent construct. An implicative dilemma arises when the correlation between a discrepant and congruent construct exceeds 0.2 and is in a direction that movement towards the preferred pole of the discrepant construct implies movement away from the preferred pole of the congruent construct (Feixas & Saúl, 2005).

Thematic analysis (Braun & Clarke, 2006)

The thematic analysis adopted a combination of inductive and deductive approaches. While initially driven by data emerging from the phase two interviews, the PCP theoretical underpinning and research questions influenced the researcher.

Thematic analysis offered a flexible, simple approach to analyzing the data from the semi-structured interviews, which is independent of theory but applicable across a range of theoretical approaches (Braun and Clarke, 2006). Its ability to reflect reality and how that is constructed socially through the processes of identification, organisation and reporting of patterns within data was advantageous.

Braun and Clarke's (2006) and Huberman and Miles's (1994, cited by Joffe & Yardley, 2004) guidelines informed the stages of thematic analysis. Interviews were recorded and listened to as soon as possible afterwards to allow the researcher to reflect on the data as well as learn from the limitations of the interview process. Listening back to recordings immediately after the interview enabled the researcher to make links between phase one and two findings. As the interviews progressed, recurrent and new topics emerged.

Each transcript was read repeatedly. Phrases and sentences from the data expressing feelings, ideas and experiences were highlighted and coded manually using extracts from the data to illustrate each code. A large number of codes were identified which led to a further exploration of the relationship between them, how they hung together and made sense of the data. This led to the creation of a smaller number of overarching themes with subthemes illustrated with excerpts from the data.

The process was then applied across all three transcripts, exploring how the individual themes fitted with the overall data and shifting about as necessary to ensure coherence and to highlight consistencies and contradictions within the themes. At that stage there were many overlaps so the codes were further refined into main themes and sub-themes based on a combination of emerging data and the research questions.

Chapter 3: Results

This chapter reports individual and group findings of the repertory grids and semi-structured interviews as relevant. Phase one findings influenced phase two. Results from phase one-only participants and the group analysis are presented first. Participants' in both phase one and two results follow and are reported chronologically to aid coherence for the reader.

3.1 Demographic Information

Full demographic details of participants are in Table 3.1.1. A ratio of 5:3 males to females participated. The proportion of females exceeded that expected and found in other studies (Baron-Cohen & Wheelwright, 2004). Participant ages ranged from 29 to 66 years (mean = 49.5, SD = 12.7), a unique aspect being that half were over 50 years old.

The sample was diverse, with half from black and minority ethnic groups. Participants were single (n=6), divorced (n=1) and married (n=1). Two-thirds had Bachelor's degrees. All described difficulties in employment but only one person of working age was unemployed.

Table 3.1.1: Demographic data for participants who completed repertory grids

Demographic Information			
		n	**%**
Gender	Male	5	62.5
	Female	3	37.5
Current Age	26-30	1	12.5
	31-35	-	-
	36-40	1	12.5
	41-45	1	12.5
	46-50	-	-
	51-55	3	37.5
	56-60	-	-
	61-65	1	12.5
	66+	1	12.5
Ethnicity	Asian British	2	25.0
	Black British	2	25.0
	White British	4	50.0
Religion	No religion	3	37.5
	Buddhist	1	12.5
	Christian	2	25.0
	Muslim	1	12.5
	Sikh	1	12.5
Marital Status	Single	6	75.0

	Divorced	1	12.5
	Married	1	12.5
Highest Qualification	O-Level / GCSE	2	25.0
	Bachelor's Degree	5	62.5
	Diploma	1	12.5
Employment Status	Part-time	4	50.0
	Full-time	1	12.5
	Self-employed	1	12.5
	Unemployed	1	12.5
	Retired	1	12.5
MH diagnosis currently/in the past	Yes	8	100.0
	No	-	-
Age at Diagnosis	26-30	1	12.5
	31-35	-	-
	36-40	2	25.0
	41-45	-	-
	46-50	3	37.5
	51-55	2	25.0

3.2 Access to Mental Health Services

All participants had accessed community mental health teams (CMHT) for depression, anxiety, psychoses, obsessive-compulsive disorder and suicide attempts prior to their AS diagnosis. All had received medication or therapeutic interventions for their mental health difficulties but only one had continued to receive this after the AS diagnosis. Three were offered and accepted post-diagnostic therapeutic support following diagnosis. Two participants never heard back from services.

Table 3.2.1: Descriptive statistics of participant access to mental health services before and after diagnosis of AS

	Mental Health Services Accessed			
	Before diagnosis of AS		**After diagnosis of AS**	
	n	**%**	**N**	**%**
Yes	8	100.0	2	25.0
No	-	-	6	75.0

3.3 General Health Questionnaire (GHQ-12)

GHQ-12 scores are presented in Table 3.3.1. Table 3.3.2 shows the descriptive statistics and indicates the sample was moderately skewed towards low scores for psychological distress.

The youngest participant scored within the 'severe psychological distress' range. He was accessing private psychotherapy for depression and anxiety. Another participant scored within the 'evidence of distress' range but was not receiving psychological support, having had negative experiences of services. Six participants scored within the 'non-clinical' range, one of whom was receiving psychology support in a CMHT.

Table 3.3.1: Descriptive statistics of GHQ-12 with clinical descriptor by participant

	Demographic information				**GHQ-12 Scores**	
	Gender	**Age**	**Age at diagnosis**	**Years diagnosed**	**Raw score**	**Clinical descriptor**
Judy	Female	51	50	0.5	6	Non-clinical
Tariq	Male	39	38	1	8	Non-clinical
Hazel	Female	51	50	1	12	Non-clinical
Peter	Male	28	26	2	22	Severe psychological distress
Fahim	Male	42	39	3	12	Non-clinical
Stella	Female	56	53	3	19	Evidence of distress
Jack	Male	63	51	12	10	Non-clinical
David	Male	66	48	18	12	Non-clinical

Table 3.3.2: Descriptive statistics of GHQ-12 for the total sample

	Total Sample						
	n	**Mean**	**SD**	**Median**	**Minimum**	**Maximum**	**Skewness**
GHQ-12	8	12.6	5.4	12.0	6	22	0.83*

* GHQ-12 scores are moderately positively skewed.

3.4 Repertory Grids for Tariq, Peter, Fahim, Jack and David

3.4.1 Tariq's Repertory Grid

Tariq was 39 years old and diagnosed with AS for thirteen months. He reported employment difficulties. Following a tribunal against his employers when he was 27, he experienced severe depression and contemplated suicide. He engaged with a cognitive behavioural therapist through a CMHT. Tariq found the therapy useful and would obsessively research terms and techniques he had learnt. He found that cognitive distortions were common among people with AS and on returning to his therapist with this information he was referred for an assessment.

Tariq was pleased with the outcome of the assessment and felt the diagnosis explained many of his difficulties. It gave him an alternative and "less critical" view of himself.

The repertory grid method intrigued Tariq and rather than spread the time over two sessions he preferred to complete it in two and a half hours. Tariq's grid and the tables illustrating the Idiogrid analysis can be found in Appendix 5.

Raw grid data *(Table A5.1)*

Defining the self before diagnosis

The self before diagnosis was construed extremely, often using unfavourable construct poles. Tariq construed the self before diagnosis as self-hating, unfocussed, unspontaneous, uncomfortable in his own skin, a black and white thinker, emasculated, self-centred, scared of consequences, physically rigid and monotone.

Defining the self after diagnosis and self now

On ten of thirteen constructs Tariq construed the self after diagnosis in the same way as the self before diagnosis. The self after diagnosis was unfocussed, unspontaneous, uncomfortable in his own skin, a black and white thinker, emasculated, self-centred, scared of consequences and physically rigid. He was less self-hating and rather more eloquent than monotone.

Tariq construed self now as focussed, unspontaneous, uncomfortable in his own skin, black and white thinker, self-centred, physically rigid and eloquent. Though similar to Tariq's construal of the self before and self after diagnosis, a complete reversal from being unfocussed to focussed was significant. Tariq associated this change with him being set on pursuing a career as an artist and this being the main focus of his attention.

Defining the ideal self

Tariq construed the ideal self as accepting of self, confident, world-weary, manly, someone who helps others, free flowing (not physically rigid) and eloquent. The ideal self would be focussed but less so than the self now. This suggests Tariq perceives advantages and disadvantages to the level of focus he has currently.

Defining the social self

Tariq construed that other elements would share the view of him as accepting of himself, focussed, a black and white thinker and eloquent. A person with AS would construe him as loud, whereas an NT person would see him as quiet. An NT person would also define him as world-weary, manly, self-centred, manipulative, mentally carefree, physically rigid and eloquent, though his construal using the supplied construct implies an NT person would not recognise him as having AS.

Defining AS

Tariq construed AS elements as uncomfortable in their own skin, quiet, scared of consequences, emasculated and physically rigid, whereas NT elements were confident, manly, loud, mentally carefree and physically free flowing. These constructs are likely to be used by Tariq to distinguish between AS and NT.

Tariq construed the self before and after diagnosis, self now and one AS element using the AS pole. Both NT elements and the self as a NT sees him were construed using the NT pole. The ideal self was construed at the midpoint of the construct, suggesting Tariq perceived advantages of both construct poles. It is possible Tariq used the NT pole rather rigidly but viewed the rest of the scale as a spectrum of AS.

Content categorization of Tariq's constructs (Table A5.2 & Table A5.3)

Thirteen constructs were categorised into six categories using the CSPC (Feixas et al., 2002), all of which were used to define self-elements.

Slater analysis

Correlations between supplied and elicited constructs (Table A5.4)

Five of Tariq's constructs correlated strongly with the supplied construct. The other constructs were moderately correlated but will not be reported here. This was in contrast to other participants and indicated that many of the constructs were associated with the meaning of AS for Tariq. Strong correlations indicated that AS was associated with being unspontaneous (r=0.84), uncomfortable in own skin (r=-0.77), emasculated (r=-0.83), scared of consequences (r=0.94) and physically rigid (r=0.75). By contrast, Tariq associated being NT with being spontaneous, confident, manly, mentally carefree and (physically) free flowing.

Distance between elements (Table A5.5)

The self before and self after diagnosis were close in distance and therefore construed similarly. Both were construed differently to the ideal self. Large distances were also found between the self now and both NT elements, further supporting the finding that Tariq construed himself quite differently to them. The distance between the self now and ideal self was neither particularly high nor low (Winter, 1992).

Measure of elaboration: sum of squares (Table A5.6)

Of the self-elements, the self before diagnosis and self as a NT person sees him were most elaborated and meaningful. Perhaps his difficulties in employment had been influential in elaborating these elements for him. It is also possible that the reduced percentage total sum of squares for self after diagnosis and self now indicate a reduction in his sense of self.

Superordinate constructs (Table A5.7)

The percentage total sum of squares for Tariq's constructs shows the greatest variation in Tariq's rating of the 'self-centred-helps others' and 'unspontaneous-spontaneous' constructs, which indicates they are likely to be superordinate.

Principal component analysis: percentage variance accounted for by principal components (Table A5.8, A.5.9, A5.10)

A relatively large percentage of variance was accounted for by the first principal component and a relatively small amount by the second principal component. This might be indicative of a tightly structured construct system that is cognitively simple.

The loadings of elements and constructs on the first principal component indicate that this contrasts self before diagnosis with both NT elements. The first principal component discriminates between people who are ‘unspontaneous’ and ‘uncomfortable in own skin’ and those who are ‘spontaneous’ and ‘confident’.

The loadings of elements and constructs on the second principal component contrast an NT element and AS element with self as a NT person sees me. It concerns ‘self-centred-helps others’ and ‘monotone-eloquent’ constructs.

Principal component analysis plot (Figure 3.4.1)

Few elements appear close to the origin of Figure 3.4.1 because Tariq frequently used extreme ratings. The ideal self appeared in the same quadrant as NT elements, indicating similarities in how Tariq construed them. The self after diagnosis appears in the opposing quadrant as it was construed very differently.

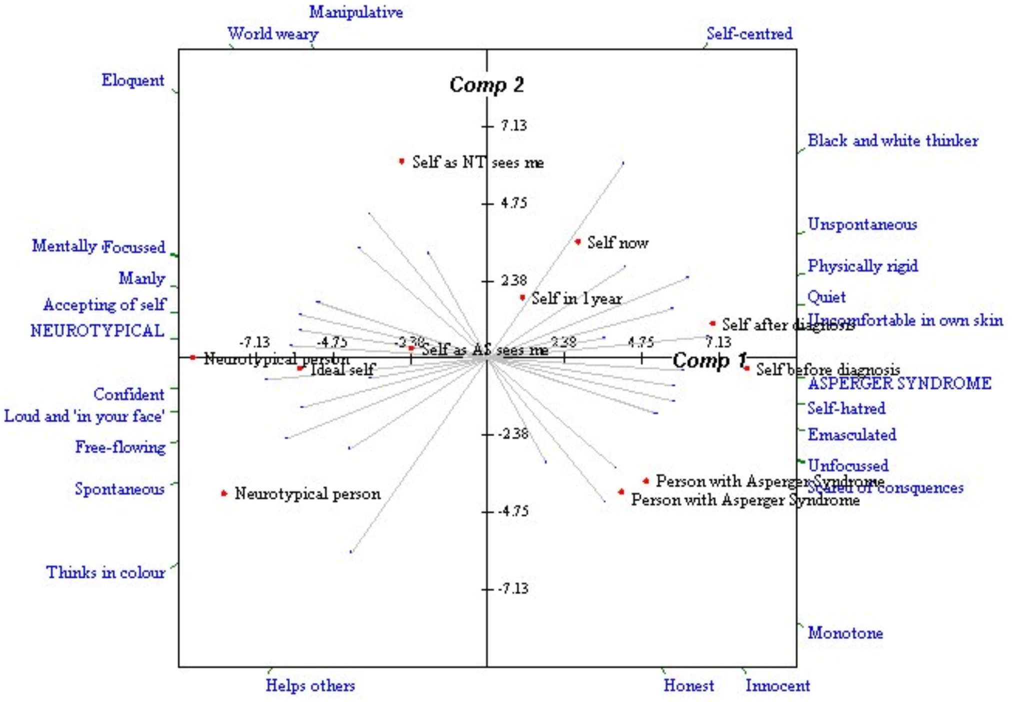


Figure 3.4.1 Tariq’s principal component analysis plot (Axis Range: -9.50 to 9.50)

Implicative dilemmas

Idiogrid found no implicative dilemmas in Tariq’s construct system using the congruent construct criterion of 0.2. Four of Tariq's constructs were found to be congruent. He would be resistant to change his position on 'accepting self-self-hatred', 'focussed-unfocussed', 'quiet-loud and 'in your face'' and 'monotone-eloquent' constructs.

3.4.2 Peter's Repertory Grid

Peter was 28 years old and diagnosed for two years. Peter had worked in a supermarket for 12 years and people had often commented on his blunt responses and lack of eye contact. Peter experienced a prolonged episode of severe depression and was seen in a CMHT. The psychiatrist suggested he might have AS. Following his diagnosis he was discharged from the CMHT and offered Cognitive Behavioural Therapy. However, after a year of no contact from the service Peter found a private therapist whom he continued to see weekly.

Peter hoped the interview would further develop his understanding of himself and AS. He completed the repertory grid over two sessions and reported he had spoken about it with his therapist. Peter's grid and the tables illustrating the Idiogrid analysis can be found in Appendix 6.

Raw grid data *(Table A6.1)*

Defining the self before diagnosis

Peter construed the self before diagnosis using extreme ratings and unfavourable construct poles. Self before diagnosis was construed as unable to help self, jumps to conclusions, ignored, worries about talking to people, relates superficially to others, lonely and isolated, makes people feel uncomfortable, makes little eye contact and acts without full facts.

Defining the self after diagnosis and self now

Peter's construal of self after diagnosis was less extreme but generally remained unfavourable. The self after diagnosis was construed as someone who worried about talking to people, related superficially to others, was lonely and isolated, made people feel uncomfortable, and made little eye contact.

Self now was construed more favourably on several constructs though all ratings were at or close to the midpoint of the scale.

Defining the ideal self

Peter used only extreme values to construe the ideal self. Peter's ideal self would understand self, recognise subtle differences, fit in, be extrovert, have friendships, be composed and rational, outgoing, integrate with others, make the right eye contact, be knowledgeable, affable, grounded and realistic.

Defining the social self

From Peter's perspective, people with AS would construe him favourably as able to understand himself, recognise subtle differences, fitting in, knowledgeable, affable, and grounded and realistic. By contrast Peter construed that NTs would see him as unable to help himself (through lack of understanding), someone who jumps to conclusions, worries about talking to others, relates superficially, is unpredictable, lonely and isolated and makes little eye contact. This perhaps reflects Peter's experiences of NT people commenting on his behaviours compared to people with AS who, by virtue of a shared experience, might construe him rather differently.

Defining AS

Peter's construct about eye contact made a clear distinction between AS elements and NT elements, with the former making 'little' and the latter making 'the right amount'. His construal of AS elements was variable across elements, while his construal of NT elements was more uniform. He construed NT elements as extroverts, who have friendships, are outgoing and integrate with others.

Peter construed the self before and after diagnosis at the AS pole of the supplied construct. The ideal self and other AS elements were construed at the midpoint of the scale, whereas the NT elements were construed at the NT pole. The AS pole or label might be more complex and like a spectrum than the NT pole, which is more definitive.

Content categorization of Peter's constructs (Table A6.2 & A6.3)

Twelve constructs were classified into six categories and eight subcategories of the CPCS (Feixas et al., 2002). Self-defining constructs for the self before diagnosis and ideal self were most elaborated and classified as emotional, relational, personal, existential and concrete descriptor constructs. Table 3.5.9 shows fewer types of construct were used to define other self-elements.

Slater analysis

Correlations between supplied and elicited constructs (Table A6.4)

Five of Peter's constructs correlated strongly with the supplied construct: 'extrovert-introvert' (r=-0.74), 'relates superficially to others-has friendships' (r=0.80), 'outgoing-lonely and isolated' (r=-0.85), 'integrates with others-makes people feel uncomfortable' (r=-0.84) and 'little eye contact-right amount of eye contact' (r=0.82). This means that Peter construes people with AS to be introverted, relate superficially to others, lonely and isolated, make people feel uncomfortable, and make little eye contact.

Distance between elements (Table A6.5)

The self before and after diagnosis was very similar. Peter construed the self now and both

AS elements similarly. By contrast, there was a very large difference between the ideal self and self before diagnosis, and to a lesser extent self after diagnosis. A large distance was found between the self as a NT person sees me and ideal self. This would indicate that Peter would like to be perceived very differently to the way he is perceived by NT people.

Measure of elaboration: sum of squares (Table A6.6)

Descriptive statistics for elements indicate the self before diagnosis and ideal self were most highly elaborated. By contrast, the self after diagnosis and self now were viewed less extremely. These findings would suggest Peter was less able to make sense of himself following his diagnosis.

Self as a NT person sees him and both NT elements were highly elaborated. This is likely to be due to Peter construing NT elements in extreme ways and was likely to have been influenced by his experiences of people who are NT commenting on his style of interaction.

Superordinate constructs (Table A6.7)

The percentage total sum of squares for constructs shows the greatest variations in the following constructs, which may be superordinate: ‘little eye-contact-right amount of eye contact’, ‘extrovert-introvert’, ‘outgoing-lonely and isolated’, and ‘relates superficially to others-has friendships’.

Principal component analysis: percentage variance accounted for by principal components (Table A6.8, A6.9 & A6.10)

A large percentage of variance was accounted for by the first principal component, and the second also accounted for a comparatively large percentage, suggesting Peter has a tightly structured construct system that is cognitively simple.

The loadings of elements and constructs on the first principal component of construing contrast self before diagnosis and ideal self. The first principal component discriminates between people who make little eye contact and relate superficially to others with people who are extroverted.

The loadings of elements and constructs on the second principal component contrast an NT element and self as a NT sees me. The second principal component discriminates between people who jump to conclusions and people who are knowledgeable.

Principal component analysis plot (Figure 3.4.2)

The self before diagnosis is plotted close to the self as a NT person sees me, indicating a similarity in the way Peter construed them. Their difference from the ideal self and self as a person with AS sees me is apparent in their position in the opposing quadrant. Peter construed the self after diagnosis and self now very differently to NT elements, which appear in the opposite quadrant.

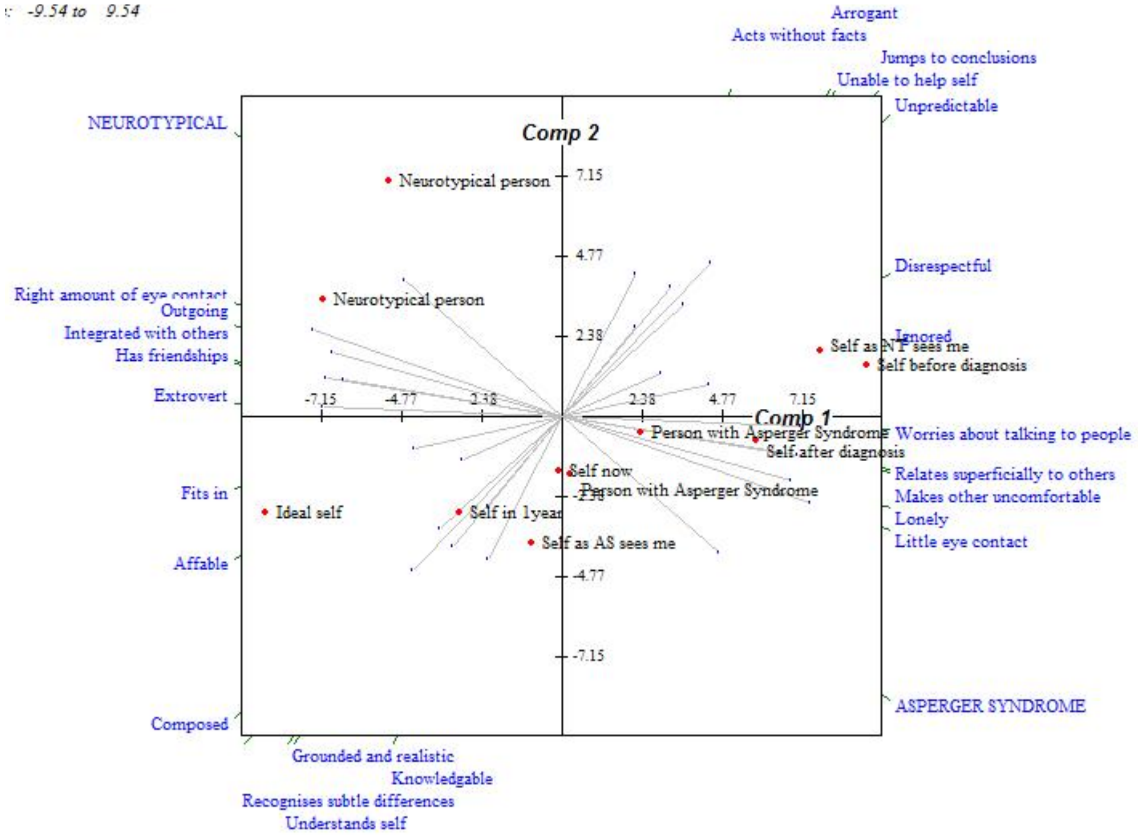


Figure 3.4.2 Peter's principal component analysis plot (Axis Range: -9.54 to 9.54)

Implicative dilemmas

Idiogrid calculated the implicative dilemmas in Peter's construct system using the congruent construct criterion of 0.2. Ten congruent constructs were identified but no dilemmas were identified. The two constructs that were not congruent were 'disrespectful-affable' and 'arrogant-grounded and realistic'.

3.4.3 Fahim's repertory grid

Fahim was 42 years old and diagnosed with AS three years ago. Fahim had always had difficulties maintaining relationships and knowing whom he could trust. He had spent time in prison for offences in which people had taken advantage of his trusting nature. For several years Fahim had engaged with a CMHT for obsessive-compulsive disorder.

When Fahim's two children were diagnosed with autism, he recognised similar traits and his partner supported him to seek an assessment. He was pleased to have an explanation for his difficulties but frustrated that no support was available to help manage them.

Although Fahim volunteered to participate, he expressed anxiety as the interview approached and requested that his partner was present. Fahim enjoyed completing the repertory grid but found the social-self elements challenging. He could not identify personal acquaintances with AS but decided on a famous businessman who best fitted Fahim's construction of AS. Seven constructs were elicited during the session. Fahim's grid and the tables illustrating the Idiogrid analysis can be found in Appendix 7.

Raw grid data *(Table A7.1)*

Defining the self before diagnosis

Fahim construed the self before diagnosis using less favourable construct poles. It was confused, controlled by rituals and anxious.

Defining the self after diagnosis and self now

The self after diagnosis was rated more favourably than the self before diagnosis on six constructs, suggesting a change in his construal of self since receiving a diagnosis. The self after diagnosis was able to identify problems and easy to talk to but still confused. Fahim construed the self now using midpoints of the scale, which indicated a reduction in his sense of self.

Defining the ideal self

Fahim rated the ideal self extremely on all constructs. The ideal self was construed as able to identify problems, understand clearly, free from rituals, sociable, settled in ways, easy to talk to and happy. The self in one year was close to the ideal self, indicating a confidence that he would move towards the ideal self.

Defining the social self

Fahim construed that people with AS would see him as someone who understands clearly but is controlled by rituals. The self as a NT person would see him was more elaborated. It was construed as able to identify problems, free from rituals, sociable and friendly, and easy to talk to. Fahim explained that most people would not notice a difference in him upon first meeting but that this may change over time.

Defining AS

Fahim construed AS and NT elements as able to identify problems. The AS element, unlike Fahim, was free from rituals. Fahim justified this in view of the businessman's success, which would not have been possible if rituals controlled him.

Fahim construed the self before diagnosis and ideal self at the AS pole, but the self after diagnosis and self now at or near the midpoint of the scale. Fahim construed the element with AS towards the NT end of the construct, which is perhaps due to his celebrity and speculated diagnosis. NT elements were construed extremely at the NT pole.

Content categorization of Fahim's constructs (Table A7.2 & A7.3)

Seven constructs were classified into four categories and six subcategories of the CPCS (Feixas et al., 2002). The ideal self was most elaborated using emotional, relational, personal and intellectual/operational constructs.

Slater analysis

Correlations between supplied and elicited constructs (Table A7.4)

None of Fahim's constructs correlated strongly with the supplied construct.

Distance between elements (Table A7.5)

The self after diagnosis and self now were most alike. The self before diagnosis and ideal self were most dissimilar. Fahim's ideal self was unlike the social-self elements, suggesting he would like to be viewed differently by others.

Measure of elaboration: sum of squares (Table A7.6)

Findings indicate Fahim's ideal self was the most elaborated element. This means it was construed extremely compared to other elements. Fahim's self before diagnosis was highly elaborated. By comparison, his sense of self now appears significantly reduced.

Superordinate constructs (Table A7.7)

Constructs 'clear understanding-confused', 'happy-anxious', and 'free from rituals-controlled by rituals' had the greatest variation across elements and may be superordinate.

Principal component analysis: percentage variance accounted for by principal components (Table A7.8, A7.9 & A7.10)

A relatively small percentage of variance was accounted for by the first principal component and a relatively large percentage by the second. Though the grid is small, this points towards a looser construct system that is cognitive complex.

The loadings of elements and constructs on the first principal component of construing contrast the self before diagnosis with the ideal self. The first principal component discriminates between happy people, and those who understand clearly and are free from rituals.

The loadings of elements and constructs on the second principal component of construing contrast a NT element and the self before diagnosis. The second principal component discriminates between AS and being able to identify problems.

Principal component analysis plot (Figure 3.4.3)

The self before and after diagnosis, and self now appear in the same quadrant, indicating similarity in their construal. They contrast with both NT elements, which appear in the diagonally opposing quadrant.

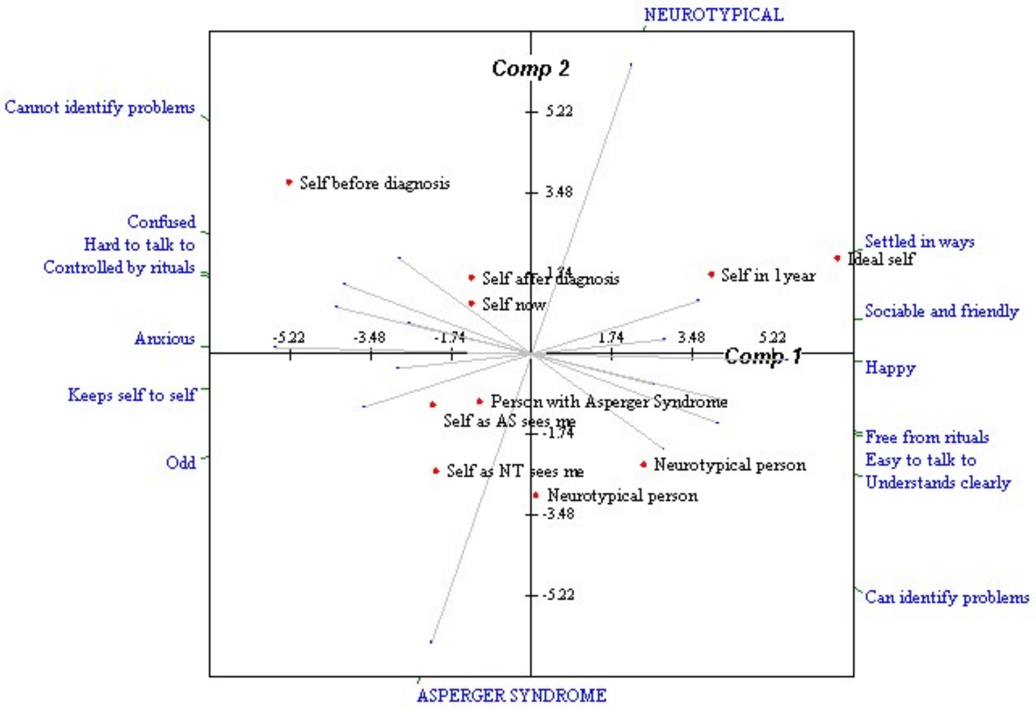


Figure 3.4.3 Fahim's Principal component analysis plot (Axis Range: -6.96 to 6.96)

Implicative dilemmas

Idiogrid calculated the implicative dilemmas in Fahim's construct system using the congruent construct criterion of 0.2. Four congruent constructs were identified but no dilemmas were identified. Congruent constructs which Fahim would be reluctant to change on were 'can identify problems-cannot identify problems', 'sociable and friendly-keeps self to self', 'settled in ways-odd' and 'easy to talk to-hard to talk to'.

3.4.4 Jack's Repertory Grid

Jack was 63 years old and diagnosed 12 years previously. He was married and had a daughter. Jack had experienced several episodes of severe depression throughout his life, had taken medication and engaged with psychotherapy. Approximately thirteen years ago, his family saw a television programme on AS and mental health which resonated with Jack's experience, so he requested an AS assessment.

Since being diagnosed Jack continued to work in a highly specialist field as a national consultant. He believed the traits he now associated with AS helped him to this senior position.

Jack did not enjoy the repertory grid process. He found triadic elicitation particularly difficult. He found dyadic elicitation more acceptable but a tiring process. Only seven constructs were elicited and he chose not to meet again. Jack’s grid and the tables illustrating the Idiogrid analysis can be found in Appendix 8.

Raw grid data

Defining the self before diagnosis

Unlike other participants, Jack construed the self before diagnosis favourably, though often at or close to the midpoint of the scale. The self before diagnosis was defined by highly specific knowledge.

Defining the self after diagnosis and self now

The self after diagnosis was more defined and construed as having highly specific knowledge, things made sense, quirky, and standing out in a crowd. The self now was construed similarly, with the exception of a less extreme rating of ‘stand out in a crowd-normal’. Jack construed the self in a year the same as the self now, indicating he did not anticipate change.

Defining the ideal self

Jack used extreme values to construe the ideal self. The ideal self was construed as caring, having highly specific knowledge, easy to talk to, things make sense, quirky and endearing.

Defining the social self

Jack construed the social-self elements similarly to the construal of other self-elements, which means others share the view he has of himself.

Defining AS

Jack construed AS elements more variably than NT elements. NT elements were construed the same on all but the ‘endearing-difficult to warm to’ construct. It is possible that the similarities were a result of NT elements representing his wife and daughter and his familiarity with them. Alternatively it may be an indication that other constructs or factors were more important than the AS diagnosis. This is further supported by Jack’s utilisation of the supplied construct. Both NT elements were construed at the NT pole, while self-elements and AS elements were construed at different points along the scale. The ideal self was construed to be at the midpoint of the scale suggesting there may be advantages of both poles.

Content categorization of Jack’s constructs (Table A8.2 & A8.3)

Jack’s constructs were classified into four categories and six subcategories of the CPCS

(Feixas et al., 2002). The ideal self was defined by emotional, relational, intellectual/ operational and existential constructs.

Slater analysis

Correlations between supplied and elicited constructs (Table A8.4)
Strong correlations with the supplied construct indicated that Jack associated AS with having highly specific knowledge (r=0.80) and standing out in a crowd (r=0.83), whereas being NT was associated with having a broad general knowledge and appearing normal.

Distance between elements (Table A8.5)
Jack construed the self before and after diagnosis, and self now in a similar way. The largest distance, indicating the most difference, was between the ideal self and one AS element.

Measure of elaboration: sum of squares (Table A8.6)
Jack had highly elaborated other-elements; one AS and both NT elements. The ideal self was the most extremely construed of all self-elements.

Superordinate constructs (Table A8.7)
The percentage total sum of squares for all constructs shows the greatest variation in Jack's rating of the supplied construct, which may be an artefact of the limited range of elements. Jack's elicited construct 'stand out in a crowd-fit in' showed a high level of variation and may therefore be a superordinate construct for Jack.

Principal component analysis: percentage variance accounted for by principal components (Table A8.8, A8.9 & A8.10)
The second principal component accounted for a relatively small percentage of variance. Owing to Jack's being a very small grid it was not possible to interpret this as a measure of construct structure or complexity.

The loadings of elements and constructs on the first principal component of construing contrast an AS element and a NT element. The first principal component discriminates between people who stand out and people who are endearing.

The loadings of elements and constructs on the second principal component of construing contrast people with AS and Jack's ideal self. The second principal component discriminates between people who are horrible and people who are quirky.

Principal component analysis plot (Figure 3.4.4)
The self before diagnosis is plotted in the opposing quadrant to the ideal self. This means

the two are construed very differently. The self after diagnosis is plotted close to the self now, which appears opposite to both NT elements and an AS element. This would indicate that Jack construed the latter elements to be similar to each other but different to all other self-elements and the other AS element.

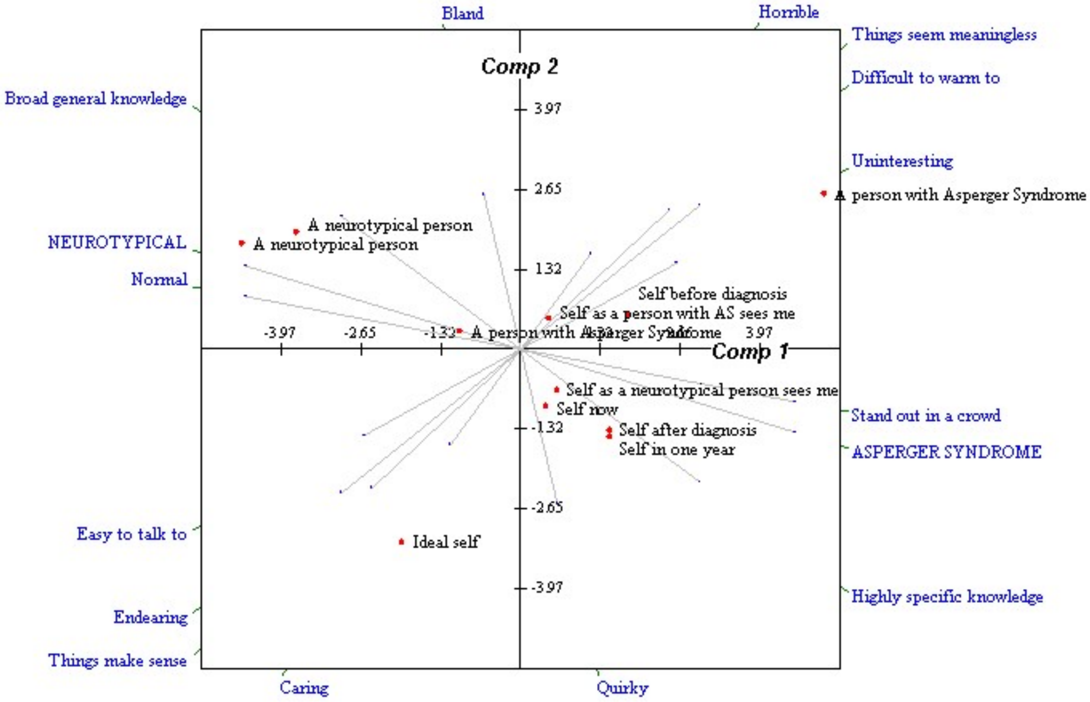


Figure 3.4.4 Jack's principal component analysis plot (Axis Range: -5.29 to 5.29)

Implicative dilemmas

Idiogrid calculated the implicative dilemmas in Jack's construct system using the congruent construct criterion of 0.2. All of Jack's constructs were found to be congruent and therefore he would reluctantly change his position on any of them, indicating he is self-satisfied.

3.4.5 David's Repertory Grid

David was 66 years old and diagnosed with AS aged 48. David described several episodes of psychoses and depression in his twenties, which required him to be hospitalised. He had always been puzzled by the difficulties he experienced at work. Following a redundancy and difficulties finding work he read an article about AS which resonated with his own experience. He contacted the National Autistic Society, who supported him to get an AS assessment. David viewed the diagnosis as an explanation for his behaviours and difficulties in relationships. He was cautious about sharing it, as he was fearful of negative reactions.

David's repertory grid and tables detailing the Idiogrid analysis can be found in Appendix 9. David found the structure of the interview "easy to follow". He used few extreme ratings, instead using ratings close to and including the midpoint, and this may indicate a level of constriction, drawing in of the boundaries of the perceptual field (Winter, Sireling, Riley, Metcalfe, Quaite, & Bhandari, 2007).

Raw grid data *(Table A9.1)*

Defining the self before diagnosis

David construed the self before diagnosis using less favourable construct poles. The self before diagnosis did not have an explanation for actions, was a walk over and preferred solitude.

Defining the self after diagnosis and self now

The greatest difference between David's construal of the self before and after diagnosis was that the latter had an understanding of actions. Seven other constructs moved by one point from the self before diagnosis rating but these remained close to the midpoint of the scale. The self after diagnosis understood actions and was selective in who they talked to.

David construed self now similarly to the self after diagnosis. He changed ratings by one point, towards his preferred pole, on five constructs but these remained on or close to the midpoint.

Defining the ideal self

The ideal self was construed as understanding actions, fitting in, socially adept, assertive, empathising with others and high functioning.

Defining the social self

From David's perspective, a person with AS would recognise that he understands actions. A NT person would construe him as someone who joins in socially but has rigid routines, specialist interests, accepts things rather than being ambitious, and does not ask questions. This represents David's opinion on what others were most likely to notice or comment on about him, most likely developed as a result of experience.

Defining AS

David construed NT elements similarly across most constructs. He used constructs linked to communication and being high functioning to define them. They were construed as empathetic towards others, able to talk to anyone, high functioning and preferring to join in socially. By contrast, AS elements were jointly construed as having rigid routines but varied on all other constructs.

David used extreme ratings for only four elements in the grid. The self after diagnosis and an AS element were construed close to the AS pole and both NT elements were construed at the opposing pole. David's preference for construing elements at or near the midpoint of the scale may indicate he was unable to apply it to the elements in a meaningful way.

Content categorization of David's constructs (Table A9.2 & A9.3)

David's constructs were classified into four categories and seven subcategories of the CPCS (Feixas et al., 2002). One third of David's constructs were categorised into the extrovert-introvert subcategory of the relational domain. Other constructs were categorised in personal, intellectual/operational and concrete descriptors.

Slater analysis

Correlations between supplied and elicited constructs (Table A9.4)

AS was strongly associated with having specialist interests (r=0.71), being selective rather than talking to anyone (r=0.70) and not able to communicate (r=-0.77). This means NT people were likely to have a broad knowledge, talk to anyone and be high functioning.

Distance between elements (Table A9.5)

The self before and after diagnosis, and self now were construed similarly. The self before diagnosis, AS elements and one NT element were construed very differently to the ideal self.

Measure of elaboration: sum of squares (Table A9.6)

David construed an AS and NT element most extremely. For David, the ideal self was construed more extremely than other self-elements. The reduction in the percentage total sum of squares between David's self before diagnosis and self now suggests David may be less able to make sense of himself since his diagnosis.

Superordinate constructs (Table A9.7)

David's construct 'understands actions-actions unexplained' showed more variation than other constructs and is therefore likely to be superordinate.

Principal component analysis: percentage variance accounted for by principal components (Table A9.8, A9.9 & A9.10)

David's first principal component accounted for 44.67 per cent of variance. This increased to a cumulative figure of 69.35 per cent when the second principal component was included. The findings might point towards greater differentiation or complexity, which are properties of a looser construct system.

The loadings of elements and constructs on the first principal component of construing contrast NT elements with AS elements and the self before diagnosis. The first principal component discriminates between those who talk at people and those who are socially adept.

The loadings of elements and constructs on the second principal component of construing contrast David's self after diagnosis and an AS element. The second principal component discriminates between people who understand actions and those who talk at people.

The loading for the supplied construct is also high but this is likely to be an artefact of the limited range of elements used.

Principal component analysis plot (Figure 3.4.5)

The plot shows the self before diagnosis in an opposing quadrant to the ideal self, illustrating the very different ways in which David construed them. NT elements appear in a quadrant on their own, which emphasises the earlier finding that David construed them similarly. These are in opposition to the self after diagnosis and self now, which shows he construes himself quite separately from the NT label.

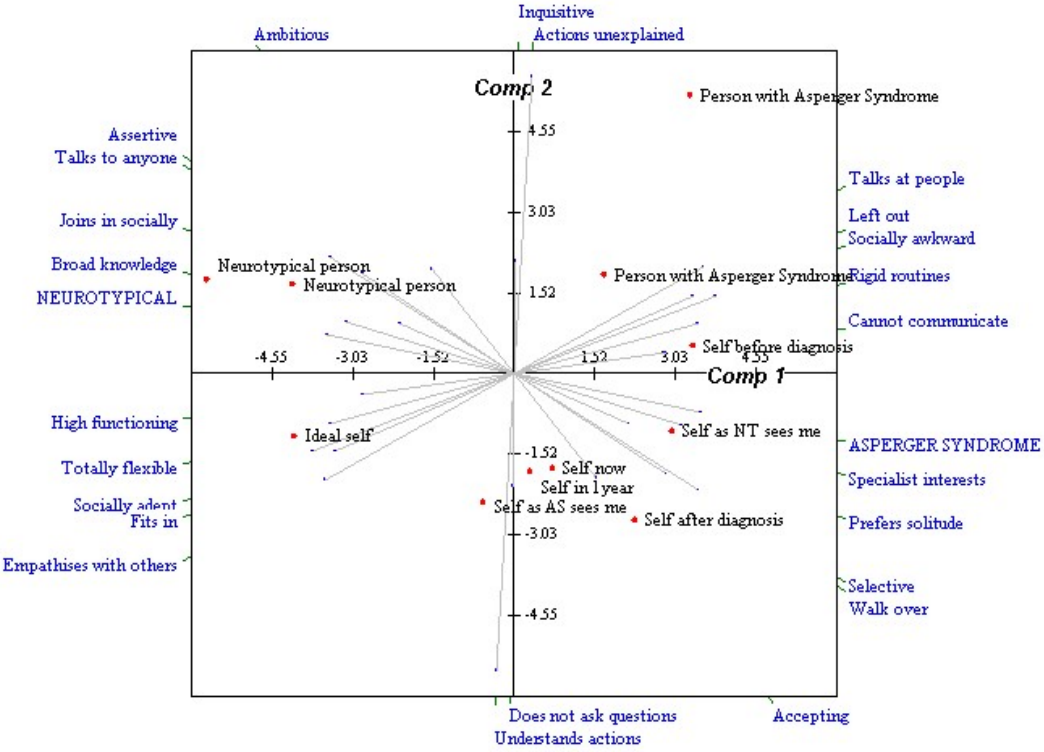


Figure 3.4.5 David's Principal component analysis plot (Axis Range: -6.06 to 6.06)

Implicative dilemmas

The implicative dilemma analysis performed by Idiogrid using the congruent construct criterion of 0.2 found three implicative dilemmas in David's construing. Congruent constructs for David were 'understands actions-actions unexplained', 'assertive-walk over', 'selective-talks to anyone' and 'does not ask questions-inquisitive'. He would resist change on any of these constructs and that would lead to the dilemmas below.

David construed self now as selective, while ideal self talks to anyone. The dilemma for David was that people who talk to anyone tend to be people who do not understand actions (r=0.38). David’s self now was construed as someone that does not ask questions, while ideal self was construed as inquisitive. The dilemma for David was that in order to be inquisitive, one tends to not understand actions (r=0.35) and tends to talk at people (r=0.31).

3.5 Group Analysis of Repertory Grids

This section combines the data from all eight repertory grids implemented as this analysis informed the phase two semi-structured interviews. Findings from the grids that were followed up in phase two are presented in the following section to facilitate a better flow for the reader.

Raw data analysis

Defining AS (Table A.10.1)

Almost exclusively NT elements were rated extremely NT on the supplied construct. All remaining self and other elements were rated rather less extremely, suggesting AS construct pole may be more variably conceptualised by participants.

Content Analysis of All Elicited Constructs (Table A10.2)

Relational (30.2%) constructs were most frequently elicited, within which the extrovert-introvert subcategory was most frequent (14.0%) using the CSPC (Feixas et al., 2002). Personal (25.6%) and emotional (14.0%) domains were next most frequently used in line with Hardison and Neimeyer’s (2007) findings. More unusually, supplemental existential and concrete descriptor categories were elicited. No values/interests constructs were identified.

Content Analysis of Self-Defining Constructs (Table A.10.3)

Almost a third of all self-definitional constructs were categorised as personal (28.37%) followed by relational (23.40%) and intellectual/ operational (18.44%). No differences in this pattern were identified between self-elements.

Slater analysis

Correlations between supplied and elicited constructs (Table 3.5.1)

A total of seventeen constructs correlated strongly with the supplied construct. Almost half of these were relational constructs (n=7), elicited by four participants. Of this number, Peter was seen to elicit four relational constructs, the greatest for any individual. Though Tariq elicited relational constructs in his grid, they did not correlate strongly with the supplied construct. Three participants elicited Intellectual/operational and concrete descriptors constructs.

Table 3.5.1 Constructs strongly correlated with AS by CSPC category (Feixas et al., 2002) and participant.

	Construct poles strongly correlating with AS*				
Content category	**Hazel**	**David**	**Peter**	**Jack**	**Tariq**
1. Moral					
2. Emotional					Unspontaneous (r=0.84) Scared of consequences (r=0.94)
3. Relational	Stands out (r=0.84)	Selective (r=0.70)	*Introvert (r=-0.74)* *Relates superficially (r=0.80)* *Lonely & isolated (r=-0.85)* *Makes others uncomfortable (r=-0.84)*	Stands out in a crowd (r=0.83)	
4. Personal					Emasculated (r=-0.83) Uncomfortable in own skin (r=-0.77)
5. Intellectual / Operational	Incompetent (r=-0.75)	Cannot communicate (r=-0.77)		Highly specific knowledge (r=0.80)	
6. Values and Interests					
0. Existential					
7. Concrete Descriptors		Specialist interests (r=0.71)	*Little eye contact (r=0.82)*		Physically rigid (r=0.75)

**No strong correlations were found for Stella and Judy's constructs so they are excluded from this table.*

Distance between elements (Table A10.4)

A Wilcoxon Signed-ranks test indicated that the distance between the ideal self and self before diagnosis (Mdn = 1.37) was significantly greater than between ideal self and self after diagnosis (Mdn = 1.11) (z = -2.37, *p* = .018, two-tailed).

The negative ranks show that for seven of the eight participants, distance between self before diagnosis and ideal self was greater than the distance between self after diagnosis and ideal self, indicating greater difference between self before diagnosis and the ideal self. In one instance there was no difference in distance between the ideal self and self before and ideal self.

Measure of Elaboration: sum of squares (Table A10.5)

Self before diagnosis and self after diagnosis

A Wilcoxon Signed-ranks test indicated that the percentage total sum of squares for self before diagnosis (Mdn = 11.09) was significantly greater than for self after diagnosis (Mdn = 5.44) (z = -2.24, *p* = .025, two-tailed). This means that the self before diagnosis was more meaningful and elaborated than the self after diagnosis, indicating that the group were less able to make sense of the self after their diagnosis. Judy and David, the participants closest to and furthest from their diagnosis, had an increased sense of self.

Self now and ideal self

A Wilcoxon Signed-ranks test indicated that the percentage total sum of squares for self now (Mdn = 3.29) was significantly less than for the ideal self (Mdn = 12.85), Z = -2.52, *p* = .012, two-tailed). This means that the ideal self was more meaningful and elaborated than the self now.

Superordinate constructs (Table A10.6)

The supplied construct was found to be superordinate for five participants. Superordinate constructs were most frequently categorised as relational (n=7) and personal (n=7). This finding fits with Butler's (2006) factor analysis of core constructs, which identified *making sense* and *relatedness* as the first two factors.

Principal component analysis: percentage variance accounted for by principal components

Table 3.5.2 shows Fahim, David and Judy, in terms of the percentage of variance accounted for by the first principal component had looser construct systems that point towards greater cognitive complexity. Other participants indicated construct systems that were tightly structured and more cognitively simple.

Table 3.5.2: Eigenvalue decomposition

	Tariq	**Peter**	**Fahim**	**Jack**	**David**	**Judy**	**Hazel**	**Stella**
Component 1	60.24	70.03	49.84	63.63	44.67	47.85	58.29	74.06
Component 2	17.56	21.12	22.77	25.59	24.69	20.28	12.57	13.26
Cumulative %	77.80	91.15	72.16	89.22	69.36	68.13	70.86	87.32
Cognitive Structure	Tight	Tight	Loose	Tight	Loose	Loose	Tight	Tight

3.6 Repertory Grid and Semi-Structured Interviews

3.6.1 Case Study: Judy

Judy was 51 years old and diagnosed six months previously. Judy was a secondary school teacher. Her colleagues and friends described her as “blunt”, “rude” and “cantankerous”. Judy used self-help books to improve her communication style. Following an incident at work, a friend with a son diagnosed with AS encouraged Judy to visit her GP, who referred her for an assessment. Despite agreeing to the assessment Judy was certain she would not get a diagnosis. She said, “They [other people] were the ones with the problem”.

Judy had no difficulty completing the grid. She gave quick answers, which she then deconstructed before offering a final response. Judy used extreme values more frequently than other participants. Judy’s repertory grid and tables detailing the Idiogrid analysis can be found in Appendix 11.

Raw grid data *(Table A11.1)*

Defining the self before diagnosis

Judy construed the self before diagnosis as hardworking, focused, caring, driven, self-confident, having self-worth, giving grace to others and open-minded.

Defining the self after diagnosis and self now

Judy construed the self after diagnosis and self now similarly to before diagnosis, though they were less hardworking and more distracted. The self now was also construed as less caring and less giving grace to others.

Defining the ideal self

The ideal self was construed as focussed, intelligent, caring, driven, self-confident, having self-worth, giving grace to others and open-minded. It was less hardworking than the self before her diagnosis and more hardworking than both self after her diagnosis and now.

Defining the social self

From Judy’s perspective, NT people would construe her positively. By contrast, people with AS would construe her less definitely. This perhaps reflects Judy’s perception that other people with AS often lack insight and/or awareness. The follow-up interview verified this.

Defining AS

Judy construed NT elements variably across all constructs. Judy construed AS elements variably on her constructs about giving grace to others and open-mindedness. However, both AS elements were construed similarly in terms of being hardworking, focussed, driven and having self-worth.

Judy construed the self before diagnosis towards the NT pole of the supplied construct. This reversed following diagnosis and the self after diagnosis, now and ideal were construed at the AS pole. Judy construed the self in one year as fitting the label less. Other-elements in the grid were rated extremely at the corresponding pole, suggesting Judy used the construct rigidly.

Content categorization of Judy's constructs (Table 3.6.1)

Judy's constructs were classified into four categories and eight subcategories of the CSPC (Feixas et al., 2002). Half were categorised within the personal domain and other constructs were categorised within moral, relational and intellectual/operational domains. Intellectual/ operational constructs were used to define self before diagnosis and ideal self but not self after diagnosis or now (Table A.11.2).

Table 3.6.1: Content categorization (Feixas et al., 2002) of Judy constructs

Content category		**Constructs elicited**
1. Moral	b. Altruist-Egoist	Caring-Thoughtless
3. Relational	h. Sympathetic-Unsympathetic	Gives grace to others-Selfish
4. Personal	c. Hardworking-Lazy	Hardworking-Lazy
	e. Decisive-Indecisive	Driven-No direction
		Self-confident-Follow the pack
	f. Flexible-Rigid	Open-minded-Black & white thinker
	i. Self-acceptance-Self-criticism	Self-worth-Neglects self
5. Intellectual / Operational	b. Intelligent-Dull	Intelligent-Idiot
	d. Focussed-Unfocussed	Focussed-Distracted

Slater analysis

Correlations between supplied and elicited constructs (Table A11.3)

The supplied construct was not strongly correlated with any of Judy's elicited constructs.

Distance between elements (Table A11.4)

Judy construed most of the elements in a similar way. The largest differences were between the ideal self and self as a person with AS sees me; the ideal self and an NT element; and the self now and an NT element.

Measure of elaboration: sum of squares (Table A11.5)

Table 3.4.5 indicates the second NT element was the most salient element, perhaps because it was construed negatively, followed by the ideal self. An increase in the percentage total sum of squares indicates Judy could make more sense of her self now than before her diagnosis.

Superordinate constructs (Table A11.6)

The supplied construct had greatest variation. 'Open-minded- black and white thinker', 'self worth-self neglect', 'driven-no direction', and 'self-confident-follow the pack' showed more variation than other constructs and are likely to be superordinate.

Principal component analysis: percentage variance accounted for by principal components (Table A11.7, A11.8 & A11.9)

Table 3.4.7 shows the first principal component was found to account for a relatively small percentage of the variance and the second component a comparatively large percentage. These findings might be indicative of loose construing and greater cognitive complexity, though this interpretation remains tentative due to the size of the grid and the relative homogeneity of its elements.

The loadings of elements and constructs on the first principal component of construing indicate a contrast between the ideal self and elements with AS with one NT element. The first principal component discriminates between AS and people who give grace to others.

The loading of elements and constructs on the second principal component indicate that this contrasts self after diagnosis and an AS element. The second principal component discriminates between being open-minded and focussed.

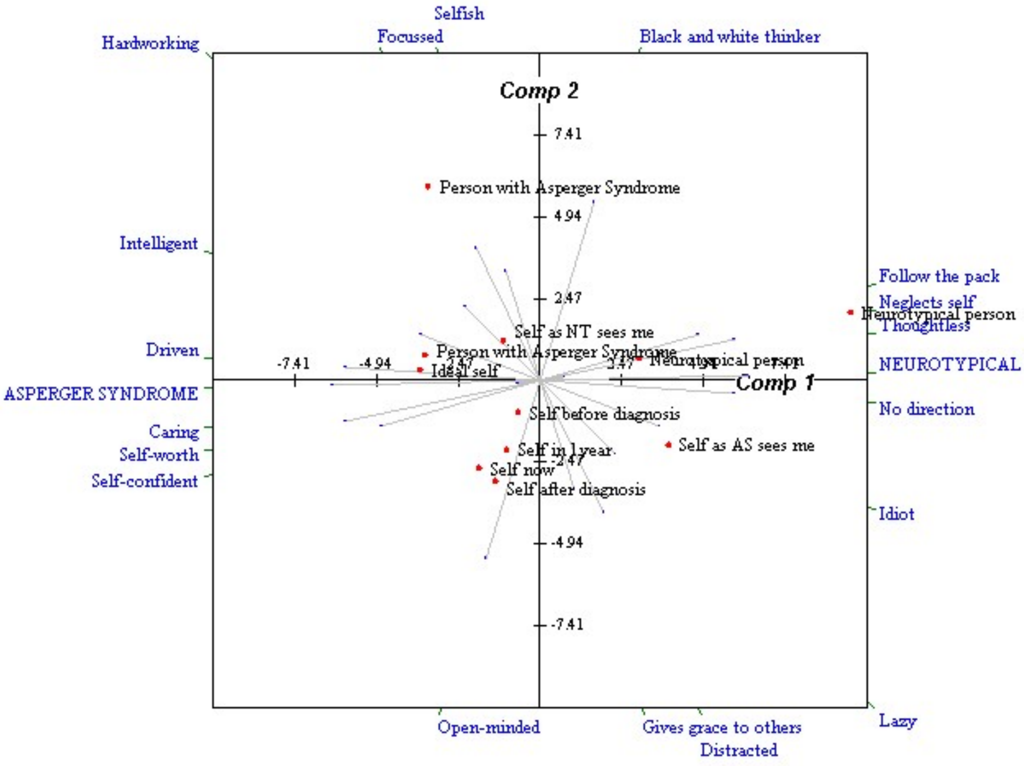


Figure 3.6.1 Judy's principal component analysis plot (Axis Range: -9.88 to 9.88)

Principal component analysis plot (Figure 3.6.1)

Figure 3.6.1 illustrates how Judy construes elements in her repertory grid. The self before and after diagnosis, and self now appear in the same quadrant, indicating they were construed similarly. An NT element appears in the opposing quadrant, indicating least similarity.

Implicative dilemmas

The implicative dilemma analysis performed by Idiogrid using the congruent construct criterion of 0.2 identified two implicative dilemmas. Judy's self now was construed as distracted, whereas the ideal self was construed as focussed. The dilemmas for Judy arose because Judy construed focussed people as tending to be selfish (r=0.37) and black and white thinkers (r=0.28), neither of which she would wish to be.

Congruent constructs for Judy were 'hardworking-lazy', 'caring-thoughtless', 'driven-no direction', 'self confident-self worth', 'gives grace to others-selfish' and 'open-minded-black and white thinker'. The supplied construct was also found to be a congruent construct. She would resist change on these constructs.

ABC Technique (Figure 3.6.2)

Judy provided the advantages and disadvantages of AS and neurotypical poles of the supplied construct. Judy associated the AS pole with being totally independent, which included not thinking about other people. To achieve this she believed she would need to not have a family. It seemed Judy was in a dilemma between being independent and lonely or sacrificing some independence to have a family and friendships. The middle position on the construct equated to being in "no-man's land" and would be highly problematic for Judy.

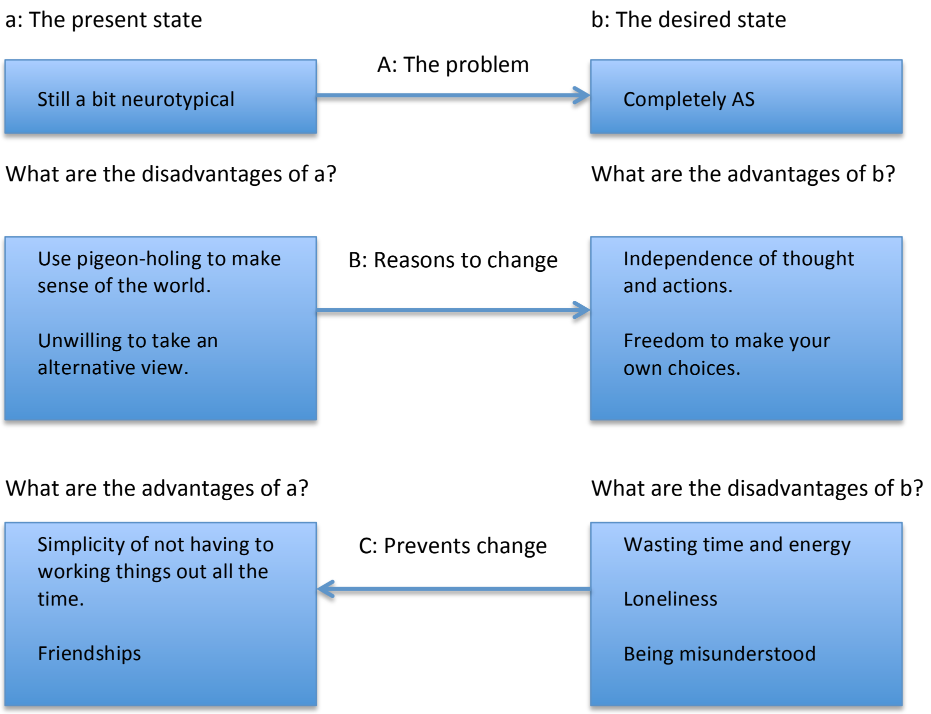


Figure 3.6.2 Judy's ABC Analysis (Tschudi, 1977)

3.6.2 Case Study: Hazel

Hazel was 51 years old and diagnosed one year ago. Hazel had experienced several life events that had caused her to feel depressed and suicidal. A CMHT psychologist suggested an AS assessment. Having worked in social care, she was familiar with the diagnostic criteria of AS and did not believe she fitted them. She was surprised by the diagnosis but pleased to not have been labelled with a personality disorder.

Hazel valued the systematic method of the repertory grid that she completed over two sessions. Hazel's repertory grid and tables detailing the Idiogrid analysis can be found in Appendix 12.

Raw Grid Data *(Table A12.1)*

Defining the self before diagnosis

Hazel construed the self before as hopeless, self-critical and scared. These constructs were rated extremely. Less extremely, self before diagnosis was construed as anxious socially, set in her ways, standing out, incompetent and slow.

Defining the self after diagnosis and self now

Hazel construed the self after diagnosis and now less extremely than the self before diagnosis. The self after diagnosis was hardworking, set in ways, stands out, scared, slow and stupid. Hazel used less extreme values for the self now.

Defining the ideal self

The ideal self was construed, using extreme ratings, as hardworking, interesting, ultra positive, comfortable socially, creative, capable, confident, efficient, gives a good impression and has total control over life.

Defining the social self

For Hazel, a person with AS would construe her as set in her ways whereas a NT person would construe her as hardworking but difficult to talk to, anxious socially, incompetent and scared. The follow-up interview indicated the high value Hazel places on others' perceptions of her.

Defining AS

Hazel construed AS elements as difficult to talk to. NT elements were ultra positive, self-accepting, creative, capable and give a good impression. On all other constructs differences were found between individuals.

Hazel construed self-elements using the AS pole of the supplied construct with the exception of the ideal self, which was construed as NT. AS elements were construed less extremely than NT elements.

Table 3.6.2: Content categorization (Feixas et al., 2002) of all Hazel's constructs

Content category		**Constructs elicited for Hazel**
2. Emotional	c. Optimist-Pessimist	Hopeless-Ultra positive
	e. Specific emotions	Confident-Scared
3. Relational	a. Extrovert-Introvert	Comfortable socially-Anxious socially
	b. Pleasant-Unpleasant	Interesting-Difficult to talk to
	h. Sympathetic-Unsympathetic	Stands out-Fits in
4. Personal	a. Strong-Weak	Total control over life-No control over life
	c. Hardworking-Lazy	Hardworking-Lackadaisical
	i. Self acceptance-Self critical	Self accepting-Self critical
5. Intellectual / Operational	a. Capable-Incapable	Capable-Incompetent Efficient-Slow
	b. Intelligent-Dull	Gives a good impression-Stupid
	e. Creative-Not creative	Creative-Set in ways

Content categorization of Hazel's constructs (Table 3.6.2)

Hazel's constructs were classified into four categories and eleven subcategories of the CSPC (Feixas et al., 2002). A third were categorised as intellectual/operational and this relates to her follow-up interview discussion around the importance of achievement. The self before diagnosis and ideal self were uniquely defined using emotional constructs (Table A12.2)

Slater analysis

Correlations between supplied and elicited constructs (Table A12.3)

Hazel's constructs 'stands out-fits in' (r=0.84) and 'capable-incompetent' (r=-0.75) correlated strongly with the supplied construct. Therefore, AS was associated with standing out and being incompetent, whereas NT was associated with fitting in and being capable.

Distance between elements (Table A12.4)

The self after diagnosis and self now were most similar. The ideal self was most different to self before and self after diagnosis, and self now. The large distance between self now and ideal self indicates Hazel may have low self-esteem.

Element distances indicate that people who have AS might construe Hazel as more similar to the ideal self than the people who are NT. This fits with her comments that people who have AS were often surprised that she has too while NT people reported difficulties in relating to her.

Measure of elaboration: sum of squares (Table A12.5)

Hazel's ideal self was the most elaborated element, followed by the self before diagnosis. The large reduction in percentage total sum of squares between the self before diagnosis and self now suggests Hazel may be less able to make sense of herself since her diagnosis. The follow-up interview indicated the AS diagnosis had helped explain some of her difficulties but she remained unable to do anything differently. This may help to explain the reduction in understanding herself.

Superordinate constructs (Table A12.6)

The percentage total sum of squares for Hazel's constructs, denoting superordinate constructs, shows the greatest variation in Hazel's rating of the supplied construct. Hazel's ratings of the construct 'stand out-fit in' also showed greater than 10 per cent variation. It is an example of a core construct that is comprehensive, meaning it is applicable to a wide range of events. It is also not too permeable which means Hazel self identity is more likely to maintain some stability while still being open to new events.

Principal component analysis: percentage variance accounted for by principal components (Table A12.7, A12.8 & A12.9)

A relatively large percentage of variance was accounted for by the first component and a relatively small percentage by the second principal component. This tentatively indicates a fairly tightly structured construct system, which is quite cognitively simple.

The loadings of elements and constructs on the first principal component of construing indicate that it contrasts self before diagnosis with ideal self. The first principal component discriminates between people who are confident, efficient, and creative and those who are viewed to have AS, stand out and feel hopeless.

The loadings of elements and constructs on the second principal component of construing indicate that it contrasts self in a year with NT person. The second principal component discriminates between people who have no control over their life and people who are self-critical.

Principal component analysis plot (Figure 3.6.3)

The self before diagnosis appearing in an opposing quadrant to the ideal self indicated differences in the way they were construed. The ideal self was plotted furthest from the origin of the graph, indicating it was construed most extremely. Self after diagnosis, now and in a year appeared in the same quadrant, indicating similarity between them.

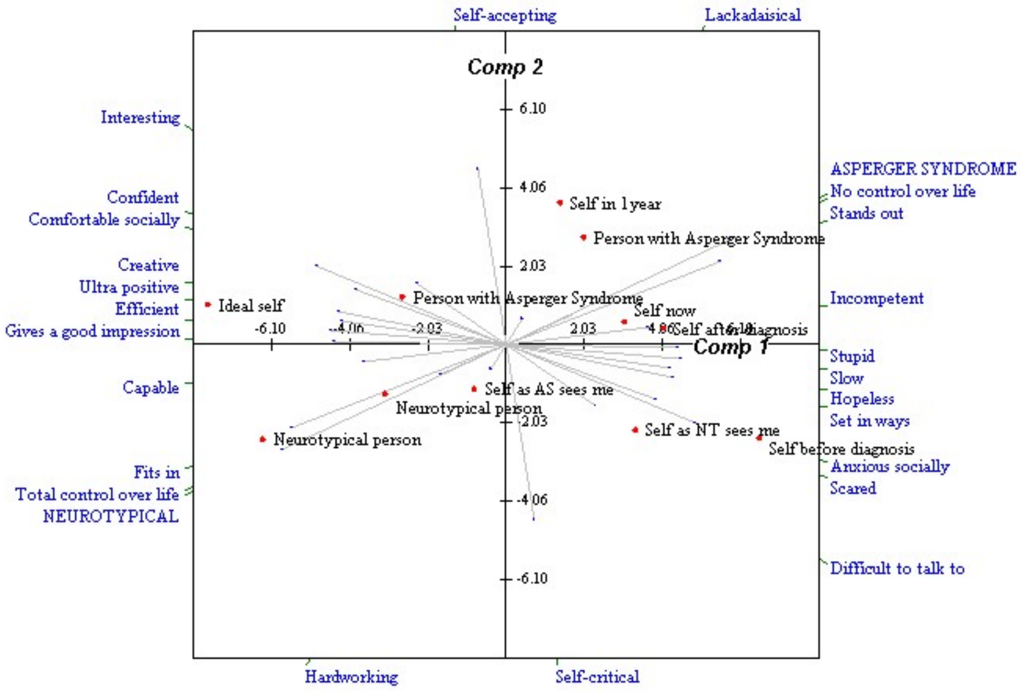


Figure 3.6.3 Hazel's Principal component analysis plot (Axis Range: -8.13 to 8.13)

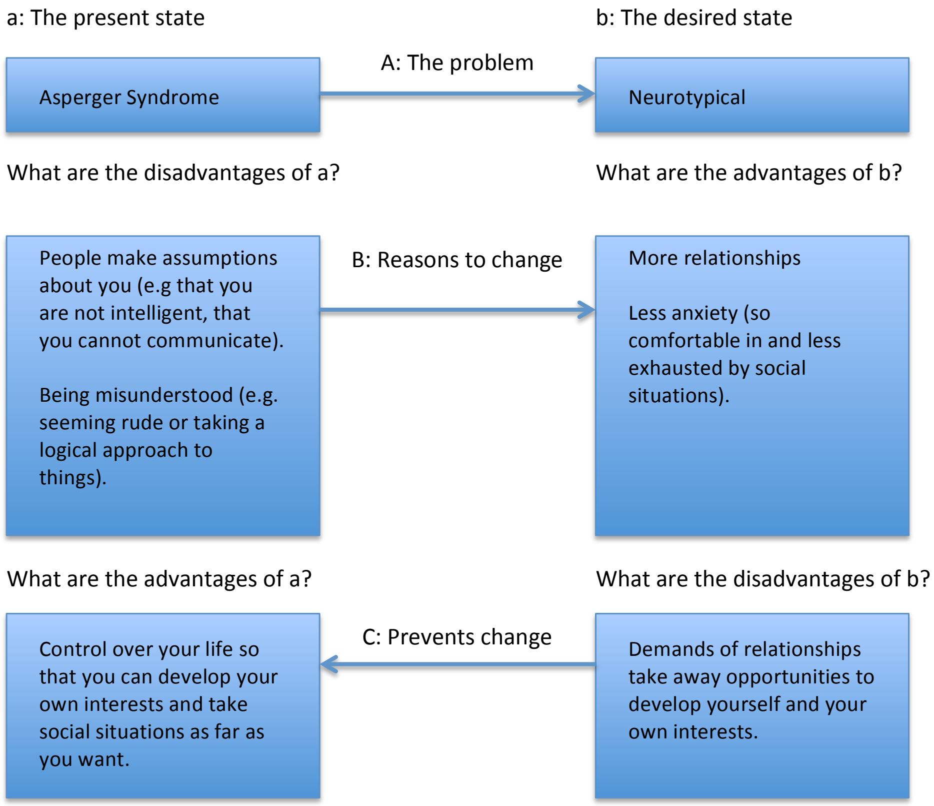
Implicative dilemmas

Idiogrid, using the congruent construct criterion of 0.2, found no implicative dilemmas in Hazel's construing. Congruent constructs, which she was reluctant to change, were 'hardworking-lackadaisical' and 'total control over life-no control over life'.

ABC Technique (Figure 3.6.4)

Hazel's desire to be neurotypical on the ideal self-rating of the supplied construct was explored. She stated, *"in an ideal world I would just be a different person"*, but following completion of the ABC technique Hazel changed her ideal position to that of being totally defined as AS. Being free from people's assumptions would be needed for her to feel *"okay with it [AS]"*. Hazel articulated the predicament she currently finds herself:

> *"As far as I am concerned, I am not totally on the spectrum because I have got an insight. I am not sure but that's my definition of Asperger's being different from autism, is that you have got one foot on the spectrum and one foot out of it with Asperger's."*



People make assumptions about you (e.g that you are not intelligent, that you cannot communicate).

Being misunderstood (e.g. seeming rude or taking a logical approach to things).

More relationships

Less anxiety (so comfortable in and less exhausted by social situations).

Control over your life so that you can develop your own interests and take social situations as far as you want.

Demands of relationships take away opportunities to develop yourself and your own interests.

Figure 3.6.4 Hazel's ABC Analysis (Tschudi, 1977)

3.6.3 Case Study: Stella

Stella was 56 years old and diagnosed three years ago. Stella attended a CMHT for anxiety but had "never found that anything worked". Her son was diagnosed with High Functioning Autism aged eighteen. As she learned more, she recognised traits in herself. When he moved away she sought an assessment to confirm her belief that she too had AS.

Stella found the repertory grid structure helped focus her responses over two sessions. She found it difficult to identify NT elements as she felt "everyone was on the spectrum" really. She selected a neighbour and celebrity that she construed as NT. Stella's repertory grid and tables detailing the Idiogrid analysis can be found in Appendix 13.

Raw grid data *(Table A13.1)*

Defining the self before diagnosis

Stella defined the self before diagnosis using unfavourable construct poles. Only three were self-defining constructs: unsettled mind, minds own business, and withdrawn and insulated.

Defining the self after diagnosis and self now

Stella defined the self after diagnosis more favourably, again using few extreme ratings. The self after diagnosis had a healthy sense of identity and would mind her own business. The self now was construed similarly but also able to say no, independent, values self and free. These four changes may suggest progression towards her preferred construct poles.

Defining the ideal self

Stella construed the ideal self with only extreme values on elicited constructs. The ideal self was defined as having a healthy sense of identity, able to say no, independent, organised mind, warm, valued self, minds own business, confident, successful and free. These ratings were the same for the self in a year from now, suggesting that Stella feels close to her ideal self.

Defining the social self

For Stella, a person with AS would construe her as someone who minds her own business. The self as construed by a NT person would be a failure but independent, valuing self, minds own business, successful and free. This may suggest Stella has elicited two constructs that relate to different meanings of success and failure.

Defining AS

Stella construed both AS elements as withdrawn and insulated, not living up to expectations and experiencing life as a chore. NT elements were construed differently to each other, with the celebrity being idealised and the neighbour construed around the midpoint value on all constructs.

Stella’s construal of self on the supplied construct showed a shift from the midpoint value before diagnosis to the AS pole now. However, Stella construed the ideal self at the midpoint, suggesting that she perceives benefits to both poles.

Content categorization of Stella’s constructs (Table 3.6.3)

Ten constructs were classified into four categories and nine subcategories of the CSPC (Feixas et al., 2002). The self now and ideal self were most elaborated and included personal and existential constructs (Table A13.2).

Table 3.6.3: *Content categorization (Feixas et al., 2002) of Stella's constructs*

Content category		**Constructs elicited**
2. Emotional	b. Warm-Cold	Warm-Unapproachable
	c. Optimist-Pessimist	Failure-Able to say no
	d. Balanced-Unbalanced	Confused about identity-Healthy sense of identity
3. Relational	a. Extrovert-Introvert	Minds own business-Inquisitive Confident-Withdrawn and insulated
	f. Dependent-Independent	Independent-Controlled by others
4. Personal	c. Hardworking-Lazy	Successful-Not living up to expectations
	d. Organised-Disorganised	Organised mind-Unsettled mind
	i. Self-acceptance-Self-criticism	Value self-Treated badly by others
0. Existential	a. Purposeful-Purposeless	Free-Life is a chore

Slater analysis

Correlations between supplied and elicited constructs (Table A.13.3)

None of Stella's constructs correlated strongly with the supplied construct.

Results indicated a large number of strong correlations (r=0.7-0.9) between elicited constructs; a healthy sense of identity, being independent, having an organised mind, being warm, valuing self, confidence, success and feeling free. Some had correlations greater than 0.9, which may suggest some overlap in meanings.

Distance between elements (Table A13.4)

The self after diagnosis and self now, ideal self and celebrity NT element showed most similarity. Large differences were found between self before diagnosis and ideal self, and ideal self and an AS element.

Measure of elaboration: sum of squares (Table A13.5)

Stella's ideal self was the most elaborated self-element. The self now was more elaborated than the self after diagnosis, suggesting she had gained a better sense of self since her diagnosis.

One AS element (her son) and the celebrity NT element were highly elaborated. This may be due to Stella's intimate knowledge of her son's difficulties and idealisation of the celebrity.

Superordinate constructs (Table A13.6)

Constructs accounting for more than 10 per cent of total sum of squares were 'confident-withdrawn and insulated', 'successful-not living up to expectations', 'confused identity-healthy sense of identity' and the supplied construct.

Principal component analysis: percentage variance accounted for by principal components (Table A13.7, A13.8 & A13.9)

The first principal component accounted for 74 per cent of variance, which increased to 87 per cent cumulatively when the second component was added. Although the grid was limited in size and elements, this analysis points towards a construct system, which is tightly structured and cognitively simple.

The loading of elements and constructs on the first principal component of construing contrasts NT elements with AS elements. The first principal component discriminates between people who have a confused identity and those who are confident.

The loading of elements and constructs on the second principal component contrasts the self now and the self as viewed by a NT person. The second principal component discriminates between people who mind their own business and those who are a failure.

Principal component analysis plot (Figure 3.6.5)

The self after diagnosis and both AS elements appear in the same quadrant, indicating similarities in the way Stella construed them. The self before diagnosis appears in an opposing quadrant to the self now and ideal self, illustrating a difference in Stella's construal of them.

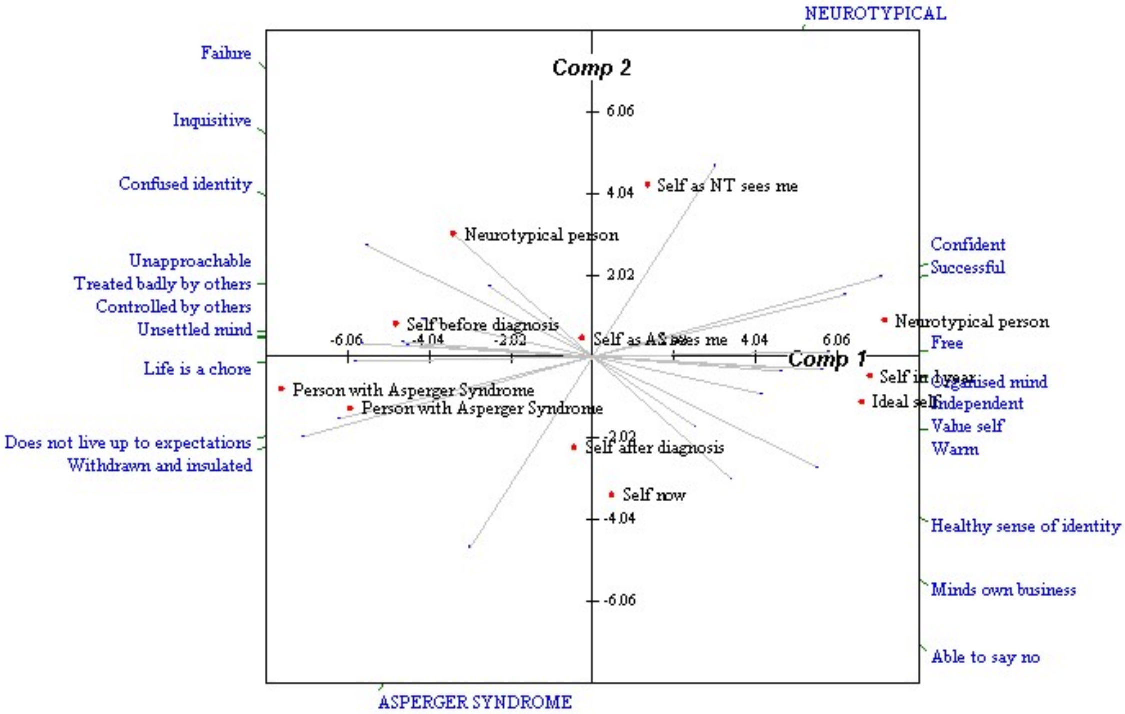


Figure 3.6.5 Stella's principal component analysis plot (Axis Range: -8.08 to 8.08)

ABC Technique (Figure 3.6.6)

Stella's construal of the advantages and disadvantages of AS compared to NT positioned them in extreme and unmoveable contrast to each other. Exploration of the advantages and disadvantages of being somewhere in the middle created new and less extreme possibilities for Stella. She thought being able to take multiple perspectives would help her and others to be *"more lenient or understanding"*. She felt this position would require particular focus but that this fitted with her view that *"life is about the journey, not the destination"*.

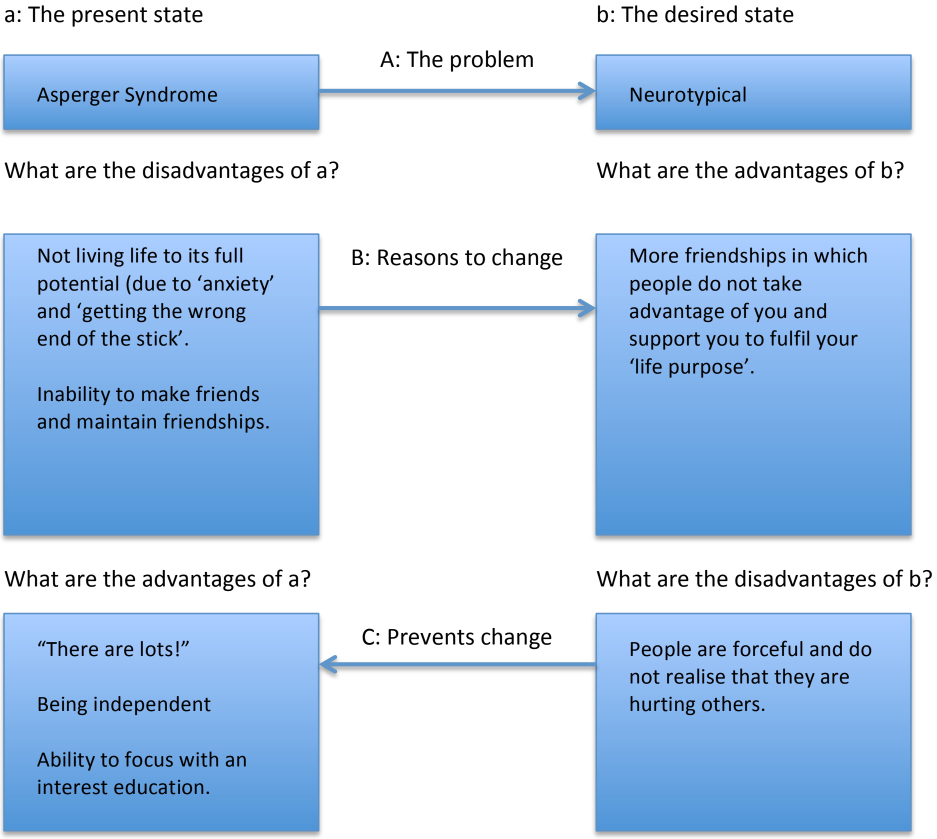


Figure 3.6.6 Hazel's ABC Analysis (Tschudi, 1977)

3.7 Group Thematic Analysis of Follow-up Interview

The transcripts showed a good degree of consistency across the three interviews, elaborating some of the findings of the repertory grids and the psychological distress identified by the GHQ. A number of common themes emerged across the data in response to specific questions, and the semi-structured format, which allowed individuals to partially express what was important to them.

Each interview was analysed separately and the emerging themes coded. Recurring themes across all the transcripts were then identified using a combination of inductive and deductive approaches to thematic analysis (Braun & Clarke, 2006). One over-arching superordinate theme was identified, which was divided into three themes, each with a number of subordinate themes (see Figure 3.7.1).

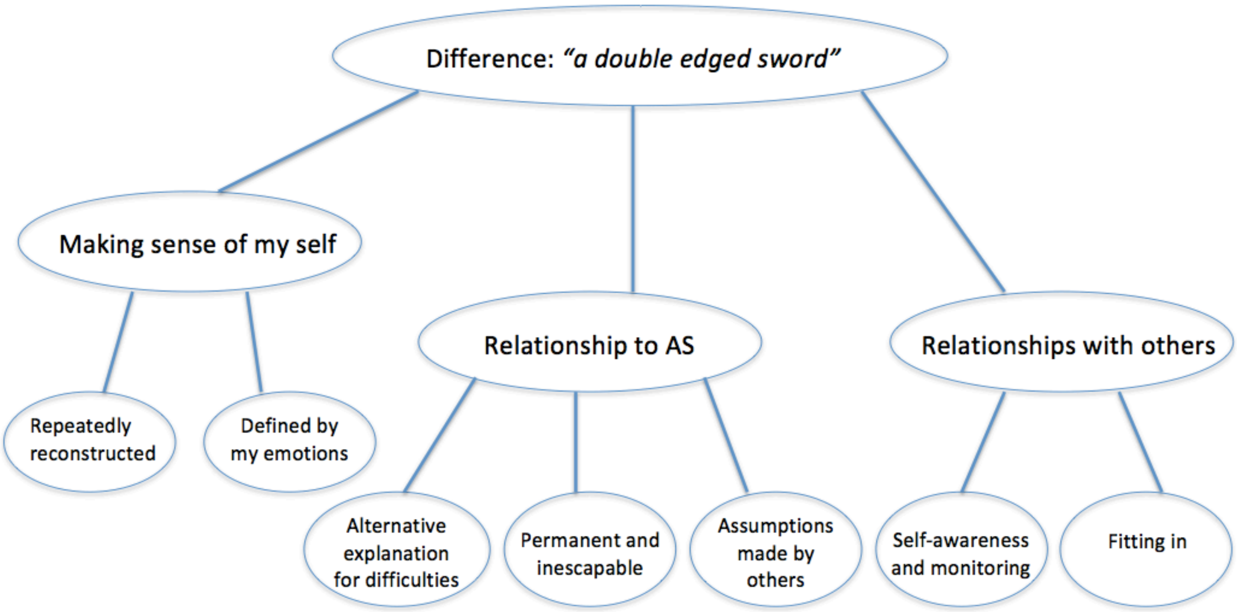


Figure 3.7.1 Group Thematic Analysis Map

Superordinate theme: Difference: "Double-edged sword"

The superordinate theme identified was about difference, with a particular focus on the perilous *"double-edged sword"* nature of it. Difference was pertinent in responses both to the specific questions relating to the research questions, and voluntary participant responses. Participants were prompted to explore their construal of self before and after the AS diagnosis. The data indicated the diagnosis offered an alternative way to construe themselves and their relationships, which was useful but threatened their own sense of self. Participants made sense of the diagnosis in relation to themselves in different ways, construing both strengths and difficulties. There was a resounding sense of difference to others who were NT, and to others with AS, although this was more varied across the women's stories. The sentiment of difference in this quote by Stella was a consistent theme across participants:

> *"We are all unique but I am uniquely unique… I feel so different from everyone."*
> ~ Stella

Among the benefits that their difference afforded them such as focussed attention, were also emotional distress and experiences of isolation. AS was a key factor in explaining both positive and negative implications of difference but participants recognised personal characteristics and life experiences as significantly influential factors. Judy's metaphor of a *"double-edged sword"* and the following quote illustrate the unsatisfactory position participants found themselves in as a result of the AS diagnosis:

> *"What I have got [AS] is a blessing as well as a curse."*
> ~ Judy

Making sense of my self

Repeatedly reconstructed

The data suggests participants often reconstructed the self in response to difficulties and the difference they experienced throughout their life. Their on-going re-construction of self in the context of a relatively recent diagnosis was evident. The quote below illustrates how Judy grappled with the extent to which the diagnosis would define her, the threat being that the aspects of herself she valued might be subsumed by the diagnosis:

> *"If somebody came along and took the Asperger's out of me, I wouldn't know what was remaining."*
>
> ~Judy

Defined by my emotions

Extreme emotional states were often used as self-defining characteristics, which made them different to other people. Prior to their diagnoses Hazel and Stella were anxious, self-critical and frightened, while Judy often felt irritated and angry. These emotional states were construed as less extreme following the diagnosis except during times of stress or unpredictability.

> *"So sometimes I don't feel that confident in myself. It is when something happens. I am sometimes kind of like out of my control."*
>
> ~Stella

Relationship to AS

Alternative explanation for difficulties

This theme captures participants' relationships to the AS diagnosis and within that, the sense they made of it. It seemed diagnosis made sense to them in various ways. Judy and Stella associated AS with confusion in social situations. This quote articulates the sense Judy made of this confusion and its implications for others:

> *"…It's about just not getting the message and therefore not giving the right one back, and people getting quite upset because it is plain as day to them that I should understand what it is that they are saying."*
>
> ~Judy

For Hazel, exhaustion from social situations was associated with AS. Prior to her diagnosis she had construed herself as a failure and faulty due to the exhaustion she experienced, whereas the diagnosis of AS helped her to take less critical view of it. In this quote she articulates the change in her thinking as far as to recognise she may be functioning better than other people with AS:

> *"I thought that it was just me being a bit hopeless…not really competent but now I feel considering I have got these difficulties, I have managed as well as I can. I am holding a job down which is a lot more than a lot of people with Asperger's manage to do."*
> ~ Hazel

All participants held intelligence and conscientiousness in high regard and though constant throughout their lives, this was another attribute of their difference which was partially attributed to AS. The ability to be focussed and determined in problem solving was viewed positively. However, their unrelenting standards left them feeling exhausted, anxious and neglectful of other parts of their lives. The diagnosis had created an opportunity for them to stop and try to redress the imbalance:

> *"The ideal one [self] is someone who is not working to the point that they are making themselves sick…it's being able to find the balance to do things well but not overdo it."*
> ~ Judy

Permanent and inescapable

The more problematic aspects of AS were construed as disappointingly permanent and inescapable by all participants. The idea of permanency was particularly upsetting for Judy and she became tearful when articulating the following:

> *"…if I didn't know that I had it, I would have just gone on in life believing that I was normal... So the sad thing is… the problem is with me and it's not going away."*
> ~ Judy

All participants expressed a desire for relationships but it seemed their construal of AS as a permanent part of their identity limited their hope for achieving this. In this quote Judy articulated how her understanding of difficulties in relationships had changed, and she was now condemned to not having a relationship by her diagnosis:

> *"Before it was about personalities, clashes, not sharing the same values or whatever and so you just move on because you are going to meet somebody else who is likely to have and share the same things as you. Knowing that I have got Asperger's and this is what puts people's back up, I am not going to find anyone and that's, that's the frustrating thing."*
> ~ Judy

Assumptions made by others

All participants appeared sensitive to the assumptions of others and often this stifled relationships, though Stella had isolated herself to avoid social mishaps. Hazel and Judy both articulated their frustration at the assumptions made about them. In particular they raised the loss of respect that others seemed to have for their point of view. Both quotes below are presented to highlight the consistency of their experiences:

> *"…my opinions don't count to anything because "she is just one of them dodgy ones"... She has got Asperger's."*
> ~ Judy

> *"…if I have a disagreement with people who know that I have got Asperger's, they've got a patronising attitude. Like, "she doesn't realise she is wrong because she has got Asperger's"."*
> ~ Hazel

Relationships with others

Self-awareness and monitoring

All participants experienced significant difficulty in communicating and relating to other people, and this was influenced by and influential for the sense they were able to make of themselves. They made different decisions about publicising the diagnosis. For Judy and Stella, it had been useful in reducing misunderstandings to share the diagnosis with family and close friends. For Hazel, sharing her diagnosis at work facilitated access to support in the workplace. However, it seemed other people's understanding of AS was limited. The consequence was that participants continued to feel misunderstood and their difficulties dismissed. In this quote, Hazel expresses frustration at people's attempts to normalise her anxiety:

> *"I feel like a lot of people say "yeah I get anxious too…what you are saying is totally normal" and I feel like saying, "oh, do you get anxious to the point where you beat your arms black and blue?!"*
> ~ Hazel

Relationships were construed as out of the ordinary and fraught with misunderstanding and frustration. Since the AS diagnosis, participants' awareness of the difficulties they presented to others was raised. With heightened attention to potential misunderstandings, participants exhausted themselves monitoring their interactions at home and work, often with little resource to make effective changes:

> *"I try to be as alert as I can but sometimes I do miss things. I tend to get the wrong end of the stick. Someone says something and I would get a completely different meaning."*
> ~ Stella

Judy used powerful metaphors about *"speaking Chinese and French"* to illustrate difficulties relating to others in the context of her AS:

> *"Knowing that I have got Asperger's is actually telling me, "well you know what, you are speaking French when they are speaking Chinese and that's the reason why they don't understand you." … so it allows me to think more about what is the message that they are trying to send me...what can I do to communicate better with this person?"*
> ~ Judy

She used terms like *"no-mans-land"* and the *"Gaza Strip"* to refer to the middle ground between AS and NT, further emphasising the challenge posed by communications with NT people. The warzone language she uses reflects the intensity of her experience and the struggle to make life more predictable. However, ultimately Judy felt at a loss as to how to change the difficult experiences she now construed to be the result of her *"problem"*:

> *"I am trying my best here. And you know, I am still not getting the kind of responses that I would like and so that leads to the unhappiness and the confusion."*
> ~ Judy

Fitting in

A final tension for participants was the identification of a fundamental but invisible difference from people who are NT. Physically the women appeared to *"fit in".* However, interactions with NT people were marred by recurrent misunderstandings and frustrations, exacerbating the extent which participants felt like they *"stand out"* as different. All three participants gave examples of this and the following description by Hazel powerfully illustrates how different she still feels. Her creation of phony words that are similar to real words, shows the subtlety of her difference:

> *"I'm odd. Miss Odd from Oddington, Oddfordshire"*
> ~ Hazel

Participants had few relationships with other people with AS which they viewed as significant friendships. Each expressed a desire to meet women with AS, and Stella expressed a particular interest in meeting Black women with AS in the hope that such meetings might reduce their feelings of difference and isolation. The final quote from Stella demonstrates that while she continued to feel out of place among the general public, she found solace in her membership of the support group for other people with AS:

> *"When I am here [local area] I don't feel as if I belong. When I go shopping or whatever, I am isolated... I don't feel as if I belong but when I go to the group [for AS] I know that is where I belong."*
> ~ Stella

Chapter 4: Discussion

This chapter presents the main findings of this study, in response to the research questions and in relation to existing literature. The clinical implications of the findings are considered and the limitations of the study are reviewed. A number of areas for future research are proposed to build on these findings and continue to offer insight into an under-researched area.

Summary and discussion of main findings

This research illustrates that a diagnosis of AS in adulthood plays a significant role in shaping the self and individual identities, which may in turn impact on quality of life and relationships. Recruitment from a voluntary sector support group provided a diverse community sample, not found in previous research. A striking finding captured by the demographic and GHQ-12 findings was the prevalence of mental health difficulties historically and presently within this self-selecting community sample. The mixed-method approach afforded a richness of data to demonstrate themes and patterns of construing and experience, while honouring the idiosyncrasies between participants. The repertory grid offered a helpfully structured format to provide intricate data about the construing of individuals. This was elaborated by the semi-structured interviews with a subsample of participants. It is the author's view that this combination and sequence of methods enabled a breadth and depth of data, which would not have been possible with any single method.

Overview of sample

The sample recruited for this research was diverse in many ways, though demographic similarities were found. In comparison to other studies (Baron-Cohen & Wheelwright, 2004) females were more represented in this sample. While age varied among the self-selecting males, female participants were close in age at diagnosis and represented a unique sample. In the absence of sufficient literature on the prevalence of AS in different ethnicities (Brugha et al., 2012), the recruitment strategy did not specify ethnic groups for participation. Interestingly, half of participants were from ethnic minority groups. This may be an artefact of the London-based sample. The majority of participants were of working age and most had experienced difficulties in employment. This is consistent with previous literature on adults with AS (Barnhill, 2007; Howlin et al., 2005; Hulbutt & Chalmers, 2004).

As a group they had diverse and often complex life experiences, some traumatic, which complicated their negotiation of relationships and impacted on the way they anticipated themselves and the world. This finding fits with social constructionist and constructivist perspectives on the importance of the other in defining the self (Kelly, 1955; Mead, 1934) and highlights the importance of psychological formulations which take account of and support individuals and their systems to make sense of past, present and future challenges.

All participants reported historical experiences of mental illness for which they had sought professional support. This is consistent with the literature indicating high prevalence rates of mental illness among adults with AS (Abel & Hare, 2005; Hofvander et al., 2009) such as depression (Stewart, Barnard, Pearson, Hasan & O'Brien, 2006), anxiety (Hare et al., 2014), and suicidal ideation (Paquette-Smith, Weiss & Lunsky, 2014; Spencer et al., 2011). In PCP these difficulties could be understood in relation to difficulties in making sense of the world and themselves. As cited by Winter (1992; p.95), "depressives and suicidal individuals, like neurotics, tend to make polarised judgements" in order to avoid invalidation, particularly when applied to the self.

Guerts and Jansen (2012) reported mental illness as the main reason for a referral for an AS assessment in their sample but this was true for only two participants in this study. The diagnosis of family members or friends was the most common reason for seeking a diagnosis. This indicates that difficulties may not have been identified by services, which may suggest professionals have a limited understanding of or confidence in using the AS label. Increased recognition and understanding of AS, which goes beyond the medical/psychiatric paradigm is needed and will hopefully be supported by dissemination of the findings of this research and the autism strategy (DOH, 2010).

One quarter of participants reported psychological distress within a clinical range on the GHQ-12; however this may be an underrepresentation. During repertory grid and semi-structured interviews participants talked openly about experiencing high levels of anxiety and symptoms typical of depression. This may reflect the complex comorbidity of psychological difficulties with AS symptoms. Since the measure has not been used with this population before, comparison with other studies was not possible. Although the measure has been used with other clinical populations, there is a possibility that the response scale's reference to typical functioning (e.g. more so than usual; less so than usual) alters the threshold for clinical distress. For example, a person with AS might regularly have difficulty concentrating which impacts their functioning and would warrant psychological support and so rating this item on the GHQ-12 as "same as usual" would not indicate psychological distress. Future studies should explore the validity and reliability of the GHQ-12 and other psychological screening tools among this population to ensure their needs are accurately identified and appropriate services enacted to support them. Without appropriate screening tools, the psychological needs of this population will continue to be overlooked (National Audit Office, 2009).

How do people diagnosed with AS during adulthood construe the self?

The findings of this study indicate the ways adults diagnosed with AS construe the self are unique to the individual but also that there are themes and patterns of construing across the group. The design did not require a control group of people without an AS diagnosis so it is not possible to assert whether the themes and patterns are unique to the AS population.

An adapted design that includes a control group without AS would help to establish whether the themes are unique to this population. Aside from this uncertainty, a number of striking themes in construing remain important.

Cognitive structure

In terms of cognitive structure, this study found both tight and loose construers. Tariq, Peter, Jack, Hazel and Stella were found to have tight construct systems that were cognitively simple. When a person's construing is predominantly tight their thinking will be concrete and lacking in new ideas (Bannister & Fransella, 1986) and perhaps therefore what we might anticipate among people with Asperger Syndrome. An alternative construction, which does not view tight construing as symptomatic of AS, may suggest such cognitive structures could explain Tariq and Hazel's history of depression and suicide attempts and Peter's experience of long-term depression. Such individuals tend to be characterised by interpersonal difficulties, including impairments in predicting the construing of others, integrating conflicting information about other people and communication skills. Thus they also have restricted options available to them.

Kelly (1955) proposed that tight construing might be employed as a defensive strategy to counter anxiety, often by people who are aware of a threat. For these individuals, constructs have strong interrelationships and so invalidation of almost any construct may carry the implication of a direct threat to the core constructs used to make sense of the self. In order to avoid potentially catastrophic invalidation, tight construers may actively seek or even fabricate validation. The following examples can be understood in the context of tight construct systems. Tariq's construal of himself was incredibly focused on his artwork, as this was an area of success for him and provided an extreme contrast to earlier episodes of depression and suicidal ideation. However, he construed his intense focus on his artwork as unfavorable in the repertory grid. It is possible that the intensity of his focus on artwork was evidence of him actively seeking validation of his self-concept to avoid potentially catastrophic invalidation. Hazel and Stella's preference for isolation, in spite of a desire to have relationships, could also be understood in the context of their tight construct systems. It seemed both women actively sought evidence to support the view that they were better off when they were isolated from others. For example, they talked about the benefits of being independent rather than having to compromise in relationships with others. By isolating themselves they reduced the likelihood of invalidation. These examples of limiting interests and opportunities might also be evidence of constriction, a protective strategy involving drawing in of the perceptual field to cope with the incompatibilities in construing (Winter, 1992).

By contrast loose construing or cognitive complexity is associated with weak interrelationships between constructs. According to Kelly's (1955) organisation corollary, constructs that are related impact upon each other and have the potential to be strengthened or weakened by validation and invalidation. The benefit of a loose construct system is that it defends an individual against the risk of invalidation (Winter, 1992). However, Winter (1992; p.89) states the disadvantage is the ability "to generate few, if any, coherent anticipation of events". Interestingly Judy, a participant found to have a loose construct system, expressed psychological distress in her follow up interview. Judy's psychological distress might be understood in the context of her loose construct system, perhaps reflecting Kellyan anxiety as she struggled to make sense of her world. Furthermore, the content of David's constructs shows some permeability, which may be indicative of dilation, a strategy used to accommodate incompatibilities in construing (Winter, 1992). For example, 'understands actions – actions unexplained' is open to newly perceived information, may relate to diagnostic criteria about cognitive flexibility and was found to be a superordinate construct for David. In consideration of Adams-Webber's (1969) findings, this strategy may mean David is more able to have a varied view of other people's construing in social situations and so may be adaptive.

In the context of an AS diagnosis there are likely to be both benefits and disadvantages of both types of construing (Winter, 1992) and the data from this study provides a snapshot of some of these. Individual experiences prior to and post diagnosis will have impacted on the variation in structure of construing between participants and are likely to be significant factors on lifetime trajectories (Perkins & Berkman, 2012). A larger study would enable further exploration of patterns within the group, and may also enable consideration of the impact of diagnosis on experience and creativity cycles (Kelly, 1955).

Construct content

The CSPC (Feixas et al., 2002) content analysis of all individual and the group's constructs indicated a disproportionate number of relational constructs, followed in frequency by personal and emotional constructs. Self-definitional constructs were most frequently categorised as personal on the CSPC (Feixas et al., 2002), followed by relational and intellectual/ operational. While 'relatedness' has been identified as a common factor in core construing (Butler, 2006), these findings contrast with other PCP research where moral constructs were found to be most frequent (Feixas et al., 2002; Hardison & Neimeyer, 2007). This may indicate uniqueness in construing for this population.

PCP suggests that individuals experiencing difficulties in a particular area elaborate their construct systems; this is then reflected in the relatively large number of constructs they have available in that area (Winter, 1992). It seems therefore, that people diagnosed with AS, who have experienced social and relational difficulties (APA, 2013; WHO, 1992), may have elaborated their construct systems to better anticipate life. Importantly however, the self-defining constructs were not primarily associated with relationships. It is possible that personal constructs that concern personality or character traits are significant for this group, whose sense of self was threatened by the diagnostic label received in adulthood. This idea was corroborated in the phase two interviews. Jack, the participant who had a successful marriage and career, was the only participant not to elicit 'personal' constructs. Further research might explore how life experiences influence self-defining constructs.

Superordinate constructs

The supplied construct was found to be superordinate for five of the eight participants, indicating it was in some way central to their approach to themselves and others. Patterns to explain the difference between participants were not identified. It is possible that the limited range of elements influenced the superordinacy of this construct.

Superordinate elicited constructs were most frequently categorised as relational or personal on the CSPC. While relational constructs concerned types of relationships, personal constructs indicated personality or character traits. Interestingly Judy, most recently diagnosed, had the highest frequency of personal constructs. Her phase two interview highlighted the reconstruction of self, as her construal of self was threatened by the AS diagnosis. The following quote illustrates Judy's perspective:

> *"If somebody came along and took the Asperger's out of me, I wouldn't know what was remaining."*
> ~Judy

Cridland et al. (2014) proposed that high functioning autistic adolescents would have difficulty developing superordinate constructs due to their minimal use of hierarchical organisation of constructs and Procter (2001) theorised that people with ASD experience a poor sense of identity. In this study of high functioning adults receiving a diagnosis in middle to late adulthood, participants articulated a reasonable sense of self and identity but this was somewhat shaken by their diagnosis.

The "uniquely unique" self

A major theme of construing was around how differently participants construed the self in relation to others both with and without AS. This theme encapsulating the self construal of all participants was illustrated by the following quote from Stella:

> *"We are all unique but I am uniquely unique… I feel so different from everyone."*
> ~Stella

A number of participants elicited constructs in their grids associated with standing out, which correlated strongly with the supplied construct and were categorised as relational using the CSPC (Feixas et al., 2002). The self was generally construed as standing out and this was corroborated in the thematic analysis of phase two interviews where difference was identified as the superordinate theme. The phase two interviews indicated the difficulty associated with the invisibility of their difference, which was made apparent through interactions. It seemed this conflict between the physical normality and interactional difference led to misunderstandings and troublesome relationships. Others rarely construed participants' differences positively and consequently people made few allowances or adaptations in relationships and interactions. Furthermore, phase two interviews found the AS diagnosis had increased participants' awareness of the difficulties but offered limited resources to make changes to the way they interact or relate to others. This finding supports the social constructionist perspective of Molloy and Vasil (2002), which asserts the problem to be addressed is within the fit or flexibility of the social context a person lives in.

In what ways, if any, is the self before and self after diagnosis construed differently?

This research found the self before and self after diagnosis were construed differently. Statistically, the self before diagnosis was very meaningful and elaborated. The repertory grid required participants to take a retrospective view of the self before diagnosis. Within the PCP framework the interpretation individuals make of events influences their responses to them and future responses (Butt, 2008). The retrospective view was therefore more important than the accuracy of their recollection. Remarkably, seven of eight participants construed the self before diagnosis critically. Kelly (1955) emphasized that the possibility of an imminent comprehensive change in one's core constructs is threatening and possibly also guilt-provoking. The participants in this study experienced comprehensive shifts in their self-perceptions following diagnosis, which they viewed positively and negatively. Various means of dealing with consequent threats and/or guilt can be seen in the grids and the phase two interviews. The elaboration of the self before diagnosis may represent an attempt to reconstrue the current self in positive ways.

Judy, less than one year from her diagnosis, was the exception and she construed the self before diagnosis favourably. In the phase two interview her difficulties in striking a balance between maintaining the self she knew before and accommodating the diagnosis were more apparent than in interviews with other participants. In PCP terms this balancing process could be the result of Kellyan guilt. The author hypothesises therefore, that there is a critical period following diagnosis during which there is a need to make sense of past and present experiences of self and the diagnosis. This supports Punshon et al.'s (2010) hypothesis that adults may benefit from psychological support which helps them to explore the meaning of the diagnosis in the context of the construal of self.

The findings of both repertory grids and follow-up interviews indicate participants made attempts to better understand their experiences prior to the AS diagnosis, often resulting in alternative psychiatric diagnosis or labels. Similar findings are present in the literature (Griffith et al., 2012; Punshon et al., 2009). Fahim and David's superordinate constructs related to an understanding of themselves and Stella articulated that she had been *"searching for answers"*. Stella had labelled herself a *"highly sensitive person",* whereas Hazel had questioned whether she had experienced a brain-injury as a child. These can be understood as examples of being unable to make sense of the self and world, and then using Kellyan aggression to widen the perceptual field. While aggression can be beneficial in PCP terms, aggressive people can experience interpersonal difficulties if it is not found to be socially acceptable or does not fit with the way the self is construed (Winter, 1992).

The self after diagnosis was construed less critically than the self before diagnosis. For Tariq and Peter the reduction in self-criticism was more apparent between the self before diagnosis and self now. The measure of elaboration using the percentage total sum of squares for elements indicated that six participants were less able to make sense of the self following their diagnosis compared to the self before diagnosis. Beyond the sense of self, results indicated the diagnosis of AS helped to explain some of the difficulties they had experienced previously. For example, Fahim and David's repertory grids indicated that in general they were less confused by social situations. However, the phase two interviews highlighted how the diagnostic explanation had done little to help participants make adaptations to their own behaviours and instead meant that they invested a lot of energy in self-monitoring. Participants described how exhausting and often unsatisfying it was to monitor their own and others' responses. These findings replicate previous research (Müller et al., 2008).

Fransella's (1970, 1972) work with people who stutter offers a potential explanation for the reduced sense of self following diagnosis. Fransella (1970, 1972) found that the symptom of stuttering had become "a way of life". This meant it was elaborated and meaningful in such a way that it effectively helped stutters to anticipate themselves and others. By contrast, the self that did not involve stuttering was far less meaningful and so did not provide a framework that helped individuals anticipate the world. Fransella (1970, 1972) concluded that the stutterer needed support to elaborate the self who did not stutter to make it more meaningful. Participants in this study had experienced a range of symptoms of AS for as many as 53 years before their diagnosis. Although these may have posed difficulties, there is a high likelihood that they influenced the way participants anticipated the world. The diagnosis of AS may have offered an alternative perspective on the symptoms or difficulties but it is likely this perspective was comparatively less elaborated. The quote from Judy used earlier in this chapter neatly exemplifies the lack of elaboration of the self with a diagnosis. Furthermore, participants in this study did not receive support following diagnosis. Therefore, the self after diagnosis and current self were less elaborated than the self before diagnosis, even for David, who was eighteen years from his diagnosis.

Phase two interviews indicated the process of reconstruction of the self following diagnosis. Participants were six months to three years from their diagnosis. Judy, closest to her diagnosis, articulated the greatest level of reconstruing during her interviews. It seemed the permanent diagnosis threatened her construal of self. She described her self before diagnosis as "normal" but the diagnosis had been invalidating and had shaken her assumptive world. Resigned to the permanent diagnosis of AS, she faced Kellyan guilt. Kelly (1955; p.909) stated “it is generally difficult to sustain life in the face of guilt”. Winter (1992) presents the findings of research which found hostility and constriction were often responses to guilt. The hostility and constriction may manifest as a construction of the self as autonomous and a distinction between the role played socially and the core role. In this sense a person may invest in relationships or activities, which validate the core self, but react with constriction or hostility to the loss of them. It is likely Judy had invested in relationships and activities that validated her construal of self as “normal” previously. Faced with Kellyan guilt after diagnosis, she hostilely construed herself as very different to other people and had a very negative view of the practice of “pigeon-holing” people.

How does the construal of the self before and self after diagnosis compare with the ideal self, and does this indicate any preference for having the diagnosis or not?

The ideal self was found to be meaningful and highly elaborated in comparison to other elements in the grid. It is common for the ideal self to be salient (Winter, 1992). Statistical analysis indicated the distance between the self before diagnosis and the ideal self was greater than between the self after diagnosis and the ideal self. This suggests the diagnosis was preferable to no diagnosis. However, the phase two interviews indicate the complex process which participants negotiated following their diagnosis. These findings support others which allude to the importance of support to understand what the diagnosis means to individuals in the context of the way they construe the self (Griffith et al., 2012; Punshon et al., 2009).

Judy and Stella were the only two participants who had an increased sense of self following their diagnosis. They both construed the current self close to the ideal self, a finding not so apparent for other participants.

How do people diagnosed with AS during adulthood construe other people with and without AS, and in what ways is this similar or different to the way they construe themselves?

The commonality corollary reminds us that despite the different ways individuals perceive and experience the world, they have the same desire for acceptance, and repertory grid explorations of the social self indicated that participants’ experiences and interactions with others played an important role. Participants frequently received feedback from other people, replicating the finding of other studies (Barnhill, 2007; Cridland et al., 2014). Tariq, Peter, Fahim, David and Hazel’s grids indicated they felt some of their difficulties were not apparent and that neurologically typical people misunderstood or had a negative view of them. This finding was corroborated by phase two interviews, where participants felt reduced to the label, negating more positive qualities. The grids indicated that participants perceived other people with AS as having a more realistic view of them and recognising positive qualities.

The grids and follow-up interviews indicated significant variation in the way people with AS were construed. The findings suggest participants' construal of AS was complex and that individuals with the label could be more different than those without. Overall, elements labelled as NT were construed similarly to each other and they were distinguishable as group. Repertory grid analyses suggested neurologically typical people were construed to have positive and negative traits. Analysis of phase two indicated that AS people had more positive traits than neurologically typical people. Construal of self-elements indicated participants shared characteristics with both AS and NT elements.

What are the clinical implications for understanding how the self is construed for individuals diagnosed with AS in adulthood?

The autism strategy (DOH, 2010) and NICE guidelines (2012) suggest all adults receiving a diagnosis of AS should be offered psychological support at the time of their diagnosis. Co-morbid mental health difficulties should also be treated. However, the guidelines for when, how and what specifically might be beneficial are unclear. The findings of this study indicate appropriate, timely services to meet individual needs were rarely offered. Sadly this replicated earlier research findings (Punshon et al., 2009; Griffith et al., 2012) and suggests that people with AS continue to be marginalised by services (National Audit Office, 2009). While enhancement of social skills is the main support offered to people with ASD, and social interactions were a dominant area of difficulty for participants, the phase two interviews offered several ideas, which warrant further exploration. Judy was offered time-limited support following diagnosis, but was not offered the opportunity to spread sessions out over a longer period of time. As evidenced by some changes in her construal and understanding of AS between phase one and phase two interviews, Judy felt an approach which recognised the journey of making sense of her diagnosis would likely be protracted and would require different input at different times.

An underdeveloped sense of self may be an important factor in the poor social and emotional adjustment of this population, which may be amenable to psychological therapy (Szatmari et al., 1995; Jackson et al., 2012). Cridland et al. (2014) advocates support to make sense of experiences during unique life stages for adolescents with high functioning autism. This research has highlighted the complex and dynamic nature of people's lives preceding and subsequent to the AS diagnosis and a stage-based approach is unlikely to meet the complex needs of this group. However, an experience-based approach that takes account of factors such as chronic or life-threatening illness, relationship breakdown or employment difficulties (Howlin et al., 2005) may be a viable alternative.

This research has indicated the repertory grid technique may be a very useful clinical tool for exploring multiple aspects of self and others. In the case of all participants, undertaking the repertory grid process was the first experience of exploring the way they construed themselves and the transition from before to after diagnosis. This process of self-reflection continued in between meetings in much the same way that a therapeutic encounter might. The repertory grid is therefore recommended as a useful post-diagnostic assessment tool to identify areas for further support and a therapeutic tool to aid adjustment to the diagnosis. Furthermore, Procter's (2002, cited in Fransella et al., 2004, p.79) perceiver elements grid may be a useful clinical tool for exploring the interpersonal construing of this population or deconstructing the label of Asperger Syndrome with groups of people with and without a diagnosis. For example, the grids could be used with newly diagnosed adults and members of their family or work colleagues.

The decision to interview only females in phase two of the research was a strength of this study. The dominant discourse around gender differences might assume the females interviewed would have a different perspective to males and therefore further research, to explore the views of males is needed. However, unprompted by the interview questions, Judy, Hazel and Stella independently identified an unmet need for psychological support specifically for women to be delivered in a variety of formats. This research has shown that female participants had unique constructions of events but similarities and commonalities were also found. In addition, they showed an awareness of the impact of the way they view the world on the ways others view them and the world. Gender-specific support, which targets Kellyan corollaries of individuality, commonality and sociality is therefore recommended. Such an approach might elaborate multiple aspects of self, the AS diagnosis and AS-related dilemmas. It would support people to widen their perceptual field to alternative ways of construing and adjusting to change.

Strengths and Limitations of this study

The literature search identified a paucity of research in the field of adults with AS, of which a minuscule proportion focussed on people diagnosed during adulthood. This research therefore makes an important contribution towards a psychological understanding of this unique but significant population. Previous studies have often been small and the size has limited the extent to which people wish to make generalisations. However, this exploration, though also small, has supported the findings of other studies indicating the need for post-diagnostic support that recognised the diagnosis as part of a process rather than a single event (Punshon et al., 2009). As Stella said of her diagnosis;

> *"This is a journey, not a destination."*
> ~ Stella

From a positivist position, the small sample size limits the generalizability and transferability of the experiences of these eight participants to the wider population. However, given the consistent reports of difficulties with support services, and parallels with previous research (Griffith et al., 2012; Hurlbutt & Chalmers, 2004; Müller et al., 2003; Müller et al., 2003; Punson et al., 2010), it is probable that the issues highlighted in the current study are a good reflection of the experiences of many people with AS. Furthermore, from social constructionist and constructivist perspectives, this research has adopted and applied methods to develop a novel understanding of the impact of an AS diagnosis of the self. True to her epistemological standpoint, the author recognises that at another time, with another sample, the findings might be different. Even this small sample offers fresh insight into a virtually unexplored population which, through dissemination, may influence the way clinical psychologists and other practitioners work to support adults diagnosed with AS.

A further strength of this research was the uniqueness of the sample in terms of age, diversity and female only follow-up. The sample age ranged from late twenties to sixties, with each decade represented. Furthermore, five participants were aged 50 years or older, making this research the first to begin to address a gap in understanding the experience of an older population of people with AS (Happe & Charlton, 2012; Perkins & Berkman, 2012; Tantam, 2014). Participation was voluntary and the skew towards this age range was not anticipated. Several questions for further research arise from this: what is the age profile of adults being diagnosed with AS in the UK; is there an increasing number of older adults being diagnosed; what factors influence whether a person seeks an AS assessment in later life?

Repertory grids provided a useful structure within which to begin discussions with this sample. Only one participant disliked the method and it is possible the author's relative inexperience in eliciting constructs compounded her ability to work flexibly to meet his needs. As Hare et al. (1999) found, completion was time-consuming, which may be a consideration if used in further research. However, the wealth of information gathered, particularly from a group of people who may find social situations difficult, was immense and beyond the word limit for this thesis. The repertory grid technique was a useful springboard to the semi-structured interview, which enriched the data further. Procter's (2002, cited in Fransella et al., 2004, p.79) perceiver elements grid may be a useful tool to explore the interpersonal construing of this population.

The implementation of Tschudi's (1977) ABC method did not contribute much to the data and it would seem is better suited to clinical work than research. However, in developing the research design the method was elaborated by two additional aspects: firstly, exploring participant ideas about what might need to happen for the desired position to be achieved; and secondly exploring the advantages and disadvantages of a middle position. Development of these aspects could add to the systemic elaborations to the model outlined by Tschudi and Winter (2012).

Results of this study should be interpreted with the following limitations in mind. Participants were recruited from a support group for adults with AS. As a result, the sample is biased toward the population who identify with the AS label. A future study may look to recruit directly from a diagnostic service to capture the views of those who chose not to accept the diagnosis. If such a study were to be adopted, a repeated measures design which collated repertory grids before and after diagnosis would offer an opportunity to explore transitions, which may offer insight into the experience and creativity cycles of this group.

Recommendations for future research

Several ideas for future research have been presented throughout this discussion. They included:

- Evaluation and development of appropriate mental health screening tools for this population
- Control group study to establish the uniqueness of themes to this population
- Further exploration of patterns of cognitive structure in this population
- Impact of life experiences on self-defining constructs
- Extension of phase two to incorporate male perspectives
- Study of AS and aging
- Exploration of interpersonal construing using Procter's (2002) perceiver elements grid
- Exploration of the sense of self among adults who choose to reject the AS diagnosis.

The following recommendations build specifically on particular elements of this research. The GHQ-12 identified psychological distress in two of the eight participants. However, all participants had experienced and sought help for mental health difficulties in the past. Punshon et al. (2009) found participants had complex psychological and relationship histories, which are likely to have influenced the construal of self. The impact of a diagnosis for people with different experiences, including mental illness, and routes to diagnosis would be an interesting area for further investigation. This study used a cross-sectional design to gather a snapshot of the sense of self; perhaps a narrative approach to explore changes over time would add to this. To build specifically on this research study, and to begin to address the gap in the literature on AS in older people, such a study might focus on women diagnosed with AS aged 45 years (approximate age of the menopause) and over.

Conclusion

This research has shown that receiving a diagnosis of AS in adulthood is an important step towards people's understanding of themselves and their experiences, which can impact upon their quality of life and relationships. What follows the diagnosis in terms of making sense of the self is highly complex and individuals would benefit from therapeutic input. The mixed method approach has found similarities and patterns in the ways this group of people construe the self while also capturing the individuality of people’s construing. This has provided a novel perspective on the experience of this underexplored population. The author hopes to continue to develop this research in the future while clutching at the following quote from George Kelly (1955, p.15):

> “We take the stand that there are always some alternative constructions available to choose among in dealing with the world. No one needs to be the victim of his biography.”

Chapter 5: References

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Chapter 6: Appendices

Appendix 1: Literature Search Strategy
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Appendix 14: Example coding frame with quotes

Appendix 1: Literature Search Strategy

A review of relevant literature was undertaken to develop the research questions. Major psychology, social science and medical databases were searched including Web of Science, PsychINFO and Pubmed.

The key words identified by the authors of the most relevant articles guided the use of some of the search terms. These included:

1. *a. Asperger Syndrome: Asperger**
   b. Autism: Autis, high functioning autism, pervasive developmental delay*
2. *Adulthood: adult**
3. *Self, self-concept, identity*
4. *Identity formation*
5. *Experience, beliefs, views, concepts, perspectives, construct*
6. *Personal Construct Psychology: personal construct*, repertory grid, Kelly G*
7. *Methodology: meta-analysis, systematic review, review, cohort study, survey, quantitative, qualitative, mixed method**

The search terms from category 1a, 1b and 2 were searched together initially and were later combined with search terms 3-7. In the instances of few or no literature found, the search was extended to include search terms 1b.

Exclusion criteria included:
1. Literature not reported in English
2. Literature focusing only on child and adolescent populations

Additional search strategies

Ancestry search (footnote chasing):
Relevant studies were also retrieved from the references of papers identified in the database searches.

Relevant journal search:
To complement the database search, specific journals and academic or clinical publications were searched for relevant articles. Journals included; *Autism Research, Journal of Autism and Developmental Disorders, Autism, Focus on Autism and Other Developmental Disabilities, Research in Autism Spectrum Disorders.*

A systematic search of the *Journal of Constructivist Psychology: Personal Construct Theory and Practice (online journal)* was also completed.

Relevant UK Policy and Legislative Document search:

Recent governmental policies relating to autism and Asperger Syndrome in adulthood, such as those published by the Department of Health (DoH) and the Department for Education and Skills (DfES) were also reviewed.

Voluntary sector internet sites were also searched, including the www.austism.org.uk; Mind (www.mind.org.uk); and Mental Health Foundation (www.mhf.org.uk).

Appendix 2: Interview Schedule

Review the repertory grid analysis.

- *Is this how you would see things?*
- *Explore similarities and differences between the following elements*

  - Self before diagnosis – Self after diagnosis
  What characteristics describe each of these?
  - Self now – Ideal self
  What characteristics describe each of these?

- *What characteristics describe a person with Asperger Syndrome and a Neurotypical person?*

ABC

- *What are the disadvantages of being a person with Asperger Syndrome?*
  - *What kind of bad or less desirable characteristics or qualities would you use to describe someone who has Asperger Syndrome?*
  - *In what ways do you think you fit this description?*
- *What are the advantages of not being a person with Asperger Syndrome?*
  - *What kind of good or desirable characteristics or qualities would you use to describe someone who does not have Asperger Syndrome / is neurotypical?*
  - *In what ways do you think you fit this description?*
- *What are the advantages of being a person with Asperger Syndrome?*
  - *What kind of desirable characteristics or qualities would you use to describe someone who has Asperger Syndrome?*
  - *In what ways do you think you fit this description?*
- *What are the disadvantages of being neurotypical?*
  - *What kind of bad or undesirable characteristics or qualities would you use to describe someone who does not have Asperger Syndrome / is neurotypical?*
  - *In what ways do you think you fit this description?*
- *What might be the dis/advantages of the middle position of the scale?*
  - *What kind of characteristics or qualities would you use to describe someone at the middle position of the scale?*
  - *Can you describe someone that you know who might fit your view of what this middle position would be like?*
- *What would need to happen in order to achieve this position?*

Additional questions

Defining Asperger Syndrome

- *What does the term Asperger Syndrome mean to you?*
    - *Diagnostic criteria?*
    - *What does it mean for an individual to have Asperger Syndrome?*

        - *In what ways is this different to being neurotypical?*
        - *If participant indicates more similarity than difference then explore this with them*

Impact of diagnosis

- *What impact has your diagnosis of Asperger Syndrome had on you?*
    - *Sense of self*
- *In what ways do you feel you share qualities with other people who have the same diagnosis? Or that you are different?*

Post-diagnostic support

- *What was your experience of the diagnosis process?*
- *Have you received any support in understanding what your diagnosis means?*

Appendix 3: University of Hertfordshire Ethics Approval

UNIVERSITY OF HERTFORDSHIRE
HEALTH AND HUMAN SCIENCES

MEMORANDUM

TO **Susan Tilki**

CC **David Winter and Nick Wood**

FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman

DATE **5 February 2014**

Protocol number: LMS/PG/UH/00159

Title of study: A mixed methods exploration of the sense of self among a group of people diagnosed with Asperger Syndrome in adulthood.

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 5 February 2014

To: 31 July 2014

Please note:

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Appendix 4: Information Sheet and Consent Form

Participant Consent Form (Version 11.12.13)

AN EXPLORATION OF THE SENSE OF SELF AMONG A GROUP OF PEOPLE DIAGNOSED WITH ASPERGER SYNDROME IN ADULTHOOD

Researcher: Susan Tilki

Supervisors: Prof. David Winter, Dr. Nick Wood, Dr. Myooran Canagaratnam & Dr Sarah Helps

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Please respond to each question and sign below to say that you have read and understood the information given.

1. The study and what it involves has been explained to me	**Yes/ No**
2. I have had the chance to ask questions and discuss the study.	**Yes/ No**
3. All of my questions have been answered.	**Yes/ No**
4. I have received enough information about the study.	**Yes/ No**
5. I understand that my involvement is voluntary - I am free to leave the study at any time, and I don't have to give a reason for doing so.	**Yes/ No**
6. I understand that deciding against taking part in this study will not affect my access to any services.	**Yes/ No**
7. I understand that the interviews will be audio-taped and transcribed.	**Yes/ No**
8. I understand that the results of the study will be written up for Susan Tilki's Doctoral thesis but that she will remove any information (e.g. my name and age) that might mean that people can identify me.	**Yes/No**
9. I understand that the results of the study may be published in an academic journal or other publication.	**Yes/No**
10. I agree to take part in this study.	**Yes/ No**

PARTICIPANT NAME: ______________________________

SIGNATURE: ______________________ DATE: ________________

RESEARCHER: SUSAN TILKI

SIGNATURE: ______________________ DATE: ________________

This research has been reviewed and approved by University of Hertfordshire Research Ethics Committee.

Participant Information Sheet (Version 11.12.13)

AN EXPLORATION OF THE SENSE OF SELF AMONG A GROUP OF PEOPLE DIAGNOSED WITH ASPERGER SYNDROME IN ADULTHOOD

What is this information sheet about?

You are being invited to take part in a research project. Before you decide whether you would like to take part, it is important for you to understand why this research is being carried out and what it will involve. Please read the following information, think about it and talk about it with other people if this will help you to decide whether you want to take part. If you are not sure about something or if anything is unclear then please ask me about it and I will be glad to discuss this with you.

Who are you and who else is involved in this research?

My name is Susan Tilki and I am in my final year of completing a Doctorate in Clinical Psychology (*DClinPsy*) at the University of Hertfordshire. As part of this Doctorate, I need to complete what is called a *Major Research Project*. As well as doing research, I have experience of working in a range of NHS and charity services over the last ten years, before and during my training.

This research will be supervised by Prof. David Winter, a Consultant Clinical Psychologist and the Course Director of my course; and Dr. Nick Wood, a Clinical Psychologist and tutor on my course. Both have extensive experience of working with individuals and families, and in carrying out and supervising research.

Dr. Myooran Canagaratnam is a Consultant Psychiatrist, and Dr. Sarah Helps is a Consultant Clinical Psychologist at the Tavistock and Portman Learning Disability Service. Both will be offering their expertise to ensure the research is relevant to the diagnostic and therapeutic services offered to adults with Asperger syndrome.

We would like to invite you to take part in this research, but it is up to you to decide.

Why are you doing this research?

In doing this research, we would like to know more about how adults who are diagnosed with Asperger syndrome view themselves. We are interested in how this may be similar or different to how they viewed themselves before getting their diagnosis.

Why do you want to know about this?

There has been very little research into the experiences of people who are diagnosed with Asperger syndrome in adulthood. Finding out more about the experiences of this group of people may help professionals (like clinical psychologists) to understand more about what support they may need.

What will happen if I decide to take part in the research project?

If you agree to take part in this research, I will contact you and arrange to meet at a location which is best for you. Initially I would need to meet with you for a maximum of 90minutes to ask you some questions about how you view yourself now you have a diagnosis of Asperger syndrome. I may ask you to be interviewed for 60 minutes on another day to explore some of the things you said in our first interview in more detail.

How will you gather information?
I will make notes during the interviews which you will be able to look at it you want to. I will also audio-record the interviews so that I can listen again and relate your information to the information of other participants. I will look for similarities and differences and other interesting themes. The audio recordings will be deleted following transcription.

Can I take part if I don't speak English?
Unfortunately, I don't have access to an interpreter so the interview will need to be in English. If you have any concerns about this then please talk to me about it.

Will what I say in the interview be kept private?
Any personal details you share with me, like your name and age, will kept be confidential. This means that I will not share this with anyone else. This information will be kept separately from notes, interview audio-recordings and transcripts. These will also be anonymised, which means that your name and other personal information will not be linked to the interviews. I will take whatever steps possible to ensure that you cannot be identified in parts of the transcript which are included in the write-up of the research or any future articles which are submitted for publication (for example, by removing any place names).

Are there any exceptions?
The only reason that I would have to give anybody this information would be if, during an interview, I have serious concerns about your safety or the safety of somebody else. In this instance, I will have to share this with an appropriate professional (such as a health or social care worker). If this happens I will usually try to talk to you about it first.

Do I have to answer every question that you ask me?
You can decide whether or not you wish to answer all of the questions. You do not have to talk about anything that you are not comfortable with. You can let me know if this is the case without telling me why, and we can move on to the next question.

Are there any risks that come with taking part in the research?
It is possible that you may find some aspects of the interview upsetting. Sometimes people find that talking about their experiences can be upsetting or emotional for them. This might be relating to difficulties in getting a diagnosis. However, sometimes people also find it good to talk about their experiences with somebody that they don't know and won't see again, and help to make other people more aware of some of the things that have happened to them.
If you become upset during the interview, I will ask you if you would like to take a short break, which you can do if you need to. I will check that you are ok to continue. If you still want to take part but don't feel that you can carry on with the interview at this time, we can arrange another meeting on a different day to finish the interview.

This research has been reviewed and approved by University of Hertfordshire Research Ethics Committee.

What happens at the end of the interview?

After the interview is finished, I will talk to you about how you have found the meeting, and ask you if you have any questions or concerns. We can talk in more detail about the research if you would like to. If you feel that you need to talk some more about the interview or anything that has come up, we can talk about how you could get further support. This could be from your GP, another health professional or Autism London. I will give you some contact details of services that may be of help, if you would like this.

Do I have to take part in the research?

You do not have to take part in this study if you do not want to. Whatever your decision, your access to services will not be affected.

What happens if I change my mind about taking part in the research?

You can decide you do not want to take part in the research at any time, if you change your mind. You do not have to give a reason for this. It will not be possible to remove your interview data from the research project once it is written up for the thesis or publication.

Do I get paid for taking part?

Participating in this research is completely voluntary and so you will not get paid. You will however, be given money back for all travel costs.

What will happen after the research is finished?

This research is conducted as part of the thesis requirement for a Doctorate in Clinical Psychology and will be submitted at the University of Hertfordshire for marking. The write-up (thesis) will be shared with the Tavistock and Portman Lifespan Autistic Spectrum Disorders. It may later be published in a journal. However, all information will be anonymous and readers will not be able to identify individual participants.

Will the findings of the research project be available to me?

If you would like, I would be happy to share with you a summary of the findings at the end of the study in October 2014.

Any Questions?

If you have any questions please do not hesitate to contact us using the contact details below:

Susan Tilki
Department of Clinical Psychology
University of Hertfordshire
College Lane
Hatfield
Herts, AL10 9AB
e-mail: s.s.tilki@herts.ac.uk

Prof. David Winter
Department of Clinical Psychology
University of Hertfordshire
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Herts, AL10 9AB
e-mail: d.winter@herts.ac.uk

Thank you for taking the time to read this information.

This research has been reviewed and approved by University of Hertfordshire Research Ethics Committee.

Appendix 5: Tariq's Repertory Grid Data and Analysis

Table A5.1: Tariq's repertory grid

		ELEMENTS										
CONSTRUCTS (rated 7-1)		Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
1	**Accepting of self**-Self-hatred	1	2	5	7	6	6	6	5	2	7	6
2	**Focussed-**Unfocussed	1	1	7	6	7	6	6	5	3	6	7
3	Unspontaneous-**Spontaneous**	7	7	7	3	7	4	3	4	4	1	1
4	**Confident**-Uncomfortable in own skin	1	1	2	7	4	4	4	2	2	7	6
5	**World weary-**Innocent	3	3	4	6	4	4	7	2	1	2	7
6	Thinks in colour-Black & white thinker	1	1	2	4	2	2	1	4	1	6	5
7	**Manly**-Emasculated	2	2	3	6	4	3	6	2	2	6	7
8	**Self-centred**-Helps others	6	6	7	2	5	3	7	2	2	1	1
9	Quiet-**Loud and 'in your face'**	4	4	3	3	3	1	6	6	5	1	1
10	Honest-Manipulative	4	3	3	4	4	3	2	6	6	4	2
11	Scared of consequences-Mentally care-free	6	6	5	4	6	3	1	6	6	2	2
12	Physically rigid-**Free-flowing**	6	6	6	2	5	4	6	7	6	1	2
13	Monotone-**Eloquent**	6	3	2	1	2	2	1	6	4	3	1
	Asperger Syndrome-Neurotypical	6	6	6	4	6	3	2	7	5	1	1

Table A5.2: Content categorization (Feixas et al., 2002) of Tariq's constructs

Content category		**Constructs elicited**
1. Moral	b. Altruist-Egoist	Self-centred-Helps others
2. Emotional	a. Visceral-Rational	Unspontaneous-Spontaneous
	c. Optimist-Pessimist	World weary-Innocent
	d. Balanced-Unbalanced	Scared of consequences-Mentally care-free
3. Relational	b. Pleasant-Unpleasant	Monotone-Eloquent
	g. Peaceable-Aggressive	Quiet-Loud and 'in your face'
	i. Trusting-Suspicious	Honest-Manipulative
4. Personal	a. Strong-Weak	Manly-Emasculated
	f. Flexible-Rigid	Thinks in colour-Black & white thinker
	i. Self-acceptance-Self-criticism	Accepting of self-Self-hatred
		Confident-Uncomfortable in own skin
5. Intellectual / Operational	d. Focussed-Unfocussed	Focussed-Unfocussed
7. Concrete Descriptors	a. Physical characteristics	Physically rigid-Free-flowing
	b. Social roles	

Table A5.3: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
1. Moral	b. Altruist-Egoist	x	x	x	x
2. Emotional	a. Visceral-Rational	x	x	x	
	c. Optimist-Pessimist				x
	d. Balanced-Unbalanced	x	x		
3. Relational	b. Pleasant-Unpleasant	x	x	x	x
	g. Peaceable-Aggressive				
	i. Trusting-Suspicious				
4. Personal	a. Strong-Weak	x	x		x
	f. Flexible-Rigid	x	x	x	
	i. Self-acceptance-Self-criticism	x	x	x	x
5. Intellectual / Operational	d. Focussed-Unfocussed	x	x	x	x
7. Concrete Descriptors	a. Physical characteristics	x	x	x	x

Table A5.4 Construct Correlations

	Accepting of self	Focussed	Unspontaneous	Confident	World-weary	Thinks in colour	Manly	Self-centred	Quiet	Honest	Scared of consequences	Physically rigid	Monotone	ASPERGER SYNDROME
Accepting of self	1.00													
Focussed	0.90	1.00												
Unspontaneous	-0.59	-0.43	1.00											
Confident	0.84	0.66	-0.77	1.00										
World-weary	0.50	0.50	-0.29	0.48	1.00									
Thinks in colour	0.66	0.51	-0.72	0.75	0.10	1.00								
Manly	0.76	0.64	-0.73	0.89	0.72	0.61	1.00							
Self-centred	-0.36	-0.24	0.74	-0.59	0.16	-0.76	-0.32	1.00						
Quiet	-0.44	-0.40	0.31	-0.59	-0.18	-0.52	-0.43	0.40	1.00					
Honest	-0.30	-0.29	0.10	-0.27	-0.78	0.04	-0.54	-0.39	0.40	1.00				
Scared of consequences	-0.66	-0.54	0.76	-0.70	-0.63	-0.42	-0.82	0.20	0.38	0.64	1.00			
Physically rigid	-0.63	-0.45	0.69	-0.92	-0.32	-0.76	-0.77	0.63	0.79	0.28	0.60	1.00		
Monotone	-0.65	-0.65	0.32	-0.62	-0.76	-0.14	-0.72	-0.03	0.43	0.71	0.63	0.51	1.00	
ASPERGER SYNDROME	-0.56	-0.44	0.84	-0.77	-0.49	-0.50	-0.83	0.41	0.54	0.53	0.94	0.75	0.58	1.00

Table A5.5 Element Euclidean Distances (standardised)

Element pairs	**Element Euclidean Distances (standardised)**
Self before diagnosis/Self after diagnosis	0.31
Self before diagnosis/Self now	0.80
Self before diagnosis/Ideal self	1.35
Self after diagnosis/Self now	0.67
Self after diagnosis/Ideal self	1.24
Self now/Ideal self	0.97
Self as person with AS see me/Ideal self	0.59
Self as NT person sees me/Ideal self	0.86
Self now /Person with AS	Person 1: 0.85 Person 2: 0.87
Ideal self /Person with AS	Person 1: 1.09 Person 2: 1.12
Self now /NT person	Person 1: 1.29 Person 2: 1.23
Ideal self /NT person	Person 1: 0.63 Person 2: 0.52

Table A5.6: Descriptive statistics for elements

Element	**Sum of squares**	**Percentage total sum of squares**
Self before diagnosis	74.82	12.72
Self after diagnosis	58.55	9.96
Self now	31.73	5.40
Ideal self	43.45	7.39
Self as NT sees me	62.09	10.56
NT person	90.45	15.38
NT person	89.64	15.24

Table A5.7: Descriptive statistics for constructs

Element	**Sum of squares**	**Percentage total sum of squares**
Self-centred-Helps others	57.64	9.80
Unspontaneous-Spontaneous	54.55	9.28

Table A5.8: Eigenvalue decomposition

	Percentage variance	**Cumulative percentage**
Component 1	60.24	60.24
Component 2	17.56	77.80

Table A5.9: Element Loadings

	First Principal Component	**Second Principal Component**
Self before diagnosis	0.42	-0.03
Self after diagnosis	0.37	0.10
Self now	0.15	0.35
Ideal self	-0.31	-0.03
Self in 1year	0.06	0.18
Self as AS sees me	-0.12	0.03
Self as NT sees me	-0.14	0.59
Person with AS	0.22	-0.41
Person with AS	0.26	-0.38
NT	-0.43	-0.41
NT	-0.48	0.00

Table A5.10: Construct Loadings

	First Principal Component	**Second Principal Component**
Accepting of self	-0.30	0.09
Focussed	-0.28	0.17
Unspontaneous	0.33	0.25
Confident	-0.36	-0.07
World-weary	-0.19	0.43
Thinks in colour	-0.23	-0.28
Manly	-0.31	0.13
Self-centred	0.22	0.59
Quiet	0.19	0.06
Honest	0.10	-0.32
Scared of consequences	0.27	-0.17
Physically rigid	0.30	0.15
Monotone	0.21	-0.33
ASPERGER SYNDROME	0.32	-0.04

Appendix 6: Peter’s Repertory Grid Data and Analysis

Table A6.1: Peter’s repertory grid

		ELEMENTS										
CONSTRUCTS (rated 7-1)		Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
1	**Understands self**-Unable to help self	2	5	5	7	6	6	2	5	5	4	3
2	Jumps to conclusions-**Recognises subtle differences**	7	4	3	1	2	2	7	5	4	4	6
3	Ignored-**Fits in**	7	5	3	1	2	2	4	2	3	2	2
4	**Extrovert**-Worries about talking to people	1	2	5	7	6	5	1	4	4	7	7
5	Relates superficially to others-**Has friendships**	7	6	4	1	3	4	7	5	4	1	1
6	Unpredictable-**Composed and rational**	5	4	3	1	2	3	7	4	2	3	5
7	**Outgoing**-Lonely and isolated	1	2	3	7	4	3	1	3	4	7	7
8	**Integrates with others-**Makes people feel uncomfortable	1	2	4	7	5	4	2	4	5	7	7
9	Little eye contact-**Right amount of eye contact**	7	7	5	1	4	5	7	7	7	1	1
10	**Knowledgeable**-Acts without facts	2	3	5	7	6	6	4	4	4	3	2
11	Disrespectful-**Affable**	4	4	3	1	3	2	4	5	2	1	4
12	Arrogant-**Grounded and realistic**	4	4	3	1	2	2	4	3	2	2	5
	Asperger Syndrome-Neurotypical	7	7	5	4	5	6	5	5	5	1	1

Table A6.2: Content categorization (Feixas et al., 2002) of Peter's constructs

Content category		**Constructs elicited**
1. Moral	b. Altruist-Egoist	Arrogant-**Grounded and realistic**
2. Emotional	a. Visceral-Rational	Jumps to conclusions-**Recognises subtle differences** Unpredictable-**Composed and rational**
3. Relational	a. Extrovert-Introvert	**Extrovert**-Worries about talking to people Relates superficially to others-**Has friendships** **Outgoing**-Lonely and isolated **Integrates with others-**Makes people feel uncomfortable
	b. Pleasant-Unpleasant	Disrespectful-**Affable**
	h. Sympathetic-Unsympathetic	Ignored-**Fits in**
4. Personal	g. Thoughtless-Shallow	**Knowledgeable**-Acts without facts
0. Existential	a. Purposeful-Purposeless	**Understands self**-Unable to help self
7. Concrete Descriptors	c. Specific behaviours	Little eye contact-**Right amount of eye contact**

Table A6.3: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
1. Moral	b. Altruist-Egoist				x
2. Emotional	a. Visceral-Rational	x			x
3. Relational	a. Extrovert-Introvert	x	x		x
	b. Pleasant-Unpleasant				x
	h. Sympathetic-Unsympathetic	x			x
4. Personal	g. Thoughtless-Shallow	x			x
0. Existential	a. Purposeful-Purposeless	x			x
7. Concrete Descriptors	c. Specific behaviours	x	x		x

Table A6.4: Construct Correlations

	Understands self	Jumps to conclusions	Ignored	Extrovert	Relates superficially to others	Unpredictable	Outgoing	Integrates with others	Little eye contact	Knowledgeable	Disrespectful	Arrogant	ASPERGER SYNDROME
Understands self	1.00												
Jumps to conclusions	-0.96	1.00											
Ignored	-0.73	0.69	1.00										
Extrovert	0.61	-0.66	-0.84	1.00									
Relates superficially to others	-0.50	0.57	0.78	-0.98	1.00								
Unpredictable	-0.89	0.89	0.56	-0.64	0.59	1.00							
Outgoing	0.40	-0.45	-0.73	0.92	-0.98	-0.52	1.00						
Integrates with others	0.50	-0.53	-0.83	0.95	-0.98	-0.56	0.97	1.00					
Little eye contact	-0.30	0.42	0.62	-0.88	0.93	0.38	-0.92	-0.87	1.00				
Knowledgeable	0.85	-0.87	-0.58	0.37	-0.26	-0.64	0.14	-.26	-0.17	1.00			
Disrespectful	-0.55	0.69	0.45	-0.58	0.63	0.70	-0.59	-0.60	0.57	-0.49	1.00		
Arrogant	-0.83	0.85	0.54	-0.48	0.43	0.85	-0.37	-0.45	0.27	-0.78	0.79	1.00	
ASPERGER SYNDROME	0.02	0.04	0.56	-0.74	0.81	0.06	-0.85	-0.84	0.82	0.17	0.33	0.03	1.00

Table A6.5: Element Euclidean Distances (standardised)

Element pairs	**Element Euclidean Distances (standardised)**
Self before diagnosis/Self after diagnosis	0.48
Self before diagnosis/Self now	1.02
Self before diagnosis/Ideal self	1.87
Self after diagnosis/Self now	0.63
Self after diagnosis/Ideal self	1.50
Self now/Ideal self	0.92
Self as person with AS see me/Ideal self	0.83
Self as NT person sees me/Ideal self	1.75
Self now /Person with AS	Person 1: 0.42 Person 2: 0.35
Ideal self /Person with AS	Person 1: 1.22 Person 2: 0.99
Self now /NT person	Person 1: 0.91 Person 2: 1.02
Ideal self /NT person	Person 1: 0.70 Person 2: 1.09

Table A6.6: Descriptive statistics for elements

Element	**Sum of squares**	**Percentage total sum of squares**
Self before diagnosis	91.26	18.51
Self after diagnosis	35.90	7.28
Self now	3.99	0.81
Ideal self	88.63	17.97
Self as NT sees me	69.63	14.12
NT person	66.72	13.53
NT person	77.63	15.74

Table A6.7: Descriptive statistics for constructs

Element	**Sum of squares**	**Percentage total sum of squares**
Little eye-contact-Right amount of eye contact	68.18	13.83
Extrovert-Worries about talking to people	52.73	10.69
Outgoing-Lonely and isolated	51.64	10.47
Relates superficially to others-Has friendships	50.91	10.32

Table A6.8: Eigenvalue decomposition

	Percentage variance	**Cumulative percentage**
Component 1	70.03	70.03
Component 2	21.12	91.15

Table A6.9: Element Loadings

	First Principal Component	**Second Principal Component**
Self before diagnosis	9.09	1.53
Self after diagnosis	5.76	-0.72
Self now	-0.10	-1.63
Ideal self	-8.83	-2.85
Self in 1year	-3.05	-2.86
Self as AS sees me	-0.89	-3.75
Self as NT sees me	7.68	1.97
Person with AS	2.33	-0.48
Person with AS	0.26	-1.72
NT	-7.12	3.49
NT	-5.13	7.00

Table A6.10: Construct Loadings

	First Principal Component	**Second Principal Component**
Understands self	-3.24	-3.88
Jumps to conclusions	4.44	4.58
Ignored	4.38	0.95
Extrovert	-7.11	0.27
Relates superficially to others	7.02	-1.12
Unpredictable	3.61	3.34
Outgoing	-6.80	1.93
Integrates with others	-6.47	1.10
Little eye contact	7.40	-2.60
Knowledgeable	-2.1	-4.24
Disrespectful	2.94	1.28
Arrogant	2.19	2.68
ASPERGER SYNDROME	4.66	-4.04

Appendix 7: Fahim's Repertory Grid Data and Analysis

Table A7.1: Fahim's repertory grid

		ELEMENTS									
	CONSTRUCTS (rated 7-1)	Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A NT person	A NT person
1	**Can identify problems**-Cannot identify problems	3	6	5	7	6	4	6	7	7	7
2	**Understands clearly**-Confused	2	2	3	7	6	7	3	3	6	5
3	**Free from rituals-**Controlled by rituals	2	4	4	7	6	2	6	6	3	7
4	**Sociable and friendly**-Keeps self to self	3	5	5	7	6	4	6	3	4	5
5	**Settled in ways-**Odd	3	4	5	7	6	4	3	3	4	5
6	**Easy to talk to**-Hard to talk to	4	6	5	7	6	4	6	4	6	7
7	**Happy**-Anxious	**2**	3	3	7	6	3	1	4	5	5
	Asperger Syndrome-Neurotypical	6	5	4	7	6	2	1	3	1	2

Table A7.2: Content categorization (Feixas et al., 2002) of Fahim's constructs

Content category		**Constructs elicited for Fahim**
2. Emotional	d. Balanced-Unbalanced	**Happy**-Anxious
3. Relational	a. Extrovert-Introvert	**Sociable**-Keeps self to self
	b. Pleasant-Unpleasant	**Easy to talk to**-Hard to talk to
4. Personal	a. Strong-Weak	**Free from rituals-**Controlled by rituals
	f. Flexible-Rigid	**Settled in ways-**Odd
5. Intellectual / Operational	b. Intelligent-Dull	**Can identify problems**-Cannot identify problems
		Clear understanding-Confused

Table A7.3: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
2. Emotional	d. Balanced-Unbalanced	x			x
3. Relational	a. Extrovert-Introvert				x
	b. Pleasant-Unpleasant		x		x
4. Personal	a. Strong-Weak	x			x
	f. Flexible-Rigid				x
5. Intellectual / Operational	b. Intelligent-Dull	x	x		x

Table A7.4: Construct Correlations

	Can identify problems	Understands clearly	Free from rituals	Sociable and friendly	Settled in ways	Easy to talk to	Happy	ASPERGER SYNDROME
Can identify problems	1.00							
Understands clearly	-0.46	1.00						
Free from rituals	0.75	-0.63	1.00					
Sociable and friendly	0.40	0.01	0.62	1.00				
Settled in ways	0.34	0.30	0.47	0.74	1.00			
Easy to talk to	0.67	-0.15	0.65	0.79	0.63	1.00		
Happy	0.66	0.15	0.53	0.45	0.82	0.57	1.00	
ASPERGER SYNDROME	-0.20	0.44	0.11	0.28	0.53	0.06	0.29	1.00

Table A7.5: Element Euclidean Distances (standardised)

Element pairs	**Element Euclidean Distances (standardised)**
Self before diagnosis/Self after diagnosis	0.76
Self before diagnosis/Self now	0.74
Self before diagnosis/Ideal self	1.75
Self after diagnosis/Self now	0.33
Self after diagnosis/Ideal self	1.21
Self now/Ideal self	1.18
Self as person with AS see me/Ideal self	1.47
Self as NT person sees me/Ideal self	1.51
Self now /Person with AS	Person 1: 0.63
Ideal self /Person with AS	Person 1: 1.33
Self now /NT person	Person 1: 0.80 Person 2: 0.78
Ideal self /NT person	Person 1: 1.27 Person 2: 0.93

Table A7.6: Descriptive statistics for elements

Element	Sum of squares	Percentage total sum of squares
Self before diagnosis	41.47	19.53
Self after diagnosis	9.07	4.27
Self now	4.47	2.11
Ideal self	48.47	22.83

Table A7.7: Descriptive statistics for constructs

Element	Sum of squares	Percentage total sum of squares
Understands clearly-confused	36.40	17.15
Happy-Anxious	35.60	16.77
Free from rituals-controlled by rituals	34.10	16.06
ASPERGER SYNDROME-NEUROTYPICAL	44.10	20.77

Table A7.8: Eigenvalue decomposition

	Percentage variance	Cumulative percentage
Component 1	49.84	49.85
Component 2	22.77	72.61

Table A7.9: Element Loadings

	First Principal Component	Second Principal Component
Self before diagnosis	-4.61	3.39
Self after diagnosis	-0.35	1.34
Self now	-0.80	0.73
Ideal self	6.07	2.35
Self in 1year	3.52	2.07
Self as AS sees me	-3.70	1.15
Self as NT sees me	-1.37	-3.98
Person with AS	-0.43	-2.47
Person with AS	n/a	n/a
NT	-0.85	-1.30
NT	2.51	-3.28

Table A7.10: Construct Loadings

	First Principal Component	**Second Principal Component**
Can identify problems	3.02	-2.32
Understands clearly	-0.52	3.84
Free from rituals	4.81	-2.51
Sociable and friendly	2.98	0.14
Settled in ways	3.44	1.52
Easy to talk to	2.77	-0.75
Happy	5.12	0.67
ASPERGER SYNDROME	2.59	5.44

Appendix 8: Jack's Repertory Grid Data and Analysis

Table A8.1: Jack's repertory grid

		ELEMENTS										
	CONSTRUCTS (rated 7-1)	Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
1	Horrible-**Caring**	3	3	3	1	3	3	3	4	2	3	3
2	**Highly specific knowledge**-Broad general knowledge	7	7	7	7	7	5	6	7	5	4	4
3	**Easy to talk to**-Uninteresting	5	5	5	7	5	5	5	3	5	6	6
4	**Things make sense**-Things seem meaningless	4	6	6	7	6	5	6	3	6	6	6
5	**Quirky**-Bland	5	6	6	6	6	5	6	4	5	4	4
6	Stand out in a crowd-Normal	5	6	5	4	5	5	6	7	5	2	2
7	**Endearing**-Difficult to warm to	4	5	5	7	5	5	5	2	5	6	5
	Asperger Syndrome-Neurotypical	5	5	4	4	6	5	4	6	3	1	2

Table A8.2: Content categorization (Feixas et al., 2002) of Jack's constructs

Content category		**Constructs elicited**
2. Emotional	b. Warm-Cold	Horrible-**Caring**
3. Relational	b. Pleasant-Unpleasant	**Easy to talk to**-Uninteresting **Endearing**-Difficult to warm to
	e. Conformist-Rebel	Stand out in a crowd-Normal
5. Intellectual / Operational	e. Creative-Not creative	**Quirky**-Bland
	f. Specific abilities	**Highly specific knowledge**-Broad general knowledge
0. Existential	a. Purposeful-Purposeless	**Things make sense**-Things seem meaningless

Table A8.3: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
2. Emotional	b. Warm-Cold				x
3. Relational	b. Pleasant-Unpleasant				x
	e. Conformist-Rebel		x		
5. Intellectual	e. Creative-Not creative		x	x	x
/ Operational	f. Specific abilities	x	x	x	x
0. Existential	a. Purposeful-Purposeless		x	x	x

Table A8.4 Construct Correlations

	Horrible	Highly specific knowledge	Easy to talk to	Things make sense	Quirky	Stand out in a crowd	Endearing	ASPERGER SYNDROME
Horrible	1.00							
Highly specific knowledge	0.00	1.00						
Easy to talk to	-0.76	-0.32	1.00					
Things make sense	0.70	-0.21	0.80	1.00				
Quirky	-0.40	0.63	0.19	0.50	1.00			
Stand out in a crowd	0.30	0.71	-0.75	-0.48	0.41	1.00		
Endearing	-0.78	-0.26	0.93	0.91	0.39	-0.51	1.00	
ASPERGER SYNDROME	0.27	0.80	-0.59	-0.48	0.42	0.83	-0.51	1.00

Table A8.5: Element Euclidean Distances (standardised)

Element pairs	**Element Euclidean Distances (standardised)**
Self before diagnosis/Self after diagnosis	0.55
Self before diagnosis/Self now	0.55
Self before diagnosis/Ideal self	1.12
Self after diagnosis/Self now	0.29
Self after diagnosis/Ideal self	0.88
Self now/Ideal self	0.78
Self as person with AS see me/Ideal self	1.00
Self as NT person sees me/Ideal self	0.88
Self now /Person with AS	Person 1: 1.23 Person 2: 0.55
Ideal self /Person with AS	Person 1: 1.89 Person 2: 0.86
Self now /NT person	Person 1: 0.80 Person 2: 0.78
Ideal self /NT person	Person 1: 1.19 Person 2: 1.08

Table A8.6: Descriptive statistics for elements

Element	**Sum of squares**	**Percentage total sum of squares**
Self before diagnosis	5.21	4.51
Self after diagnosis	4.40	3.80
Self now	2.03	1.76
Ideal self	15.31	13.25
Person with AS	32.31	27.94
NT person	24.49	21.18
NT person	18.12	15.67

Table A8.7: Descriptive statistics for constructs

Element	**Sum of squares**	**Percentage total sum of squares**
Stand out in a crowd-Fit in	24.18	20.91
Highly specific knowledge-Broad general knowledge	16.00	13.84
Endearing-Difficult to warm to	14.91	12.89
Things make sense-Things seem meaningless	12.73	11.01
ASPERGER SYNDROME-NEUROTYPICAL	24.91	21.54

Table A8.8: Eigenvalue decomposition

	Percentage variance	**Cumulative percentage**
Component 1	63.63	63.63
Component 2	25.59	89.22

Table A8.9: Element Loadings

	First Principal Component	**Second Principal Component**
Self before diagnosis	1.80	0.56
Self after diagnosis	1.48	-1.35
Self now	0.42	-0.94
Ideal self	-1.97	-3.19
Self in 1year	1.48	-1.45
Self as AS sees me	0.47	0.51
Self as NT sees me	0.60	-0.70
Person with AS	5.04	2.57
Person with AS	-1.01	0.30
NT	-4.59	1.75
NT	-3.72	1.94

Table A8.10: Construct Loadings

	First Principal Component	**Second Principal Component**
Horrible	1.16	1.59
Highly specific knowledge	2.96	-2.20
Easy to talk to	-2.60	-1.44
Things make sense	-2.47	-2.31
Quirky	0.62	-2.55
Stand out in a crowd	4.55	-0.88
Endearing	-2.97	-2.37
ASPERGER SYNDROME	4.55	-1.37

Appendix 9: David’s Repertory Grid Data and Analysis

Table A9.1: David’s repertory grid

CONSTRUCTS (rated 7-1)		ELEMENTS										
		Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
1	**Understands actions**-Actions unexplained	2	6	5	6	6	6	5	3	1	2	3
2	**Fits in**-Left out	3	4	5	6	5	5	3	5	2	6	5
3	Rigid routines-**Totally flexible**	5	5	5	3	5	4	6	7	6	2	5
4	**Socially adept**-Socially awkward	3	4	4	6	4	5	3	3	2	6	5
5	**Assertive**-Walk over	2	3	3	6	5	4	3	6	5	6	5
6	Talks at people-**Empathises with others**	4	3	3	2	3	3	5	5	6	2	2
7	Specialist interests-**Broad knowledge**	5	5	4	3	5	5	6	4	5	3	2
8	Selective-**Talks to anyone**	5	6	5	3	5	4	5	6	3	2	2
9	**High functioning**-Cannot communicate	4	4	5	6	4	5	4	5	3	6	6
10	Joins in socially-Prefers solitude	2	3	3	4	5	5	6	3	5	6	6
11	**Ambitious**-Accepting	3	4	4	5	4	3	2	6	5	5	5
12	Does not ask questions-**Inquisitive**	5	5	5	3	5	5	6	4	2	5	5
	Asperger Syndrome-Neurotypical	5	6	5	4	5	5	4	5	6	2	2

Table A9.2: Content categorization (Feixas et al., 2002) of David's constructs

Content category		**Constructs elicited**
3. Relational	a. Extrovert-Introvert	**Assertive**-Walk over
		Socially adept-Socially awkward
		Selective-**Talks to anyone**
		Joins in socially-Prefers solitude
	h. Sympathetic-Unsympathetic	**Fits in**-Left out
4. Personal	b. Active-Passive	**Ambitious**-Accepting
		Does not ask questions-**Inquisitive**
	f. Flexible-Rigid	Rigid routines-**Totally flexible ***
	g. Thoughtless-Shallow	**Understands actions**-Actions unexplained
5. Intellectual / Operational	f. Specific abilities	**High functioning**-Cannot communicate
7. Concrete Descriptors	c. Specific behaviours	Talks at people-**Empathises with others ***
		Specialist interests-**Broad knowledge**

Table A9.3: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
3. Relational	a. Extrovert-Introvert	**x**	**x**		**x**
	h. Sympathetic-Unsympathetic				**x**
4. Personal	b. Active-Passive				
	f. Flexible-Rigid				
	g. Thoughtless-Shallow	**x**	**x**		**x**
5. Intellectual /Operational	f. Specific abilities				**x**
7. Concrete Descriptors	c. Specific behaviours				**x**

Table A9.4: Construct Correlations

	Understands actions	Fits in	Rigid routines	Socially adept	Assertive	Talks at people	Specialist interests	Selective	High functioning	Joins in socially	Ambitious	Does not ask questions	ASPERGER SYNDROME
Understands actions	1.00												
Fits in	0.38	1.00											
Rigid routines	-0.14	-0.61	1.00										
Socially adept	0.36	0.86	-0.87	1.00									
Assertive	-0.16	0.55	-0.26	0.41	1.00								
Talks at people	-0.40	-0.81	0.78	-0.92	-0.19	1.00							
Specialist interests	0.21	-0.67	0.45	-0.66	-0.59	0.65	1.00						
Selective	0.38	-0.26	0.60	-0.53	-0.51	0.40	0.65	1.00					
High functioning	0.12	0.87	-0.60	0.86	0.49	-0.77	-0.85	-0.50	1.00				
Joins in socially	-0.05	0.12	-0.26	0.30	0.42	-0.14	-0.18	-0.65	0.21	1.00			
Ambitious	-0.36	0.40	-0.04	0.19	0.79	-0.12	-0.69	-0.31	0.39	-0.04	1.00		
Does not ask questions	0.34	0.16	-0.06	0.17	-0.51	-0.31	0.18	0.30	0.14	0.11	-0.61	1.00	
ASPERGER SYNDROME	0.21	-0.52	0.52	-0.64	-0.40	0.57	0.71	0.70	-0.77	-0.60	-0.18	-0.31	1.00

Table A9.5: Element Euclidean Distances (standardised)

Element pairs	**Element Euclidean Distances (standardised)**
Self before diagnosis/Self after diagnosis	0.71
Self before diagnosis/Self now	0.64
Self before diagnosis/Ideal self	1.31
Self after diagnosis/Self now	0.35
Self after diagnosis/Ideal self	1.01
Self now/Ideal self	0.83
Self as person with AS see me/Ideal self	0.71
Self as NT person sees me/Ideal self	1.33
Self now /Person with AS	Person 1: 0.76 Person 2: 1.18
Ideal self /Person with AS	Person 1: 1.11 Person 2: 1.45
Self now /NT person	Person 1: 0.79 Person 2: 0.79
Ideal self /NT person	Person 1: 0.95 Person 2: 1.66

Table A9.6: Descriptive statistics for elements

Element	**Sum of squares**	**Percentage total sum of squares**
Self before diagnosis	22.81	9.46
Self after diagnosis	14.81	6.14
Self now	6,45	2.67
Ideal self	25.81	10.71
Person with AS	43.08	17.87
NT person	40.72	16.89

Table A9.7: Descriptive statistics for David's constructs

Construct	**Sum of squares**	**Percentage total sum of squares**
Understands actions-Actions unexplained	36.91	15.31

Table A9.8: Eigenvalue decomposition

	Percentage variance	**Cumulative percentage**
Component 1	44.67	44.67
Component 2	24.69	69.35

Table A9.9: Element Loadings

	First Principal Component	**Second Principal Component**
Self before diagnosis	3.37	0.52
Self after diagnosis	2.26	-2.76
Self now	0.72	-1.77
Ideal self	-4.13	-1.17
Self in 1year	0.30	-1.84
Self as AS sees me	-0.58	-2.42
Self as NT sees me	2.96	-1.09
Person with AS	1.71	1.86
Person with AS	3.32	5.22
NT	-5.77	1.77
NT	-4.15	1.67

Table A9.10: Construct Loadings

	First Principal Component	**Second Principal Component**
Understands actions	-0.32	-5.58
Fits in	-3.35	-1.45
Rigid routines	3.45	0.95
Socially adept	-3.78	-1.46
Assertive	-2.85	1.89
Talks at people	3.54	2.00
Specialist interests	3.16	-0.96
Selective	3.46	-2.19
High functioning	-2.85	-0.39
Joins in socially	-2.15	0.95
Ambitious	-1.54	1.98
Does not ask questions	-0.04	-2.11
ASPERGER SYNDROME	3.52	-0.73

Appendix 10: Group Analysis Tables

Table A10.1: Participant ratings of the supplied construct

		ELEMENTS										
SUPPLIED CONSTRUCT (rated 7-1): ASPERGER SYNDROME-NEUROTYPICAL		Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
Participant	Judy	3	6	7	7	5	2	1	7	7	2	1
	Hazel	6	6	6	1	6	2	4	7	3	4	1
	Stella	5	6	7	4	3	5	2	6	5	1	2
	Tariq	6	6	6	4	6	3	2	7	5	1	1
	Peter	7	7	5	4	5	6	5	5	5	1	1
	Fahim	6	5	4	7	6	2	1	3	-	1	2
	Jack	5	5	4	4	6	5	4	6	3	1	2
	David	5	6	5	4	5	5	4	5	6	2	2

Table A.10.2 Frequency of type of construct according to CSPC (Feixas et al., 2002)

Content category	n	%	Content Subcategory	n	%
1. Moral	3	3.5	a. Good-bad	-	-
			b. Altruist-Egoist	3	3.5
			c. Humble-Proud	-	-
			d. Respectful-Judgemental	-	-
			e. Faithful-Unfaithful	-	-
			f. Sincere-Insincere	-	-
			g. Just-Unjust	-	-
2. Emotional	12	14.0	a. Visceral-Rational	3	3.5
			b. Warm-Cold	2	2.3
			c. Optimist-Pessimist	3	3.5
			d. Balanced-Unbalanced	3	3.5
			e. Specific emotions	1	1.2
			f. Sexuality	-	-
			o. Others	-	-
3. Relational	26	30.2	a. Extrovert-Introvert	12	14.0
			b. Pleasant-Unpleasant	6	7.0
			c. Direct-Devious	-	-
			d. Tolerant-Authoritarian	-	-
			e. Conformist-Rebel	1	1.2
			f. Dependent-Independent	1	1.2
			g. Peaceable-Aggressive	1	1.2
			h. Sympathetic-Unsympathetic	4	4.7
			i. Trusting-Suspicious	1	1.2
			o. Others	-	-
4. Personal	22	25.6	a. Strong-Weak	3	3.4
			b. Active-Passive	2	2.3
			c. Hardworking-Lazy	3	3.4
			d. Organised-Disorganised	1	1.1
			e. Decisive-Indecisive	2	2.3
			f. Flexible-Rigid	4	4.5
			g. Thoughtless-Shallow	2	2.3
			h. Mature-Immature	-	-
			i. Self-acceptance-Self-criticism	5	5.7
			o. Others	-	-
5. Intellectual / Operational	12	4.0	a. Capable-Incapable	2	2.3
			b. Intelligent-Dull	4	4.7
			c. Cultured-Uncultured	-	-
			d. Focussed-Unfocussed	2	2.3
			e. Creative-Not creative	2	2.3
			f. Specific abilities	2	2.3
			o. Others	-	-
6. Values and Interests	-	-	a. Ideological, political, religious, social, moral and gender values	-	-
			b. Values and specific interests	-	-
			o. Others		
0. Existential	3	3.5	a. Purposeful-Purposeless	3	3.5
			b. Growth-Stagnation		
			c. Fulfilment-Emptiness		
7. Concrete Descriptors	4	4.9	a. Physical characteristics	1	1.2
			b. Social roles	-	-
			c. Specific behaviours	3	3.5
			o. Others		
Totals	**86**	**100**	**Totals**	**88**	**100**

Table A10.3: Frequency of type of self-defining constructs

Content category	Total % (n)	Self before diagnosis % (n)	Self after diagnosis % (n)	Self now % (n)	Ideal Self % (n)
1. Moral	6.38 (9)	5.71 (2)	6.90 (2)	8.33 (2)	5.66 (3)
2. Emotional	12.77 (18)	14.29 (5)	10.34 (3)	12.50 (3)	13.21 (7)
3. Relational	23.40 (33)	22.86 (8)	24.14 (7)	20.83 (5)	24.53 (13)
4. Personal	28.37 (40)	31.43 (11)	27.59 (8)	29.17 (7)	26.42 (14)
5. Intellectual / Operational	18.44 (26)	17.14 (6)	20.69 (6)	16.67 (4)	18.87 (10)
6. Values and Interests	(0)	(0)	(0)	(0)	(0)
0. Existential	4.96 (7)	2.86 (1)	3.45 (1)	8.33 (2)	5.66 (3)
7. Concrete Descriptors	5.64 (8)	5.71 (2)	6.90 (2)	4.14 (1)	5.66 (3)
Totals	100 (141)	100 (35)	100 (29)	100 (24)	100 (53)

Table A10.4: Element Euclidean Distances (standardised)

Element pairs	*Judy*	*Hazel*	*Stella*	*Tariq*
Self before diagnosis/Self after diagnosis	0.58	0.63	0.71	0.31
Self before diagnosis/Self now	0.69	0.69	0.90	0.80
Self before diagnosis/Ideal self	0.69	1.81	1.39	1.35
Self after diagnosis/Self now	0.21	0.32	0.26	0.67
Self after diagnosis/Ideal self	0.69	1.47	0.86	1.24
Self now/Ideal self	0.65	1.32	0.80	0.97
Self as Person with AS see me/Ideal self	1.14	1.05	0.84	0.59
Self as NT Person sees me/Ideal self	0.82	1.46	0.93	0.86
Self now /Person with AS	P 1: 0.73 P 2: 1.09	P 1: 0.56 P 2: 1.02	P 1: 1.05 P 2: 0.89	P 1: 0.85 P 2: 0.87
Ideal self /Person with AS	P 1: 0.21 P 2: 0.92	P 1: 1.32 P 2: 1.07	P 1: 1.68 P 2: 1.50	P 1: 1.09 P 2: 1.12
Self now /NT Person	P 1: 0.86 P 2: 1.56	P 1: 0.96 P 2: 1.23	P 1: 1.00 P 2: 0.96	P 1: 1.29 P 2: 1.23
Ideal self /NT Person	P 1: 0.95 P 2: 1.66	P 1: 0.93 P 2: 0.64	P 1: 0.35 P 2: 1.32	P 1: 0.63 P 2: 0.52
Element pairs	*Peter*	*Fahim*	*Jack*	*David*
Self before diagnosis/Self after diagnosis	0.48	0.76	0.55	0.71
Self before diagnosis/Self now	1.02	0.74	0.55	0.64
Self before diagnosis/Ideal self	1.87	1.75	1.12	1.31
Self after diagnosis/Self now	0.63	0.33	0.29	0.35
Self after diagnosis/Ideal self	1.50	1.21	0.88	1.01
Self now/Ideal self	0.92	1.18	0.78	0.83
Self as Person with AS see me/Ideal self	0.83	1.47	1.00	0.71
Self as NT Person sees me/Ideal self	1.75	1.51	0.88	1.33
Self now /Person with AS	P 1: 0.42 P 2: 0.35	P 1: 0.63	P 1: 1.23 P 2: 0.55	P 1: 0.76 P 2: 1.18
Ideal self /Person with AS	P 1: 1.22 P 2: 0.99	P 1: 1.33	P 1: 1.89 P 2: 0.86	P 1: 1.11 P 2: 1.45
Self now /NT Person	P 1: 0.91 P 2: 1.02	P 1: 0.80 P 2: 0.78	P 1: 0.80 P 2: 0.78	P 1: 0.79 P 2: 0.79
Ideal self /NT Person	P 1: 0.70 P 2: 1.09	P 1: 1.27 P 2: 0.93	P 1: 1.19 P 2: 1.08	P 1: 0.95 P 2: 1.66

**P1 and P2 refer to first and second identified other-elements.*

Table A10.5: Descriptive statistics for elements

Element	**Percentage total sum of squares**							
	Tariq	Peter	Fahim	Jack	David	Judy	Hazel	Stella
Self before AS	12.72	18.51	19.53	4.51	9.46	3.68	15.81	8.77
Self after AS	9.96	7.28	4.27	3.80	6.14	4.73	6.21	1.85
Self now	5.40	0.81	2.11	1.76	2.67	5.10	3.90	4.07
Ideal self	7.39	17.97	22.83	13.25	10.71	5.98	20.06	12.45

Table A10.6: Frequency of superordinate constructs by CSPC category (Feixas et al., 2002)

	Tariq	**Peter**	**Fahim**	**Jack**	**David**	**Judy**	**Hazel**	**Stella**	**TOTAL**
1. Moral	1								1
2. Emotional	1		1					1	3
3. Relational		3		2			1	1	7
4. Personal			1		1	4		1	7
5. Intellectual/ Operational			1	1					2
6. Values and Interests									0
0. Existential				1					1
7. Concrete Descriptors		1							1

Appendix 11: Raw repertory grid data for Judy

Table A11.1: Judy's repertory grid (preferred poles are in bold throughout this chapter)

		ELEMENTS										
CONSTRUCTS (rated 7-1)		Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
1	**Hardworking-**Lazy	7	5	5	6	5	3	7	7	7	5	5
2	**Focussed-**Distracted	6	3	3	7	4	3	7	7	7	5	5
3	**Intelligent-**Idiot	4	4	4	7	4	5	6	7	6	4	2
4	**Caring-**Thoughtless	7	7	6	6	6	3	7	7	5	5	7
5	**Driven-**No direction	6	6	6	7	6	3	7	7	7	5	1
6	**Self-confident**-Follow the pack	7	7	7	6	7	5	7	5	7	5	1
7	**Self-worth**-Neglects self	7	7	7	7	7	5	7	7	7	4	1
8	**Gives grace to others**-Selfish	7	7	6	6	6	5	4	6	2	4	7
9	**Open-minded**-Black & white thinker	7	7	7	7	7	7	7	7	1	6	3
	ASPERGER SYNDROME-NEUROTYPICAL	3	6	7	7	5	2	1	7	7	2	1

Table A11.2: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
1. Moral	b. Altruist-Egoist	x	x	x	x
3. Relational	h. Sympathetic-Unsympathetic	x	x	x	x
4. Personal	c. Hardworking-Lazy	x			x
	e. Decisive-Indecisive	x	x	x	x
		x			x
	f. Flexible-Rigid	x	x	x	x
	i. Self-acceptance-Self-criticism	x	x	x	x
5. Intellectual / Operational	b. Intelligent-Dull	x			x
	d. Focussed-Unfocussed	x			x

Table A11.3 Construct Correlations

	Hardworking	Focussed	Intelligent	Caring	Driven	Self-confident	Self-worth	Gives grace to others	Open-minded	ASPERGER SYNDROME
Hardworking	1.00									
Focussed	0.85	1.00								
Intelligent	0.47	0.62	1.00							
Caring	0.61	0.32	-0.10	1.00						
Driven	0.66	0.45	0.72	0.25	1.00					
Self-confident	0.31	0.01	0.41	0.00	0.83	1.00				
Self-worth	0.44	0.18	0.63	0.12	0.91	0.92	1.00			
Gives grace to others	-0.21	-0.37	-0.42	0.50	-0.29	-0.25	-0.13	1.00		
Open-minded	-0.19	-0.28	0.16	0.12	0.25	0.35	0.40	0.50	1.00	
ASPERGER SYNDROME	0.25	0.07	0.47	0.09	0.62	0.46	0.64	0.00	0.00	1.00

Table A11.4: Element Euclidean Distances (standardised)

Element pairs	**Element Euclidean Distances (standardised)**
Self before diagnosis/Self after diagnosis	0.58
Self before diagnosis/Self now	0.69
Self before diagnosis/Ideal self	0.69
Self after diagnosis/Self now	0.21
Self after diagnosis/Ideal self	0.69
Self now/Ideal self	0.65
Self as person with AS see me/Ideal self	1.14
Self as NT person sees me/Ideal self	0.82
Self now /Person with AS	Person 1: 0.73 Person 2: 1.09
Ideal self /Person with AS	Person 1: 0.21 Person 2: 0.92
Self now /NT person	Person 1: 0.86 Person 2: 1.56
Ideal self /NT person	Person 1: 0.95 Person 2: 1.66

Table A11.5: Descriptive statistics for elements

Element	**Sum of squares**	**Percentage total sum of squares**
Self before diagnosis	12.05	3.68
Self after diagnosis	15.50	4.73
Self now	16.69	5.10
Ideal self	19.60	5.98
NT person	100.96	30.83

Table 11.6: Descriptive statistics for Judy's constructs

Construct	**Sum of squares**	**Percentage total sum of squares**
ASPERGER SYNDROME-NEUROTYPICAL	66.55	20.32
Open-minded-Black & white thinker	42.00	12.83
Self-worth-Self-neglect	38.00	11.60
Driven-No direction	36.73	11.22
Self-confident-Follow the pack	33.64	10.27

Table A11.7: Eigenvalue decomposition

	Percentage variance	**Cumulative percentage**
Component 1	47.85	47.85
Component 2	20.28	68.13

Table A11.8: Element Loadings

	First Principal Component	**Second Principal Component**
Self before diagnosis	-0.64	-0.97
Self after diagnosis	-1.32	-3.05
Self now	-1.85	-2.65
Ideal self	-3.59	0.32
Self in 1year	-1.00	-2.12
Self as AS sees me	3.91	-1.99
Self as NT sees me	-1.08	1.18
Person with AS	-3.45	0.75
Person with AS	-3.37	5.85
NT	3.00	0.66
NT	9.40	2.01

Table A11.9: Construct Loadings

	First Principal Component	**Second Principal Component**
Hardworking	-2.28	2.20
Focussed	-1.93	4.01
Intelligent	-3.59	1.38
Caring	-0.67	-0.07
Driven	-5.85	0.41
Self-confident	-4.77	-1.38
Self-worth	-5.85	-1.24
Gives grace to others	1.06	-3.32
Open-minded	-1.63	-5.37
ASPERGER SYNDROME	6.28	-0.16

Appendix 12: Raw repertory grid data for Hazel

Table A12.1: Hazel's repertory grid

		ELEMENTS										
CONSTRUCTS (rated 7-1)		Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
1	**Hardworking**-Lackadaisical	5	6	6	7	5	5	6	5	3	7	5
2	**Interesting**-Difficult to talk to	4	4	4	6	4	4	2	6	6	7	4
3	Hopeless-**Ultra positive**	7	4	4	2	4	3	5	4	3	2	2
4	**Comfortable socially**-Anxious socially	2	4	3	6	4	3	2	4	6	4	6
5	**Self-accepting**-Self-critical	1	4	4	5	7	4	3	4	5	2	2
6	**Creative**-Set in ways	2	2	2	6	5	2	3	4	4	6	6
7	Stands out-**Fits in**	6	6	6	3	6	3	5	6	1	2	1
8	**Capable**-Incompetent	2	4	4	7	4	5	5	4	4	6	6
9	**Confident**-Scared	1	2	3	7	4	5	2	4	6	3	5
10	**Efficient**-Slow	2	2	3	7	3	3	2	4	3	4	6
11	**Gives a good impression**-Stupid	2	2	4	7	4	4	3	4	3	6	6
12	**Total control over life**-No control over life	5	5	5	7	5	4	4	2	4	4	6
	ASPERGER SYNDROME-NEUROTYPICAL	6	6	6	1	6	2	4	7	3	4	1

Table A12.2: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
2. Emotional	c. Optimist-Pessimist	x			x
	e. Specific emotions				
3. Relational	a. Extrovert-Introvert	x			x
	b. Pleasant-Unpleasant				x
	h. Sympathetic-Unsympathetic	x	x	x	
4. Personal	a. Strong-Weak				x
	c. Hardworking-Lazy		x	x	x
	i. Self-acceptance-Self critical	x			
5. Intellectual / Operational	a. Capable-Incapable	x	x		x
	b. Intelligent-Dull		x		x
	e. Creative-Not creative	x	x	x	x

Table A12.3: Construct Correlations

	Hardworking	Interesting	Hopeless	Comfortable socially	Self-accepting	Creative	Stands out	Capable	Confident	Efficient	Gives a good impression	Total control over life	ASPERGER SYNDROME
Hardworking	1.00												
Interesting	0.05	1.00											
Hopeless	-0.19	-0.53	1.00										
Comfortable socially	-0.18	0.56	-0.76	1.00									
Self-accepting	-0.19	0.08	-0.24	0.32	1.00								
Creative	0.20	0.54	-0.69	0.70	0.12	1.00							
Stands out	0.19	-0.42	0.73	-0.67	0.15	-0.57	1.00						
Capable	0.51	0.28	-0.85	0.54	0.08	0.69	-0.61	1.00					
Confident	-0.20	0.47	-0.75	0.81	0.50	0.56	-0.64	0.61	1.00				
Efficient	0.29	0.48	-0.73	0.74	0.06	0.78	-0.54	0.77	0.74	1.00			
Gives a good impression	0.46	0.48	-0.80	0.58	0.05	0.82	-0.55	0.87	0.64	0.91	1.00		
Total control over life	0.33	-0.13	-0.23	0.37	0.04	0.28	-0.21	0.37	0.27	0.48	0.40	1.00	
ASPERGER SYNDROME	-0.04	-0.10	0.66	-0.56	0.07	-0.47	0.84	-0.75	-0.69	-0.65	-0.62	-0.51	1.00

Table A12.4: Element Euclidean Distances (standardised)

Element pairs	Element Euclidean Distances (standardised)
Self before diagnosis/Self after diagnosis	0.63
Self before diagnosis/Self now	0.69
Self before diagnosis/Ideal self	1.81
Self after diagnosis/Self now	0.32
Self after diagnosis/Ideal self	1.47
Self now/Ideal self	1.32
Self as person with AS see me/Ideal self	1.05
Self as NT person sees me/Ideal self	1.46
Self now /Person with AS	Person 1: 0.56 Person 2: 1.02
Ideal self /Person with AS	Person 1: 1.32 Person 2: 1.07
Self now /NT person	Person 1: 0.96 Person 2: 1.23
Ideal self /NT person	Person 1: 0.93 Person 2: 0.64

Table A12.5: Descriptive statistics for elements

Element	Sum of squares	Percentage total sum of squares
Self before diagnosis	55.40	15.81
Self after diagnosis	21.77	6.21
Self now	13.68	3.90
Ideal self	70.31	20.06

Table A12.6 Descriptive statistics for constructs

Construct	Sum of squares	Percentage total sum of squares
ASPERGER SYNDROME-NEUROTYPICAL	47.64	13.59
Stands out-Fits in	44.91	12.81

Table A12.7: Eigenvalue decomposition

	Percentage variance	Cumulative percentage
Component 1	58.29	58.29
Component 2	12.57	70.86

Table A12.8: Element Loadings

	First Principal Component	**Second Principal Component**
Self before diagnosis	6.59	-2.44
Self after diagnosis	4.11	0.41
Self now	3.09	0.58
Ideal self	-7.74	1.02
Self in 1year	1.44	3.65
Self as AS sees me	-0.79	-1.18
Self as NT sees me	3.37	-2.24
Person with AS	2.02	2.75
Person with AS	-2.68	1.21
NT	-3.11	-1.31
NT	-6.29	-2.47

Table A12.9: Construct Loadings

	First Principal Component	**Second Principal Component**
Hardworking	-0.40	-0.64
Interesting	-2.30	1.59
Hopeless	4.26	-0.62
Comfortable socially	-3.89	1.43
Self-accepting	-0.73	4.56
Creative	-4.35	0.85
Stands out	5.56	2.14
Capable	-3.68	-0.45
Confident	-4.92	2.04
Efficient	-4.55	0.36
Gives a good impression	-4.48	0.09
Total control over life	-1.72	-0.78
ASPERGER SYNDROME	5.80	2.73

Appendix 13: Stella’s Repertory Grid Data and Analysis

Table A13.1: Stella’s repertory grid

		ELEMENTS										
CONSTRUCTS (rated 7-1)		Self before diagnosis	Self after diagnosis	Self now	Ideal self	Self in one year from now	Self as a person with AS sees me	Self as a NT person sees me	A person with AS	A person with AS	A NT person	A NT person
1	Confused about identity-**Healthy sense of identity**	5	2	2	1	1	4	5	7	4	1	5
2	Failure-**Able to say no**	5	3	2	1	1	4	6	3	4	1	4
3	**Independent**-Controlled by others	3	5	6	7	7	5	6	4	3	7	4
4	**Organised mind**-Unsettled mind	2	5	5	7	7	4	5	2	3	7	4
5	**Warm**-Unapproachable	4	5	5	7	7	5	4	3	4	7	4
6	**Value self**-Treated badly by others	3	5	6	7	7	5	6	3	4	7	4
7	**Minds own business**-Inquisitive	6	6	6	7	7	6	6	5	6	7	2
8	**Confident**-Withdrawn and insulated	2	3	3	7	7	5	6	1	1	7	3
9	**Successful**-Not living up to expectations	5	4	4	7	7	5	6	1	1	7	3
10	**Free**-Life is a chore	3	5	6	7	7	5	6	2	2	7	4
	Asperger Syndrome-Neurotypical	5	6	7	4	3	5	2	6	5	1	2

Table A13.2: Content categorization (Feixas et al., 2002) of self-defining constructs

Content category		**Self before diagnosis**	**Self after diagnosis**	**Self now**	**Ideal self**
2. Emotional	b. Warm-Cold		x	x	x
	c. Optimist-Pessimist			x	x
	d. Balanced-Unbalanced				x
3. Relational	a. Extrovert-Introvert	x	x	x	x
	f. Dependent-Independent			x	x
4. Personal	c. Hardworking-Lazy				
	d. Organised-Disorganised	x			x
	i. Self-acceptance-Self- criticism			x	x
0. Existential	a. Purposeful-Purposeless			x	x

Table A13.3: Construct Correlations

	Confused identity	Failure	Independent	Organised mind	Warm	Value self	Minds own business	Confident	Successful	Free	ASPERGER SYNDROME
Confused identity	1.00										
Failure	0.76	1.00									
Independent	-0.75	-0.66	1.00								
Organised mind	-0.88	-0.68	0.94	1.00							
Warm	-0.93	-0.79	0.83	0.91	1.00						
Value self	-0.84	-0.62	0.96	0.97	0.87	1.00					
Minds own business	-0.60	-0.41	0.53	0.47	0.61	0.57	1.00				
Confident	-0.66	-0.45	0.89	0.89	0.83	0.89	0.48	1.00			
Successful	-0.66	-0.36	0.79	0.78	0.80	0.79	0.55	0.92	1.00		
Free	-0.80	-0.55	0.95	0.94	0.85	0.95	0.48	0.92	0.89	1.00	
ASPERGER SYNDROME	0.16	0.02	-0.38	-0.48	-0.36	-0.41	0.09	-0.63	-0.52	-0.42	1.00

Table A13.4: Element Euclidean Distances (standardised)

Element pairs	**Element Euclidean Distances (standardised)**
Self before diagnosis/Self after diagnosis	0.71
Self before diagnosis/Self now	0.90
Self before diagnosis/Ideal self	1.39
Self after diagnosis/Self now	0.26
Self after diagnosis/Ideal self	0.86
Self now/Ideal self	0.80
Self as person with AS see me/Ideal self	0.84
Self as NT person sees me/Ideal self	0.93
Self now /Person with AS	Person 1: 1.05 Person 2: 0.89
Ideal self /Person with AS	Person 1: 1.68 Person 2: 1.50
Self now /NT person	Person 1: 1.00 Person 2: 0.96
Ideal self /NT person	Person 1: 0.35 Person 2: 1.32

Table A13.5: Descriptive statistics for elements

Element	**Sum of squares**	**Percentage total sum of squares**
Self before diagnosis	32.72	8.77
Self after diagnosis	6.90	1.85
Self now	15.17	4.07
Ideal self	46.45	12.45
Person with AS (son)	64.90	17.40
NT person (celebrity)	56.54	15.15

Table A13.6: Descriptive statistics for Stella's constructs

Construct	Sum of squares	Percentage total sum of squares
Confident-Withdrawn & insulated	56.91	15.25
Successful-Not living up to expectations	48.73	13.06
Confused identity-Healthy sense of identity	42.55	11.40
ASPERGER SYNDROME-NEUROTYPICAL	37.64	10.09

Table A13.7: Eigenvalue decomposition

	Percentage variance	Cumulative percentage
Component 1	74.06	74.06
Component 2	13.26	87.32

Table A13.8: Element Loadings

	First Principal Component	Second Principal Component
Self before diagnosis	-0.45	-2.26
Self after diagnosis	0.49	-3.43
Self now	6.68	-1.14
Ideal self	6.86	-0.47
Self in 1year	-0.25	0.45
Self as AS sees me	1.36	4.24
Self as NT sees me	-7.70	-0.79
Person with AS	-5.97	-1.30
Person with AS	7.23	0.87
NT	-3.42	3.03
NT	-0.45	-2.26

Table A13.9: Construct Loadings

	First Principal Component	Second Principal Component
Confused identity	-5.56	2.74
Failure	-3.45	3.04
Independent	4.58	-0.27
Organised mind	5.70	-0.34
Warm	4.20	-0.95
Value self	4.68	-0.34
Minds own business	2.54	-1.72
Confident	7.15	2.00
Successful	6.28	1.53
Free	5.86	0.14
ASPERGER SYNDROME	-3.03	-4.71

Appendix 14: Judy's coding frame with quotes

Relationship to change and its limitations	**Relationship to self**	**Being and Staying 100% Judy**	p3,l48 Lots of things might change the way Judy relates to herself – "I don't know whether it's knowing that I have got Asperger's or whether it is just coincidental with me hitting the big five O and trying to make changes in my life." p9,l33-37 Me acting in the only way that I knew how or trying to act in the best way that I could because even though with reading all these books, it is still getting people upset. So that was the unhappiness and the confusion because I am trying my best here. And you know, I am still not getting the kind of responses that I would like and so that leads to the unhappiness and the confusion. P10,40-41 "It's better that I see myself as superior rather than inferior. Yeah and it is, to me it's a blessing. It is, it really is." P10,l46-48 "The ideal one is someone who is not working to the point that they are making themselves sick. You know, it's being able to find the balance to do things well but not overdo it. " P11, l2-4 ". I think about others, sacrificing myself you know and I think the balance would be someone who thinks about others but thinks about themselves also." P11,l27-32 "I didn't really want it but I was doing that, sacrificing myself for the sake of my mum and my family and that is what, you know, that is a really good example of the type of thing that I have been doing all my life. I picked the crap, you know just to benefit the other people around me and so I just feel now, I don't know whether it's because like I said I have turned fifty or whether it is because you know of the Asperger's. But now I need to find the balance and that's it really." P13, l45-47 "I believe somebody with Asperger's doesn't think about that. You know, they think about what's needed, what's right and they just get on with it." P15, l 35-36 "…the only thing is is that people put a label on me and as far as I am concerned I am Judy B who does what she does and it's everyone else that has told me I have got this label." P16, l2-3 "I walk down the street and erm I see people sitting in a bar or sitting in the park with their mates. I miss that because I don't have any friends" P16, l15-19 "I just think independence of thought is desirable and an advantage and you have got freedom because you are not thinking about what other people think. You have got freedom to make your own choices without being influenced by what other people want or what other people think. But there is a price to be paid and that price is basically being on your own." P17, l5-9 "You see I wouldn't know whether that's just me or whether that is the trait. Somebody's come along and told me "you have got Asperger's". Okay you know I am 100% Judy. I would not know what percentage or which parts were Asperger's and which parts were Judy and if somebody came along and took the Asperger's out of me, I wouldn't know what was remaining." P20, l30-36 "there was nothing wrong with me. Nothing at all. I think, I think what's really hard is knowing that as far as I am concerned being a neurotypical person who is inferior in the sense that yeah they are sheep and knowing that and the disappointing side is that I am the problem because I am not a sheep. [Tearful] You know. I think it's great that I am not a follower. That I am not a sheep. However, the frustrating thing is that is not how society sees it. You know society is a load of sheep and that's what they want." P22, l 44-48 "If I had a verruca or a wart, say I had a big wart on my forehead, I could get it frozen off and it's gone. The Asperger's is not going anywhere and now I know that it's, it's, it's quite sad really because if I didn't know that I had it, I would have just gone on in life believing that I was normal and anybody who had a problem with me, that was their problem. So the sad thing is that you know the problem is with me and it's not going away. That's the sad thing. [Choked with tears]"

		Reduced to a label **P13,l6-7 “That is the frustrating thing to hear. You know because of this label, you know, people use it as justification for various things.”**	P5,l14 “You know somebody outside there has managed to put a label on it and call it this thing but it’s still me and my personality” P6,l43 “…remember the category of people with Asperger’s and me is very different.” P7,l29-30 “It’s really not me but now when I pose in photographs [does an exaggerated smile and then laughs] and then it looks alright but it’s not me!” P7, l40-41 “you know people with Asperger’s they are not all identical are they.” P8,l14-15 “he said “you as well?” and I went, “yeah”… it’s just everyone’s different.” P12,l39-43 “Well having the label is like anything that I do is put down to the fact “she ain’t quite right. She’s got Asperger’s”. It’s got nothing to do with my personality, my judgements or my opinions. It’s “no, she is saying what she’s saying or she’s behaving the way she is because she has Asperger’s”. You know, so it kind of negates anything that you know, anything that I do or opinions that I have” P13,l4-5 “You know there are so many different things that make up a person.” P13,l6-7 “That is the frustrating thing to hear. You know because of this label, you know, people use it as justification for various things.” P13, l23-24 “it means then you know my opinions don’t count to anything because “she is just one of them dodgy ones” you know. She has got, she has got Asperger’s.” P17, l44 “If you had not put Asperger Syndrome and neurotypical [as supplied construct] I would have put independent thinker, a crowd follower.” P20, l50 “she will say “oh well you know Judy the reason why, you know, you are so focussed or successful” or whatever the way she wants to see me, “that’s the Asperger Syndrome” you know. **It’s not Judy, it’s the Asperger’s.”** (even the strengths are taken away from her)
	Negotiating Asperger Syndrome	**Being human**	P6,l49-50 “I have learnt to smile. I have learnt to ask people things just to get conversations going and things like that.” P7, l10-17 “I have read a lot of self improvement books and you know it talks about… you know there is one I have got Dale Carnegie ‘How to win friends and influence people’ and he talks about making connections with people, remembering their birthdays, making their birthdays, listening to them, taking down details if they talk about people they care about and in another conversation bringing that in. You know that way you connect. So I have learned things like that. You know a lot of people used to say about me smiling. Not smiling, so I learned and then I learned that, particularly in photographs I have to do bigger, a big smile because it doesn’t come across well.” P15, l15 “The only thing that fits it is the fact that I am human with two legs and two arms and a brain. That’s it.” P15, l21-22 “Independence of thoughts and actions. I think the disadvantage is loneliness.” P16, l47-50 “Because we still need to think about you know, think about the people around you. You know think about your family and you think about, yeah for me it’s my family and the odd friend. You think about them so when you are making decisions you know you still have to think about them.”

		Being different	P8,l2 & l6-7 "he was trying to be very nice to everybody, hello, hi…[Waving and smiling]… when he cracked a joke it wasn't funny but I understood the logic of it... he was just trying to connect…" P8,l14-15 "he said "you as well?" and I went, "yeah"… it's just everyone's different." P8,l43 "Yeah they noticed that I was different." P8,l47-48 "Whether the differences they notice are the same as what they notice in him I can't tell you but they noticed that I was different." P9,30-33 To me there is no point skirting around. You know skirting around and it's not clear what people they are talking about. I just say it direct and people know but a lot of people can't cope with that. P9,l42-45 "It definitely is frustrating … It's kind of a 'double-edged sword' because before I used to say it is their problem. I still feel it's their problem but I can appreciate what they are going through now." P10,l8-9 [On being told she has AS] "it doesn't actually change very much but it's an appreciation of knowing that, you know, knowing that it's more to do with me than it is to do with them." P1o-,l19-21 Knowing that I have got Asperger's is actually telling me, "well you know what, you are speaking French when they are speaking Chinese and that's the reason why they don't understand you." You know, so it allows me to think more about what is the message that they are trying to send me. You know, what can I do to communicate better with this person. P13,l25-27 "I am not phased by what people think of me. So it allows me to get on with doing the things that I want to do or the things that need doing because I am not picking up on feuds where people are upset or whatever."
		Avoiding negation P12,l43-45 "An example is that I was talking to Anthony the other day and he said "well it's because you've got the Asperger's. I am not going to go there I am going to forgive you for that…"	P5,l14 "You know somebody outside there has managed to put a label on it and call it this thing but it's still me and my personality" P7,l29-30 "It's really not me but now when I pose in photographs [does an exaggerated smile and then laughs] and then it looks alright but it's not me!" P7, l40-41 "you know people with Asperger's they are not all identical are they." P7,l35-36 "some of the things I do to be accepted" P12,l49-51 "that got me really upset because it means then that nothing that I say is valid because I am not this. Because I am not [neurotypical]." P13, l13-15 "as far as he was concerned I was cantankerous, argumentative, I was this but now, now he says now that he knows that I have got this he is able to take a deep breath and let it go!" P17, 30 "If I didn't want to be lonely the best position to be in would be [neurotypical]" P21, l 25-27 "I get into situations where I think you know already they are beginning to misread me. Should I tell them? Shouldn't I? Should I? Shouldn't I? But if I tell them then it's going to be the Anthony and the Cathy thing."

	A melting pot of NT	**Follow the pack**	P13, l38-42 “there are so many examples of people who follow their peers and follow the norm even when they know it’s wrong. They don’t raise their head above the parapet and say “this is wrong, we need to be doing…” They melt back into the pool and do what everybody else is doing and there are examples of that. There are loads of examples with you know some real bad atrocities.” P14, l2…l12 “I think the disadvantage is that they need things to be pigeon holed… You know if things don’t fit in a pigeon hole it confuses them. They don’t know what to do. You know whereas if I come across something that’s different I take it for what it is you know and work out how I am going to deal with it at that particular time. In fact that is almost what I do every single time because I haven’t got these pigeon holes.” P15, l42-44 “Once it’s in the pigeon hole you were doing what you are supposed to do and because you are part of the pack you are not lonely.”
		Inferior / ignorant of AS	P10,l34-36 “You have got to modify the language that you use and the way that you speak to them and by knowing that I have got this ‘superior Asperger’s’ I have to communicate with these babies in a different way” P13,l1-4 “There is a matrix of different personalities and everything else and even if I haven’t got Asperger’s, even if someone has got Asperger’s, there are other tendencies that people have you know but we don’t know what the hell they have got. You know but because we don’t know what they have got, they don’t have a label.” P14, l2…l12 “I think the disadvantage is that they need things to be pigeon holed… You know if things don’t fit in a pigeon hole it confuses them. They don’t know what to do. You know whereas if I come across something that’s different I take it for what it is you know and work out how I am going to deal with it at that particular time. In fact that is almost what I do every single time because I haven’t got these pigeon holes.” P14, l47 “I just think they are blinkered” P19, l 12 “even that [asd assessment] was too pigeon-holed”

	Communicating with people with NT	**Speaking different languages**	**P1-,l19-21 Knowing that I have got Asperger's is actually telling me, "well you know what, you are speaking French when they are speaking Chinese and that's the reason why they don't understand you."**	P4,l23-26 "Yeah if there was conflict, because generally there would be. People would be… They'd be angry for something couldn't even fathom. You know. [Laughs] I didn't care. I didn't bother thinking about it. It's not my problem. It's theirs. Let them get over it and I just coped with what I was doing." P4,l26-28 "I find it frustrating knowing that I have it because when people are getting irritated and upset with me I know now the reason why but I am still not in a position to do anything about it." P5,l34 & 38-39 "The easiest thing is that to sum it up is that 'I don't get it'… I don't get it. I mean and I don't get it in so many ways. When people talk to me I misunderstand what they say." P6,l29-32 "it's just about just not getting the message and therefore not giving the right one back and people getting quite upset because it is plain as day to them that I should understand what it is that they are saying." P7,l35-36 "some of the things I do to be accepted" P8,l2 & l6-7 "he was trying to be very nice to everybody, hello, hi…[Waving and smiling]… when he cracked a joke it wasn't funny but I understood the logic of it... he was just trying to connect…" P8,l43 "Yeah they noticed that I was different." P8,l47-48 "Whether the differences they notice are the same as what they notice in him I can't tell you but they noticed that I was different." P9,l22-24 "if I am doing something wrong tell me how I should do it. If you can tell me how I should do it then I can do it and up to now I have not been given a solution, by no one." p9,l33-37 Me acting in the only way that I knew how or trying to act in the best way that I could because even though with reading all these books, it is still getting people upset. So that was the unhappiness and the confusion because I am trying my best here. And you know, I am still not getting the kind of responses that I would like and so that leads to the unhappiness and the confusion. P9,l42-45 "It definitely is frustrating … It's kind of a 'double-edged sword' because before I used to say it is their problem. I still feel it's their problem but I can appreciate what they are going through now." P1-,l19-21 Knowing that I have got Asperger's is actually telling me, "well you know what, you are speaking French when they are speaking Chinese and that's the reason why they don't understand you." You know, so it allows me to think more about what is the message that they are trying to send me. You know, what can I do to communicate better with this person. P23, l 22-23 "everyone's got their own different sets of references in the world, in their world"

		Potential for war	You need to think about others p4,l10 P5,l2-5 “if you have got a team of people and you have all got these targets to achieve, and one of them [person in the group] is working really hard and not conforming with the rest of the group and making the rest of the group look lazy, then they are not going to like you for it” P6,l2 “I have lost the will to live” P7,l35-36 “some of the things I do to be accepted” P8,l47-48 “Whether the differences they notice are the same as what they notice in him I can’t tell you but they noticed that I was different.” P9,l22-24 “if I am doing something wrong tell me how I should do it. If you can tell me how I should do it then I can do it and up to now I have not been given a solution, by no one.” P22, l 34-38 “Before it was about personalities, clashes, not sharing the same values or whatever and so you just move on because you are going to meet somebody else who is likely to have and share the same things as you. Knowing that I have got Asperger’s and this is what puts people’s back up I am not going to find anyone and that’s, that’s the frustrating thing.”
Other Important Findings			Therapy: p20, l4-5 “they didn’t tell me that when they started that which I wish I knew because then I would have spaced it out” Maybe once a month I want a lesson on how to communicate or how to talk you know or what’s the best way to speak to people. I don’t want to be in a situation where I am coming back and basically crying my sorrows because I have had this situation with this particular person and they misunderstood me and I misunderstood them and how do you feel about it. No just give me some skills.