

Hermeneutical Phenomenology:  
Experiences of girls with Asperger's  
syndrome and anxiety, and Western  
Herbal Medicine.

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# Hermeneutical phenomenology: experiences of girls with Asperger's syndrome and anxiety and Western Herbal Medicine.

## **Abstract**

Anxiety in young people with Asperger's syndrome (AS) is of serious concern. With a greater prevalence of girls with AS than previously considered, there is a paucity of research into experiences of anxiety in this population. Girls with AS and their parents may seek help through professional Western Herbal Medicine (WHM), the practice of which has little research evidence. The aim of this study is to explore experiences of girls in Scotland with AS and anxiety during a course of WHM treatment, described by the girls, their mothers and the herbalists.

A Hermeneutical or Interpretive Phenomenological longitudinal case-study approach included a purposive sample of 3 girls, their mothers and 3 Western Medical Herbalists (WMH) (n=9). Innovative methods developed to address specific needs of the girls comprised of licensed computer interview software 'In My Shoes' and an online diary facility. Individual interviews took place with all participants, second interviews held with girls and mothers, were transcribed verbatim and thematic analysis carried out.

The study was endorsed by Edinburgh Napier University Faculty of Health, Life and Social Sciences Research Ethic and Governance Committee and the National Autistic Society. Informed consent was given by all participants.

*Where can we be what we are?* was identified as a theme within a narrative of marginalisation in which individuals whose needs are marginalised turn to a treatment marginalised within the prevailing biomedical health care model. Anxiety manifests in girls with AS in a number of ways including chronic insomnia, emotional outbursts and school refusal. The WHM treatment had beneficial effects. However, access to, and compliance with, the treatment, may be inequitable. There is an urgent need for greater support for girls with AS and families, with an evidence base underpinning appropriate intervention.

Diagnosis needs to be accompanied by acceptance in society and the availability of future opportunities. Further qualitative research in this area would increase insight and understanding and provide support for the development of

larger scale studies. The creation of 'best practice' guidelines in WHM for the treatment of girls with AS is recommended as is a pragmatic clinical trial of WHM for girls with AS and anxiety.

key terms: Girls, Asperger's, anxiety, Western Herbal Medicine, hermeneutic interpretive phenomenology, methods, In My Shoes.

## **DECLARATION**

I certify that the work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text, and that the material has not been submitted, either in whole or in part, for a degree at this or any other university.

Catriona A. Stewart December 2010

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Finally, to those that participated in my research study: my colleagues, the herbalists, who offered time and a willingness to allow me some insight into their working practices; the girls' mothers who trusted me to listen; and most of all, the girls, outstanding in the strength of their characters and their abilities, despite all the challenges they face in their daily lives - I offer my thanks, along with this body of work, which is the product of all our efforts.

## List of Acronyms

<b>AA</b>	<b>Atypical Autism</b>
<b>AS</b>	Asperger's syndrome
<b>APA</b>	American Psychiatric Association
<b>ASD</b>	Autism Spectrum Disorder
<b>BMA</b>	British Medical Association
<b>BMJ</b>	British Medical Journal
<b>BYI</b>	Beck's Youth Inventories
<b>CAM</b>	Complementary and Alternative Medicine
<b>CPP</b>	College of Practitioners of Phytotherapy
<b>EBM</b>	Evidence Based Medicine
<b>EHTPA</b>	European Herbal and Traditional Practitioners Association
<b>ESRC</b>	Economic and Social Research Council
<b>GP</b>	General Practitioner
<b>HFA</b>	High Functioning Autism
<b>IMS</b>	In My Shoes
<b>IPA</b>	Interpretive Phenomenological Analysis
<b>MRC</b>	Medical Research Council
<b>NAS</b>	National Autistic Society
<b>NCAS</b>	National Centre for Autism Studies
<b>NIMH</b>	National Institute of Medical Herbalists
<b>NT</b>	Neuro-typical
<b>OCD</b>	Obsessive Compulsive Disorder
<b>PDD-NOS</b>	Pervasive Developmental Disorder-Not Otherwise Specified
<b>PECS</b>	Picture Exchange Communication System
<b>RCT</b>	Randomised Controlled Trial
<b>SCAS</b>	Spence's Child Anxiety Scale
<b>SIGN</b>	Scottish Collegiate Guidelines Network
<b>TOM</b>	Theory of Mind
<b>WCC</b>	Weak Central Coherence
<b>WHM</b>	Western Herbal Medicine
<b>WHO</b>	World Health Organisation
<b>WMH</b>	Western Medical Herbalists

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## **Chapter 1 Introduction**

### **1.1 The impetus to this study**

Ten years ago, I was training to qualify as a Western Medical Herbalist. My children were still at primary school and I was approached one morning in the school playground by another mother, a Clinical Psychologist, who specialised in childhood Autism assessment. She asked if I knew anything about the use of herbal remedies – Glycyrrhiza glabra, Liquorice, specifically – for the treatment of Crohn's Disease in Autistic children; she and a colleague were developing a research funding proposal looking into the use of herbal extracts for this population. I responded that I did not, but that I would find out what I could.

That investigation led to a Master of Science degree. In my research study I discussed to what extent Western Herbal Medicine (WHM) can respond to the issues raised by the complexity of the disorder known as Autism. I found that there was controversy within groups of professionals and between professionals and parents of children with Autism Spectrum Disorder (ASD) as to theories of aetiology and approaches to treatment.

Parents do bring their children with ASD to professional herbalists. As reported by both herbalists and parents, parents rarely bring their children to herbal clinics complaining 'of autism' but with one or more of a range of problems, such as: insomnia (most commonly), obsessive behaviour, school refusal, eating problems and eczema. High levels of anxiety were additionally identified as associated with experiences of ASD for parents and children (Stewart 2004).

I found that WHM may potentially offer support and a viable treatment option for children with ASD and their families but that there is a lack of awareness of WHM treatment, a lack that extends further than families with members with ASD.

### **1.2 WHM in 21<sup>st</sup> century.**

There is a paucity of research evidence established within the field of contemporary WHM as to its provenance and thus it is necessary to look to other disciplines. Many academic fields - sociology, anthropology, ethno-botany, medical history - have contributed to increased understanding of contemporary

medicinal herb use and its role as a health care practice in the United Kingdom (UK).

The point is often made by WMH that from a global and a historical perspective there is a case for considering herbal medicine as the most conventional of all forms of medicine (Conway 2005). A substantial proportion of modern pharmaceutical drug production is still based on plant derivatives and for a large part of the world's population, medicinal plants are still the primary therapeutic agents in use (Farnsworth et al. 1985). Terms such as 'orthodox' and 'alternative' are indeed relative (Saks 1992).

There is, however, a profound difference between medical approaches with the philosophical, social or historical – or economic - factors underpinning them and the therapeutic agents they employ. Throughout human history, evidence is available of a continuing therapeutic relationship with, or dependence on, plant materials, but the modality of use has differed, fluctuated and evolved (Dickson & Dickson 2000; Milliken & Bridgewater 2004). The only constant is in the use of the plants themselves (Evans 2009).

Current orthodox medicine is regarded as primarily carried out from a biomedical perspective that evolved from the rationalist modernism of the 19<sup>th</sup> and 20<sup>th</sup> centuries. From this perspective, the body is viewed mechanistically and treatment applied through direct intervention in individual parts or systems (Saks 1992). The term Complementary and Alternative Medicine (CAM) is often used to describe healthcare approaches not considered orthodox and that are usually not provided under the National Health Service (NHS). CAM, when regarded as a cohesive entity, is associated with a move to postmodernist values in health-care. Postmodernism in this context questions concepts of the 'scientific method' as a neutral activity, free of value-judgement and based on objective truth. It also questions the role of such science when carried out, for example, in the form of Randomised Controlled [Clinical] Trials (RCT) to assess health-care interventions.

There are profound difficulties with such assumptions on several levels, not least that CAM is a broad term referring to a large number of widely disparate treatment modes, in which terms such as medicine and therapy may contain

very different materials and actions, which may be embedded in different philosophical paradigms and some of which are relatively modern.

Terms such as 'medicine' and 'therapy' are therefore ambiguous. The biomedical system uses medicines that, although often derived from plant-based materials, are in the form of standardised, usually synthesised, pharmaceutical products. In WHM, prescriptions are individually tailored mixes of herbal medicine 'simples' (single plant extracts). Simples are based on extracts of whole, or whole parts of, therapeutic plants, as alcohol and water macerates or hot water infusions. Standardisation applies to alcohol and water ratios, depending on chemical constituent balance in the individual herb, desired strength and protocols for preservation of the product. However, that there will be differences in the constituent parts of any herbal plant harvest depending on a range of environmental factors is both acknowledged and accepted, even incorporated, into WHM practice. Such flexibility is not tolerated within the reductionist parameters of the biomedical health-care system that is the contemporary 'orthodox' approach.

In this flexibility, Western Herbal Medicine distinguishes itself from orthodox medicine further. This tolerance of difference does not apply only to medicines. 'Medicine' in WHM is rarely regarded as a discrete, entire treatment prescribed in isolation but as part of a complex 'three-fold therapeutic' approach to health (Nissan 2009). A definition of the term 'post-modernity' as encompassing 'diversity, multiplicity, flexibility and a willingness to combine multiple discourses' (Saks 1998) resonates with the practice of WHM.

However, WHM – or indeed CAM generally - is seen by many, practitioners and consumers, as a return to the 'pre-modern', pluralistic approach to healthcare that included 'astrology, herbalism and healing on both self-help and practitioner-delivery basis' (Larner 1992). This is often associated with a romantic view of WHM (Evans 2009) as exemplifying a pre-modernistic 'holism' practised before modern health-care became a profession predicated on objectification and depersonalisation of the patient within a positivistic framework. 'Postmodernism', however is inherently eclectic (Saks 1998); 'pre-modernist' practice may well have included a multiplicity of approaches but was perhaps united at any point in history by a more comprehensive ontology than is

currently the case. While such a debate is not the focus of this study, it is worth commenting that WHM's philosophical roots may be more complex than widely perceived.

The cultural dominance of biomedicine that began in the early 20th century and the process and reasons for this have been extensively commented on (Porter 1997; Saks 1992, 2003; Kelner et al. 2000; Gabe et al. 2006). Commentators from outside the herbal profession have identified ways in which the practice of WHM has been marginalised throughout the last one and a half centuries (Friedson 1988; Saks 1996, 2003; Kelleher et al. 2006) and how practitioners have either sought to combat that marginalisation or to accommodate and work within it (Saks 1992, 2003; Sharma 1992; Gabe et al. 2006). Such a marginalisation led to a forty-year long disenfranchisement of WHM in the UK in the 20<sup>th</sup> century, more recently followed by a notable upsurge in public interest and use over the last four decades.

Challenges to the biomedical hegemony have been met by the medical profession using a combination of strategies (BMA 1986) ranging from extreme scepticism as to the scientific validity of anything lying outside of its own methods and measures (Gabe et al. 2006) to the attempted incorporation of some 'outlying' techniques into its work. The inherent contradictions contained within mainstream medicine's attitude towards WHM are exemplified by Ernst, who in 2000, wrote:

“...the medical professions have to face [this] reality, regardless of whether they are proponents or opponents...Medical herbalism thrives on its long and diverse traditions...safe and effective therapies have emerged and are continuing to emerge from the archives of ethnopharmacology. The careful and intelligent synthesis of traditional knowledge with modern scientific phyto-pharmacological evidence shows us an effective way forward.”  
(Ernst 2000 p109)

However, despite the above assertion, Ernst was highly visible throughout 2009 and 2010 arguing vociferously against the Statutory Regulation of WMH on the grounds that WMH, according to Ernst, do not practice EBM – despite there being, ironically, no evidence to support this claim.

Indeed some commentators reflect the anxieties of some WMH (see [www.saveourherbs.org.uk](http://www.saveourherbs.org.uk)) and argue that herbal medicine's acceptance as part

of mainstream healthcare is conditional on its knowledge base being reinterpreted in ways that are congruent with mainstream science and biomedicine. This reinterpretation is regarded as a challenge to the long-term ability of practitioners to maintain their professional identity (Saks 1992; Saks 2003; Coulter 2004).

The implications of this, and the differences between traditional knowledge and the evidence-based medicine espoused by the biomedical model, are discussed by Evans (2009). Evans outlines the current conflict as an example of the tensions experienced by traditions which culturally locate themselves close to power (Gross 1992). Conflicts are raised when traditions move to become located firmly within modern society, bringing the challenge of maintaining identity without excessive and inappropriate compromise:

‘so close to power and money’ (Gross 1992 p122).

For some WMH, this challenge is seen as being unachievable. However, epistemological debate is ongoing and can be seen to be affected by the political and social conflicts surrounding the practice and use of WHM. A cohesive response to the challenges posed by the changing political and social environment in issues of health (Saks 1998) is required to support the practice of WHM into the future. In this thesis, I adhere to the concept of WHM as a phenomenological practice, with philosophical roots extending back as far as the Laws of Plato (360BC).

Research enquiry into experiences of the practice of WHM has been carried out from ethnographic, sociological, historical and feminist perspectives. That further research into practitioners’ and patients’ lived experiences of WHM makes for a constructive progression to these perspectives has been identified (Stewart 2004; Evans 2009; Nissan 2009). For families with members with ASD specifically, more needs to be known before WHM can be viewed widely as an appropriate and readily available resource. This thesis aims to address this need, at least in part. A hermeneutic, phenomenological approach to ‘ways of knowing’ (Van Manen 1990) inherent in the practice of WHM is embedded in this thesis and revisited throughout.

### **1.3 An insider's perspective**

A research study such as this requires a personal commitment to the phenomenon under scrutiny not in terms of breaching the boundaries between researcher responsibilities and personal agendas but in terms of explicit acknowledgement of the role of the researcher within the research process. Practising and teaching in Scotland over the last ten years I have been inevitably aware of the conflicts and tensions coming from both within and outside the profession (McGrath 2010).

Some years ago, while I was lecturing on the BSc Herbal Medicine course at Edinburgh Napier University, I asked a class of students a question: "What would you do if an embarrassed, anxious young man comes into your clinic complaining of 'a lump'". They looked at me blankly, there was a pause, and then one student answered briskly, "Tell them to go to their doctor of course, we don't mess about on this course". "I don't 'mess about' in my clinic either", I replied mildly, "but I also don't have the power to vet who is going to come in my door. Whether you are able, or prepared, to treat, or not, you have to decide if you are there to help people or are you going to put up a notice that says "Don't come in if you don't fit the following criteria...."? You are training to be effective and safe. You have to know what you are going to do when required to deal with the unusual, the difficult and the downright worrying. When you gain membership of the National Institute of Medical Herbalists (NIMH), you will take a solemn vow to do your utmost to help people, to 'be respected by all people in all times'. You need to think about what that means."

Now, as I write the background to my thesis, I revisit that same question. I consider the tensions inherent in our training which asks us to think like 21<sup>st</sup> century western medics but to practise in ways that are described as 'traditional', 'holistic'. How do we reconcile the demands of modern science, the skills we have learnt, the love of our craft and the reality of people's lives here in Scotland in the 21<sup>st</sup> century? How do we practise as we vow we are going to? These questions have remained in the background of this study.

As a practising professional WMH, training mentor, clinic supervisor, academic lecturer and researcher, I have worked to promote public understanding of and access to WHM. I have worked also within the profession to progress its



professional status and its validity as a contemporary form of primary health care. Inevitably, within this is the individual professional persona attached to my own experiences of training and practice and the implicit allegiance held to these things. I have an 'insider's perspective' on the phenomenon I aim to investigate (Robson 2002).

As described by another herbalist 'insider researcher':

"research which encourages self and social understanding and change-enhancing action on the part of 'developing progressive groups' requires research designs that allow us as researchers to reflect on how our value commitments insert themselves into our empirical work. Our own frameworks of understanding need to be critically examined as we look for the tensions and contradictions they might entail (Lather 1991 p80 from Nissan 2009).

This study is not only a research project, it is also a process of personal development, through which some answers are found, and new questions created. I have had, in the course of this study, to review my perspectives on the contemporary practice of WHM. The hermeneutical process is one that alters our field of vision, shifts the boundaries of our horizons. Furthermore, I am not only an 'insider herbalist'. I am a mother, of two adolescent girls. This fact locates my place as insider researcher from other perspectives. To the participants in this study, I am not only a researcher, I am a mother-figure, or a colleague, or someone who might understand, or, conversely, judge? As an 'insider' researcher-mother, I have my own experiences of parenting and understanding of what it means to be a 'mother'. This too is an evolutionary process, a 'human becoming' (Parse1991), one inextricably interwoven with the other.

In the process of carrying out this study, I have had cause to reflect on what I have heard and understood of the experiences of the participants in the context of the WHM treatment from a multiplicity of perspectives: the patients', their mothers', the consultant practitioners' and my own, herbalist, teacher, mentor, mother of two adolescent girls, observer. I have therefore had to consider the implicit blurring of boundaries between my professional and personal self and the researcher's role as 'objective outsider' (Denzin & Lincoln 2000). Such considerations are embedded in the choice of methodological framework and are discussed further in Chapter 3 of this thesis.

## 1.4 Background

In the following chapter sections, explanations of the key terms used are given. Background to the main areas of focus of this thesis, being Autism Spectrum Disorder (ASD), Asperger's syndrome (AS), and anxiety are presented, including prevalence, sex differences in AS, mental health concerns, prognosis and treatment options. What is known about the use of WHM with ASD and AS is summarised. This chapter finishes with a description of the thesis structure including indicators to the following chapters.

### 1.4.1 Definitions

This thesis explores the interrelation between a number of entities, terminology for which may be poorly understood or require clarification. In this section of Chapter 1, definitions are given for a number of key terms used throughout, being:

- Western Herbal Medicine (WHM)
- Western Medical Herbalist (WMH)
- Complementary and Alternative Medicine (CAM)
- Autism Spectrum Disorder (ASD)
- Asperger's syndrome (AS)
- Anxiety

#### 1.4.1.1 *Western Herbal Medicine*

Herbal Medicine has been defined as a Traditional Medicine by the World Health Organisation (WHO) with a broad definition of approaches and methods used in the prevention and treatment of both physical and mental health including:

“... the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures...”

([www.who.int/medicines/areas/traditional/definitions/en/index.html](http://www.who.int/medicines/areas/traditional/definitions/en/index.html) accessed 9.6.06)”

‘Western’ differentiates herbal medicine as practised from within a European philosophical basis and utilising primarily plants native to Europe (or North America). The terms ‘western herbal medicine’, ‘traditional herbal medicine’

(Evans 2009) 'herbal medicine' and 'phytotherapy' are used to describe this practice (Weiss 1998, Ernst 2000).

Differences between these terms are primarily differences of emphasis (Griggs 1997) but are additionally associated with how practitioners position themselves in relation to mainstream medicine (Evans 2009, Saks 1992, Kellner et al. 2000). German practitioner Weiss (1998) for example, distances himself from what he describes as "ancient 'herbalism'" and allies himself with the use of phytochemical-containing medicinal plants as a scientific subject. Some herbalists view the practice as the continuation of a cultural heritage of whom Culpepper (1653) was one exemplar (Tobyn 1997), Grieve (1931) another; others as a feminist one (Griggs 1993; Nissan 2009). Hoffmann (1990), alternatively, describes herbalism as being practised from within a 'holistic paradigm' allied to an environmentalist or 'Gaian' perspective on health and disease. 'Holistic' commonly refers to the individual in the context of their total social environment (Saks 1992), and in WHM often with reference to the Hippocratic emphasis on maintaining a balanced, measured approach to life for the promotion of good health (Weiss 1998; Hoffmann 1990; Mills 1991; Bartram 1995).

In practice, it has been found that many herbal practitioners use both 'scientific' herbal medicine and 'traditional' herbal medicine and that, within the UK, not all herbalists differentiate between the two terms (Evans 2009). Differing perspectives and preferences may be reflected in an individual practitioner's approach, but herbalists may include both 'tradition' and 'science' in their work. (Mills 1991, Nissan 2009, Evans 2009)

The term Western Herbal Medicine (WHM) is used in this thesis to describe the practice of herbal medicine carried out by professional practitioners as described below.

#### *1.4.1.2 Western Medical Herbalist*

For this thesis, the definition of herbalist as a:

"health practitioner who engages in the extemporaneous compounding of herbs for therapeutic purposes for individuals under his or her care" (Lin et al. 2005 from Evans 2009)

is appropriate although not entire. Herbalists are also described as practising to a 'three fold therapeutic' model of treatment that includes dietary and lifestyle advice as well as the prescribing of herbal medicines (Nissan 2009). This approach is arguably a cornerstone of contemporary WHM and is perceived by some practitioners as being the key difference between their health practice and that of the mainstream. Implicit in this perception is that extending the scope of treatment beyond that which may be addressed by the taking of pharmacologically measureable herbal medicines is one of the means by which WHM fulfils its claims of 'holism'. The 'essential tradition' of the clinical case history (Foulcault 1973) is structured, in WHM, to elicit more than just details of physiological functioning but additional social, relational and emotional experiences of the individual patient. The importance of narrative in WHM in the clinical setting is emphasised and the role of 'listening to their stories' (Nissan 2009; Evans 2009; Van Marie 2002).

A Western Medical Herbalist (WMH) defines those herbalists working from within a Western philosophical paradigm (Evans 2009). Training in the UK is to professional standards established by accrediting bodies such as the National Institute of Medical Herbalists (NIMH) or the umbrella organisation, the European Herbal and Traditional Practitioners Association (EHTPA). Minimum training is expected to be to BSc level. Membership of NIMH is contingent on achieving the required academic qualification, a minimum number of clinical training hours and passing a final clinical examination.

In summary, the practice of WHM, as in any healing modality, is geared towards finding answers to the questions 'what is wrong?', 'can it be fixed?' and 'if so, how?' Answers are pursued in WHM using a range of tools including many that overlap with those used in contemporary biomedicine. Students are taught western biomedical models of anatomy, physiology and pathology and are expected to own the conventional principles of differential diagnosis (DD). The main diagnostic tool employed is the case history, which is guided by a structure of systematic physiological enquiry. Clinical examination may be employed and herbal patients may be asked to seek laboratory tests via their General Practitioner or specialist clinic. A core part of any NIMH-accredited course is the 500 hours of supervised clinical training during which students are

expected to learn through observation and, as they advance, practice, the 'art of the science' of WHM (Walker 2005).

Despite the training standards demanded of members of the EHTPA and of NIHM, in law at the point of writing, anyone in the UK may call themselves 'herbalist'. The term Western Medical Herbalists (WMH) is used in this thesis to include only those practitioners who have trained at an NIHM or EHTPA accredited institution to at least BSc level in WHM, or to an equivalent, professionally recognised level and who hold membership of a recognised professional body such as NIMH or the College of Practitioners of Phytotherapy.

#### *1.4.1.3 Complementary and Alternative Medicine*

Use of the term CAM, whilst convenient, can be problematic, as it implies a uniformity and homogeneity of practice, practitioners and use and does not describe important epistemological differences within the range of approaches included (Cant and Sharma 1999; Singer and Fisher 2007). 'Complementary' is applied to acknowledge on some level that medical pluralism is viable even in a predominantly biomedical system and that diverse healing approaches 'can work alongside and in conjunction with orthodox medical treatment' (British Medical Association (BMA) 1993). Implicit in the term however are unequal levels of status and power relative to biomedicine (Saks 1992, Nissan 2009). Some prefer the terms 'alternative medicine', 'alternative therapies', 'alternative healthcare' or 'alternative health practices' as a way of promoting a concept of health practices operating outside mainstream provision; in recognition of the use and practice of different modalities as an alternative choice to biomedical provision; and to reflect the ontological and epistemological differences between many alternative and biomedical health practices (Saks 1992, Nissan 2009).

However, CAM is used as standard in much sociological and medical literature (Kelner et al. 2000) and is inclusive. Western herbal medicine as practised in the UK is encompassed within both terms: it may be used as complementary (Mills 1991; Weiss 1998; Ernst 2000), or as an alternative, to mainstream medicine (Hoffman 1990). The term CAM is thus used pragmatically for the purposes of this thesis. Any reference to CAM is done so with the caveat that the term is often not representative of the specifics involved in WHM.

#### 1.4.1.4 ASD

“Autistic spectrum disorders are lifelong, complex, controversial, challenging to service providers, they can cause severe impairments and they are not uncommon.”

(PHIS Report 2001, p.7)

Characterisation of Autism is manifold with definitions including: as a pervasive developmental disorder (PDD); as a disorder of affective contact; as an organic dysfunction of biological origin, and as a neurological or brain disorder, that affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment, each in varying degrees. Those affected by autism fall along a spectrum of “high-functioning” individuals to individuals who lack any means of communicating with others (Marwick et al. 2005). That autism, along with other PDDs, manifests such diverse and changing expression over the course of development presents many challenges for all aspects of involvement.

More than twenty years after Kanner's original (1943) paper on ‘Childhood Autistic Psychopathy’, the definition of Autism as a medical condition or neurological disorder requiring special educational treatment was pioneered in the UK by Dr Lorna Wing (Wing 1969). Current concepts of autism are broad, ranging from those with severe disabilities to those with more subtle problems and limited social skills.

The term Atypical Autism (AA) may be used when a disorder differs from classical autism due to a later age of onset, atypical or ‘sub-threshold’ symptoms, or all of these. This category is sometimes referred to as ‘Pervasive Developmental Disorders – not otherwise specified’ (PDD-NOS) (Marwick et al. 2005). Autism may exist alongside learning disabilities or other developmental disorders or co-morbidly with other physical or psychological difficulties and so the concept of an ‘autism spectrum’ has evolved (Marwick et al. 2005).

Autistic Disorder or ‘classic autism’ is diagnosed principally in terms of the two international classification systems, the International Classification of Diseases 10 (ICD-10) (WHO 1993) and The Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV) (American Psychiatric Association (APA) 1994) which have similar criteria for the diagnosis of autistic spectrum disorders. Both

describe behavioural criteria based on the triad of impairments described below, with certain diagnostic categories further expanded.

Autism is given as having three basic diagnostic criteria, known as the 'Triad of Impairments' being:

- 1) impaired reciprocal social development
  - 2) impaired language development or communication
  - 3) insistence on sameness or restricted, stereotyped, repetitive behaviour.
- (Wing and Gould 1979).

However, the issue of diagnostic criteria for this broad spectrum has not been resolved.

#### *1.4.1.5 Asperger's syndrome (AS)*

AS is a severe developmental disorder characterised by major difficulties in social interaction, and restricted and unusual patterns of interest and behaviour. Its diagnostic definition has only been in place since the mid-1990's (Volkmar 1994). To some extent, differentiating AS from other ASD or PDD has relied on individual clinical interpretation, due to there being no consensual, as well as until so recently, no 'official' definition of AS, leading to inconsistencies in diagnosis.

While ASD is described as a spectrum, it has been argued the underlying neurological developmental fault is the same no matter at which end of the spectrum it appears and that the severity of presentation depends on other aggravating or mitigating factors, such as additional learning handicaps or high intellectual ability (Frith 1991). This can be described thus:

"Individual autistic children differ in their intelligence, capacity for learning and use of language, but all are abnormal in the ways they relate to other persons" (Trevvarthen et al 1998 p25)

A clear definition of AS is considered to be less than straightforward, however, and confused by the introduction and use of several diagnostic criteria including Gillberg (1991), Szatmari et al. (1989 a), the ICD-10 (WHO 1993) and the DSM IV (American Psychiatric Association 1994). In contrast to classic autism, language development in AS is not assumed to be delayed and normal cognitive and self-help skills should be present in the first 36 months.

Table 1 Showing diagnostic criteria for Asperger syndrome according to Gillberg (1991)

- Social impairments
- Narrow interests
- Repetitive routines
- Speech and language peculiarities
- Non-verbal communication problems
- Motor clumsiness

However neither Gillberg's (1991) and Szatmari's (1989a) criteria require 'normal' early development but regard language and communication differences to be a defining feature, along with, in the case of Gillberg's definition, motor clumsiness, more advanced theory of mind (TOM) and higher intellectual functioning (Leekham et al 2000). Gillberg's criteria are cited by some as being the closest to Asperger's own (Leekham et al. 2000, Fitzgerald & Corvin 2001).

The term 'High Functioning Autism' (HFA) may be applied to those with autism but of average or above-average intelligence. There are therefore many similarities with autism without mental retardation or HFA and AS and the issue of whether AS and HFA are different categories has not been fully resolved (Frith 2004, Klin et al 2005). Certainly, the main diagnostic systems currently define Asperger's syndrome as distinct, although within the same developmental category, that is, a PDD, from ASD (APA 1994). However, revisions to the DSM currently being worked on for a forthcoming DSM V propose to subsume AS into a category defined as 'Autistic Disorder (Autism Spectrum Disorder)' (website of the APA, accessed 26 November 2010). Mainstream consensus, certainly, is that AS is not quantitatively or qualitatively different from autism and forms part of the spectrum of autistic disorders (PHIS, 2001).

Asperger's syndrome (AS) is described as being on a 'phenomenological continuum' with autism (Volkmar et al. 2005), with specific associated problems in relation to social and communication functioning. Those with AS have by definition been assumed to function in the normal to above-normal range of intellectual ability (Baron-Cohen & Bolton 1993) some, although rarely, showing evidence of exceptional savant skills.

There are several issues with this definition and the assumptions that go with it, one being that many children diagnosed with AS have very uneven intellectual



profiles and may register as having extremely high IQ results in one category while being below average in another (Attwood 2006). The achievement of early language milestones may be uncertain in AS, while the term 'little professor' (Attwood 2006) is commonly applied to some AS children who demonstrate a precocious vocabulary but they may have limited ability to use the words in an appropriate context. This can be described as a difference in intellectual and functional retardation (or ability); one relates to the capacity of an individual to accumulate information, the other to how that individual functions in the world in being able to act on information in the context in which it is created (Williams 1998).

Another issue is in criticisms levied at the use of standard IQ assessments with this population (Baron-Cohen 2000; Bogdashina 2004). Created to measure intellectual ability in a neurotypically developing population (NT), they may not be appropriate for people with alternative processing systems and linguistic understanding. Additionally, some people with ASD may receive a low-functioning label as a consequence of an IQ test result because of sensory processing problems and communication difficulties (Grandin 2002).

Bogdashina (2004) refers to Asperger's own definition of an 'autistic intelligence' being unconventional and creative and argues thus:

"the triadic impairments of social interaction, communication and imagination are better described as qualitatively different ways to interact, communicate and process information which do not coincide with conventional ones" (p15).

Some researchers and commentators argue that people with AS process and use information in ways that may be different to those with typical neurological development, but that in suitable and supportive circumstances, those differences can lead to great achievements and may have many benefits to society as a whole (Baron-Cohen 2000, Bogdashina 2004, Elder 2005; Lawson 2006).

There have additionally been calls to redefine AS as a condition rather than a disorder (Jordan 2007, Baron Cohen 2008). However, while manifestations of AS may be variable in individuals and for those who do not have additional difficulties, are supported and well placed socially, can be thought of as reflecting cognitive differences or styles in effect, it is the case that many

individuals with AS experience great difficulties in their lives directly as a consequence of their developmental differences (Marwick et al. 2005). Renaming AS will not necessarily benefit these individuals.

Throughout this study, the term Autism Spectrum Disorder (ASD) is used to define the autism spectrum as a whole, including those diagnosed as having Pervasive Developmental Disorder (Not Otherwise Specified) (PDD-NOS), High Functioning Autism (HFA), Atypical Autism (AA) and Asperger's syndrome (AS), unless explicitly detailed otherwise. Asperger's syndrome (AS) is used with regards to children, or adults, with that diagnosis, but also recognising the diagnostic complexities involved.

#### *1.4.1.6 Anxiety*

One key aspect of the difficulties experienced by people with AS is a higher than normal prognosis for the development of mental health problems, with anxiety one of the most common. (Volkmar et al. 2005) Whether heightened levels of anxiety are intrinsic to AS or consequential to environmental circumstances is widely debated (Ghaziuddin et al. 2002; Ghaziuddin 2005). What is known about anxiety in individuals with AS is discussed in Chapter 2.

Anxiety as a natural physiological response is differentiated from Anxiety Disorders as medically defined (Tortora and Grabowski 1996; Haslett et al 1999). Anxiety is defined according to the epistemological perspective of the model used and from within a range of theories of emotion, including developmental, social and clinical (Strongman 1998, 2003; Morris & March 2004). It is not the purpose of this thesis to argue the case for any individual emotions theory: not all theories address Lazarus' (1991) criteria for 'good' theories of emotion (Strongman 1998, 2003); moreover some theories are more suited to clinical application than others.

In the context of this thesis, post-modernist theories of emotion are acknowledged, including phenomenological theories, in particular those described by Denzin (1984) as being concerned with emotion as it is lived and experienced (Strongman 1998). Denzin's view that all emotion, being mediated by social interaction, is dependent on social relationship and culture may find challenge, or conversely, endorsement, in individuals whose relationship with society and understanding of culture is, by definition, unusual and whose

'autistic intelligence' has been described as "scarcely touched by tradition and culture" (Bogdashina 2004).

However, and encompassing multiple perspectives, how any individual across the population responds to anxiety-provoking events will depend on the interrelation of a very complex range of factors, including their individual physiological, cognitive and neurological profiles (Vasa & Pine 2004) combined with previous experience, conditioning and learnt behaviour (Eley & Gregory 2004).

Perhaps the most succinctly inclusive and therefore useful, definition of anxiety is: "a response to the experience of stress involving cognitive, emotional, somatic and behavioural responses" (Seligman et al. 2001). Stress as a concept of experience leading to psychopathological disturbances is difficult to define although it is central to many theories of anxiety as a disorder (Compas 1995; Groden et al. 2006). Lazarus and Folkman (1984) have defined the term 'stress' as being a relationship between a person and their environment that is perceived by them to exceed his/her resources and jeopardise his/her wellbeing.

#### **1.4.2 Context of the study**

This next section situates the phenomena studied within its contextual background. Key aspects of the study are summarised, being ASD, AS and WHM, including what is known about prevalence, sex differences in AS, mental health concerns, intervention, prognosis and the use of WHM. For a summary explanation of the origins of the terms 'Autism' and 'Asperger's syndrome', see Appendix

##### *1.4.2.1 Prevalence*

Despite a great increase in interest in ASD over the last twenty years, knowledge is still limited and available information inconclusive (Medical Research Council (MRC) 2001, Volkmar et al. 2005, Marwick et al. 2005). That so much that is known about this disorder remains within the realms of theory or debate provides impetus for further research. Additionally and, despite a generally greater awareness with increased rates of diagnosis, ASD is still considered to be under-diagnosed in Scotland which suggests it to be a continuing and growing issue for individuals, carers and service providers. (Marwick et al. 2005)

Autism was once thought to be relatively rare at 2-4 autistic children in every 10,000 of the population (Rutter 1985). Wing and Gould's Camberwell Study (1979) identified 5 per 10,000 children having 'classic autism' and 15 per 10,000 children with a broader presentation of ASD. More recently estimated cases of ASD per population in the UK have risen to 60 per 10,000 (PHIS, 2001), 90 per 10,000 (UK) (Green et al. 2005 i) or 116 in 10,000 for all autism spectrum disorders (Baird et al. 2006). Currently, the figure is approximated at over 500,000 people in the UK having some form of ASD (from the website of the National Autistic Society (NAS) accessed November 2010, available at <http://www.nas.org.uk>).

Reasons for rising numbers of ASD in general are widely discussed (MRC 2001, Marwick et al. 2005). Two reasons commonly cited are firstly, alterations to the diagnostic inclusion criteria, which took place in 1994 and secondly, increased awareness. Despite lack of evidence supporting any particular theory of aetiology and the controversy surrounding some proposed, however, that there may be a true rise in actual figures of children developing an ASD has not been excluded (Rutter 2005).

Earlier estimates of 25% of known cases of ASD being associated with genetic disorders such as Fragile X syndrome or damage caused by infectious diseases such as congenital rubella (Trottier 1999) have been reduced more recently to about 10% (Rutter 2005). Experienced clinicians will recommend a thorough appropriate medical assessment of all individuals thought possibly to have ASD to ensure an adequate differential diagnosis (Rutter 2005, Volkmar et al. 2005). For a detailed list of known biomedical associations with ASD refer to Volkmar et al. (2005), MRC (2001) or the National Autistic Society (available at <http://www.nas.org.uk> ).

Figures specifically for Scotland are incomplete. The most accurate data is held by Local Authorities (LA) which naturally refers to a school age population. Recent UK-based research may reflect a wider picture, for example, Webster et al.'s (2004) England-based study has been used to infer similar trends in Scotland, with the consequent implications for the planning of local services Marwick et al. (2005):

“Reflecting a trend that has been observed in the UK and elsewhere, Bristol has seen a sharp rise in the numbers of children diagnosed with ASD from 125 in 1998–9, to 194 in 1999–2000, an increase of 30 percent per year and estimated to affect approximately 500 children in a school population of 51,400 (Bristol City Council, 2000)” (Webster et al. 2004 p.32).

The situation has been described by one expert clinician as being on the brink of presenting a ‘public health disaster’ (Stewart 2004), with each individual diagnosed with ASD in the UK costing a possible £3,000,000 for a lifetime’s care.

Recording the prevalence of AS alone has been problematic, as estimates depend on the clear definitions and consensual approaches to diagnosis which have been missing in this area (Wing and Potter 2002). A 2006 study (Baird et al.) identified very few children with AS but its authors acknowledge there would be omissions of those with no statement of special educational need. Numbers of AS should therefore be considered as a minimum (Baird et al. 2006). In parallel to ASD, the number of those with AS also appears to be rising.

Prevalence of children with ASD overall, then, cannot be precisely fixed at this time. No prevalence studies have been carried out on adults. However, it has become increasingly clear, certainly in the western world, including Scotland and the UK, there are significant numbers of individuals who are in need of appropriate services and support (Fombonne 1999; Marwick et al. 2005).

#### *1.4.2.2 Girls and Asperger’s syndrome*

There is little evidence available detailing sex differences in people with ASD (McLennan et al. 1993) although some people working in the field of AS have made observations based on clinical experience (Attwood 2008; Faherty 2002). Estimates of ASD in boys and girls have consistently shown that ASD is more common in boys, and that there is a significant preponderance of boys (Ehlers & Gillberg 1993) in more able individuals.

The ratio of boys to girls diagnosed with ASD is estimated at around 4:1; this up until very recently was more than doubled in Asperger’s syndrome, at around 9:1. As the emerging consensus developed that Asperger’s syndrome is an ASD, such a statistical anomaly was clearly unsustainable.

Awareness of the previously hidden nature of HFA or AS in girls and women has increased significantly in a very short space of time and it is now believed to be at least at ASD levels, at 4:1, possibly up to 2:1 (Gillberg 2005). Attwood (2006) has reported a ratio of 2:1 male: female in adults presenting in his clinic.

Furthermore, as autobiographical and autoethnographic publications have begun to emerge, and adult women with AS are highly visible as speakers and advisers there is a manifest discrepancy between the assumed prevalence of AS in females and the numbers of female authors and women available for comment including Grandin (1996), Lawson (1998), Willey (1999), Sainsbury (2000), and Blackburn, who is often a guest speaker at conferences and seminars. There may be several reasons for this, but that AS affects females is clear.

Gillberg (2005) has speculated that there may be an underdiagnosis of more able females with AS whose presentation may be different in nature from their male counterparts. This would not be inconsistent with Baron-Cohen's work on systematising and empathising mental domains associated by gender (Baron-Cohen 2002,). Implicit in Baron-Cohen's theory is that females with AS are more likely to be able to relate to others, and their social difficulties may be less obvious.

These more adept social skills in women with AS are also self-reported by women with AS. (Willey 1999) While some commentators describe this as having less pronounced difficulties (Marwick et al. 2005), it may be more a case of having the tools to do a better job – ie of developing social skills - but still having to 'put in overtime'. It has been described as being "like a swan, appearing to the onlooker as gliding serenely and gracefully across the water while paddling furiously underneath the surface..." (Ludlow 2004) That girls with AS in may represent an under-diagnosed section of the population whose needs are unaddressed and whose abilities are unsupported is of increasing concern.

#### *1.4.2.3 Mental Health in Asperger's syndrome*

Prognosis for the development of mental health problems as adults in young people with AS is worryingly high. Anxiety and/or depression in individuals with AS have been estimated at reaching as high levels as around 65% (Ghaziuddin

2002, Klin et al. 2005; Attwood 2006) and has been identified as a priority area for research in this population (Ghaziuddin et al. 2002, Klin et al. 2005).

The 1996 update of Wing's authoritative 1971 publication "Autistic Children: A Guide for Parents" only gives the subject a half-page length paragraph under the heading "Anxiety and Special Fears". In this, Wing refutes the idea autism might be a consequence of high levels of anxiety experienced from early childhood. Wing's observations led her to the conclusion that while some individuals with ASD seem to be anxious much, if not all, of the time, most are not, in fact, intrinsically anxious – in fact are often dangerously unaware of issues of risk – but experience anxiety in "situations they cannot understand and therefore find confusing and distressing" (Wing 1996). The development of specific fears around things or activities normally perceived as being without threat was also noted.

Since then, emerging evidence of poor prognosis in terms of mental health in this population, combined with clinical observation, has led to the call for further research. Prevalence of psychiatric disorders in ASD has not been definitively measured but existing research data and clinical experience leads to high estimates compared to normal, with depression being associated most often and anxiety disorder following (MRC 2001).

Despite Wing's (1996) observations, Ghaziuddin (2005) argues against perceiving anxiety in adolescents with ASD as entirely heterogenous and therefore non-pathological. The positive impact of identification and treatment of mental health symptoms in young people with ASD, with improved quality of life, facilitated learning at school, more positive role in the community and a wider positive effect on family and carers has been reported (Ghaziuddin 2005). With poor mental health prognosis identified and high levels of anxiety potentially a key factor, then the possibilities of both extrinsic and intrinsic causes must warrant attention.

#### *1.4.2.4 Intervention and Treatment*

Heterogeneity of presentation brings further challenges for intervention in ASD, and consequential additional levels of stress and anxiety for those affected and their families (Brogan 2002). The question of whether there are interventions

that are more or less suitable for particular sub-groups of individuals with ASD has still to be answered, although it may be that a more verbal population may be able to participate better in group settings for example while another group may require considerable visual support (Marwick et al. 2005).

Volkmar et al. (2005) write:

“...there is no single, right formula for every child or adult with autism. A community and nation should strive to have available a spectrum of services to satisfy the varied and changing needs and values of individuals with autism and their families” (pxvii)

and in relation to AS specifically:

“...As in autism, treatment of AS is essentially supportive and symptomatic...Unfortunately there is currently a paucity of systematic data demonstrating the effectiveness of particular interventions...” (p113)

While the majority of interventions in autism in this country are psycho-educational, based on a range of behavioural approaches none are universally endorsed and applied. The Scottish Intercollegiate Guidelines Network (SIGN 2007) guidelines do endorse parent-mediated programmes along with early intervention for the promotion of communication skills; occupational therapy offered in Scotland through the main assessment and diagnosis centres in Glasgow and Edinburgh and behavioural therapy may be considered for specific behaviours such as self-injury or aggression as well as to support daily living and social skills (SIGN 2007).

There is little available specifically for young people with AS. Cognitive Behaviour Therapy (CBT) in an adapted form has been explored as a possible intervention for anxiety and depression (Sofranoff et al. 2005) but results so far are inconclusive; as with all interventions with this population, it may work to some degree with some individuals. (Judith Gould Director Autism Radio 4 interview 11.6.10)

Transitional stages are reported as particularly difficult times for young people with ASD. As a developmental disability, not a learning disability or a mental health problem, many people with ASD and particularly those with AS or HFA fail to meet the criteria for available services (NAS 2010)

Prescription pharmaceutical medications for children or young people with ASD



are controversial; a few are cautiously endorsed and with caveats (Volkmar et al. 2005, SIGN 2007; Howlin 1998) There are anecdotal reports that prescription medication is commonly given in the UK, especially for problematic behaviours, such as the antipsychotic Risperidone, sometimes given in response to aggressive or self-injurious behaviours but there is lack of evidence on the long-term effects in children and unwanted effects can be severe (Volkmar et al. 2005).

Adolescents and young adults with AS may receive pharmacological treatment for anxiety or stress including the anti-depressant selective serotonin reuptake inhibitor (SSRI) Fluoxetine, about which there is little evidence in terms of both efficacy and long-term safety, and Methylphenidate (Ritalin) for hyperactivity. Melatonin is sometimes used to treat sleep problems although it is also not licensed for public access in the UK and again, carries concerns regarding long-term effects (SIGN 2007). Accordingly, exploring alternative interventional approaches can be seen to be essential in the treatment of anxiety in this group.

#### *1.4.2.5 The use of WHM and AS*

Isolating what the huge upsurge in public interest in CAM therapies that has taken place over the last two decades (Fulder 1992; Mills & Budd 2000) means for the practice of WHM in the UK now is problematic. Consumer market surveys and academic research studies tend to amalgamate therapies from different modalities, for example homeopathy and WMH, or WMH and TCM, or are geared towards 'Over-the-counter' (OTC) products, or both (Mintel International Group 1995; Ross et al 2006; Guo et al 2007; Mintel International Group 2009).

Ross et al. (2006) surveyed the prescribing of "homeopathic/herbal" (sic) remedies in primary care in Scotland. Ross does not differentiate these two different therapeutic modes nor explain how many, if any, of the primary care providers included hold concurrent qualifications in Homeopathy or WMH.

A Threshold survey study of 2001 showed that nearly 20% of the UK population had purchased herbal remedies 'over-the-counter' (OTC) in the previous 12 months and approximately 32% in their lives. In 1998, when the survey was conducted, that would equate to around 20 million people having purchased OTC herbal products. Less than 1%, however, admitted to visiting a herbal

practitioner in the previous 12 months, 4.4% in their lives (Thomas et al. 2001) demonstrating a discrepancy between levels of interest in, and use of, herbal medicines and people consulting trained practitioners before using herbal remedies for themselves or their families. However, with the opening of BSc training courses across the UK at the beginning of the century, numbers of available practitioners has also increased dramatically over the last ten years which may well influence the number of consultations taking place currently.

Research from North America indicates that higher numbers of families with children with neurodevelopmental disorders, such as autism, turn to CAM therapies. (Levy & Hyman 2003, 2005, 2008; Golnick & Ireland 2009) In a survey of 3 private practices in New York and Jersey, around 95% of participant parents, (n=77) had used some form of CAM therapy for their ASD child (Harrington 2006). In another survey of 112 families, 74% were using complementary and alternative medicine (CAM) for their child with ASD (Hanson et al. 2007). Again, however, the term CAM in both the studies cited, includes a widely disparate range of modalities and definitions are unclear in relation to WHM. Nor are demographic differentials, such as socio-economic factors, related in these statistics.

Figures relating to CAM use overall show that users are predominantly female and from higher income brackets. Although in general I would say that twelve years experience of clinical practice does support these figures, it would not be true to say that all my patients fit those criteria. I have over the years treated a proportionately significant number of men, and many people of both sexes who have obviously had to make a financial sacrifice to enable attending a private practitioner.

CAM use for children with ASD has been described as including: supplementary multi-vitamins, essential fatty acids, melatonin, probiotics, withholding or delaying immunisations, chelation therapy, anti-infectives and secretin (Levy & Hyman 2003). Levy and Hyman's (2003) study was based on a review of 284 case charts drawn up at regional autism centre located within a children's hospital in USA and found that more than 30% of the cases studied involved the use of CAM, as defined by the authors. However, clarification was not given as to what these headings encompass, for example, if therapeutic herbs such as

*Echinacea angustifolia* are included under the heading of 'anti-infectives' or if such remedies would be purchased OTC or accessed through professional practitioners. Additionally, listing 'withholding or delaying immunisations' as a CAM 'therapy' is fundamentally misleading and especially when professional practices such as WHM are perceived as being encompassed by the term 'CAM'.

Wong and Smith's (2006) survey of CAM therapy use by parents for their ASD children does break down the data into individual approaches, but differences in practice and access in Canada, where the study was conducted, is reflected with WHM not listed as a discrete modality although possibly hidden within the heading of 'Naturopathy'. Numbers in this study are small, only 50 children in each group, those with ASD and the control.

Chronic illness, in adults and children, has been associated with higher CAM use than the general population (Cuzzolin et al. 2003; Wong & Smith 2006). Reflecting this figure perhaps the most notable point about Wong and Smith's (2006) survey is that over 50% of the parents in the ASD group taking part reported using, or having used in the past, at least one non-mainstream therapy for their child, as opposed to 28% in the control group.

Parents with children with ASD in Wong and Smith's (2006) survey were reported as primarily turning to CAM therapies as part of a general health maintenance or disease prevention strategy, rather than to treat specific symptoms. However, within the paper, the figures reveal concentration, relaxation, sleep disorders and gastro-intestinal symptoms, among others, to all be higher in terms of specific parental goals than general health.

No research into the use of WHM specifically for children and young people with ASD or AS is available, apart from the MSc study previously discussed (Stewart 2004). One paper was found that did not fulfil the literature search inclusion criteria but because of its relevance is mentioned here. Mendel (2004) argues that WHM is a particularly suitable mode of intervention for young people with AS and describes AS as being potentially a 'niche' for herbal medicine. Experiences of treating two adolescent boys with AS within a clinical practice are described and the successful outcomes perceived in alleviating anxiety in both cases (Mendel 2004).

That families in the UK containing members with ASD turn to therapies not available on the NHS (Le Breton 2001), including herbal medicine (Stewart 2004), is reported (MRC 2001). Some alternative or complementary approaches are listed in reviews and best practice guidelines such as those published by the Scottish Intercollegiate Guidelines Network (SIGN) (2007).

The use of vitamin and mineral supplements, EFA supplementation (Richardson 2003, Portwood 2004) and dietary modification, such as the gluten-free/casein-free protocol (GF/CF) (Le Breton 2001; Knivsberg et al 2002; Shattock 2002), are all interventions that may be included within or supported by a course of professional WHM (Stewart 2004). SIGN reviews the use of melatonin and the GF/CF diet in its main document while Herbal medicine is listed as a non-reviewed item in Appendix 3 (SIGN 2007). The British Medical Journal (BMJ) 'Best Practice' review of interventions for AS include the GF/CF only, and illustrate the lack of evidence available on all other forms of 'non-drug' treatments (BMJ 2010).

This is perhaps the most cogent illustration of a key issue: many families with children with ASD, including Asperger's syndrome, are likely to at least try some element of what might be available as WHM. However, they may do so not necessarily within a professional context and with professional trained guidance. OTC 'herbal' products, mineral and vitamin supplements, 'detox' regimes and the gluten-free/casein-free dietary protocol are promoted to parents of children with ASD in magazines, newspapers, on the internet and in books (Shaw 2002). Lack of awareness of the difference between such interventions and what would be offered within a professionally constructed course of western herbal treatment is of concern. There are no best practice guidelines available in this area which would support access to trained and professional levels of help.

#### *1.4.2.6 Reasons for the use of WHM*

The recent increase in public demand for herbal medicine has not been accompanied by a large-scale rejection of biomedicine. Popularity for alternative approaches to healthcare may be usefully understood as a public demand for a level of medical pluralism, with consumers having access to both biomedicine and non-biomedical therapies (Siahpush 1998, Nissan 2009). Although

resurgence in popularity for what is viewed as 'natural medicine' (Evans 2009) has been associated with the rising disillusionment with biomedicine, and also by a new emphasis on patients' rights (Baer, 2001; Griggs, 1997; McKee, 1988; Saks 2003), rather than the replacement of one medical monopoly with another, consumers want access to a range of options and commonly combine health modalities (Sharma 1992; Kelner & Wellman 1997; Thomas et al. 2001; Evans 2009) This has led to the term 'smart consumers' coined by Kelner and Wellman (1997), people who address specific health complaints by drawing on a pragmatic form of medical pluralism (Sharma 1992) and demonstrate a lack of loyalty or commitment to any healing modality (Evans 2009).

The most frequent reasons cited for looking beyond biomedicine include chronic, painful and non-life threatening illness which biomedical treatment has failed to address (Kelner & Wellman 1997; Cant & Sharma 1999; Mitzdorf et al. 1999). Concerns over potential toxicity and the iatrogenic effects associated with biomedicine are also cited (Vincent & Furnham 1996; Astin 1998; 2000; Furnham & Vincent 2000; Kelner et al. 2000; Schneirov & Geczik 2003; Conboy et al. 2007). Users also value the more participatory relationships with their practitioner, practitioners' emphasis on listening and the opportunity to spend more time in consultations – a typical first consultation with a WHM for example lasts for about an hour - than in biomedical healthcare situations (Sharma 1992; 1996; Mercer & Reilly 2004; Xing & Long 2006; Conboy et al. 2007). Within these may be specific reasons for choosing WHM and by specific groups.

In Thomas et al.'s (2001) UK study, and in line with figures on CAM use overall, a higher percentage of women than men had consulted an herbal practitioner (12.5% to 8.8%) and purchased OTC herbal remedies (33% to 12%). These findings may reflect the position of women as primary healthcare providers within family and friendship networks who were buying not only for themselves but also for their children and male partners or other family members (Nissan 2009).

This thesis is not concerned with theoretical positions on the use of WHM but in describing the experiences of a particular population of WHM users. The reasons for any individual choosing one, or a combination of therapeutic modalities, to address their healthcare concerns, are likely to be multiple and

complex and situated within a range of contextual factors, social, historical, economic. Questioning of conventional criticisms that CAM use is dictated by parental desperation in developmental disabilities, such as Down's syndrome, has found alternative narratives of advocacy, and disability rights (Prussing et al. 2005). In the case of AS, available evidence on existing treatments for anxiety specifically in relation to efficacy and side effects is discouraging and theories as to motivation in this population to seek alternative strategies would not be difficult to formulate in this context. Hanson et al's. (2007) questionnaire survey of 112 families with children with ASD cites concerns among parents with the safety and side effects of prescribed medications as the main reason for choosing alternatives for their children.

## **1.5 Conclusion**

In this thesis I have aimed to neither establish a prescriptive protocol for the use of WHM with AS nor to prove the efficacy of any particular herbal treatment. Nor do I propose a sociological model within which to examine the practice of WHM. This thesis seeks to offer insight into experiences of western herbal treatment as it is really practised and experienced by a particular group of patients, in this case, girls with AS, their mothers and the professional herbalists consulted.

### **1.5.1 Thesis Structure**

#### *1.5.1.1 Chapter 2 The literature*

In order to pursue the research aims, existing research literature was examined. Chapter 2 includes a description of the search strategies used, a discussion of what was found and identifies areas of deficit in the research literature which this study aims to address.

#### *1.5.1.2 Chapter 3 Methodological Issues*

Research questions arising out of the literature search are identified in Chapter 3 and appropriate means of answering them discussed. Qualitative research inquiry, while encompassing multiple methods and approaches, is located in the lived world of the participants. The qualitative researcher uses interpretive practices that seek to understand human experience and the meanings brought by the individual to their experience. (Denzin & Lincoln 2005) The aim of phenomenological research is to construct new understanding from the multiple

perspectives of those involved and to provide greater illumination of what is studied from within those perspectives; it makes room for differences, multiplicity and the voices of 'those on the margins'. Phenomenological research therefore lends itself to exploring any mode of health intervention from the perspectives of patients, carers and practitioners. Different approaches to phenomenology and their application within this study, along with how questions concerning rigour and ethics in researching are addressed, are detailed in Chapter 3.

*1.5.1.3 Chapter 4* describes the findings of the study, presented as examples of the case, each example consisting of one girl with AS, her mother and the WMH involved. In this presentation, rich text description is embedded in the authentic voices of the participants with extensive verbatim quotation included. The findings from the IMS interviews are also presented.

*1.5.1.4 In Chapter 5* an analysis, carried out in accordance with Hermeneutic Phenomenological methodology, of the findings described in Chapter 4 is discussed in relation to the literature.

*1.5.1.5 Chapter 6* concludes the thesis and offers a summary of this study's contribution to the areas of research included and recommendations for future research directions

## **Chapter 2 The Literature**

### **2.1 Introduction**

The aim of this study is to describe the lived experiences of girls with AS and anxiety undergoing a course of WHM. This chapter presents the literature search strategy, relevant literature and provides a critical review.

To clarify presentation of the literature, this chapter has been divided into 3 parts, as outlined below.

#### ***2.1.1 Literature: Initial Search Strategy***

The first part of this chapter describes the initial literature search, databases and terms used, inclusion and exclusion criteria and results. As the study progressed and in response to the initial lack of relevant research literature, the original searches were repeated; relevant papers found are included in this chapter. Additional papers that emerged throughout the process of the research study have also been considered.

#### ***2.1.2 Literature: Theoretical perspectives on developmental differences in ASD and AS, the causes and consequences.***

In order that the experiences described may be understood within the social and medical contexts in which they occur, literature on ASD and AS within these areas was examined. Accordingly, the second part of this chapter is used to explore theories of aetiology in the ASDs, and AS specifically, and their implications for mental health, in terms of both experience and intervention.

#### ***2.1.3 Literature: Interpretive studies of adolescent girls with AS.***

Additionally to the search protocol first used, a further search was instigated, for interpretive studies of experiences of young and adolescent girls with anxiety, initially and then adolescents generally, with AS. The third part of the chapter presents a discussion of the relevant interpretive studies found. There then follows a summary overview and conclusion to the chapter.

### **2.2 Key literature sources**

This current study is set in Scotland, therefore, particular reference is made to information sourced in Scotland where available such as the review of literature on ASD and AS by Marwick et al. (2005) as cited below. However, due to the



nature and scale of the subject, and the limited amount of published research in any of the key areas involved - girls with AS; anxiety in children and adolescents with AS and WHM - literature published in English from other locations has been considered, with acknowledgement that there may be elements of environmental and cultural difference. In particular is noted that WHM as defined for the purposes of this thesis is not practised in North America. Naturopathy is the main 'holistic' or 'vitalist' mode of practice in the USA, Canada, and is practised in Australia, and includes the prescribing of herbal-based medicinal products. Alternatively, herbal medicine is prescribed legitimately in parts of Europe, for example Germany, by mainstream medical practitioners such as GPs but is otherwise illegal, whereas throughout the UK the practise of WHM is carried out by trained practitioners as defined in Chapter 1.

Similarly, literature available in English from the USA, Europe and other parts of the world on ASD and AS was considered, with the understanding that cultural differences may be inherent to the perspective taken. In the USA, for example, issues of diagnosis may be weighted by the potential of additional resource allocation or impact on health insurance.

Literature reviews carried out on behalf of specific UK professional bodies reflected the scope and extent of this review, in particular the Medical Research Council (MRC) *Review of Autism Research* (2001), the Public Health Institute of Scotland (PHIS) (2001) *Autistic Spectrum Disorders, Needs Assessment Report* and the National Centre for Autism Studies (NCAS) *Literature Review of Autism for HM Inspectorate of Education* (Marwick et al. 2005). For information on the relevant perspectives and theories in ASD and AS such as aetiology, mental health consequences and potential intervention strategies, as outlined in the second section of this chapter, academic and scholarly publications by clinicians and researchers such as Wing (1971, 1981, 1996), Frith (1986, 1989, 1991, 2004), Trevarthen (1996, 2002), Gilberg (1998, 2001, 2002), Vermeulen (2001); Aston (2005) and Attwood (2006) were utilised. Key texts such as Volkmar et al.'s (2005) *Handbook of Autism* are referred to.

Additional material has been included throughout this study in the form of personal accounts by adults with HFA or AS. Most authoritative and scholarly texts include such accounts in their list of references; for example, Temple

Grandin's *Emergence: labelled autistic* (1986), *Pretending to be Normal* by Liane Holliday Willey (1999) and Claire Sainsbury's *Martian in the Playground* (Sainsbury 2000).

Lived experience research is closely allied to narrative enquiry, which places experience in the foreground. Research analysis and interpretation is shaped by 'our own narratives of experience' (Connelly & Clandinin 1999). In keeping with the methodological approach taken in this thesis and its philosophical underpinnings, such autoethnographic accounts are included in order to engage and enable both researchers and readers to build a "cross-cultural coalition" between self and others (Chang 2008). Autoethnography and narrative enquiry are increasingly incorporated into qualitative research, but are accompanied by questions concerning validity and worth (Krizek 2003). To avoid pitfalls of over-reliance on the personal (Chang 2008), auto-ethnographic or autobiographical accounts are used as additional sources of information and as a means of enriching other academic or clinically focussed work.

### **2.3 The searches**

The literature review is presented with reference to Cooper's (1988) Taxonomy of Literature Reviews. Initial focus was on research outcomes, with a view to implications for clinical application and included peer-reviewed study papers on the use of western herbal treatment for symptoms of anxiety in girls with Asperger's syndrome.

An initial literature search was carried out through OVID of Embase, Medline, CAB, CINAHL and Psychinfo. Key terms Autism, autistic disorder, Asperger, Asperger syndrome, Asperger's syndrome, anxiety, anxiety disorders, generalised anxiety disorder, and herbal medicine were used. Studies of the medicinal herb, *Hypericum perforatum* or St John's Wort and its potential use in anxiety or anxiety disorders as a single medicine, have been enough to warrant a Cochrane review (Millward et al 2004) and *Hypericum* was added as a search term in order to provide a benchmark but the results are not relevant to this study. With nothing initially found, 'girl' and 'female' were removed from the search terms and the search redone.

There were two parts of the initial literature search. The first included autism, AS, herbal medicine and anxiety using CINAHL, CAB and EMBASE. The

second set was for autism and anxiety only using Medline, and Psychinfo. The strategy for each database search including date range and key terms is presented in tables 1 - 5 below. The search was rerun periodically during the course of the study, up until March 2010.

### **2.3.1 The initial search strategy Part 1: Autism Spectrum Disorder, Asperger's syndrome, Herbal Medicine and anxiety.**

Inclusion and exclusion criteria and results for ASD/AS, herbal medicine and anxiety were as follows:

#### **Inclusion criteria**

- peer reviewed outcomes study of western herbal treatment for anxiety

#### **Exclusion criteria**

- non-peer reviewed
- not available in English

Keeping to the forefront the question asked in this study, the abstracts of the results were assessed. Papers within the inclusion criteria relating to the question were sought. Papers that were too broad or not relevant (eg "A CAM approach to anxiety", "Cross-cultural herbal medicine and the Victorian Foundation for survivors of torture") or that did not meet the criteria, ie, no version in English, non-peer reviewed were excluded. On the basis of these, there were no papers available for review. An update to this search within the same parameters was carried out in 2010, with nothing further to add in this area.

#### **2.3.1.1 Research in WHM**

Academic research into herbal medicine is established in clinical and pharmacological studies which aim to determine the efficacy and safety of individual medicinal plants for medical use (Ernst 2000; Mills & Bone 2000; Mills 2005). Practitioners of WHM seek to find evidence for the effectiveness of professional herbal practice (Green et al. 2007; Nissan 2009). Issues of how the efficacy and safety of medicinal plants and herbal medicine can be evidenced in contemporary terms are of concern (Whitelegg 1994; Vincent & Furnham 1997; Mills 2002; Green et al. 2007) while claims of the effectiveness of herbal medicines are often founded on a long history of the traditional use of plants in

the prevention and cure of ill-health (Griggs 1981; Mills 2002; Nissan 2009). Most recently, practitioner herbalists and researchers have turned attention to issues arising from the 'modernisation of herbal knowledge' (Nissan 2009) (VanMarie 2002; Conway 2005; O'Sullivan 2005; Jagtenberg et al. 2006; Singer and Fisher 2007; Evans 2009).

Table 2 Search strategy using EMBASE 1980 to April 2006

1	term	exp *Autism/ or exp *Asperger Syndrome/	7216
2	term	exp *ANXIETY DISORDER/ or exp *ANXIETY/ or exp *GENERALIZED ANXIETY DISORDER	43903
3	1 and 2		117
4	from 3 keep 1-117		117
5	term	exp *Herbal Medicine/	3356
6	term	exp *HYPERICUM/ or exp *HYPERICUM PERFORATUM/	247
7	5 or 6		3575
8	3 and 7		0
9	1 and 7		0
10	2 and 7		22
11	from 10 keep 1 - 22		22

Table 3 Search strategy using CINAHL 1982 to April 2006

1	term	exp *Autistic Disorder/ or exp *Asperger Syndrome (abstract, title, original title, broad terms, heading words)	1375
2	term	exp *Anxiety/ or exp *Anxiety Disorders (abstract, title, original title, broad terms, heading words)	5598
3	1 and 2		8
4	from 3 keep 1-55		0
5	term	exp *Medicine, Herbal	1624
6	3 and 5		0
7		exp Hypericum	208
8	3 and 7		0
9	2 and 5		33
10	2 and 7		0
11	from 10 keep 1 - 11		0
12	term	exp clinical trials	36495
13	5 and 12		95
14	from 13 keep 1-11		11
15	from 3 keep 1-8		8
16	from 9 keep 1-33		<b>33</b>

Table 4 Search strategy using CAB 1973 to March 2006

1	term	asperger* (abstract, title, original title, broad terms, heading words)	25
2	term	autis* (abstract, title, original title, broad terms, heading words)	111
3	1 or 2		131
4	term	anxiety	725
5	3 and 4		2
6		exp herbal drugs	6867
7		exp Hypericum	1659
8	6 or 7		8308
9	3 and 8		0
10	4 and 8		36
11	from 10 keep 1 - 36		36

Two PhD theses were completed in 2009, using qualitative approaches, being the first from within the profession. (Evans 2009, Nissan 2009) They each locate contemporary practice of WHM within a sociological framework, describe experiences of WHM practice and provide context and direction for further research in this area (Evans 2009; Nissan 2009).

By highlighting two different paradigmatic positions within which modern herbal practitioners are expected to operate, which she has labelled as 'biomedical' and 'alternative', Nissan (2009) positions herself within a post-modern perspective. Nissan's feminist perspective simplifies the history of medicine to a history of these two headings. There is a lack of clarity, within this perspective, on the vast array of different practices or philosophical underpinnings, contained within the term 'alternative' although Nissan does acknowledge there are differences contained within the term. Nor does Nissan address issues of socially constructed health inequities beyond those of gender (Oakely 1992). However, what Nissan (2009) has done, along with Evans (2009), cogently and from an 'insider's perspective', help to contextualise the current practice, and use, of WHM.

Western Herbal Medicine is carried out in the UK from within a range of ideologies and practices (Nissan 2009; Van Marie 2002) while concepts of 'holism' are widely described as being at the root of professional WH practice. Clinical practice includes holistic approaches to ways of knowing as well as 'being practical' (Van Manen 1977), the phenomenology of WHM (Mills 1991).

Nissan (2009) has reported that WMH practitioners demonstrate a number of different ways in which they understand the principle of holism in the context of their practice. Concepts of holism include approaches to somatic symptoms as interlinked within the whole human organism and therefore the consultation includes as thorough an interrogation of all the physiological systems as feasible. 'Holism', however, in WHM, also refers to the contextual nature of the individual's symptomatic presentation and 'holistic' as concerning their total social environment (Saks 1992).

The discursive nature of the clinical consultation may be understood as a hermeneutical process through which patient narrative is analysed as text, each section explored for its meaning, then related to all the other sections and back to the whole story (Gadamer 1989; Outhwaite 1996). Practitioners' interpretive, narrative selves are embedded in the situated actions and interactions of their consultations (Atkinson 1990; Birch 1998). This process is not distinct to WHM (Usherwood 1999), but practitioner preconceptions informing interpretation of the patients' stories possibly are, the text critically understood as the answer to a different question (Gadamer 1989).

There are attempts within WHM to redress the 'assymetry of power' (Usherwood 1999) inherent in a clinical consultation. WMH aim at facilitating their patients' ability to make informed choices through providing education, with 'increasing self-knowledge and self-care', 'improved quality of life' and 'growing control over body, health and/or life' (Nissan 2009). Such aims are closely allied to concepts of empowerment in mainstream healthcare (Freire 1970; Rappaport 1981; WHO 1986; Clark & Krupa 2002; Herbert et al 2009).

Treatment strategies are constructed within WHM with the intention of acknowledging individual lived experience, to promote autonomy in healthcare and personal change, perceived as offering an alternative to an increasingly state-mediated 'niche standardisation' (Epstein 2010) with its related issues of inclusion and marginalisation within modern health-care 'biopolitics' (Foucault 1980 a & b). Patient experiences resonate, in Nissan's study, with the WMH practitioners' values, their distinct aims and the 'three-fold treatment strategies' they adopt (Nissan 2009).

In Evans (2009) thesis she describes WHM as seen from the perspective of her place as a practitioner and lecturer working in South West Australia. Evans explores the historical and philosophical background to current tensions within the practice of CAM generally, but WHM specifically, and argues that herbalists (in the UK as in Australia) were marginalised more than a century ago as a result of a particular combination of cultural circumstances involving the economy, the State, and the interests of competing groups of professionals. Its subsequent move towards mainstreaming is similarly consequent to a change in those cultural circumstances. (Saks 1992; 2003; Kelner et al 2000; Kelleher et al 2006)

Evans identifies, in her thesis, a deficit of research studies into contemporary experiences of WHM as practised. This current study aims to address this deficit.

### **2.3.2 The initial search strategy Part 2: Autism, Asperger's syndrome and anxiety**

The second part of the initial search using only the terms Autism, Asperger's syndrome, anxiety and anxiety disorders are described below. Inclusion and exclusion criteria and results for ASD/AS and anxiety:

#### **Inclusion criteria**

- peer reviewed research study papers

#### **Exclusion criteria**

- non-peer reviewed
- not available in English

Similarly to the first search, papers initially within the search criteria were then examined and where too broad or not relevant (eg "Scientifically unsupported and supported intervention for childhood psychopathology" or "OCD symptoms in parents of Tourette syndrome probands or autism spectrum probands") were not included for this review.

The results were revealing as to the paucity of information on a number of fronts – girls with Asperger's syndrome as a discrete population requiring focussed consideration; anxiety in adolescents with AS generally and specifically girls with AS. With nothing initially found, 'girl' and 'female' were removed from the search terms and the search rerun.

Table 5 Search strategy using Medline (R) 1966 to April 2006

1	term	exp *Autism/ or exp *Asperger Syndrome	9366
2	term	exp *ANXIETY DISORDERS/ or exp *ANXIETY/	54830
3	1 and 2		62
4	from 3 keep 1-62		62

Table 6 Search strategy using Psycinfo 1967 to April 2006

1	term	exp *Autistic Disorder/ or exp *Asperger Syndrome	7034
2	term	exp *Anxiety/ or exp *Anxiety Disorders/	41628
3	1 and 2		55
4	from 3 keep 1-55		55

Out of the 2<sup>nd</sup> phase search of peer reviewed journals, four papers were retrieved that reported on research into anxiety in children and adolescents with AS. With one being an article based on clinical experience, three were appraised. These papers were:

1. Kim JA, Szatzmari P, Bryson SE, Streiner DL and Wilson FJ (2000) The prevalence of anxiety and mood problems among children with autism and Asperger syndrome *Autism* 2000; 4; 2; 117-132
2. Gillot A, Furniss F. and Walter A (2001) Anxiety in High-Functioning Children with Autism *Autism* 2001; 5; 277
3. Russell E. and Sofronoff K. (2005) Anxiety and social worries in children with Asperger syndrome *Australian and New Zealand Journal of Psychiatry* 39 (7), 633 -638

The same search carried out subsequently revealed one further study carried out in Australia (Farrugia & Hudson 2006) which however contributed nothing further to the discussion. In 2009 a review of the available research literature on anxiety in children and adolescents with ASD was published which is included for discussion below:

4. White SW., Oswald D., Ollendick T. and Scahill L. 2009 Anxiety in



Other papers found which did not fit the inclusion criteria, but which for the purposes of this study were particularly relevant, and given the paucity of available literature, were also considered. A study found in the general research process deemed particularly relevant, although not having a title that fitted the search criteria, has also been included for discussion, being:

5. Meyer JA., Mundy PC., Vaughan Van Hecke A. and Durocher JS. (2006) Social attribution process and comorbid psychiatric symptoms in children with Asperger syndrome *Autism* 2006; 10; 383

#### *2.3.2.1 Discussion and critique of the results*

The studies raise notable questions in relation to researching with children and young people with AS (or HFA) and also in relation to prevailing theories and debates on the nature of anxiety in this population.

The nature and role of anxiety in autism has been long debated. Kanner (1943) suggested that many of the core features of autism, for example, insistence on sameness and fixed behaviours, need for routine and obsessions found in ASD, were anxiety driven. Researchers and clinicians have subsequently considered anxiety as both a possible consequence of, and a possible cause of, aspects of the behaviour of children with autism (Gillot et al. 2001). Schopler et al (1998) suggested that resistance to change in autism is due to difficulty in understanding what is happening in the environment with a consequent feeling of constant uncertainty. Other authors have viewed some features of autism as mechanisms for coping with the anxiety induced by this primary difficulty in comprehending the environment. Stereotypical behaviours such as echolalia, twirling, rocking, flicking and hand flapping (Howlin, 1998) or behaviours such as repetitive questioning (Thomas et al., 1998) often increase when children are distressed or anxious, suggesting that these behaviours may act as self-calming strategies for children with autism. Engagement in obsessions and rituals therefore has been perceived as a coping strategy for keeping anxiety under control (Howlin 1998).

The studies examined highlight the lack of previously established research in this field in many aspects. Lack of consistency in the diagnostic protocols

applied in relation to PDD, HFA and AS cause difficulties in research design. The inclusion criteria stipulation imposed by Kim et al. (2000) for example, that AS had to mean ASD along with delayed or unusual language development, does not concur with the DSM IV diagnostic criteria. The fact that this study was based in Canada may have influenced definitions the children defined as having AS in their study would not necessarily be defined as such by others.

Questionnaire data was used in Kim et al.'s study with questionnaires adapted from existing tools and standardised to a community sample of 1751 children which they then used to draw a comparison against. The cohort of 59 ASD children, age range 9-14 yrs, with AS (19) and high functioning autism (40), (as defined by Kim et al. 2000) was selected through multiple assessment centres at the ages of 4-6 years with the follow-up assessment taking place 6 years later.

Establishing differentials for categories of ASD, specifically between HFA and AS, or in predictive risk factors, such as early autistic symptoms as described above, for the later development of affective disorders such as anxiety and depression were not achieved, although that a substantial proportion of their ASD cohort scored higher than control and clinically significant levels on the chosen scales, including depression and generalised anxiety, was found.

Some investigators have cautioned that diagnosing affective disorder in this population may be difficult owing to a limited ability to communicate emotions both verbally and through facial expression (Ghaziuddin et al.1995). This would not be inconsistent with later reports that anxiety and depression have been proposed as being more prevalent in HFA or AS than ASD generally, a suggestion that remains under scrutiny. Children with AS in Kim et al.'s (2000) study were not found to have higher levels of anxiety and mood problems than other high functioning PDD; their findings also go against the theory that the greater verbal language ability associate with a diagnosis of AS would lead to greater ability to verbally express themselves; early language skills were not found to be predictive of later co-morbid problems or perhaps more cogently, reported prevalence is not necessarily a reflection of the ability to express feelings of anxiety or sadness. The hypothesis that early repetitive stereotypical

activities, would correlate with later evidence of co-morbid anxiety disorders, was not found to be the case.

Theories as to the predictive nature of early cognitive and language skills were not confirmed but neither were previous reports suggesting anxiety and mood disorders to be associated with being female and lower functioning. The study by Kim et al (2000) was, at the time it was carried out, the only longitudinal outcome study of an inception cohort of children with ASD and AS and it was the only study to have systematically investigated the prevalence of co-morbid psychiatric problems against a general population.

It used questionnaires adapted from existing tools and standardised to a community sample (n=1751) which was then used to draw a comparison against. The main tool used was the Ontario Child Health Study Scales - Revised (OCHS-R). (Boyle et al. 1993) The ASD cohort (AS n=19; HFA n=40) was selected through multiple assessment centres at the ages of 4-6 years with the follow-up assessment taking place 6 years later.

The authors sought to test at least the lower functioning aspect of the above hypothesis through exploring any possible correlation between language ability and the development of affective disorders. Such a correlation was not confirmed and the numbers of girls involved did not allow for any conclusions. Findings in relation to girls in all the studies examined were unhelpful. Gillot et al.'s study (2001) had only two girls in each group (ASD, Specific Language Impairment (SLI) and normally developing). Russell and Sofranoff (2005) did not differentiate results for girls; Meyer et al. (2006) did detail numbers of each sex in their study, but again, had no discussion specific to girls.

The study by Gillot et al. (2001) aimed to establish the role of anxiety in autism in the context of the prevailing theories, whether anxiety is a primary characteristic in children with the disorder or a secondary consequence to the social challenges experienced by them. 15 children with HFA were matched for age and gender with 15 children with SLI and 15 normally developing children. The results were not conclusive in several areas of their enquiry, as follows. Although in their study the children with HFA were found to have higher levels of anxiety in some areas than both their control groups, they did not in general report levels of anxiety commensurate with clinically defined levels. Additionally,

they had comparatively high levels of anxiety in certain areas ie separation anxiety, panic (with or without) agoraphobia, physical injury fears and OCD but, against expectation, not social phobia or generalised anxiety disorder.

The children in the HFA group scored higher levels of social worries than either the SLI or normally developing group in the pupil version of the questionnaire; the parents reported considerably higher levels in their children than the children did themselves. These findings were at odds with the results for social phobia; however, the two subscales measure different aspects of social concerns. The Spence Children's Anxiety Scale (SCAS) (Spence et al. 2003) social phobia scale relates to covert internal states such as worries about other peoples' opinions, whereas the Social Worries Questionnaire (SWQ) (Spence 1995) social worries scale asks questions relating to actions, such as going to parties or asking other children to play with them.

The authors concluded that discrepancies between the subscale reports on social phobias and social worries are minor and that children with HFA overall demonstrate elevated levels of anxiety about social situations whether on a ruminative level or through active avoidance. What the authors are unable to consider, however, is whether reported avoidance of certain social situations is due to social anxiety or is made by choice from personal preference ie because the children's sensory and perceptual characteristics mean that situations involving high volume noise, casual intrusion into personal physical space and being expected to eat unpalatable foods are something they prefer to avoid. Nor are they able to derive any insight into what causes the anxieties reported.

The stated objective of Russell and Sofranoff's (2005) study was to examine anxiety and social worries in a group of children with Asperger syndrome. The participants were recruited on the basis of parent-reported anxiety and were part of a larger study to evaluate an anxiety management intervention carried out in Queensland, Australia, being Cognitive Behavioural Therapy (CBT). Diagnosis of AS was confirmed and included children were then assessed using the same scales as in Gillot et al.'s (2001) study, being SCAS and SWQ, as before. The results were compared to existing data on normally developing children, children previously diagnosed with Social Phobia, and clinically anxious children from Spence (1997), Gillot et al. (2001) and Nauta et al. (2004). The main part of this

data was through parent reports.

The study only partially supported previous assertions that children experience more social worries than norm (Gillot et al 2001) and found that parent and self-reports diverged in relation to social skills and social worries, with children with AS rating themselves considerably higher in social skills than their parents (Russell & Sofranoff 2005). The authors propose that this is a consequence of the children lacking insight into their difficulties in contradiction to current prevailing theories that elevated levels of anxiety overall are caused in adolescents with AS by an increased self awareness.

This divergence in self and parent reports has been found in other studies, such as Meyer et al.'s (2006) study of the relation of social attribution processes to comorbidity in children with AS. 31 children with AS, aged 7 years 9 months to 13 years 9 months, 26 of which were boys, were compared with 33 neurotypically developing children of similar age. The groups were matched for verbal and non-verbal mental ages. In some aspects of the assessment, there were discrepancies between the parents and children with AS' reports, with children generally rating themselves as having higher social skills than did their parents. However, in line with other emerging literature (Gillott et al. 2001) the children themselves did report greater symptoms of anxiety and depression than the NT group in line with their parents' reports. They also reported higher rates of social anxiety and social stress.

Inconsistencies in the research evidence may be partly due to the age ranges involved. All the studies cited here involved children in a generally younger age range than in the current study. Clinicians report 11 to 12 years as being the key age range for children with AS beginning to develop the characteristic social and behavioural difficulties often leading to a diagnosis of AS (Ludlow 2004). It is possible that some of the children in the older ranges in these studies may have been experiencing difficulties due to their age rather than because of the intrinsic severity of their difficulties and furthermore, that the same cohorts assessed at a more advanced age may have manifested consistently different profiles.

Russell and Sofranoff (2005) found that children in their study with AS but without a clinical diagnosis of anxiety were reported as having higher overall

levels of anxiety than norm, commensurate with children in a comparison group with clinical anxiety in terms of level, but different in profile. The children with AS were reported by their parents as having higher than norm levels of overall anxiety, in contrast to Gillot et al's (2001) study, and with more obsessive-compulsive symptoms and physical injury fears than the clinically anxious.

These studies found higher than normal physical injury fears reported in the groups with ASD. This may be understood in the context of what is known about the sensory perceptual sensitivities often experienced by these children, discussed in the next section of this chapter. Distress caused by casual touch, the noise and general activity of the school environment combined with an increased risk of being bullied may be causal to increased anxiety and fear surrounding the possibility of physical injury (Russell & Sofranoff 2005). Obsessive Compulsive behaviours were also reported as higher than normal, by the children themselves. This suggests the children are indeed capable of insight and judgement as to their own difficulties (Meyer et al. 2006).

Depression is highlighted as an affective disorder in this population by Kim et al. (2000). A substantial proportion of the cohort of children in their study scored clinically relevant levels on the chosen scales, higher than the community sample used as control, including depression and generalised anxiety; such problems were found to have an important and negative impact on the lives of the children and their families. Anxiety and mood problems were, for example, associated with higher levels of aggression and impaired relationships with teachers, peers and family members.

Kim et al. (2000) also cite reports that children with ASD suffering from depression experienced significantly more life events in the preceding 12 months (i.e. change in group homes, change of education programmes, family sickness, bereavement etc.) than those who did not experience depression (Ghaziuddin et al. 1995 b). There is a suggestion then that children with ASD may react no differently than the general population when faced with negatively impacting life events. Additionally and consistent with this hypothesis, Ghaziuddin et al. (1995b) reported that ASD children who suffer from depression are more likely to have a family history of depression than non-depressed children with ASD. It is suggested, therefore, that mood and anxiety

problems in this population may be normal manifestations of environmental stressors. In relation to the three studies of anxiety appraised, the children in Gillot et al.'s (2001) study, for example, were matched for age and gender, but not for abilities or for family circumstances and neither of the other appraised papers discuss these potential influences.

Further methodological limitations were identified in these studies, such as lack of differentiation of ability within the cohorts. While I have included Gillot et al.'s (2001) study for the purposes of my literature review, despite the title relating to HFA and not AS, because of the relevance of its contents to my study, Kim et al. have extended this generic approach to cover the whole Autism Spectrum. All participants were considered to be of average intelligence, with all of the ASD and normal children attending mainstream school; 8 of the SLI children attended mainstream school and the others a specialist school for children with language disorders and average intelligence. However, the study groups were not matched for intelligence or other kinds of ability. The authors do not explain their criteria for diagnosis or clarify any differentials within the group. Nor were measures used to identify existing pathologies in the participants. Diagnostic limitations within Kim et al.'s (2000) study have already been discussed.

The theory that higher functioning young people with autism or AS are better able to articulate their anxieties and would therefore score higher in assessments than other young people with ASD has not been supported, although this would be difficult to do given the lack of diagnostic clarity involved. The associated theory that evidence of affective disorders could be used as a diagnostic marker remains likewise unconfirmed.

Overall, the often quoted belief (Attwood 2006) that the elevated levels of anxiety in AS relative to others with ASD are due to an increased self-awareness is not entirely supported by the available evidence in these studies which show mixed results. In fact, Meyer et al.'s (2006) observation that young people with AS vary in their self and social awareness seems the most astute. Nor have any alternative theories as to causes of anxiety and depression or any of the other mental health concerns identified in this population been upheld.

Russell and Sofronoff's (2005) study being carried out as part of larger scale research into an intervention (Sofronoff et al. 2005), while perhaps facilitating

ease of access to the participants may also have had an influence on the perspectives of the researchers. Preconceptions were noted as to the reliability of self-report measures with this population due to lack of insight into their differences. While these findings could be seen as confirming existing views that children with AS may lack insight into their social and emotional difficulties, the authors do not consider the parents may also experience elevated levels of anxiety, both in themselves, as people with a genetic connection to their children (Asperger 1944 from Frith 1991) and as parents of children with AS. Given its wider context, this study may represent a lost opportunity to explore what anxiety means to young people with AS, how they experience and express anxiety in their daily lives and therefore how they may best be supported.

Russell and Sofranoff (2005) conclude from their findings children with AS may lack insight into their difficulties and that parent reports are more accurate than the children's own. This is in contrast to Meyer et al.'s (2006) conclusions that such insight and self awareness is likely to be variable and that greater social awareness is associated with higher levels of anxiety. Furthermore, that for the more highly socially motivated individuals with AS, repeated experiences of rejection and other unsuccessful social interactions may contribute to the development of anxiety and depression.

The studies discussed above are included in White et al.'s (2009) review of the literature on anxiety in children and adolescents with ASD. Reports published between 1990 and 2008 which were considered within the context of three categories of aims, being 'prevalence', 'phenomenology' and 'treatment'. Those that specifically differentiate the diagnostic categories of ASD and AS, were in the first instance examining prevalence (Bellini 2004; Gadow et al. 2005; Melfsen et al. 2006; Sukhodolski et al. 2008); secondly, phenomenology (Pfeiffer et al. 2005; Weisbrot et al. 2005; Green et al 2000; Thede & Coolidge 2006; Williamson et al. 2008) and thirdly, treatment (Ozbayrak 1997; Namerow et al. 2003; Reaven & Hepbourne 2003; Sofranoff et al. 2005; Chalfont et al. 2006). The papers cited above were not individually appraised for the purposes of this study, other than those already discussed.

#### *2.3.2.2 Summary of discussion*

White et al's (2009) assessment of the available research concurs with the



findings of this review. These are: that anxiety is commonly prevalent in children with ASD, but with widely varying levels and profiles; that children and young people with AS may experience higher levels of anxiety than other sub-groups of ASD was found in some studies; that experiences of anxiety may be context-dependant and that reports from parents and teachers and self-reports often differ; that research in this area is still limited and the findings tenuous. Further, that there are no empirically supported treatments that specifically target the behavioural and emotional concerns presented by school-age children and adolescents with AS and very little research on alternatives to the limited pharmaceutical interventions (White et al 2009).

Limitations imposed by standard instrument questionnaires with this population are illustrated in all of the studies considered here. The discrepancies in parent and self-report parts of these instruments raise serious questions as to the validity of existing assessment tools using self-reports with this population to measure anxiety, a finding that has been paralleled in a survey of tools for the assessment of depression in ASDs (Stewart et al. 2006). Furthermore, and partly perhaps as a consequence, there is an ongoing deficit in understanding of what anxiety means for a child or young person with AS.

These studies do indicate that children and young people with HFA and AS suffer overall elevated levels of anxiety and other mood disturbances compared to a NT population, commensurate in level with children fitting criteria for anxiety disorders but with varying characteristics. They also illustrate how little is known on both how and why this is the case. There is a consequent lack of direction in relation to intervention strategies and how best to support these young people. Intrinsic to this lack is the question of appropriate methodological approaches to researching with this group. Assessment of anxiety in ASDs requires the development of appropriate modalities and to be conducted with the inclusion of multiple informants (White et al 2009). Lack of clarity might improve through more in-depth data, for example through interviews with parents and children. It is clear that there is an urgent need for further, including qualitative, research in this area.

## **2.4 Theoretical perspectives on developmental differences in ASD and AS, the causes and the consequences.**

As outlined in Chapter 1, clinical and academic ideas on the aetiology of developmental differences in ASD and AS are still largely theoretical. This section of the chapter has been constructed to provide a context in which to consider the research and its findings. The literature therefore is drawn from a number of different sources, including research papers and academic texts, autoethnographic sources such as books, and presentations. Additional academic texts on theories of child and adolescent development in the general population were also accessed. Authors such as Piaget, Erikson and Goffman are cited in relation to mental health concerns in adolescents in order to provide a contextual and comparative background to experiences of adolescent girls with AS in this study.

### **2.4.1 Cognition, perception and communication**

In the following, what is known and theorised about the differences in information processing in people with ASD and AS, the consequent responses and the implications for mental health are discussed.

“What is ASD? It’s not a behavioural syndrome, as there can be no definitive list of behaviours that people with ASD do (and people without do not). It is a (neuro) developmental phenomenon, but again, attempts to specify which developmental processes are always (and exclusively) affected have largely failed. Rather than behaviour or development, I think it’s helpful to focus on processing.” (Ludlow 2010)

#### *2.4.1.1 Cognition*

Presented initially as an explanatory model for cognitive differences in ASD, Theory of Mind (TOM) identifies the fundamental deficit in autism as failure of ‘thinking about thinking’ (Frith 1989). TOM refers to the ability of an individual to theorise about how another person might be thinking in a particular situation (and then to respond appropriately). (Baron-Cohen et al. 1985) TOM includes understanding of pretence, irony, non-literal language (bluffing) and deception (telling of ‘white lies’) (Hill & Frith 2003).

Dissenters have argued that the deficits of social interaction show in autistic children before the age when they would normally be expected to develop TOM (about two or three years old) (Trevvarthen et al. 1998) and that:

“...children do not develop, nor do they need, a ‘theory’ about the mental life of others. What children acquire is knowledge that other people have minds” (Hobson 1990b, p199 from Trevvarthen et al. 1998).

It has also been argued that only people with ASD, rather than NT (who use instinct and possibly ‘mirroring’) who are required to develop TOM in order to understand others’ intentions and feelings (Williams 2004). Certainly, TOM is not universally accepted as definitive to cause:

“Brain research does not support ... the hypothesis that the central deficit in autism is the lack of a cognitive capacity to ‘represent mental states’ [...] we cannot hope to localise a single mechanism in the brain for this functional disorder, because the whole of the human brain has been transformed in the evolution of a mind that has a need to develop by learning a culture – by education.” (Trevvarthen et al 1998 p116)

Verbal skills, at any age, may be implicated in individuals’ TOM ability (Happe 1994). However, Klin et al. (2003) argue that people with AS are only able to appropriately answer TOM problems in situations where the tasks are explicitly formulated, through the use of logical or verbal processing, and are unable to do the same in real life situations requiring identification of salient cues as to the problem to be solved. Social interaction requires instantaneous and intuitive responses to events too rapid to be decipherable through slow, sequential mental processing (Asperger 1944, Klin et al. 2005).

Frith (2004) has further argued that a milder impairment in TOM in people with AS may be a reflection of high verbal ability and intelligent reasoning being applied to problems posed in a research setting rather than social or empathetic responses. However, describing as ‘impairment’ the use of reason, high verbal ability, intelligence and logical inference to solve a problem in the absence of instinct or empathy is a value judgement. These qualities, approaches and abilities all have value and meaning in context and are held by people in both AS and NT populations to varying levels.

Furthermore, lack of socially motivated learning seen in another context as a deficit may facilitate individuals with AS in finding unique and innovative ways of solving problems. Negative interpretations of AS characteristics, such as those described in DSM-IV as 'repetitive behaviour or restricted interests' can be viewed as 'expertise' and 'detailed perception' for example, (Baron-Cohen et al. 2003).

Further cognitive theories based in concepts of executive functioning, have been developed, not inconsistent with TOM, including Weak Central Coherence (WCC) (formulated by Frith in the 1980s). Again, while people with ASD may be biased to focus on detail, they can also perceive global meaning (Rajendran and Mitchell 2003) and WCC is now considered to be a cognitive style rather than a deficit or dysfunction and part of a multiple deficit picture rather than a definitive one (Happe 1999 a, b; Happe & Frith 2006).

#### *2.4.1.2 Perception and communication*

Individuals with ASD often have differences, sometimes to a high degree, in perception. Heightened sensitivity to noise, in particular (Bogdashina 2003; Williams 1998) and unusual responses to foods (Le Breton 2001) or being touched, by people, things or materials is widely reported by clinicians (Volkmar et al. 2005; Attwood 2006) and individuals with ASD or AS, as is reduced sensitivity, for example, to pain, in some instances. (Asperger 1944 transl by Frith 1991) As a consequence of these differences which are endemic to those with ASD and which often have profound consequences for the individual, there have been calls to have 'sensory sensitivities' included as a diagnostic marker (Bogdashina 2004).

Unusual perceptual faculties are allied to exceptional cognitive processing in ASD and AS. The term 'monotropism' is used to describe the way in which those with ASD cope with what often threatens to be an overwhelming level of information to deal with at once, by shutting out everything but a very limited amount of information to process at any one time. This monotropic style of information processing means, for example, the shutting out of what NT people might deem important general information, such as the situational context of a problem, or perhaps what another person looks like or their responses to events (Murray et al. 2005).

Another trait of this style of processing is finding any kind of distraction from the main focus of attention unbearably frustrating and in some cases, physically distressing. An example of this would be an adolescent with AS wanting to learn but being unable to hear what a teacher was saying in class because of the background noise of other pupils chatting or clicking their pens or rustling crisp packets (Hall 2001; Bogdashina 2004).

Some with ASD are reported as having remarkable perceptual memory faculties (Willey 1999, Grandin 1986, 1996; Bogdashina 2004, Stillings 2007). Grandin (1996) describes herself as 'thinking in pictures'. This has been explained as the retention of a dominant sensory or literal style of perception with many individuals with ASD either developing a dominant verbal perceptive style later in life or as a secondary language. This is in contrast to typical development, where although sensory and verbal perceptions co-exist, verbal perception is dominant (Williams 1998).

Linguist Stillings (2007) describes her own perceptual experiences thus:

"There is no such thing as "one" autistic viewpoint...I personally have no problems with abstract concepts. My own autism has taken the form of being unable to connect "emotion words" to the emotions they name. At any given time, I have absolutely no idea what I am feeling about something. I know I am feeling something, but I cannot tell you what it is. I cannot even distinguish "like" from "dislike" because I honestly do not know..." Medscape Psychiatry and Mental Health accessed online 12.10.07 at [www.medscape.com/viewarticle](http://www.medscape.com/viewarticle)

This difficulty in being able to express verbally affective experience, especially when under stress, can lead to behaviours perceived as aggressive and sometimes even lead to violent outburst, in adolescent boys in particular. Difficulty with emotional regulation is reported widely (Volkmar et al. 2005; Attwood 2006).

It has been argued that the conceptual foundation underpinning existing studies into TOM and other theories of cognition, may lead to lost opportunities for investigating what is unique about autistic thinking and means of communication (Rajendran & Mitchell 2003). Terms such as 'impairment' and 'deficit' could perhaps be accurately replaced by others such as 'difference' and 'alternative'. However, Rajendran & Mitchell's (2003) 'unique autistic communication' may not exist, according to Stillings (2007), as quoted above. Where people on the AS

spectrum do not intuitively absorb the cultural meanings and socially defined modes of communication, they each, as individuals with their own individual strengths, weaknesses and cognitive abilities, may develop their own strategies for making sense of the world and of expressing their experiences. Jordan et al. (1998) describes this thus:

“Individuals with autism may be more different from one another than others because of their lack of socialisation into a common culture” (p29)

Bogdashina (2004) suggests we require to both understand and to communicate with children with ASD in a way likened to becoming familiar with a new language and a different culture. It might be more apt to relate children or young people with ASD, specifically with AS, to ‘Third Culture Kids’, described by Molloy and Vasil (2002, 2004) as those who have spent a significant proportion of their developmental years in a culture alien to their parents’ and who have consequently established a relationship with all of the cultures in which they have found themselves while not being fully comfortable in any.

#### **2.4.2 Mental health in adolescence and implications for young people with AS**

Anxiety disorders are among the most prevalent of paediatric psychopathologies within the population as a whole, although understood to be commonly transitory (Herbert 2003, Vasa & Pine 2004). That children entering adolescence in a vulnerable state psychologically or socially are likely to experience greater difficulties is clear (Peterson & Leffert 1995). Clinical levels of anxiety in adolescents across the population, as well as in AS, is a significant cause for concern (Wadsworth et al. 2001), and is associated with serious mental health problems such as Generalised Anxiety Disorder (GAD), Obsessive Compulsive Disorder (OCD), selective/elective mutism, social anxiety, school refusal, substance abuse, depression and increased risk for the development of a severe mental health problem in adulthood (Morris & March 2004, Adams & Berzonski 2006).

Difficulties experienced by young people with AS - cognitive, perceptual, communicative - are inevitably compounded by the challenges posed by adolescence for all young people. In early adolescence, most young people in the UK will experience the physiological changes of puberty (Herbert 2003),

developmental changes in cognition (Piaget 1960, Byrnes 2006) and the addition of numerous major externally imposed changes, including school settings transition. (Petterson & Leffert b1995)

The most marked feature of this period in physiological, emotional, cognitive and social terms is change. (Alsaker 1996; Petterson & Leffert b1995) Change is only partly a function of the natural development of the individual, it is also imposed by social expectation, and too much change is potentially damaging. (Crockett et al. 1989) Children with AS may be additionally challenged through poor comprehension of, and uncertainty around, how to respond to situational events. (Schopler & Mesibov 1994) Clinical experience suggests that anxiety develops in people with AS as a secondary response to a sense of being overwhelmed by the fast paced, competitive social demands of peer interaction coupled with feelings of lack of control (Klin et al. 2005; Attwood 2006). However, the literature found for this current study does not entirely endorse this view, as previously discussed.

Kelly et al. (2008) have reported children and adolescents with AS as experiencing a range of affective characteristics to a greater degree than NT young people. These have been described as: problems with anger management, rapid mood changes, feeling anxious, feeling sad, seeking solitude when distressed and difficulty articulating thoughts (Attwood 2006).

### **2.4.3 Mental health and girls with AS**

Girls and women with AS are now believed to be under-diagnosed (NAS 2010). With little existing research literature in this area, clinical observation (Attwood 2006, Nichols 2009) and autoethnographic writing (Sainsbury 2000, Willey 1999; 2003) was referred to. Again, existing academic texts on adolescent development in the population as a whole were utilised as a way of defining benchmarks and context for the findings, such as Griffiths (1995), Santrock (2001) and Herbert (2003). Beyond the aetiology of AS and how this might manifest in each of the sexes, cultural expectations may influence both the social expectations on each and the coping mechanisms available to them. For example, aggressive behaviours in adolescent boys with AS may provide the trigger for assessment and diagnosis. However, such behaviour is less likely to be observed or identified in girls with AS. (Attwood 2006)

Another example is in the role of peer friendship; friendships in adolescent girls may provide not only companionship and protection but emotional and developmental support, vital for the healthy growth of identity and self-esteem (Griffiths 1995). The main features of this kind of friendship are fun along with confirmation of values and identity or:

“...physical closeness, ‘having a laugh together’, talking and sharing confidences...trust and loyalty...intimacy and self-disclosure” (Griffiths 1995 p54)

These valuable features of peer friendship may be elusive for girls whose developmental differences often lead to social exclusion (Willey 1999; Sainsbury 2000).

In response to these challenges, adolescent girls with AS may manage to negotiate the social demands of the school environment in different ways to boys, by using one or more of a number of strategies, such as finding a protector and mentor. (Attwood 2006) NT girls are more likely than boys to mother and protect a peer whom they perceive to be vulnerable or naive, but who has the valuable qualities of loyalty and discretion. It has been suggested that girls with AS are more likely than boys to receive extra-curricular training such as in drama or dance, which may help the development of skills of imitation and pretence. These skills may be utilised to help the girl with AS to blend in with her peers (Willey 1999), described as ‘cloaking and shadowing mechanisms’ (Attwood 2006) or ‘masquerading’ (Carrington & Graham 2001).

However, adult women with AS have reported feeling pressurised, judged or excluded on the basis of their seeming lack of what may be seen culturally as feminine characteristics or of displaying male ones (Faherty 2002; 2006). Erikson’s theories on psychosocial development (Erikson 1968) in adolescence are cited in respect of self-esteem and identity formation during adolescence (Pettersen & Leffert 1995a, Santrock 2001, Herbert 2003, Adams & Berzonski 2006). Unhealthy development and damaged identity specifically in young women may lead to the creation of defensive strategies, imitation, identity confusion and negative identity adoption, ultimately leading to despair and self-destructive behaviours (Sainsbury 2000, Herbert 2003, Attwood 2006) An example of self-destructive behaviour that has been proposed as possibly being found in girls with ASD is the development of Anorexia Nervosa. It has been



suggested a high proportion of girls diagnosed as having Anorexia Nervosa are on the Autism Spectrum. However, exact figures are not known (Gillberg & Copp 1992).

Dr Willey (2003) an author with AS describes her own experiences of anxiety as a girl:

“It is my not so humble opinion that the effects of anxiety on the psyche, body and indeed society are completely underestimated. I am always vulnerable to anxiety...this was particularly true when I was an adolescent....” (Willey 2003)

A higher IQ, or in other words, a diagnosis of AS rather than other ASDs, has been associated with higher levels of anxiety in young people (Gadow et al. 2005; Volkmar et al. 2005; Attwood 2006). It is ironically, the greater ability and higher intelligence along with increased self-awareness that may lead to higher anxiety levels – young people with AS may become all too aware of how different they are from their peers, generally at a time when all young people are in the process of metamorphosing from children into adults with all the challenges to identity and self-esteem associated (Erikson 1968, Goffman 1968, Santrock 2001, Kroger 2006, Duseck & McIntyre 2006). In the light of the available research reviewed for this study, this has not been proven. However, that anxiety, along with depression, poses a profound threat to the mental health and potential life outcomes for young women on the autism spectrum is clear.

#### **2.4.4 Implications for mental health consequences of AS in the family**

Receiving a diagnosis of AS will impact upon the quality of life of the whole family, and will inevitably have an effect upon relationships within the family (Brogan 2002, Marwick et al. 2005; Allik et al. 2006). Comparisons with families of children with chronic illness or disabilities not autism-related suggest the impact of having a child with ASD holds differences and similarities to other special needs, such as learning difficulties (LD), (Heiman & Berger 2008); grief as a response to diagnosis for example (Jardine 2008; Siegal 1997). The impact, however, of having a child with a developmental disorder is most profound relative to long term illnesses or conditions such as HIV or asthma (Hastings & Johnston 2001; Sivberg 2002; Pakenham et al. 2004; Gupta 2007). Much is known about the fundamental importance of support to parents of children with chronic conditions and/or disabilities, but less about whether or not

that knowledge been adequately transferred to the care of children with autism (Woodgate et al. 2008).

It has been found that parents of children with AS are required to provide more intensive levels of care, such as structuring their child's daily activities and providing companionship, than would be expected normally (Heiman & Berger 2008). Mothers with a child with AS have been found to experience significantly more stress with a reduced quality of life than fathers (Boyd 2002; Allik et al. 2006); they also perceive greater stress for other family members and are more likely to seek professional help, to take medication for depression and to be more pessimistic about their child's future (Little 2002b). However, the evidence available also suggests that severity of autism characteristics is, as might be expected, related to the severity of impact on the family overall. Access to social support also mediates for improved outcomes (Boyd 2002).

Pyles (2003) discusses adolescence for people with AS in a broad context and stresses the importance of parents maintaining an active role in the school life, building relationships and informing the teachers of their child's special needs. Willey (2003) and Attwood (2006) report that adolescents, both girls and boys, have extraordinary issues over sexual development and behaviour, boys with AS not always being able to understand what is appropriate or inappropriate in their behaviour towards others and girls with AS being especially vulnerable to abuse and so there is a vitally important role for parental involvement in informing their adolescent children and advocating for them if and when necessary (Debbault 2003). Willey (2003) describes the importance of parental support in outcomes for adolescent girls with AS while Howlin (2003) points out that potential for dependency conflicts are exacerbated within families with an adolescent with AS, as the vulnerability of the child and their parents' needs to protect conflicts with the child's desire and need to be independent.

There are additional factors that must be involved in family dynamics where there is a child with AS. Asperger (1944 transl. Frith 1991) himself reported that often the parents showed similar characteristics to their offspring. As the genetic association with ASD including AS is generally now accepted, then it should be considered that a proportion of the parents, fathers and mothers, of adolescents with AS may well have at least some, if not all, of the associated characteristics

of AS. (Fombonne et al. 1997) On the one hand, that may lead to a greater level of understanding and empathy with the difficulties experienced by their child, on the other it may create additional challenges. For example, Howlin (2003) describes the risk of maladaptive behaviours emerging in families of adolescent with AS where the parents “experience normal transitions and changes as threatening” and develop a reactive and stifling parenting style.

These are perhaps anxious parents of anxious girls; mothers themselves may share some characteristics with their daughters, may be prone to elevated levels of anxiety, and possibly have difficulties articulating their emotions clearly. Relationships between mothers and daughter may be affected both positively and negatively. Mothers who themselves have characteristics of AS may be able to relate to their girls in ways others cannot. They may, whether they have AS themselves or not, act as social intermediaries or translators and advocates for their children (Willey 2003).

While the popular picture of pubertal relationships with parents in the general population is one of strife and conflict during the developmental transition from child to independent adult, it is also the case that while relationships do change over this period, the process of transformation is not necessarily pathologically stressful or negative. A positive parent-child relationship may be maintained alongside the adolescent's maturation and development of autonomy and self-identity (Petersen & Leffert a, b 1995). Parent rearing style and practice, while mediated by factors such as physical growth and timing of pubertal changes, school environment and achievement, (Duseck & McIntyre 2006) is one of the most important influences on the development of self-esteem in adolescents and in the prevention of self-destructive strategy development (Petersen & Leffert a, b 1995; Granik et al. 2006, Zimmer-Gembeck and Collins 2006).

Little is available on the impact of family dynamics on the mental health of adolescents with AS, although research is ongoing. The influences, both negative and positive, of interpersonal family relationships have long been considered in relation to vulnerable people generally (Burman & Margolin 1992; Kiecolt-Glaser et al. 2003) while negative relationships both familial and peer, may lead to diminished mental health in the individual (Hawker & Boulton 2000). High levels of family conflict have been linked with increased severity and co-

morbidity in children with Attention Deficit Disorder (eg Biederman et al. 1995, 2002; du Paul et al. 2001); obsessive compulsive disorder (Piacentini et al. 2003) and mood disorders (Rice et al. 2007). However, how or if these findings may generalize to young people with ASD, including AS, is poorly understood.

Additionally, most research on the influence of and on family interaction in relation to ASD is focused on the impact on parental wellbeing (Allik et al. 2006; Boyd 2002; Kelly et al. 2008; Little a,b 2002). Kelly et al.'s (2008) study of family and peer relationship impact on children with ASD suggests that conflict within the family carries exaggerated and detrimental consequences. The key findings of the study were that anxiety and depression and ASD symptomatology were significantly related and that family conflict (defined as consistent openly expressed anger amongst family members) was associated with increased levels of anxiety and depression for those with ASD.

While the findings of the study were surprisingly and in contradiction to other Humphrey and Lewis' (2008) findings, discussed further on in this chapter, that peer support did not affect levels of anxiety and depression, having family support to combat peer-initiated bullying was associated with a decrease in likelihood of experiencing family conflict. The study offered no insight into why young people experience increased levels of stress and anxiety in comparison with NT children when dealing with family conflict and was focussed on parent reports only. However, according to the authors, family conflict levels were, on average, at the level of non-distressed families with children without ASD, implying even low to average levels of conflict within the family to be distressing for children with ASD (Kelly et al. 2008). These findings, while tentative, are not inconsistent with Wood et al.'s (2003) study on sibling relationships which underlined the importance of considering family context.

The increased levels of stress imposed on families with children with ASD or AS reported (Allik et al. 2006; Boyd 2002; Gupta 2007; Hastings & Johnston 2001; Heiman & Berger 2008; Pakenham et al. 2005; Woodgate et al. 2008) increase the potential for split relationships leading to further difficulties and anxieties. However, while research tends to focus on the negative aspects of separation or divorce of parents, there are differentials affecting outcome other than separation alone. Examples are: the age of the primary caring parent, usually

mother, and its mediating influence on parenting styles; the degrees of conflict involved in the separation process and other stresses associated such as reduced income for the family, change of living arrangements and so on. There are many variables relating to family leading to outcomes in adolescence, including socio-economic status, positive role models, family influences, neighbourhood influences, parenting style and within-family variations, such as differential treatment of siblings (Petersen & Leffert 1995, Duseck & McIntyre 2003).

Autoethnographic accounts by adults with AS rarely discuss parental and adolescent relationships. (Willey 1999; Sainsbury 2000) An exception is Willey's (2003) guide to raising children with ASD from the perspective of a mother with AS which offers an 'insider's perspective'. However, it is a publication aimed at mothers, and therefore not written from an adolescent perspective. The mother of the internationally renowned cattle expert Temple Grandin has published her autobiographical version of Grandin's childhood and adolescence (Cutler 2009), in which lack of understanding or support by close family, including Grandin's father, and the professional world is highlighted, along with Cutler's (2009) accounts of how she had to defy the prevailing wisdom of the day to do what she felt she needed for her daughter. Sainsbury's (2000) autoethnographic book in which she describes her childhood experiences makes little reference to her parents in relation to her home life or the relationships therein, focusing instead entirely on the school environment.

In the next section of this chapter, what is available in terms of qualitative research data on experiences of adolescent girls with AS is discussed and appraised.

## **2.5 Interpretive studies: experiences of adolescent girls with Asperger's syndrome in the literature**

Limited access to research relevant to the focus of interest in this study prompted a broad sweep of what is available; to hermeneutic, Interpretive phenomenological, ASD, Asperger, and anxiety, the terms 'narrative' and 'experience' were added and the results assessed. In order to achieve the aim of this case study, multiple voices were used to 'narrate the story' of these girls' experiences within their lived world. Studies into the effects of a diagnosis of

ASD or AS within a family, or the experiences of living with these, have primarily and perhaps understandably, focussed on the impact on parents (Brogan 2002; Gray 2001, 2003; Fleischmann 2005; Jardine 2008). Literature on the experiences of parents with children with AS was therefore also considered in order to inform the context of the study findings. Literature published up to March 2010 was included.

### **2.5.1 The literature: key studies**

Several studies have focussed on the impact of a diagnosis within the family of ASD or Asperger's syndrome in terms of parental responses, including coping strategies. Wiebe's (1990) 'insider's perspective' as the mother of a girl with AS describes her parenting experiences as transitional; from seeking to 'fix' her daughter's differences to learning how to understand and support them. Interpretive and hermeneutical studies have described parents' experiences as 'Living in a world of our own' (Woodgate et al. 2008) and themes including 'confusion' (Midence & O'Neill 1999), 'feeling alone' (Jardine 2008), 'fighting all the way' (Woodgate et al. 2008) encompassed as narratives of 'accommodation, resistance and transcendence' (Gray 2001).

The impact of a diagnosis within the family on siblings of those with ASD or AS is beginning to be addressed, at least in the form of general guidance literature being made available through specialist publishers and research is ongoing. However, my current study does not include the voices of siblings, except as reported by the girls with AS interviewed and their mothers and so the literature in this area was not reviewed for these purposes.

The studies included for this section of the review are, as described in the introduction to this chapter, qualitative and focus on the experiences of young people with ASD. The literature searched using the criteria outlined revealed only 2 studies considered apt for this study, both exploring the experiences of adolescents, male and female, with ASD. The studies, while using the generic terms ASD or autism, involve young people with AS, in one case referred to also as HFA. The two studies discussed are:

1. Humphrey and Lewis 2008 Make Me Normal: the views and experiences of pupils on the autistic spectrum in mainstream secondary schools  
Autism 2008 12;23

2. Huws JC. and Jones RSP 2008 Diagnosis, disclosure and having autism: An interpretive phenomenological analysis of the perceptions of young people with autism.

#### *2.5.1.1 Discussion and appraisal of the interpretive literature*

Both studies took place within an educational setting, with participants drawn from, in one study, a specialist college and in the other, from four schools within close locality to each other. Humphrey and Lewis (2008) paper was drawn from data collected within a broader research project, the purpose of which was to develop an understanding of and thereby inform the inclusion process in secondary education for pupils with AS.

An interpretive phenomenological approach was used to explore how students with AS within a mainstream secondary school make sense of their educational experiences using a purposive sample of 20 pupils aged 11 to 17 years. Participant students took part in semi-structured interviews and were also asked to keep diaries for a month. The diaries were constructed with prompts such as 'What good things happened in school today?' Only 5 students recorded their diaries for a full month (of 20 days), 1 managed 3 weeks and 3 for 2 weeks. One participant chose to draw his experiences of life in school. Data were analysed using Interpretive Phenomenological Analysis (IPA), a method developed within Psychology research to provide a framework for qualitative study of lived experiences (Smith & Osborne 2003).

Humphrey and Lewis (2008) carried out the study within Merten's (2005) 'transformative' framework used in research to confront inequities that lead to social exclusion. They argue that individuals with AS and HFA (referred to throughout as AS) may be considered as a marginalized group within educational and social settings (Billington 2006, Osler & Osler 2002). Anxiety and stress in school were identified as central thematic findings.

Experiences were interpreted as revolving around a central theme of what AS meant to the participants. This was often negative in character, relating to perceptions of their differences as 'being retarded' or having a 'bad brain', perceptions which the authors discuss in relation to the 'pathologising' of AS with the consequent impact on the young peoples' self-concept and ongoing

debates as to appropriate definitions of AS (Baron-Cohen 2002, Molloy & Vasil 2004). Links between these perceptions and reported difficulties with their peers and teachers as well as a desire to 'fit in' were included in the findings. Experiences of being exploited by peers, for entertainment, were described, as were incidents of bullying, including violent assaults, teasing and name-calling. Social isolation was a potential consequence, although some of the participants were able to report occasions when other pupils gave them support and protection. The importance of such support and friendship from peers in facilitating a positive sense of self and therefore resilience against feelings of depression is emphasized by the authors.

Previous research findings suggesting that adolescents with AS are more likely than NT to experience high levels of anxiety (Kim et al 2000, Gillot et al. 2001, Russell & Sofranoff 2005, Meyer et al. 2006) was endorsed by the authors of this study. However, previous assumptions as to the causes of anxiety being associated with difficulties in social reasoning or specific learning disabilities were only partially upheld. The school environment itself was found to be a considerable source of anxiety and stress. Order and predictability were described as providing a sense of security that allowed participants to function; such order and predictability is difficult to maintain in the typically noisy, jostling and unpredictable environment of a mainstream secondary school.

Issues of additional support within the classroom, the nature, consistency of such support and how visible it was were raised within the context of relationships with teachers and other staff. Support provision varied widely within the four participant schools, from little or no additional support, to support in almost every lesson. Such support, although it might be welcomed by some and perceived as alleviating school-related anxiety, often made the students feel their differences were made more visible and accentuated. Additionally, lack of training and confidence on the parts of the teachers as to how to respond to pupils with additional support needs resulted in a reduction in teacher/pupil engagement. Teachers relied more heavily on the support staff and interacted with their AS pupils less.

The study also highlighted the difficulties experienced by participants in their confusing state of being the 'same but different' and their struggles to negotiate



their differences. In order to be accepted by their peers they found they had to adapt and modify their personalities, described by others as 'masquerading' (Carrington & Graham 2001), thereby compromising their individual identities. There was conflict in relation to disclosure, where the label of AS, with its pathological connotations, was itself seen as a barrier to acceptance, while facilitating, in some cases, extra support from the school. In some cases, where disclosure is dealt with sensitively (Gus 2000) and in circumstances where 'diversity becomes the norm' (Humphrey & Lewis 2008) the authors found that disclosure to staff and peers could be supportive. However, for some participants, the overriding experience was one of wanting help to 'make me normal'.

The authors conclude that from the students' perspectives, the 'distinct needs' (Norwich & Lewis 2005) of young people with AS are not being adequately met within mainstream secondary school provision.

Assumptions are made that because a pupil with ASD is academically able, they should then be able to function within a mainstream setting. However, a number of barriers to them being able to make the most of their education is identified. Consequently, this study reports parents as losing confidence in the effectiveness of mainstream inclusion at secondary level and notes that it is during this period young people with AS are most likely to develop mental health problems (Barnhill & Myles 2001).

The authors discuss in detail the issues involved in research involving such a group as adolescents with AS and describe how these were addressed within this study. The authors highlighted that young people with AS constitute a group whom research is more often conducted on, rather than with and describe the steps they took to actively engage and involve the participants in the research process. This study is unusual and therefore highly valuable in that it was structured specifically to include experiences of young people with AS described by the young people themselves.

The objectives of the study were clearly delineated, although only the first 2 out of 4 were discussed in detail in the paper appraised for this review. These were to explore the views of pupils with AS about mainstream education and to document their everyday experiences in mainstream schools.

Although there may be points for debate in theoretical terms around the methodology chosen, which was IPA (the authors might, for example, have considered Van Manen's pedagogical hermeneutical phenomenology an appropriate methodology especially given the context of their study), the approach is robustly justified as an appropriate one for the research aims.

This sample group is taken from a section of the population that constitutes a minority and while the four schools have their differences, some aspects of experience within these may well be universal. Examples are the pressure on adolescents to 'fit in' with their peer group and the physical demands of large, busy mainstream secondary schools with the likely impact on pupils with their specific cognitive and perceptual characteristics.

Humphrey and Lewis' (2008) study is contained within a larger research project that was carried out within a specific research context, being that of LA education policy. The study consequently only focuses on the school setting and the participants' experiences within that setting. It does not therefore refer to wider social or family circumstances and the impact or influence these things might have on the school experience or conversely, how the school experiences influence the pupils' wider social or home relationships. Stress and anxiety was highlighted as a theme and mental health consequences were referred to; that an education policy of inclusion on its own was not enough to meet the special needs of these young people was also concluded; however the authors were 'deliberately cautious and tentative' in making any recommendations from their findings. Further and more extensive qualitative research is one clear recommendation.

Similarly, the other paper appraised for this current study, Huws and Jones (2008) study was located in an educational setting, but in a specialist college for young people with ASD. The participants were all defined as having High Functioning Autism (HFA), by the authors, or autism plus an IQ in the normal range or above (Baron-Cohen 2000). The study design was underpinned by Interpretive Phenomenological Analysis (IPA), a method developed within Psychology research to provide a framework for qualitative study of lived experiences (Smith & Osborne 2003). The study's aim was to explore

experiences of autism as described by 9 young people aged between 16 and 21 years, three female and 6 male.

The study title refers to the generic term autism rather than HFA or AS, however the participants are all high functioning. Diagnosis and disclosure may have different meanings for less able individuals with autism who are unlikely to have access to a further education college, such as the one in which this study was set. Such facilities are not universal and the participants in this study belong to a particular group in an unusual situation. Interpretive phenomenology is indeed ideographic, but the authors make no mention of the specific circumstances of their participants as a factor in their experiences.

Huws and Jones (2008) did not aim at the outset of the study to explore experiences of diagnosis and disclosure. The authors are transparent about the flexible and adaptive approach they took to the research process as a consequence of unexpected early findings. Although comments relating to experiences of diagnosis were not explicitly sought at the outset of the study, the first three participants described experiences of diagnosis as central to their perceptions of having autism. In subsequent interviews if participants did not introduce it themselves, the researchers raised the subject in order to explore it further.

Analysis is integral to the process of ongoing data collection in Interpretive phenomenological research and therefore adapting the research aims to fit the emerging data is commensurate with the methodology used. However, by doing so, the authors may have pre-empted the findings which were that experiences of 'diagnosis' and 'disclosure of diagnosis' were embedded in the participant's descriptions of 'having autism'.

The study highlights the difficulties faced by individuals and their families in the process of gaining a diagnosis of ASD, especially in the case of AS; the current situation has not been demonstrated to have improved from 1999 when it was found to take up to 8.5 years from the point where parents are first concerned about their children to diagnosis of AS (Howlin and Asgharian 1999). There is a substantial and growing body of research literature examining the process of assessment and diagnosis as experienced by parents (Brogan 2002; Brogan & Knussen 2003; Gray 1993, 2001; Mansell & Morris 2004; Midence & O'Neill

1999). Conversely, there is very little that focuses on the experiences of the children or young people, a situation seen by the authors as reflecting a general tendency of researchers and policy-makers to focus on the experiences of parents rather than the individuals with AS (Sloper 2002; Connors & Stalker 2007).

Despite this paucity of research into the experiences of diagnosis for young people with HFA or AS there are many claims that diagnosis may enhance an individual's self esteem (Jones 2001). Attwood's (2006) *Complete Guide to Asperger's Syndrome* contains no reference to potential disadvantages of diagnosis from the perspective of the child or adolescent, only advantages as perceived by the adults around them, parents and professional, and reports of mixed responses by adults receiving a diagnosis late in life. Huws and Jones (2008) found that, for example, Willey's (1999) personal account of diagnosis of AS in adulthood (which came about when her daughter was diagnosed) is often cited as a positive event, one that enabled her to finally come to terms with her lifelong difficulties. However, the reverse is also known as in Johnston's description of becoming suicidal after receiving a diagnosis of AS at the age of 52. (MacLeod & Johnston 2007)

In their study of adolescents and young people Huws and Jones (2008) found diagnosis to be associated with a range of mixed responses, including shock and disappointment, especially in cases where disclosure to the individual had been delayed by their parents, sometimes for years, after initial diagnosis. There were also experiences of diagnosis as a 'disruption' to their plans for the future, as the implications of the diagnosis were absorbed by the individuals. Fears of stigmatisation were expressed, sometimes driven by their own preconceptions of what it means to have autism but in some cases, experienced in their daily lives consequent to disclosure. However, some participants experienced diagnosis as positive, especially where associated with new opportunities, such as being able to attend the college.

The authors drew parallels with Bury's (1982) concept of 'biographical disruption' in chronic illness as a disruption to the 'structures of everyday life' (Bury 1982 from Huws & Jones 2008). Questioning of the 'taken-for-granted' assumptions, rethinking of biography and self-concept for the young people was

found in the study. Whether the diagnosis of autism was experienced as positive or negative or mixed, all the participants were found to have reworked to some extent, their self-identity. The authors concluded that further research into the experiences of individuals with autism should be considered, especially in relation to the effects of diagnosis and disclosure of diagnosis.

The study has identified key areas of deficit in the research literature and especially the paucity of research into the experiences of young people with autism, in this case described as HFA. The research aim was to listen to the voices of young people with autism, rather than their parents or other carers. The methodology used was commensurate with the aim of the study, using principles of interpretive phenomenology; sampling, recruitment and methods of data collection and analysis were clearly delineated.

The authors conclude that despite the experiences of the young people being central to the study, complementary interviews with the parents might have enhanced the study findings. They additionally identify that disclosure of diagnosis from the perspective of the individual with ASD should be given consideration for future research as well as their involvement in shaping autism-specific services.

## **2.6 Conclusions**

The literature search for this study has highlighted the lack of existing research material on any aspect of WHM, either in terms of clinical outcomes or in clinical practice or experience of treatment. Research literature in any methodological mode on WHM is limited but especially on current practice. None was found on WMH treatment of anxiety in those with AS. There were no reports found of studies involving the treatment of anxiety by WHM or of the treatment of patients of any age with autism or AS. A need for work that explores issues of personal experience in CAM therapies overall and in WHM specifically has been highlighted (Sharma 1994; Cant & Sharma 1999; Evans 2009).

As described in Chapter 1, evidence that parents of children take their children for WHM treatment is available. However, there is no 'best practice' guidance available for practitioners and no research literature to guide any such practice; neither is there any literature to inform potential patients, in this case, parents

and AS children or adolescents or other service providers involved. There is clearly a need for such information.

Existing research literature on anxiety in adolescents with ASD or AS is limited and is acknowledged as having methodological flaws. Lack of internal validity in existing assessment tools when used with this population and that further, qualitative research is required, has been identified. The literature was revisited at regular intervals during the time-span of this study. Qualitative and interpretive research has increased in recent years, with several studies published since 2005, primarily focussing on parental experiences. Literature for the purposes of this review published up until March 2010 was included. There is no existing qualitative research literature describing experiences of girls with AS and very limited on experiences of adolescents with Asperger's syndrome overall. The research that has been done in this area has primarily been within the context of Local Authority (LA) education policy. Issues around disclosure of diagnosis, discrimination, concerns for the future, and mental health problems such as anxiety, disrupted self-identity and low self-esteem, have been identified in young people with AS within this context.

Until very recently, Asperger's syndrome has been considered almost exclusively to affect males and therefore almost all existing research has been carried out on this basis. Although studies often state the numbers of girls included, differentials in the findings are rarely articulated (Kim et al. 2000). That girls indeed do make up a significant number of this population, with specific problems, strengths or experiences, has recently come to attention and a small number of general information books published (for examples, see Attwood 2009; Nichols et al. 2009) However, there is still a paucity of research literature and no qualitative research specifically on the experiences of girls with Asperger syndrome. The Research Autism and NAS organisations have, in the last year (2009 to 2010) publicly announced the prevailing deficit of such research. (For example, see interview with Richard Mills, Research Director of both organisations, available from the Times newspaper online version, Feb 6<sup>th</sup> 2010). My study aims to address this gap. As there was no literature found on the precise area of this study at its outset, interrelated questions were raised

about what is already known and what is theorised on girls with AS, including health issues.

Responses to urgent calls for research into anxiety in people with ASDs (Volkmar et al. 2005) have been primarily directed towards assessment of treatment approaches rather than on experiences of anxiety in this population. Additionally, lack of congruence of standard assessment tools for anxiety poses methodological challenges. Tools such as Beck's Youth Inventories (BYI), now superseded by BYI 2<sup>nd</sup> Edit (Beck et al. 2005) or Spence's Child Anxiety Scale (SCAS) (Spence et al. 2003) have limitations in measuring these children's status and progress as reported by the children themselves.

A need for further qualitative study on this crucial area has been identified (Kim et al. 2000; Humphrey & Lewis 2008; Huws & Jones 2008) and to which my study responds.

In this current study, an interpretive case-study approach was considered as a methodologically appropriate design that would enable all aspects of the area being explored to be addressed. In Chapter 3, such questions of methodology are discussed, the reasons for choosing the methods used are explained, and how the study was carried out described.

## Chapter 3 Methodological Considerations

### 3.1 Introduction

In the process of developing this study and in response to the paucity of literature available in the areas considered, different methodologies and methods were examined. The areas of enquiry were as follows:

- 1) experiences of anxiety in girls with AS
- 2) experiences of WHM treatment of girls with AS

Examination of the literature, as described in Chapter 2, reveals a lack of appropriate research and methodological flaws or limitations in many of the existing studies. A need for further research into experiences of anxiety in young people with AS, is apparent (Kim et al. 2000; Gillot et al. 2001; Russell & Sofranoff 2005, Meyers et al. 2006) and especially research focussed on the perspective of the young people (Kim et al 2000). A multi-perspective approach has also been proposed as an appropriate method for this area of enquiry (Huws and Jones 2008).

*The questions that evolved from the literature search correspondingly are:*

- *How do girls with AS experience anxiety?*
- *How do girls with AS experience WHM treatment and its impact, if any, on their experience of anxiety?*
- *What are the experiences of the girls' mothers of their child's anxiety during a course of WHM?*
- *What are the experiences of the WMH during their treatment of girls with AS?*

In order to answer these questions, this study has taken an approach grounded within the interpretive tradition of hermeneutic phenomenology, informed by Van Manen's pedagogical model.

In this chapter the rationale behind this choice and its congruence to the areas of study involved is discussed. Firstly, there are particular methodological issues relating to researching within WHM and these are outlined.

A general overview of the theoretical principles underlying the research study is then given. The suitability and choice of methods is discussed in the second



part of the chapter and the process of how these were implemented described. Clarification is given for the choice of hermeneutical phenomenological approach based on the interrelatedness of the research aims, the suitability of the methods and the particular epistemological choices

### **3.2 Methodological choices.**

#### **3.2.1 General considerations**

In order to address the sometimes hotly debated subject of 'appropriate' methodological approaches to research in WHM, commentators and researchers must take cognisance of the role of methodology in any research in any field: that is, the appropriate methodology is that which is best suited to answer the question being asked (Lewith et al. 2002; Best & Glik 2000; Denzin & Lincoln 2005).

The drive for clinical evidence in both herbal medicine and treatment of symptoms in AS might point towards a quantitative Randomised Clinical Trial (RCT) (Pocock 1993). There are key factors to consider in the process of the research design that are discussed below, however, that led to the decision to carry out this study from within a qualitative framework and that suggested the choice of methodology.

The process of western herbal treatment does not fit well into the comparatively modern philosophical paradigm in which the RCT is based (Saks 1992; Lewith et al 2002; Best & Glik 2003; Saks 2006). As stated by the World Health Organisation:

“efficacy assessment of traditional medicine may be quite different to that of conventional medicine. As traditional medicine relies on a holistic approach, conventional efficacy assessment measures may not be adequate” (WHO 2000).

Quantitative research seeks to test hypotheses already formulated, sometimes from previous qualitative work, using experiment and controlled variables and in health care may be used as a means of evaluating treatment efficacy and safety, in the case of new pharmaceutical drugs for example, or in the assessment and planning of a particular treatment approach (Burns & Grove 2005). There are limitations inherent to the stringent reductionism and narrowness of control format of the orthodox RCT which does not address the

multilayered nature of WHM practice. The complexities involved in the 'three-fold therapeutic approach' of WHM (Nissan 2009) demand commensurate research methodologies (Lewith et al 2002, Verhoef 2004). Therefore, a quantitative approach was rejected for this study as being incompatible with the research questions.

Furthermore, the philosophical foundations underpinning the practice of WHM affect choices of research methodology. Epistemological considerations form the basis for all research approaches, quantitative and qualitative, from the choice of the research question, the study design and research methods, to the presentation of the research findings – epistemological perspectives dictate what constitutes 'findings' and the criteria by which they are to be judged (Robertson 2008). The modernist paradigm that is the basis for the RCT does not house comfortably the postmodernist approach of WHM in its lived practice.

Training courses in WHM instruct that while Evidence Based Medicine (EBM) must be core to modern practice WHM is a profession with its roots firmly embedded in traditional methods of health care based on ancient philosophical principles. Much of the promotional material produced by herbalists in leaflets and on websites refers to the 'tradition' of the practice as do many introductory passages in published literature by practitioner authors.

It must be acknowledged, however, that the evidence for this genuinely held belief is limited. Research into professional WHM as it is actually practised in the 21<sup>st</sup> century, whether it has any practical grounding in traditional or ancient philosophical approaches or how it relates to contemporary biomedical practice is scant. How contemporary practice is experienced by herbalists or their patients is similarly almost absent from the literature, with one or two notable attempts to fill this gap (see Pitman 2005, Evans 2009, Nissan 2009).

The place of WHM in the context of 21<sup>st</sup> century UK society is uncertain, despite the recent surge in public interest and there is remarkably little known about WHM as it is actually practised in the UK by professional WMH. Core reading lists for training courses include 'Herbal Medication: A Clinical and Dispensary Handbook' (Priest & Priest 2000) based on a therapeutic modality known as 'physiomedicalism' developed in Northern America in the 19th century by Samuel Thomson (1769-1843) and others. Some WMH concurrently practise

from within other traditions (Tobyn 1997, Evans 2009, Nissan 2009), sometimes referred to as 'energetic' modes of practice, but which all are practised from within an epistemological pluralism combining empirical evidence with belief in a unifying entity, such as Humoralism (Holmes 1997; Tobyn 1997), Ayurveda (McIntyre 1997) and Traditional Chinese Medicine (TCM) (Kaptchuk 1983, 1996; Lad 1998) or alternatively, Steiner's Anthroposophy and Goethean research methodologies (Colquhoun & Ewald 1996; Heal 1999).

Common to all these practices are concepts of 'vital energy' or the 'Vital Force' (Priest & Priest 2000; Hoffman 1990; Mills 1991; Kaptchuk 1996) an entity common to all naturally occurring things that transcends physiological or biological functioning. Some herbalists have turned to Canguilhem's (1975; 1988, 1994) review of 'Vitalism' as an all-encompassing concept from which it might be possible to develop a philosophical framework for practise (Tobyn 1997; Evans 2009).

The term 'Vitalism' has become widely associated within the life sciences with lack of intellectual rigour, even superstition, and while sometimes perhaps as a more serious perspective, still untenable (Greco 2005). However, from being regarded with derision as a negative frame of reference against which the study of life sciences has progressed, 'Vitalism' may, according to Canguilhem, be regarded as:

'an imperative rather than a method and more of an ethical system, perhaps, than a theory' (Canguilhem 1994 p288)

while Foucault described the concept of 'Vitalism' as being, while not necessarily:

"true. . . . it has had and undoubtedly still has an essential role as an 'indicator' in the history of biology." (Foucault 1980 p18)

The dangers for WHM inherent in adopting a term with such historical, philosophical and scientific ambiguities as well as opposition have perhaps still to be addressed and not within the scope of this thesis. However, this particular issue does serve to exemplify some of the difficulties faced by researchers of WHM in the UK.

What is evident then is that current WHM may encompass a range of philosophical traditions and modalities. How these pluralistic approaches,

diagnostic systems and treatment strategies may be assimilated into a cohesive professional practice is as yet uncertain and has recently come under scrutiny from both within and outside the profession. Current pressures on WHM are seen by some as constituting yet another episode in an ongoing struggle for power between opposing paradigms (Saks 1992; Kelleher et al 2006; Evans 2009).

Issues of epistemology and debates as to the meaning of terms such as 'paradigm' positioned in relation to Kuhn's theories do not necessarily address the complexities of WHM practice in the 21<sup>st</sup> century. Arguments over issues of efficacy and safety of WHM practice are foremost in a biomedical culture (Ernst 2000; O'Sullivan 2005; Saks 2003); this emphasis is problematic given the multi-layered nature of the treatment approach and the polypharmacy of the prescribing practice.

However, qualitative research is often used to develop concepts from which the experience of social phenomena within a natural, as opposed to experimental, setting can be described and understood (Mays & Pope 1996). Qualitative research may be defined as a:

“systematic, interactive, subjective approach used to describe life experiences and give them meaning” (Burns & Grove 2005 p23).

A requirement for future research directions that include experiences of WHM as practiced in real life has been identified (Evans 2009). In health care, qualitative methods are used to study the experiences of disease, service, intervention or treatment approach, from the perspective of any, or all, of the people involved, in keeping with the research requirements for WHM (Best & Glik 2000; Lewith et al. 2002; Mills 2002).

The history of qualitative research methodologies and methods has been shaped by people worldwide in varying fields of investigation and professional practice, with widely disparate personal and political perspectives (Denzin & Lincoln 2005). There are many different approaches to qualitative research to be considered in the context of the research question. However, there has developed a growth in confidence and experience in the different fields where exponents have seen the need for a greater understanding of the 'lived

experience', a growth from 'pariah paradigm to newfound respectability" (Barbour 2003).

The major qualitative approaches in current use are Grounded Theory (see Glaser & Strauss 1967), Phenomenology and Ethnography (Denzin & Lincoln 2005). Phenomenology is concerned with concepts of communication and interpretation, and how these shape human experience. Phenomenology is an:

"effective methodology to discover the meaning of a complex experience as it is lived" (Burns & Grove 2005 p 27)

and was the methodology chosen for this study because it is congruent with the research aims, the questions being asked and the subject of the study; that is, girls with AS and their experiences of anxiety and herbal treatment. The practice of WHM is based in phenomenological principles (Mills 1991) and points towards the adoption of phenomenological research methodologies.

### **3.2.2 Interpretive or Hermeneutic Phenomenology**

Phenomenology can be conducted in different ways, depending on the philosophical perspective of the researcher as well as the context of the research setting and participants. There are a number of branches of phenomenology including Interpretive or Hermeneutic, which was the one chosen, and which is outlined below.

Hermeneutics refers traditionally to a theory of interpretation founded possibly in ancient Greek philosophy. The term 'hermeneutic' is believed to conceptually refer to the figure of Hermes, the Greek mythological interpreter of the gods, who may have originated in the ancient Egyptian philosophical figure, Hermes Trismegistus (Salaman et al 1999, Mahe 1999, Salaman 2007). In 'Aesclepius: the Perfect Discourse of Hermes Trismegistus' (Salaman 2007) is taught that in the search for knowledge or 'truth', the quality of the answer depends on the quality of the question asked as well as the receptiveness of the student to its meaning, a description of what has come to be known as the 'hermeneutic circle'. Hermeneutics:

"involves the art of reading a text so that the intention and meaning behind appearances are fully understood" (Moustakas 1994 p 10).

The term was applied to the interpretation of religious texts, later extended to include study of ancient and classic cultures. Schleiermacher (1768-1834)

studied hermeneutical phenomenology from the perspectives of communication and language, influencing in turn, and most notably, Dilthey (1833-1911), Heidegger (1889-1976) and Gadamer (1900-2002) (Ramberg & Gjesdal 2008).

There is some debate of just how essential it is to have a detailed understanding of the philosophical theory underpinning any research design methodology (Barbour 2001, 2003; Willig 2001; Mielewczyk & Willig 2007, Koch 2006, Chamberlain 2000, Rolfe 2006, Crotty 1996). A great deal of time and effort may be expended on defending the theory behind any one approach and the final decision may well be informed by requirements of pragmatism as much as by deeply held philosophical principles or possibly as the result of what Heidegger referred to as 'undifferentiated' rather than 'authentic' thinking (Heidegger 1978).

There is indeed a challenge in an enterprise that seeks to relocate philosophy from the intellectual and academic world of epistemological debate to that of the world of healthcare practice and many criticisms of the resulting research studies, especially within nursing and psychology research where the phenomenologies are used extensively (Lawler 1998, Mielewczyk & Willig 2007, Crotty 1996). Lawler writes this in the context of difficulties with appropriate adherence within a clinical research setting to the underlying philosophical paradigm:

“One of the great dramas...is making the transition from philosophy to methodology. In the case of phenomenologies, the philosophy seems to overpower the methodology” (Lawler 1998 p109)

Complaints of 'methodolatory', or 'the privileging of methodological concerns over other considerations' (Chamberlain 2000) within areas of qualitative research study have been expressed along with concerns that in a drive to increase acceptability mirroring that of quantitative research, ontological and epistemological congruence with research aims and questions is being overtaken by 'checklists' and 'technical essentialism' (Barbour 2003). Qualitative researchers are cautioned against remaining too attached to a specific methodology and allowing science to become “subservient to method...so that method rules instead of liberating” (McManus Holroyd 2007).

In answer to this concern, Gadamer's interpretive hermeneutical inquiry aims to transcend the use of method as it is customarily understood and especially as it

relates to any assumption of a monopoly of the truth (McManus Holroyd 2007). Gadamer (1996) argues for a hermeneutic approach to human health care, illuminating the paradox inherent in Western medicine which focuses in theory on the body as 'object' while in reality dealing with people who are 'subjects' (Lingiardi & Grieco 1999). The work of Plato is recalled and the description of physicians as philosophers who 'do not know everything' but 'like Socrates, ask questions' (Gadamer 1989) and who transform patients into physicians (Lingiardi & Grieco 1999) or 'wounded healers' (Frank 1995).

Phenomenological research has been described as being imbued with the qualities of 'intentionality' or 'caring', its motivation to:

"serve and to share our being with the one we love." (Heidegger 1978 pp 6,7)

Van Manen (1990) expands and reverses this concept and argues we can only come to a greater understanding of what or whom about which we care. Our understanding of ourselves and our relationship with what we perceive, when we look out on the phenomenal world is a sense of:

"wonder...as when something familiar has turned profoundly unfamiliar, when our gaze has been drawn by the gaze of something that stares back at us" (Van Manen 1990 p 5).

Van Manen here thus reinterprets the hermeneutic cycle, a process of communication and interpretation that arguably transcends the clinical and limited 'gaze' of the biomedical model (Foucault 1973) to illuminate and inform medical practice (Gadamer 1996; Usherwood 1999). As in other modes of health care, herbal treatment in this context may be seen in the light of the hermeneutic process, requiring an ongoing reciprocal process of communication and understanding between the practitioner and the patient:

"...understanding the meaning of the patient's experience in context...[and] an interpretive process taking place in the realms of a dialogue..." (Benaroyo and Widdershoven (2004) p297)

Van Manen's (1984; 1990; 2002) pedagogical context for interpretive phenomenological enquiry resonates well with the practice of WHM, with its aim of empowering people through the transferring of information (Nissan 2009) and was chosen as the model for my study. Hermeneutic or interpretive phenomenology was also considered to be an appropriate approach to exploring lived experiences of a course of WHM for the population involved, as described

further below.

### **3.2.3 Research into the experiences of young girls with AS**

This research explores the interaction and interrelation between two entities, being girls with AS who have anxiety and the practice of WHM, and so the methodology and the methods chosen require being appropriate to both. Early in this study, a search for possible outcome tools to measure treatment progress for anxiety in children with AS found inconsistencies in those available, as identified in Chapter 2. (Kim et al. 2000; Gillot et al. 2001; Russell & Sofronoff 2005)

This exemplifies a fundamental query, not just about pragmatic considerations of research methods, or about appropriateness of the methodology for the treatment approach being observed but what is an appropriate approach to research with this population. In this study, I sought to address this by the methodological underpinning of my choice of methods. Interpretive phenomenology keeps to the fore, not:

“...what methodology is ‘best’ or even necessarily what method is right for the question being asked ... [but] what it means to be a person” (Benner 1994 P 44).

In health research child-centred approaches and a corresponding movement towards the development of appropriate tools for communication with children of all ages, backgrounds and abilities are being developed (Curtis et al. 2004). In this context and as the Asperger’s population becomes more self aware, confident and articulate, the drive to allow young people with AS their own individual ‘voices’ is becoming more apparent (Murray & Aspinall 2006, Lawson 2006).

Research involving all children but possibly this group especially, with its particular communication characteristics, continues to pose challenges in terms of both ethics and methods (Curtis et al. 2004). In relation to research involving children the 1989 United Nations Convention of the Rights of the Child is often cited. It does have critics and many points for debate have been raised. For example the Convention defines children according to age, rather than competency; it explicitly includes issues mainly involving boys such as enforced conscription but fails to address issues affecting mainly girls, such as child



marriage. Further it has been accused of being naive in its assumptions about what constitutes 'family' across the world and of being ethnocentric as well as gender-biased. Qualitative sociological research in the 20<sup>th</sup> century has been on some levels a form of parallel research into the politics, morals and consequences of colonialism, feminism, class, race and sexual inequalities (Denzin & Lincoln 2005). Hill and Tisdall (1997) argue that legislative implementation of children's rights in the UK since the Convention has not been comparatively comprehensive, relating mainly to areas of social work services or family and childcare proceedings.

However, as a starting place and declaration of intent, the Convention has been a milestone and the basis for ongoing debate on the question of 'rights' for children and as well as the responsibilities that go with them. This debate is part of an increased awareness of the role of the researcher in all areas as representative of the political, moral and philosophical culture from within which we operate, awareness which is inherent to the process of research methods as outline below.

Phenomenologists consider the physical body to be the vehicle through which people experience all of life's experiences and learn about themselves and others in the world. In a phenomenological approach, it is the interplay between a person's multiple, co-existing experiences of embodiment that leads to that individual's idiosyncratic understandings of the world (Robertson 2008). A phenomenological approach to the human body draws distinctions between co-existing dimensions of the experience of embodiment. The term "subjective body" refers to the experience of having a body that is unselfconsciously engaged in daily activities and tasks, without reflection. This is sometimes described as the "lived body" and by Sartre (1969) as the body that is passed by in silence. The "objective body" refers to a conscious, perspective taking of the same physical body, either by others or by oneself.

With the onset of pain or during illness, when the body can no longer be 'passed by in silence' because of the disruption to normal functioning, one's consciousness of one's own body is likely to shift into greater awareness of the body as 'object' (Toombs 1993). Frank (1995) describes serious illness as an assault on the individual's sense of self, but also as a 'dangerous opportunity'

(Frank 2002) that allows for a reappraisal of one's self while even minor illness or discomfort may disrupt the unconscious 'lived body'. Conversely, in the phenomenology of WHM, the somatic and the psychic are not treated as distinct entities, but interrelated aspects of the individual's embodied experiences.

A third dimension of embodiment relates to the experience of self-consciousness that arises from the awareness of other people's judgements about us, based on being observed by others. Van Manen (1990) describes this last dimension:

"This "feeling looked at" may make it difficult to behave naturally and to speak freely...All of a sudden all the eyes are on me and these eyes rob me of my taken-for-granted relation to my voice and my body. They force me to be aware of my experience while I am experiencing it. The result is awkwardness" (p35)

While young people with AS are not critically ill, in the way that Frank (1995) describes, their physical ease may be influenced by Van Manen's 'feeling looked at'. Although diagnosis of Asperger's Syndrome in children and young people is based on a process of interpreting behaviours, it is not the behaviours that describe what it is to be - 'the way of being' (Van Manen 1990) – for a young person with Asperger's syndrome:

"The essence of autism does not lie in external behaviour and is not outwardly visible. It is a problem of being unable to assign meaning to things." (Vermeulen 2001 p14)

How the behaviour of another human being is perceived by the observer is dependent to a great extent the context for that observation as well as the context of the behaviour:

"To situate our understanding in practices is to see it as implicit in our activity, and hence as going well beyond what we manage to frame representations of...But it is not only my grasp on the inanimate environment which is thus embodied. My sense of myself, of the footing I am on with others, are in large part also. The deference I owe you is carried in the distance I stand from you, in the way I fall silent when you start to speak, in the way I hold myself in your presence". (Benner 1994 pxvi)

Lacking access to the socially preconceived way of being that is 'taken for granted' (Heidegger 1978) by others, people with AS often break the unwritten rules of social conduct in their embodied selves. Being excluded, stared at or

bullied as a consequence of their perceived differences may lead to issues of stigma and 'spoiled identity' (Goffman 1968). Under these circumstances, under the:

“...critical gaze the body may turn awkward, the motions appear clumsy, while under the admiring gaze the body surpasses its usual grace and its normal abilities.” (Van Manen 1990 p. 104)

Frank asserts the way many people transcend the experience of illness is through the process of narrative or the telling of their story. They progress from being a victim of illness to a proactive narrator or 'wounded storyteller' (Frank 1995).

This study is not presented as from within a social sciences narrative methodology. However narrative is intrinsic to interpretive phenomenological study; both offer a vehicle for accounts of lived experience (Van Manen 1990; 2000; Denzin & Lincoln 2005). Frank's (1995) ideas of narrative as part of a healing process are additionally encompassed within the practice of WHM and the meaning people bring to their experiences of health and illness. Mills (1991) describes WHM as practising from within phenomenological principles which enable patients to reclaim their experiences of illness as their individual stories. Despite modern emphasis on objective measurement of clinical evidence:

“the success of rational thought is success at a price, perhaps a price that may yet be too much to bear... patient after patient... say that the priest of rationalist scientific medicine either is no longer effective or does not even seem able to understand their story any more”.  
(Mills 1991 pp 16-17)

Narrative, in WHM, is the story told within the clinical setting and written down as a patient's case history (Mills 1991; Evans 2009). In parallel, the research data within my hermeneutical phenomenological study is made up of collections of 'personal life stories' (Van Manen 1990). The aim of hermeneutical research in health-care is to develop a narrative that will offer an insight into the experiences of people involved in a particular practice or medical process (Benaroyo & Widdershoven 2004). Hermeneutic phenomenology in the context of this study is seen as being the philosophical basis from which to create a narrative of the experiences of the girls with AS, their parents and the medical herbalists treating the girls.

### **3.3 Method**

#### **3.3.1 The case for case study.**

This research has been carried out using a case study approach. This approach is in keeping with hermeneutic phenomenological research inquiry where lived experiences of individuals are explored with the aim of providing insight into a wider population and advancing our understanding into a wider area of interest (Stake 1995, 1998, 2000, 2005).

The case study model has evolved through its use in a wide range of fields including in the practice of many of the social and health sciences, where the case study is used as a means by practitioners of recording the details of each of their cases, both individuals and groups. The kinds of details recorded may depend on the professional field involved and the information required, but is often a combination of quantitative and qualitative data. Case studies in the health professions of individual patients include information from in-depth interviews with participants and key informants, a review of the medical records, observation, and excerpts from patients' personal writings. Case studies in this context have a practical purpose and are used to inform the participants' diagnosis or treatment (Zucker 2001).

The term 'case study' is commonly perceived as referring to a qualitative approach to research within primarily the social sciences (Hammersley & Gomm 2000). However, as a research strategy, case study may be encompassed by different epistemological assumptions (Mays & Pope 2006, Miller & Crabtree 1998, Fishman 1999; Stake 2005). The case study is not a methodological choice but a choice of what is to be researched (Gomm et al. 2006). The methods by which the research is carried out depend on the standpoint of the researcher, the aim and the questions being asked (Stake 2005).

Similarly, the use of the case study has been developed by researchers across the fields (Hammersley & Gomm 2000). Case study research may be approached from different ontological and epistemological perspectives in each field and may utilise a wide range of methodological approaches. Stake (1995, 1998, 2000) for example, describes the case study in a pedagogical context, while drawing from a range of research philosophical and methodological

traditions, including ethnography, phenomenology and biography. For Stake (1998, 2005) the case study is defined as a bounded, integrated system, a study of what is unique.

Fishman (1999), from the perspective of research methods in psychology, has looked at the use of case study across three paradigms, positivist, pragmatic and hermeneutic. However, case study is not a methodological choice but a choice of what is to be researched and the methods by which the research is carried out will depend on the standpoint of the researcher, the aim and the questions being asked (Stake 2005).

The case study approach is commonly applied in health care where the aim is to study a particular health care intervention or assess the implementation of a new policy (Mays & Pope 2006, Miller & Crabtree 1998, Stake 2005). Benner (1994) and Zucker (2001) have investigated the use of case study approaches to research within nursing, but from different perspectives. Benner (1994) sees the case study as a strategy for the organisation of data within an Interpretive Phenomenological framework while Zucker (2001) makes an argument for the development of case study as a methodical approach appropriate to nursing research.

While case study research is sometimes carried out with a large number of participants in each case, the interpretive phenomenological context for my study demands an ideographic approach with an emphasis on the suitability of the individual case to answer the research question rather than on how many are available to answer the question (Reid et al. 2005). I have taken an instrumental approach (Stake 2005) in which interpretation of the participants' stories are presented in this study as an opportunity to:

'engage in the practical world of the participant and come closer to the lived experience, the understanding of the transition as it unfolds, or a particular way of being in the world' (Stake 2005 p114).

The major limitation of case-study research within a qualitative approach is perceived as being the inability to generalise findings to other cases, settings or populations. Responses to this perception may aim at compensating for perceived deficits through an increasing accumulation of data. Yin (1984, 1994) for example, recommends that the case study should include as many examples or cases as possible in order to justify findings being generalised to a wider

context. This approach reflects late 20<sup>th</sup> century positivist, quantitative emphasis in human science research and not a commitment to a deeper understanding of the 'lived experience' (Van Manen 1990).

Case study research is also described as 'basically a sampling method' (Barbour 2006) and sampling within case study research aimed at achieving 'diversity rather than representativeness' (Barbour 2006).

However, Barbour's statement implies that the case study approach requires a number, and by implication, as great a number as possible, of examples in order to include a wide range of diversity.

The development of hermeneutic phenomenological approaches in health care research has included the concept of the 'paradigm case' as a means of describing otherwise poorly understood events where the reader is offered an interpretation and opportunity to engage in the practical and lived experience of the researched, and to increase understanding of a phenomenal transition or:

'a particular way of being in the world' (Benner 1994 p114).

However, to Benner, the paradigm case has value mainly as a starting place from which to compare other cases in the same research set as well as a strategy for presenting the findings. Benner's hermeneutical phenomenological approach is explicitly founded on Heidegger's critique of the Cartesian model in human science research as being:

'deprived of and disengaged from the understanding [of everyday being-in-the-world] that presupposes it' (Benner 1994 p74).

The case study methodical approach is described as being in keeping with hermeneutic phenomenology and as offering a vehicle for the telling of each unique participant's story. However, despite this, Benner recommends finding as many examples within a case study in order to provide evidence of generalisability, thereby reflecting Yin's positivist perspective.

There has been an evolution from this positivistic stance on case study research into a greater understanding of the case study as carried out from within alternative paradigmatic perspectives. Fishman (1999), for example, views the case-study as core to a 'pragmatic' perspective in psychology research. Fishman, however, differentiates research underpinned by the philosophically-

based hermeneutics from his 'pragmatic' definition. In the field of health psychology, Interpretive Phenomenological Analysis has developed a definitively ideographic approach. Emphasis is clearly on the suitability of the individual case to answer the research question rather than on a drive to create diverse and numerous answers to the question (Reid et al 2005). Arguments in favour of ideographic methods within case-study research have included those in support of causal or narrative analysis as a way of creating more in-depth and realistically grounded accounts of causal processes (Becker 2000). However, this raises questions as to whether the approach is more of an appendix to outcome-based research than an alternative approach in itself (Gomm 2000). It can be argued that only a comparative analysis of a number of cases can realistically provide the appropriate setting for any kind of causal inference (Hammersley et al 2000).

Concepts of 'naturalistic generalisability' from within case-study research, or transferability, offer alternatives to propositional generalisability as pursued within quantitative research. Stake's arguments for this alternative perspective (1995, 2000) reflect precepts of hermeneutic phenomenology within human science research.

Limitations of current health practice mean the individual patient's lived experience is interpreted from the perspective of a paradigm that seeks to quantify and contain both the manifestations of illness or disorder and any therapeutic intervention. By doing so, modern health practice describes the story of the individual's experience in such a way as to obscure the thoughts, feelings and perceptions of the individual and therefore the meaning of the experience to them (Frank 1995). Hermeneutic phenomenological research seeks to address this by offering illumination to individual experience, albeit it illumination within the boundaries of a particular horizon.

The case study approach has been termed a:

'triangulated research strategy' (Tellis a, b 1997)

However, what is understood by 'triangulation' in research may vary and the use of a triangulation technique in a case study is not inevitable. Triangulation across the research approaches has been used with data, between investigators, theories, and even methodologies (Denzin 1984, Annells 1996,

Tellis a, b 1997). The use of data-source triangulation in ethnography, involving data from a number of respondents within one study is discussed by Hammersley & Atkinson (2005). Although the discussion is articulated in the language of validity, it does raise concerns as to the dangers of assuming multiple perspectives in themselves bestow credibility and they also suggest that there is no right and wrong perspective on a phenomenon, only a contextual one. However, a concept of triangulation commonly held is that it is a means of providing confirmation or corroboration by using data from a number of sources or mixed methods (Keen & Packwood 1995).

This concept is not relevant to the hermeneutic phenomenological inquiry. Concepts of credibility, transferability and dependability are proposed as alternatives (Koch 2006). In hermeneutical phenomenology, a constructivist perspective acknowledges that no observations or interpretations are identical and seeks further understanding through a process of dialogue, a dialogue that takes place between researcher and text, or researcher and participants in an evolving process termed the hermeneutic circle or cycle.

Bender (2000) describes her hermeneutic phenomenological approach from a relativist perspective that the only significant, or possible, meaning is that attributed by the reader of a text, and always brought to a phenomenon, not derived from it. However, Bender (2000) does expand on this with an explanation of the hermeneutical research process in which the researcher or author, while acknowledging the importance of context, also has what Stake (2005) describes as a responsibility to the interpretations derived by the reader. The researcher, according to Bender (2000) is required to follow contradictory paths, both maintaining the autonomy of the research subject and developing great familiarity with it. The researcher must articulate the meaning of the phenomena from their own and the subjects' epistemological frames of reference. They must at least strive, in other words, not so much to follow contradictory paths but to bring them to a common way, to bring about a merging of horizons of all participants.

The context of this research study created its own boundaries and limitations. Limitations of lack of generalisability are only limitations if generalisability is what is required. However, arguments in favour of authenticity rather than



generalisability may be countered by acknowledgement all research is bounded within the restrictions imposed by the research setting and by the perspective taken by the researcher themselves. Hermeneutic phenomenological research addresses this through its theoretical foundations with the role of the researcher explicitly defined in relation to the lived experience of the research participant. However, that all research studies carry their own limitations cannot be refuted. The specific limitations of this study are discussed further in Chapter 6.

In the context of therapeutic intervention for those with ASD, the quotation below reflects the widely reported experiences of clinicians and professionals working across the disciplines, that manifestations of the autism traits and the difficulties, and therefore management, therapeutic or educational interventions require to be unique to each individual (Klin et al. 2005, Vermeulen 2001).

“...each autistic person’s experience of autism is different from every other person’s experience of autism because the linguistic causes differ in each case. There is no such thing as “one” autistic viewpoint.” (Stillings 2007 Medscape Psychiatry and Mental Health posted online 28.9.07 accessed 12.10.07 at [www.medscape.com/viewarticle/554579](http://www.medscape.com/viewarticle/554579))

It is in this context combined with the other factors described that it was decided to conduct this research using a case study approach. The case study approach is in keeping with hermeneutic phenomenological research inquiry, which is founded on:

“a philosophy or theory of the unique” (Van Manen 1990 p 7)

Approaches to case study research are all grounded in the ‘singular’, or unique, case but each approach may be ‘intrinsic’, ‘instrumental’ or ‘collective’. The differences are between a single, particular case chosen to illustrate a particular problem, issue or situation (intrinsic), studies where the area of interest is a population or general condition (collective), and studies where the aim is to provide insight into an issue or indeed to question existing generalisations and where cases are chosen to advance our understanding into a wider area of interest (instrumental). This study has taken an instrumental case study approach (Stake 1995, 2005). In this study, the individual cases studied have been chosen because they each represent a specific lived experience but may provide alternative perspectives and insight into a wider population, that of girls

with Asperger's syndrome and a wider situation of interest, that of treatment of anxiety in girls with AS by medical herbalism.

The best case for case study in research may be that it adds to our existing understanding of human experience. In turning its spotlight on the unique, the case study is likely to investigate the nature of the case, its historical and physical settings, other contexts such as political or economic (or perhaps social), other related cases and:

“those informants through whom the case can be known” (Stake 1998)

There is a paucity of literature on girls with AS from any methodological perspective. The findings in the available research literature show that children and adolescents with AS, boys and girls do experience elevated levels of anxiety but the ways this manifests are variable and resist quantification. Girls may manifest anxiety in different ways to boys. Existing assessment tools are shown to have inconsistent results. A case-study approach therefore, was chosen for the current study in order to address the need for examining experiences of anxiety with the aim of informing intervention and treatment.

In this case, the informants were identified as being the girls, their parents and the herbalists who attended the girls. In each case study of a girl with AS, a parent's views were explored as a means of adding to an illumination of their child's experiences as well as expressing their own. The experiences of all three participants in each case set were taken as a means of elucidating the phenomenon.

In my study, each girl's story was considered in the context of a 'data set' of participant girl, her mother and the WMH with whom they consulted. These data sets represent examples of the case studied, which is girls with Asperger's syndrome and anxiety undergoing a course of WHM as described by the individuals best positioned to articulate the phenomenon, the girls, their mothers and the WMH involved.

### **3.3.2 Sampling**

In qualitative research, unlike quantitative sampling where the aim is to involve a representative population, the findings about which can be generalised to a larger population, the aim is to develop a deeper understanding of the

phenomenon under investigation. Methods of sampling in qualitative research enable the researcher/s to select the participants most able to provide extensive, in-depth, pertinent data to the research questions being asked.

In order to gather the richness of data that would provide the depth of understanding sought, I adopted sampling methods most appropriate to finding those participants (Van Manen 1990; Stake 2005). Purposive sampling is used where the aim is to include participants who are best placed to help achieve in-depth, explanations of the phenomena under investigation and therefore, I instigated a purposive strategy for my sampling. Additionally, the purpose of the sampling method for this study was to find a small number of participants with very specific inclusion criteria. Therefore a combination of purposive and networking methods was used for this study.

Networking, or snowballing, is sometimes used in quantitative research but more often in qualitative research. It uses social and other network systems to find potential participants otherwise difficult to reach, who may be out-with government service provision in health or social care, but who may be reached through informal, voluntary or self-help groups and networks (Burns & Grove 2005). At the onset of my study, there was an absence of research data from within any methodology on girls with AS. It was officially still considered at that point that girls were proportional to boys with AS at a ratio of approximately 9:1 (Volkmar et al 2005). This has since changed to 4:1 (see NAS website), although girls with AS obviously still represent a small minority.

As the sample population I was seeking was very small with progress in diagnosis and service provision primarily parent-led, networking was considered to be an appropriate sampling method. Additionally, profound difficulties with the diagnosis of young people with AS generally, but girls more specifically, was already reported with diagnosis often being unhelpful (eg Atypical Autism) or even misleading (eg Semantic Pragmatic Language Disorder) I was seeking children, moreover, whose difficulties were at a stage of development where parents are often actively searching for support structures or appropriate interventions but whose special needs may fall between local service provision structures (Brogan 2002).

### **3.3.3 Inclusion criteria**

#### **3.3.3.1 Girls**

- to have been assessed and diagnosed according to recognised guidelines, by a suitably qualified professional or assessment team
- between the ages of 10 to 15 years inclusively
- no evidence or diagnosis of a serious co-morbid condition such as cancer, or to have been previously diagnosed as having a clinical anxiety disorder or mental health condition for which was currently receiving pharmaceutical medication.
- access to computer and internet facilities for reasons described below under the section on data collection methods, and to be able to use them.

This last would obviously create some further limitations to the recruitment population with the risk of excluding families with poor socio-economic status. Consideration was given to ways of circumventing this, including investigating the possibility of the girls using school facilities. However, I felt it important that the girls were able to access the online diary facility at a time that suited them and so decided to include the home computer access in the criteria.

#### **3.3.3.2 Mothers**

Initially recruitment was for a parent of each participant girl to be involved; however, it was mothers only that fitted the criteria for those that responded to the study information disseminated.

- to live full time with the participant girl
- no evidence or diagnosis of a serious condition such as cancer or a previously diagnosed mental health condition for which receiving treatment, such as depression or GAD.

#### **3.3.3.3 Herbalists**

The herbalists were qualified professional medical herbalists, holding a recognised academic qualification, current professional insurance and membership of the National Institute of Medical Herbalists (MNIMH). The herbalists who took part were recruited using a direct purposive approach through the professional network and selected because of their training, experience and professional status and to provide a broad geographical spread. As described in Chapter 1, my insider status within this study means I have access to the membership of the NIMH as well as other herbalists who have chosen not to take membership. I personally contacted a number of herbalists I

knew professionally, either as colleagues, or in 2 cases as WMH who had been involved in my own training to initiate recruitment. When individual herbalists expressed an interest in taking part in the study, I sent them the information packs (see below) for their consideration for a minimum of two weeks.

### **3.3.4 Recruitment**

Volunteer participant girls and their parents were sought in the following ways:

Adverts for suitable volunteers were placed through the Strathclyde Autism Network Newsletter which is funded by the National Centre for Autism Studies and which publishes a regular online newsletter.

The research department at the National Autistic Society was approached for help with recruitment and adverts for participants were placed on the NAS website (Appendix 3).

The NAS 'Help' Programme in Scotland sent details out to families with girls with AS on the 'Help' database.

Approaches were made to individual parent-led and voluntary groups across the country with information packs sent out to named members. (For contents of information packs, see Appendix 4).

Details were also posted on the websites of the Scottish Autism Service Network, an international discussion forum for parents and professionals, and the Special Needs Information Point (SNIP) in Edinburgh.

- Napier University posted a press release on their website, from which an article was printed in a local newspaper.
- Details of the study were sent out to 10 families identified as having girls with AS within the age range via SNIP, a parent-led voluntary organisation associated with the Dept of Community Health at the Royal Hospital for Sick Children in Edinburgh

The participants initially were four young girls aged 10 to 15 years with a diagnosis of Asperger's syndrome living in Scotland, their mothers and five professional medical herbalists recruited, although only 3 herbalists were eventually required for the study. The recruitment information asked for girls with AS within the age group and a parent of each, but it was mostly mothers who

applied with their children. This reflects the available research literature, that mothers carry a greater level of burden in the care of children with ASD or AS, are more likely to suffer anxiety and increased stress levels and to seek external support (Allik et al 2006 ). One father did apply to take part, but with his son, should the study expand to include boys. Several parents applied to take part with their children but were not included on the grounds of locality (eg London); sex of child (several mothers of boys with AS contacted the study); diagnosis (some were still seeking diagnosis of AS) and age (one phone call was received from the mother of a woman in her twenties). All people who applied were replied to and if appropriate offered contact details of organisations such as NAS or NIMH. Those who fitted the criteria were sent an information pack and consent forms.

Four girls and their mothers were initially recruited; one of these girls and her mother withdrew from the study. Although the girl, according to her mother, had initiated interest in the study after reading about it in a local newspaper, when she arrived for her initial IMS interview, it was apparent she was extremely uncomfortable, at one point becoming quite aggressive with her mother, and I suggested we defer. The mother had felt it would be better to hold the meeting at my house, but in the event, this may have been a mistake. We agreed on another meeting date, at their home, but again, the girl appeared reluctant to participate. However, when I stopped trying to talk with her and turned instead to the mother, the girl gravitated towards where we were sitting and sat very close, not taking part, but clearly interested. She did agree with me she would attend the herbalist and did indeed attend her first consultation. The herbalist reported, however, that she found it very difficult to carry out a conversation with the girl who appeared reluctant. Although the mother carried out an initial interview with me and expressed her willingness to have the data collected included in the study, I considered this not appropriate in relation to the consent terms and therefore it is not included in the findings. Steps taken to facilitate informed consent are detailed below in 3.3.5.2.

### **3.3.5 Ethical considerations.**

#### *3.3.5.1 General Principles*

The consideration of ethical issues in any kind of research is paramount. Where

the research involves people, there are specific issues identified as issues of rights; safety, and wellbeing; consent and confidentiality (MRC guidelines 2004). 'Rights' means the protection of those factors necessary for human self-respect, dignity and health, defined as the rights of self-determination, privacy, anonymity and confidentiality, fair treatment and protection from discomfort and harm (Burns & Grove 2005) The ethical principle of beneficence maintains a requirement to do good, but above all, to do no harm; participants' safety and protection must be ensured (Burns & Grove 2005).

Therefore, before proceeding with this study, permission was sought and gained from the Edinburgh Napier University Faculty of Health, Life and Social Sciences (FHLSS) Research and Ethics Governance Committee. Ethical approval and endorsement was also sought and given by the research branch of the National Autistic Society.

#### *3.3.5.2 Informed consent*

Information sheets designed for the girls, on the study and on WHM, along with consent forms to sign were sent on application. They were then given a period of a minimum of two weeks to consider the information and discuss with their mothers before commencement of the study.

The girls were informed that all information and website material they provided during the study would be held by the researcher only and they would be given anonymity. That they did not have to participate in the study and that they were free to withdraw at any time was stated on the information and consent forms. The girls (and their mothers) were told that if they found the keeping of the diary too difficult or distressing then they should not feel obliged to keep going, even if they intended to come back for the next interview.

Issues of confidentiality and anonymity, as discussed above, were also addressed for the parents taking part. The parents were given written information sheets outlining the purpose, aims and procedures for the research. Written consent was also gained from the parents.

All the information sheets and consent forms were sent out in the form of information packs, along with details for an independent named contact who would be aware of the study and able to answer questions. My university

address, telephone number and email details were also given. Self addressed and stamped envelopes for the return of the consent forms were supplied with the information packs. For an example of the information pack, see Appendix 4.

The herbalists were also given information sheets and consent forms to sign. They were offered anonymity and each given, or chose for themselves, a pseudonym. The profession is a small one however, and during the course of writing up the findings, I realised that giving anything but the most basic of information on the herbalists would almost certainly identify them, at least to other WMH, but also perhaps to some of their patients or members of their families. I returned to each of them to ask for clarification, with assurances there was no preference at all on my part. Two chose to limit the background information given and to retain their anonymity; one asserted their willingness to have their own identity used.

#### *3.3.5.3 Further considerations*

##### *i) Data protection:*

In the course of this research it was also important to ensure protection of the herbalists, to ensure their professional integrity was not compromised. Professional Medical Herbalists are expected to adhere to the requirements of data protection law in the UK, as detailed in the Data Protection Act 1998 (Information Commissioner's Office [www.ico.gov.uk](http://www.ico.gov.uk) accessed 16.2.07) which means safeguarding their patients' anonymity and confidentiality. Therefore patient case notes are held by the herbalists in accordance with data protection requirement.

All data collected from all participants is stored in secure conditions with access only by the researcher.

##### *ii) Child Protection:*

I undertook Child Protection training in line with The Children (Scotland) Act 1995 (summary available at [www.scotland.gov.uk](http://www.scotland.gov.uk) accessed 16.2.07). The girls were informed that should I become aware of any situation where the girls were being harmed I would have to inform whichever adults would be appropriate to the situation. This would have ranged from a parent if they revealed they were being harmed out-with the home to a relevant service provider in cases of abuse



or neglect in the home. This course of action was not required during the study.

iii) Supported information:

It is recognised that having a child receive a diagnosis of AS can cause a great deal of distress for parents (Allik et al 2006). While it was likely the parents of participants in this study would already have a support structure in place, a list of contact details of statutory and voluntary services was made available, such as *Help!* which is run by the National Autistic Society and is a service offered to parents of children recently diagnosed with AS.

iv) Therapeutic intervention:

Consideration was also given to the ethics involved in offering a form of therapeutic intervention itself. There is a changing attitude in research emerging that questions assumptions about the position of children with an increasing shift in emphasis in both social and health research from children as 'objects' of research, from 'becoming' human adults, to 'being' themselves (Clark 2004). Hart's (1992) 'Ladder of Participation' defines 8 steps to levels of children's participation in decision-making processes, ranging from non-participative ('manipulation', 'decoration', 'tokenism') to 'adult initiated, shared decisions with children' and 'child-initiated, shared decisions with adults'. There is an emerging sociology of childhood that sees children as actively constructing their own lives, participating in and negotiating their own health care, education and social welfare, having knowledge and skills that often go unrecognised, and being "competent reporters of their own experiences" (Elliot & Watson 2000). As well as theoretical recognition of the right of children to have their experiences heard there is evidence to suggest children who are consulted on their medical conditions are more likely to be compliant to treatment and to have better health outcomes (Alderson, 1995). Therefore there is a balance to be found in order to allow young people to have their voices heard while recognising the role of the responsible parent or carer who must make decisions regarding their child's healthcare.

In light of this, and in line with the ethical requirements of carrying out research in the area of health-care interventions under any circumstances, it was important the participants had the opportunity to continue treatment after completion of the study as agreed between the girls, their mothers and the

herbalists. It is not always possible to predict the effectiveness of treatment or how long the process should continue in WHM – this will vary with each individual case.

Lack of state-mediated subsidy and the consequent cost of treatment is an issue still to be addressed in WHM. Social inequities dictating access to resources and influencing their patients' lived experiences cannot be ignored. Participants were aware the WHM treatment would be paid for by the study for its duration, including the cost of the initial hour-long consultation and three follow-ups, and any herbal medicine prescribed by the WMH for that time. Participants were given information regarding reduced rate clinics in case they wished to continue with herbal treatment but were unable to finance it. Out of the three participant sets, or examples of the case, in one the question of cost was explicitly raised when discussing the possible continuation of the herbal treatment. Both the girl and her mother had seen a marked improvement in the girl's overall wellbeing since starting the herbal treatment and the girl wanted to continue with it. However, her mother expressed concern at the prospect of financially committing to further treatment. The offer of reduced-cost treatment was reiterated but ultimately the decision had to rest with the girl's mother.

### **3.3.6 Data Collection**

#### *3.3.6.1 General principles*

Qualitative researchers can draw from a range of diverse traditions within research methodologies, some of which are allied to particular disciplines in social science, such as phenomenology from philosophy and ethnography from social anthropology (Burns & Grove 2005). The process of data collection within a qualitative framework may be complex and "multi method". Studies employ, for example, a selection of methods from participant observation, individual interviewing, focus group interviewing and others. Further, there are multiple approaches to analysing the data generated by qualitative enquiry, including qualitative content analysis, grounded theory, discourse analysis and hermeneutic phenomenological analysis (Lawler 1998; Robertson 2008). Nonetheless, there are characteristics that are associated with qualitative research generally. Induction underpins the design, fieldwork and analysis of most qualitative work. Reflexivity and subjectivity are important characteristics of

approaches to data collection within qualitative studies.

### *3.3.6.2 Questions of rigour*

Debates on questions of methodology extend beyond philosophical interpretation to issues of quality and the development of criteria for judging the research study (de Witt & Ploeg 2006). In quantitative research, criteria are based within concepts of internal and external validity and reliability, criteria based on a rationalist world view that the role of scientific research is to increase our knowledge of external, verifiable truths, independent of our own perspective. Rigour is the term set to encompass these criteria. Criteria for judging quality, or what constitutes validity, in qualitative research have been developed against this positivist world-view backdrop dominating 20<sup>th</sup> century thinking in health care (Denzin & Lincoln 2005).

However, there is still no agreed set of quality criteria in qualitative research. (Sandelowski & Barroso 2002) The appropriateness of using predetermined criteria to judge qualitative work has been questioned on the grounds that there is no unified research paradigm within the field of qualitative research Rolfe (2006) and a suggestion made that:

‘The search for a generic framework for assessing the quality of qualitative research should be abandoned in favour of individual judgements of individual studies.’ (p309)

Rolfe makes use of Sandelowski’s (1993) terminology to describe quality as ‘subject to the wise judgement and keen insight of the reader’ (Rolfe 2006). Moreover, for some:

‘use of a generic set of qualitative criteria of rigour for interpretive phenomenological studies is problematic because it is philosophically inconsistent with the methodology and creates obstacles to full expression of rigour in such studies’ (de Witt & Ploeg 2006 pp215-229).

Questions of what constitutes rigour in qualitative research including interpretive or hermeneutical phenomenology are controversial but inextricably bound up with the philosophical basis of the research approach. In hermeneutical teaching, the quality of the answer not only reflects the quality of the question, but the receptiveness of the questioner to hearing the response. Preparation for this must, however, surely include clarity of judgement criteria, although those

criteria may be broad and inclusive and certainly be different than those used in quantitative modes of research.

Criteria widely accepted in qualitative research termed 'transparency' and 'trustworthiness', (Lincoln & Guba 1985; Koch 2006) have been revised by Denzin & Lincoln (2005) who have offered the criteria 'trustworthiness and authenticity, including catalyst for action'. In relation to my study, this last criteria can only be judged as a consequence of future events, but the case-study approach, described below, is in keeping with Fishman's (1999) advocacy model in qualitative research, which by definition suggests a 'call', if not a 'catalyst' to action. Trustworthiness is to be found in the presentation of the data. Clear documentation of the various decisions made during the different stages of analysis as defined by Lincoln and Guba (1985) is answered in interpretive phenomenology, by analysis that is embedded in rich description of the data (Van Manen 1990).

Terms such as credibility and confirmability are also used to define foundational components of trustworthiness (Clayton & Thorne 2000). The credibility of my study is based on steps I have taken to ensure the perspectives of my study participants are represented as clearly as possible, such as extensive use of quotations from the textual data.

Confirmability is sometimes dealt with by returning to participants at defined stages of the research process; the hermeneutic cycle of moving from detail to whole is ongoing throughout the research process, as knowledge is constantly evolving. I moved from each stage of the research using the knowledge gained to inform the next in each example of the case; the IMS interviews and the online diary entries examined with a view to the second interviews. Findings from each stage of data collection were checked with participants at the next. Records of consent, the interviews, transcripts and stages of thematic analysis were kept, along with the audio and written records of reflexive notes. Confirmability is entrenched in transparency of the research process and an ongoing principle of the study. Concepts of trustworthiness and transparency are therefore interrelated as are trustworthiness and authenticity.

Authenticity is found in the articulation of the methodology chosen and an awareness of the role of self as researcher. The authentic voice is clearly heard

in description of the research process articulated while carrying it out through a process of reflexivity (Koch & Harrington 1998; Denzin & Lincoln 2005). The role of reflexivity is discussed below.

### 3.3.6.3 *Reflexivity*

Hermeneutic phenomenology may be defined within human science research as offering:

‘not to develop a procedure for understanding but to clarify the conditions that can lead to understanding’ (McManus Holroyd 2007 p1).

McManus Holroyd (2007) further provides a metaphor for the process of hermeneutic phenomenological inquiry as a process of parenting: as a non-parent, we are likely to have a preconception of what we believe parenting to be. Those preconceptions may include judgemental attitudes towards parents who do not appear to fulfil our expectations of what a parent should be and do. It is only through the different reality experienced in being a parent ourselves that we come to an understanding of parenting beyond our intellectual conceptualisation.

Reflexivity is consciously reflecting on the personal perspectives owned as researcher:

“Thus we are certainly interested in the subject matter, but it acquires its life only from the light in which it is presented to us. We accept the fact that the subject presents different aspects of itself at different times or from different standpoints. We accept the fact that these aspects do not simply cancel one another out as research proceeds, but ... exist by themselves and combine only in us” (Gadamer 1996 p 285)

All research, including that carried out from a reductionist or positivist perspective within the human sciences, is historically and contextually bound. The interpretation of any text, or data, be it historical or the results of modern scientific research is determined by the significance it assumes in the perspective of the investigator. The concept of objectivity in any research is not accepted from within this methodology (Gadamer 1996). Hermeneutic phenomenological interpretation requires acknowledgement of this perspective.

As an individual, I speak and write as a person with a point of view. Moreover, as a practising WMH I have another perspective on what I have seen and heard

in the course of the study. Plato's description of the physician's practice (Jowett 1861) is echoed in descriptions of interpretation in phenomenological research as analogous to the process of clinical practice requiring:

'the ability to do engaged reasoning in particular situations and particular texts' (Benner 1994 p103).

In this context, the clinician must learn to defer judgement, which in a clinical setting is usually required to be immediate. The clinician is asked to develop the faculty of reflexivity along with a relinquishing of preconceptions related to clinical and health related interventions. In other words, the clinician involved in hermeneutic phenomenological research must learn the skill of inaction in order to allow the lived experience to be expressed. 'Patience' and 'silence' are cited as important factors in the data collection process (Van Manen 1990). The purpose of this patience and reflexivity is to allow a closer and more direct encounter with the experience as lived. To reflect phenomenologically on accounts of others' lived experiences is to reflect from the perspective of one's own.

My insider's perspective as a practitioner and teacher of WMH is acknowledged and every effort was made to maintain as realistic a perspective as was possible. Throughout this research memories of clinical and teaching situations were recalled and their meanings to me explored in relation to the emerging data. Throughout the course of this study I created reflexive notes and records in different media, depending on the circumstances. Sometimes I wrote, in a notebook kept for the purpose; sometimes, audio recordings were made, for example, sitting in my car after an interview, in order to capture my first thoughts and impressions. At one point, while investigating the possibilities of an online blog diary as a data collection method for the girls, I created one for myself and used it to hold my reflexive diary entries.

I am also a parent, a mother of two adolescent girls. MacManus Holroyd's (2007) metaphor of parenting becomes a reality for a herbalist-researcher, mother of two girls, exploring lived experiences of girls with AS described by the girls, their mothers and the WMH involved. The further understanding described by MacManus Holroyd, is, of course, of the experience of parenting as lived by us, within the cultural, social, individual environments in which we operate and therefore, our experiences do not necessarily reflect entirely another parent's.

However, our search for meaning within our own lived experiences leads us to understand more deeply what it is to be a person carrying out that role within the social, cultural and historical context in which it is situated (Van Manen 1990).

My experience of parenting, to use McManus Holroyd's example, will not be exactly that of another mother at my child's primary school but it will inform my understanding of her individual parenting experiences. It will also inform my understanding of the parenting experiences of a mother living in a war-torn area of the world or a country ravaged by drought and famine, albeit in a different way, where the implicit similarities between us may well serve to accentuate the differences in our lived situations. Offering a 'philosophy or theory of the unique' (Van Manen 1990) hermeneutical phenomenology brings together, through the lived experiences of the researcher, ontology and epistemology, or 'ways of being with ways of knowing' (McManus Holroyd 2007).

Some years ago, despite varying levels of scepticism, patronage and even antagonism, I had my younger daughter assessed by a specialist clinical psychologist who found her to have an "off the scale" IQ. Her intellectual profile was exceptional. At 9 years old on the day of her assessment our consultant declared she would probably get on well with his fifteen-year-old son and his son's friends on the grounds of her then current interests, language, sense of humour. Culturally, intellectually, socially, my daughter would almost certainly, at least for the duration of her younger years, find herself out of place in any mainstream educational or social setting. What I had perceived in my daughter at eight years old, the reasons for this trip to the psychologist, were the beginnings of the development of a profound loneliness and boredom and a degradation of her self-esteem.

Our consultant expressed two major concerns, one being that because I was the only other adult who had become aware of my daughter's increasing struggles to make sense of her world and her growing unhappiness, I had to be prepared to be accused of being the 'creator of problems' – in other words, if her teachers and other adults around her didn't see there was a problem, it would be assumed the problem was mine. The other strongly expressed warning was that because my daughter is perceived as being hugely capable – which, in many ways, she is - then people throughout her life will have high

expectations of her and will not always understand or even be prepared to acknowledge she has her own struggles.

Since then, my daughter has found a place at a specialist school for gifted children, where her peers are talented, motivated children and where they all, no matter their country of origin or cultural background, have a common language. Her strengths are respected, her individual characteristics are accepted as part of her and the primary focus in her school environment is on her exceptional abilities. At the moment my daughter's unusual intellectual profile is being addressed, her needs are being met.

Although the events described took place after I had started work on this research study, they describe a period the experience of which forms the horizons of my gaze. The stresses and anxieties involved in realising a child has special educational needs are no longer academic to me. Many tears were shed, arguments carried out, battles fought, criticisms and judgemental incomprehension ignored, help sought. My view of, my understanding of, the experiences of both girls and their parents involved in my study are altered immeasurably by the changes wrought in my life and those of my family after I first realised my younger daughter was 'different'.

While allowing the autonomous voices of the participants to be heard, as researcher I must accept the responsibility of authorship, with the choices and decisions I make about what to include and what to leave out and the presentation of the research. I may not be able to determine how the text will be read (Van Manen 1990; Alldred & Gillies 2002), but accountability to the research participants as well as to the readers is an aspect of author responsibility (Gadamer 1996; Lawler 1998; Doucet & Mauthner 2002). There is a challenge in fulfilling my commitment to respect and honour the narratives presented by the individuals involved and to do justice to their stories (Nissan 2009). I too have aimed to find a way to reconcile my point of view with the voices of the participants in my study.

#### *3.3.6.4 Data collection strategies*

The data collection strategy should be consistent with the research philosophical methodology underpinning it while at the same time, the researcher may need to be flexible in response to the unfolding requirements of a developing study.



Qualitative research often involves collecting different kinds of data in order to gain the depth of information required for the aims of the research study and to fulfil the requirements of the philosophical perspective from within which the study is being conducted (Burns & Grove 2005). Additionally there is the case for selecting methods appropriate to the participant population, in this study, girls with Asperger's syndrome.

The term "bricoleur" is used in qualitative research to describe contextual sensitivity, or even creative inventiveness towards the use of data collection techniques. The 'bricoleur' addresses the specifics of the phenomena or question by:

"deploying whatever strategies, methods or empirical materials are at hand" (Becker 1998 p2)

In creating the 'bricolage', the researcher draws from a wide range of methods, materials, and practices within the context of their own practice. Denzin and Lincoln (2005) describe the qualitative interpretive researcher as a:

"maker of quilts who...uses the aesthetic and material tools of his or her craft, deploying whatever strategies, methods and empirical materials are at hand...if the researcher needs to invent, or piece together, new tools or techniques, he or she will do so" (p4-6).

This concept of quilt-maker inventing or piecing together of new tools and techniques in order to elicit the required data was used as a particularly appropriate analogy for research involving girls with AS. A great deal of consideration for this study was given as to the best way of facilitating ease of communication and expression on the part of the participant girls and with computer-mediated techniques as well as semi-structured qualitative interviews and online diaries part of the response as described below.

### **3.3.7 Computer mediated online diaries**

#### **3.3.7.1 Diaries**

Diaries have long been used as a source of data for historians and biographers. In the field of sociology, journal-style diaries have become a way of documenting the lived reality as experienced by individuals, or groups, while the use of diary surveys has become increasingly popular with economists and market researchers as well as sociologists (Corti 1993). There are well-documented advantages to the use of diaries in health research in terms of the

rich textual data they can provide on individuals' health experiences (Verbrugge 1980) and they are often used in clinical settings to evaluate the efficacy of prescribed treatment with children (Burkhart et al. 2001). Diaries may provide a reliable alternative to traditional interview methods that are vulnerable to recall problems and difficulties associated with collecting sensitive information in a personal interview as well. An early example of the use of diaries in a research setting involving children is Charlotte Bulher's 1930 study of experiences of teenage girls (Greene & Hill 2005).

Diaries can supplement data derived from the interview setting with rich data from the daily experiences of the participants. Following a period of diary keeping by in-depth interview referring to the diary entries is considered to be one of the most reliable methods of data collection (Corti 1993). A version of this method was chosen for my study, with an initial interview being followed by a period of diary keeping, using the data derived to supplement and inform a further interview.

Diaries are not infallible, however, with common flaws in diary use being incomplete or inadequate recording (Verbrugge 1980) and respondent conditioning in children specifically ie the participant children creating entries geared to what they perceive is wanted (Burkhart et al. 2001). Sample selection bias is also cited as a problem in diary data collection (Corti 1993). This was not considered to be an issue in my study, where the participants were purposively sampled. However, one of the participants was deemed by her mother to be incapable of fulfilling the online diary requirements and so I created a hard-copy version, as a booklet, to take away and fill in, to be returned at the second interview stage. This was not achieved, whereas the other participants did use the online version and so there was an element of self-selection bias within this sample.

Of the other two weakness in diary method cited, neither of the girls who used the diary facility used it consistently but both made entries that were revealing as to their daily concerns and which were used to enrich the second interviews.

#### *3.3.7.2 Visual and pictorial methods*

The use of visual and/or pictorial techniques to communicate with children in a research context additionally has a great deal of precedence. Research projects

worldwide have used pictorial techniques to allow children tools for expressing their own perspectives of their experiences (Gosling 2003). Wilkinson (2000), describes how many of the methods used in participatory research involving children from around the world use visual techniques including include maps, Venn diagrams, flow diagrams, diaries, photos, video recordings, matrix scoring and network diagrams. Other techniques used include essay writing and poetry, storyboards and individual or group drawings. (for example, see [www.savethechildren.org.uk/eyetoeye](http://www.savethechildren.org.uk/eyetoeye))

The description 'visual thinker' has been found to often apply to those on the autism spectrum (Grandin 1996, 2002) with pictorial aids to communication and learning being developed in response in a range of settings (Pierce & Schreibman 1994; Hodgdon 1995; Dettmer et al 2000). Widely promoted for home and educational use are Carol Gray's 'Social Stories' and 'Comic Strip Characters' (Gray & Arnold 1991) which use cartoons and drawings to visually represent social situations and interactions as a tool for the development of social skills and which Gray developed from a nine-year old girl with AS' own self-initiated strategy for learning. There are several such pictorially-based tools for learning and communication now available, such as 'Talking Mats' developed at Stirling University (Murphy 1998). Diaries may be pictorial, using photos, video clips, montage and drawing as well as text. The development of computer software tools such as WebCT and VISTA and the growth of internet 'blogs' has expanded the concept of diary, in terms of access and mixed media.

For the purposes of my study, multi-media methods of recording the girls' experiences were considered as developmentally appropriate ways of facilitating the girls' participation (Hogan et al. 1999); investigation was carried out into the development of an online computer-based website facility in the form of a protected 'blog' style computer-based tool for the participants to use as a daily emotions diary, with the aim of offering a range of different media to describe their experiences – eg text, photographs, audio clips and so on. Although the blog is mostly known for its extrovert public, and social use, it can be used as a personal journal with a range of creative features attached – the ability to download photographs, for example, or audio clips, or to set up links to favourite internet sites.

Face to face communication normally includes the exchange of multiple, interpersonal cues, from personal appearance and dress, body language, gestures, eye contact, facial expressions and tone of voice and delivery speed. Whether the loss of these may be categorised as a potential advantage of computer mediated methods, specifically online communication, or a potential disadvantage is contested. Some authors (for example, Chen & Hinton, 1999) argue that taking part in on-line research demands greater motivation and engagement in the research from participants than would be required in a conventional, face to face setting. It has also been suggested that the absence of face to face cues and reliance upon only written text can result in more detached, less personal on-line communications and adversely influence the quality of research data gathered there (Clarke 2000). However, being able to interact, unseen, with others in a virtual environment may encourage less confident and less vocal research recruits to have a “voice” through their computers and so generate research data that would not otherwise have been realised (Meho 2006).

This perspective does rely on keyboard-literacy on the part of the participants. In answer to this and to address ‘visual-thinker’ requirements, the possible use of creative methods was explored (Christenson & James 2000) and I envisaged a multi-media tool for the girls to use. This did not prove feasible however, but other steps were taken to address potential lack of textual literacy. Particularly relevant to young people with AS, Clarke also points out the lack visual cues in a communication setting may constitute a social facilitator for people who might be less comfortable in a face-to-face setting (Clarke 2000). The case for computer access for people with ASD has been promoted by a number of people working in the field, most notably Murray et al. (2005), who argue that the monotropic style of perceptual processing in ASD is suited to computer-mediated communication. Computer technology is being investigated as a tool for learning and communication (Murray & Aspinall 2006) for children and young people with ASD, including those with AS. Young people with ASD may find computers easier to engage with than people, in that they can focus on the task in hand without having to also deal with another person’s facial expressions, body language and other distractions (Murray & Aspinall 2006).

### *3.3.7.3 Internet-based research methods*

Benefits in a general population of the use of online communication are outlined, which may also be appropriate with this specific group, ie girls with AS:

- An asynchronous system containing persistent textual records that can allow people separated across distance, time zones, activities can interact.
- Although such communication is subject to disruption, the availability of the text record facilitates participants to manage the interaction more coherently.
- Online activities are reportedly perceived as real and interactive
- Online communications may result in more honest responses, particularly from participants who are asked to reveal sensitive, personal information.
- the asynchronous electronic communication's capacity to provide opportunity for reflection and editing of messages before sending them contributes to the production of a closer fit between ideas, intentions and their expression in writing.
- Responding at their convenience instead of waiting for turn-taking, as required in face-to-face interactions, potentially provides more equality of participation to more reserved participants (Clarke 2000):

There are complex ethical issues raised over the use of internet facilities in research of this kind. The personal site may be given protection from public view if the settings are adjusted and is password accessed. Enthusiasts of the blog are adamant they can be private and confidential, however there is some concern as to whether this really is the case and the consensus within academic circles appears to be developing that it is probably not. Because of the relatively recent development of internet technology as a medium for research, ethical issues as well as logistical ones are emerging on an ongoing basis. Specific qualitative research methods make their own demands concerning implementation of ethical codes. There is no international consensus as yet as to whether the laws concerning ethical governance of the country of origin or country of destination applies to research on the internet with implications for research conducted across national boundaries (Clarke 2000). This concern was not an issue for my study but concerns as to privacy

were. According to Clarke (2000) the answer to questions of privacy, anonymity and confidentiality assurance in online research is negative and United States federal funding agencies will not support such research as encryption and security levels are not adequate, as yet, to ensure privacy and confidentiality.

The point has been made that Internet research is not necessarily inherently more difficult to carry out or riskier to participants than more traditional methods but because of the relatively new nature of the technology, there are questions raised that have been long addressed in more conventional research settings (Meho 2006). Researchers working in this area need expertise, about both online behaviour and technology, involving such issues as security, digital signatures, procedures for stripping identifying information, provisions for one-on-one debriefing all of which require specialised technical expertise in being able to protect the privacy of participants and maintain the confidentiality of data.

In the process of investigating the blog I found that when a user enters a host site to access their blog, they have to negotiate an initial 'home' page, some containing serious news items. I was concerned this might prove a distraction for the participants and at worst, upset or even traumatise younger participants. Alternative technologies such as the 'e-portfolio' tool were investigated. (see [www.pebblepad.co.uk](http://www.pebblepad.co.uk) eg) The 'e-portfolio' provides a host of facilities, including online journal and blog and interactive e-learning facility and may provide much of what was being asked for in this study, but it became apparent it was too complex in terms of ethics, confidentiality and in terms of ease of daily use by the participants. This kind of medium for creating diary-based data within qualitative research might well be a possible method for future study and holds some exciting promise in this area. However, it proved too complex for the current level of website provision through Edinburgh Napier University and using a public server was considered too difficult to navigate for the girls and for the purposes of this study.

What was developed instead was an easily navigated interactive webpage. It was password protected, with a simple text and visual tool, entries into which by the participants could be emailed directly to the researcher. This webpage was served in-house by Edinburgh Napier University's own WebCT provision. The

webpage was very simple and consisted of a thermometer-like design with a scale of five 'temperature' levels in different shades of lavender/purple. As the cursor was carried over each button, a separate heading was revealed 'Very good', 'Good', 'OK', 'Bad' and 'Very Bad' with each button given a number, 1-5. The participant was invited to choose a level to represent the kind of day they felt they had had and then to enter the button number into the buttons below the picture of the 'Feelings Thermometer'. A text box was also available for participants to expand on any aspect of their feelings they wish.

At the beginning of the study, the participant girls were each shown how to access and use the webpage. They were asked to use this facility as a personal journal during the period of the study, which included a 'lead up' period of at least one week to the first consultation with a medical herbalist and the commencement of herbal treatment; it also included a period of four weeks of treatment and one post-treatment. These entries were directly accessible through the website by the researcher and helped to inform the interviews. The entries into this 'diary' were used to inform the next interview with the girls and were also analysed as data sets as part of the overall data analysis. In this respect, the entries were included as textual data.

Examples of these diary entries are given below:

date	time
xx.xx	xx.xx
<b>name:</b>	Lottie
<b>radio:</b>	2 This number refers to the scale, 2 = Good
<b>comments:</b>	I'm good at the moment. I had some herbal stuff and it's not bad.

date	time
xx.xx	xx.xx
<b>name:</b>	Lottie
<b>radio:</b>	3 = OK
<b>comments:</b>	I've had a good day but I tried to do my science homework and I couldn't answer a single question because I was off when my class doing the topic it's about. I can't believe my teacher shoves homework in my face expecting me to know everything about it!

A concern for researchers using online research methods can be the question of the true identities of those taking part in the research (Greenbaum 2002). A researcher's inability to verify the authenticity of on-line participants may not

necessarily invalidate research conducted in cyberspace and the likelihood of enrolling recruits who are not whom they claim to be - and the impact of this on findings - will vary according to different enquiries. Concerns about verification of participants' authenticity were reduced in the case of the on-line diary used in this study because the participants had been met personally by the researcher and the diary tool discussed. The main question-mark would be over the girls' privacy within the home and whether others in the family would be tempted to intervene in any way. In the course of the study, entries received from the girls were of a nature that suggested it unlikely there had been any interference or inhibition. Many of the other issues raised over internet-mediated communication became irrelevant in the context of this study as was there was no interaction involved online.

Finally, Clarke (2000) points out that 'technology will fail' and indeed it does. On one occasion there was consternation for one of the girls at finding the webpage not working. The situation did resolve.

### **3.3.8 Interviews**

#### *3.3.8.1 General principles*

Interviewing is a widely used method and primary research tool (Rubin and Rubin 1995 p 3), effective in many different forms, in different settings, for different purposes: academic, therapeutic, political, market research, marketing, service provision policy, as a tool for social reform and of course, for entertainment (Silverman1994). Techniques range through individual face-to-face interviews using verbal interaction, to computer-mediated communication, telephone interviews, focus-groups (Fontana & Frey 2005). An interview may last a few minutes or may be held over weeks and months (Clarke 2000). Interview techniques vary widely, depending on the requirements and design of the study. My study used the semi-structured world view method in order to obtain participants' own descriptions of their lived experiences. These descriptions were used to build a richness and depth of information from which to interpret the meaning of the described phenomenon (Kvale 1996).

It may be argued that constructed and informed by the context, the perspectives of the interviewer, the physical setting, the cultural, historical background of interviewer and interviewee lead to any findings being situated in the time and



context of the interview. However, the goal of most qualitative interviews and especially the in-depth or semi-structured forms is to improve understanding of social and cultural phenomena and processes rather than to produce objective facts about reality, prove hypotheses or make generalizations to given populations (Meho 2006).

Challenges identified with in-depth interview methods include cost, time, and limited access to research participants (Denzin & Lincoln 2005; Kvale 1996; Strauss & Corbin 1998). In this study, because of the relatively small numbers involved as well as the particular needs of the participants it was considered a combined methods approach using in-depth, semi-structured and structured interviews using computer-mediated techniques would be most appropriate.

The researcher in the role of interviewer is integral to:

“a highly personal process where meanings are created through personal interaction” (Chen & Hinton 1999 3.1)

The context of any interview in historical, political and cultural terms is integral to both method and outcome. All research is shaped by its social and historical location and the researchers will bring the values and interests of their own situated perspectives (Hammersley & Atkinson 1995; Chen & Hinton 1999) By implication, no research endeavour can be an objective exercise. Furthermore, qualitative researchers may hold a world view that posits the existence of created, negotiated, multiple realities and emphasises the relationship between the researcher and what – or who - is being researched. The focus of qualitative enquiries is on processes and subjective meanings with two or more people involved in the creation of a collaborative,

“contextually bound and mutually created story” (Denzin & Lincoln 2005 p 696)

In this view, there are no enduring, context-free statements of “truth”, qualitative findings are situated in a specific time and place and therefore the context, the perspective of the interviewer and constraints on the interviewee, situational, contextual, are acknowledged. These fundamental issues, both practical and conceptual were considered in relation to interviewing with children and young people specifically (Westcott & Littleton 2005).

### *3.3.8.2 Interviewing using the In My Shoes computer interview programme*

Qualitative interviewing is based on an understanding that comes from placing peoples' description of their experiences 'in their own terms' (Rubin & Rubin 1995) foremost. Designing methods by which young girls with AS who may have difficulties in verbal communication could express their experiences was a core part of the challenge presented in this research – visual methods of representation and expression were proposed as a means of expanding and supporting other, more verbal, data, in diary form as described above.

The use of computer software to support the interview process with the girls was chosen as an approach to this work because it was considered potentially more supportive of the girls' individual requirements than to try to use more conventional interviewing techniques for those experiencing AS. The girls were interviewed using a computer software-aided interview technique 'In My Shoes' (IMS). The aims of this interview were firstly, to discuss the girls' experience of anxiety in their daily lives, secondly to discuss their experience of the herbal consultation and any treatment prescribed, additionally referring to the website diary entries and how they used these to describe their experiences. They were interviewed again at the end of the treatment.

I undertook training in IMS and gained a licence to use the interview programme which has been developed as a tool for gaining understanding of children's experiences and emotions, for therapeutic purposes and for sharing information in assessment and forensic contexts. (Glasgow, Calam & Broadhurst 1996) It is used with vulnerable children and adults in a variety of settings, such as foster placing interviews, forensics, with children with Asperger's syndrome and adults with learning difficulties (Calam et al 2000).

The potential use of this package has been summarised by its authors in this way:

"In particular, it has become clear the real value of the package appears to lie in the potential that it offers to establish a point of contact with children who have difficulty in engaging or communicating in assessment or therapy"

The interviews are carried out by the researcher with the child or young person but with the computer as the focus of the interview. The programme is primarily

visual/pictorial and can support communication and expression where there are difficulties in these areas. It also helps to alleviate any stress potentially experienced for someone on the Autism Spectrum of being asked to answer direct questions in a face-to-face situation (Calam et al 2000). It is designed in flexible modules with a range of choices in terms of order, structure, elements within some modules, settings. The emphasis in IMS is the enabling of emotional expression and description of lived experiences.

Pilot interviews were carried out for my study. The purposes of the pilot interviews were threefold. Firstly, to test the appropriateness and efficacy of the In My Shoes software programme as a research tool with children and young people that could facilitate the sharing of their experiences of herbal treatment; secondly, as part of the IMS training to assess my abilities to use the software appropriately and effectively; finally, to test the software's effectiveness with the research study group in articulating their emotional experiences. For this study, five children were interviewed at this second stage. Four of the children comprised two girls of 12 and 13 years and their younger brothers at 7 and 8 years who had all been attending the Medical Herbal student training clinic at Napier University. The fifth was an 11 year old girl who has been diagnosed as having Atypical Autism. Parents and children were informed these interviews were part of the training process in for the use of 'In My Shoes' and a pilot for the main research study and consent was given by the parents and children involved.

The four children, who had been receiving herbal treatment, after the initial modules on emotions and people, were asked questions focussing on their visits to the herbal clinic, their experience of the process of receiving herbal treatment and the effectiveness of their treatment. The fifth girl who had not attended the herbal clinic but who did have a diagnosis of ASD was interviewed with a greater emphasis on her expression of emotional experiences and understanding.

A number of issues arose in the course of the pilot interviews, leading to decisions about the structuring of future interviews and modifications to individual modules within the programme, such as sending examples of the 'Emotions palette' to the girls prior to their first interview in order to make the

process simpler and quicker for them. A fuller discussion of the IMS pilot study is given in Appendix 6.

### *3.3.8.3 The study interviews*

I initially tried to pare down the number of meetings the girls would be asked to attend, on the basis that the less the girls were asked to do, the less stressful it would be for them. The importance of allowing the girls time to accept me as someone who would be asking them questions and to introduce myself to them in person was considered; furthermore, that being in an environment which is familiar and comfortable for them and in which they perhaps had their own 'exit strategies' might be appropriate. Therefore, I asked for an initial meeting, preferably in the girls' homes if acceptable to them and with their mother, during which I explained the interactive diary, gave them the web-page address and login details, and showed them the computer programme that was to be used for the interview. I then made arrangements with the mothers and the girls for the initial interviews.

The process of data collection and analyses is cyclical in Hermeneutical Phenomenology, with each exchange being the basis for the next and understanding derived from the interaction between researcher and study participants, this new understanding being then used to underpin the following exchange. Therefore it is in keeping with this philosophical approach to revise each stage on the basis of what is revealed through the previous (Lingiardi & Grieco 1999, Moran & Mooney 2006). To this end, it was important to clarify that each interview with the girls, although involving the use of different modules within the IMS programme, would not represent a section of one single overall interview but one of a series of complete individual interviews.

The first interview was carried out by me with each of the girls using the 'In My Shoes' computer interview programme as previously described above. From this first interview was gained a computer programme log, with visual and textual data and a recording of the verbal exchanges from the interview.

The aim of the first interviews with the girls was to serve a number of purposes. The first was to gain an initial understanding of the context of each girl's experiences, their school, social and home environments. The second was to establish a basic understanding of their emotional vocabulary, their ability to

identify, as well as articulate, their emotional experiences. The third aim, with reference to the known impact of high levels of anxiety in adolescents, and in particular adolescents with AS, was to gain a greater understanding of the meanings they ascribe to their daily experiences.

Questions around the constructed nature of all research interviews but specifically with children and in particular, the power dynamics inherent in such situations are embedded in a reflexive approach to research. The tendency to assume entire responsibility for the data collection on the basis of choosing the 'right' method or finding the 'right' questions for the interviews is perhaps endemic. However, there is inevitably a gap between experience and expression in anyone, not just children or young people or those with AS and in any interview context. There are distinctions between the life as lived, experienced and told:

“A life lived is what actually happens. A life experienced consists of the images, feelings, sentiments, desires, thought and meanings known to the person whose life it is...A life as told...is a narrative, influenced by the cultural conventions of telling, by the evidence and by the social context” (Bruner 1984 p7)

An understanding of the role of participants in research interviews, adults or children, as co-constructors of any interactive encounter, is required (Westcott & Littleton 2005). Similarly, the participant's relationship with the research study and their view of the interviewer both as instrument of the research study and as an individual must have an impact on what they are prepared or able to reveal about themselves and their experiences. For example, attempts were made to make the interviews with the girls as relaxed as possible. Acknowledging that the choice of where to carry out research may be as important as how to carry it out (Morrow & Richards 1996), choices were offered to the participants as to where they wanted the interviews to take place. This was in retrospect perhaps not wise and my initial instinct, that the interviews should take place in the girls' homes if at all possible, correct. Two of the girls came to my house, but I felt they were less comfortable in that situation than they might have been at home.

One girl, for example, was obviously disconcerted when she saw I had children (their artworks were on my wall). I went from being a researcher to another mother, perhaps, and with an adolescent whose anger towards her mother

became apparent during the interview this was possibly a further barrier to communication with me. Another of the girls wanted to play with our Playstation and look around the house and her attention had to be encouraged to turn from exploring my environment to telling me about her life in the context of hers.

The IMS interview programme is designed specifically with an open-ended mode of questioning in order to elicit non-directed responses from the participants (Glasgow, Calam & Broadhurst 1996; Calam et al 2000). It does have strengths and limitation in relation to these. Its strengths include that it has been specifically designed to be used with children and adults whose ability to express themselves verbally are hampered by their own developmental abilities, emotional vulnerability or situated circumstances. The programme facilitates identification of people, situations, events and feelings using multiple means of expression. It leads the same situations or events to be revisited throughout the interview but from a slightly different perspective, encouraging disclosure and also enabling confirmation. It also creates a setting where the child is not directly confronted within the interview situation but offers mediation and a neutral area of focus. It provided a distraction, in my study, for one participant in particular who reacted to the event initially with anxiety but who became quickly absorbed by the programme and we were able to carry out a very rich interview.

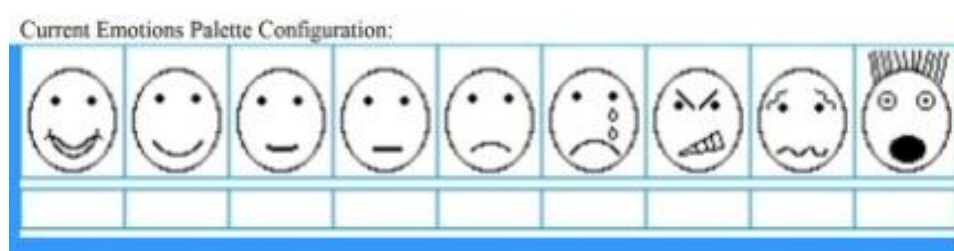
In the context of my study, the weakness of the IMS programme identified is its modular nature. In qualitative research, the interview is designed to be fluid and open-ended, with interpretive phenomenological interviewing encouraged to include few questions on the part of the interviewer (Smith et al. 2003). Although its design does allow for flexibility and expansion and overall, I felt it to be appropriate for the purpose, IMS is inevitably prescriptive to some extent.

In preparation for the initial In My Shoes interview with each girl, and along with the recruitment pack, was sent a sheet containing the faces from the In My Shoes 'Emotions' palette with a request for the participant to label each face with an emotion – in accordance with the interview software programme, the girls were asked to use their own words, and assured there was no 'right or wrong answer'; also that if they didn't know what an expression meant, they should just leave it blank. The response to this was then logged textually into the In My Shoes programme prior to the initial interview. This had several

functions, saving time during the first interview, but also engaging the participant in the process and personalising the programme for each at the start.

The term 'anxiety' was not used in the key questions and in fact was specifically avoided throughout the interviews with the girls in order to avoid pre-empting what might emerge from the data. Rather than ask about experiences of anxiety, the questioning was designed to encourage thought, recall and disclosure of experiences or events that may or may not be associated with anxiety. The aim of the emotions palette was not to ascribe any of the facial expressions specifically to feelings of anxiety in the girls in the first instance but to provide an introduction to each girl's individual emotional vocabulary and understanding which would then be used in the main interviews.

Two of the participant girls took part in two interviews each; the third took part only in the initial IMS interview. The interviews took approximately an hour each. Although every entry in the IMS interview programme using the computer keyboard or mouse is logged by the software and there are facilities within the programme to add notes and indices, any verbal exchange between child and interviewer not recorded on the computer may be lost. It was decided all the interviews would be recorded on an audio digital recorder and the records transcribed verbatim for analysis. An example of an IMS interview log is provided at the end of the thesis as Appendix 7



An example of the IMS emotions palette.

The participant was invited on the Emotions palette sheet to consider and label each expression in turn with a word or words they felt most closely described the expression on the face. If they did not know what any facial expression meant, they were asked to leave the space for the label blank.

#### *3.3.8.4 Interviews with mothers*

The phenomenological interview is suited to hermeneutic enquiry as it applies a mode of understanding in which participants are helped to describe their lived experiences and the meanings they attach to them in their own words (McIntosh 2005) thereby facilitating the means for creating an authentic narrative (Westcott & Littleton 2005). The key research question for the mothers was worded in an interview-friendly form, written down, placed beside me. I led an introductory exchange in which I asked the mother what had brought them to the point of having their child diagnosed. Although this was a different question to the main one it was used to engage the participants and the answers were used to supplement the interview. It is the responsibility of the researcher to encourage reflection and exploration on the part of the participants (Van Manen 1990). In line with the philosophical basis of interpretive phenomenology or hermeneutics where the researcher brings to the situation their own previous experience, knowledge, opinions (Lingiardi & Grieco 1999; Moran & Moony 2006), and in order to make the conversation flow, further questions were asked but only as supplements to the key question.

The open-endedness of the key question was aimed at eliciting subjective and personal responses from the participants as were supplementary questions as the interviews progressed. The question asked of the mothers was:

‘What ideas or perceptions do you have about how your daughter experiences ordinary daily life with all its ordinary demands and challenges?’

The interviews with the mothers took place at: my home on one occasion; the participants’ homes on the others. There was no remarkable difference to the quality of the interviews within these settings and the three mothers who stayed in the study all offered rich and full interviews. Each interview took at least an hour to complete. The interviews were recorded digitally.

#### *3.3.8.5 Interviews with herbalists*

The interviews with the herbalists took place at their places of work, which in one case was the herbalist’s home, where she holds her clinic, one case was at a complementary therapies clinic and the third was in a private space at the university where he works.



The question asked of the herbalists was

‘What were your experiences of treating the girl with AS?’

Each of the interviews took between an hour and an hour and a half to complete and were digitally recorded

### **3.3.9 Treatment of Data**

All interviews were recorded digitally, with the recordings password protected and accessible only to the researcher. All the aural recordings were then transferred digitally to a professional transcription service where they were processed using an ‘intelligent verbatim’ transcription method which transcribes verbatim but with the omission of ‘ums’ and ‘ers, coughs and other involuntary noises, while indicating pauses or other meaningful but non-verbal expressions. Digitally stored transcripts are also password-protected and where printed in hard copy, held securely in a locked container. The IMS computer logs are password protected and accessible only to the licence holder, who in this study is me.

### **3.3.10 Analysis**

Analysis is a process that takes place between data description and interpretation, the two are intrinsically bound. The primary challenge of ‘writing up’ qualitative research according to Wolcott (2001) is one of authenticity. An aspect of that authenticity is about recognising the position of the researcher within the research:

“One of the opportunities – and challenges – posed by qualitative approaches is to treat fellow humans as people rather than objects of study, to regard ourselves as humans who conduct research *among* rather than *on* them” (Wolcott 2001 p20)

Integral to the interpretive phenomenology of this hermeneutical study is a process of reflecting on the descriptive texts of the participants. Texts in this context refers to all descriptions, including those that are non-linguistic ie the IMS transcripts including the emotions palettes (Moustakas 1994). The aim is to identify thematic aspects of the phenomenon, or structures of the phenomenal experience; in hermeneutical enquiry, themes are not categorical or conceptual statements but indicators guiding us to see aspects of the lived experience (Van Manen 1984; 1990).

The 'attentiveness' (Gadamer 1996) required in the context of the medical clinical interview is transferred to a research one; reflecting on the interview or other text continues 'the attentive practice of thoughtfulness' (van Manen 1990) or 'caring attunement' (Heidegger 1978). As an 'insider researcher', I used my training in clinical practice, not only in the course of carrying out the interviews but in the analysis. Reflexive practice is embedded in consideration of the clinical case history (Gadamer 1996; Usherwood 1999) and in initial response to the data, I reflected on each stage of collection and how it added to my previous perceptions. In contrast to quantitative techniques where analysis is held back, in general, until all data has been collected, qualitative research often involves the simultaneous analysis of data along with its continuing collection; the processes of data collection and analysis are interlinked, insights gained from early data collection may be used to inform the next steps (Benner 1994; McManus Holroyd 2007). In this way, analysis takes the form of a dialogue between data and reflection and back to the data again. The hermeneutic tradition stresses the essential nature of dialogue, the flow of question and answer to question and answer as the means of eliciting the meaning behind the language used (Salaman 2007; Gadamer 1996). In phenomenological analysis, this process is one of attending to the meaning of the participants' stories as they have narrated them while being aware of our own perspectives.

After completing the first interview with each girl, I listened to the recording as soon as possible after, to 'run over' in my mind the contents of the meeting, to get a sense of whether it had flowed well, if the questions had sounded relevant and the answers meaningful; to form a picture in my mind of the girl, their environment, the context of their family and their experiences. After the first interviews, immediate impressions and comments were recorded as a diary note (audio file). The tape recordings of the interviews were subsequently transcribed verbatim. Each first interview was listened to at least twice and the transcripts read over several times. I used Van Manen's (1984, 1990) combined thematic 'highlighting' and 'line-by-line' approach to gain an initial impression of emerging thematic areas or the 'structures of experience' before written analysis was carried out. This entailed marking every sentence, word or passage that I judged exemplified some aspect of the discussion taking place in the interview. I then started to group these excerpts under headings that

seemed to encompass all the segments, passages or words. This was a process that was carried out for all the transcripts. I initially embarked on this part of the process digitally, by formatting the text into table form with marked passages in one column, comments in another, tentatively posited thematic terms in another. It did not work. The words looked flat and meaningless in their boxes.

Writing and rewriting are central to phenomenological analysis. It is in the act of writing itself that progress is made towards enlightenment as a synthesis of interpretive perspectives (Van Manen 1990, 2000; Wolcott 2001). This is how I made progress, by returning to the text many times and by regrouping and rewriting the meanings I was making of it. It is more than tempting during analysis, probably inevitably so, to try to mould the data to fit a theory already at hand, to see the text as resonating with what is already known on the phenomena. I noted in my reflective diary at one point that I finally understood what it was that was making the process so frustrating. I had been trying to take several steps at once and to analyse without firstly faithfully describing the experiences expressed to me by the study participants. I returned to the text and began to rewrite...

Hermeneutic phenomenology is often described as a process of moving in a spiral or circle. Earlier concepts of this hermeneutic spiral, in the context of religious or historical texts, referred to a relationship between the text as a whole and its individual parts or the relation between text and traditional perspectives on meaning (Van Manen 1990, 2002). Heidegger reconceptualised this as a process involving recognition of the non-static, evolving nature of everyday existence and the interplay between self-knowledge and our knowledge of the world. Both these concepts of the hermeneutic spiral are used in contemporary research (Benner 1994; Van Manen 1990, 2002; Fontana & Frey 2005). Some refer to the hermeneutic spiral as a way of describing the expansion and alterations to accumulated knowledge that occur through time (Brady 2005). Moments of interpretive interest described by Heidegger as 'coming to a clearing in the woods' are seen in terms of a 'paradigm shift' (Conroy 2003) or alternatively moments of illumination (Van Manen 1990) or 'transformation' (Wolcott 2001).

My choice of words is inevitably made on what I have interpreted from the choice of words of the participants in my study responding to my choice of words... While it can be agreed that data analysis does indeed consist of a “series of transformations during which concrete data are transformed across several levels of abstraction” (Burns & Grove 2005) the outcome is less a “theoretical schema that imparts meaning to the phenomenon under study” (Burns & Grove 2005) than an indication towards a phenomenological experience. In writing comes the language through which the themes are identified that make up the phenomenological experience; it is the themes that offer the light by which we can ‘navigate and explore the universes of meaning’ and which illuminate the writing of the phenomenological description (Van Manen 1984).

### **3.4 Summary**

In this chapter I have given a background to the methodology chosen, which is Hermeneutic Phenomenology. The rationale behind my choice has been outlined in relation to my aim of exploring the lived experiences of girls with AS undergoing a course of WHM. Theories underpinning the application of this approach have been summarised in order to explicate the practical processes used. These include sampling and recruitment strategies, the use of case-study to provide structure, the IMS computer-mediated interview software programme and online diaries for data collection with the girls and semi-structured in-depth interviews with the mothers and herbalists. Ethical considerations have been explored and the steps taken listed. I have described how questions of rigour have been addressed by providing transparency and, in the use of a personal and authentic voice and in the structure of the writing, reflexivity.

## Chapter 4 The Case: presentation of the findings

### 4.1 Introduction:

The theoretical framework for the analysis of findings in this study has been discussed in Chapter 3. In this chapter, the findings are presented in each of the examples of the case and structured as a 'data set' of participant girl, her mother and the WMH. These are shown in table 7 below. The participants' pseudonyms are used to protect their identity.

Table 7 showing the example sets of girl, mother and herbalist, using pseudonyms

Example set	girl	mother	herbalist
1	Sally	Joanne	Alice
2	Lottie	Kate	David
3	Madison	Anne	Laurie

These data sets represent examples of the case studied, being girls with Asperger's syndrome and anxiety undergoing a course of WHM. To present the findings coherently they are organised in each case as firstly the girl, then her mother and then the herbalist. For the purposes of the ongoing process of interpretation and in order to ensure analysis was embedded firmly in the data itself, each example of the case was initially considered individually. The thematic structure of the first example set guided those that followed, with ongoing and extensive cross-referral to the textual data in each as the description of the findings progressed.

Rather than describing each set as 'an example of the case' or an 'example set', to allow a more personal engagement with the participants' experiences, they are presented under the heading of the girls' pseudonyms, as narratives of experience. They are presented in this chapter in the order in which they were interviewed, in line with ongoing interpretation of data and to fulfil the hermeneutic cycle. The subsequent chapter discusses the findings presented in this.

Each of the stories starts with a description of the background, a summary of the participants, their circumstances and what brought them into the study. The

structures of the participants' experiences are described. These make up the first part of this chapter. Emerging themes are then presented in the next part. Experiences common to the girls are described as are those common to the mothers and finally, to the herbalists. Experiences unique to any individual participant but perceived as being essential to them are included. The girls' individual experiences of their herbal treatment as expressed through the data included in their online diary entries and second interviews are described from the girls' perspectives and from those of their mothers and the herbalists.

#### **4.1.2 The IMS interviews**

The first of the interviews held with the girls were mediated through the In My Shoes (IMS) computer-based interview protocol. From these first interviews were gained computer programmed logs, with visual and textual data along with recordings of the verbal discussion which were then transcribed verbatim and analysed in the same way as the other interview data. The results of the IMS 'emotions palettes' and the allied emotions module are given for each of the girls as integral to their personal narrative. The results of the somatic complaints module for each of the girls are also presented in this chapter.

Verbatim extracts from the interview transcripts are included in this presentation, in order to embed interpretation in the data. Editing of any section, for example where there was a lot of repetition or where there has been a word or facilitating comment by me, that does not change or add to the meaning of the quote but takes up unnecessary space, is indicated by the use of square brackets and dots: [...]. Where there are no brackets, the use of a series of three dots indicates a pause in the real time of the recorded interview.

### **4.2 Sally**

#### **4.2.1 Background**

Sally is ten years old. She lives with her parents in a detached modern suburban villa. Sally's mother, Joanne, and her husband adopted Sally as a baby. The circumstances around Sally's adoption were tragic, the facts of which Sally discovered by accident, through overhearing a conversation about her biological mother's death not intended for her. There has been a great deal of uncertainty over Sally diagnosis and although she has since been given a diagnosis of

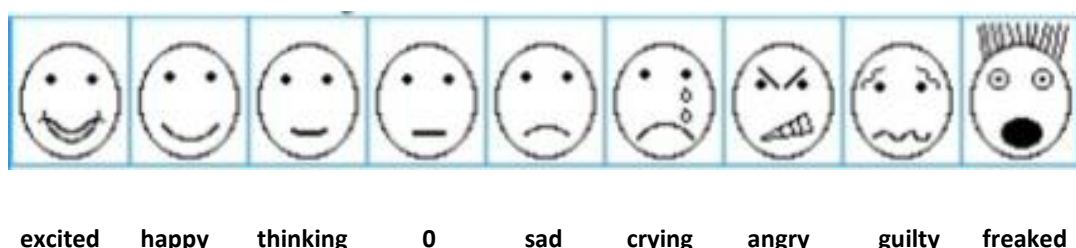
Asperger's syndrome, she was previously placed in an educational unit for children with Semantic Pragmatic Language Disorder. At the time of the study, she was still there, although Joanne did not believe it was meeting Sally's needs or that Sally herself felt she belonged there.

Sally and Joanne entered the study after seeing an article about it published in a local newspaper. Joanne thought it might be too distracting for Sally to be in her own home for our meetings so we arranged for them to come to my house. I held the initial interview with Sally using the In My Shoes programme. The name Sally picked for herself in the course of the interview was 'Happy cats and dogs!' but for the purposes of the analysis and writing of this material, this seemed to me to be too impersonal as well as unwieldy and so I have called her Sally.

#### 4.2.2 Sally's IMS emotions palette

Sally filled in all items of the emotions faces palette prior to the first interview. Some of the words she used described what she saw the faces doing, rather than what they might represent in terms of feelings. Face no 6 for example, was 'crying' rather than 'sad' or 'unhappy'. Face no 3 was 'thinking', which could however, be translated directly as 'thoughtful'. These emotions words and faces were referred to throughout the interview and they provided the verbal and visual palette for the expression of Sally lived experiences.

#### Sally's emotions palette



One of the faces she had labelled as 'unsure' and while she claimed at that point she knew the face expressed the feeling 'unsure', later in the interview she clarified she didn't know what the word meant. During the course of the IMS interview, each facial expression was used to build up a set of descriptive

words, expressions, feelings, events and people around Sally associated with each.

**4.2.2.1 Excited** Excitement was associated with fun, or the possibility of passing a test at school and the anticipation of being able to tell her parents the good news. In Sally's words:



"When I was at the Nintendo game or I came home and I got marks."  
Sally Interview 1 p 12

Sally's dog, who she had already said she loved, was second choice to be with her when excited, after her grandmother. She described a game she had played with her pet dog as exciting, playing computer games was exciting, as was being in the playground at school.

**4.2.2.2 Happy** Happy, like excited, was firstly associated with school tests and the possibility of passing or even doing very well. Sally described herself as being happy 'loads' and



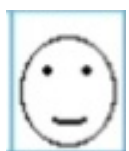
"Of course I'm happy. I'm happy in my life!" Sally Interview 1 p15

Sally felt happy on her way to school and associated the feeling with being with her family. Sally also quite clearly loved her pet dog.

**4.2.2.3 Thinking** According to Sally:

"...thinking, of course I think. I think about sums"

Sally Interview 1 p 16



Thinking, like 'angry', involved solitude, although in this situation solitude had a very different emphasis.

**4.2.2.4 Unsure** Sally had labelled one of the emotions palette faces as 'unsure' and tried to explain that she knew what the face meant to her, it meant 'unsure'. However, further on in the interview it became apparent she had meant she was unsure as to the meaning of the face's expression; she asked what 'unsure' meant and tried to find examples to illustrate. The example she described most clearly was going home after school where she knew she would probably be bored after the structured activities of the day. Going home meant:



"I know, I know, I'm a bit....not sad – unsure - about going home"  
Sally Interview 1 p 25



#### 4.2.2.5 Sad



“Of course I’m sad. Everyone’s sad. I always feel sad, all the time, but not now. Right now I’m feeling pretty happy.”

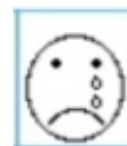
Sally Interview 1 p 13

Feeling sad might happen when all of her family were around, with Sally’s mother being placed first and then her grandfather, herself and her grandmother. She described her dog as being in the garden and she thought perhaps she should also bring in her father because

“...he’s always watching football.”

Sally Interview 1 p 13

Sally was unable to say what things made her sad.



**4.2.2.6 Crying** Crying for Sally was associated with hurting herself, having accidents. She also described how the feelings in her head, her ‘fuzzy, buzzy’ head, made her cry, because of being “really sore” (Sally Interview 1 p16) and when this happened her mother and father would hug her and try to comfort her.

**4.2.2.7 Angry** Sally felt anger at being left alone in the playground or spilling her food at lunchtime and explained she was angry



“a lot these days. Very angry...plenty of time, once a week”

Sally Interview 1 p14

but she couldn’t explain why at that point. Angry’ was used at one point to go with something she described as a ‘buzzing head’ but she then altered that to ‘sad’.

**4.2.2.8 Guilty** Guilty was originally used to describe one the facial expressions but when it came to the interview, there was some doubt for Sally over the word. She immediately associated a picture of a girl with a dog with this face, but initially described the feeling as ‘frightened’:



“Because she thinks the dog is going after her...because she’s scared of the dog...because she’s frightened he’s going to bite her...”

and then:

“because she’s stolen the dog.”

Sally Interview 1 p15

However, later on in the interview, Sally said she didn't know what the word meant, although my interpretation of "when you know you've done something wrong" (Sally Interview 1 p18) was accepted.

**4.2.2.9 Freaked** Freaked was used to describe getting a 'fright', imagining someone seeing a ghost or in her own experience, her father dressing up as a wolf and playing a trick on her.



Scared was suggested by Sally, tentatively, as another word for freaked. Scared was associated with school, in class, and school tests. The term "freaked", for Sally, therefore, may be seen to have both enjoyable and fearful connotations.

### **4.2.3 Sally's emerging themes**

#### **4.2.3.1 peace to think**

Sally succinctly described her need to be left alone when she was thinking about something:

"When I'm thinking...I need peace" Sally Interview 1 p 16

#### **4.2.3.2 out of my head**

Sally related the feelings of anger she experienced regularly to a video she had seen of a baby having a screaming tantrum:

"That's what I'm like. I am actually, aren't I? That's what I do when I throw a tantrum, that's what I'm like, only worse. That's what I do. It's so weird. It gets out of my head, you know?"

Sally Interview 1 p 34

This, according to Sally, happened with her about once a week. Her mother interjected at this point to tell us it was closer to almost once a day.

Anger was the only emotion on the palette associated for Sally with complete aloneness. She described the reason as being her tendency to 'hit out' when angry – she couldn't hit if there was no one there to hit.

#### **4.2.3.3 getting marks**

School work was associated with excitement for Sally and the prospect of gaining good marks for class tests. She looked forward to the school day and felt happy at the prospect of going. She also looked forward with excitement to

the reaction from her parents if she was able to tell them she had done well. She was less certain about returning after school generally with the uncertainty of what she might do once she got home.

#### **4.2.3.4 Fuzzy, buzzy head**

Sally's most significant complaint was described by her as a 'fuzzy, buzzing head':

"That's what makes me bad actually...mad, mad, mad...that's me, all the time. That's what my head's doing"

Sally interview 1 pp 19 - 20

She added an emotion face to the picture, initially the one she had labelled as "angry" but then changed that to "sad, crying" because "it's really sore". Sally interview 1 p 21

Sally was reluctant to finish the interview and insisted on finding items on 'YouTube' to illustrate both things she liked, such as videos of kittens, and a baby having a screaming tantrum which she described as being how she experienced her 'fuzzy, buzzy head' and the behaviour that went with it. She insisted the video of the baby was very funny although these tantrums clearly caused her as well as her mother a great deal of distress.

#### **4.2.4 Sally's mother: Joanne**

##### **4.2.4.1 Uncertain, unhelpful and undermining**

There were ongoing controversies over Sally's diagnosis. Joanne was given a range of contradictory labels for Sally, including Semantic Pragmatic Language Disorder before Asperger's syndrome, and assessments made from the perspectives of different psychological models. Psychiatric terms such as 'lack of attachment' presented to Joanne previously only served to add to her confusion. Having been placed in an alternative educational setting, Sally's continuing difficulties led to further assessments, which in themselves were not constructive for Joanne. The confusion and dissent around Sally's diagnosis only served to undermine Joanne's self confidence and increase her underlying feelings of inadequacy and failure:

“...it is very, very stressful and it’s very emotional, I mean there’s nothing worse than sitting there around a table with about ten professionals and they’re all talking about basically a child which is your responsibility, ie maybe not biologically yours but your responsibility, and you know she’s just to the wall, it’s pretty awful [...] you do feel...you do look back and think, well is it something I have done, have I been too hard on the discipline, have I...?”

Joanne Interview 1 p 22

Having a label for Sally that fitted her perceptions of her adopted daughter and that would offer a definitive explanation for her difficulties, was an elusive goal, as was guidance as to how to deal with them. Although she had attended a number of special parenting classes, she felt they had not addressed hers or Sally’s specific needs. The shifting sands of diagnostic labels and interventions led to Joanne increasingly coming to distrust the professional services.

Joanne explained some of the difficulties Sally has experienced at schools in the past and how she feels they hadn’t been dealt with appropriately:

“She was doing okay, but the anxieties were huge and she’d be doing this masturbation in class ... they used to just send her and get her to sit in P1, they took her out of class, she was sitting in with the...they really didn’t handle...and she had a terrible experience there.”

Joanne Interview 1 p 10

Sally was effectively expelled from her previous school, with her parents feeling pressurised to pull her out at no notice. This had a profoundly damaging effect on them all. Although it was reported by the current school authorities that Sally was making ‘huge improvements’, things had deteriorated at home for Joanne and her husband. Although Joanne found it difficult to believe anything she was told, she was desperate to find something that would create some meaning for her of what was happening to Sally, herself and her husband:

“I mean I sometimes think she’s schizo, is that a possibility? They all say there’s no such thing as childhood schizophrenia, don’t they? But I don’t know.”

Joanne Interview 1 p 13

According to Joanne, Sally had expressed her own feelings she did not belong in the school setting in which she had been placed:

“She has nothing in common with those children, she doesn’t even interact with any of them and they’ll tell you at school she’s more interested in the adults..... she talks about them being E people (I said ‘What do you mean, E people?’ ‘When they can’t think of a word they go e-e-e-e-e...’) and not having any language and she doesn’t get anything from them”

Joanne Interview 1 p 8

What was clear was the level of Joanne's own anxieties, both for Sally, and for herself and her husband, and her feelings of exhaustion, failure and frustration. Anxiety in Sally, as perceived by her mother, overlapped with her mother's own.

#### **4.2.4.2 Going 'AWOL'**

Sally's information processing characteristics and her heightened sensory sensitivities created daily challenges for the whole family. Routine was essential to Sally in every aspect of her life, from how toiletries were arranged in the bathroom to how she got dressed in the morning. Her clothing and shoes had to be arranged in a certain way, partly because she was sensitive to physical sensation and Joanne explained that Sally could have her hair brushed 'all day', as she found it soothing. Any kind of uncertainty or unexpected event could overwhelm her. Moreover, Joanne believed that Sally was aware of her problems and saw that as being another source of anxiety for her – not just that she couldn't express herself but that she knew she couldn't.

"When she's very anxious she can't actually get herself dressed... I think the anxiety levels are too great for her, I don't even know...I don't actually think Sissy really knows what she wants to do [...] But she wants, she's desperately wanting something but she doesn't know what it is..."  
Joanne Interview p13

Sally's inability to express or communicate her feelings and what she wanted could lead to tantrums, and fights between Sally and her mother who was beginning to avoid any situation that she thought might lead to a confrontation. One of the reasons a previous school had asked her to be removed was that Sally had been hitting out at classroom assistants, unable to express herself appropriately. Remedial steps to calm her down had been tried, for example wearing earphones and calming music, both at home and at school. This had helped, especially at school, but Joanne felt it was not enough and the transition from school to home in itself could undo any benefits. It could take Joanne two hours to calm Sally down once she came home.

What Joanne described as 'anxiety' in Sally when her inability to deal with incoming information became critical, could also be seen as a reaction to extreme frustration or even pain:

"If she starts off telling you something she'll say 'Don't interrupt, don't nod your head, don't say yes, don't say okay, just listen. So you have to sit there like that while she gets it out...if you say yes, or interrupt it

starts off anxieties to such a degree that she can't then process the language [...] If you interrupt, she goes AWOL, she just gets really, really frustrated, bangs her head, can't think of the word. I mean it's shocking to see it, absolutely shocking to see it."

Joanne Interview 1 p 8

Being offered any kind of choice caused anxieties. Her parents tried to avoid giving Sally choices in, for example, what she might like to eat for lunch. Trips to the shops were fraught and stressful; if Sally thought she was going to one shop but then they went to another; if the stock had been moved; if something she wanted wasn't available; all these things could cause Sally intolerable stress.

Anticipation of any event caused anxiety:

"She wants to go, she thinks she knows what she gets there, when she gets there she's just so high and so hugely anxious the whole shop nearly knows about it...she'll all the time be going to the shop saying, can I have such a thing, what if it's not there, what if the last one's gone, what do I do?"

Joanne Interview 1 p 7

Joanne's expressed difficulty in understanding where Sally's perceptual anxieties came from. There was also the effect on Joanne's ability to carry out daily household work, which was tiring and frustrating.

#### **4.2.4.3 torn between**

Sally's excitement when anticipating a forthcoming event combined with her difficulties in foreseeing what might be required of her in a new situation to create dilemmas for her parents. Joanne expressed her frustrated attempts to avoid the pressures of expectation. Trying to pre-empt Sally's anxieties by giving short notice of a planned event had its own consequences:

"She's excited, she wants to go...as soon as she gets up that's what she's homing in on, are we going now, are we going?...what if, what if, what if?...[but] if you leave it...'Why didn't you tell me, had you already arranged that, did you know we were going last night and you didn't tell me, why didn't you tell me, why are you only telling me now? ...well, I don't know what to do now, what am I going to do, I'd better take this and...' It goes on and on and on"

Joanne Interview 1 p 23

Exhaustion on the part of Sally's parents led at times to them responding in ways that only increased Sally's uncertainties:

"One day [on holiday] we were going to go down for something to eat and it got into such a spiral, [husband] said, I'm sorry, I can't go, I'm so stressed out now I can't go and the whole thing's called off.....and we've done that a couple of occasions thinking, well,

she's going to learn, but she doesn't learn that. And I actually think that actually adds to her stress because now when she's getting into that sort of anxiety she then wonders, are we actually going to call it off."

Joanne Interview 1 p 23

There was a tyrannical aspect to Sally's need to control her environment and events which Joanne found hard to accept:

"...that's how she takes everything, in control, she's to be in control of everything. So how can anybody play with her or show her anything because she won't let you?"

Joanne Interview 1 p 21

#### **4.2.4.4 loss**

For Joanne, Sally's disorder meant loss, not only of the child she had hoped for in Sally, but of her own previous self and the lifestyle she and her husband had enjoyed. She talked about what she described as her 'pre-Sally' life and how the demands of Sally's special needs had caused a deterioration of their income and a reduction in their quality of life. The disappointment of Joanne's previously held expectations were intertwined between her own future and that of her adopted child. Her concerns that Sally had no friends or independence were bound up with her frustration at having to parent Sally beyond a point she might have expected. Her memories of the newly adopted Sally as a smiling baby who "was just a lovely bundle of fun actually, really, really fun loving child" offered a stark contrast to the current scenario:

"...well, I've been a member of [exclusive sports club], I've been a member of [private gym], I've had all those things, I'm not a member any more...she should be participating in a swimming club or something like that, swimming with other kids...instead of that, silly old mother is standing there shivering on the sides..."

Joanne Interview 1 p 12

She also found it hard to reconcile Sally's behaviour towards her and everything Joanne felt she had sacrificed for her.

"she'll say, you've spoilt my life completely, and yet I said to the social worker on Friday afternoon, I said, I'm not looking for her to turn around and say, you're the best thing that's ever happened to me, I'm not ever hoping that anything like that will be said. I'm only hoping that she would do what I asked her to do and have reasonable modified behaviour"

Joanne Interview 1 p 13

Joanne expressed embarrassment and disappointment at having a daughter who did not behave in a way she thought of as 'normal'. She described Sally's behaviour as:

- absolutely crazy
- horrible behaviour
- shocking
- doolally
- bizarre
- Jeckyl and Hyde
- schizo

#### **4.2.4.5 no more than a breath away**

Joanne was concerned that Sally was so dependent on her for company and stimulation and felt that Sally should be playing with children her own age. She talked about her growing reluctance to spend time with Sally as she found it so unrewarding. Although she expressed her anxiety that Sally might be becoming less independent than she had been, despite the school authorities maintaining there had been advances for Sally, she also admitted her own tolerance levels had diminished to the point where she no longer felt able to cope. Joanne was sure Sally was aware of her parents' difficulties in coping with an inevitable impact on Sally's sense of security:

"Her anxiety's huge, I think her anxieties are huge, she knows we can't cope and I think, she's wondering what is going to happen to her. I actually do think that is a big, big problem"

Joanne Interview 1 p 12

Joanne felt that being adopted was an issue with Sally and that she identified with the main character she saw in a television series about a girl in a foster home who was constantly getting into trouble and being rejected by potential foster parents:

"I think she does have issues with the adoption in a very odd, strange sort of way because she has the Asperger's and she doesn't understand a lot of things that go on. So how is she going to understand adoption..? ... she asks sometimes 'what happened to my mum' or sometimes it throws itself up...and she's watched Tracy Beaker.

Joanne interview 1 p 12

Joanne described Sally's behaviour as becoming more 'aggressive' and that she now avoided engaging with Sally in areas that might lead to any kind of confrontation. She admitted she and her husband felt they no longer had a meaningful relationship with Sally. Joanne said she was aware of Sally's



uncertainty over her status within the family. She also admitted she and her husband were close to crisis.

...And, in effect, she's not far away from it if I'm being honest, she actually isn't more than a breath away from it because we just can't handle her. But how can you, I don't know, I just don't know, it's the last thing either of us want to do but we've no relationship with her now, it's basically broken down so badly."

Joanne Interview 1 p 12

Joanne described other aspects of her anxieties for Sally and her future. As well as a perceived reduction in Sally's independence, there were concerns to do with Sally's safety around her sexual behaviour. There was the ongoing uncertainty around different professional perspectives and models of intervention. Finally, there was the big uncertainty that hung over all their futures:

"Is she going to go into care? Is she going to go to boarding school? Is she going to go to prison? What is going to happen to Sally?"

Joanne Interview 1 p 12

#### **4.2.5 Alice, Sally's herbalist**

Alice has been in clinical practice as a WMH for 15 years and based in Scotland for over 10. As well as running her own private clinical practice, she teaches, supervises and mentors herbal medicine students and new graduates. She has two adult patients currently with AS but is not aware of having previously treated any children or adolescents with AS. At Joanne's request, Alice went to Sally's family home for her consultations.

Alice reflected on the case, through all its stages, from the setting in which the consultations took place, to her approach to the consultation, what she appraised from the case history, her treatment strategy and the choice of herbs used, to the results and conclusions.

##### **4.2.5.1 Creating a bit of space**

During the first consultation Alice felt that her work had been made harder by the timing of it; when she arrived at Sally's home, there had just been a visit from a social worker and Alice felt Sally was already excited and – along with her parents – tired out. Joanne appeared very anxious and was constantly trying to apologise and compensate for Sally's behaviour. However Alice felt the

meeting went generally well and found Sally expressive, engaging and demonstrably affectionate, both with her and Joanne.

Alice had researched some information on AS prior to meeting Sally and prepared herself for meeting with communication difficulties and in gaining a first-hand account of the child's experience:

“you’re possibly relying on somebody else to tell you that. And you’re not getting it first hand, you’re getting a relative, mother, parent, getting their account of it, so it’s not really how that child feels. You don’t know for sure that that’s how they feel”.

Alice Interview p 17

In order to get the information she needed for her case history, Alice tried to respond to Sally by joining her in her lived world:

I thought she was really good, actually, she was quite happy, if I gave her a bit of space and she could show me what she wanted to show me with her computer and her musical instruments and things like that, she was happy to tell me in between what was going on with her. She just needed a bit of space so that she could do all her other little things as well [...] I felt it went very well, I thought she was very good at expressing herself, she gave me a lot of very useful information”

Alice Interview p 3

For Alice, it was clear Sally's insomnia had a profound effect on Sally's state of mind, her ability to cope and her relationships. Sally described an ongoing buzzing noise she experienced, not in her ears, but in her head and a strange sensation in her tummy, which Alice found more difficult to interpret. She thought perhaps Sally meant she had 'butterflies' in her tummy. Satisfied she had enough information to complete her case history, Alice was able to decide on a treatment strategy and make up a prescription herbal medicine for Sally.

Alice felt their second meeting did not serve well as a consultation for Sally. Alice felt the consultation served more as an opportunity for Joanne to:

“get things off her chest and have a good cry [...] she wasn't really in any state at all”

Alice Interview p 5

She described Joanne as 'very, very distressed'; they had just come from a meeting with a psychiatrist. Joanne felt that she was not being listened to by the professional services. Alice observed that Sally was aware her mother was upset and was concerned.

#### 4.2.5.2 Trying to get a balance

Alice's approach to working with a child with AS was similar to the way she would usually work:

"It's a similar process in that you're trying to sort of see what the psycho-physical connection is, if there's an emotional connection to any of their symptoms, well, I would have thought it was very similar".  
Alice Interview p 17

Alice had picked what she defined as a very gentle herbal medicine for Sally. Although she described her approach to treating a young girl with AS as being the same she would normally use, she also acknowledged she was wary of taking too robust an approach with Sally. Knowing that people on the autism spectrum sometimes have unusual reactions to all sorts of things had made Alice cautious in her choice of herbal medicines.

Alice described her strategy:

"what we were trying to do was to get a balance, that she was getting a good night's sleep, so she had plenty of energy in the morning and could cope with school and then just got tired in the evening. So we were just trying to sort of rearrange her day really, and rearrange her energy levels."  
Alice Interview p 6

After the first consultation, Alice was told Sally had been prescribed Melatonin by a psychiatrist. Alice felt that Sally should try one approach at a time and so Joanne agreed to defer the herbal treatment.

Melatonin was highly effective in getting Sally to sleep which benefited the entire family; its effect had been to 'knock Sally out'. They were all better rested, more relaxed, more hopeful. There are concerns that Melatonin, which is not licensed for public sale in the UK, may have as yet unknown long term effects, especially on the developing hormone system of a young girl (SIGN 2007). After a while, Joanne decided to stop the Melatonin and to try the herbal medicine with Sally.

The results of this had been:

"she was calming down, she did get calmer, but she wasn't knocked out as she was with the melatonin".  
Alice Interview p6

Although the herbal medicine was effective and helped to calm Sally down, it did not have the same impact the melatonin had. There was also an issue with the taste of the herbal medicine which Sally did not like. Alice was informed that

Sally started to refuse to take her herbal medicine and they had decided to stop trying for a while.

#### **4.2.5.3 being privileged**

Alice felt she had learned a great deal from the individual circumstances and that it had also raised questions for her:

“I felt I’d learned a lot about, not just the condition but about the individual circumstances and having had the privilege to go into somebody’s home and seeing how it all works in a family situation...good and bad, or does it work, and having seen a mother/daughter relationship that clearly wasn’t working, how much of that is partly due to the condition and how much is just circumstances...”  
Alice p 25

Alice discussed whether or not Sally was intrinsically anxious or made so by her environmental circumstances

But I don’t think that she was suffering from anxiety as a sort of an intrinsic part of herself, I think there are things that make her anxious, her situations and her mother being upset, things like that [...] it’s their nature to be made anxious very easily, isn’t it, I mean this little girl for example, she had a toy that sat on the top of the bookshelves, and it had to sit on the – you can’t move that toy because then it would make her very agitated [...] I think it’s hard to really say from that point of view whether they’re suffering from anxiety or whether they’re okay in given circumstances.

Alice p 13

She described all her patients as being opportunities for learning, for adding to her clinical experience and therefore expertise. She found Sally especially interesting and appreciated having had a reason to do some research into AS.

### **4.3 Lottie**

#### **4.3.1 Background**

Lottie is 14 years old and lives with her mother and three sisters (one older and two younger) in a semi-detached terraced house with tightly limited communal space and 3 bedrooms. Lottie shares a bedroom with her elder sister, while her two younger sisters share a room. The living area is restricted; a sofa, tv, dining table and computer desk are in one small space. Her parents are divorced. Lottie is scheduled to see her father once a week and sometimes sees him additionally at weekends, although this can be erratic. Lottie attends the local secondary school, where her mother also works part time. Lottie is academically

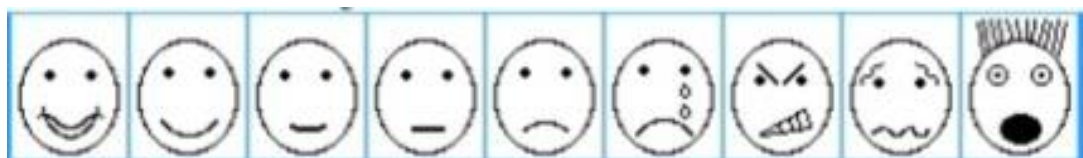
very able, and rarely achieves less than grade A results in her school work; however, her mother arranged for Lottie to be held back a year, because of difficulties in coping with school generally, and so she is only in the second senior year. Lottie is especially good at English. She loves drawing and produces accomplished and highly expressive graphic figures in pencil or ink. Lottie's favourite subjects were those that come under the heading of the 'expressive arts'. Her mother reported that Lottie's drawing attracts other children and especially has a calming influence on other children, with learning disabilities, who like to watch her as she draws. She enjoys some comedy programmes, is passionate about films and music, especially scores from her favourite films and musical soundtracks.

Lottie's mother contacted me by email after reading the initial recruitment information that had been disseminated through a number of support groups for parents of children and young people with a diagnosis of AS. I first met with Lottie a few days before our first interview meeting when I explained the IMS program and the webpage diary process.

#### **4.3.2 Lottie's IMS emotions palette.**

Lottie had not completed all of the Emotions Palette prior to our first meeting

##### **Lottie's emotions palette**



happy   not quite happy   okay   0   sad   depressed   angry   nervous   scared

and when we reviewed her entries, she still could not find a word to describe two of the facial expressions. Those for which Lottie could not find a word did have meaning for her and she used one of them later in another IMS module, although was still unable to think of a word to describe it at that point. Lottie struggled to find any words to describe facial expressions that did not display extreme emotions, such as crying or widely smiling.

**4.3.2.1 Happy** Happiness for Lottie was described as including 'friends' and doing the things she likes most, which are:



- listening to music
- watching favourite films, mostly musicals,
- watching comedy tv programmes
- favourite subjects at school which are music, drama and

art.

She associated happiness with friends, being with her dog and after some thought, possibly her mother.

**4.3.2.2 Not quite happy** Lottie labelled the emotions 'face' she described as 'not quite happy', although its meaning was hard to pin down. She wasn't aware of feeling this emotion herself, but she did use the face for one of the emotions scenes.



**4.3.2.3 Okay** Lottie could feel 'okay' with any of her family around her. The face from the emotions palette labelled 'okay' was used to describe her when she was at school and "doing a school subject she's not rubbish at" but not particularly interested in and although she didn't like being 'bored', it was 'okay' to have an ordinary day.



Feeling 'okay' went with:

"...usually it's just a normal day - like a day – like same daily routine all the time and I'll just do the same thing and... just when I'm sitting in the house or something like...just doing something. Like I don't like being bored but if it's not something I like very much, it's alright."

Lottie Interview 1 p

'Okay' meant 'alright' and comfortable. However, 'okay' was also used to describe states of 'not being' ie not quite happy, not sad, not comfortable, not certain, not scared.

**4.3.2.4** This face was given no label



**4.3.2.5 Sad** Sad for Lottie was being alone, with no one to

play



with her. Sad was associated with arguments in the home, between her mother and her sisters as well as arguments involving her. She expressed feelings of sadness and powerlessness, when those around her were unhappy:

“Usually when it’s other people that I like who are sad or something, like something’s wrong with them [...] ...and I feel I can’t do anything about it”  
Lottie Interview 1 p

Sadness was also a reaction to feeling misunderstood by her family and Lottie described feeling misinterpreted and judged. Telling her family about her need for some personal space had led to her feeling accused:

“oh you just want to get rid of [elder sister] and everything, ‘you’re horrible’”.  
Lottie Interview 2 p

Expressing her own needs, therefore, could lead to sadness for Lottie. Being unhappy was connected to the headaches she experienced regularly and which were described by her in the ‘somatic’ module as a sharp pain in her head experienced regularly. It would come on sometimes when she’d been thinking hard, for example, in a maths test at school, and being ‘upset at school, irritated’ (Lottie IMS script Interview 1 p22)

**4.3.2.6 Depressed** Arguments, or any kind of conflict, between her and her sister or between her mother and her sister, made Lottie feel depressed, especially and feelings of being:



- scared
- angry
- let down by someone
- sad
- nervous
- misunderstood
- stressed out

Other causes included:

- having a hard day at home
- fear of conflict - scared of being shouted at by her mum or sister
- fear of being ‘grassed on’ by her younger sisters
- not being believed
- feeling misunderstood, for example, when her needs conflict with others’ such as a need for space
- “Other people having problems and feel I can’t do anything about it” (Lottie Interview 1 p12)

Lottie found the behaviour of other school students unacceptable and depressing. She described these as:

- People I can’t trust
- kids who:
  - are very cheeky and stuff
  - ask daft questions
  - are rude and noisy

- are rude to teachers
- waste time

**4.3.2.7 Angry** Lottie experienced lack of acceptance for her own perceived 'differences'. Displays of intolerance or exclusion towards anyone made Lottie angry.



Lottie also felt anger at times towards her mother and siblings.

**4.3.2.8 Nervous** Lottie associated school with being nervous and she described sometimes feeling very confused if she felt she had forgotten something during class tests. Being at school had other aspects to it that for Lottie brought feelings of nervousness, mainly being around people she felt she could not trust. These people were for Lottie was the same people she found irritating and who made her angry, those that were intolerant and:



“very cheeky and stuff”

Lottie Interview 1 p14

Nervousness was associated with the 'sickly feeling' she described as having in her stomach which was brought on by 'arguing' and 'as if something bad is going to happen, violence eg.' (Lottie IMS script p 23) She felt nervous when her elder sister returned home in the evening, anticipating more arguments.

**4.3.2.9 Scared** Lottie was scared on occasion by the dynamics of her family, with the possibility of her younger sisters 'grassing' on her, her mother shouting at her, arguments and shouting between her elder sister and her mother.



### **4.3.3 Lottie's emerging themes**

#### **4.3.3.1 not being horrible...**

For Lottie, being unable to have a personal space to which she could retreat and recover from the demands of the school day was detrimental not just to her relationships but to her ability to cope with the demands of daily life. Having to share a room with an older teenager who expected to be able to come in and out whenever she wanted, sometimes late at night, was causing a lot of problems for the whole family. Lottie's anxiety levels would escalate throughout the evening so that by bed-time, Lottie was too agitated to sleep. There were



family rows and often, when disturbed by her sister coming home late or snoring, Lottie would resort to sleeping on the sitting-room sofa. If she had had a bad night, then she could be angry when woken.

Lottie described with visible distress her grief at being judged by her family for expressing what she felt was perfectly understandable relief at the prospect of her elder sister moving out to go to college. This would mean that Lottie had a bedroom to herself, something she desperately wanted:

“But mum keeps saying I’m being horrible and [sister] keeps saying I’m being horrible as well but I’m not. [...] Because I want [sister] to go to university and everything because like let her do what she wants and everything like get a good job and everything.”

Lottie Interview 2 p23

Lottie expressed her feelings of insecurity within the family:

“They [little sisters] make out they’re better than me because my mum keeps calling them her favourite children as a joke and they think it’s true...they’ll start saying that mum hates me...”

Lottie Interview 1 p16

Her anger at her younger sisters when they said these things was fuelled by her anxieties that they might be true. Lottie was uncertain sometimes as to what other people wanted of her and she was hurt at being misunderstood and judged. She was not entirely secure that her mother did not ‘hate’ her and preferred the younger girls. Her headaches and her feelings of sickness were associated with the anxiety and fear of family arguments.

#### **4.3.3.1 ...and not being an EMO**

The theme of feeling judged and labelled continued at school. Lottie saw no irony in her use of the term ‘Chav’ to describe someone with an overt lack of tolerance for other people’s differences, or resenting the term ‘Emo’ in one context while using it herself to describe others:

“What I don’t like is when people keep classing Tim Burton fans as Emos, because I’m not an Emo [...] Like you get a lot of...there’s all these people who are just themselves who are fans, and I don’t like that. I hate those stereotypes as...I hate those sort of stereotypes and stuff, like people have to be labelled a lot”

Lottie Interview 1 p8

However, Lottie’s dislike of stereotyping and the marginalisation of anyone perceived as different, extended to feelings of protectiveness towards those she

cared about and she expressed anger at the thoughtlessness of others. Lottie described how some of the students at her school made her feel:

“like they have to take advantage of people like that, like they make me think that they think...I just don't like how they judge people, and everything [...] they're just not aware of other peoples' problems, or anything.” Lottie Interview 1 p24

Lottie found it difficult to understand other people's behaviour and found their unpredictability frightening and sometimes depressing. She was highly critical of people behaving in ways that did not conform to her expectations, breaking rules, being 'cheeky' and not listening to the teachers in the classroom. She described herself as feeling 'let down' by people.

#### **4.3.3.3 getting in the way of what's important**

When asked about her mother's concern she worried too much about tasks set for school, for example, remembering to take in a letter or an assignment, Lottie's response was she wanted to get such tasks done in order to free herself up for more interesting activities. It was important to her to get any tasks out of the way, otherwise, they stayed with her mentally and 'got in the way' of focussing on other things, or even just being able to relax. Being regarded well by her teachers was important to Lottie and she wanted them to know she took her work seriously:

“...I just [...] don't want them to think I don't care or anything[...]...don't care less. Lottie interview 2 p

#### **4.3.3.4 the one thing they forgot to put on the sheet**

School work was sometimes an area of anxiety for Lottie. She worried about school tests and she would get frustrated if she was unable to perform to her best ability, for example if there were questions in a written test on a subject she had not covered:

There was anger as well if she felt unfairly disadvantaged, for example, a teacher not having given her a chance to catch up if she had been off school for any reason or being given no warning of something being included in a test.

“I tried to do my science homework and I couldn't answer a single question [...] I can't believe my teacher shoves homework in my face expecting me to know everything” Lottie online diary

#### **4.3.3.5 feeling sickly**

Lottie identified three somatic issues, areas of pain or discomfort that she would discuss with the herbalist when she had her first consultation. These were:

- recurring head pain
- a sickly feeling in her stomach
- leg pain

Both the head pain and the sickly feeling were identified with being sad or anxious, for example feeling nervous at school or when there were arguments at home. The consultation with the herbalist further identified insomnia as a key issue for Lottie.

During the course of herbal treatment, there was heightened conflict within the family. Arguments between her elder sister and her mother were ongoing. She found arguments between other members of the family very upsetting; raised voices made her feel sad and frightened. Lottie was also saddened and frustrated at her inability to help when confronted with other people's difficulties. These were emotional issues for Lottie and manifestly caused her pain.

Lottie's reactions to her sensory sensitivities, lack of privacy and sleep deprivation continued. Her general frame of mind deteriorated after a prolonged period of arguments at home, during which she felt let down by her family. After one particularly difficult night she had a confrontation with her mother which led to Lottie asking for a meeting with the school counsellor and Kate together in the hope of gaining some understanding from her family.

The herbal medicine seemed to work well for Lottie; she slept better, was more relaxed during the evening and her ability to cope with daily life was improved. Despite the rows at home, Lottie was able to describe herself as having felt 'happy, happy, happy and I don't know why' and 'I love today'.

#### **4.3.5 Lottie's mother: Kate**

##### **4.3.5.1 just a paranoid mother**

Kate had had years of struggling to have Lottie diagnosed, although she had been aware for a long time that something was unusual about her second daughter. Kate illustrated how she had become aware to begin with her

daughter was different from other children with a stark example of when Lottie was very young and at nursery school:

“And there was one time I got a phone call [...] all the children at one end of the nursery and Lottie at the other [...] they were throwing bricks, lego bricks at her across the nursery into the book corner where she was sitting reading a book, and she just started screaming, she started just really screaming, because that’s what they were trying to get her...” Kate Interview 1 p13

Self doubt accompanied the process of having Lottie’s problems given a diagnosis, exacerbated by reactions from other family members and a perceived lack of support from the professionals. Kate had felt judged by her GP:

“...I think basically he thought I was just a paranoid mother, because I was saying ‘There’s something but I don’t know what it is. There’s various things. I’m sure it’s her hearing...’ and ‘no, no, no she’s fine’...” Kate interview 1 p15

That Kate’s husband, Lottie’s father, was unable to accept his daughter was different added to the pressures on Kate and the rest of the family. He refused to compromise in his behaviour towards Lottie, insisting she was, and therefore had to be treated, the same as the other children. He had eventually left the family. Kate went on to describe the impact on her self-esteem, especially when other people were judgemental or criticised Kate’s parenting skills:

“It was a really stressful time for me because I was so worried about Lottie. And you turn it round, you think, this is something I’m doing. I’m not doing something right. And then you would get useful comments from my mother who would say things like ‘It’s because you had [Lottie’s younger sisters], it’s really upset her’. And at the time you’re thinking ‘God it’s all my fault [...] what am I doing wrong here?’” Kate interview 1 p2

#### **4.3.5.2 getting into trouble**

Lottie’s sensory and perceptual characteristics had been noticeable from an early age and had impacted on the whole family in many ways. Kate had been frustrated by the time and effort it could take to get Lottie ready in the morning when all the children were younger. Getting Lottie dressed in itself could be a challenge. Lottie had gone through a phase of not wanting to be dressed at all and then her clothes had to be put on in a particular order. She had to be allowed ample time to get ready; trying to rush could be disastrous. Lottie was

also sensitive to the feel of fabrics on her skin and clothes had to be bought 2 sizes extra large for her to tolerate them. According to Kate, this was still an issue although Lottie was 'kind of learning' (Kate Interview 1 p20).

Lottie's sensory sensitivities extended to personal contact with other people and she rarely hugged or cuddled family members or friends. Kate perceived this as having had an impact on her close relationships. Lottie was uncomfortable with being casually hugged by her mother, but she was jealous when Kate cuddled the younger sisters. Kate described how her best friend was able to breach Lottie's reserves:

"... if you're going to hug her, like my friend Pam does it to her, she'll go, come on Lottie, give me a real big hug! And you've got to give her a really big hug. Normally she stands over there, and she'll go okay..."  
Kate Interview 1 p20

Sensitivity to noise had had a long term impact on Lottie's ability to socialise or take part in extra-mural activities. She had no tolerance for any closed space involving a lot of people so group activities such as Rainbows or Brownies were unworkable. After-school club had also failed. According to Kate, it was too noisy and perhaps most importantly, had no quiet area where she could go to be at peace. Lottie's drawing skills drew other children to her, and if she tried to sit and draw quietly, she would soon be surrounded by onlookers.

At school, sensory and perceptual differences had a profound effect. Any kind of group-work was difficult for Lottie to cope with and there were classes she had not been able to complete. Despite her abilities, which were high in some areas, Kate had kept her back a year to allow her to 'catch up'. There were instances of Lottie being unable to work because of distractions such as another student continuously 'clicking' his pen, and Lottie had had to have her seat moved. Lottie had been moved to the front in other classes after Kate had intervened on her behalf:

"everything that was going on between her and the teacher was really bugging her, like she'd get really stressed [...] if somebody was messing around or wasn't doing this or somebody was doing this, and she used to come home and she'd be like this. She would go, 'It was a horrible lesson, it was a horrible lesson. I hated it. Nobody listens to the teacher, nobody listens [...] she seems to be a lot better [...] It's all behind her so she can actually focus on the teacher'"

Kate Interview 1 pp9-10

Kate described Lottie as someone who would read instructions manuals from cover to cover and get upset when others did not similarly comply. She needed to know what the 'rules' were and Kate perceived her to be overly concerned with rules and regulations at school.

"And then she'll remind you several times about little things like, 'this letter's got to be in today'. You know? It seems like she worries about little things that a lot of kids have forgotten that today, 'I'll just do it tomorrow'. But it's like, 'no, no, no, no – you have to sign this now. It has to be in today. You have to do this now.'"

Kate Interview 1 p

On occasions, Lottie had found herself in trouble at school because she had not understood what she was being asked to do or had misinterpreted an instruction. Karen described Lottie's reactions to being 'told off' for something at school she did not understand:

"It's just she doesn't get a lot of what people say, and I think that's quite stressful and then the teacher will then give her a bit of a row about something but she has picked it up as being something else, so she gets all stressed about that. [...] 'well why am I getting into trouble?' [...] If she doesn't get clear instructions, like at school a lot of the time the instructions are not clear at all ...."

Karen Interview 1 p12

Any kind of change in Lottie's routine or when her expectations were not met caused anxiety. Lottie liked to know what she was doing on a daily basis and found security in having a weekly schedule. However, Sunday nights were commonly difficult, as were the returns from holidays, with Lottie in tears at the thought of going back to school the next day.

"going back to school is going to be awful. I know come Saturday/Sunday she's going to start saying 'I hate school, hate school, hate school. And it's just...it's quite wearing at times. You just think, we've been through this so many times before and it's fine once you're in. You would think she would know that by now, but she doesn't seem to..."

Kate interview 1 p9

#### **4.3.5.3 trying to do what everyone else is**

Kate grieved for her daughter and what she perceived as being the normal experiences expected for a child that Lottie was missing in her life. She described how when Lottie was younger she would go down to the school playground to watch through the railing at Lottie sitting or standing around on her own and how she feels as she sees her still doing the same. It had never

been in her experience that Lottie would go out to play with other children and she still did not mix with others out of school, by her own choice as much as through lack of opportunity. Kate felt sad that her child was not like other children:

“then there are times at school when I just see her... she wanders around on her own, you know? Hundreds of kids around and she just wanders around on her own, and she’s probably quite happy - do you know what I mean – but as a mother you kind of think [...] And I find that quite hard as well. I think well, she’s missing out on so much, you know?”

Kate interview 1 p11

Kate had tried to both maintain and present what she thought of as being a normal family life. Implicit in this was a reluctance to admit there were problems within the family. She had:

“never, ever asked for help or looked for it or anything”

Kate Interview 2 p3

This had recently changed as Lottie’s school difficulties had become more pronounced and Kate did feel things were beginning to be put in place for Lottie at school as a response. However, for Kate, this in itself also brought unease. She had difficulties in accepting the enormity of many daily activities for Lottie or the impact of Lottie’s struggles with her environment and often compared her behaviours against those she perceived in ‘normal’ children. She was disturbed to discover that Lottie was taking her family issues to the school guidance teacher and asking him for help. Unhappiness that their personal affairs were being discussed with other members of staff was compounded by a sense of embarrassment that her daughter should be asking for help for things that Kate felt were ‘such a big fuss over nothing’:

“We seem to be at the guidance teacher all the time, and I kind of feel sorry for him because he’s busy enough [...] And she goes in and tells him everything, you know about how (elder sister) snores and keeps her awake and then she can’t focus”.

Kate Interview 1 p13

School requirements for subject choices had brought particular difficulties for Lottie and Kate. Lottie found it difficult to understand why she had to choose her subjects from group listed in columns, instead of freely and all her preferred choices were clumped together in one or two of the columns:

“And it was awful because all the stuff that she was interested in wasn’t in the right column and she got really upset about it all and distressed [...] it was drama and art and music and everything like that [...] It is distressing for other kids to try to make these choices but for Lottie [...] So we got it sorted so she’s going to do the ones that she wants to do next year [...] and I don’t want her getting stressed out about stuff that really she’s not interested in.

Kate interview 1 p24

Lottie’s mother summarised her feelings about the levels of Lottie’s anxieties:

And you think well...she’s worrying about everything, she just worries about everything. That’s what I feel like, she’s worrying about everything, you know?”

Kate interview 1 p11

The feelings engendered by having a child with developmental differences were complex. Grief for what she felt her child was losing or perhaps never have and frustration for her own unfulfilled expectations merged with anxieties of parenting a child whose developmental outcome was unknown but unlikely to be normal:

“Well the hardest thing I found was when you’ve got children, you go up to school, you go to plays, you do this and that, and you always want your child to be doing what everyone else’s children are doing. It’s like, well are they doing the same thing? Can they do that? Can they do that?”

Kate interview 1 p17

#### **4.3.5.4 tiptoeing around**

Lottie’s need for personal space, intolerance of noises and dislike of having her things touched created stress in the household and this was exacerbated by the lack of space in the home. From early childhood she had become agitated if her younger sisters went into her bedroom or touched her things and Kate had had to put a lock on Lottie’s bedroom door. Having to share a bedroom with her elder sister caused ongoing conflict and stress.

Kate felt torn between her children. Although Kate described her eldest daughter as sometimes behaving in typically adolescent self-centred ways, she also felt that Lottie’s direct way of expressing herself could be tactless. Lottie’s anticipation of her gaining her bedroom to herself on her sister’s move to college was seen, by both her sister and Kate as being hurtful:

“[Sister] was quite upset one day. [She] said, Lottie, you don’t like me, do you? ‘No, no, I do, but I’d just prefer it if I had my own room.’”

Kate interview 1 p



Kate described Lottie as being obsessed with her particular interests. When focussed on something, she wanted no one around, no-one to interrupt her and was likely to find:

“everything annoying, everything you know, everything’s irritating her or annoying her.”  
Kate interview 1 p6

Kate agreed with her elder daughter’s complaint that everyone in the family had to ‘tiptoe’ around Lottie. Kate described her feelings that Lottie would probably have preferred to be an only child and mostly preferred to be on her own, with the choice to join her family on occasions as she wanted to. She was happy to spend time with her sisters, but only if they were prepared to sit quietly with her, perhaps watching a film of Lottie’s choice.

However, it was clear that Lottie cared deeply about other people; she was concerned for two other children at school she thought of as her friends who had their own difficulties and she was puzzled and angered at others’ intolerant behaviour towards them. She also demonstrated her attachment to all her siblings from the way she had brought home information on drugs from school and insisted on sitting her younger sisters down to talk to them about what she’d learned, to telephoning Childline for help when she was worried about her elder sister’s developing eating disorder. This had caused Kate embarrassment but also reflected her more general concerns about Lottie’s future and her way of approaching other people for help, whether she knew them or not.

“I was like, my God, you can’t phone these people [Childline]. And she got so distressed about it all, really to the point that she was making herself ill worrying”  
Kate interview 1 p1

Lottie had difficulties, according to Kate, in reading other people’s faces or understanding that their facial expressions may not always reflect their feelings towards her; that they might sometimes be thinking about other things. She could get angry or upset and would accuse her mother in particular of hating her. She was insecure, often expressing her belief Kate loved her younger sisters more than her.

Kate found it similarly hard to read Lottie’s feelings. She felt that Lottie either gave nothing away or was ‘way over the top’. She thought Lottie looked far too deeply into events that most people would dismiss or simply accept.

“that’s really hard for us. As [elder sister] put it, we just spend our lives tiptoeing round her so we don’t upset her, which is quite difficult because you think, am I doing the right thing, should we just be getting on with it, and she has to learn to cope with everybody.”

Kate interview 1 p16

As well as feeling torn between her children, Kate expressed doubt over her own parenting skills and uncertainty as to the best approach to helping Lottie. She found it increasingly difficult to have a sense of how Lottie might be feeling, whether she was happy or not. She was anxious that she was not parenting Lottie as she should and torn between trying to make allowances for her and therefore make her current life easier to manage, or expecting her to ‘fit in’ with what might be perceived as normal, as a way of preparing her for the future:

“I don’t know. This is my major thing at the moment; am I dealing with her the right way or not? – You know, should she be experiencing things and learning to deal with them or should we be making allowances for her, because she’s got to go out in the big world soon [...] So it’s difficult; are you doing the right thing or not? I don’t know. “

Kate interview 2 p10

#### **4.3.5.5 Not the real world**

Kate was finding life at home increasingly difficult. She perceived Lottie’s characteristics as having become more exaggerated as she got older, but she described her own abilities to cope as being variable and thought her tolerance was failing. Taking time out to do something outside the home, such as going to see friends, could be difficult to organise as Lottie rarely went out with friends or spent time outside the home. Organising any kind of social event was additionally complicated by the potential for things to go wrong for Lottie. Kate, however, was considering trying to organise a holiday for herself during the summer although without any support, either financial or in terms of time commitment from Lottie’s father, this was likely to be difficult. She expressed guilt in her feelings of wanting to get away for a while along with her feelings of exhaustion:

“that sounds awful because I feel really guilty because it’s like I’m sending her away [...] it’s little blips, you know, and out of the ordinary things that happen, and you know, she just doesn’t cope. I think some of the times I don’t cope with the repetition, you know, of the day, being asked the same thing over and over every day. Some days I just think, oh God you know, you know what’s

coming...sometimes it's very wearing. At other times I'm fine, but I think it just depends how I'm feeling." Kate interview 2 p2

Embedded in Kate's expressions of weariness and lack of confidence was her anxieties for the future. She was extremely concerned at Lottie's direct approach in tackling other people for help, partly because it was so unlike her own reticent style, partly because she perceived Lottie as overstepping social boundaries and partly because such openness could leave Lottie vulnerable. She described how Lottie had, as a very young child, worried her by asking an unknown man at a playground to push her on the swing, and then more recently, emailing directly a film animator she admired to ask for advice about her illustrations. Kate was appalled at this behaviour. She felt that Lottie had somehow to learn to fit in with other people's expectations of what was normal.

"you kind of think, you know, there's not a lot of people out there that will know what she's like, and – oh we'd better not do this and you know, her boss is not going to say, oh well, Lottie, do you know, if you don't like that we'll change it [...] I just feel you can't really sort of let her do everything her own way because that's not the real world"

Kate Interview 2 p4-5

#### **4.3.6 The herbal treatment**

Kate described Lottie as being much calmer while taking the herbal medicine; she believed Lottie was sleeping better, that she was easier to be around and that she even looked different, her face had a more relaxed appearance. She knew that Lottie wanted to continue seeing David and taking the herbal medicine but she was reluctant to commit to the expenditure long-term.

#### **4.3.7 David**

##### **4.3.7.1 Background**

David trained in Scotland and has worked as a practitioner in WHM for 8 years; he teaches and supervises herbal medicine students at BSc degree level. David agreed to visit Lottie at home.

##### **4.3.7.2 The nuts the bolts the lot**

Lottie's consultations with the herbalist also took place in her home. What was presented to David was what he perceived to be normal family scene, the two younger sisters were sitting at the computer, giggling and whispering, while Lottie, her mother and David sat together on the sofa. David felt that the

interactions between Lottie and her family and between Lottie and him were, surprisingly to him, what he would expect with any adolescent. He found Kate sometimes unnecessarily interrupted or tried to answer on Lottie's behalf but, again, this was in line with his previous experiences of consultations involving mothers and children. He found Lottie articulate and outgoing enough to gain a working understanding of what she wanted and any need to probe or encourage was as he would expect in someone of her age. He described her case:

"it was a vicious cycle that the disturbed sleep lead to irritability... lead to increased lack of concentration ... lead to increased irritability during the day with noise distraction [...] getting irritable during the day would be compounded by the fact that when she got home from school at about four or five o'clock she would actually start to become agitated as well about the thought of going to bed and not being able to get a full night's sleep with her elder sister coming in."

David p9

David had been surprised at how willing, pleasant and calm Lottie had been during the consultations and thought she was surprisingly well-balanced considering her difficulties. He was pleased to have been able to meet her in her home environment and to gain some understanding of the context of her family home:

"I always enjoy being in someone's house because you get to see the whole environment, you get to see the nuts and bolts, the lot, and I really like that".

David p20

David felt the initial consultation had gone well, that he had managed to achieve a working relationship with Lottie and draw up a satisfactory clinical case history.

#### **4.3.7.3 A simple plan**

David had not made any dietary or lifestyle suggestions to Lottie or her mother in order to simplify what they had to deal with. Although Lottie's diet was not very good, it was probably in line with many adolescents. David described his therapeutic approach:

"the key to the whole thing was actually calming her down and being able to get some good quality sleep in there to try and break that cycle. So it was a simple herbal plan in the end really and that was deciding just to...just to calm things down and a good sleep mix just to get her off to sleep at night, which she complied with very well."

David p15

David reflected on how feeling constrained to treat Lottie, as he expressed it 'symptomatically' had influenced his own concerns about the outcome. His experience with adults had taught him that often the best results long term, especially in chronic conditions, were to be found in making fundamental changes to the diet and lifestyle. Having taken a very simple approach to Lottie's treatment, which was based entirely on the herbal medicine, he was pleasantly surprised at the speed at which there had been a positive effect. The improvements had continued for the next few weeks and David saw Lottie again another two times.

#### **4.3.7.4 taking people as I find them**

David described himself as having held 'prejudices' as to what he would find in Lottie. He had decided not to do any research into AS prior to meeting her as in his usual practice he only does so in exceptional circumstances and he was reluctant to create preconceptions in his mind as to what to expect:

"I like to take people as I find them"

David p3

He realised on reflection that he already did hold preconceptions, partly influenced by his previous experience with more overtly disabled people with ASD and also with what he had absorbed through newspaper articles and so on. His expectations, on meeting Lottie, had been confounded:

"interestingly those prejudices were altered as a result of having met her [...] It was quite a revelation actually because she made full eye contact, she wasn't shy in any way whatsoever and I would not have been able in a crowd of her age, her peers to be able to point out and say she's the most likely one that is on that scale. I don't think I would have been able to do that."

David p3

David had been excited at the prospect of taking Lottie as a patient, partly because it was a new experience for him to work with someone with AS. He saw this as an opportunity for personal and professional development. He felt he had learned a great deal from having worked with Lottie and especially pleased he had been able to visit her in her home, where he was able to see her interacting with members of her family.

David was 'over the moon' at Lottie's response to the herbal treatment. At their second meeting, Lottie had reported a considerable lessening of her general irritability and anxiety and much improved sleep. David was surprised,

therefore, at the responses he perceived in Lottie and her mother who he described as being 'underwhelmed' by these improvements.

"I was thinking god, this is a great improvement [...] I thought, what I felt was a breakthrough with her, would be hailed with a bit more enthusiasm [laughs]. So that was the biggest, most interesting thing from that consultation was how under-whelmed they both were"

David p15

#### **4.3.7.5 Enjoying the experience**

He also described how he was interested in learning more about AS and that:

"It fascinates me anyway, that whole...anything that goes on with the mind I find absolutely fascinating".

David p20

David expressed his great enjoyment of the whole experience, from its potential as a learning experience to interacting with Lottie, which he had found rewarding, to the outcome of the treatment which had endorsed his approach and affirmed his choice of herbs.

"So for all levels I was really pleased and I enjoyed the experience. It knocked away some of my prejudice that were there which I think is very good. I found her fascinating, I found her great company [...] and I enjoyed their family interaction and despite their difficulties I thought it was very good. Aye, I really enjoyed the whole experience."

David p20

### **4.4 Madison**

#### **4.4.1 Background**

Madison is 14 years old and lives with her mother and 3 sisters in a modern detached house with its own garden, in a city, but situated in a pleasant-looking leafy residential area. She has her own bedroom.

It took years of repeated requests through a variety of professional services before a diagnosis was gained for Madison. Her mother, Anne, described how behavioural problems were initially attributed to the many changes that had taken place in the family over a short space of time. Madison's second younger sister had been born after a gap of five years, the family had moved house around the same time and after looking forward to her middle sister joining her at school, Madison was upset to discover her class was going to be moved to a different campus and her teacher had also been changed at the last moment. Concern that her eldest daughter was having difficulties coping had prompted a

referral – in itself a lengthy process - to the Educational Psychologist who had failed to recognise Madison's difficulties as anything other than behavioural and the result of poor parenting.

Anne finally received a diagnosis for Madison of AS six years later. The parents separated after Madison's diagnosis but she sees her father regularly. Sam does manage to work part-time, although she was driven to leaving a previously better paid job when her employers had refused to allow her to reduce her working hours in order to accommodate her families' needs. There is little support from the girls' father in terms of time commitment, but he does support them financially.

Madison became involved in the study when Anne heard about it through a parent-led voluntary organisation for families of children with special needs and was encouraged to see someone 'was doing something with girls because no one is'. Anne describes Madison as being able academically, but as having especially good computer skills and as being 'absolutely brilliant' at art. She is also interested in drama and makes short films on her computer.

Madison's interviews took place in her home, in the open-plan kitchen and dining space, but at a time when her siblings were out, in order to ensure some peace and privacy.

#### **4.4.2 Madison's emotions palette**

Two of the emotions palette faces were initially unnamed by Madison. Throughout the emotions and people module she identified herself as alone, without the company of any of her family

##### **Madison's emotions palette**



happy/v happy 0 0 OK sad upset angry confused scared

**4.4.2.1 Happy** This face was happy or very happy. Madison saw herself as being without any members of her family when feeling like this. She also described herself as being happy with friends but clarified that as being happy when talking to friends on her computer.



**4.4.2.2** This face was initially unidentified by Madison, although she tentatively then labelled it 'happy' (2). She did not recognise it as having any meaning for her within her own experience.

**4.3.2.3** This face was left unidentified and had no meaning for Madison although she wrote next to it in relation to who might be with her when experiencing any feelings associated with this:



"no one – tell everyone to go away". Madison Interview 1 p9

**4.4.2.4 OK** OK was how Madison felt on arriving at school. She also attached it to history lessons, although she later placed the subject under the heading of 'bad'.

**4.4.2.5 Sad** Madison identified this face as being 'sad' but had no associations attached to it.



**4.4.2.6 Upset** Madison associated being upset with school. She described this as her experience of



"Being picked on at lunchtime, things being thrown at me, being laughed at" Madison Interview 1 p18

**4.4.2.7 Angry** There were no experiences associated initially for Madison with feeling angry, although she did relate it to how she sometimes feels in maths classes along with 'confused'.



**4.4.2.8 Confused** This feeling was associated with being confused in maths classes at school.

**4.4.2.9 Scared** Madison was scared at school, where she felt

"fear of someone starting to pick on me" Madison Interview 1 p18





### **4.4.3 Madison's emerging themes**

#### **4.4.3.1 a question of perception**

Madison was capable of gaining high marks at school but had managed to persuade her mother and the school authorities to allow her to drop some of the subjects she found most difficult, which included French and some of the English classes. She was also threatening to stop Maths. As well as problems in the classroom of disruption and bullying from other students in her classes, Madison found it difficult to understand sometimes what she was being asked to do. Even in Art, which she enjoyed, she described how the teacher had to give her an idea of how to answer a brief before she could start working; once she had taken hold of a suggestion she would carry it out and often to a high standard. She described how her inability to interpret written tests or folio instructions affected her work at school:

"I was really falling behind [...] because I didn't understand the questions on the paper. So she just explained what the question was actually asking and then told me, to, like, write. She didn't tell me what to write, she just told me what it was and then I wrote it and then she came back to explain another question."

Madison Interview 2 p23

Madison's style of information processing could lead her into trouble, especially when she was with people who did not know or understand her:

"It's a new teacher [...] She shouted at me for ...on the first today for me not having enough room in my school bag for another jotter. I had my PE kit that day so there wasn't really enough room and my teacher ended up having to take my bag off me and putting it in herself".

Madison Interview 2 p23

One of the reasons Madison disliked some of her classes was her perception that the teachers did not like her, or she would feel 'picked on' or humiliated by them if they singled her out for any kind of attention:

"I think my maths teacher thinks I'm going to fail because I just don't get along with my maths teacher at all; he'll just pick on me whenever I ask for help"

Madison Interview 2 p17

#### **4.4.3.2 I'm on my own**

Madison was apologetic at having not continued to fill in the diary. She explained that she had been anxious and distracted by a school exam. Having slept badly in the lead up to it, she'd then had a period of feeling exhausted and

prolonged sleeping before returning to her habitual insomnia and mysterious aches and pains. Madison expressed her anxieties around her school work:

“I worry about failing my exams so I just don’t want to take them [...] just the thought of failing and then my mum getting angry at me [...] my dad would get angry at me too “

Madison Interview 1 p16-17

She worried mostly about her parents’ reaction to the possibility of her failing the exams more obviously than about any possible direct consequences for her own future. She was concerned that her father had threatened to turn his back on her if she failed them and believed that he might carry this out.

#### **4.4.3.3 Negotiating relationships**

Madison was experiencing ongoing conflict with the eldest out of her younger siblings. She felt that her sister deliberately did things that she knew would upset Madison or was, at least, uncaring about the effect of her actions. She conversely got very angry with her sister for reacting negatively to Madison’s own behaviour:

“my sister is not... doesn’t respect it at all. She just does it... she just often wears them to freak me out [...] She doesn’t care a thing about me”.

Madison Interview 2 pp14-15

Madison described having an opportunity to make friends with a girl new to the school. She sat next to the girl in several classes and teachers had encouraged them to work together. The other girl had asked Madison to ‘hang out’ one day after school, but Madison explained it was a day she was going to see her father and that he did not like Madison to go out. She had not invited the girl to her house since then, the reason given being that they’d only known each other for a couple of months.

#### **4.4.3.4 Aching all over**

Madison chose three somatic complaints that she planned to discuss with her herbalist. These were:

- itchy skin, mostly on the insides of her elbows and the backs of her knees;
- aches and pains, occasionally her entire body ached, sometimes just parts, like an ankle or a wrist
- aching all over

Madison experienced what she described as very itchy skin; sometimes she felt itchy all over but mostly the itching was worst behind her knees and in the crooks for her elbows, which are the key places for eczema. Sometimes, Madison said, she felt itchy all over. The itchy skin was given the face Madison had not labelled and the aching was matched with 'sad'.

Madison had chronic insomnia, described initially by Anne but then reported by Laurie and talked about by Madison herself during her 2<sup>nd</sup> interview. During Madison's follow-up interview, she also complained of headaches, which she associated with being angry and again of pains which she described this time as 'cramp' and a 'shooting pain up spine' (Madison Interview 2 pp2-4)

Madison had not found the herbal treatment very useful. She disliked intensely the taste of it to the extent it made her angry, something she expressed in the online diary and to her mother and subsequently to Laurie who had tried an alternative prescription and suggested an alternative method of taking it. Madison's main hope was for improvement in her sleep and when this did not happen immediately she was disappointed. The benefits she did gain from visiting Laurie were in being persuaded and managing to take, firstly, a smoothie at lunchtime and then to eat a proper lunch. What appeared to be of most importance to Madison was that a girl at school she considered to be a friend had encouraged her to try the smoothie and she had been able to sit with some other girls in the school dining room and eat. She was also persuaded by Laurie, as was her mother, to reduce the amount of caffeine she was taking in the form of cups of tea and coffee, especially at night.

#### **4.4.6 Madison's mother: Anne**

##### **4.4.6.1 She's just bad**

The 6 year process of reaching a diagnosis for Madison with no external support for her needs had had damaging consequences for Madison and the whole family. Anne described the experience of having too much to cope with:

"You know, we had a new baby in the house, we had just moved house, you know, all the rest of it, I had [the baby], I had three kids to cope with, one of whom was a new baby and one of whom was obviously having difficulties"

Anne Interview 1 p4

After repeated attempts to have Madison assessed, they had finally been given a referral to the Education Psychologist who had told Madison's parents that their 7 year old daughter:

"...was just bad [...] His words, she was just bad and whenever she had an episode we were to send her to her room and tell her she wasn't allowed to come out until she could behave and she could do things on my terms."

Anne Interview 1 p4

Although Anne described Madison's behaviour as 'really, really bad' both in school and at home, she had instinctively known that whatever was leading to Madison's tantrums and resulting in her being sent out of the classroom regularly was 'more than just bad behaviour'. After these episodes, Madison would be remorseful:

"She was extremely upset, extremely upset, and really apologetic and really upset that she had been causing all this trouble as she saw it."

Anne Interview 1 p4

Support from the local services had been sporadic and inconsistent since the family had been given Madison's diagnosis. She did have learning support at school, but it was only for eight hours a week in a class with one member of staff along with all the other children with special needs, which included dyslexia and ADHD as well as Madison's AS.

The previous year Madison had been offered a course of Speech and Language Therapy provided in groups, aimed at helping develop life skills, where she had been the only girl. Both Madison and Anne had found the opportunity to discuss the impact of AS on their lives invaluable. Madison had kept in touch with a couple of boys from the group via an online social network. Anne had enjoyed meeting other parents of adolescents with AS and having an opportunity to chat.

Anne was currently in the process of planning a meeting at Madison's school of people across the different service providers, including Social Work, a GP from the Community Health team, the Community Paediatrician and Speech and Language Therapists who had been teaching Madison social skills the previous year. Although the meeting was planned under the auspices of the school, it was primarily being driven by Anne, who was doing most of the inviting. She had hopes that this would provide a constructive 'joined-up' infrastructure of support for Madison. She had also recently discovered she might be entitled to

claim disability support for Madison which she planned to put aside in a savings account as contingency for her future.

#### **4.4.6.2 going absolutely mad**

Anne described Madison as being:

‘completely stressed by the slightest thing’. Anne Interview 1 p9

Anne tried to give Madison notice of any activity and this included all daily domestic events, such as tea being ready for her; it was not possible to give her notice of more than one event at a time or to give her notice of any activity or event while she was still involved with anything else. Entering Madison’s room without warning could provoke Madison to shout at her, with accusations that her mother was ruining her life and abusive language Anne sometimes found difficult to cope with.

“I’ve given her the fright of her life just by knocking on the door. I used to knock [loud knocking sound], now I just do [quiet knocking sound] like that, really quietly [...] and then when I get it loud enough for her to hear, it makes her jump out of her skin, because she’s so focused on what she’s doing [...] It’s almost like she can only think about one thing at a time which is not usual for females, you know, we can think of lots of things at the same time” Anne Interview 1 p9

Madison was sensitive to the feeling of fabrics and irritated by certain sensations, for example, labels on the insides of clothes, which had to be removed. She had disliked noisiness. She coped badly with groups of people and was becoming increasingly insular. Anne compared Madison with her other older daughter, who spent hours on her appearance and described Madison as having no interest in personal grooming, fashion or make-up but who was becoming acutely aware of her own appearance compared to her peers. Hormonal changes seemed to have made things much worse for Madison in Anne’s perception, combined with Madison’s dislike at having to deal with the changes in her body; she had expressed hating having periods and had become especially self conscious since she had recently gained a lot of weight. This Anne put down to Madison’s lack of activity and reluctance to leave the house. She refused to walk to school as that would entail meeting up with other students on the way and she had to be put on the school bus by her mother at one end, her younger sister at the other.

“She screams, she cries [...] She hates being out with other people, she hates being out of the house basically. She just wants to be in the house all the time. She hates strangers. She hates that whole thing of looking at clothes and looking at anything really, she hates all of that. She doesn’t want me to choose clothes for her, she doesn’t want to choose clothes for herself. I actually even – oh my God when I think about it! [...] I took her and [sister] shopping one day thinking that I could buy them some nice clothes, and Madison, I had to get her out of the shop” Anne Interview 1 p13

Anne was surprised Madison was doing as well as she seemed to be at school given the circumstances and that Madison did little school work at home; she didn’t accept the idea of doing homework; for Madison, school work was something that was done at school, not home. However, the majority of teachers were full of praise for Madison as a lovely, well-behaved child. Only in some subjects did the behaviour of other students upset Madison and cause her to want to leave.

Anne also noted that Madison’s obsessive washing of her hands was much worse during the school term; this sign of stress and others relaxed during the school holidays.

#### **4.4.6.3 I wish we could have a normal life**

Anne felt she was generally coping well with the demands of her family including having a daughter with AS. She had tried a number of parenting strategies over the years, with mixed success. Trying to write up lists and daily schedules currently caused anger and resentment in Madison who accused her of ‘telling her what to do’ although the alternative – not giving notice of planned events – was often greeted by outbursts and tantrums. Anne’s approach to coping with her daughter’s diagnosis had been to be as accepting and positive as she could towards it:

“I’ve always tried to be positive about it rather than grieving for the kid that I wish she was. I try and be positive and think, well she’s not going to die from it and she’s got qualities that [sister] just doesn’t have [...] Madison will do anything for me [...] loves nothing more than to sit and chat with me “ Anne Interview 2 p15

Anne had tried to encourage Madison’s interest in drama by enrolling her in art classes but Madison had been unable to cope and they’d had to leave. She was proud of her daughter’s abilities:

“Madison’s got loads of imagination and she’ll make up little slide shows on her PC and things, you know, some of the stuff she does I just think is amazing and she’s taught herself all of that. But the thing with the drama, she wanted me to take her and she didn’t like it when we got there, but she still keeps on at me to get her into drama class.”  
Anne Interview p26

Anne had continued to try to include Madison in family activities throughout the years, although outings often ended with her having to take Madison home. Going to the cinema was usually fine, but anything involving social interaction was difficult. Anne had lost friends over the years but retained a small number who could accept the family’s difficulties.

Despite Anne’s attempts to be positive and to intellectualise their difficulties, there was a profound grief and sense of loss:

“I just feel desperately sad [...] I wish we could have a normal life”  
Anne Interview 2 p14

#### **4.4.6.4 like full-scale war**

Madison’s difficulties, which were worsening, were beginning to overwhelm Anne, as was having to cope with the sometimes conflicting needs of the two older girls. The situation was increasingly exacerbated by the middle daughter’s attitude, which was becoming increasingly disruptive and hurtful for Madison. Anne had come to dread the two girls returning from school as they often had already started to argue on the school bus and the fights would continue at home. Anne thought the younger girl resented Madison receiving extra attention as she had been particularly antagonistic towards Madison around the time of the school meeting. The two younger girls stayed more often with their father, in order to avoid the rows at home and Anne felt life had been much easier when her second daughter had been away on school trip.

Madison was behaving in an increasingly agitated manner at home and while Anne explained she had always had a tendency to talking to herself, this had begun to escalate. She would talk to herself furiously or start shouting, hitting herself about the head or banging her head on the wall or computer desk, which infuriated her younger sister.

“her computer will freeze or something and she gets really, really angry and starts throwing things round the room and she’ll start banging on her desk like this and banging her head and screaming and talking to herself really angry [...]”  
Anne Interview p14

Anne felt caught between her two daughters and described their current home life as like living in the middle of a “full-scale war”:

“[sister] will start saying, Madison, shut up, shut up and stop being so crazy and shut up [...] and actually being violent with each other and then I’ll plough in there and try and break it up and then [sister] will turn on me and Madison will get more and more angry with me.”

Anne Interview p14

#### **4.4.6.5 Uncertain futures**

At school, Madison was finding the school environment increasingly challenging and would manipulate ways, according to Anne, of getting out of classes she did not want to be in. Although she was highly capable, her difficulties were getting in the way of her abilities. Targeted by bullies, she had few friends to support her and any attention from the teacher, such as comments at her lack of concentration or application to the work, she found intolerable. Sometimes she would just walk out of class. She was becoming more and more reluctant to go to school at all.

Madison did have one friend who went to the same school as her. However, this girl had also been made the target of bullying because of her association with Madison who accepted this girl would only now talk with her via the computer online networks or sometimes see her out of school if arranged by their mothers. There was sadness for Anne, for Madison and her isolation:

“...if I had a magic wand but not one that would take the Aspergers away? Just keep her as she is but what could we do for her?...I would like it if she had a really close group of friends. I would like that because that’s what she would like more than anything. She’s envious of (sister) and her friends and the friendships that she has. I would like her to have some really good friends [...] you know, some friends that would take her out.

Anne interview 2 p2

There was a great deal of concern for Madison whose behaviour was becoming increasingly disturbed. She was cutting herself, not with serious injury, but had also expressed suicidal thoughts. The school authorities had phoned Anne as an emergency one day and told Anne she had to take Madison away, she was in danger of harming herself: they described this to Anne as a ‘child protection issue’ and suggested she seek psychiatric help for Madison.

Anne was aware her daughter had valuable attributes. She described how willing Madison was to help her, how she would spend time with her younger



sisters looking after them or helping around the house and how much she enjoyed her mother's company when she was able to get her to herself. Anne acknowledged Madison's abilities and admired her talents. However she was becoming increasingly concerned for Madison's future. She described how what might be regarded as normal adolescent behaviours appeared extreme in Madison, not only her mood swings and angry behaviour, but her seemingly total dependence on her one friend as a model for what to be. Anne's plan to start a savings account for Madison reflected her anxieties over Madison's school refusal and the implications for her future. Most immediately, Anne had concerns Madison was in serious danger of physically harming herself.

#### **4.4.7 Laurie, Madison's herbalist**

##### **4.4.7.1 Background**

Laurie has been in practice as a WMH for about 15 years. She works primarily as a private practitioner, but she has also taught herbal medicine at BSc level. Laurie saw Madison and her mother in the city-based therapy centre where she rents clinic space. She has had little experience of working with children with AS although she has treated two adults with AS previously.

##### **4.4.7.2 First impressions**

Laurie's first impression of Madison was that as a teenager being brought by her mother, she was unexpectedly relaxed and open in the clinical setting. Laurie was dismayed to find that the two youngest girls were with Madison and Anne, but relieved when they occupied themselves peacefully. Laurie was also struck that Anne avoided interfering excessively in the consultation. The family gave the impression of being peaceful and relaxed:

"So I felt like the family was quite... there was a good kind of atmosphere" Laurie p3

The consultation was productive for Laurie who felt she had formed a good working relationship with Madison. The teenager had impressed Laurie as being articulate and clear about her needs:

"because she seemed very self aware, it was like she knew what she wanted as well, and straightaway she just said, I want help with anger, I'm getting angry and that's what I want help with, and then we talked why, what's the sort of triggers for it". Laurie p3

In the course of the discussion, Laurie was able to establish that Madison's anger was mostly triggered by events at school, although she also described how sometimes she could not identify why she felt angry and that upset her. It was apparent that Madison was having a lot of bad experiences at school:

"sometimes she doesn't want to go to school because she doesn't like school, but it came down to the other kids, she felt uncomfortable with them and a bit paranoid and things"

Laurie p3

Madison had explained to Laurie that sometimes she:

"could be a bit funny at school and couldn't always answer the questions in the same way as them"

Laurie p4

and that her peers made fun of her; Madison felt the other children thought she was stupid. She told Laurie she would get anxious and couldn't get to sleep at night; she would text her friend or work on her computer. This was an issue for Anne, who was concerned that sometimes Madison kept the household awake through her restlessness. Madison's sensitivity to noises was also discussed. Noise, such as her younger sister playing music too loudly, was another source of anger for Madison.

#### **4.4.7.3 Testing the water**

Laurie had focussed on Madison's tendency not to eat during the school day as a health priority. Explaining to Madison the effect of low blood-glucose levels, they had discussed ways of encouraging her to have something nutritious during the day. Laurie reflected on how she had tried to add positive elements into Madison's day, rather than trying to take things out of it ie: she had avoided telling her to stop eating sweets. She had, however, recommended Madison cut down on the numbers of cups of caffeinated tea she was drinking, which was substantial, especially in the evening. Laurie had prescribed a herbal medicine, designed to help calm Madison and to promote liver activity.

Reflecting on her approach to working with Madison, Laurie felt it was in line with any other of her patients, although she did describe it as being more cautious and that she took:

"...a bit more time to speak to her, to see how she was feeling, because although she was being quite expressive, and that was good, I was trying to kind of delve in a little bit deeper, but being

aware that I didn't want to upset her [...] I may have gone a bit slower in asking more personal questions, I think, just to see, I think I was sort of testing the water.” Laurie pp15-16

On their second meeting, Madison had reported that she had enjoyed taking smoothies to school for lunch, had cut down on her cups of tea and that she had felt some benefit but complained she hated the taste of the medicine, and so Laurie had changed both the content and her recommended method for taking it.

#### **4.4.7.4 Being not in control**

She was disappointed and frustrated that Anne had not contacted her to let her know Madison was having difficulties taking the medicine. She thought she had made it very clear she wanted both Madison and Anne to feel they could phone if they wanted to in between appointments. This frustration was made worse when after the second appointment, she did not hear from them again. She was very disappointed, especially as she felt some good things had come out of the treatment for Madison even in the short time; Madison had been persuaded to cut down on the amount of caffeinated tea she was drinking as was Anne and they had both reported sleeping better. Madison felt better for having taken smoothies to school; and Laurie felt just having the consultation with the opportunity to talk about her problems had been positive for her.

Laurie had considered contacting them to see if she could persuade them to return, but had decided in the end not to:

“she'd made some lifestyle changes which had made a big difference, I felt that there was still stuff that we could do together. And I think I was a bit upset as well that I felt like because of the way she'd kept on taking the herbs when it probably wasn't...the best thing because I would have said to stop it [...] look, it doesn't matter, look at what else you're doing and maybe at some point you could try something else if you wanted to. But I felt if I phoned her up and she was... yeah, I was worried that I was going to be being pressurising” Laurie pp11 -12.

Although Laurie felt she had focussed on Madison only as a patient and not as someone with AS, she was aware of Madison perhaps having different needs than most of her patients and had gone to extra effort to accommodate her individual characteristics. She had hoped over time to suggest Madison attend the consultations by herself, without Anne, to give her more freedom and

independence. She had been anxious to help Madison feel she was in control of her circumstances eg her ability to cope with school and also in control of the treatment:

I also wanted it to be something that she did herself, not that her mum was saying like, you're going to do this, it was very much trying to empower her [...] I thought that was quite important so that she feels that she's got some control over it, because she was saying that sometimes she felt out of control and she couldn't do it.

Laurie p17

#### **4.4.7.5 Learning something**

Laurie had given a great deal of thought to why Madison had not returned to see her again and her frustration at not having been given, as she saw it, the opportunity to make things better for Madison. Laurie expressed feelings of having invested in Madison as a patient, and how she then had to go through a process of detaching again. She felt she had learned something about not making assumptions about people with AS' ability to express themselves. However, although Madison had been articulate and expressive at her consultations, Laurie was left trying to make sense of why neither Madison nor her mother had contacted her since.

#### **4.5 Conclusion**

In this chapter I have described the findings in each example of the case, constructed of a background narrative to each participant girl, her mother and the WMH they consulted, and the experiences described by each. In keeping with interpretive phenomenological approaches, the titles used to describe a meaning of each 'structure of experience' (Van Manen 1990) were laid out as constituting the subordinate themes of each example of the case represented by the three groups of girls, their mothers and the herbalists.

Subordinate themes were re-examined in the light of all that had been described. Arranging and re-arranging the headings led to the identification of those themes that encompassed the experiences of individuals within each group across the examples, sharing a commonality of lived experience.

Table 8 The subordinate themes

Sally	Joanne	Alice
<ul style="list-style-type: none"> <li>* peace to think</li> <li>* out of my head</li> <li>* getting marks</li> <li>* fuzzy buzzy head</li> </ul>	<ul style="list-style-type: none"> <li>* uncertain, unhelpful, undermining</li> <li>* going AWOL</li> <li>* torn between</li> <li>* loss</li> <li>* no more than a breath away</li> </ul>	<ul style="list-style-type: none"> <li>* giving a bit of space</li> <li>* trying to get a balance</li> <li>* being privileged</li> </ul>
Lottie	Kate	David
<ul style="list-style-type: none"> <li>* get it out of my way</li> <li>* the one thing they forgot to put on the sheet</li> <li>* not being horrible...</li> <li>* ...and not being an EMO</li> <li>* feeling sickly</li> </ul>	<ul style="list-style-type: none"> <li>* just a paranoid mother</li> <li>* getting into trouble</li> <li>* tiptoeing around</li> <li>* wanting your child to do what everyone else's are</li> <li>* not in the real world</li> </ul>	<ul style="list-style-type: none"> <li>* the nuts the bolts the lot</li> <li>* a simple plan</li> <li>* taking people as I find them</li> <li>* enjoying the experience</li> </ul>
Madison	Anne	Laurie
<ul style="list-style-type: none"> <li>* a question of perception</li> <li>* I'm on my own</li> <li>* negotiating relationships</li> <li>* aching all over</li> </ul>	<ul style="list-style-type: none"> <li>* she's just bad</li> <li>* going absolutely mad</li> <li>* like full-scale war</li> <li>* I wish we could have a normal life</li> <li>* uncertain futures</li> </ul>	<ul style="list-style-type: none"> <li>* testing the water</li> <li>* being not in control</li> <li>* first impressions</li> <li>* learning something</li> </ul>

## **Chapter 5 Discussion of findings**

### **5.1 Introduction**

The literature reviewed for this study showed that young people with AS suffer from high levels of anxiety compared to the NT population but with unusual profile characteristics and that there are difficulties in identifying precipitating factors. Methods for the assessment of anxiety in young people with AS have been lacking.

In response, an interpretive case-study approach was adopted in this study as a methodologically appropriate design that would enable all aspects of the area being explored to be addressed, as described in Chapter 3. The use of unusual data collection methods with the girls with AS in the IMS computer interview software and online diaries created an exceptional richness and depth to the data, the findings in which have been described in the previous chapter.

In this chapter the findings of the study are considered in the context of the relevant literature on experiences of AS girls, anxiety in young people with AS and what is known about the practice of WHM. The analysis was carried out in accordance with an interpretive phenomenological approach (Van Manen 1990). Essential themes derived from the hermeneutical process as described in Chapter 4 are discussed and related to fundamental thematic structures of human lived experience as explicated by Van Manen (1990, 2002).

The case itself is that of girls with Asperger's syndrome and anxiety, their mothers and the WMH consulted. Each example of the case comprises a girl, her mother and the herbalist. The essential themes derived for each group of participants from each example of the case are considered in this chapter. The case is then summarised as a whole.

Interpretation is inherent to the process of description. The selection of words used is representative of the author's verbal language and illustrative of his or her perspective on the phenomenon being explored. Choices are made in what is emphasised and what is relegated or omitted altogether. These choices are deliberate and conscious, instinctual and automatic. Inevitably, the words chosen constitute a fusion of the horizons of the author and those of the participants in this study. The findings represent, therefore, one locus of

interpretation of the phenomenon described (Weibe 1990). In the analysis of data this study distinguishes the term ‘theme’ as created from a process of ‘seeing’, or clarifying, the lived experiences of the participants, rather than quantifying or coding selected terms (Van Manen 1990).

Table 9 The emerging themes

girls	mothers	herbalists
<ul style="list-style-type: none"> <li>• out of my head</li> <li>• I’m on my own</li> <li>• not being horrible</li> <li>• fuzzy, buzzy head</li> </ul>	<ul style="list-style-type: none"> <li>• just a paranoid mother</li> <li>• torn between</li> <li>• I wish we could have a normal life</li> <li>• no more than a breath away</li> </ul>	<ul style="list-style-type: none"> <li>• the nuts the bolts the lot</li> <li>• testing the water</li> <li>• being privileged</li> <li>• learning from the experience</li> </ul>

From the subordinate themes, the meanings derived from the findings were distilled down into what is described as ‘emerging themes’ (Van Manen 1990). The emerging themes from each group were examined and essential themes identified, those that express something core to the experiences described. One essential theme was identified for each group of participants across the sets, being the girls, their mothers and the herbalists.

### 5.1.2 The essential themes

Phenomenological science research explores the world as experienced in everyday situations and relations. The case, therefore, was examined with reference to four fundamental existential structures of lived experience: spatiality, corporeality, temporality, and relationality (Merleau-Ponty 1962 from Van Manen 1990). These four categories are not definitive, but guides to reflection only. The categories are fluid and interconnected, but with universal relevance to lived experience.

Spatiality describes not only space that is measurable, but that which is felt. Dimensions of scale and distance and our experiences of ourselves in the world are situated within space. Home is described as an essential location of spatial experience involving a:

‘fundamental sense of our being...that secure inner sanctity where we can feel protected and by ourselves...Home is where we can be what we are.’ (Van Manen 1990 p102)

Corporeality refers to our embodied self through which we experience all our relationships with others, and with our environment and through which we subsequently respond to these experiences. This thematic category includes then our awareness of ourselves as embodied beings as well as our unconscious physicality, expressed in the way we hold ourselves, our physical gestures and our somatic health. The girls’ experiences of corporeality are described by the physical or somatic concerns they discussed with the WMH.

Temporality refers to our subjective experience of time, our stage in life and the temporal dimensions of past, present and future. Memories, hopes and expectations are embedded within temporality. Our sense of who we are is founded on our past experiences and our aims for the future.

Relationality is the way we relate to others within the interpersonal space shared. This space may be conversational or physical but it also incorporates our preconceptions, expectations, and physical identities. It also in a wider context refers to the meaning we make of our existence within society, or as existential beings.

In this study the essential theme of the girls’ experiences is described as ‘*Where can we be what we are?*’ This thematic category refers to experiences of being different and of not having needs met in the context of Van Manen’s (1990) phenomenological perspective of ‘home’. Experience of spatiality was inherent in many of the experiences described by the girls, on initial analysis, and contained within the other fundamental categories. The girls’ perceptual characteristics and their sensory sensitivities impacted profoundly on their sense of space, their corporeal experiences, their abilities to learn within a comfortable and facilitating environment and their relationships with others, family members, peers and teachers. The girls’ differences can be seen to impact upon all fundamental aspects of their lives, spatial, corporeal, temporal and relational.

For the mothers, an essential theme of ‘*no more than a breath away*’ encompasses experiences of space and temporality and challenges to their



relational selves as the struggles and disappointments of the past underpin their present difficulties as well as their fears for the future.

Philosophies of knowledge ground interpretation of the data gathered and articulate the 'ways of knowing' that inform the interpretive process. Within this understanding, questions around the translation of theory into practice, as in any pedagogical context, are foremost in the study of WHM (Van Marie 2002; Evans 2009; Nissan 2009). Acknowledging the phenomenology inherent in the practice of WHM (Mills 1991), this study seeks not to quantify or systematise WHM but to locate its practice within the lived experiences of those involved.

The emerging themes of all the participants were revisited in the light of the four fundamental existentials presented at the beginning of this chapter. An exegetical approach led to the phenomenological categories 'ways of knowing' and 'ways of being practical' (Van Manen 1977). In order to cohesively present the complexity of experiences and practices in the lived world of the participants, in discussion of the findings relating to WMH, the interpretive constructs of 'ways of knowing' and 'ways of (being practical) doing' are linked with 'ways of being'.

Table 10 The essential themes as developed for each group

	girls	mothers	herbalists
Set 1	Sally	Joanne	Alice
Set 2	Lottie	Kate	David
Set 3	Madison	Anne	Laurie
Emerging themes	peace to think I'm on my own I'm not being horrible fuzzy, buzzy head	just a paranoid mother torn between wishing we could have a normal life no more than a breath away	the nuts the bolts the lot testing the water being privileged learning from the experience
<b>Essential themes</b>	<b><i>where can we be what we are?</i></b>	<b><i>no more than a breath away</i></b>	<b><i>ways of being...practical</i></b>

Analysis of the data therefore resulted in the emergence of three main themes, described as the essential themes, those that are core to the experiences described and which incorporate the emerging themes already defined. The key points raised by these themes are explored in relation to the primary aim of the study, which is to illuminate the experiences of girls with AS and anxiety undergoing a course of WHM, including the experiences of the girls, the mothers and the herbalists.

The themes are therefore:

- Where can we be what we are?
- Only a breath away
- Ways of being...practical

## **5.2 The girls: where can we be what we are?**

Within this theme, the girls' experiences of difference, being judged and marginalised and their emotional and physiological responses were explored.

### **5.2.1 Peace to think**

Adopting the cognitive style termed monoproducting (Williams 1996) or monotropism (Murray and Aspinall 2006) is seen as a coping strategy in response to potential sensory-perceptual overload. Monotropic processing was apparent in the girls and anxiety a response to their sensory and information processing requirements being only partially or not met. When triggered as a response to sensory overload in the classroom, where there was constant noise and interruptions, frustration and anger could sometimes erupt.

In this study, the girls expressed a desire to do well at school; willingness to comply; frustration caused by the marginalisation of their needs; sadness as being judged and excluded; anger at a school system experienced as inconsistent and obstructive and a fear of failure.

Sally's need to have 'peace to think', when frustrated, caused aggressive outbursts at school and at home. Sam described how Madison would start shouting or hitting herself on the head if she was not able to think clearly. In the following quote, Lottie's mother describes the day she was called to take Lottie home from nursery:

“.... she would be sitting focussing on something that she would spend ages just playing with the sand, just or the water doing it. And then somebody would come over and then she would start screaming and screaming and then the kids realised, oh hey, wait a minute, we can have a bit of fun here...” Kate Interview 1 p13

Anxiety as a response to the increased social and academic demands that develop at secondary school has been cited widely as the key factors leading to elevated anxiety levels in adolescents with AS (Capps et al 1995; Marwick et al 2005; Attwood 2006). Alternatively, Humphrey and Lewis (2008) found the school environment itself to be a source of considerable anxiety. This study supports Humphrey and Lewis (2008) findings and presents the girls' monotropic responses to their perceptual and cognitive characteristics as a major causative factor.

Order and predictability were identified in Humphrey and Lewis' (2008) study as important factors in the young peoples' ability to cope. In this study, the girls' cognitive and perceptual characteristics required clear and consistent parameters and predictable conditions to enable them to function comfortably, described as a 'security blanket', but often absent from the noisy, chaotic and unpredictable school setting.

Madison described how her anxiety over going to a music class had become so unacceptable, she had eventually given up attending the class:

“Because I just ran out of time and I was just running around all the time. I was going up the music stairs which is top floor and the stairs are murder to get up and I was just like every day literally crawling up the stairs every Wednesday to check the time and then to go down and then go back up and I was actually going up the stairs like four times a day and it was just annoying.”

Madison Interview 1 p27

Lottie was perceived by her mother to be overly concerned with rules and regulations with school tasks being a source of anxiety for Lottie. This was an extension, according to Kate, to her need for strict routines and predictability, which had been apparent from a young age:

“And then she'll remind you several times about little things like, 'this letter's got to be in today'. You know? It seems like she worries about little things that a lot of kids have forgotten that today, 'I'll just do it tomorrow'. But it's like, 'no, no, no, no – you have to sign this now. It has to be in today. You have to do this now.’”

Kate Interview 1 p5

When asked about her mother's concern she worried too much about tasks set for school, for example, remembering to take in a letter or an assignment, Lottie's response was that she wanted to get such tasks done in order to free herself up for more interesting activities – if a task did not get done it stayed with her mentally and 'got in the way' of concentrating on other things. She wanted it 'out of her head', so that she could get on with concentrating on other, more enjoyable, or more important things. Lottie also wanted the school staff to know she took her work seriously:

“...I just [...] don't want them to think I don't care or anything [...] don't care less.”  
Lottie interview 2 p20

Sally, from the findings of her IMS interview, seemed to feel happiest while in the school classroom, with perhaps the order and predictability it provided. Joanne reported Sally as being indistinguishable from her school peers within the classroom setting and it was the playground setting that caused most difficulties for her. Sally asserted that sometimes she had good times and sometimes not, in all areas of her life, and that it was impossible for her to generalise. However, the emerging picture from her IMS interview was that the time of greatest uncertainty for her was her return from school to home. The order and predictability of the school classroom was in contrast, not only to the playground environment, but also to a comparative lack of routine and predictability at home.

Clarity about what was being asked of them and a fair adherence to rules by teachers and other students was a recurring feature of the girls concerns. Kate gave examples of what happened when Lottie was given instructions that were too vague for her to process:

“And she said to me she had put these instructions on the board and she said to the class 'Now, just work through them in any order you like'. So Lottie sat there and sat there and sat there. And the teacher went up and said, 'Lottie, why haven't you started?' And she said 'Because I don't know which one to do first'”

Kate Interview 1 p11

Uncertainty at one extreme and panic at another could be caused when rules were broken or ignored by others or transgressed by the girls, even accidentally. Kate described Lottie's feelings of injustice if being 'told off' for something at school she did not understand:

“the teacher will then give her a bit of a row about something but she has picked it up as being something else, so she gets all stressed about that. [...] If she thinks she’s getting into trouble she gets really distressed because she doesn’t understand, ‘well, why am I getting into trouble?’ [...] If she doesn’t get clear instructions, like at school a lot of the time the instructions are not clear at all, and she gets... if I didn’t work there I think it would be quite difficult.”

Kate Interview 1 p12

As they worked to establish a system of rules that allowed them to function ie systems of behaviour relating to logic, sustainability, cause and effect and predictable outcomes, fairness, they were expected to function in a world of people whose behaviour does not adhere to that system. The meaning they are able to make of their life experiences were often challenged with a consequent assault on both their sense of security and their self esteem.

From special consideration having to be made before any attempt to join in after-school or extra-mural activities, to where they sat in class, the girls were identified as ‘different’. Their special needs often caused them to be marginalised and targeted by their peers.

“I’ll say look can I please just leave this class room, everyone’s like throwing things at me and everything....It used to be really bad but the seating plan changed a bit”.

Madison Interview 1 p17

As adolescents, action had sometimes been taken to help at school but this often led to them being singled out even further as ‘different’ and as a target for bullies, findings that reflect those of Huws and Jones (2008) study. For example, as an adolescent, the pattern described above from nursery experience in Lottie’s case continued:

“It was kind of like very rude stuff, like he was like doing *that* behind me, and stuff, and I pushed him. It was like while I was going into the ... through the door and no one else saw, apart from his friend who was laughing, and I just shoved him right into the cupboard and continued going, but he was still bothering me and I pushed him again. Luckily my maths teacher didn’t see because it was just as we were going to the classroom and I pushed him and I shoved him into the cabinet”.

Lottie Interview 1 p15

Both the examples above demonstrate instances where the girls’ differences attracted, sometimes extreme and unpleasant attention from others and sometimes physical assault, or alternatively precipitated violent reaction from the girls. Elevated physical injury fears have been reported in children and young people with AS (Kim et al 2000; Gillott et al 2001; Russell & Sofranoff

2005). Both Madison and Lottie reported having progressively limited their extracurricular and physical activities, in the case of Lottie, cycling, for example, because she had become too nervous cycling out in the streets. However, in the context of the experiences described, anxiety around physical safety can be seen to have some reasonable foundation.

### **5.2.2 I'm on my own**

The social isolation and bullying described by the girls (and also their mothers) has been reported in autoethnographic accounts (Sainsbury 2000, Willey 1999, 2003), by clinicians and in academic reviews (Attwood 2006, Marwick et al 2005). An interpretive phenomenological study of adolescents with AS attending mainstream school published in 2008 reflects these findings but also that occasionally, a good friendship for these girls could emerge (Humphrey & Lewis 2008). The positive impact of peer-friendship and support on daily life along with a positive sense of self-esteem and resilience, in the authors' words:

“cannot be overstated” (Humphrey & Lewis 2008 p35)

The girls felt themselves to be judged. Lottie, for example, saw no irony in her use of the term 'Chav' to describe someone with an overt lack of tolerance for other people's differences, or resenting the term 'Emo' in one context while using it herself to describe others:

“What I don't like is when people keep classing Tim Burton fans as Emos, because I'm not an Emo [...] Like you get a lot of...there's all these people who are just themselves who are fans, and I don't like that. I hate those stereotypes as...I hate those sort of stereotypes and stuff, like people have to be labelled a lot”

Lottie Interview 1 p8

The findings of Huws and Jones' (2008) study that for many adolescents, the diagnosis itself is pivotal to their experiences of having AS, was not reflected explicitly in this study. The girls did not describe feeling excluded or stigmatised as a consequence of the AS itself. Stereotyping, marginalisation, being targeted by bullies, were all behaviours condemned on a general level, as in Lottie's quote above, rather than specifically in relation to being labelled as having AS, while the girls' experiences of being victimised were personal. One incident described by Madison in her diary was having her new school bag kicked about by a group of boys, causing the domestic science food she had made in class to

burst and spill all over the bag contents. Other similar incidents were described by Madison and Lottie, however, that they felt targeted because of their AS was not discussed.

The aim of Huws and Jones (2008) study was different to the aim of this current study. While the questions asked of Huws and Jones' (2008) participants were directed towards experiences of autism specifically, the terms AS or autism or ASD were not used in this current study during the interviews with the girls. That diagnosis of AS was key to the girls' experiences may have been implicit. Alternatively, the girls may not have seen themselves as 'having AS' but as being targeted or marginalised for other reasons, not discussed. However, Anne reported that Madison had described AS as 'this disease' (Anne Interview 1 p21):

'I want to go to the hospital and get this disease taken away from me. I want to be like ordinary kids! I hate this.'

Anne Interview 1 p21

Experiences of young people responding to the perceived 'pathologising' of AS along with the impact of being diagnosed and given AS as a 'label' on the individual's self-identity has been discussed (Huws & Jones 2008).

Although Madison and Lottie both described themselves as having 'friends', it was apparent that the friends were few and not always prepared to risk their own social status by showing loyalty to girls who were perceived to be 'different'. In Sally's situation, Sally was described by her mother as being academically capable but unable to cope with the school playground environment. Sally had expressed her own perception she had nothing in common with the other children at her school:

"I don't want to be in this school [...] I want to be with normal children and play with normal kids..." Joanne Interview 1 p20

The experiences of the girls in this study reflect previous findings that children with Asperger syndrome report more loneliness than typically developing peers (Bauminger et al. 2003) and are also more often subject to exclusion and bullying by their peers (Little 2002c). Deficits in social communication skills have been proposed as being related to the increased risk of developing depression or anxiety disorders in this population (Kim et al. 2000), possibly because these

children and young people have a better awareness of their difficulties and of their consequences (Capps et al. 1995; Marwick et al. 2005).

For many young people with AS high academic achievement provides a route to positive identity and self-esteem. Potential academic failure threatens that identity. For some, increased levels of anxiety or depression may manifest in violent outbursts, which is more likely in young boys than girls (Attwood 2006). For others, self harm, or school-refusal may be the response (Sainsbury 2000; Murray 2005; Nicholls 2009) Madison expressed her anxiety over her coming exams:

“I worry about failing my exams so I just don’t want to take them [...] just the thought of failing and then my mum getting angry at me [...] my dad would get angry at me too” Madison Interview 1 p 16

Madison expressed her dismay at the potential consequences of not doing well at school:

Madison: My mum’s just told me that if I fail my exams then I’m on my own, he’s [father] not going to help me.

C: Right. Do you think he means that?

Madison: Probably. Madison interview 1 p 17

In Madison’s case, anxiety over her performance was directing her towards school refusal, despite her high academic abilities. Sally was described as being very ‘bright’ but had difficulties coping. Lottie was determined to do well at school but her anxiety impacted on her daily at school and at home.

### **5.2.3 I’m not being horrible**

The girls’ sensory perceptual differences were pervasive. They not only had a profound impact on the girls’ education and carried additional social and health consequences. Perhaps most insidious was the impact of their differences on the girls’ lives at home and their relationships with their families. Although the mothers were all aware of the processing and sensory differences experienced by their daughters, being aware did not necessarily ameliorate the impact on their daily lives. Sensory sensitivity extended to personal contact as well as reactions to fabrics and other materials, inevitably impacting on the girls’ relationships with other people. This applied to family members as well as others. For example:



“She didn’t like me hugging [her younger sisters]. If we were sitting, she didn’t really like that, but if you tried to give her a cuddle she didn’t like it. Kate interview 1 p 20

The family home was not always experienced by the girls as somewhere they could be themselves in comfort or security. There were both common and individual experiences for the girls encompassed within this theme.

Lack of personal space in Lottie’s case, and her insecurity in relation to her mother’s relationship with the younger siblings were areas of anxiety and conflict in her home life; for Madison, feeling pressurised at home to cope with a school environment she experienced as increasingly hostile was leading to emotional outbursts and school refusal; for Sally, chronic insomnia had a profound impact on both her and her parents. Her hyperactivity, her need for routine and certainty were compounded by anxieties around her adoption and her relationship with her parents.

One item found for this discussion was psychotherapist Aston’s (2005) account of working with families with members with AS. Aston cites Gillberg (1998) and Willey (1999) to support her observations that while, where they are able to articulate insight and understanding as to their own developmental profile, an AS adult can provide extremely good parenting for both their AS and non-AS children, where such ability is lacking, the consequences may be less positive for the children. Aston has listed a number of possible areas of conflict in families with AS in one or both parents, including: displays of favouritism towards individual siblings, valuing achievement in the child rather than the child themselves; difficulties coping with the challenges to their control intrinsic to adolescence (a clinical observation supported by Howlin) and relating competitively to their adolescent child.

It is not possible to assess whether or not the parents in this study had characteristics of AS or even would receive a full diagnosis. As described by Asperger (1944 transl Frith 1991) some aspects of the girls were clearly reflected in their mothers, one in particular who echoed her daughter’s lack of ability to articulate responses to questions on feelings and emotional experiences. However, such a diagnosis was not available, nor within the scope of this study. The mothers of the 2 non-adopted girls were asked if they were

aware of the fathers manifesting AS characteristics. It is interesting to note that neither appeared to have considered the idea previously.

Furthermore, where neither parent has a diagnosis of AS, Volkmar et al. (2005) has observed that having a child who is less communicative and less accessible, possibly less affectionate, is likely to have some impact on the ways in which other, non-AS, family members communicate with that individual. It is reasonable to believe this must have an impact on the individual's perception of themselves within the family.

The impact of having a child with AS within the family on all members has recently begun to receive research attention (McGrath 2006). That having a child within the family with ASD brings profound challenges to the welfare of the family has previously been identified by Gray (2001, 2003), Allik et al. (2006) and Woodgate et al. (2008). Specific issues arising from family members having AS are less well documented although gender differences have been identified as being important. (Gray 2003) Stress-related impaired quality of life for mothers, more than for fathers, of children with AS, has been found (Allik 2006; McGrath 2006). As discussed in Chapter 2, there is little known about the effect of AS on relationships between parents and their offspring, parents and other siblings or between siblings where one has a diagnosis, although autoethnographic accounts and parental guidance or self-help books are emerging from within this area and research is ongoing. The importance of family dynamics and family conflict has been identified as an important area for study. (Kelly et al. 2008) The attitude of parents and siblings towards both the label and the consequences of AS obviously has implications for the member of the family diagnosed.

Lottie described with visible distress her grief at being judged by her family for expressing what she felt was perfectly understandable relief at the prospect of her elder sister moving out to go to college. This would mean that Lottie had a bedroom to herself, something she needed:

“But mum keeps saying I’m being horrible and [sister] keeps saying I’m being horrible as well but I’m not. I mean like they don’t realise that there are a lot of younger siblings out there who would react the same way and not be horrible. But they say I’m being horrible and I’m not. Because I want [sister] to go to university and everything

because like let her do what she wants and everything like get a good job and everything.” Lottie Interview 2 p23

All the girls were sensitive to the possibility of rejection from their parents. Although it may be possible to interpret the dynamics operating within some of these families as reflecting ‘normal’ family behaviour, emerging evidence has suggested that adolescents with AS experience ‘normal’ levels of conflict within the family as more threatening than is usual. (Kelly et al. 2008) Concern, anxiety and a genuine belief they were the least preferred children of their parents was expressed by the girls in the current study with siblings.

Lottie for example described her anger at her younger sisters when teased about being the least preferred daughter. Kate expanded on this theme and how Lottie would get very upset with her siblings, but also described another aspect to Lottie’s difficulties in her family relationships. The findings of Lottie’s IMS emotions palette, that the more ‘neutral’ of the facial expressions were hard for her to identify was reflected in Kate’s descriptions of family life. Lottie, according to Kate, had difficulty in recognising how other family members might be feeling unless overtly expressed, for example, in smiles and seemed only able to recognise extremes of emotion. ‘Neutral’ facial expressions were often interpreted by Lottie as meaning people were angry with her, or disliked her and she would respond accordingly.

In all these examples, fears of rejection or abandonment had a basis in their lived experience. Three of the girls who originally agreed to participate in the study were from families where the parents had split subsequent to, or during, the diagnostic process and the fourth was adopted under tragic circumstances. Inconsistent access arrangements and changes of plan could cause comprehensible distress or disappointment; however, the degree to which these things have an exaggerated impact on these girls is unknown.

Out of the examples of this case, Sally’s situation was perhaps especially complex. In Sally’s example, there were serious concerns as to her future place within the family. That Sally had been adopted raised its own issues, both for Sally and for her adoptive parents.

Sally had learnt, according to Joanne, about her adoption through overhearing a conversation not intended for her. She also knew her biological mother had

been found dead not long after she gave Sally up for adoption. How this knowledge might have impacted on Sally was not clear. However, that being adopted had specific meaning for Sally's experiences was. Diagnosis and disclosure has been found to be embedded in the experiences of adolescents with AS (Huws & Jones 2008). Delayed disclosure in particular, where young people have been told of a diagnosis, sometimes years later, may be shocking and upsetting as they are made aware of the previously 'absent presence' of autism in their lives. Sally experienced more than one form of 'absent presence', as the facts of her adoption had been revealed to her accidentally and not discussed with her directly. Similarly, her diagnosis of AS was the focus of many discussions, meetings with strangers, her mother's distress which took place around her, but without her direct inclusion.

Awareness of her parents' difficulties in coping had an inevitable impact on Sally's sense of security. Joanne described the situation:

...And, in effect, she's not far away from [being sent into state care] if I'm being honest...because we just can't handle her. But how can you...? I don't know, I just don't know, it's the last thing either of us want to do but we've no relationship with her now, it's basically broken down so badly." Joanne Interview 1 p 12

The girls' lack of security over their position in the family finds parallel in the mother's experiences of being 'torn between' which is discussed below.

#### **5.2.4 Fuzzy buzzy head**

Sensory and perceptual differences have already been discussed but the extent of the impact of these may be underestimated (Bogdashina 2004). It was apparent that the consequential feelings of uncertainty or insecurity pervaded every aspect of the girls' lives. Moreover, it was allied to somatic disturbances.

All the girls were reported and reported themselves, to suffer from chronic insomnia, with a profound impact on their own and their families' daily lives. In Lottie's case, she found difficulty coping with having to share a room with an older girl who expected to be able to use it when she wanted:

"Like if [elder sister] went to bed before me and then started snoring... like I'm fine if she stays up for a little while and then lets me get a chance to go to sleep [...]"

“I got really stressed and everything and I sort of got really...I was sort of shouting and stuff and my mum was shouting and things like that and my sister...”  
Lottie interview 2 p 9

For all the girls, and especially articulated by Sally and Lottie and their mothers, their difficulties in sleeping led to a kind of ‘vicious circle’ where their anxiety would increase throughout the evening at the prospect of not being able to sleep so that by the time it was bedtime, they were so anxious there would be fights or tears.

Transient and puzzling muscular pains were also a feature in the girls’ experiences. The pains added further anxiety when the girls had no way of assessing the cause or the seriousness of their discomfort and were unable to demote to what might be seen by others as proportionate levels of importance. For Madison, for example, a sore ankle meant discomfort and frustration while for her mother it was merely an excuse for Madison to avoid school. The principle of shared horizons suggests that both may be true – the strange and flitting pains both very real and uncomfortable AND an excuse not to go to school. For Madison, these pains were a physical representation of anxiety and fear caused by her school experiences:

“Occasionally my entire body just starts aching but I do tell my mum but she just kind of says you’re always in pain. She says angrily that I’m always in pain so I just kind of ignore it.”

Madison Interview 1 p23

Madison also experienced what she described as very itchy skin; sometimes she felt itchy all over but mostly the itching was worst behind her knees and in the crooks for her elbows. Madison’s description fits the diagnosis for eczema, which is associated with ‘stress’ or anxiety, but it is unknown whether stress is causative. (Haslett et al. 1999)

Sally’s ‘fuzzy, buzzy head’ was allied to her ‘meltdowns’ which she described by finding on the computer a ‘YouTube’ video of a young child having a screaming tantrum:

“That’s what I’m like. I am actually, aren’t I? That’s what I do when I throw a tantrum, that’s what I’m like, only worse. That’s what I do. It’s so weird. It gets out of my head, you know.”

Sally Interview 1 p 34

All the girls described situations where they were involved in physical aggression, precipitated by others but also themselves. Lottie's 'sore head' was associated with

“...it's really loud and like people are fighting and it's really loud and stuff”  
Lottie Interview 2 p 22

Anger and depression are closely related in people with AS and unusual emotional regulation patterns observed (Attwood 2006). People with AS are likely to revert to a younger child-like state when under stress with a lower and more rapidly escalating anger threshold (McKenzie 2004, Aston 2005; Attwood 2006). Abnormal cortisol levels, likely to have a profound effect on the ability to cope with stress and change, have been found in some young people with AS (Brosnan et al. 2009). However, whether these findings are allied to cause or an effect of long term elevated anxiety levels is unknown.

The IMS somatic experiences module was found to be useful in helping the girls to describe their somatic concerns. Its visual nature offers different means of expressing the feelings experienced. However, it does have its limitations. Insomnia, for example, is not easily described within the module and Sally had not mentioned it in her interview with me, although it was the main focus of her consultation with Alice.

Almost all the girls somatic disorders are categorised as being signs or symptoms of anxiety (APA 1994; Haslett et al. 1999) apart from Madison's eczema which is also associated with stress as described above. The girls' signs and symptoms were:

- 'Fuzzy, buzzy head'
- Headaches
- Insomnia
- Transient muscular skeletal pains
- Gastrointestinal (GIT) disturbance
- Itching and eczema
- Irritability
- apprehension

The most profoundly disturbing for the girls and their families was clearly insomnia.

### **5.3 The mothers: no more than a breath away**

#### **5.3.1 just a paranoid mother**

There is extensive research examining parental experiences of assessment and diagnosis of a child's ASD (Brogan & Knussen 2003, Gray 1993, 2003; Midence & O'Neill 1999; Mansell & Morris 2004; Brogan 2002). High levels of stress and impaired quality of life are associated with a diagnosis of a child with ASD, including AS (Boyd 2002; Sivberg 2002; Heiman & Berger 2007). The additional burden associated with uncertain or conflicting diagnosis (Huws and Jones 2008) has been previously identified with consequent stress and especially for mothers in studies such as Brogan (2002) and (Jardine 2008). Woodgate et al.'s (2008) hermeneutical study of the experiences of parents with an ASD child describes a world of isolation and the parents as "Living in a world of our own". The study indicates that although much is known about the importance of support to parents of children with chronic conditions and/or disabilities, this knowledge has not been adequately transferred to the care of children with autism.

The participating mothers understood this study to be exploring the experiences of girls with AS undergoing a course of WHM with a view to building on what is understood about anxiety in the girls and approaches to treatment for them. In this context it is possible they were led to interpret some of their children's behaviour as stemming from anxiety, in their drive to find a meaningful explanation. It was clear the mothers did indeed perceive their children to be experiencing high levels of anxiety. However, that the mothers were experiencing their own anxiety was also apparent.

Uncertain and conflicting information around their children's diagnosis had taken its toll over the years. Three of the families who started the study had broken marriages consequent to diagnosis and one family, where the parents ran their own business, associated their plummeting income with a lack of appropriate diagnosis and professional support. It had taken five or six years to gain a diagnosis for Madison; Sally was still receiving conflicting assessments; with Lottie it had similarly taken years for her mother's concerns to be addressed. The timescales for diagnosis in this study demonstrate small improvement from the late 1990's, when it was reported diagnosis of AS could take up to 8.5 years (Howlin & Ashgarian 1999).

Kate described how she had felt judged by her GP:

“...I think basically he thought I was just a paranoid mother, because I was saying ‘There’s something but I don’t know what it is. There’s various things. I’m sure it’s her hearing...’ and ‘no, no, no she’s fine’...”  
Kate interview 1 p15

Kate went on to describe the impact on her self-esteem of the situation and of other people’s responses:

“It was a really stressful time for me because I was so worried about Lottie. And you turn it round, you think, this is something I’m doing. I’m not doing something right. And then you would get useful comments from my mother who would say things like ‘It’s because you had the [younger sisters], it’s really upset her’. And at the time you’re thinking ‘God, it’s all my fault’”.  
Kate interview 1 p20

### **5.3.2 torn between**

While much of the literature focuses on the effect of increasing levels of change and uncertainty in adolescence at school, in many ways the impact on home life and family relationships is harder to address. (Aston 2005; Attwood 2006) Previous thematic findings from interpretive study of parents’ experiences have included that of ‘sustaining the self and family’, a concept which in this study can be seen to be one of conflict and stress as the needs of adolescent siblings with and without AS became more demanding and harder for the mothers to meet (Woodgate et al. 2008).

The mothers all expressed feelings of being ‘torn between’. For Joanne, that ‘torn between-ness’ referred to her feelings of responsibility and of exhaustion and defeat. For Anne and Kate, who had more than one child, being a mother of an adolescent with AS was experienced as being ‘torn between’ their children’s needs which they sometimes saw as being in conflict. Family resources inevitably had an impact on the family dynamics, for example, in Lottie’s case, her need for a private space was not able to be met. Balancing the needs of each of her four children was an issue for Lottie’s mother:

“But sometimes they can be a bit noisy and wind her up which is a natural thing for them to want to do. They know the things that trigger her off and they do wind her up. And then I’ve got [elder sister] upstairs who gets quite upset. She says, ‘Why does everybody have to tiptoe around Lottie?’ It’s like you have it from all different angles.”  
Kate interview 1 p10



Willey (2001) has described this experience as one of 'Teeter Totter' and another mother as a 'push-me-pull-me feeling'. These could be seen, in this study, to be part of the mothers' experiences of uncertainty and self-doubt over their ability to parent their children. Woodgate et al.'s (2008) theme of 'vigilant parenting' was reflected in this study. All the mothers questioned their parenting skills in the course of the interviews held, either in relation to fulfilling the needs of all their children or in terms of attempts to 'normalise' their AS child. Kate:

"This is my major thing at the moment; am I dealing with her the right way or not – you know, should she be experiencing things and learning to deal with them or should we be making allowances for her? [...] But I feel you can't really sort of let her do everything their way because that's not the real world, you know."

Kate interview 2 p10

Anne gave this example of the stress of being 'torn-between':

"...her computer will freeze or something and she gets really, really angry ...and she'll start banging on her desk like this and banging her head and screaming and talking to herself really angry ... it's a modern house, the walls are thin, so [sister] will start saying, Madison, shut up, shut up and stop being so crazy... they'll start coming out of their bedrooms...actually being violent with each other and then I'll plough in there and try and break it up and then [sister] will turn on me and Madison will get more and more angry with me".

Anne Interview 2 p13

The mothers all expressed feeling exhausted and sometimes defeated by the struggles of coping with the consequences of their daughter's autism. One of Joanne's coping strategies was avoidance, where she not only tried to avoid behaviours or situations she knew were likely to precipitate Sally's anxieties, but sometimes avoided confronting situations she knew she should tackle. She expressed her anxiety that Sally might be becoming less independent than she had been, despite the school authorities maintaining there had been advances for Sally; she also admitted her own tolerance levels had diminished to the point where she no longer felt able to cope. She described a situation where it was her husband who had stopped coping:

"... by the time I set off I thought, I don't know why I'm doing it...one day at the caravan we were going to go down for something to eat and it got into such a spiral, Duncan said, 'I'm sorry, I can't go, I'm so stressed out now I can't go' and the whole thing's called off..."

Joanne interview 1 p

Kate:

“I think some of the times I don’t cope with the repetition, you know, of the day, being asked the same thing over and over every day. Some days I just think, oh God, you know what’s coming [...]....At other times I’m fine, but I think it just depends how I’m feeling”.

Kate interview 2 p2

### **5.3.3 why can’t we be normal?**

Experiences described by the mothers of their child’s autism in this study were intrinsically bound up in the effect the autism had on the family as well as the wider social systems surrounding them, such as school. Raising a child with AS involves a range of additional difficulties for parents and an increased intensity in the level of care (Heiman & Berger 2007). Creating opportunities for socialising, structuring daily routines and providing companionship are often needed beyond the level and age expected in non-AS families (Portway & Johnson, 2005). In the process of coming to meet these additional needs, parents may respond in many ways. For the mothers in this study, the idea of being a ‘normal’ family albeit one that is coping with abnormal circumstances (Gray 2001) was at odds with their own expectations of what is ‘normal’ and their daily experiences.

This study found both similarities and differences from previous research into experiences of parents. Seigal’s (1997) proposal, that the diagnosis of an ASD brings inevitable grief but there is unlikely to be normal resolution due to the enduring nature of the developmental disorder, is reflected in this study. Grief was involved in these experiences but the mothers expressed their grief in different ways. Established models of grief did not apply to all, as has been previously found (Jardine 2008). What was also seen was the coping strategies for their loss adopted by the mothers varied from individual to individual. Gray’s (2001) narrative of transcendence was articulated by Anne, who sought comfort in an intellectual understanding of her situation and by focussing on Madison’s positive qualities:

“I’ve always tried to be positive about it rather than grieving for the kid that I wish she was. I try and be positive and think, well she’s not going to die from it and she’s got qualities that Katrina just doesn’t have....Madison will do anything for me. If I ask her to do the dishes, she’ll do them. If I ask (younger sister), she’ll say, do it yourself. If I ask Madison to play with her, to play with the little ones, then she’s, she loves to do that...loves nothing more than to sit and chat with me.

She'll chat and chat and chat and sometimes I'm cross-eyed with listening to her but I wouldn't dare say to her ...somebody did say to me a long time ago when we first got a diagnosis, try not to grieve for the child that she's not but try and ... don't wish for a normal child, just be glad that it's not something worse that she's got."

Anne Interview 2 p15

Gray's earlier findings (1993, 1997) that families with a child with ASD isolate themselves as protection against uncomfortable social encounters and Woodgate et al.'s (2008) alternative findings, that families are isolated through lack of external resources such as social understanding were both found in this study. A sense of what was 'normal' and a longing to belong to that world of 'normality' was common to all the mothers.

Additionally, in both Anne's and Kate's experiences, diagnosis had led to the split up of their marriages. Kate described Lottie's father's resistance to accepting Lottie's lack of 'normality':

"He did get quite angry [...] He was like 'No, she's not getting treated any differently. This is the way it's going to be.'"

Kate interview 1 p19

Joanne mourned what she saw as her lost self. In common with other parents of children with an ASD, she had gone from a world of belonging to feeling excluded and marginalised (Woodgate et al. 2008). Sacrifices that Joanne felt she and her husband had been compelled to make were expressed, along with references to their pre-Sally lifestyle. She talked about her growing reluctance to spend time with Sally as she found it so unrewarding; she contrasted her lifestyle as it was by then with how it had been before she and her husband adopted Sally. What was common here and to all the mothers was a sense of loss in relation to their expectation of what was 'normal', frustration and confusion as to why this had happened to their daughter and by extension to themselves and their families.

Anne summarised these feelings:

"I see other families where they'll be all, maybe, doing some activity together – having a game of Monopoly, or all watching a DVD or just – we never seem to do that, we just seem to be always screaming and shouting and fighting with each other and it just feels really, really sad and horrible and I just wish we could – even if I try and do something like take them shopping, it always descends into a huge argument and we end up storming out and going and sitting in the car because somebody, Madison will maybe start getting flustered,

because she doesn't like being in that setting. So, [sister] will say something really nasty to her like, get a grip on yourself, freak, and ... so Madison will say something back to her and then before you know it, we're all fighting in the shop and I'll just say, right, everybody in the car and it's horrible, it's horrible. I wish we could have a normal life"

Anne Interview 2 p14

#### **5.3.4 No more than a breath away**

Contrary to previous findings, that parents of children with ASD are able to attach increased value to any progress their child makes through revising their parental expectations (Jardine 2008), the not inconsiderable abilities demonstrated by their children were sometimes in this study either dismissed by the mothers or seen as evidence of their difference and a cause for concern rather than celebration. A theme of confusion has previously been identified in parents with children with AS (Midence & O'Neil 1999).

Kate described her confusion over her daughter's abilities and the way in which they made her different from her peers:

"It's funny because her teachers at school think she's quite sort of...a lot of kids get really anxious about getting up and doing talks and things. It doesn't seem to bother her. [...] She did a whole one on Monty Python and she put all the sounds in and everything, a Powerpoint thing. And it was one of the teachers said, come and see it...he said the whole of the class were just like...because it was just so totally different. It wasn't like 'my pet' or whatever..."

Kate interview 1 p3

This finding may be influenced by different expectations having been raised by the children having AS, rather than a more overtly disabling ASD. Additionally, profound anxieties around their children's futures were a major feature of the mothers' experiences and it was perhaps this anxiety that coloured their perceptions of their child's abilities and the possibilities for their future. For most families, adolescence is a period of progressing independence and autonomy, for adolescents on the autism spectrum, this is a time when family relationships may worsen excessively (Seltzer et al. 2001). Grey's (2001) narratives of 'accommodation, resistance and transcendence' in parental responses to a diagnosis for their child could be seen to have given way in these mothers to, among other things, tiredness, frustration and increasingly, fears for their future.

Previous findings that parents of children with AS are required to provide more intensive levels of care, including providing companionship, than would be

normally expected (Heiman & Berger 2008) are reflected in this current study as has that mothers with a child with AS experience high levels of stress (Boyd 2002; Allik et al. 2006) and are likely to be comparatively pessimistic about their child's future (Little 2002b).

Joanne described other issues to do with her own anxieties for Sally, her future, her perceived reduction in Sally's independence. There were also issues to do with Sally's safety around her sexual behaviour. Her lack of constraint and social awareness could make her vulnerable. Her family history indicated the possibility of her biological mother having succumbed to such vulnerabilities, a possibility of which Joanne was aware.

Kate also expressed anxieties over Lottie and her perception Lottie was both inappropriate and vulnerable in the way she approached people she didn't know for help or advice:

"I don't know how many kids would think...would pick up the phone and phone Childline about this, I was quite mortified. I was like, my God, you can't phone these people!" Kate interview 1 p14

Kate was also concerned as to how Lottie would cope with the world of work after she was finished at school.

Joanne admitted she and her husband were close to crisis. She also expressed her awareness of Sally's uncertainty over her status within the family. Joanne's anguished admission that Sally

"actually isn't more than a breath away (from being sent away)"  
Joanne Interview 1 p12

expressed the level of crisis the family had reached. Finally, there was the big uncertainty that hung over all their futures. In this context, anxiety caused by deep insecurity could be seen to be, for Sally, a reasonable response to a very real situation:

"Her anxiety's huge, I think her anxieties are huge, she knows we can't cope, clearly she knows we can't cope and I think, she's wondering what is going to happen to her. I actually do think that is a big, big problem. Is she going to go into care? Is she going to go to boarding school? Is she going to go to prison? What is going to happen to Sally?"  
Joanne Interview 1 p 12

## **5.4 The herbalists: ways of being**

### **5.4.1 The nuts the bolts the lot: ways of knowing**

While concepts of ‘holism’ are widely described as being at the root of WHM, clinical practice includes a holistic approach to ways of knowing as well as ‘being practical’ (Van Manen 1977). WMH practitioners demonstrate a number of different ways in which they understand the principle of holism in the context of their practice (Nissan 2009). For the herbalists in this study, being able to gather enough information to build a useful case history was paramount to the creation of a credible treatment strategy. A key aspect of this concept of ‘case-history’ for them was the hermeneutic interpretation of their patients’ lived experiences. An example of the WMH practitioner case-notes and prescriptions is included as Appendix 5.

Two of the three examples presented in this case carried out clinical consultations within the patients’ homes, an opportunity received as ‘a privilege’ (Alice Interview p25). For David, this meant seeing the ‘whole environment’, being able to observe his patient within the space defined as ‘home’ and in relation to other members of her family or

“the nuts, the bolts, the lot”

David p20

Conversely, however, the holistic approach did not include preparatory research in Asperger’s syndrome prior to the first consultation for two of the herbalists. Alice, who did carry out some reading beforehand, in addition had the most experience of the participant herbalists. For the others, one intention was to ‘take people as I find them’, to avoid creating preconceptions of what would be found in a specific patient and to be able to focus on the patient ‘as themselves’, not as ‘someone with AS’. However, on reflection, both David and Laurie admitted becoming aware that they already held preconceptions about what they might find and had, in the course of this study, reason to question their expectations and assumptions.

Ways of knowing were implicitly ethical as well as practical, specifically concerning the challenges of creating ways of knowing with children. From the dangers of offering clues to answers hoped for when asking questions, to making assumptions based on parental reports, a reflexive approach to

consultations was inherent. Alice, for example, was clearly aware of the relevance of the fundamentals of spatiality and relationality in the life of her young AS patient. Alice's way of knowing included creating a sympathetic environment in which Sally could feel safe and able to express herself naturally, defined by Alice as:

'giving her a bit of space'

Alice Interview p3

#### **5.4.2 testing the water: ways of doing**

For a biomedical practitioner, a treatment strategy may be a prescription for a particular pharmaceutical medicine or referral to a specialist or specialist department. For a WMH, while a treatment strategy may be as simple as a single herb prescription, this is unusual and is more likely to involve a number of complementary approaches, described as the 'three-fold therapeutic approach' (Nissan 2009) which includes the prescribing of an individually formulated combination herbal medicine, dietary changes and lifestyle recommendations. This 'three-fold therapeutic approach' is arguably a cornerstone of contemporary WHM and is perceived by some practitioners as being the key difference between their health practice and that of the mainstream. Implicit in this perception is that extending the scope of treatment beyond that which may be addressed by the taking of pharmacologically measureable herbal medicines is one of the means by which WHM fulfils its claims of 'holism'.

In the context of 'ways of doing' for WHM, 'holism' is often referred to in relation to the Hippocratic emphasis on maintaining a balanced, measured approach to life (Griggs 1981, Weiss 1998, Hoffmann 1990, Mills 1991). Balance is also taught to trainee herbalists as a driving force behind the living human organism which strives at all times to maintain internal stability or homeostasis (Tortora and Grabowski 2009) All three herbalists in this study cited 'balance' in the sense of achieving a measured and supportive structure to the girls' daily lives, as a key aim in their approach to treatment of the girls. The means by which balance was to be gained was informed by the circumstances of the individual girl, each set of problems presented and the inclination of each practitioner.

Alice, for example, aimed to redirect the dynamic of Sally's day, so that a good night's sleep would be followed by higher levels of day-time energy, better coping at school and tiredness at night, leading to a better sleep. David's

strategy with Lottie was similar and mainly aimed at relaxing Lottie enough to break the current cycle of lack of sleep, leading to poor day-time concentration, irritability, anxiety and further difficulties in sleeping. David had not pursued any dietary or lifestyle changes with Lottie. Laurie, in contrast, had focussed on Madison's poor eating habits as a cause of blood glucose level disturbance with consequent mood swings and difficulties in concentrating or coping at school. She also picked up on Madison's high tea and coffee intake, especially in the evenings, as exacerbating Madison's sleeping difficulties. All three herbalists, however, had prescribed an individually formulated prescription tincture medicine consisting of a combination of liquid herbal extracts.

Each of the herbalists had responded to the knowledge that the girls were diagnosed as having AS with a tentative approach, both in terms of consultation and in their treatment strategies, an approach described as:

“testing the water”

Laurie Interview p16

David's 'simple herbal plan' was partly founded in his feelings of constraint when dealing with an adolescent with AS. Alice had avoided giving what she would define as a 'knock-out' prescription to Sally, but had chosen 'gentle' calming and 'cooling' herbs. These included *Tilia europea* (Limeflower), *Matricaria recutita* (Chamomile) and *Nepeta cataria* (Catmint) all of which are widely considered as 'children's herbs' and commonly used for fevers and over-excitability, as digestives and relaxants. For more information on herbs prescribed and treatment strategies, see Appendix X

The herbalists all expressed uncertainty as to their approach and the potential outcome with their AS patients. This uncertainty was partly dictated by their levels of knowledge, for example, Alice's prior research and experience had made her aware of reports regarding adverse reactions to such things as medicines, foods or additives in children and young people with ASDs. Her choice of 'gentle' herbs was partly informed by this knowledge. David's caution, however, was more driven by his concern to make compliance simple for his patient who he regarded as having a typical adolescent diet in many ways and who he judged might resist too many changes. However, his clinical experience informed his usual practice of combining dietary and lifestyle changes with herbal prescriptions and he was anxious, therefore as to the outcome for Lottie



without such changes. Threaded within the uncertainty and caution for the herbalists was apparently a lack of confidence, which is discussed further below under the theme of 'ways of being'. Laurie reflected on the WMH mode of treatment and how its 'three fold approach' was limited to the extent of the herbalist's authority:

"No, because we're not treating the symptoms, the anxiety really is the symptom of something else, isn't it? It's looking for the causes, the root causes, and trying to address that as well or address... not that you can go, you can't go into somebody's school and address it, but..."  
Laurie p 20

#### **5.4.3 Ways of being...practical**

Extending Van Manen's (1977) analysis of the phenomenological structures 'Ways of knowing' and 'ways of being' from a pedagogical context to a medical one, concepts of practice as theory or 'truth' translated into 'practicality' or 'action' (Schwab 1969 from Van Manen 1977) were explored. Van Manen's pedagogical context is the basis for an argument that seeks to differentiate questions of (curriculum) content from administration or delivery. Parallels may be drawn with the practice of health care. The application of what Van Manen defines as 'scientific method' to general practice may be seen to have altered the idea of medical practice as 'an effective relationship' to medical practice as 'effective treatment'. In other words, questions of 'what is valid knowledge' subverted to 'what are valid ways of teaching the knowledge' (Huebner 1975) can be translated as questions of 'what is valid treatment?' distilled down to 'what are valid ways of applying the treatment?'. Driving through both of these threads is a means-end rationality increasingly associated with an economic model (Foucault 1989; Van Manen 1977; Epstein 2010). The question of 'what is valid treatment?' is seen as core to the holism of the 'three-fold therapeutic approach' identified by Nissan (2009) as the answer is considered as varied as the individual patient.

WMH, as are other health care practitioners, are required in the clinical setting to deal with situations requiring instant and practical decisions based on a fusion of theoretical knowledge and practical concerns (Gadamer 1996; Van Manen 1977). Practicality, it is asserted, is not founded on reflexive deliberation, but is a concern of ordinary life, expressed in uncritical, unreflective daily activity (Van Manen 1977). In contrast to this assertion, critical reflection on what constitutes

knowledge and what is practical is embedded within WHM and was apparent in the participant WMH's discussions of their experiences.

There were multiple ways the WMH practised reflexivity as they considered their clinical perspectives on the case. They reviewed their 'ways of knowing', encompassing the construction of the case history, personal impressions of their patient, additional information derived from the parent, and observations of the girl's interactions with their parent or family. Flexible approaches were taken to their ways of doing as treatment was adjusted to reflect what was additionally known throughout the course. The herbalists also demonstrated reflexivity in relation to their own clinical judgement and practice – their 'ways of being' and their 'ways of being practical' or 'doing'.

Alice, for example, had given prior thought to the potential for communication difficulties with Sally and considered how to facilitate the consultation in an ethical and constructive way. She welcomed the opportunity to gain access to Sally in her home and family situation and felt her understanding of the conflicts and difficulties within the mother-daughter relationship had been made richer as a result. Alice felt that although the herbal medicine had had a demonstrably beneficial effect on Sally, there were a number of reasons why Joanne chose not to pursue the herbal treatment long term; for example, Joanne was casting about widely for help with the family crisis, while being able to commit to no particular course of action. Alice also considered that Sally's experience of Melatonin being so positive for her and her relationship with her mother might have led her to refuse the herbal medicine in the hope of manoeuvring a return to the Melatonin. However, Alice also felt that overall she had not received a satisfactory explanation as to why the herbal medicine was not renewed, despite its apparently beneficial effects.

Reflexivity in practice was demonstrated in the way Alice experienced all her patients as pedagogical opportunities. She especially had appreciated the incentive to research AS, and the experience of working with Sally, no matter what the outcome of her treatment, as a way of informing her clinical practice.

David had similarly welcomed the opportunity to meet with his patient in her home environment. He had found Lottie engaging, calm and communicative and had been surprised at how compliant she had been. His expectations of AS had

been confounded; he felt that Lottie was less introverted and less overtly 'different' than he had expected and reflected on what had been his preconceptions, which he termed 'prejudices'. He also described himself as having swung from being 'over the moon' at the success described by both Lottie and Kate of Lottie's herbal medicine to being bemused by what he saw as their 'underwhelmed' reaction. David also expressed a positive response to the experience of working with Lottie and the greater understanding he felt he had gained of girls with AS generally.

Madison had impressed Laurie as more relaxed and communicative than she had expected and Laurie had been optimistic about the treatment. Her initial impression that Madison was self aware and clear about what she wanted, in terms of anger management. Laurie felt the consultation had been positive and that she had established a rapport with Madison. Laurie had also gained the impression that the family was cohesive and supportive of Madison's treatment. These impressions were followed by confusion as Laurie's expectations were not met. Laurie reflected on the dynamics of the family relationships and where the herbal treatment may have become a focus for conflict between the adolescent Madison and her mother. Laurie also invested time and energy examining why her treatment of Madison had not appeared to be as successful as Laurie had hoped.

All three of the herbalists questioned their relationship to the research study and ways in which this might affect their approach to the girls. They had given consideration to issues around pursuing contact, their approach to treatment and one had questioned whether my 'insider' status as researcher and WMH might affect her own therapeutic relationship with her patient.

The herbalists demonstrated a caution in their approach to the girls in this study that was partly based on the understanding they had of their patients. In David, it was expressed through his 'simple plan'; Alice had described her tentative approach with Sally and her use of gentle herbs in lieu of the stronger herbal sedatives and neurological remedies she might have prescribed; Laurie had been aware of being more cautious in her approach to Madison than she might have been in her general practice. Threaded throughout the interviews,

however, was an additional lack of confidence and feelings of professional vulnerability.

Ways in which the herbal profession has been marginalised have been identified (Friedson 1988; Saks 1996, Kelleher et al. 2006) and how practitioners attempt to counteract that marginalisation or to accommodate it discussed (Saks 1992, 2003; Sharma 1992; Gabe et al. 2006). The lack of security arising from this marginalised position and likewise, the limited ability to effect genuine empowerment central to herbal practice is implicit in the experiences of the herbalists in this study.

Feelings of professional pride, or defensiveness were expressed by two of the practitioners. For example, David was delighted to find his initial prescription for Lottie had been so successful and was confounded by what he perceived as a less than appreciative response from Kate. He reflected this reaction arose partly from his own anxiety to 'prove' the effectiveness of the herbal medicine as well as his usual personal and professional incentive.

## **5.5 Conclusion**

The importance of sensory and perceptual differences in people with AS has been noted by clinicians and researchers over the decades since AS was first described, by Kanner (1943), Asperger (1944 transl Frith 1991), Rimland (1964) and Volkmar et al. (1996). Despite these differences being identified as a core feature of the AS individual's interaction with their lived world and that

“Learning how each individual autistic person's senses function is one crucial key to understanding that person.” (O'Neill 1999 p31)

the presence of sensory differences is not included in the current diagnostic classifications. While AS is diagnosed primarily through the observation of specific behaviours, the lived experience consequences for those with AS are secondary to their diagnostic value. That the particular cognitive processing style in individuals with AS may lead to behaviours seen as bizarre or pathological by NT has been previously described. Grandin (1996), for example, asserted her childhood autistic behaviours were not random, unintelligent acts but intelligent, adaptive responses to what she experienced as a chaotic, often painful, world (Sacks 1995). There are criticisms that definition of perceptual differences in ASD is often reduced to sensory sensitivities and the profound

effect on experience and function these differences can have, poorly represented or understood (Grandin 1996; Spicer 1998; Bogdashina 2004). This current study underlines these concerns.

However perceived by others, having to respond to a neurotypically-defined world and the inherent difficulties involved manifests as reality for girls with AS. It impacts upon their daily lives in all aspects of their selves, directing the fundamental existential structures of their lives. These were:

- i) spatial, in their relationship to their environments at home and at school.
- ii) embodied, in their somatic responses to sensory overload and confusion. The girls manifested a range of signs and symptoms associated with clinical anxiety, from unidentifiable aches and pains, headaches, eczema, irritability and emotional lability, and chronic insomnia.
- iii) temporal, in their ability to learn and to accumulate cultural and social awareness
- iv) relational, in the impact on their interactions with family, peers and teachers.

Adolescence has been identified as a crucial time for those with AS, with the levels of change in all areas of their lives - social, academic, emotional and physical – increasingly challenging. This study adds to previous findings in this area. It found the school environment to be often unsupportive of the girls' needs and damaging to their sense of identity and self esteem. Nichols et al. (2009) have reported that:

'bright girls often notice the gap between their intellectual abilities and what they are able to achieve in day-to-day life. Many of the girls in our group report that the future looks very scary.' (Nicholls et al 2009 p 164)

Anxieties around such perceptions of a 'scary future' were reflected also in the experiences described by the girls' mothers. This study highlights the impact on mothers of having an adolescent child with AS and their increasing anxieties for the future, the mothers' own, as well as that of their girls. The mothers perceived their children progressively failing to meet the levels of developmental 'normality' they would wish for and which would give some assurance of a positive future for them.

This study additionally clarifies some of the areas of conflict and burden within families of adolescents with AS. These findings add to what is understood about the impact on family dynamics and especially on how those dynamics are influenced by the ability of the family to meet the special needs of the AS child. Books aimed at parents of young people or adolescents with AS may well offer cogent advice on important issues but cannot mediate for inequities in resources, either material or personal. Low levels of confidence in relation to their abilities to effectively parent were expressed by the mothers in this study and experiences of feeling torn between their AS girls and their other children. Material resources were crucial as being able to accommodate their different children's needs for their own space was not always possible. The mothers also felt torn between accommodating their AS children as they were and wanting them to be happy, and the powerfully motivated desire for their children to conform so that their future place as an adult in society could be assured.

Feelings of grief, loss and isolation have previously been identified in parents of children with ASD. Studies such as Emerson et al.'s (2006) which examines the broader social context of maternal well being in families with an intellectual disability have highlighted the serious need for further research into this area.

Whether WHM can address the complexities involved in the treatment of girls with AS must inevitably depend on the components of each case, including family circumstances, levels of social support, resources, individual responses to the medicine and the ability or willingness to comply with the treatment. These things may be additionally complicated by relationship dynamics such as those of an adolescent, with or without AS, and their need to assert independence from maternal control.

The efficacy of the herbs has inevitably to be weighed against the lived experience context. In all three examples the herbal treatment was reported as having had some level of beneficial effect and in one case was demonstrably extremely effective. Despite this, the herbal treatment in all the examples was not continued for reasons that were diverse and individual to each.

Despite their frustration at the lack of opportunity to pursue their course of treatment, the reflexivity inherent to their practice was demonstrably a positive aspect of the 'ways of being' which informed all aspects of the WMH 'ways of

doing'. Their experiences with the girls were perceived as positive opportunities by the WMH, who each created their own narrative of progress and empowerment for their professional practice.

## **Chapter 6 Conclusions**

### **6.1 Introduction**

The literature reviewed for this study has highlighted the lack of existing research material on any aspect of WHM and that there is a need for work that explores issues of personal experience in WHM. The focus in my study has been on experiences of a course of WHM for girls with AS and anxiety.

The literature search found that young people with AS suffer overall elevated levels of anxiety and other mood disturbances compared to a NT population but there is uncertain and conflicting evidence as to both how and why this is the case. While the level of qualitative research has increased in recent years in this area, focus has primarily been on parental experiences. There is a deficit in understanding of what anxiety means specifically for young girls with AS with an apparent consequential lack of direction in relation to intervention and support strategies. Intrinsic to this lack is the question of appropriate methods to researching with this group.

This study has contributed to this field of research in terms of both outcomes and processes. An innovative case-study hermeneutical phenomenological approach was developed, to enable the voices of individuals who often struggle to make themselves heard. Methods were sought out, adapted and assembled with the aim of addressing specific requirements of young girls with defined communication differences.

In seeking to fulfil the aims of this research study I have had the opportunity to enquire into the lived experiences of girls with AS and anxiety and to look, not more closely, but differently, and from a new set of perspectives, at experiences of WHM as practised in real life. As an 'insider researcher' I have gained an enhanced understanding of both. The process of learning and development involved in carrying out a research study such as this will inevitably have an impact on my work as a practitioner of WHM and as a teacher. My view on WHM and its role in relation to contemporary health care provision in this country has both broadened and become more focussed.

My personal journey in relation to both my professional self and my role as a mother has been profound and will impact on my future practice and parenting. This study could be described as a narrative of marginalisation as people



whose individual characteristics and allied special educational and pastoral needs are marginalised because of their differences turn to a form of treatment marginalised within the prevailing biomedical model of health care.

The aim of WMH to empower their patients through the acknowledgement of individual lived experience, promotion of autonomy and personal change, and increased control over their health (Nissan 2009) is not unique to WHM. Concepts of empowerment in healthcare are also found within the orthodox medical professions (Caroselli & Barrett 1998; Laverack 2006). However, the position of the WMH and their ability to affect such personal change and empowerment is likely to be different than a consultant paid for and endorsed by the authority of the National Health Service.

Empowerment is also dependent on having the tools to effect the required changes, tools which include both personal and material resources. Addressing the needs of all members of a family where one has been identified as having the special requirements of a young person with AS involves specific challenges as described by the participant girls and their mothers.

Moreover, access to the benefits of WHM can be seen to be inequitable: in terms of the cost of the herbal medicines; in the ability to carry out recommendations and in the lack of formal channels of communication between WMH and other relevant service providers.

The key findings of this study have been discussed in relation to the experiences of the groups of participants that made up the case, that is, the girls, their mothers and the WMH consulted. There are two main areas of exploration, one being the lived experiences of girls with AS and anxiety, as described by the girls and their mothers; the second, experiences of WHM as practised in real life in the UK in the 21<sup>st</sup> century. Therefore, this chapter concludes this thesis with a discussion of the contribution to research this study hopes to offer in the two areas of experience.

## **6.2 Contributions to the areas of enquiry and recommendations**

This study represents an innovative approach to researching with girls with AS. A qualitative case-study approach was developed along with novel data collection methods. The use of computer-mediated interview software IMS

along with an online diary website was adopted as a means of facilitating authentic expression of the girls' lived experiences. The diary facility in this study had specific limitations as outlined in Chapter 3; however, the concept of an online 'blog'-style diary facility has further potential for development. IMS as an appropriate tool for interviews with young people with AS in research as well as in clinical settings offers an area for potential further study.

My research study addresses gaps in what was previously known in two key areas, being:

- i) Experiences of anxiety in girls with AS.
- ii) Experiences of WHM

### **6.2.1 Experiences of anxiety in girls with AS**

This study demonstrates that girls with AS do indeed experience anxiety as manifested in a variety of ways, including chronic insomnia, regular emotional outbursts and reluctance around attending school. Furthermore, areas of stress and anxiety in the girls' lives were illuminated.

That girls with AS experience ongoing intolerance and marginalisation in the mainstream school setting is apparent. Furthermore, their unusual and specific sensory and perceptual characteristics are often not incorporated into or supported by these settings. The school environment, from the classroom setting to the common social areas, the corridors and stairs and the dining rooms, can be seen to cause high levels of stress and anxiety for these girls, inhibiting their abilities to function comfortably and leading to the consequential anxiety-provoked somatic symptoms.

The experiences of the girls in this study reflect previous observations that children with Asperger syndrome report more loneliness than typically developing peers (Bauminger et al. 2003) and they are also more often subject to exclusion and bullying (Little 2002). Impairments in social communication skills have been linked to the development of depression and anxiety disorders in this population (Kim et al. 2000, Gillot et al. 2001). The consequences of these impairments can be far reaching. It has been reported that in adulthood, high functioning individuals with ASD are less likely than their typically developing counterparts to live independently away from home, to marry or

have friendships, to complete college courses or to work independently (Howlin, 1998; Marwick et al 2005). The challenge to understand and intervene in social communication and interaction in ASD is therefore undeniable; the right educational setting must be effective, not in removing the autism, but in creating a good environment for the girls' development.

That environment can make a difference to outcomes for young people on the autism spectrum been previously expressed (Marwick et al. 2005). Barnard, Prior, and Potter's (2000) report 'Inclusion and Autism: is it working?' for the National Autistic Society shared parental perspectives on inclusion and made 16 recommendations including that awareness of autism should be part of the continuing professional development of all educational professionals; that local authorities should make autism-specific help available to mainstream schools whilst maintaining choice of autism-specific schools, and that all interventions should be made in a context of meeting the individual needs and rights of pupils with autism.

The HMIE report commissioned and published in 2005 in Scotland (Marwick et al. 2005) was done so in response to the Standards in Scotland's Schools etc Act 2000 (Scottish Executive, 2000), a report entitled, *Moving to Mainstream* (Scottish Executive Education Department, 2003) which revealed some of the budget costs of an inclusive model of education and the Education (Additional Support for Learning) (Scotland) Act 2004 (Scottish Executive, 2004). Lack of appropriate services and insufficient special education facilities was identified UK wide almost two decades ago but this situation does not appear to have been resolved. (Heiman & Berger 2008) An inclusive approach to education aimed at fostering independent participation in education and society supported by the legislation detailed above can only succeed through the application of resources. Perhaps even more cogent however, is that such resources should be directed towards an approach to inclusion that is truly based in insightful understanding. The experiences of the participants in this case study suggest that such understanding and therefore the appropriate support still is not sufficient, at least in parts of Scotland.

Home was also not always experienced in this current study as a safe place to be, but sometimes challenging and painful for the girls and for their families.

Difficulties in addressing the needs of all members of the family was a commonly experienced aspect of having a child with AS. For the girls, being judged for expressing their needs, anger at having their needs ignored, anxiety over conflict with and between family members and feelings of rejection were expressed, while the mothers experienced exhaustion, feelings of isolation and fears for the future.

For the families with girls with AS, loyalties were often challenged as mothers were 'torn between' the love for their child or sibling, and their fears at 'not being normal' and facing a future of marginalisation. Weibe's (1990) description of her 'breakthrough' when she realised that she needed to start understanding her child, not as with differences that must be 'normalised' but as 'different and equal' resonates here. It is worth noting that Weibe's experiences took place within the context of a supportive family environment and stable marriage.

This study highlights an existing need for greater support for families with children with AS. That support should firstly take the form of appropriate, efficient, speedy diagnosis which should surely, by now, be easier and less traumatic for the families. Individuals with AS may be motivated to find answers to their difficulties and the complexities of their experiences but may have mixed responses to a diagnosis (Willey 1999; Molloy & Vasil 2004; Murray 2005). Such responses are likely to be mediated by the responses of those around them, their families and their peers (Huws & Jones 2008). Given the levels of prejudice, misunderstanding and exploitation reported towards individuals with a diagnosis of AS, these responses are likely to be varied and range from supportive to devastating.

Responses by individuals to a diagnosis will also be mediated by how that diagnosis interprets their future: new opportunities, to join support groups, to find places on college courses established to cater for their special needs, to be understood and accepted by their immediate community, to look forward to finding a workplace niche that suits their skills and talents, are the kinds of positive outcomes hoped for.

"changes have to come about [...] that will foster interest, enjoyment and learning. I see that accepting a 'holistic' or inclusive attitude to humanity in all the children, as well as respect for their individualities, brings improvements. I contrast this with the

academic identification of specific deficiencies at a higher, more educated level of mental functioning, which are all measurable by controlled, pre-structured tests. While these tests, models and theories certainly illuminate puzzles that arise in the exploration of pathological effects that develop in the psychology of different groups of children, they have remarkably little practical use in helping these children". (Trevvarthen C 2000 p11)

The building of both school and social communities that value diversity and actively implement policies that support in real life that diversity may perhaps be judged to be idealistic or at the least ambitious. The benefits, however, not just for families and individuals involved in AS but for society overall, would be invaluable.

All ASDs are complex with long term implications for those affected. In the interests of supporting people with autism, there has been longstanding debate as to perceived merits of identifying, diagnosing, and consequently assessing the support needs of individuals on the spectrum, and about the relative usefulness of defining sub-groups within the autism spectrum, such as AS (Berney 2004). It can be argued that while this debate may be useful for research purposes, in practice the focus must be on the potential of any individual to benefit from any intervention (Marwick et al. 2005), an argument reflected in assertions the

'prototypical individual with autism does not exist' (Vermeulen 2001 p12)

Given the sometimes subtle nature of presentation in AS and the widely expressed concern regarding diagnosis and misdiagnosis, it is also the view of this author that definition of autistic spectrum disorders altogether and AS specifically, should lead to common understandings of this spectrum:

"amongst a wide range of professionals...essential if people with ASD are to be included in education, in services and in society"  
(Marwick et al 2005 p ).

Motivation for diagnosis lies in several areas: to provide information for parents and caregivers; to indicate potential treatment possibilities, prognosis and other aspects of clinical practice; to direct children and their parents to appropriate support groups and organisations; to provide professionals with the means of communication; to facilitate record-keeping and to enable children to have access to specialist educational provision and other resources (Berney 2004;

Marwick et al. 2005). That these resources are unevenly available across the UK is an ongoing situation. Meanwhile, families of children and young people with AS will continue to seek help and forms of intervention not supplied by the mainstream services.

### **6.2.2 Experiences of WHM**

Each of the WMH in this study demonstrated reflective consideration of their patient within their individual contexts and the application of the three-fold therapeutic approach was modelled as considered appropriate for each example. For all three examples in this case, the herbal medicine itself was reported as having had some beneficial effect, and in one case, a markedly beneficial impact. However, compliance by the girls was uneven as was the commitment of the mothers to the treatment. The overview of treatment approaches for AS is one of a clinical requirement to consider with each individual case, not 'what is the right treatment' but which treatment is most likely to be effective with which individual (Vermeulen 2001, Volkmar 2005). In line with this view and in common with other forms of treatment with this population, individual responses in girls with AS to WHM are likely to be individual and eclectic. There are further concerns, including financial stability and social support, which may make access to the WHM treatment as a privately funded form of healthcare, additionally inequitable.

WMH, with its 'three-fold therapeutic approach', its aim to provide education, and its complex synthesis of scientific and traditional 'ways of knowing' is struggling to find a cohesive and effective identity in the 21<sup>st</sup> century where EBM and 'scientific objectivity' are regarded as the epitome of professional health care practice but where OTC CAM products including many that are herbal in origin are widely available, while information and disinformation sit side-by-side on the internet. Evans (2009) compares what she describes as the often perceived 'romance' of herbal medicine with the more complex and challenging aspect of professional herbal practice. Attempts at a reinterpretation of herbal medicine in order to fit more easily into a biomedical model of healthcare and the consequences to the profession have been explored (Van Marie 2002; Saks 2003; Evans 2009) Careful management certainly is required in the modernisation of WHM as one of herbal medicine's significant contributions to

healthcare may be promoting a different way of thinking about health and disease to that of biomedicine, and by maintaining the widely holistic and inclusive, hermeneutic approach that is embedded in its core philosophical tenets (Evans 2009).

WMH have been accused of failing to address social inequalities both in terms of the ability of individuals to access WHM as a private form of healthcare and in terms of its emphasis on individual responsibility (Baer 1989; Porter 1997; Saks 2003; Evans 2009). Concepts of gender, or of culture, have additionally been little explored within WHM (Doyal 2006; Nissan 2009).

A 'holistic' phenomenological approach of WHM to the individual patient arguably drives the pastoral intention embedded in its vocational training (Van Marie 2002) rather than a politically driven inclusivity previously noted in relation to education or health care (Epstein 2010). An increasing tendency to 'niche standardisation' within health care is a concern of some from within the mainstream medical profession. Such standardisation is regarded from within the WHM profession as the antithesis of our philosophy in practice. Inclusivity is inherent in the herbalists' avoidance of pathologising our AS patients on the basis of the diagnosis, and the approach of 'taking them as I find them'.

However, greater levels of understanding of what it means to be a young girl with AS should be essential for all of those whose aim is to provide appropriate services, including WHM as an approach to treatment that claims intention to offer pastoral care and advice. Ludlow's (2010) analogy of the swan gliding in a seemingly effortless calm that disguises the frantic paddling underneath to keep them afloat is relevant here. While young girls with AS may confound preconceptions with an apparent open sociability and fluency of speech, these, along with their high, even exceptional abilities in some areas, may disguise the profound nature of the challenges they face in their daily lives. Awareness of the nature of their differences and the likely impact these will have in any individual's lived experiences I would argue should help to inform any professional health practice.

Additionally, social inequities restricting some patients' access to WHM need to be addressed. Personal experience has taught me, as a practising WMH, that enthusiasm for informing patients of the benefits of good diet and regular

exercise cannot always compensate for the burdens of low income and poor living conditions. While WHM continues to be marginalised as a profession and its costs therefore entirely carried by the individual patient, or family, equity of access will continue to be a justifiably questionable issue.

The broad scope of WHM overlaps considerably with orthodox primary healthcare, and many practitioners are not only prepared to treat their patients alongside conventional healthcare, but actively seek cooperation and integration with biomedical provision (Nissan 2009). That there are dangers perceived for the future of WHM in this has already been acknowledged (Evans 2009). However, in WHM, traditional 'ways of knowing' and 'ways of being' are allied to contemporary 'ways of being practical' or 'doing' which may need no more in some areas than the acquisition of contemporary language to be understood and accepted more widely. An example lies in the reflexivity inherent to WMH 'ways of being' which has been adopted within the NHS as a professional requirement evidenced in portfolios of reflective diary entries.

In this current study, I would emphasise that expertise gained from long experience was traditionally shared through a model of apprenticeship. Now that knowledge is transmitted through BSc courses leading to professional membership of EHTPA, CPP or NIMH, for which evidence of 500 clinical training hours –the 'ways of doing' part of the training - is a prerequisite. It is also implicit in the form of Continuing Professional Development (CPD) workshops and seminars which most often take the form of individual WMH with particular areas of expertise and experience giving talks and lectures.

To have the confidence of operating as a potent professional group means confidence in our own status as health care professionals and confidence in our own 'ways of knowing'. It is not necessary to sacrifice those, or our 'ways of being' in order to articulate what we know, and to disseminate what we know in a form that addresses contemporary enquiry. I would recommend the creation of 'best practice' guidelines in WHM in any area where there is knowledge and expertise. This could feasibly include best practice guidelines for the treatment of girls with AS.

Alongside this, being recognised as a competent health care profession should, it may be hoped, open the way to inter-professional communication. The



'privilege' described in this study of having access to a patient's home environment and the length and scope of the clinical consultation could be utilised as enhancements to current service provision within a multi-disciplinary approach to intervention and support.

I recommend strongly that WMH start writing about what they know. Case studies are a good place to start for the practitioner WMH in recording their experiences, reflecting on what can be learned and disseminating their expertise.

### **6.3 Challenges of the research and its limitations**

Such a broad remit had, as all research does, its challenges. Creating a relevant study design that could cross the two disparate fields of study, both highly complex and broad in scope, was difficult, not least as neither field had a well prepared bed of previous research material in which to plant this budding research. In fact, until the publication in 2009 of two other WMH researcher 'insider's perspectives', the WHM ground in particular was punishingly hard. Nissan's (2009) and Evans' (2009) studies offered some invaluable groundwork and also facilitated access to the views of others, 'outsiders', on the practice of WHM in the 21<sup>st</sup> century.

All research has limitations, whatever its epistemological foundations. Parents of young people with AS met since the start of this study are anxious to know the findings from a very focussed perspective: Does the herbal treatment work? The subtext of this question is undoubtedly: Would it work for my child? A case-study based interpretive model is unable to answer that question in a direct sense; it's purpose is to shed light on the possibilities and by doing so suggest directions to explore. Definitive statements and statistical probabilities are not within its scope. Specific limitations of this study are therefore embedded within the methods used and such limits already acknowledged.

Data derived from research interviews are inevitably interpretive in nature and created through a process of negotiation between the interviewer and the interviewee. How this negotiation is carried out depends on many factors. In this case, my personal identity as a middle-aged mother and herbalist may have imposed its own boundaries on the horizons shared. Reflection on how the interviews with the girls might have been carried out more effectively has

suggested that more time to get to know the participant girls before embarking on data collection might have been helpful. The nature of the participant girls' disorder and the stress embedded in their mothers' experiences created their own boundaries and limitations, including on the ability and extent of their commitment.

In a practical sense, developing methods suited to the aims of the study and its special participants was an exercise in determination and creativity. The computer-software programme IMS had its own strengths and limitations in the context of this study as previously discussed in chapter 3. The other computer-based method of data collection, the online diaries, could potentially be further developed for research participants with communication differences. Despite the limitations on such techniques imposed in this study, the introduction of computer-based interview software and visual techniques into the research arena with this population may have potential for the future. Furthermore, the use of IMS for clinical practitioners such as WMH could be an area of future exploration. The WMH involved in this study expressed enthusiastic interest in the potential for such a tool in their practice.

#### **6.4 Recommendations for future directions.**

This research study builds on what is known about young people with AS and anxiety. It has focussed specifically on girls with AS in the context of their school and home environments, while undergoing a course of WHM treatment. It extends previous work into experiences of young people with AS. It also adds to the work of Van Marie (2002), Nissan (2009) and Evans (2009) on contemporary heralism in the UK by exploring experiences of WHM in practice. Recommended steps to progress from this study are outlined below.

##### **6.4.1 Lived experiences of AS**

- further research on lived experiences of AS should be carried out in order to elucidate the needs of this population and their families and to inform policies on service provision, such as inclusivity in education and health-care intervention.

##### **6.4.2 WHM education**

- training in WHM needs to take cognisance of the issues of social inequities and resources and to investigate ways of ameliorating these.

### **6.4.3 WHM practice**

- case study documentation in WMH, as well as further work on the experiences of patients, to identify elements of best practice. This approach could be extended beyond AS.
- exploration of the possibility of co-operative strategies in intervention with young people with AS. One of the mothers in this study invited me to attend a multi-service meeting called to address her daughter's problems. There are profound potential benefits of a 'joined-up' approach.

### **6.4.4 WHM research**

- The methodological challenges in WHM research need to be addressed robustly. WHM, as a profession, is coming increasingly under pressure to re-examine our relationship to 'orthodox' medicine and to find ways of constructing a meaningful dialogue with its institutions. There may be a postmodernist acceptance of non-orthodox health practices co-existing alongside the state-endorsed and funded biomedical model. However, such apparent breadth of vision is confounded by the drive for an evidence base entrenched in a modernist positivistic world-view. WHM cannot, without a more clearly articulated narrative of practice, engage with the mainstream. Nor can it confront social inequities of access to its practices.

However, enquiry into outcomes in WHM may be addressed by the pragmatic approach. A pragmatic clinical trial (PCT), using an appropriate alternative to the placebo as control, of WHM for young people with AS and anxiety would add to this current study.

Such an approach should not replace further exploration of the hermeneutic foundations of WHM and research into the phenomenology of its practice, but serve to enhance its research base and widen its accessibility.

### **6.4 Finally**

I have approached this research study as an insider to the experiences of WHM while seeking to increase understanding of the lives of both girls with AS, of

WHM in its contemporary practice in this country and how these two things might constructively merge.

Although the study included a multiplicity of voices, in the end, I have chosen to give the last word to someone with AS, not a girl, but a young person with AS able to articulate an essential theme of their experience:

“We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support. Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something. Better than being sad about it, though, get mad about it - and then do something about it. The tragedy is not that we're here, but that your world has no place for us to be.”  
(Sinclair 1993)

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## **Appendix 1**

### **A brief history: Asperger syndrome and Autism.**

In 1938, a Viennese paediatrician named Dr Hans Asperger published a paper in which he described a small number of children he had observed in the clinic where he worked (Asperger 1938). Six years later he further published “Die autistischen Psychopathen im Kindesalter” translated as “autistic personality disorder in infancy” in which he detailed the defining characteristics of these children. He also recorded his observations that parents of these children shared some of the characteristics of their children and proposed that the condition he defined was probably genetic or neurological in origin as opposed to psychological or environmental (Asperger 1944). Hans Asperger continued to work with and for these unusual children for many years as both paediatrician and advocate. He articulated his opposition, presumably riskily, to a law introduced in Nazi-occupied Austria aimed at the annihilation of children born with hereditary disease, arguing that difference does not equate with inferiority (Attwood 2006).

The staff at the clinic in which Asperger worked developed a unique remedial approach to the children with a combination of PE, rhythm and music, traditional school lessons, speech therapy and drama. Asperger was always convinced there was a biological basis to the children’s differences, that it had a genetic component and that these children’s unusual features could be highly positive as well as causing them great difficulties (Frith 1991). Asperger’s work was not recognised widely internationally and in this country only became known later through the efforts of Dr Lorna Wing, who had already raised awareness of the disorder in children then known as Infantile Autism (Wing 1971). Asperger’s 1944 paper was not translated into English until 1991 (Frith 1991).

Meanwhile, in another part of the world, Dr Leo Kanner was making his own observations of a group of children with characteristics very similar to those appearing in children attending Asperger’s Austrian clinic. In 1943 Kanner published a paper describing his observations of “Autistic disturbances of affective contact” (Kanner 1943). Kanner is reported as having initially held

similar views to Asperger as to theories of aetiology of these children's differences. Kanner's original concept was that the autistic child is born with an innate inability to develop normal affective contact with people and that autism is a biological disorder with either an organic pathology present at birth, or the result of organic predisposition combined with specific environmental events (Woodward and Hogenboom 2002).

Kanner in the 1940s was working in the USA. The overwhelming perspective in psychology at that time and in the English-speaking world was entrenched in theories of psychoanalysis. This perspective was operating along with a prevailing post-war social impetus that saw, for example, the work of John Bowlby on child development and parenting (Bowlby 1988), being used as justification to encourage women back out of the workplace and into the home. For over two decades, Infantile Autism was treated as a psychiatric condition brought about by trauma in early childhood. The parents, specifically the mothers, of these afflicted children were deemed responsible for damaging their offspring by failing to demonstrate appropriate levels of emotional care. Kanner was persuaded to define autism as a condition precipitated by the

‘over-intellectual, emotionally inadequate and frigid characteristics of the child's parents’ (Woodward and Hogenboom 2002 p 28).

In 1967, Kanner and colleague Eisenburg were quoted by psychoanalyst Bruno Bettelheim:

‘Emotional refrigeration has been the common lot of autistic children’ (Bettelheim 1968 p389).

Although Bettelheim did accept organic pathology to be a possible aspect of aetiology, he was still recommending, as recently as the late 1960's, the removal of autistic children from their parents in order to provide them with an environment deemed more suitable for recovery (Woodward and Hogenboom 2002).

The importance of this historical setting is its role in our contemporary understanding of what are now known as Autism Spectrum Disorder (ASD) and Asperger's syndrome (AS). In the past 30 years, as psychological studies

and theories of the nature of the disorder and its development have progressed, medical definitions of autism have become less attached to concepts applied in adult psychiatry, and such diagnoses as 'mentally subnormal' and 'emotionally disturbed'. A developmental approach to theories of aetiology in ASD has overtaken a psychiatric one as being the most universally pertinent (Trevvarthen 1998). The concept of 'refrigerator mothering', has long since been refuted but it is important to remember this is the historical background to development of understanding this disorder as vestiges of the psychoanalytical model still linger in the popular consciousness (Volkmar et al 2005).

## APPENDIX 2 Table of Literature Search Results: summary of the papers

Author date country	Criteria Sample age	Design	Results	Limitation of study
Kim JA, Szatzmari P, Bryson SE, Streiner DL and Wilson FJ 2000 Canada	59 children AS (n=19) and high functioning autism (n=40) 9-14 yrs	Follow-up 6 years after diagnosis of ASD at 4-6 yrs compared with community sample (n=1751) on mood and anxiety disorders; scales used: OCHS-R	AS children higher levels of anxiety than control population	Parent reports only; difficulties with diagnostic criteria poss. non-representative sample; questions re validity of tools highlighted  Need for qualitative studies noted
Gillot A Furniss F and Walter A. 2001 UK (Eng)	45 HFA children matched age, gender 8-12 yrs	HFA children match controlled Specific Language Impairment & normally developing. Scales used for anxiety & social worries comparison: SCAS & SWQ	ASD children higher than controls in OCD and social worries. Levels of Social phobia not elevated from norm;	Small numbers; non-matched for ability;  questions around validity of self-report assessment tools  Highest self report scores on Separation Anxiety, not discussed in the literature.
Russell, E Sofronoff K 2005 (Jul) Australia	Children, 65 10 – 13 yrs	Children with AS compared with clinically anxious sample and a normative sample using parent and child reports, SCAS and SWQ	Children with AS scores higher than normal population characteristics differ from non-AS clinically anxious	Small numbers;  questions around validity of self-report assessment tools Part of a bigger study re CBT as a treatment strategy; profile of AS anxiety

## APPENDIX 2 Table of Literature Search Results: summary of the papers

Meyer JA., Mundy PC., Vaughan Van Hecke A. and Durocher JS. 2006  UK and USA	64 children 7 yrs 9 ms-13yrs9ms	AS children n=31 matched verbal + non-verbal age to control (NT) n=33	Anxiety, depression, social anxiety in AS group	Parent and child report discrepancies; identified need for qualitative research
White SW., Oswald D., Ollendick T. and Scahill L. 2009  USA	n/a	Literature review of research papers on anxiety in children and adolescents with autism spectrum disorders; criteria: prevalence, phenomenology, treatment	Anxiety found in children and young people with ASDs, including AS; research evidence limited and conflicting	Limitations of existing assessment tools identified; recommendations for research including alternative methods and multiple perspectives
Humphrey N. and Lewis S. 2008  Eng	20 school pupils aged 11 – 17 yrs	Purposive IPA study; semi- structured interview & diary	'Make Me Normal' key theme: anxiety	School setting only Part of a larger study re LA Education policy on inclusion
Huw and Jones 2008 Eng	9 students 16-21 yrs	Purposive IPA study; semi- structured interview	diagnosis, disclosure and having autism	College setting; research questions response to themes found early in study

**APPENDIX 3 Letter to Dr Mills, Research Director Research Autism and NAS**

**NAPIER UNIVERSITY**

**School of Nursing, Midwifery and Social Care**

Dr Richard Mills

Research Director and Honorary Secretary, Research Autism

Church House

Church Road

Filton

Bristol BS34 7BD

cc. Barrie Cooper *Help!* Manager NAS Scotland



7.12.07

Dear Dr Mills

I understand Barrie Cooper from the *Help!* Programme in Scotland spoke with you on Tuesday about my research and so I have enclosed a number of documents for your information:

- 1 copy of my research proposal (submitted to a Napier University internal transfer board in March)
- 2 revised information sheet for potential recruits, parents
- 3 revised information sheet and consent form for potential recruits, girls
- 4 information sheet on 'In My Shoes' computer-assisted interview programme
- 5 information sheet on Herbal Medicine for parents
- 6 information sheet on Herbal Medicine for girls

In summary, I am looking for volunteer participants, girls with Asperger's syndrome aged 12 - 15, and a parent of each girl, to take part. The girls would be asked to attend a Medical Herbalist (members of the National Institute of Medical Herbalists which means they have a BSc Degree or above level training and professional status) for a consultation and two shorter follow-ups. They would also be asked to attend two interviews with me and if they can and have the time/inclination, keep a computer-based journal. It sounds like a lot, but the amount of commitment to some areas can be flexible, in the sense that this is an exploratory study of how the girls experience events in their lives along with how they experience the herbal treatment, NOT a clinical trial of any particular treatment. I would use a computer-assisted software programme developed for use with vulnerable children called In My Shoes for the interviews

with the girls. The parents would also be asked to attend two interviews with me.

Interested girls and parents will be sent information packs with further details of what would be involved; consent will be sought from both girls and parents. The herbal treatment will be paid for by the study for its duration and there will be contact details for further support provided.

Ethical approval was given to this study in June 2007 by the Napier University Faculty of Health Life and Social Sciences Research and Knowledge Transfer Ethics Committee.

Thank you for taking the time to read this information and I do so hope you find you can approve the study for help with recruitment. I look forward to hearing from you,

Yours with Regards

Catriona Stewart

School of Nursing Midwifery and Social Care

Napier University Canaan Lane Campus

Edinburgh, EH9 2TB

Email c.stewart@napier.ac.uk tel 0131 455 xxxx or 0772 940 xxxx

### **Names and background of research team**

1. Catriona Stewart BA (Hons) MSc Herbal Medicine MNIMH (Member of the National Institute of Medical Herbalists).

Full-time PhD research student Faculty of Health Life and Social Sciences, Napier University, Edinburgh.

Lecturer BSc Herb Med. (part-time)

2. Dr Gerri Mathews-Smith Senior Lecturer Napier University.

3. Dr Maureen Macmillan Senior Lecturer Napier University.

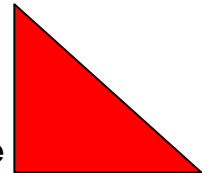
Both Dr Matthews-Smith and Dr Macmillan are experienced in PhD research supervision; Dr Macmillan is especially experienced in qualitative research. Dr Matthews-Smith has a working background in Child and Adolescent Psychiatry.

**APPENDIX 4 Information Pack**

**NAPIER UNIVERSITY**

**School of Nursing, Midwifery and Social Care**

**The Experiences of Girls with Asperger's Syndrome Receiving Herbal  
Treatment**



Dear

Thank you so much for your interest in this study. I've enclosed information packs for you and your daughter including:

Information sheet on the study for you both

Consent forms

Information sheets on Herbal Medicine

Information on In My Shoes interviews

Addressed stamped envelope

I hope it's all self-explanatory, but if not, please 'phone or email for more information.

Thank you

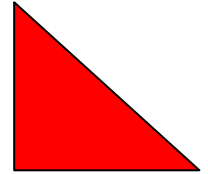
Contact details:     Catriona Stewart

Address:             Post-graduate Research in Herbal Medicine  
                          School of Nursing, Midwifery & Social Care  
                          Napier University  
                          Room G10, Canaan Lane Campus  
                          Edinburgh EH9 2TB

Email / Telephone: c.stewart@napier.ac.uk

0131 455 xxxx or 0772 940 xxxx





### Info sheet for girls

I am a Medical Herbalist. People come to me for all sorts of reasons to do with how they are feeling, for example, if they have eczema, or can't sleep at night or get a lot of stomach pain, or just want to feel happier. I talk with them about what might help and give them medicine made from special plants, called herbs. I am doing a research project for Napier University in Edinburgh. The title of my project is:



### The Experience of Girls with Asperger's Syndrome Receiving Herbal Treatment

I want to find out more about girls with Asperger's syndrome, how they feel when you are worried about anything or having a bad time, as well as when they are happy, and how they feel about going to see a herbalist. This research is important because it might help with what we know about girls with Asperger's syndrome; how they feel about your daily lives and how to make things better for them if necessary.

I am looking for girls aged 12 to 15 years with Asperger's syndrome to take part.

If you volunteer, you will be asked to:



- ❖ **visit a herbalist.** They will discuss your health with you and may prescribe some herbal medicine for you to take, but they may not - it will depend on your discussion. For more information about what a visit to a herbalist might involve, please ask your parent/s and please also read the information leaflets I have sent with the information and consent pack.
- ❖ **take part in two meetings with me** to talk about how you feel about things, such as what you like or don't like at school or what things bother you. This interview will also involve using a computer!
- ❖ **keep a computer-based journal or diary.** This will mean spending 5 minutes or longer (if you have the time!) most evenings for 4 weeks working with a computer interactive website set up for you. You and I will be the only people who can see what you put in this website – you will have a password to get into it.

### Questions you might like to ask:



- **Can I leave the project at any time?**

Yes and you would not have to tell me why.

- **Will I have to keep taking herbal medicine if I don't want to?**

No, though you should talk to your parent/s about this.

- **Will people get to know what I say to the researcher or the herbalist?**

When we meet I would like to make a recording of what we say but I will give you - or you can choose - a pretend name so no one will know it is you. Recordings will be kept safe in a locked cupboard to which only I will have the key. Whatever you talk about to the herbalist will be private between you, your parent/s and the herbalist.

- **Who will get to see my diary?** I will be able to see what you put in your diary but I will not tell or show anyone else who would know it is you.

- **What will happen to all the information?** I will write about what you and everyone else who joins in the project have told me in a book called a thesis and I might tell other people about it at meetings, but only your pretend name will be used.

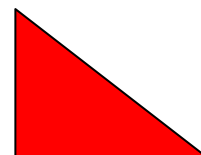
You may talk to anyone you like, such as your mother or a teacher or a friend about helping me with this project. If you would like to talk with someone who knows about this project but is not involved with it please contact Dr Dorothy Horsburgh, who teaches at Napier University, her details are below. If you are sure you understand what I have asked you to do and you and your parent/s agree then please sign your name on the other sheet to say that you will take part.

**Contact details:** Catriona Stewart  
Post-graduate Research in Herbal Medicine  
School of Nursing, Midwifery & Social Sciences, Napier Uni.  
Room G10 Canaan Lane Campus, Edinburgh, EH9 2TB  
Email / Telephone: c.stewart@napier.ac.uk  
0131 455 xxxx or 0772 940 xxxx

**Independent Advisor : Dr Dorothy Horsburgh, Lecturer**  
School of Nursing, Midwifery & Social Care, Napier University  
Canaan Lane Campus, Edinburgh EH9 2TB  
Email / Telephone: d.horsburgh@napier.ac.uk  
0131 455 xxxx/xxxx

## APPENDIX 4 Information Pack

Napier University School of Nursing, Midwifery and Social Care



### The Experience of Girls with Asperger's Syndrome Receiving Herbal Treatment

#### Consent Form for Girls.

**I have read and understood the information sheet and this consent form. I have had any questions I had about taking part answered**

- ❖ I understand that I do not have to take part in this study.
- ❖ I understand that I can stop at any time without giving any reason.
- ❖ I understand I can stop herbal treatment at any stage.
- ❖ I agree to take part in this study.

Name of participant:

\_\_\_\_\_

Signature of participant:

\_\_\_\_\_

Signature of parent: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_

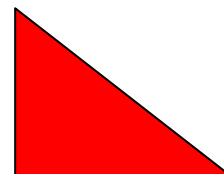
Date: \_\_\_\_\_

**Contact details:    Catriona Stewart**

Address:                    Post-graduate Research in Herbal Medicine  
                                  School of Life Sciences  
                                  Napier University  
                                  Canaan Lane Campus, Edinburgh, EH9 2TB  
Email / Telephone: c.stewart@napier.ac.uk  
                                  0131 455 xxxx or 0772 940 xxxx

## APPENDIX 4 Information Pack

**NAPIER UNIVERSITY**



**School of Nursing, Midwifery and Social Care**

### **The Experience of Girls with Asperger's Syndrome Receiving Herbal Treatment**

#### Consent Form for Parents

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I have discussed this study with my daughter and I agree she may take part in this study if she wishes.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: \_\_\_\_\_

Signature of participant: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Contact details: Catriona Stewart

Address: Room G10  
School of Nursing, Midwifery & Social Care  
Napier University  
Room G10, Canaan Lane Campus  
Edinburgh EH9 2TB

Email / Telephone: c.stewart@napier.ac.uk

0131 455 xxxx or 0772 940 xxxx

**The Experience of Girls with Asperger's syndrome Receiving Herbal Treatment**



I am undertaking a study as part of a doctoral degree in the Faculty of Health, Life & Social Sciences at Napier University in Edinburgh. It will look at how girls with a diagnosis of High Functioning Autism, Atypical Autism or Asperger's syndrome experience life and how Medical Herbal treatment might affect that. The study would involve yourself, your daughter and a Medical Herbalist who would provide your daughter with free treatment during her participation in the study.

If you and your daughter agree to participate in the study, your child will be asked to attend a consultation with a Medical Herbalist when treatment would be decided and then for two follow-up visits. I would also like to interview your daughter twice (at the beginning of the process and then at the end) and she will be asked to keep a computer-based journal. I would also like to interview you twice to understand how you think your daughter is finding life, at the start of her treatment and then four weeks later. These interviews would take place when and where it best suited you. The information that you and your daughter give will be anonymous since for the project you will both be given pseudonyms.

**Who can participate?**

I am looking for girls aged 10 to 15 years with a diagnosis of High Functioning Autism, Atypical Autism or Asperger's syndrome, along with one of their parents.

**What exactly will I have to do?**

- Take part in two one-to-one interview sessions, the first at the start of treatment and the other four weeks after that.
- Help your daughter to keep a journal by ensuring she has access to a computer with internet facilities and encourage her to spend 5 minutes each evening (or most evenings!) to work on this diary (more details on this over page).
- Arrange for your daughter to attend a consultation with a chosen Medical Herbalist and two follow-up consultations. I am a qualified Medical Herbalist and Clinical Training Supervisor and can vouch for the standard of the Herbalist that you would meet.

**What will the herbal treatment be like?**

The course of herbal treatment may last for up to four weeks with an introductory consultation when your daughter will be asked questions about her health and how she feels. At this time she may be prescribed a herbal treatment. She will then have two 'follow-up' sessions when her progress will be reviewed. There will be the opportunity to continue for longer if you both want to and the herbal practitioner agrees it is appropriate. We will fund the initial 4 week period. There are free clinics available in some parts of the country for people on low incomes.

**What will the journal be like?**

The journal that your daughter will be asked to keep is structured to help her express how she experiences daily life. She will be asked also to identify levels of anxiety on a picture of a thermometer. If she has more time and wants to, she could use her own ways of expressing how she might be feeling, using pictures, colours, poetry or other writing, or even make audio clips, however, this part is optional. Your daughter's access to this interactive website will be password protected and only she and I will have access to what she includes.

**What will the interviews be like?**

For your daughter's one to one interviews I will use a computer-facilitated programme (called 'In My Shoes'). This will help me to ask questions in a way which has been shown to be easy for girls like your daughter. Your interview too will be one to one, and tape recorded and then I will transcribe them. These will last about an hour each. I would be happy to meet you and your daughter at a time and place that suits you both. Only I and my supervisors will have access to any of this material. The tapes and transcriptions will be kept separately in a locked place to which only I will have access; they will be kept until the examination process is completed. The results will appear in a thesis, published in journals and presented at conferences. You will both have pseudonyms.

**Can I stop?**

You or your daughter will be free to withdraw from this study at any stage and you will not have to give a reason. All the information already collected would be destroyed and you would not be contacted again.

**Can I have more information?**

You can ask me anything you like about the study.

If you would like to speak to someone about the study, or about participating, but who is not directly involved in the project then please contact the Independent Advisor, **Dr Dorothy Horsburgh**, Lecturer, School of Nursing, Midwifery & Social Care, Napier University Canaan Lane Campus, Edinburgh EH9 2TB Email: d.horsburgh@napier.ac.uk Telephone: 0131 455 xxxx/xxxx.

If you want to read more about Herbal Medicine I can send you an Information Sheet on Herbal Medicine, just ask **me**. If you would like to know more about your daughter's interview then I can send you an Information Sheet about the 'In My Shoes' interview programme. Just ask **me** for this.

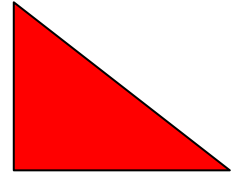
**Catriona Stewart MSc, MNIMH**, School of Nursing, Midwifery & Social Care, Napier University; Room G10, Canaan Lane Campus, Edinburgh, EH9 2TB  
Email: c.stewart@napier.ac.uk Telephone: 0131 455 xxxx

**Thank you so much for taking time to read about my project and if you think that you can help me by participating please contact me. I would be delighted to hear from you.**

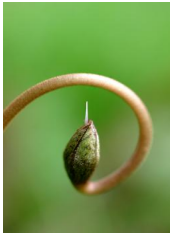
## APPENDIX 4 Information Pack

**NAPIER UNIVERSITY**

**School of Nursing, Midwifery and Social Care**



### The Experiences of Girls with Asperger's Syndrome Receiving Herbal Treatment.



#### Professional Western Medical Herbalism

A first visit to the herbalist involves talking about any particular things that may be causing problems – for example, stomach upsets, or sore throats, skin rashes, headaches, difficulties getting to sleep and so on. The herbalist will want to know about your general health, including any illnesses you've had in the past. They will want to discuss what you generally eat and drink and whether you take any exercise or have any interests or hobbies. They may prescribe herbal medicine made up of several different herbs, often as a liquid medicine called a tincture or prescribe a cream or herbal tea. They will ask to see you again in two or three weeks to see how you are getting on and may change the medicine at that point.

Professional Herbalists who have a Post-graduate Diploma from the Scottish School of Herbal Medicine trained for a minimum of 4 years. As well as learning about the herbs and their uses, we trained in many of the same areas as GPs, including anatomy, physiology and the diagnosis of disease.

There is not a great deal of modern research information on the clinical practice of Western Medical Herbalism, but the World Health Organisation has a very positive view of the use of herbal medicines – much of what we know about medicinal herbs is based on many generations of experience and observation.

At least 25% of all modern medicines are made from plants used traditionally as herbal remedies, an example being Aspirin. In its natural form of salicylic acid, aspirin is found in White Willow Bark and Meadowsweet, traditional herbal remedies still used by herbalists today.

For further information, the following websites may be useful:

[www.nimh.org.uk](http://www.nimh.org.uk)

**National Institute of Medical Herbalists**

[www.ehtpa.org.uk](http://www.ehtpa.org.uk)

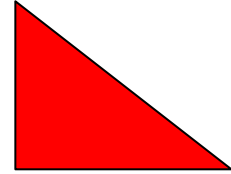
**European Herbal & Traditional  
Practitioners Association**



## **APPENDIX 4 Information Pack**

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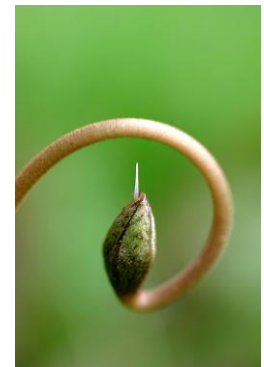
The Experiences of Girls with Asperger's Syndrome Receiving Herbal Treatment.

### **Professional Western Medical Herbalism: training & practice.**

Members of the National Institute of Medical Herbalists (NIMH) belong to an internationally recognised and respected organisation, one of the world's oldest professional bodies representing qualified herbalists. Established in 1864, NIMH is the UK's leading authority on herbal health training and practice. Members are trained to a high standard and hold professional practice insurance

#### **Training.**

Those of us holding a Post-graduate Diploma from the SSHM trained for a minimum of 4 intensive years with a combination of experienced qualified medical herbalists and NHS registered practising doctors. As well as the herbs and their uses, we are trained in many of the same areas as GPs, including anatomy, physiology and the differential diagnosis of disease. We may routinely check pulse and blood pressure, examine cardiovascular or respiratory function, take blood or urine samples for analysis.



#### **Safety.**

The World Health Organisation supports a positive view of the use of herbal medicines based on long established experience of both effectiveness and safety.

“25% of modern medicines are made from plants first used traditionally”.

([www.who.int/medicines](http://www.who.int/medicines) accessed 27.5.07).

Modern research evidence in the form of Randomised Controlled Trials (RCTs) of Western Herbal Medicine as practised by qualified professionals is an emerging field. What is known about the herbs, their use and safety, dosage amounts, any possible side effects, is based on a long history of use and observation, which has been built up over generations.



There has been modern research done on many individual herbal medicines such as St John's Wort – a comprehensive summary of available information on Elder, a herb commonly used in children's prescriptions, is included along with this information sheet as an example.

Qualified herbalists are taught to recognise diagnostic 'red flags' and when to refer on. In line with conventional GP practice, diagnosis of some diseases such as TB requires the alerting of other authorities. We keep informed about what is known regarding herb/drug interactions. We have a 'yellow card' system in place for reporting adverse reactions to the herbs.

The medicines prescribed and dispensed by qualified herbalists are extracts of whole, or whole parts of, medicinal plants, often in liquid form called tinctures. Training includes what is known about contraindications, herb/drug interactions and adverse effect reports. The treatment of children is given particular consideration.

Herbalists train in the chemical constituents of the plants and what is known about their mode of action within the human system. When we formulate our prescriptions we weigh up many factors, including the chemical make-up of the plants. For example, we are cautious with plants known to contain chemicals in the alkaloid group (of which there are many kinds, including some found in coffee!)

The herbal profession is currently undergoing a great period of change and in response to the combination of increased public interest and demand for herbal medicine, along with concern for public safety, we are engaged in a process of Statutory Self Regulation in collaboration with the Government. Members of the NIMH established the European Herbal and Traditional Practitioners Association (EHTPA) in response to UK legislative requirements and members of the NIMH are part of the UK government's exploratory Joint Working Group.



Association

For further information, the following websites may be useful:

[www.nimh.org.uk](http://www.nimh.org.uk)

National Institute of Medical  
Herbalists

[www.ehtpa.org.uk](http://www.ehtpa.org.uk)

European Herbal & Traditional  
Practitioners

## **APPENDIX 4 Information Pack**

### **In My Shoes**

A computer assisted interview for communicating with children and vulnerable adults

#### **GENERAL INFORMATION SHEET**

##### **What is In My Shoes?**

In My Shoes is a computer package that helps children and vulnerable adults communicate about their experiences including potentially distressing events or relationships. Extensive testing shows it can be used in a wide range of circumstances, including interviews with children who may have difficulties in expressing emotions, who are hard to engage or who have developmental delay or other difficulties. It has been used successfully in interviewing learning disabled adults.



##### **How does it work?**

In My Shoes uses images, sound, speech and video. Through a series of modules, children are encouraged to share information on their experiences and emotions with different people in home, educational and other settings. The interview is structured, systematic and clear. Forensic considerations have been central to its development, and the focus is on facilitation of communication about the subject areas, with leading questions being avoided.

##### **Does the child use it alone?**

The program has been designed so that a trained adult will sit alongside the child and assist, guide and interact with them through a structured interview process. The information that is gained is a product of the three-way interview; it is not a question and answer session with the computer. However, the nature of the program is such that children who are unable to use the spoken word can still, with appropriate support, use the tools within the computer program to give an indication of their experiences and feelings.

##### **Who can use In My Shoes?**

It has been used by psychologists, social workers, child psychiatrists, other mental health staff, health workers, educational workers and specialists in forensic services. In My Shoes enhances the skills of practitioners and clinicians in direct work with children and young people.

##### **Training**

Professionals require training to be able to use In My Shoes effectively. There is a two-day training course based on an action learning approach. The two training days are separated by a number of weeks, which enables trainees to try out In My Shoes in their work setting in between the training days.

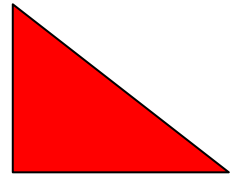
##### **For further information:**

Please contact: **Liza Bingley Miller, National Training Coordinator**, email: [liza.miller@btinternet.com](mailto:liza.miller@btinternet.com) or tel. +44 (0)1904 633417

## **APPENDIX 4 Information Pack**

### **NAPIER UNIVERSITY**

#### **School of Nursing, Midwifery and Social Care**



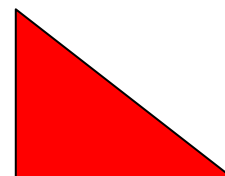
The Experiences of Girls with Asperger's Syndrome Receiving Herbal Treatment.

#### **About the researcher**

Catriona Stewart MSc qualified as a Medical Herbalist and member of the National Institute of Medical Herbalists in 2002 and has run a successful city centre clinical practice since. She works with people of all ages, including children and adolescents, and deals with a very wide range of health issues. She has lectured on the Napier University BSc in Herbal Medicine course. She is a Student Clinic Supervisor at the Preston Clinic of Herbal Medicine and is currently acting as a NIMH mentor. She gives talks and run workshops on Herbal Medicine including for adolescents and children. She has undertaken Child Protection training as well as completed professional training in aspects of working with children with ASD (through the National Autistic society and Napier University) and carrying out research involving children (at Edinburgh University along with the Economic and Social Research Council). She is a registered 'In My Shoes' interviewer.

## **APPENDIX 5 Information sheet and consent form for herbalists**

**Napier University**  
**School of Nursing, Midwifery and Social Care**  
**The Experiences of Girls with**  
**Asperger's Syndrome Receiving Herbal Treatment.**



### **Information Sheet for Medical Herbalists**

My name is Catriona Stewart. I am a Medical Herbalist (MSc Herb Med, MNIMH) undertaking a doctoral research study within the Faculty of Life, Health & Social Sciences at Napier University in Edinburgh.

This study will look at how girls with Asperger's syndrome experience difficulties in their daily lives and how medical herbal treatment might affect that experience. Information will be collected from the girls themselves, their mothers and the Medical Herbalists treating them.

It is hoped the findings of this research will be valuable as a way of improving our understanding of how best to support these girls.

I am looking for qualified professional Medical Herbalists, holding a recognised academic qualification, current professional insurance and membership of the National Institute of Medical Herbalists (MNIMH) working in Glasgow or Edinburgh, with access to their own consultation accommodation and a herbal dispensary.

#### **If you agree to participate in the study, you will be asked to:**

- take three of the participant girls as patients
- offer them each one initial consultation with two follow-up visits, two weeks apart. These consultations and any medicine you prescribe for the girls will be paid for by the study. The costs of any further treatment as agreed between you, the girls and their mothers after the study has been concluded will not be met by the study.
- take part in a one-to-one interview with me after the third consultation has taken place.

You are free to withdraw from the study at any stage, you would not have to give a reason. All the data already collected will be destroyed and you will not be contacted again in connection with the project.

All data will be kept anonymous. You will not be identifiable in anything written about the project as you will be given a pseudonym and it will not be possible for you to be identified in any reporting of the data gathered. Only the research team will have access to any tapes from the interview which will be transcribed by me only. Data collected will be kept in a secure place to which only I have access and will be held only for as long as is needed for this research. My findings will be written into a doctoral thesis, published in journals and presented at conferences.

If you have read and understood this information sheet, any questions you had have been answered and you would like to be a participant in the study, please now read the consent form.

Contact details: Catriona Stewart

Address: Post-graduate Research in Herbal Medicine

School of Life Sciences

Napier University

Canaan Lane Campus, Edinburgh, EH9 2TB

Email / Telephone: [c.stewart@napier.ac.uk](mailto:c.stewart@napier.ac.uk)

0131 455 xxxx or 0772 940 xxxx

**If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact:**

Name of independent adviser: XXXXXX

Address: Post, Subject Area, School

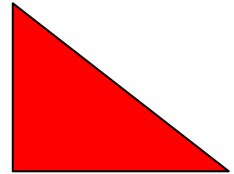
Napier University

Canaan Lane Campus, Edinburgh, EH9 2TB

Email / Telephone: [XXXXXX@napier.ac.uk](mailto:XXXXXX@napier.ac.uk) 0131 455 XXXX

**NAPIER UNIVERSITY**

**School of Nursing, Midwifery and Social Care**



**The Experience of Girls with Asperger's Syndrome Receiving Herbal  
Treatment**

**Consent Form for Medical Herbalists**

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: \_\_\_\_\_

Signature of participant: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Contact details: Catriona Stewart

Address: Post-graduate Research in Herbal Medicine

School of Life Sciences

Napier University

Canaan Lane Campus, Edinburgh, EH9 2TB

Email / Telephone: [c.stewart@napier.ac.uk](mailto:c.stewart@napier.ac.uk)

0131 455 xxxx or 0772 940 xxxx

## APPENDIX 6 Practitioner case-notes and prescriptions

### Prescription 1

Eschscholzia	25
Nepeta	25
Chamomilla	20
Stachys	20
Passiflora	15
	105 mls

sig : 2ml (40 drops) tds (lunchtime, evening and before bed)

### Practitioner case-notes and prescription 2

#### PC (presenting Complaint)

Mood swings: anxiety, anger. Anxiety general but also specifically related to eating food in front of other people, Px feels unable to eat with school friends at break times and will only drink water, avoids school canteen completely.

*Practitioner thoughts: Possible issue around weight and control of eating, anger maybe related to over-sensitivity e.g. noise – lives in small house with big family, and feelings of being different to peers / children at school reacting negatively and not understanding. We discussed some of these issues on 1<sup>st</sup> visit, but deemed inappropriate to talk in great depth by practitioner as therapeutic relationship still being established.)*

Associated symptoms:

Tension headaches associated with fatigue

Sleep disturbance, Px stays up late texting friends and finds it difficult to get to sleep, woken with nightmares on regular basis.

Diet: no breakfast or lunch, one meal a day: family meal in evening, mostly vegetarian, homemade food.

Drinks 6-7 cups of tea a day, some diluting juice and water

DH: No medication or OTC supplements

#### Therapeutic Strategy

Irregular eating pattern is causing fluctuations in blood sugars which will contribute to mood swings, excess adrenaline and contribute to anxiousness, anger and sleep disturbance. High intake of caffeine will also contribute.

#### Advice:

- Try snacking through the day to help level blood sugars e.g. nuts and seeds, oatcakes. Suggest smoothie for nutritional value of fruit and yogurt with vanilla (Px favourite flavour is vanilla, so positive association) for breakfast (Px does not feel like eating) and a smoothie to take to school to drink at break times (Px ok to drink but not eat with friends).

- Cut out caffeine, especially in evenings.
- Encourage physical exercise for excess adrenaline and mental well being / enjoyment / personal empowerment (Px likes dancing).

### **Herbal strategy:**

Adrenal support to help regulate blood sugars & adrenaline overload: aiming to alleviate associated mood swings and sleep disturbance.

Nervine support: relaxing nervines and tonics to help level anxiety and feelings of anger.

<b>Rx:</b>		<b>Practitioner comment:</b>
Borago	20	adrenal, nervine & 'for courage', cooling(heat- anger)
Scutellaria	20	relaxing nervine & 'for excess thinking', tension headaches
Glycyrrhiza	15	adrenal tonic / adaptogen, sweet taste
Avena	35	nervine, nutritive
Passiflora	10	relaxing nervine, 'specific for nightmares'
	<i>total</i>	<i>100 mls</i>
		Sig 5mls bd am and bedtime

### **Follow up 1 month later**

Px did not like taste of herbs and found them 'too strong', unfortunately mother (meaning well) persisted in trying to get Px to take herbs. Usually if there is a problem I would expect a phone call and invite a phone call / discussion to suggest ways around it e.g. lower dose, adding fruit juice to disguise flavour, or possibly changing herbal prescription if former does not make difference.

In this case Px developed an aversion to herbs and negative association and eventually stopped taking the medicine altogether.

On the positive side, Px cut out caffeine (her mother did too and said she felt better / calmer), and Px getting to sleep better, significant improvement and no nightmares.

Px liking smoothies and drinking them at break times with friends. A real break through was that she had been once to school canteen with friend but not eaten anything.

Px feeling a bit less anxious, but feels anger is still an issue. Energy improved probably due to sleep improvement / blood sugar balance.

### **Therapeutic strategy**

We discussed continuing with smoothies and avoiding caffeine and possibly going to canteen again, also discussed possible small snacks she might eat in canteen.

Prescribed some drops combining Rosa, Chamomilla and Melissa in equal parts as nervine – tonic / relaxing.



Advised follow-up, but did not happen. Long term strategy would've been to develop therapeutic relationship to provide outlet / safe place to talk if needed/ empowering patient, and improving diet and lifestyle issues. Possible use of other herbs if indicated / appropriate to Px.

## **APPENDIX 7 The In My Shoes computer software aided interviews.**

Background to In My Shoes software; training and modification for this study.

'In My Shoes' was originally created as a tool for assisting in the interviewing of children who may have been abused. It was intended as a means of gaining understanding of the child's experiences and emotions as well as having therapeutic value and of sharing information for assessment and forensic purposes (Calam et al 2007). Since then, this software has been used in a variety of settings and for a range of purposes with specific groups such as hearing impaired children and adults with learning disabilities.

In My Shoes was developed:

Rachel Calam, Senior Lecturer in Clinical Psychology, University of Manchester and Programme Director of the Doctorate in Clinical Psychology

Anthony Cox, (retired) Chair in Child and Adolescent Psychiatry at UMDS

David Glasgow, Forensic Clinical Psychologist, Calderstones Hospital

Phil Jimmieson, Senior Experimental Officer, Dept of Computer Science, University of Liverpool.

Sheila Groth Larson, Educational Psychologist.

Sheila Groth Larson was the trainer for this study.

A number of potential areas of use in clinical practice for the software assisted programme were identified and have subsequently been explored. It has been used in the context of child protection work within a social services setting (Glasgow, Calam and Broadhurst 1996) and has been accepted as a valid form of forensic evidence in a civil court setting. It has been shown to be useful in identifying therapeutic approaches for children suffering from ideopathic pain, in terms of psychological intervention and also in terms of uncovering environmental causes eg bullying at school. It is used in assessment and the formulation of intervention strategies for children with whom communication is difficult eg children with elective mutism (Calam et al 2000). It has been used in care settings with children and adults with learning disabilities as a means of enabling communication about emotions and experiences and to assist in decisions about access and placing.

The potential use of this package has been summarised by its authors in this way:

“In particular, it has become clear the real value of the package appears to lie in the potential that it offers to establish a point of contact with children who have difficulty in engaging or communicating in assessment or therapy”

Training in the use of the package is a four-stage process. The first stage is instruction in the structure of the software programme and how to use it in an interview setting. The second stage involves piloting the software with members of the client group or as in this case a study pilot group. Three interviews are held for training purposes and the transcripts produced for analysis and assessment by the training team.

For this study, five children were interviewed at this second stage. Four of the children were made up of two girls of 12 and 13 years and their younger brothers at 7 and 8 years who had all been attending the Medical Herbal student training clinic at Napier University. The fifth was an 11 year old girl who has been assessed as having an IQ within the population top percentile and diagnosed as having Atypical Autism.

The purposes of these interviews were to 1) test the appropriateness and efficacy of the In My Shoes software programme as a research tool with children and young people that could facilitate the sharing of their experiences of herbal treatment 2) to assess the interviewer's abilities to use the software appropriately and effectively as part of the training process 3) to test the software's effectiveness with the research study group in articulating their emotional experiences.

To these ends, the five interviews were structured slightly differently. The four children who had been receiving herbal treatment, after the initial modules on emotions and people, were asked questions focussing on their visits to the herbal clinic, their experience of the process of receiving herbal treatment and the effectiveness of their treatment. The fifth girl who had not attended the herbal clinic but who did have a diagnosis of ASD was interviewed with greater focus on her emotional cognisance.

The programme is designed in flexible modules with a range of choices in terms of order, structure, elements within some modules, settings. A number of issues arose in the course of these pilot interviews, leading to decisions about the

structuring of future interviews and modifications to individual modules within the programme. Issues that arose were as follows:

The software offers choices between visual and audio prompts. One of the boys interviewed exclaimed and threw up his hand in front of his face when 'Mary', the prompter represented on a video insert into the main screen, first appeared on the computer screen. He did not explain why he did this, but it did raise the question as to whether or not to include the visual prompter option in future interviews. The 'audio prompt only' option includes an illustration of 'Erika' as a cartoon bird's head and is possibly intended for a younger age group. However, as part of the reasoning to carry out the interviews with the assistance of the computer software was because of issues around facial expressions and verbal interactions for children with ASD and the discomfort induced by face-to-face questioning, it was decided that future interviews would exclude the visual prompter option in order to reduce any possible impact of the video image of a real person's face on the child being interviewed.

It was apparent in the course of carrying out these initial interviews that each interview could take a long time – well in excess of an hour – if all the modules were to be covered. Although it has been reported children are able to 'stay on task' for longer than might be expected with the assistance of this programme (Calam et al 2007) and it was certainly the case during these pilot interviews the children all appeared to engage well with the process, it is unlikely the children could be expected to see all the modules through in one sitting without becoming drained or disengaged. In practice with this programme, carrying out more than one session with a child is common. The programme is structured in such a way as to facilitate this, so that a saved interview can be added to at future sessions.

Additionally, the initial interviews planned with the study group had always been intended to reflect the ongoing process of the herbal treatment and to record any changes as the treatment progressed over the period of the study. To this end, it was important to clarify that each interview, although involving the use of different modules within the programme, would not represent a section of one single overall interview but one of a series of complete individual interviews. In Hermeneutical phenomenology, the process of data collection and analyses is

cyclical, with each exchange being the basis for the next and understanding derived from the interaction between researcher and study participants, this new understanding being then used to underpin the following exchange. Therefore it is in keeping with this philosophical approach to revise each stage on the basis of what is revealed through the previous.

The importance of recording became clear from these initial interviews. Although every entry using the computer keyboard or mouse is logged by the software and there are facilities within the programme to add notes and indices, any verbal exchange between child and interviewer not recorded may be lost. It was decided all the interviews would be recorded on an audio digital recorder and the records transcribed and analysed.

In the context of children and young people with Asperger's syndrome, the potential of this programme as a means of facilitating the expression and sharing of emotional experiences has been seen as being extremely important. In the programme's early development, that the interview package might be a useful tool for working with children and young people with Asperger's syndrome was considered. At that stage the evidence was not available as to what extent the use of computers could enhance any particular therapeutic intervention with people on the Autism spectrum. According to Calam et al 2000, the small amounts of available evidence at that time suggested, for an example, learning outcomes to not necessarily be affected by the use of computers in an educational setting (Chen and Bernardoptz 1993 from Calam et al 2000). However, there were indications people with Asperger's might engage more comfortably in an interview situation using the programme than otherwise (Briggs 1998). Since then, as discussed previously, more information is available to support the use of computer-aided techniques with this population. Sheila Groth Larsen has used the programme extensively in a clinical and education context.

Stage three of the training process is a review of the interviews with the trainer, more guidance and instruction on the use of the software and appropriate interviewing techniques. At this stage, for this study and in the light of information gained through the five pilot interviews, the interview order was revised and a modification of the structure of one of the modules developed.

Various options were considered including the possibility of arranging for the children to label a printed version of the 'emotions palette' before the first interview in order to have a basic vocabulary of emotions from the children on which to base the discussion.

## Appendix 8 Letter of confirmation of Ethical Approval

[www.napier.ac.uk](http://www.napier.ac.uk)

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& Social Care  
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e [info@napier.ac.uk](mailto:info@napier.ac.uk)  
w [www.napier.ac.uk/thls](http://www.napier.ac.uk/thls)

Ms C Stewart  
101 Clober Road  
Milngavie  
Glasgow  
Lanarkshire  
G62 7LS

25 July 2007

Dear Catriona

### APPLICATION FOR ETHICAL APPROVAL FOR A RESEARCH PROJECT

I am pleased to confirm that Ethical Approval has now been granted.

If you have any questions please do not hesitate to contact me, or Dr  
Maureen Macmillan ([m.Macmillan@napier.ac.uk](mailto:m.Macmillan@napier.ac.uk)) tel. 0131 455 5663.

Yours sincerely



Lesley Laidlaw  
Assistant Faculty Manager  
Faculty of Health, Life & Social Sciences  
Email: [L.Laidlaw@napier.ac.uk](mailto:L.Laidlaw@napier.ac.uk)  
Tel: 0131 455 5622



INVESTOR IN PEOPLE

**NAPIER UNIVERSITY**  
EDINBURGH

Wednesday, April 2, 2008 11:20:23 AM  
 In My Shoes version: 1.0.2.1  
 Program registered to: Catriona Stewart MNIMH  
 Site: Napier University  
 Registration code: f7fc-f886-9e8c-xxxx

Setting Details:  
 Setting 1 \*\*The Current Setting\*\*  
 'Where you live now'  
 There are no people currently in this setting  
 --  
 Setting 2  
 'Where you used to live'  
 There are no people currently in this setting  
 --  
 Setting 3  
 'Your School'  
 There are no people currently in this setting  
 --

11:20:45 AM: Starting 'Introduction' Module.

-----  
 11:20:48 AM: Erica: 'Hello, my name is Erica and I'm here to help you.'  
 11:20:53 AM: Drawing the intro set of people in the upper part of the people-chooser:  
 11:20:53 AM: Erica: 'Choose the picture, that looks most like you.'  
 11:22:27 AM: Leaving 'Introduction' Module.

-----  
 11:22:41 AM: Gender Indicator set to 'female'  
 11:22:41 AM: loading speech data: './Guides/English Speech/SpeechData.Rev' (Guide: 'Erica' - English Language)  
 11:22:44 AM: Starting 'Introduction' Module.  
 -----  
 11:22:46 AM: Erica: 'Hello, my name is Erica and I'm here to help you.'  
 11:22:51 AM: Drawing the intro set of people in the upper part of the people-chooser:  
 11:22:51 AM: Erica: 'Choose the picture, that looks most like you.'  
 11:22:56 AM: Leaving 'Introduction' Module.

-----  
 11:23:05 AM: Gender Indicator set to 'female'  
 11:23:05 AM: loading speech data: './Guides/English Speech/SpeechData.Rev' (Guide: 'Erica' - English Language)  
 11:23:08 AM: Starting 'Introduction' Module.  
 -----  
 11:23:11 AM: Drawing the intro set of people in the upper part of the people-chooser:  
 11:23:18 AM: Switching Source Sets down  
 11:23:18 AM: Drawing the pets set of people in the upper part of the people-chooser:  
 11:23:26 AM: Switching Source Sets down  
 11:23:26 AM: Drawing the chinese set of people in the upper part of the people-chooser:  
 11:23:28 AM: Switching Source Sets down  
 11:23:28 AM: Drawing the hindu set of people in the upper part of the people-chooser:



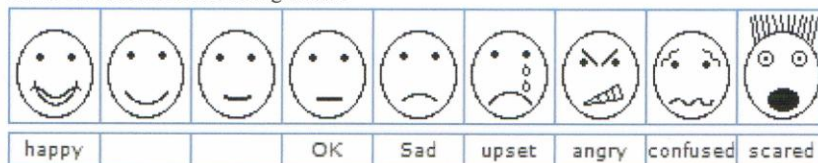
11:23:32 AM: Switching Source Sets down  
 11:23:32 AM: Drawing the sikh set of people in the upper part of the people-chooser:  
 11:23:35 AM: Switching Source Sets down  
 11:23:35 AM: Drawing the muslim set of people in the upper part of the people-chooser:  
 11:23:37 AM: Switching Source Sets down  
 11:23:37 AM: Drawing the japanese set of people in the upper part of the people-chooser:  
 11:23:39 AM: Switching Source Sets down  
 11:23:39 AM: Drawing the afrocarib set of people in the upper part of the people-chooser:  
 11:23:44 AM: Switching Source Sets down  
 11:23:44 AM: Drawing the european set of people in the upper part of the people-chooser:  
 11:24:03 AM: Person ' (big girl)' was dragged from upper to lower  
 11:24:03 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:24:16 AM: madison: madison  
 11:24:44 AM: madison: 14  
 11:24:44 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:24:53 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:24:53 AM: A thinks bubble was opened for person madison (1)  
 11:25:06 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:25:07 AM: no text was entered so the bubble was removed  
 11:25:07 AM: thinks bubble closed for person madison (1)  
 11:25:13 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:25:13 AM: A speech bubble was opened for person madison (1)  
 11:25:28 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:25:28 AM: no text was entered so the bubble was removed  
 11:25:28 AM: speech bubble closed for person madison (1)  
 11:25:38 AM: Switching Source Sets down  
 11:25:38 AM: Drawing the intro set of people in the upper part of the people-chooser:  
 11:25:43 AM: Switching Source Sets down  
 11:25:43 AM: Drawing the pets set of people in the upper part of the people-chooser:  
 11:25:49 AM: Person ' (fish)' was dragged from upper to lower  
 11:25:49 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:25:49 AM: madison: madison  
 11:25:50 AM: madison: 14  
 11:25:50 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:25:58 AM: Person ' (fish)' was dragged from upper to upper  
 11:26:03 AM: Switching Source Sets up  
 11:26:03 AM: Drawing the intro set of people in the upper part of the people-chooser:  
 11:26:08 AM: Person ' (big girl)' was dragged from upper to lower  
 11:26:09 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:26:09 AM: madison: madison  
 11:26:09 AM: madison: 14  
 11:26:09 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:26:12 AM: Gender Indicator set to 'female'  
 User Details:  
 Image: intro:5  
 Description: big girl  
 Gender: female  
 Name: madison  
 Age: 14  
 11:26:13 AM: Leaving 'Introduction' Module.  
 -----  
  
 11:26:19 AM: Starting 'Emotions' Module.  
 ----

11:29:16 AM: Description: Girl outside alone, standing close to a dog.  
 11:29:23 AM: Emotion 9 ('scared') was chosen.  
 11:29:27 AM: button "OK" clicked  
 11:29:28 AM: Loading Scene './Graphics/Emotions Module/girlandschooldesk.gif'.  
 11:29:29 AM: Description: Girl in school uniform, sitting alone behind school desk. Hand raised to head.  
 11:29:35 AM: Emotion 8 ('confused') was chosen.  
 11:29:47 AM: button "OK" clicked  
 11:29:48 AM: Loading Scene './Graphics/Emotions Module/girlandseesaw.gif'.  
 11:29:48 AM: Description: Girl sitting alone on a see-saw.  
 11:29:55 AM: Emotion 5 ('Sad') was chosen.  
 11:30:03 AM: button "OK" clicked  
 11:30:04 AM: Loading Scene './Graphics/Emotions Module/girlandskateboard.gif'.  
 11:30:04 AM: Description: Girl lying on the ground, alone, having fallen off a skateboard.  
 11:30:12 AM: Emotion 6 ('upset') was chosen.  
 11:30:18 AM: button "OK" clicked  
 11:30:19 AM: Loading Scene './Graphics/Emotions Module/girlandspider.gif'.  
 11:30:19 AM: Description: Girl alone, in a room standing near to a big spider.  
 11:30:24 AM: Emotion 9 ('scared') was chosen.  
 11:30:38 AM: button "OK" clicked  
 11:30:39 AM: Loading Scene './Graphics/Emotions Module/girlandtv.gif'.  
 11:30:39 AM: Description: Girl, sat alone on floor in front of a TV.  
 11:30:40 AM: button "OK" clicked  
 11:30:41 AM: Leaving 'Emotions & Scenes' Module.

11:30:55 AM: Gender Indicator set to 'female'  
 11:30:55 AM: loading speech data: './Guides/English Speech/SpeechData.Rev' (Guide: 'Erica' - English Language)  
 11:30:57 AM: Starting 'Emotions & Scenes' Module.

11:31:07 AM: Loading Scene './Graphics/Emotions Module/girlandtv.gif'.  
 11:31:07 AM: Description: Girl, sat alone on floor in front of a TV.

Current Emotions Palette Configuration:



11:31:16 AM: Emotion 4 ('OK') was chosen.  
 11:31:32 AM: button "OK" clicked  
 11:31:39 AM: Leaving 'Emotions & Scenes' Module.

11:32:26 AM: Starting 'People' Module.

11:32:27 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:32:29 AM: People-chooser: lower section location field clicked  
 11:32:29 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:32:29 AM: Drawing the european set of people in the upper part of the people-chooser:  
 11:34:36 AM: Person ' (woman)' was dragged from upper to lower

11:34:36 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:34:42 AM: madison: mum  
 11:34:42 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:34:46 AM: Person ' (big girl)' was dragged from upper to lower  
 11:34:46 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:34:56 AM: madison: dead annoying  
 11:34:56 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:35:07 AM: Person ' (medium girl)' was dragged from upper to lower  
 11:35:07 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:35:16 AM: madison: lissa  
 11:35:16 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:35:23 AM: Person ' (small girl)' was dragged from upper to lower  
 11:35:23 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:35:34 AM: madison: baba  
 11:35:34 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:35:39 AM: Switching Source Sets down  
 11:35:39 AM: Drawing the child set of people in the upper part of the people-chooser:  
 11:35:42 AM: Switching Source Sets down  
 11:35:42 AM: Drawing the pets set of people in the upper part of the people-chooser:  
 11:35:47 AM: Person ' (fish)' was dragged from upper to lower  
 11:35:47 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:35:56 AM: Text was deleted. The original text was:

11:36:06 AM: Text was deleted. The original text was:

11:36:18 AM: Text was deleted. The original text was:

and HA

11:36:27 AM: madison: ~~and~~ and Shalulula

11:36:27 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:36:33 AM: Person ' madison (big girl)' was dragged from lower to lower

11:36:33 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:36:40 AM: Person ' madison (big girl)' was dragged from lower to lower

11:36:40 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:36:46 AM: Person ' madison (big girl)' was dragged from lower to lower

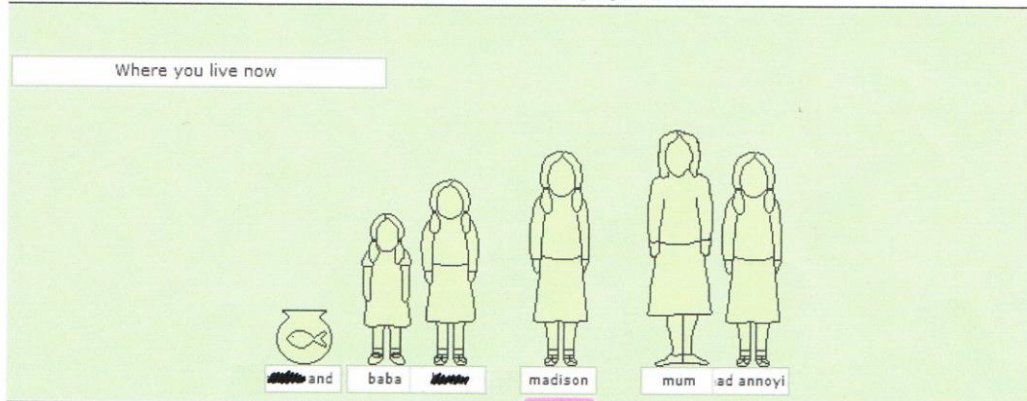
11:36:46 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:36:54 AM: Person ' dead annoying (big girl)' was dragged from lower to lower

11:36:54 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:37:10 AM: Person ' lissa (medium girl)' was dragged from lower to lower

11:37:10 AM: Drawing the dest set of people in the lower part of the people-chooser:





11:37:23 AM: Set Details:  
 1) Natalie and Shalulula (fish)  
 2) baba (small girl)  
 3) lissa (medium girl)  
 4) madison (big girl)  
 5) mum (woman)  
 6) dead annoying (big girl)

11:37:25 AM: Leaving 'People' Module.

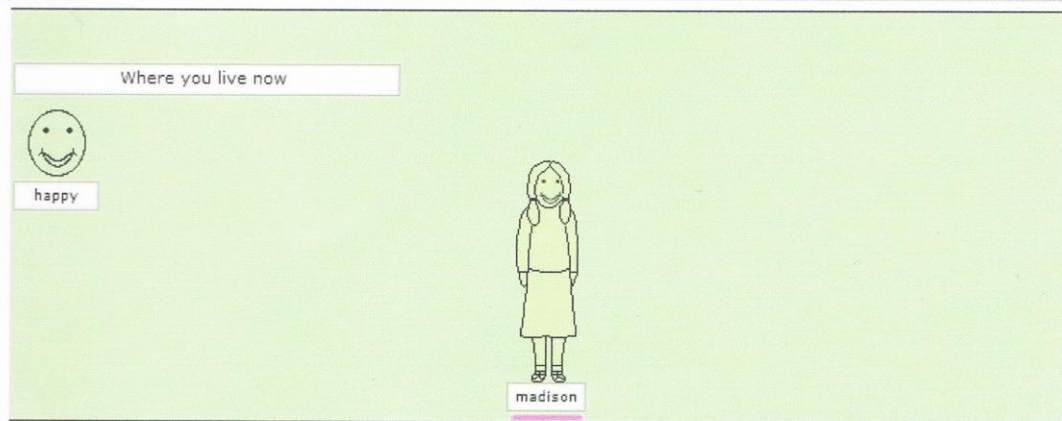
---

11:37:47 AM: Starting 'EmotionsAndPeople' Module.

-----

11:37:50 AM: Displaying face 'happy' [1]  
 11:38:01 AM: "yes" button clicked.  
 11:38:09 AM: Displaying face 'upset' [6]  
 11:38:14 AM: "yes" button clicked.  
 11:38:20 AM: Displaying face 'OK' [4]  
 11:38:41 AM: "yes" button clicked.  
 11:38:47 AM: Displaying face 'Sad' [5]  
 11:39:28 AM: "yes" button clicked.  
 11:39:34 AM: Displaying face '\*Smile' [3]  
 11:39:50 AM: "no" button clicked.  
 11:39:50 AM: Displaying face 'angry' [7]  
 11:39:55 AM: "yes" button clicked.  
 11:40:02 AM: Displaying face 'scared' [9]  
 11:41:28 AM: "yes" button clicked.  
 11:41:35 AM: Displaying face '\*Happy' [2]  
 11:41:48 AM: "no" button clicked.  
 11:41:48 AM: Displaying face 'confused' [8]  
 11:42:03 AM: "yes" button clicked.  
 11:47:23 AM: --  
 11:47:24 AM: Starting Phase 2  
 11:47:24 AM: Drawing the dest set of people in the lower part of the people-chooser:  
 11:47:25 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:  
 11:47:44 AM: Marker placed = 1

11:48:17 AM: Text was deleted. The original text was:  
 Happy with friends; talking to ~~ngds~~ on computer;  
 11:48:22 AM: Text was deleted. The original text was:  
 Happy with friends; talking to ~~ieinds~~ on computer;  
 11:48:26 AM: Text was deleted. The original text was:  
 Happy with friends; talking to ~~frds~~ on computer;  
 11:48:27 AM: The following message was entered into the results:  
 Happy with friends; talking to friends on computer;



11:48:30 AM: Summary for Expression '1 (\*Very Happy):

11:48:30 AM: Set Details:

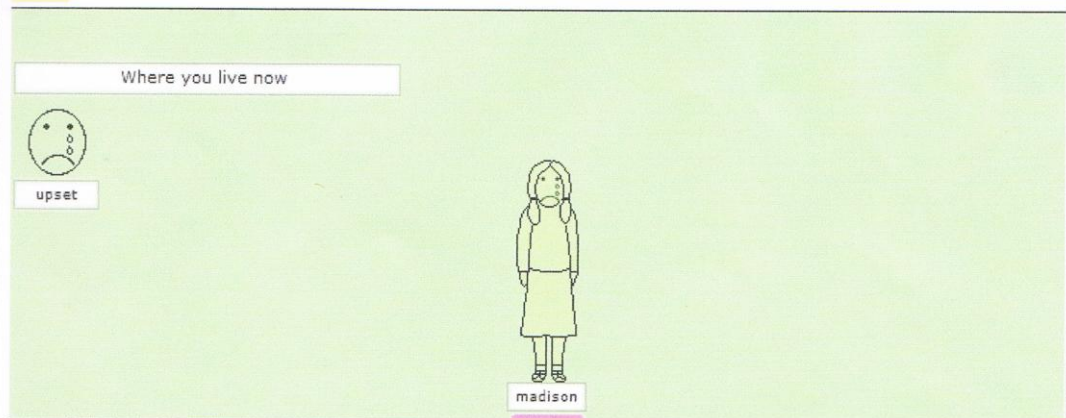
1) madison (big girl)

11:48:31 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:48:31 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:

11:48:52 AM: The following message was entered into the results:

no one



11:48:58 AM: Summary for Expression '2 (\*Sad):

11:48:58 AM: Set Details:

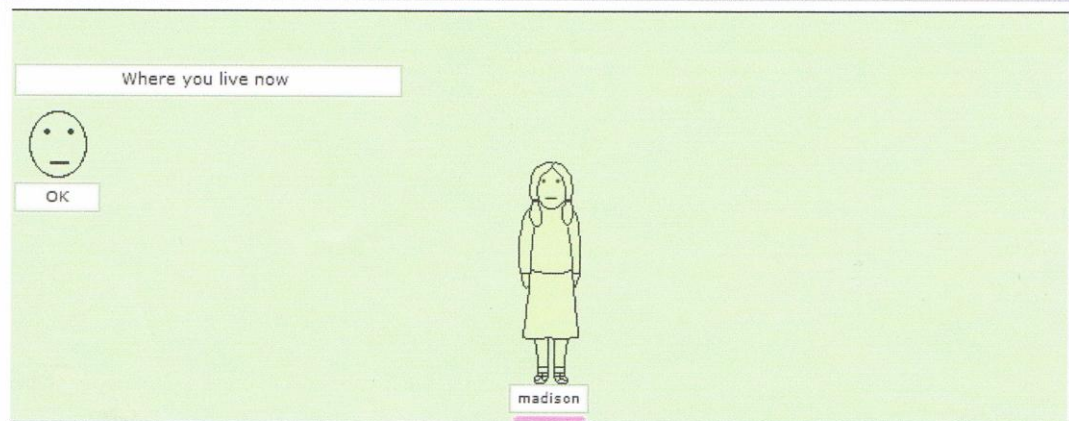
1) madison (big girl)

11:48:59 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:48:59 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:

11:49:16 AM: The following message was entered into the results:

at school



11:49:19 AM: Summary for Expression '3 (\*Neutral'):

11:49:19 AM: Set Details:

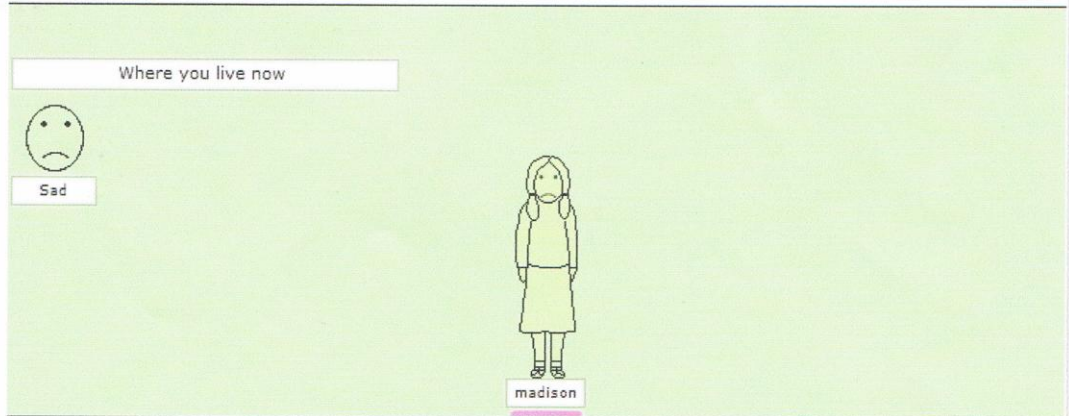
1) madison (big girl)

11:49:20 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:49:20 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:

11:49:41 AM: The following message was entered into the results:

arriving at school



11:49:43 AM: Summary for Expression '4 (\*Unhappy'):

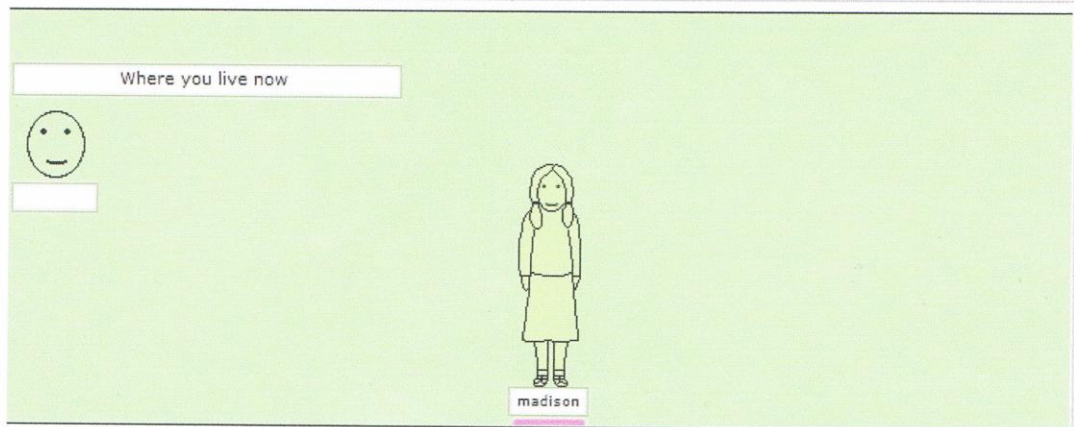
11:49:44 AM: Set Details:

1) madison (big girl)

11:49:44 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:49:44 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:





11:49:49 AM: Summary for Expression '5 (\*Smile):

11:49:50 AM: Set Details:

1) madison (big girl)

11:49:50 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:49:50 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:

11:50:03 AM: Text was deleted. The original text was:

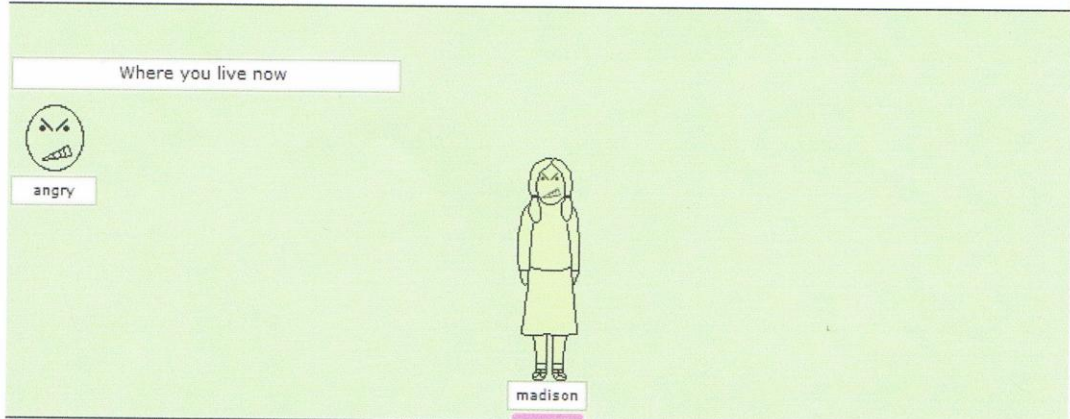
no -one -te=

11:50:11 AM: Text was deleted. The original text was:

no -one -tell everyone[do go]

11:50:19 AM: The following message was entered into the results:

no -one -tell everyone to go away



11:50:22 AM: Summary for Expression '6 (\*Angry):

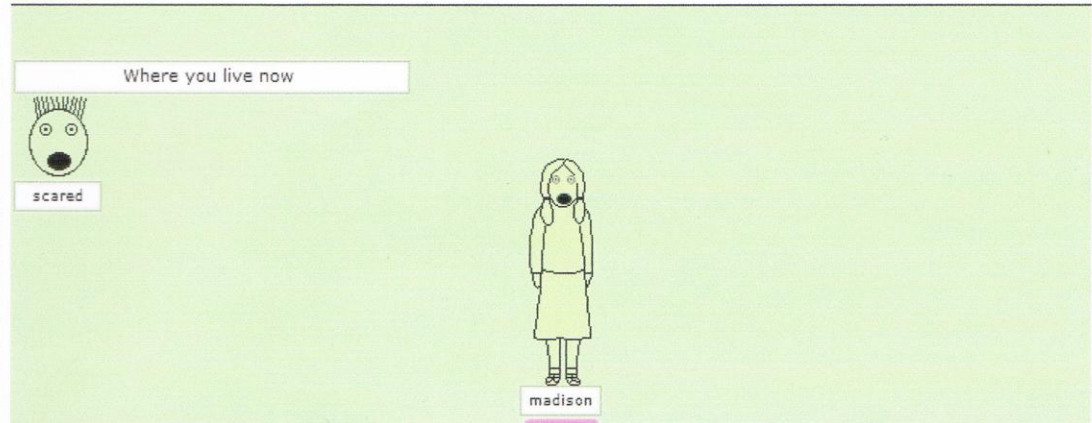
11:50:23 AM: Set Details:

1) madison (big girl)

11:50:23 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:50:24 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:

11:51:14 AM: Text was deleted. The original text was:  
 run away from place where scared; school, anywhere if someone t  
 11:51:22 AM: The following message was entered into the results:  
 run away from place where scared; school, anywhere if someone there I'm  
 scared of



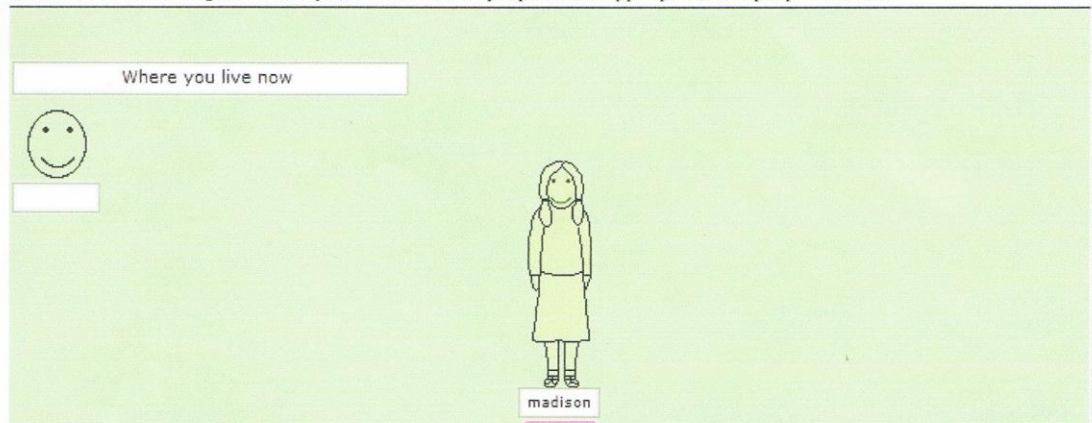
11:51:31 AM: Summary for Expression '7 (\*Scared)':

11:51:31 AM: Set Details:

1) madison (big girl)

11:51:32 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:51:32 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:



11:51:38 AM: Summary for Expression '8 (\*Happy)':

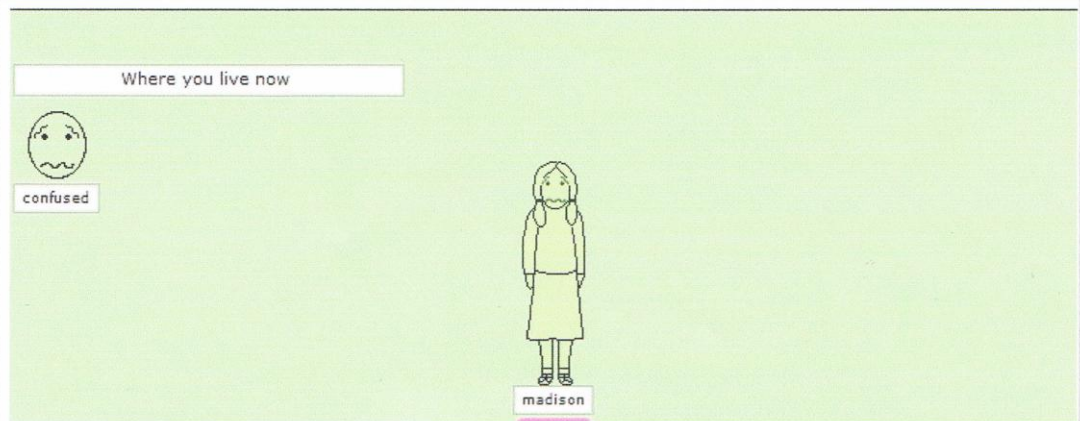
11:51:38 AM: Set Details:

1) madison (big girl)

11:51:38 AM: Drawing the dest set of people in the lower part of the people-chooser:

11:51:39 AM: Drawing the Where you live now set of people in the upper part of the people-chooser:





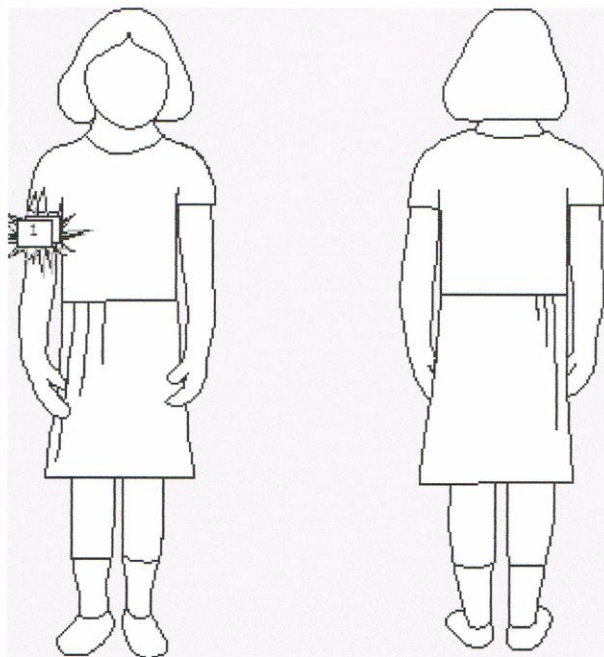
11:51:48 AM: Summary for Expression '9 (\*Puzzled/Worried):

11:51:48 AM: Set Details:

1) madison (big girl)

11:51:49 AM: Leaving 'EmotionsAndPeople' Module.

11:51:56 AM: Starting 'Somatic Experiences' Module.



Page 1

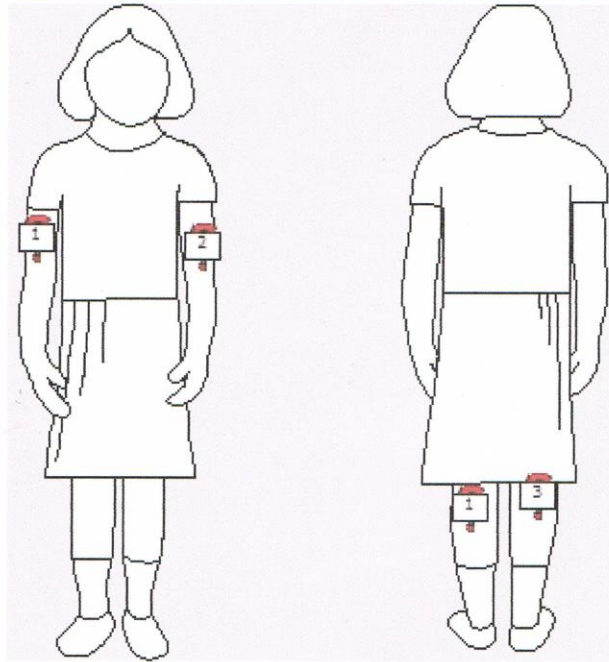
Description: 'Page 1 of 16'

Front view:

1: fading-spikes. Size: 4. Throb: 3. Label: "

2: fading-spikes. Size: 4. Throb: 3. Label: "

Back view:



Page 2

Description: 'Page 2 of 16'

Front view:

1: query. Size: 1. Throb: 3. Label: 'itchy skin'

2: query. Size: 1. Throb: 3. Label: 'itchy skin'

Back view:

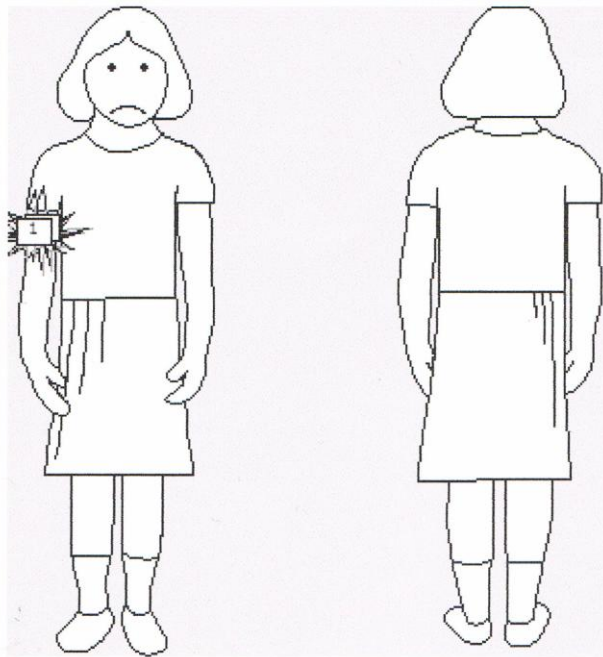
1: query. Size: 1. Throb: 3. Label: "

3: query. Size: 1. Throb: 3. Label: 'itchy skin'

11:56:37 AM: Leaving 'Somatic Experiences' Module.

11:56:41 AM: Starting 'Somatic Experiences' Module.

11:56:58 AM: Emotion 5 ('Sad') was chosen.



Page 1

Description: 'Page 1 of 16'

Front view:

1: fading-spikes. Size: 4. Throb: 3. Label: "

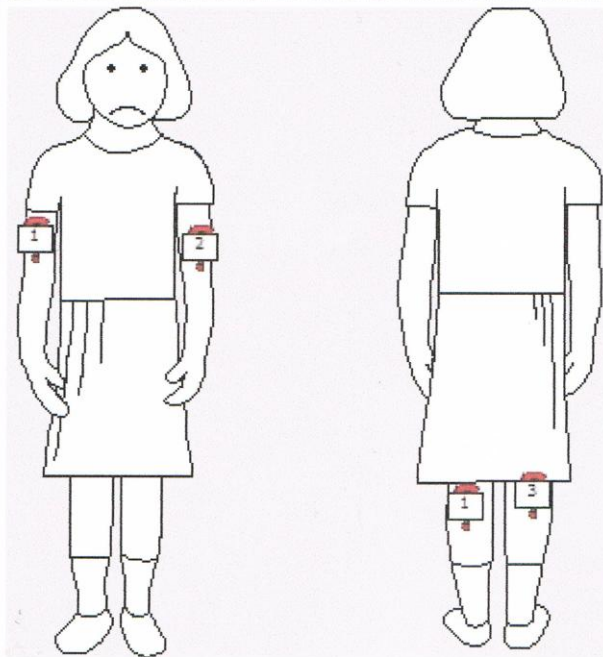
2: fading-spikes. Size: 4. Throb: 3. Label: "

---

Back view:

---

-----



Page 2

Description: 'Page 2 of 16'

Front view:

1: query. Size: 1. Throb: 3. Label: 'itchy skin'

2: query. Size: 1. Throb: 3. Label: 'itchy skin'

---

Back view:

1: query. Size: 1. Throb: 3. Label: ''

3: query. Size: 1. Throb: 3. Label: 'itchy skin'

---

11:57:08 AM: Leaving 'Somatic Experiences' Module.

11:57:13 AM: Starting 'Somatic Experiences' Module.

----

11:57:36 AM: Text was deleted. The original text was:

occasionally eyire

11:57:43 AM: Text was deleted. The original text was:

occasionally entire body

11:57:57 AM: Text was deleted. The original text was:

occasionally entire body aches, or just parts, like a

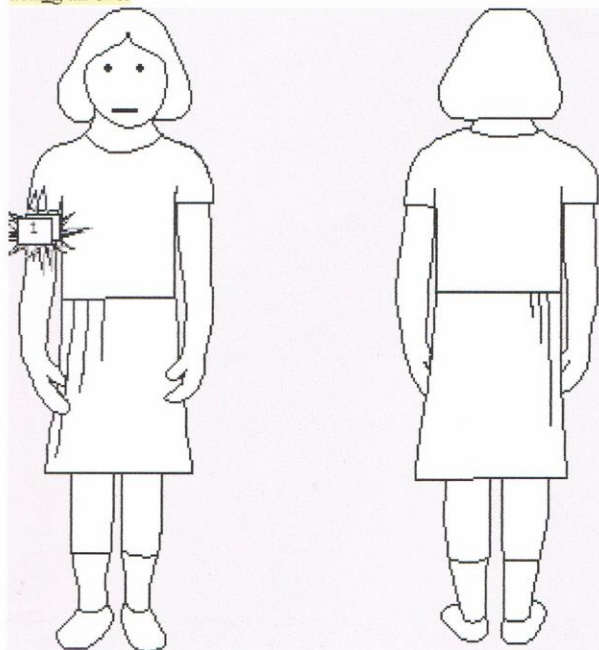
11:58:20 AM: The following message was entered into the results:

occasionally entire body aches, or just parts, like an ankle or a wrist

11:59:17 AM: Emotion 4 ('OK') was chosen.

11:59:29 AM: Text was deleted. The original text was:

achbg all over



Page 1

Description: 'Page 1 of 16'

Front view:

1: fading-spikes. Size: 4. Throb: 3. Label: "

2: fading-spikes. Size: 4. Throb: 3. Label: "

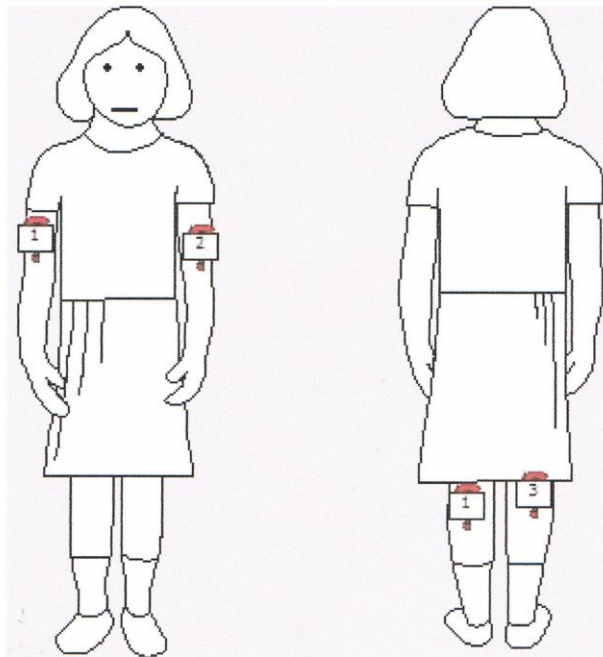
---

Back view:

---

-----





Page 2

Description: 'Page 2 of 16'

Front view:

1: query. Size: 1. Throb: 3. Label: 'itchy skin'

2: query. Size: 1. Throb: 3. Label: 'itchy skin'

---

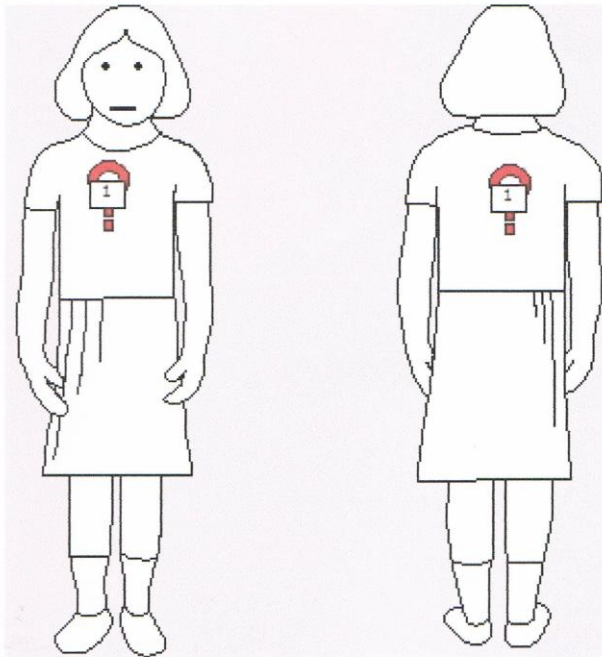
Back view:

1: query. Size: 1. Throb: 3. Label: ''

3: query. Size: 1. Throb: 3. Label: 'itchy skin'

---

-----



Page 3

Description: 'Page 3 of 16'

Front view:

1: query. Size: 5. Throb: 3. Label: "

---

Back view:

1: query. Size: 5. Throb: 3. Label: 'aching all over'

---

11:59:46 AM: Leaving 'Somatic Experiences' Module.

11:59:53 AM: Starting 'subjects' Module.

---

11:59:54 AM: Loading Scene './Graphics/Emotions Module/girlanddesk.gif'.

11:59:55 AM: Description: Girl in school uniform, sat alone behind a school desk.

Current Emotions Palette Configuration:



12:00:07 PM: Emotion 1 ('happy') was clicked.

12:00:10 PM: Emotion 1 ('happy') was moved to line 1 - ".  
 12:00:13 PM: madison: label 1 was clicked  
 12:01:08 PM: madison: Typed into label 1: Drama  
 12:01:11 PM: Emotion 4 ('OK') was clicked.  
 12:01:14 PM: Emotion 4 ('OK') was moved to line 2 - ".  
 12:01:15 PM: madison: label 2 was clicked  
 12:01:28 PM: madison: Typed into label 2: history  
 12:03:59 PM: Emotion 6 ('upset') was clicked.  
 12:04:04 PM: Emotion 6 ('upset') was clicked.  
 12:04:06 PM: Emotion 6 ('upset') was moved to line 3 - ".  
 12:04:07 PM: madison: label 3 was clicked  
 12:04:30 PM: Text was deleted. The original text was:  
 being picked on at lunchtime, things throva]a  
 12:04:43 PM: madison: Typed into label 3: being picked on at lunchtime. things thrown at me. being laughed at  
 12:04:48 PM: Emotion 7 ('angry') was clicked.  
 12:04:50 PM: Emotion 7 ('angry') was moved to line 4 - ".  
 12:04:53 PM: madison: label 4 was clicked  
 12:05:02 PM: madison: Typed into label 4: in maths  
 12:05:05 PM: Emotion 8 ('confused') was clicked.  
 12:05:11 PM: Emotion 8 ('confused') was clicked.  
 12:05:14 PM: Emotion 8 ('confused') was moved to line 5 - ".  
 12:05:15 PM: madison: label 5 was clicked  
 12:05:19 PM: madison: Typed into label 5: in maths  
 12:05:22 PM: Emotion 9 ('scared') was clicked.  
 12:05:24 PM: Emotion 9 ('scared') was moved to line 6 - ".  
 12:05:26 PM: madison: label 6 was clicked  
 12:05:46 PM: Text was deleted. The original text was:  
 fear of someone sta]ib  
 12:05:58 PM: Text was deleted. The original text was:  
 fear of someone sta]g to pick on me  
 12:06:03 PM: madison: Typed into label 6: fear of someone starting to pick on me

12:07:44 PM: Summary for phase 1  
 12:07:45 PM: label 1 (happy ) 'Drama'  
 12:07:45 PM: label 2 (OK ) 'history'  
 12:07:45 PM: label 3 (upset ) 'being picked on at lunchtime. things thrown at me. being laughed at'  
 12:07:45 PM: label 4 (angry ) 'in maths'  
 12:07:45 PM: label 5 (confused ) 'in maths'  
 12:07:46 PM: label 6 (scared ) 'fear of someone starting to pick on me'

12:07:47 PM: --  
 12:07:47 PM: Starting Phase 2  
 12:08:40 PM: summary for box 1 'Good'  
 Book 1 'Drama'  
 12:08:40 PM: summary for box 2 'OK'  
 Book 2 'history'  
 12:08:40 PM: summary for box 3 'Bad'  
 Book 3 'being picked on at lunchtime. things thrown at me. being laughed at'  
 Book 4 'in maths'  
 Book 5 'in maths'  
 Book 6 'fear of someone starting to pick on me'





12:08:41 PM: Leaving 'subjects' Module.  
-----

12:08:47 PM: Starting 'Training' Module.  
----

12:09:18 PM: Leaving 'Training' Module.  
-----

12:11:31 PM: Text for Marker 1 :

12:11:31 PM:

12:11:31 PM: Closing Results Log

12:11:32 PM: Total Session Time: 0h 51m 9s

1

☒ Setting is active

Historical

to

Current

From:

Location type:

Select one

Speech:

☒ On  
☐ Off

Where you live now

Name:

Where you live now

Reference:

Current Residential

Address:

Comment:

Current full-time residence



atalie ani   baba   lissa   madison   mum   ad annoying

Prev

Next

Print Set

New Setting

Delete Setting

Clear Set

OK

Setting Where you live now										
	on	on	on	on	on	on	on	on	on	on
First Pass	Yes	-	-	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sarah, Natalie and Sha	-	-	-	-	-	-	-	-	-	-
baba	-	-	-	-	-	-	-	-	-	-
lissa	-	-	-	-	-	-	-	-	-	-
madison	1	1	1	1	1	1	1	1	1	1
mum	-	-	-	-	-	-	-	-	-	-
dead annoying	-	-	-	-	-	-	-	-	-	-

