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**Perspectives of the Autistic 'Voice':  
An Ethnography Examining Informal Education Learning Experiences**

**Sandra Jane Ellis**

**A thesis submitted in partial fulfilment of the requirements of  
Sheffield Hallam University  
for the degree of Doctor of Education**

**January 2014**

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## **DEDICATIONS**

To my husband Joe who unknowingly gave me 24 years of autism experience, and encouraged, supported and loved me through the highs and lows

To Dr James Appleyard and Dr Jon Pritchard, who together literally saved my life, and allowed me to reach for my goals

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To the staff at Sheffield Hallam University, and in particular my Director of Studies Dr Luke Beardson who helped me develop from a student into a researcher, and Dr Manuel Madriaga for their continued support and encouragements

...And finally, to Thomas, the young man without whom, my journey along the autism spectrum would have been very different

## ABSTRACT

Using a qualitative theoretical stance of interpretivism, this study offers an opportunity for young autistic individuals to have a 'voice' and participate in a wholly reflective discussion about their informal education learning experiences. The study uses a constructivist framework to discuss various concepts including autism as a disability, the importance of recognising the heterogeneity of the autistic population, and the significance of informal education and physical activities to the lives of the participants; the aim being to create a positive learning experience where the diversity of learners is valued and recognised as well as informing professional teacher development.

An extensive examination of the literature reveals a myriad of rich intertwining perceptions that are pertinent considerations based on concerns at the root of this research: issues around the autistic mind, pedagogy and socio-cultural learning.

A pluralist methodology is used throughout to reflect the diverse autistic community, with a strong influence underlying each phase of autoethnography and self-reflection. This is crucial to the study to utilise each autistic 'voice' including that of the researcher who is an autistic adult as well as a professional within the context of the study. In addition, teachers within the field have been given an opportunity to have a 'voice' to complement and support the data.

The data has revealed a whole range of emergent themes, which can be further explored, developed and utilised outside of the this study to produce guidelines to inform a national autism specific teacher training programme for informal educators. The study has highlighted the need for flexible pedagogy, and for teachers to be conscious of the heterogeneity of their autistic students, as well as highlighting the importance of the student/teacher relationship within informal education.

## INTRODUCTION

... for me the most difficult thing is when people assume I am stupid and can't take part. Just because I am autistic doesn't mean I can't do the same things as others. I don't need special things to do – just someone to understand my difficulties and be sympathetic towards them. People around me who are willing to be flexible and help me  
(‘Scarlett’, 2012)

‘Scarlett’ (all names have been changed for confidentiality) is an autistic ‘voice’, central to this study, and is one of many individuals who participated in the research. She is representative of the young people I teach within my professional role as a karate and dance teacher. In addition I am responsible within a national martial arts governing body, for the teacher training programme which incorporates a specific autism awareness training module, and I also visit and consult with clubs and teachers nationally to advise on teaching strategies. Informal education is an area which has tended to be largely bypassed in favour of research and literature concerning school-based education. It has an important place in the lives of all children and young people, and for those with autism it offers an environment where the individual can choose to participate, can feel safe, and can make friends with the same interests. Regrettably I have encountered learning situations where this is not always the case and young autistic individuals are struggling to be understood and to get as much out of the learning situation as others in the classes.

My teaching role involves students who are both autistic and non-autistic and they all learn together. The ages range from five to seventeen years. I have been knowingly teaching young autistic individuals for fourteen years. I also have a very personal interest in this study in that I am an autistic adult.

This study will include a variety of informal education activities, the specific type not being directly relevant: it could be a sport, for example, canoeing or tennis; or activities such as scouts, music, cookery, or gardening club. The important aspect is the learning experience and how it impacts the individual. Every person with an



autism spectrum condition (ASC, also known as autism spectrum disorder (ASD)) is an individual, and 'like all individuals, has a unique personality with a unique combination of interests, strengths and limitations' (Coyne, 2004:17).

The potential for this research study is overwhelming: it explores areas of my professional practice, it relies largely on the 'voice' of young autistic individuals, and if the outcomes are achieved it will enable a more positive learning experience for young autistic students as well as pave the way for a more informed professional development programme for informal educators. The study is also very personal to me and this in itself is daunting as it will expose areas usually kept hidden behind my professional persona. Rather than consider this as a barrier to successful results, I view this as providing momentum for the study and the grounds of its importance. I have been clinically diagnosed with Asperger's Syndrome<sup>1</sup>, an intellectually high functioning presentation of autism (Attwood, 1998) and it is inevitable that this first hand experience will bring another dimension to the study, albeit one which I shall need to keep strict control over in order to keep the research results transparent and subject to unbiased scrutiny.

For the purpose of this study my starting definition of *informal education* is an 'organised educational activity outside the school curriculum, where the teacher/facilitator has appropriate experience and/or qualifications' (Ellis, 2013). This definition is based on my professional experience and insight of the activities I am using for this study, and is in contrast to *informal learning*, where daily life can become an informal learning experience (Foley, 1999). There are many parallels between formal and informal education, using my definition of the latter; and in some circumstances schools and colleges work with informal educators to offer such activities to their students as supplementary and indeed complementary education. Similarities include the use of a syllabus (curriculum) in many cases, although, informal educators are likely to have more flexibility in the teaching context of the classes. While formal education is externally assessed by OfSted

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<sup>1</sup> In 2013, The DSM5 removed the diagnosis of Asperger's Syndrome as a separate diagnostic category – see chapter 2: 16 for more details

(Office for Standards in Education, Children's Services and Skills) informal education may or may not be constrained by external validation. Sports will be governed to some extent by Governing Bodies but the running of the local clubs and classes is often left to the teachers. They will, however, need to adhere to national policies including health and safety, child and vulnerable adult protection, anti-bullying, ethics and equity, and may have grading and insurance procedures. Much of this is the same as for formal education. In addition formal education is constrained by governance and regulatory procedures, budget controls and the existence of Boards of Governors. Both formal and informal education requires the use of regular assessments and evaluations, usually based on national standards. For some informal activities there is more flexibility here than for formal education.

Formal education classes usually have one teacher for a class, perhaps with an assistant, whereas informal education classes may have more than one teacher often splitting the class into several groups, and the main teacher of the class may change on occasions. In my experience informal education tends to be varied but often follows the same routines in many cases. However I would argue it is often easier to adapt the classes for students with special needs; there may be more teachers or experienced students who can assist, often there are smaller classes or several groups; classes may be less constrained on time and more individual tuition may be possible. Teaching methods can be flexible and students can often work at their own pace without restricting other students. Informal educators tend to set examinations when students are ready as opposed to the set examination timetable constraints of formal education. It is mostly the choice of the teacher where and when the activities run, and students' needs can be met more easily. I recognise however, that both formal and informal education is subject to flexibility and have their strengths and weaknesses and I have no wish to favour one over the other for the purposes of this study. In fact I should reiterate that in my experience they complement one another well, enabling constructive learning development.

## **AIMS AND RESEARCH QUESTIONS**

I have two aims for this study:

1. To examine autistic individuals' perspectives of their physical activities and informal education learning experiences including the impact of their student/teacher relationships;
2. To critically reflect upon how these perspectives can be evaluated in order to determine whether they can be built upon to create a more positive learning experience within informal education. It is hoped that the latter will inform an inclusive curricula where the diversity of learners is valued and recognised as well as inform the professional development of teachers.

In order to achieve these aims I shall attempt to answer the following four questions:

1. What part does personal motivation play in the informal learning experience for the young autistic student?
2. How might teacher qualities impact upon the informal learning experience for the young autistic student?
3. How does the relationship between student and teacher affect the informal learning experience?
4. Are there other issues that may affect the informal learning experience for the young autistic student?

## **RESEARCH CONTEXT**

The research will be carried out using a multi-method approach which will allow the flexibility needed to take into account the participants' vulnerabilities (Liamputtong, 2007); both by being autistic and for their variation in age, from young children to young adults. Taking advantage of today's technology, one aspect of the research

will be carried out via an on-line ethnography, allowing a global 'voice'. The remainder of the research will be carried out within the context of the tangible informal education activities, at clubs, after school activities and leisure centres as well as targeting teachers of these activities both locally via clubs and nationally via sports associations and governing bodies.

## **AUTISM LANGUAGE**

It is pertinent at this stage that I address the issue of language and terminology which will be used within the thesis and that used in connection with autism.

The phrase 'young person with autism' puts the person before the condition because it humanises the individual but in some contexts makes explanations complicated; and Swain et al., (2003:14) indicate that it implies we 'only have to change our attitudes in order to change the realities'. The way in which people are termed gives rise to a lot of discussion (Barnes et al., 1999; Barnes and Mercer, 2003; Oliver, 2009). According to Oliver and Barnes (1998, cited in Swain et al., 2003:14), this phrasing also implies that 'disability is the property of disabled people and not society. It sidesteps the need for social and environmental change'. When necessary for the sake of clarity, I shall use the adjective 'autistic'; while potentially being politically incorrect, it is consistent with general use – for example, National Autistic Society; and it is the favoured term for some which emphasises the point that the person has been disabled by society and not the condition (Campbell, 2010). Certainly from my own perspective, I prefer to be an 'autistic adult' rather than an 'adult with autism'. I see my autism as a part of me not something I have as an 'add on'. This will later form part of the discussion on identity. Any other 'diagnostic labels' used will be for the accuracy of citing literature only.

Although I have used the term autism in my question, this is mainly for ease of writing. The term autism describes a broad spectrum of diagnosable conditions which include Kanner's or classic autism, Asperger's Syndrome (AS), high



functioning autism (HFA) and atypical autism (Frith, 2008; Roth, 2010). Literature referring to autism may mean any one of these specific diagnoses or may use the term in a broader sense. The phrase 'autism spectrum disorder' is often used but the term 'disorder' is inadequate in this context as it implies negative connotations, and while it may be classed as a 'disability' as I shall consider later, it does not always mean negativity for the individual. Indeed, many individuals with autism are abound with talents, often as a result of paying acute attention to detail or being driven by the need to control their environment (Baron-Cohen, 2004). Sacks (1986:204), describes 'Josè' who when encouraged to draw, started to communicate graphically, and with amazing detail in pictures or symbols. According to Fitzgerald (2004, cited in Brown, 2010:7) 'certain features of ASD, such as persistence, single-mindedness, intelligence, and non-conformity, can enhance not just the analytical process, but the creative process as well'.

For the purposes of this study, I shall be referring mainly to the intellectually higher functioning end of the autism spectrum which is recognised to indicate that the person has an average or above average IQ, and no language delay while having difficulties in other areas (Wing, 1996; Baron-Cohen, 2008). In the year leading up to the publication of this thesis there have been changes to diagnoses within autism, and this will be discussed further during Chapter 2. There will also be mention of autism as a disability; indeed it is often regarded as a 'hidden disability' (i.e., not obviously visible to the outsider) (Pandya, 2008:78, cited in Edmonds and Beardon Eds) and it is therefore more difficult to realise that autism is a 'subtle yet devastating neurological abnormality' (Frith, 2003:1). I would argue that devastating is a strong word and perhaps not necessarily true of all autistic individuals who in part consider it one of their strengths and enjoy the uniqueness and individuality it affords them.

The word 'disability' itself shows 'how deeply rooted negative perceptions are in our culture' (Swain et al., 2003:13). Sadly there has been much painful abuse of individuals with disabilities in history and this continues today. With the 'hidden' aspect of autism comes a misunderstanding of how behaviour of the individual

with autism manifests and exactly why (Kearns Miller, 2003; Baker, 2006). This can lead to examples of abuse often sent out 'from sources of medical or social power' (Murray, 2008:17).

While one could argue that the label, i.e. autism as a disability, is a social construct (Green, 2008; Beardon 2010), others see it as a legal disability, arguably also a social construct, (Crosby, 2009) and Lorna Wing, who devised the phrase *triad of impairments* refers to autism as a disability on a number of occasions (1996). Dattilo and Williams (1999:452) insist that 'society assigns stigma and deviant labels to people with undesirable differences', although I would strongly point out here that this does not presume autism is necessarily undesirable. There are many definitions and much debate about whether or not autism is a disability. In the USA for instance, autism falls under 'The Individuals with Disabilities Education Act', and is described by such as 'a developmental disability significantly affecting...' (Coyne and Fullerton, 2004:17); on the Autism Europe (which links 30 European countries) website the clear declaration is that 'autism is a serious disability' (2011) and in the UK the National Autistic Society, a founding organisation specialising in autism, describes the condition as a 'lifelong developmental disability' (2011). To add to this Iovannone et al. (2003:150) refer to autism as a 'unique and perplexing disability'. Baron-Cohen however, has questioned specifically whether Asperger's Syndrome and high functioning autism necessarily are disabilities and concludes that perhaps the term 'difference' is 'a more neutral, value-free, and fairer description and that the term disability only applies to the lower functioning cases of autism' (2000:490). Lawson (2011), herself autistic, has coined the phrase *diff-ability* as she dislikes the negative connotations of *disorder* and *disability*.

Much as I dislike the term *disability* myself, personal experience enables me to admit that there are times when Asperger's Syndrome can have the potential to be disabling, especially considering the Oxford (2006:191) definition of the term disability as 'a physical or mental condition that restricts your movements, senses, or activities'. At times when signs of Asperger's Syndrome's more challenging

characteristics are at their peak in an individual, they can very much restrict senses or activities, or sometimes both. However the key factor here is that the impact of Asperger's Syndrome can change depending on circumstances. Green argues for the term *SEN* (special educational need) to be used instead of disability (2008:189) and I am personally more inclined towards this term. It remains a contentious issue however and these discussions will no doubt continue to arise.

Baron-Cohen (2008) writes much about autism as essentially a neurological difference and indeed *the brain being wired differently* is a phrase seen increasingly in the media as an explanation for autism (Szalavitz, 2010) as well as for other conditions where a person is different from what is considered the norm by society, for example, dyslexia. Autism is a condition which presents differently within each individual and I like to think of it as diversity rather than disability. This can be considered a far more positive message to deliver and socially will 'disable' the individual to a lesser degree.

## **SOCIAL MODEL OF DISABILITY AND AUTISM**

The social model of disability (Barnes et al., 1999; Barnes and Mercer, 2003; Swain et al., 2003; Oliver, 2009) is based on the premise that it is society which disables people and loads the original impairment by 'isolating and excluding [the individual] from full participation in society' (UPIAS, 1976, in Swain et al., 2004:286). Although the original model was discussed in the context of physical impairments, it was revised in 1981 to take into account sensory and intellectual disabilities. Oliver (2004) sees the model as a practical tool rather than a theory or concept, and on this basis emancipation is not about arguing for normality or sameness but a desire for a world 'in which discrimination and injustice are removed' (Barton, 2004:287). Ideally there would be no ignorance, no fear and no stereotypes. Perceptions and definitions would be based on difference rather than disability. This vision clearly aligns itself with autism and echoes the heterogeneity of autistic individuals and the need for them to have a strong identity. Wood (1996:124) argues for this need, 'discovering our identity as

disabled people is very, very important... otherwise people won't value themselves...'. Oliver (2004) sees the model as a way for disabled individuals to think of the barriers faced so that they can be challenged and eventually overcome. He adds a caution though, warning that overzealous use of the model may cause non-disabled individuals to feel guilt over not being disabled, and this of course was never its intention. Reflecting as an autistic, and arguably 'disabled' individual, I confess that there may have been occasions when the act of championing autism and the strengths it can bring with it have tipped perilously close into this forbidden territory.

## **IDENTITY, SELF AND LABELLING**

'Autism' is derived from the Greek word *autos*, meaning self (Frith, 2003:5), combined with 'ism', meaning a state of being (Beardon, 2010). Frith describes autism as a 'withdrawal from the fabric of social life into the self'. Burns (1976, cited in Child 2007:400) offers a definition of 'self concept' that it 'is the individual's percepts, [sic] concepts and evaluations about himself, including the image he feels others have of him and of the person he would like to be, nourished by a diet of personally evaluated environmental experience'. The capacity for reflexivity is a characteristic which gives individuals the ability to reflect on who they are, the way they think, and what others' perception of them is. Since autism is a developmental condition, this self reflection may be affected or changed in some way and as part of the autoethnographic aspect of this study, I shall return to this discussion in Chapter 6.

According to social comparison theory (Festinger, 1954, cited in Crisp and Turner, 2007:14) 'we learn how to define the self by comparing ourselves with those around us'. This theory dictates that beliefs, feelings and behaviours are the result of our own deliberations and are therefore subjective. Indeed Willey (1999:96), a writer and self advocate for autism, has a clear perception of her own circumstances:



I do not wish for a cure to Asperger's Syndrome. What I wish for is a cure for the common ill that pervades too many lives, the ill that makes people compare themselves to a normal which is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach.

I agree with Willey that there is a societal assumption that 'disabled' people want to be something other than who they are. This is not necessarily the case and would mean rejecting their identity. Tollifson, (1997, cited in Swain et al., 2004:38) writes about a turning point in her life 'finally identifying myself (sic) as a disabled person was an enormous healing. It was about recognising, allowing and acknowledging something I had been trying to deny...'

Crisp and Turner (2007:2) describe the self as a fundamental part of an individual, 'a symbolic construct which reflects our consciousness of our own identity'. Like symbols, self is socially created; indeed both are interrelated.

Mead (1967), one of the founding fathers of modern self-theory, gives rise to the notion that self as a social object is different from the psychological definitions of the self. It is not personality, or identity or the individual 'actor'. The concept of self here 'is an object of the actor's own action' (Charon, 2007:72). In this way the self is part of the individual's environment which he acts towards or is part of the situation. This is an interesting concept because it is often the case that individuals with higher functioning autism find themselves 'acting' in social situations, either consciously or often unconsciously, in a way which they might identify will help them to 'fit in' (Grandin and Barron, 2005). Self as a social object will constantly be defined and redefined in social interaction depending upon the social situations encountered day to day. Berger (1963, cited in Charon 2007:73) notes that the self is '...a process, continuously created and recreated in every social situation that one encounters...' Discussing self-perception, Berger, (1963:98), argues Mead's earlier point by writing that 'identity is the naming of that self... identities are socially bestowed, socially maintained, and socially transformed'. Charon (2007:86) notes that 'identities become central to us over time as our interactions reconfirm them over and over'.

Goffman (1959:24) writes about society being organised 'on the principle that any individual who possesses certain social characteristics has a moral right to expect that others will value and treat him in an appropriate way'. This, to me, is a question of ethics for an autistic person's acceptance into society of his autistic traits and unique ways. However, Goffman goes on to write that 'an individual who implicitly or explicitly signifies that he has certain social characteristics ought in fact to be what he claims to be'. Does this then mean that the autistic person who is higher functioning, and has learned to act a social part, would then put a 'moral demand' on others to respond accordingly?

Mead, (1934, cited in Fontana 1995:255) suggests 'we should think of the self as separated into subject and object. 'I' (subject) know about 'me' (object). 'The 'I' is pure awareness, and the 'me' is the things about myself of which I am aware'. Charon (2007) suggests that the 'I' is the side of us that is spontaneous, impulsive, creative and usually out of our hands, but the 'me' is what enables us to control our actions, to make decisions and choices as to how we act. This perhaps contradicts Festinger's social comparison theory (1954, cited in Crisp and Turner, 2007:14).

Mead's description resonates in that my personality, personal image, my experiences and memories and perhaps my feelings and emotions and others' reactions to all these factors, give me a sense of who I am; and my conceptual framework of interpretivism and methodological choices have been made to see how 'who I am' affects my research.

This 'self concept' is also relevant here in that the study focuses on a central issue, that of the relationship between student and teacher and the impact of a teacher's self (personality or teaching methods) onto another person's self (learning of an autistic individual), as well as other areas of Wing's (1996) triad of impairments: communication, language and social issues.

The diagnosis of autism in an individual can be seen in society as a personal tragedy (Smeltzer, 2011), and the media is inundated with individuals and organisations focusing much of their time trying to find a cure or treatment, to make it go away. A person being given the 'label of autism' is, in itself, regularly discussed in education and national debate (Murray, 2008; Kamins, 2011). Many are of the opinion that a 'label of autism' would be stigmatising and would lead to 'low expectations' of the young person. This links to the deviant or 'labelling' theory of Goffman (1990) who discusses the realities of a person being 'labelled', a theory which is embedded in symbolic interactionism, 'emphasising the importance of identity as a sociological concept' (Charon, 2007:215).

There is a school of thought that a correct diagnosis of autism will go a long way to prevent wrongly influencing labels such as, for example, that of being 'bad' or 'aggressive'. Fontana (1995) suggested that labels often influence behaviour and Merton (1957, cited in Charon, 2007:150) agrees that if we wrongly label someone, it can 'actually influence their action and they will eventually become and act according to the label'. A child might be labelled 'slow' or 'stupid' for example, and therefore surely the use of 'autism' is preferable to these negative labels. It will allow people to realise why certain behaviours or characteristics are evident and enable a smoother transition through activities which may otherwise have been impossible with such negativity. There are, however, many parents in particular who hide their child's diagnosis in the hope that the child will be treated in the same way as other children. This is especially prevalent in the social and education environments, ironically two areas where the child may need more help and understanding. Jordan and Powell (1995:6) argue that not making a teacher aware 'of the difficulties engendered by autism... would not result in the child being label-free' since behaviour could be 'misinterpreted as rude or lazy'. They further point out that the child may in fact be given 'a plethora of labels' instead of just one of autism, to 'explain some behaviours'.

Setting the discussion within the context of this research, within informal education it is possible that the informal educator (teacher) may not acknowledge or take

time to learn about a student's individual needs. 'Labels' given previously could well influence the young person's behaviour and expectations and those of the teacher. The impact of the student-teacher relationship is, I would suggest, key to achievement and taking time to get to know the student is essential especially for autistic students. Self esteem may be affected as the student struggles to make sense of a new social situation, and the teacher may well be able to influence how well this is achieved. 'This [may] entail submitting their perceptions to a continuous process of reflection, checking and analysis' (Crosby cited in Deer Richardson and Wolfe, 2001 Eds). Peck (1990, cited in Deer Richardson and Wolfe, 2001:55) calls this 'extending ourselves'; this being a commitment to finding out everything possible to ensuring a good learning experience for a student. An example of this was given by Beale-Ellis (2009) when she spoke about her first experience of teaching a young person with Asperger's Syndrome. Upon finding out his diagnosis, she bought a book about it and did further research so that she could improve her knowledge and in turn impact on his learning. Eventually it led to more young people with autism being helped. She 'extended herself'. Crosby (ibid), goes on to make a very relevant point here, that in order to work with others, teachers need to work with themselves as well in order to stop their 'own desires, beliefs, prejudices, assumptions and needs [clouding their] view of them (others)'. Significant to this and the process of 'extending ourselves' is what Peck (1990, cited in Deer Richardson and Wolfe, 2001:55) calls 'the work of attention' which is working against what may be natural for us to tend to the needs of others.

## **BRIEF OVERVIEW**

In Chapter 2 I explore established literature within the areas of the study, seeking to lay a solid foundation upon which to build the empirical research. This will cover specialist autism literature and that which concentrates on pedagogical aspects as well as more context based literature within informal education. In addition, I shall frame the research by examining theoretical literature within the various relevant topics. Throughout I shall endeavour to seek out any literary gaps which may potentially be filled by the outcome of the research.



Chapter 3 will outline my ontological and epistemological positions and explain how they have influenced my chosen methodologies. It will also include details about the pilot study undertaken prior to this research and how this together with my positionality impacted the decisions made in the research design for this study. Finally, it will highlight the necessity for a pluralistic approach to the research; with the participants being part of two vulnerable groups i.e. autistic and young, a degree of flexibility was essential.

Chapter 4 explains how each phase of data collection was undertaken and issues which arose including those of ethics, along with reflection. In addition it introduces the participants for the more detailed phase two of the research.

Chapter 5 presents the abstracted data within several matrices along with examples of particular cases to demonstrate pertinent points which are based on the research questions.

Chapter 6 is a general discussion around the results of the data, picking out themes and autism related areas. It will include discussion around the methodology, and will also include autoethnographic memoirs and self-reflection by me as a researcher and as an autistic adult.

Finally Chapter 7 will conclude with a summary of the study; recommendations for future research areas and for working with informal educators (teachers) to enable learning experiences for young autistic individuals to be effective and enjoyable.

## **CHAPTER TWO - LITERATURE REVIEW**

This chapter lays out a foundation for my empirical research, and will enable me to set the study within an established body of literature. I propose to search various academic and research areas in an attempt to unravel what has been written about my area of practice and the surrounding significant topics. I further intend to draw on the review to determine the study's natural progression by ascertaining areas which need to be expanded upon as far as possible by my research.<sup>2</sup>

### **DEVELOPING THE LITERATURE REVIEW**

In order to answer the questions outlined in the previous chapter, I shall need to address what kinds of literature need to be reviewed and what boundaries I shall place on the extent of the literature I choose. Without the luxury of limitless time, it would be impossible to read every piece of relevant literature and to engage with every argument and debate within my field of interest both nationally and internationally. I therefore need to plan my search with a systematic and proportionate approach, taking into account conceptual, theoretical and pragmatic dimensions. Methodological dimensions of the study will be discussed in Chapter 3 where they can be explored in more depth. I shall begin by a general sweep of the databases using key topics relevant to my aims and research questions, and attempt to follow to some degree the search parameters outlined by Hart (1998:39), that is, to start with the key authors and research, mapping out a subject 'relevance tree'. I shall also use the technique of cross-classification, as this will allow me to consider or recognise viewpoints of arguments from various angles, thus giving me a richer analysis of the literature. Wright Mills advises to 'know when you ought to read, and when you ought not to' (1967:214) and with the wealth of resources available, this will certainly be at the forefront of my mind as I trawl the literature; additionally following the advice of Coldron during a lecture

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<sup>2</sup> I have already addressed the issue of language and terminology in chapter one but it is anticipated that additional issues may arise during the review of the literature and I recognise this possibility.

(2010), 'when you reach cruise point and nothing new comes to mind, you have read enough'.

I consider it is important during the review of autism based literature that I take into account the author's positionality within it, whether the author is autistic or not, whether the author has personal experience of autism, or whether the author is writing from a purely independent, professional or perhaps theoretical perspective. By doing this I can consider whether the information is relevant simply theoretically or more pragmatically. This becomes important when comparing it with the empirical research – will it help a teacher to recognise effective ways to deliver information, or will it better enable a young person's learning experience? The research brought out issues about the ways in which teachers teach, and therefore the literature review was expanded to take this into consideration.

According to Magnusen (2005:23) teachers who deliver effective training to young people with autism are those 'who can combine theory with practice in a creative, intuitive way'. In order for me to achieve my aims, then, I need to search for the most appropriate theories which can later be put into practice following the research. Premack and Premack (2003: 227) emphasise that 'a theory of education could only be derived from understanding the mind that is to be educated'. Taking this into account then, in order to successfully explore effective pedagogy for young people with autism, it is essential that I first explore the autistic mind.

I shall discuss pedagogy and attempt to work through a number of suggestions of what the term really means. It is agreed though that pedagogy is a complex term with varying views on its meaning and usage (Mortimore, 1999; Norwich and Lewis, 2001; Hall et al., 2008). I shall further focus on pedagogy in context and explore issues around children with autism and the special educational needs which may exist with this condition; pedagogical practice within informal education settings and especially in sport and physical activities; and lastly the important issue of teacher-student relationships, before returning to the premise that theory

is necessary for academic research (Schratz and Walker, 1995; Grix, 2001; Mason, 2002). Thus I shall discuss a number of pedagogical theories I consider to be relevant and how they underpin the contextual issues and challenge common discourses.

I shall also discuss the relevant issues from the extensive, and, to me fascinating topic that is motivation. Rather than search the length and breadth of motivation as a psychologist might, I have elected to look at it from a more educational standpoint as this is far more pertinent here; both with the research topic and it being a professional Doctor of Education thesis as well as being much more manageable in the time available.

## **THE AUTISTIC MIND AND RELATED LITERATURE**

As with neurotypical individuals (also known as the predominant neurotype (Beardon, 2008)) there is an enormous array of traits associated with the autistic person and each is blessed with them to a lesser or greater degree (Furneaux and Roberts, 1979; Jordan, 1999; Peeters and Gillberg, 1999; Ortiz, 2008). I shall concentrate more on the intellectually higher functioning end of the autism spectrum, the end where high functioning autism (HFA) and Asperger's Syndrome (AS) sit, the side where those on the spectrum have at least an average IQ and have had no language delay (Attwood, 1998; Jordan, 1999; Baron-Cohen, 2008). Separately HFA (although not as a distinct subcategory) and Asperger's Syndrome fell under the classification of Pervasive Developmental Disorders, in the Diagnostic and Statistical Manual Disorders (DSM-IV-TR, APA, 2000). In the 2013 fifth edition, Asperger's Syndrome as a distinct diagnostic subcategory was eliminated, although in the years leading up to the change, this was a highly emotive and for some controversial move according to many including Baron-Cohen (2010); Ghaziuddin (2010); Happé (2011); Wing et al. (2011). For the purposes of this thesis and beyond, I shall continue to refer to Asperger's Syndrome as many of the participants have this diagnosis as do I. I acknowledge however, that this diagnostic 'label' may eventually 'fade from the vernacular'



(Hammel and Hourigan, 2013:3). According to Carpenter et al. (2009:30), HFA and Asperger's Syndrome share various common features including social differences, repetitive behaviours and limited interests, but early language development is the differing feature at diagnosis. Language development for children with HFA is usually more delayed although in the longer term the differences are not found to be significant. They do both often differ from the non-autistic (neurotypical) individual however, in that speech may be pedantic, slow and repetitive with an inclination to steer conversations toward them or their special interests, or even to walk away from conversation if they become bored (Bogdashina, 2005); and language may be highly developed in contrast with an almost naive understanding of simple phrases and idioms used in non-autistic conversation. Individuals with autism experience differing levels of language depending upon their ability profiles. One issue is often with receptive language: processing the information causes difficulties and this may impact negatively on the way the individual responds to another. For example, an individual may be part of a group discussion; by the time that individual has processed what is being discussed and tries to find the right words to respond, the conversation has often moved on. Another issue is with expressive language: with a topic of interest, the flow of language can be confident and complex (ibid). If the topic is not of interest, the autistic individual can often be stuck for words, or in my own experience, not even concerned about finding the words. There is often a danger that speech and language are confused when they are used in discussions surrounding autism (Twachtman-Cullen, 1995). With the recent decision to remove the separate Asperger's Syndrome diagnosis, that and HFA may now be closer than ever before.

This being the case, I recognise that there may be merit in bringing into discussion the ways in which other presentations of autism can be compared and how pedagogies may be affected in these circumstances. Central to this study is the juxtaposition of teacher and learner as well as the issue of autism and how it meets with environmental factors such as relationships. It is important then that

autism is not viewed as a completely separate entity but remains embedded within this juxtaposition.

Magnusen (2005:25-26) explains that autism should be seen as a 'dynamic combination and interchange of communication, adaptive behaviour and sensory integration issues' and that certain combinations of these determine 'how a child with autism appears'. I should, however, delve into history and begin my search by looking back to the pioneers of childhood autism, Kanner in 1943 and Asperger in 1944 who each independently published case studies and attempts at theoretical explanations of a condition which saw 'strange children who had in common some fascinating features...seemed to be unable to establish normal relationships with their peers' (Kanner, 1943, cited in Frith, 2003:5). Kanner's key paper focused on a study of 11 children and discusses 'autistic aloneness', 'desire for sameness' and 'islets of ability' (Kanner, 1943, cited in Frith, 2003:6). Asperger (1944, cited in Frith, 2003) offers more detailed descriptions about behavioural and expressive phenomena of his case studies. Both Kanner's and Asperger's autism have similar features, and experts are often divided as to whether they should have separate diagnostic categories although it is mainly agreed that both are variants of the same underlying developmental disorder (Wing, 1996; Frith, 2003). Interestingly, as indicated earlier, both are now under the DSM-V category of *autism spectrum disorder* (American Psychiatric Association, 2013). This term was originally coined by the defining study involving Wing and Gould in the 1970s (Wing and Gould, 1979 cited in Wing, 1996), as was the *triad of impairments* which is used to describe the main areas of difference for a person with autism. The triad included impairments of social interaction, social communication, and social imagination. Wing (a Consultant Psychiatrist) and Gould (a Consultant Clinical Psychologist), subsequently went on to be involved in a plethora of studies and papers (for example Prior et al., 1998; Leekam et al., 2002; Murphy et al., 2005) each looking at aspects of autism, and all cited on a regular basis, as well as a follow up study to their original one (Beadle-Brown et al., 2002). Attwood, also a Clinical Psychologist, has written key texts (1998, 2006, 2008) on autism

and in particular Asperger's Syndrome, his work was my own professional introduction to autism many years ago.

Frith (2003), a Professor of Cognitive Development, is another leading author in this fascinating field. She has a reputation for a deep empathy with the individuals about whom she writes. As well as discussing the issues surrounding autism, she writes about its relationship with history and challenges theories and research in a way which engages the reader and allows a deeper, more compassionate understanding of autism. Happé (1994), once a student of Frith, and now Professor in Cognitive Neuroscience, takes her work in different directions in that, unlike Frith who prefers to concentrate on the cognitive issues surrounding autism, Happé also includes the biological and behavioural aspects, and she has become a very well respected instigator within this field of work. While my own professional or personal interest does not lie in the biological details, it is clearly an area which needs to be understood by many and Happé does an excellent job of discussing this area in an accessible way. (sentence deleted)

There have also been a growing number of authors who have themselves been given a diagnosis of autism and have chosen to study and write about their experiences, to present autobiographic accounts. These have given an entirely different and enlightening view of the autistic mind and although unmistakably accurate in their particular cases, the reader must bear in mind that their views do not necessarily represent the autistic experience in general. Luke Jackson's *Freaks, Geeks and Asperger Syndrome* (2002) which elaborates on behaviours and characteristics that prevail within his family, most of whom are on the autistic spectrum including himself with Asperger's Syndrome is one such text. Another is written about the same family but from the mother's viewpoint (Jackson, 2004). These books are not typically theoretical nor do they involve academic debate, but I would suggest they are equally important to the field of literature as they highlight the issues from an experienced 'user' or practical perspective, and conceivably allow an insider's perspective of the autistic mind. Temple Grandin, whose revolutionary book, *Thinking in Pictures* (2009), has changed many opinions on

how the autistic mind works although not all autistic people think simply in pictures, despite some general opinion. Grandin discusses other ways autistic individuals tend to think; i.e., in patterns and words. She endeavours to put across the message that everyone thinks in different ways, even those with autism. It should never be presumed that autistic individuals are all alike. This underlying message here is fundamental within autism literature, and Grandin is very eloquent in highlighting it. In support of this concept of heterogeneity of autism, a study carried out by Newson et al. (1984, cited in Happé, 1994: no pagination) involved a large group of 'able autistics' and found a great variation in their presentations of autism and underlying differences.

Other texts worth pointing out include Jim Sinclair's essay *Don't Mourn For Us* (Sinclair, 1993), which is a very powerful view of autism, and a not so well known text but to me makes an invaluable contribution, *Women From Another Planet* by a collection of women with autism (Kearns Miller, 2003). This really explores the way these women think, feel and perceive their lives and is an insightful text which adds a wealth of knowledge to the autistic mind debate. In addition it follows an autoethnographic path in a way which inspires others and has informed my own reflexive practice. *Whichever way you look at it, it's still autism*, a DVD produced by autistic advocate Larry Arnold (2006) is also worth mentioning here as it is becoming an important autoethnography in this field. In addition there is a plethora of scholarly and professional journals and magazines which cover this field extensively: *Good Autism Practice*, a Journal founded to disseminate good practice in the UK (Jones and Attfield, 2000-2014) and the *Autism File Global* (Tommey, 1999-2014) are just two which merit a mention.

## **PEDAGOGY**

Before I explore the contextual pedagogical practice currently being used in the field of this study, I must first address the concept of pedagogy and join the continuing debate about its definitions. I believe that without the exploration of pedagogy, the ability to change or develop an educational area may be limited and



this, in my view, is particularly important in the specialist area of special needs' education. With so many educators', sociologists', philosophers' and psychologists' discussions of pedagogy impacting education, this is no easy task but I shall endeavour to draw attention to what I consider fundamental points within the boundaries of this thesis so that these may be built upon during my empirical research and beyond. Drawing on my own experience and philosophy of education, I consider pedagogy to be *the juxtaposition of teaching and learning*. I am strongly of the opinion that teachers learn from their students as much students from their teachers.

In the past there have been quite clear ideas on how one educates students with *special needs* (Swain et al., 2003) and with increased knowledge about many diagnosed conditions as well as advances in diagnosis and treatments in some, and an increasing public awareness of the presentations of conditions such as autism for example, the need to find more effective ways to teach and for students to experience learning continues to grow in importance. In particular the ways in which students, and especially young people, with autism are educated not only impacts on their knowledge and skills but also, and I would argue more importantly, impacts on their social development and consequently their quality of life. I would also put forward the suggestion that informal education sessions are of equal importance to these students as the more formal 'school' education. Most encourage a more relaxed means of socialisation and learning which can create other benefits including for instance: increased confidence, a way of meeting others with similar special interests, sharing experiences, and coming to terms with particular difficulties while finding effective resolutions. In addition as it is a choice whether or not the individual attends the activity, he or she may be more likely to be personally motivated (McLean, 2009).

I shall begin my search of pedagogy with Friere who, forty years ago, first expressed his landmark views about individuals having the right to speak out about their education. Friere (1996:30) makes the point that pedagogy must be '*with*, not *for*' the group to be educated, in his own work with the oppressed. He

viewed pedagogy as a way to become liberated and wrote that 'people educate each other through the mediation of the world' (1996:14). I am particularly drawn to his insistence on positioning educational activity in the lived experience of participants, and the way he recognised the importance of informal educators. I aim to expand Friere's ethos to working with autistic children; exploring their perspectives as co-educators rather than simply students. This is reflected in my chosen methodologies and will further continue with the apparently more recent recognition for pedagogy to be interactive in nature (Murphy, 2008:29). Murphy discusses Shulman's (1987, cited in Murphy, 2008:29) insistence that 'accounts of practice must include the management of students...and the management of ideas within...discourse'. She argues that this may present difficulties for the professional in the classroom. Shulman (ibid) however, points out that this interactive stance advances teacher reform. As a professional myself, I certainly welcome the interactive practice between students and teacher and have no doubt in my mind that this brings with it a new and more effective pedagogy.

More simply Watkins and Mortimore's definition of pedagogy starts from the premise of 'any conscious activity by one person designed to enhance learning in another' (1999:3), although they later suggest that the concept has become more multifarious and give three 'main phases' of understanding needed (3-12): (1) teacher types, (2) teaching contexts, and (3) teaching and learning. In their summary of current views of pedagogy they propose a model where these three phases are related to each other. Watkins and Mortimore's definition has a hint of Friere's influence about it and is a useful, if not simplistic, way to think about pedagogical practice. They also use Bruner's dominant models of learners (1996) as an influence of their focus on teaching and learning. The first of these is how children think and understand; and the second sees children as being knowledgeable. Pramling (1990, cited in Watkins and Mortimore, 1999) builds upon these models by noting that as children learn and become more involved, they will view themselves as active agents in learning, thus increasing their learning still further. I have always seen teaching and learning as a two way process and on reflection of my own professional practice consider that I learn as

much from my students as they do from me. In fact this could be considered a type of action research process where teacher and learner reciprocate and thus the pedagogical process is significantly enhanced by the inevitable continuing learning and adaption cycle. It is essential to good practice that students are actively involved in the pedagogic process and that their opinions and views are taken into serious consideration (Ireson et al., 1999). Alexander (2008:3) notes that 'pedagogy encompasses the performance of teaching together with the theories, beliefs, policies and controversies that inform and shape it', that is, pedagogy is about both teaching and discourse and I would agree that it would be difficult to separate the two as pedagogy must be undoubtedly influenced by underlying experience. Vygotsky (1997) suggested that ideas of education were developed by social formation. Social circumstances are particularly important in his view of pedagogy. Based loosely on the influences of Vygotsky, Popkewitz (1998:536) broadly identifies pedagogy as 'a practice of social administration of the social individual...from which the child can become self-governing and self reliant'. Once again this has the influence of Friere about it. Alexander's definition seems to me to make a lot of sense along with Vygotsky's sociocultural slant to the discussion; together forming a significant contribution to my understanding of this complex concept. Indeed I was increasingly struck by the emphasis on learners being involved, social structure, and underlying interaction and beliefs, all of which have featured within my own philosophy of professional practice. This will be discussed further throughout the thesis.

It is now important that I turn to pedagogy in the context of this study and now aim to explore literature more specifically around the pedagogy of special needs and autism, children and young people, and informal education. I must point out here that much of this discussion is around education as a general concept, and that it relies largely on literature focusing on school-based education. As I concede later in this chapter, there is a distinct lack of literature based within the specific context, i.e. informal education, of this thesis and therefore my review should be taken as a comparable one.

## PEDAGOGY IN CONTEXT

Pan and Frey (2006) imply that young people with autism are unlikely to be successful in integrated activities because of their special needs. However, from personal experience I suggest it may well be these traits which enable them to shine above their non-autistic peers; traits of intense passion, attention to detail and ability to focus (Grandin, 2009). Pan and Frey (2006) frequently consider the social model of disability, and how young autistic people are disadvantaged by the way society reacts to them rather than by their actual autistic characteristics, meaning in some way that society is at fault for the lack of opportunities available. They also convey concern of a lack of qualified and experienced teachers for these young students, also resulting in less availability of programmes aimed at these individuals. Whilst I agree that within many areas of informal education there is a distinct lack of awareness of issues affecting autistic individuals, I am loathe to concede that teachers need to be autism 'experts' in all circumstances. Many teachers of all kinds: those within schools, colleges and universities, and those within informal education have a wealth of experience in teaching students with a myriad of personality traits, behavioural issues, learning preferences, and external issues which affect their learning, and they often have excellent people skills. This powerful combination will often give them the advantage of being able to determine and understand each individual student and adjust their method of teaching appropriately. In fact I am unsure whether any individual can ever become a complete 'expert' in any subject, including autism; subject knowledge is rightly always developing and progressive interpretation of theory must surely be subjective. What happens one day may be out of date the next and this is how learning continues. Falvey (2005) points out the importance of 'believing in children's capacities, highlighting children's strengths, gifts and talents, and assuming children with disabilities are competent' (cited in Melber and Brown, 2008:36). Corbett and Norwich (1999:123-4) go further and write that 'pedagogies can become punitive, destructive and ineffective however, if they overlook individual identity to focus only on the disability rather than the person'.



One key point often debated is whether students with autism should be educated alongside students without autism? Although some may wonder whether the autistic student's presence is likely to cause disruption (Jordan and Powell, 1995) others would argue that the learning experience is actually enhanced for non-autistic students and would certainly increase awareness (Chandler-Olcutt & Kluth, 2009), although it would depend on the subject of the class whether this interpretation of awareness would be helpful in the class context. For example, it would be more valuable in a social studies class than a pottery class, and in physical activity classes it would promote a sense of coming together as a group. Tinning (1997:103) advocates more focus on 'participation discourses' which are 'about inclusion, equity, involvement, enjoyment, social justice, caring, co-operation, movement and so forth'. With the right teacher focus, all students can be encouraged to appreciate that other people matter. Whatever happens, it is equally important that both the non-autistic and the autistic students are not put to any kind of disadvantage and will all benefit from the classes. Jones (2002:40) makes a case for other students learning 'how to relate to someone who was different'.

It is essential for this mixed learning to work in a class of young people then, that the teacher understands the diagnosis of autism and how it might 'affect an individual student's experiences' (Kaweski, 2011:14), although as I argued earlier, not necessarily be an 'expert'. This knowledge and understanding allows a teacher to foresee potential challenges and provide opportunities for support for the student's unique personality profile; the characteristics, behaviours, strengths and weaknesses. Indeed Block (2000:33) reminds us that 'one of the greatest misconceptions of inclusion is that all students must somehow fit into the existing curriculum'. One potential risk here however, is that a teacher with knowledge of autism, takes for granted that all students will have the same differences, the same difficulties and the same needs. This will almost certainly not be the case and could in fact be worse than having no knowledge at all (Magnusen, 2005). Indeed it might be that some teachers with no awareness of autism may consider individual differences in students, the risk here being an incoherent class and

everyone being treated differently. Some special education teachers (for example Solity and Bull, 1987) refute the need for different teaching but advocate 'refinement of similar kinds of teaching' (cited in Corbett and Norwich, 1999:117). Corbett and Norwich however, suggest that this stance denies that children have different educational needs. I would argue that this stance depends wholly on the range of individual needs and requires tacit experience to recognise which pedagogies are more suited to individual students over an extended period of time. It is also important to have a cohesive teaching and learning environment to promote teamwork and peer assisted learning which can be useful as well as reducing a classroom where individuals are made to feel different.

One further point worth acknowledgement here is that to some (e.g. Dowty and Cowlshaw, 2002), home education could be considered under the informal education label, and is a considered alternative for autistic individuals. I would argue that this type of education, while being undertaken in isolation, is still 'formal' in that school curriculum based activities and learning is taking place, usually in preparation for national examinations in the same way as children educated in school. Indeed Lawrence (2012:15) uses the term 'flexischooling', also referred to as home schooling as a method of part time educating an autistic child jointly with school, to enable flexibility. I recognise that other learning activities may be taking place, for example, learning to deal with the complexities of life and autism. Some parents will also choose to follow alternative routes such as Option or Lovaas programmes (Jones, 2002) involving various therapists. Therefore while I acknowledge the importance of home education in this context I shall not be considering this as part of the study.

Although I have already discussed the *autistic mind* to some degree, it is important at this stage, to recognise specific features of autistic thinking or behaviour which may affect pedagogic practice and specific changes in the ways students learn. Powell and Jordan (1997:4) offer the suggestion that 'there are four key interconnected features' to be considered. These are not necessarily negative

'features' but largely different to the neurotypical or non-autistic student and therefore relevant at this juncture.

1. Perception
2. Experiencing the world
3. Memory
4. Emotion

These four features are also discussed by many other writers (Wing, 1996; Peeters and Gillberg, 1999; Sainsbury, 2000; Grandin and Barron 2005; Shore and Rastelli, 2006; Baron-Cohen 2008) in various guises. I shall go into more detail about these four features here as they are important in helping to understand students with autism further and consequently see how pedagogical practice may differ. It is important to recognise however that 'children with autism are as diverse as they are similar' (Magnusen, 2005:11).

The first stage of perception is sensation followed by interpretation and finally comprehension (Bogdashina, 2005). Senses develop as people grow older and in a person with autism these may over develop (hypersensitivity) or under develop (hyposensitivity) (Happé, 1994; Bogdashina, 2005). This may cause a maelstrom of the senses and sensation may be altered and is therefore not necessarily experienced in the same way as others do. In turn, this alters comprehension, thus perception is challenged. Factors such as the environment and its stimuli, other people, or simply the weather are known to affect an autistic person's perception. Inconsistency of perceiving information may change daily, or perhaps even by the minute (Bogdashina, 2006) and may cause sensory overload which to the non-autistic person is not necessarily noticeable. Bogdashina (2010:35) describes the autistic person's senses as 'too open' thus 'incoming information is not filtered or selected'.

...Meanwhile you struggle to filter out the background noise they so easily seem to ignore, processing maybe 50% of what they say...When I appear zoned out in a world of my own...I'm just trying to forage through the thicket of input that overwhelms me...  
(Golubock, 2003:63-71)

The more information which is taken on board, the worse the overload gets. If this overload continues without respite, it may cause excessive anxiety, frustration or anger, and almost certainly will cloud judgement and perception, and also the ability to deal with given situations (Bogdashina, 2010).

Applying this knowledge to pedagogy, for non-autistic students, the shared perceptions are usually central to the learning situation, and therefore from what is known about autistic perception, it is clear that learning may be transformed due to the lack of commonality. This concept of *lack of commonality* also has touches of the social learning discussed earlier and of Vygotsky's theory of sociocultural learning which I shall build upon later in this chapter.

It is not enough to experience the world, but also that we learn from our experiences and consciously put these experiences to use in our futures. Powell and Jordan (1997:6) consider that this '[conscious awareness] is essential if learning is to be transferable and eventually generalisable'. They suggest that the relationship between self and experience is unique in autism (Jordan and Powell, 1995) and therefore does this mean that although autistic students are having the experience they do not necessarily understand it fully and know how to use it meaningfully? Mead (1967:135) argues that 'the self...arises in the process of social experience and activity...' Again the social experience comes into play. Is this yet another hurdle for the autistic student to jump metaphorically speaking? This unique way of experiencing the world is something for teachers to consider when designing lessons and programmes of learning for autistic students and for them to turn into a positive rather than a negative which is habitually the way autism is often viewed (Murray, 2008). Often 'neurotypical society' sadly has a tendency to see autistic differences before appreciating their often outstanding capabilities (Magnusen, 2005). In addition, teachers need to think about the way



the autistic memory works. Individuals with autism learn well by repetition (Furieux, 1979) and therefore rote memory is a benefit which can be capitalised on in the learning situation. Indeed many individuals with autism have an increased ability to memorise large amounts of information and to recall it upon demand (Roth, 2010). This skill is often considered alongside Savant syndrome, which is a rare but extraordinary condition in which individuals with neurological disabilities, including autism, have outstanding skills (Treffert, cited in Happé and Frith, 2010). Stephen Wiltshire is an individual with such prodigious skills; he has the skills to glance at architecture and then later remember every last detail in order to produce phenomenal artistic recreations of them. Other individuals' memory skills lie in mathematics, numbers, or languages. Daniel Tammet is one such individual, able to learn a language in a week, or recite the decimal places of 'pi' to thousands of digits (Tammet, 2006). The shorter term personal memory, however, may be more of a difficulty and need enough reminder cues from the teacher without too much being revealed.

Magnusen (2005:14) insists that teaching autistic students is 'challenging' as they 'are not very predictable' and they tend to be 'consistently inconsistent'; I find this to be delightfully ironic since one particular trait for autistic individuals is that they like routine and things around them to be predictable. The contradiction is significant to this study in supporting the diversity of autism.

Hobson (1986, cited in Harris, 1989) questioned whether autistic children were aware that different non-verbal signals often conveyed the same emotion. After several studies, he concluded that this was indeed the case. Furthermore it is clear that this is not a childhood or developmental phenomena but continues into adulthood (Harris, 1989). So how then does this different perspective of emotional signals affect pedagogy? An autistic student may learn well by rote but 'for learning to be meaningful it has to change to some degree the way in which the learners perceive the world...' (Powell and Jordan, 1997:10). This change requires some kind of reflection on the part of the learner, and the ability to consider the new information in relation to what he or she already knows. They

also suggest that this could be 'why people with autism may have strong emotions but yet be unable to use them to direct their thinking and learning' (Powell and Jordan, 1997:10). It is clear then, that autistic individuals have strong emotions themselves, but because of a supposed lack of ability to read others' emotions from their body and facial expressions, they may struggle to appreciate 'other people's desires, beliefs, and emotions' (Harris, 1989:214) and thus learning may be restricted. I would argue that the student at the intellectually higher functioning end of the autism spectrum would find ways to overcome this 'impairment' of judgement. For example, as a person with Asperger's Syndrome myself, I frequently ask questions, sometimes obvious ones to others, or watch a person almost too carefully, to glean as much information as possible about the person or situation. I have no doubt some individuals find me inquisitive, stupid, annoying or even rude, but my methods work for me and I can not always be concerned about others' opinions, although paradoxically I usually am. Indeed many individuals are so good at copying behaviours that they fool everyone into thinking that is who they really are. People have actually said to me 'but you appear so normal'. What they really mean is you appear to be like us...but does this make me 'normal'? Masilamani (2003:112-113) points out:

people often say, when coming into contact with my personas, that they have never met anyone who understands them as well as I do. They say things like, 'you think or feel exactly like me'...obviously some people are more engaging or interesting for me and this is usually when it happens...

Echopraxic behaviour may be likened to a performance: the performer is asking the audience to believe his reality; he is putting on a show in an attempt to be a part of the situation rather than an outsider looking in. It may be for his own comfort; or as Goffman (1959:28) suggests 'for the benefit of other people'; perhaps to make them feel more comfortable. Transferring this behaviour to the educational situation; a student may put on a show for his classmates if he is feeling alone or exposed; but an effective teacher will be able to see through this and work with the student to make the performance a reality over a period of time.



Building upon the discussion, Koegal and Koegal (1995:2) remind us that 'characteristics of autism vary greatly across children' and not every autistic person will exhibit them all. Simply having autism does not particularly generate a difficulty with learning, rather it is the specific characteristics and behaviours, as well as these four features which may alter the way learning takes place and subsequently have an impact on pedagogical practice. Furthermore there are likely to be cognitive and language ability variants which will also need to be considered for each individual.

Each curriculum area will have its own language and as teachers introduce new concepts, more language ensues. For the child with greater language delays this may cause a problem and even if the child does not have language delay, simple interpretation of new language may cause complications. In addition there is also a tendency for teachers to talk endlessly throughout new tasks, adding comments and additional words, which, to the individual with autism, may make the instruction even more confusing (Jordan and Powell, 1995).

As I have indicated my professional area of education is teaching physical activities including martial arts and dance. These areas can be challenging for students with autism as they involve co-ordination, balance, and motor skills, often lacking in autistic individuals (Coyne and Fullerton, 2004). However for the very same reasons, these activities are of benefit to these students and will teach body, spatial and self awareness as well as social interaction which will teach awareness of the self and of others (Rubio, 2008). Lord (cited in Powell and Jordan, 1997:85) suggests 'the inclusion of activities... which generally enhance levels of development and specifically address some of the problems unique to autism'. These are repetitive activities relying on routine of classes, and structured learning patterns. Often students are dressed similarly and discipline is required to prevent injury and incident. In theory individuals with autism are likely to be suited to these structured activities, but often in reality find it difficult to adapt to such different environments to those they are used to in formal education. Brewster and Coleyshaw (2010:289) consider that this type of education, which they describe as

'leisure activities' 'are likely to offer much less structure, consistency and predictability' and they argue that young people are likely to face more challenges than in school education. However, issues they mention including safety and the need for ample information before making a decision to take part, all help toward making the experience comfortable and rewarding for the young individuals. In my own experience as an autistic individual, even as an adult the same two considerations are at the top of my list of priorities when I take up a new activity; extensive research is carried out and plenty of questions asked before a decision is made.

So then, in order to get the balance right, further investigation of pedagogy in less formal environments is required. Indeed, Lord (1997:79-80) agrees that 'by teaching and developing fundamental skills... children can be given the opportunity to rehearse and develop these in new and different situations'. Green (2008:67) however puts forward the point that 'relatively few disabled youngsters take part in extra-curricular PE' and that this may be explained by more competitive or team sports, for example football or netball, being prominent in extra-curricular or informal education. However the activities I am concerned with are not all team sports, and do not have to be competitive and I would argue are very suitable for children on the autism spectrum, in part for these reasons. Jackson (2002) supports this argument and notes additional benefits of martial arts for example, for individuals on the spectrum. In addition Foley (2003), touches upon ways she has discovered to help her autistic teenage son, and includes Scottish dance and swimming as successful educational activities.

According to Green (2008) a major pedagogic concern for teachers of students with SENs is that of control. More particularly, students with motor learning difficulties are more inclined towards 'social and behavioural difficulties' (Mannisto et al., 2006, cited in Green, 2008:198). A further concern within the physical activity environment is that of assessments and students not being able to satisfy the specific criteria due to motor difficulties. I would argue that this is where informal education in this area succeeds because flexibility of pedagogy is more

easily achieved and assessment can usually be tailored for individuals providing the teacher has sufficient knowledge of autism. Of course the former concern is an area where martial arts in particular excel in that there should be a good deal of emphasis on self control and discipline. Nevertheless it must always be remembered that autistic individuals can be unpredictable in their behaviour and this knowledge must be taken in consideration when classes are planned as I know only too well from personal teaching experience.

My professional area is relatively specialised and much of the literature available concerning pedagogy for autistic children concentrates on practice within formal or traditional education, that is, in schools. Debate continues about the definition of informal education, with those who believe it is simply learning during normal daily life (Coombes and Ahmed, 1974; Jeffs and Smith, 2005), to those who describe it as specific learning projects we seek out for ourselves often related to work (Dale and Bell, 1999), and those who view informal education as being involved in youth or community organisations (Macalister Brew, 1946). I have always considered informal education to be that which is outside the traditional school schedule but involves teachers with relevant qualifications and/or experience. Smith (1999) suggests it is informal simply because of its location. What frustrates me is reading about informal education just happening, and not being something which is planned or organised. I refute this completely and as an informal educator I spend as much time planning sessions, assessing, evaluating and so on as my colleagues who work in formal education. Indeed having previously worked in further education and prison education, I know this to be a solid comparison.

I shall discuss situated learning which is a form of informal learning as it is based in particular and specific situations. There is extensive literature about physical education and autism but again a lot of this is school-based rather than the more informal physical activities which are where my interest lies. Recently there has been research specifically investigating the experiences of autistic children in physical education (Healy et al., 2013) which has similarities, but also is based within the school curriculum. On reflection I concede that my professional area is a

niche which needs to be developed and this finding should have a positive and productive impact on my future empirical research. Indeed my research will allow me to expand this area of knowledge so that individuals with autism can develop and become more confident students and the teachers can offer a more advanced and suitable pedagogy. An expansion of this type of knowledge can be used in other forms of informal education, other physical activities and sports and extend to other environments where it may make a positive difference to lives of these unique individuals. It should also provide a platform for informal educators to prove their worth and, in my experience, gain some much needed respect in the field of education.

There is a danger when discussing pedagogy in this specialised area of education, to be searching for best practice or ideal teaching methods (Jordan and Powell, 1995). Do we concentrate on the child having autism first, or the curriculum or what is being taught? I would put forward that although teachers require some guidance, as I have suggested they must use their own knowledge of autism and individual students as well as their own subject knowledge and experience to blend the two together in harmony. Teachers must use this experience, tacit knowledge and importantly intuition to work against pre-conceived ideas of best or good practice. I argue that there is unlikely to ever be an exact method of what to do and how to do it but ideas of what to consider and how to put these into practice as necessary.

Magnusen (2005:15) wonders to what degree learning and behaviour 'can be shaped by events in the environment' and suggests that if teachers decided that environmental factors did not affect pre-set biological learning capacities, autistic children would be at a disadvantage 'as they would never be capable of overcoming their challenges'. One of these influential environmental factors, and central to this study, is the student/teacher dynamic. How does one affect the other, and do personalities and personal motivation play important roles here? Personality was discussed to some degree in Chapter 1 together with identity, but here I would like to put forward the view that people bring their own tendencies



into a situation which are then adapted by the environment and circumstances, thus causing a change; either temporary or perhaps more permanent (Dweck, 2000). She explores various personality theories which affect an individual's motivation, but seldom mentions how one person can influence or impact another. Instead she focuses on traits, biology, motives, goals, attributes and self; all theories which play their own part in motivation, but I suggest that relationships are also a critical factor to consider here. Dweck (ibid) does however, concede that temperament is no doubt influenced by the environment including parents, peers and teachers; and one wonders whether this is also the case for young autistic individuals who by the definition of their autism, may be prone to anger for example, hyperactivity or excessive anxiety. Do the people around them change their 'biological' tendencies? I hope to demonstrate later in this study that my research has shown that the student/teacher relationship does have an impact although to what degree is yet to be determined.

One example of the impact a teacher may have on a young student is the way that feedback can change self belief. Kamins and Dweck (1999) explored the differences between 'person oriented' and 'process oriented' praise and criticism and found that the two methods taught young people to think differently which then led to different responses to problems. It also suggested that these differences played an influential role in their personalities, and in turn in their motivation. Indeed Gilbert (2002:31) discussing motivation concedes that over praise can lead to a 'child... just doing enough to receive praise and then stops' and recognises that children need to be motivated by internal success and achievement, and by being the best they can be.

Skinner (1993, cited in McLean, 2003:23) believes that teachers always affect student motivation and that they adjust their behaviour based on 'their perception of student response'. Of course this means that a motivated student will undoubtedly draw a more engaged teacher and students who seem less inclined to show an interest are more likely to attract a less than enthusiastic teacher.



These negative cycles may need intervention to change such 'problematic patterns of interactions' (McLean, 2003:24).

Throughout this review thus far, there has been abundant discussion around the reciprocal relationships of both teacher and student and clarity that both play an important part in pedagogy. It is certainly an issue which can be further explored during the empirical research.

I shall now attempt to analyse some pedagogical theories which I consider to be relevant here and hope that they will further be of assistance for me to fulfil the study's aims.

## **PEDAGOGICAL THEORIES AND THEIR IMPORTANCE**

I shall work my way through a number of pedagogical practice theories, some of which have been in use for many years and are deep seated in education, and others which have been used more recently. What they all have in common, however, is their relevance to eventually finding effective ways to teach students with autism. There is also a core social theme running through all of them which I consider to be imperative to this research area for reasons I shall expand upon.

I shall begin my exploration by briefly looking to Bruner who views the function of education 'to enable people, individual human beings, to operate at their fullest potential, to equip them with the tools and the sense of opportunity to use their wits, skills and passions to the fullest' (1996:67). This is how I see my research enabling individuals with autism. So what theories will best allow this to happen?

I alluded earlier in this paper to Vygotsky and his theory of sociocultural learning. One of his central beliefs was the importance of sociocultural factors in 'shaping the situation of a child's development and learning' (Kozulin et al., 2003:2) and he was clear about the magnitude of the role of parents, teachers and peers in developing interaction 'between children and their environments'. He advocates

the use of a *more knowledgeable other* which could be an adult or peer, the key is to have better understanding or higher ability level than the learner (Vygotsky, 1978). If learning for individuals with autism is to be effective, I believe that social skills and social interaction are key elements to achieving this. It is one of the main areas where autistic people struggle (Gutstein, 2003) but from personal experience of teaching physical activities, I fiercely stand by my belief that autistic students can be made to feel more comfortable and that their social skills *can* be improved, not necessarily greatly, but enough to facilitate learning. It is my belief that disability can be seen as a social construction and it seems that Vygotsky had the same view (Gindis, 2003:202-3); that is 'his perception of disability as a sociocultural developmental phenomenon' provides a distinctiveness to his theory. 'Vygotsky argued that a disability is perceived as an *abnormality* only when and if it is introduced into the social context' (ibid). He referred to this as a 'secondary disability', the primary disability being the biological impairment. He was of the opinion that if the secondary disability was not dealt with, it was likely to make the primary disability worse (Gindis, 2003:203). Swain and French (2000, cited in Swain et al., 2003:68) extend the social model of disability to form the affirmative model; this focuses on 'the benefits and positive aspects of being disabled and having an impairment'. They set out to challenge the 'disabling physical and social' barriers they believe cause disability. While they do not specifically cite Vygotsky in relation to this model it is interesting then, that another of Vygotsky's approaches to education of children with special needs was the constant positivity and his predilection for identifying strengths and not weaknesses, which he called 'positive differentiation' (Vygotsky, 1993:30). I am of the belief that this is vital when working with autistic children; they possess many strengths and by utilising these their confidence is built thus creating a more positive learning experience. A fascinating argument for the *benefits* of a disability come from a citation by Shakespeare et al., (1996, cited in Swain et al., 2003:69) who describe a disabled man announcing he felt liberated as society's expectations and requirements are so difficult to satisfy, acceptance of his disability releases him from the pressure. I think I know what he means; my autism allows me to be who I am and not what

society expects me to be. Indeed increasingly there are discussions about ableism rather than disableism (Wolbring, 2008).

It is remarkable that Vygotsky was writing about positive versus negative judgements in relation to special needs some eighty years ago, yet here we are in the 21<sup>st</sup> century still having the same debate and still fighting negative opinion as Swain and French (2000, cited in Swain et al., 2003) attest to. One wonders why, when Vygotsky had such a great impact on special education and according to Gindis (1999) has had a plethora of devoted followers in the last thirty years or so, this has not translated into practice.

On reflection of what was discussed in Chapter 1 about disability versus difference and building upon Lawson's phrase *diff-ability* (2011) it is interesting that Vygotsky was of the same view 'a child whose development is impeded by a defect is not simply a child less developed than his peers but is a child who has developed differently' (Vygotsky, 1993:30). I would suggest that Vygotsky's socially, developmentally, and culturally influenced theories for children with special needs and education generally has been of immense constructive influence on more recent learning theorists and pedagogical practices and many include his theories in their literature (Donaldson, 1978; Lave and Wenger, 1991; Wilde Astington, 1994; Wenger, 1999; Magnusen, 2005; Watkins et al., 2007; Rogoff, 2008).

What is pertinent in the context of this research about Vygotsky's theories is his emphasis on individuality. He encourages us to really think about what our students want and to enquire about their visions. He has a tendency to look at relationships, between language and thought for example, and pedagogy and student development. He also encourages the concept of the ideal teacher asking us to indicate what we want, and need; a role model, someone to pass on knowledge, someone to act as intermediary or facilitator (Kozulin et al., 2003). His theories work well with the autistic mind, the way each student will present differently, and the flexibility needed to suit each of these individuals. In particular his views of disability and special needs are very positive and I believe allow a firm

theoretical frame within which to position a potentially developing pedagogy in the area of informal education and autism.

One Vygotsky influenced practice, that of cooperative learning, allows the students to be at the centre of the learning by working together in structured groups. For this to be successful, individuals need to depend on the rest of the group, take accountability for behaviour, engagement and outcomes, be able to work in close proximity with the other students, and develop interpersonal skills such as listening and decision-making (Dyson et al., 2004). Cohen (1994, cited in Dyson et al., 2004:233) offers this type of group work as 'a strategy for enhancing social and academic development'. Although this approach to pedagogy is extremely useful for developing social interaction, one must proceed with caution when using it with autistic students. Yes, it is a useful tool and allows students to gain confidence working with one another yet remaining autonomous in terms of accountability; but if forced onto the student with no easy way out, it could actually have the reverse effect of making the student less confident and more introverted. Having said that, it is very useful in the pedagogy of physical activities including sport (Dyson et al., 2004) and therefore it is worth a trial.

Dyson et al. (2004:234) maintain that cooperative learning could represent 'legitimate peripheral participation' (LPP) and thus we move to situated learning and the brainchild of Lave and Wenger (1991:29) who 'rescue[d] the idea of apprenticeship' which was discussed in the eighties, and developed it into LPP. A central characteristic of this conceptual framework is that students participate within communities of practice, and for the purposes of this paper, the community of autism and contextually the communities of informal education activities. This participation transforms the new student into a practitioner 'whose changing knowledge, skill, and discourse are part of a developing identity' (Lave and Wenger, 1991:122), that is, the student becomes a more erudite member of that existing community. In order to personify social participation Wenger (1999:5) presents four components which are fundamental in the learning and knowing process:



1. Meaning
2. Practice
3. Community
4. Identity

Meaning is the way we experience our lives and the world around us. Practice is all about learning in action. Community is about belonging to a 'social configuration'. Identity is the way we change through learning. 'These elements are deeply interconnected, and mutually defining' (Wenger, 1999:5). Wenger introduces *communities of practice* as a broad conceptual framework although it also works independently of and with situated learning theory. Participation in social communities is less traditional than formal education. It involves new ways to engage students using methods which will enhance their learning and development as students, and as individuals. They can become inherently involved in the process of pedagogy, contributing when they can, enjoying discussion and then reflecting on their learning to enhance and contribute to their community. While this is an ideal theory of pedagogy and I can see it is far more meaningful for the general population of learner, I wonder whether it will put additional pressure on the autistic learner who may struggle with the underlying premises of this theory which include the assumptions that 'we' (as a society) are social beings, and that knowing is about 'active engagement in the world'. (Wenger, 1999:4). However difficult, I suggest that this notion must be considered as it is critical to the student/teacher relationship. It must be realised however that the success parameters will be different when an autistic student is involved. In my professional experience the ways in which the autistic student engage and contribute will vary, with some enjoying the opportunity to 'have their say' and be a part of the decision making process. Others will prefer to stay back and be told what to do.

As I alluded to earlier, cooperative learning, situated learning and communities of practice are all theories which come under the *sociocultural umbrella* and have in



common social participation, relationships, the setting of activity, and historical change (Brown et al., 1989).

It is perhaps oxymoronic that individuals with autism find difficulties with socialising and social interaction, but that I have chosen to explore theories which have a social essence in order to benefit these same individuals. In my mind in order to find the most effective pedagogic practices for autistic students, or indeed any students, one must prioritise tackling the areas which are most challenging. Returning to the premise of Vygotsky, one can only benefit the primary disability (biological impairment), by dealing with the secondary disability (social context) (Gindis, 2003:203).

## **THE NEXT STEP**

This somewhat whistle-stop search of the literature relevant to my aims and questions, has been frustrating at times. There is a myriad of literature bordering the questions, but literature within the specific field of autism and informal education, or indeed motivation for autistic individuals to seek out of school education has not seemed so clear. Research and literature, it appears, mainly targets school education and even discussions about life outside or beyond school, rarely give it a mention. It is my view that informal education deserves more respect than it often is given credit for. There are some wonderful informal educators who truly change lives. For example, Melanie Coid, a special education dance teacher in New South Wales who runs a dance school specifically for students with a wide range of disabilities including autism (Dance Oolites, 2013). Another teacher, Sue Blaylock in the North of England, has dedicated her life to helping disabled children take up cycling (Keegan, 2011). It is my belief that this less formal but equally valuable arm of education, can play an important role in developing autistic individuals and encouraging them to be more confident and perhaps more social individuals. Personal experience of autism has allowed me to open my mind to the benefits of informal education and leisure activities, both as a teacher, and more recently as a learner of a new activity, namely the art of

fencing. The literature at times (e.g. Phemister, 2005) leads us to believe that traits of autistic individuals may prevent progression, may cause pedagogic 'nightmares' and may lead to withdrawing to the extent that no social interaction is possible. My experiences, professional and personal, allow me to believe that this is not necessarily the case and my empirical research seeks to listen to the 'voices' of those who matter, the young individuals with autism who take part in informal education activities. It will also 'listen' to the teachers of these individuals to get a different perspective, or using the universally known autistic symbol, a different piece of the autistic puzzle. In summary, the empirical research should allow an opportunity, not only to answer my research questions and fulfill my aims; but to start to fill the literature gap which is clearly needed.

The literature has also opened my mind to the possibility of developing a somewhat different model of pedagogy which may be 'at odds' with and would be potentially autonomous in relation to the wider social culture of the formal classroom; by developing an autism specific learning environment where various activities were introduced, and would allow the differences of the autistic student to be developed and enhanced in a positive way without the negative influences of neurotypical society. However this would potentially be a controversial and not necessarily practical or ideal and the empirical research will be critical in evaluating whether this is a viable or even beneficial possibility.

I shall now go onto explain how my chosen methodologies will take the current field of literature and develop any visible gaps to form additional knowledge and potentially new theories or models within this field of autism in relation to informal education.

### **CHAPTER 3 – METHODOLOGY**

As the literature has shown there is clearly a need for further exploration in the area of informal education, and especially how it impacts young autistic individuals and their learning experiences. This chapter will explore my chosen methodologies, how I arrived at the decisions to use these over other available options, and how the study will develop. I propose to outline my pilot study here and explain how this shaped the progression to this research. Furthermore I shall use this opportunity to introduce my ontological and epistemological positions and reflect upon how they might give me data which will enable me to achieve a reliable and effective outcome against my research aims and questions.

As a researcher I resonate with Mason's description of qualitative methodologies, that they 'celebrate richness, depth, nuance, context, multi-dimensionality and complexity' (2002:1) and truly believe that these terms fit well with my research aims and my own epistemology. After trawling through much of the methodology literature, both qualitative and quantitative, I am confident that this study is more at home within the qualitative paradigm as the underlying theme is less about facts and statistics and more about experiences. Indeed Corbin and Strauss (2007: no pagination) discuss qualitative researchers enjoying 'endless possibilities to learn more about people' and furthermore that they want 'the opportunity to connect with [participants] at a human level'. It is crucial for me to connect with my own participants, that is, young autistic students within informal education; and ascertain their perspectives of their learning experiences. In addition I shall seek the views of teachers of such young people as well to bring an additional layer of richness to the data.

I recognise however that as the study develops it may be necessary, especially during the analysis stage, to dip into the quantitative paradigm for useful tools. Much informal education and especially sports related research has historically been quantitative; surveys and questionnaires for example are very common in this area (Recours et al., 2004; Pan, 2009). While sports research is starting to use

ethnography more (Gratton and Jones, 2004; Fitzgerald, 2009), the foray into the disability field continues to lean towards quantitative data, mainly due to the potential challenges and ethical issues with vulnerable communities. Recours et al. (2004) suggests that interpretive studies are mainly concentrated on a smaller scale and infer that the outcome of this is paying little attention to the detail of categories studied. I would argue the opposite however; that by studying fewer cases in more detail, the researcher will achieve a useful set of data which, once categorised and analysed, can then be expanded if this is considered necessary. The benefits of using the qualitative paradigm in this area, thus, outweigh any difficulties, and while complex issues will undoubtedly arise, the additional work involved will ensure that these individuals are heard. I will go further to suggest that this plainly indicates an originality of the research.

Furthermore I aim to demonstrate that by using an adapted version of Clark's Mosaic approach (2004:160) to suit a diverse population that is individuals with autism, I shall enable the 'voices' of children and young people agency by playing 'a central role in revealing their own priorities and interpreting meanings with adults'. This data collection will be competently supported, and indeed complemented, by introducing an autoethnographical element to the thesis, reflecting throughout in a variety of ways. It will include my interpretations from personal experiences as an autistic individual and professional in addition to the critical eye of a researcher. To this end I recognise the need here to keep a necessary level of objectivity which will be essential for effective data analysis throughout the study, if it is to be truly valuable and reliable while still remaining true to my epistemology.

## **QUALITATIVE RESEARCH**

I shall use qualitative research as my research paradigm and outline the reasons for its suitability. In relation to the difference between qualitative and quantitative paradigms Bryman suggests 'there would seem little [to distinguish] other than the fact that quantitative researchers employ measurement and qualitative



researchers do not' (2008:21). Similarly Punch (2005) uses a simplified distinction as quantitative data being numbers and qualitative data not being numbers before moving on to dissect the two designs. The simplicity of these notions does not adequately describe other differences discussed among theorists including the deductive versus inductive generation of data, and ontological and epistemological orientations. Indeed, Ratnesar and Mackenzie (2007) berate the trend to simplify the qualitative-quantitative divide and citing Burns (2000) as an example, suggest the dichotomy of the two research paradigms is not as clear cut as many would have us believe. Newman and Benz (1998, cited in Creswell, 2009) suggest that they represent different ends on a continuum. Many methodologies encompass both paradigms by using the same strategies but in different ways. For example, emancipatory methodology can be both quantitative and qualitative: by using a questionnaire of some sort, different data can be obtained – either statistics or people's views and experiences. This seems to show that there can be flexibility in research design and it does not have to be a choice of one or the other necessarily, although Smith and Heshusios (1986, cited in Robson, 2002:43) argue 'it is now clear that there is a basic incompatibility between the two approaches' and therefore the debate should end so that researchers can get on with their work in their own way. Tashakkori and Teddlie (1998:3-11) note that the qualitative-quantitative debate has become increasingly unproductive and Layder (1992) agrees that it is no longer useful. Perhaps so, but surely researchers should have the right to make the decision of whether both paradigms can work together for their own research rather than being dictated to in a somewhat political manner? I believe Becker (1986, cited in Denzin and Lincoln, 2008:14) has a valid point when he writes about qualitative and quantitative researchers, that they 'think they know something about society worth telling to others, and they use a variety of forms, media and means to communicate their ideas and findings'. Similarly according to Creswell (2009:3), researchers 'increasingly use a theoretical lens or perspective' for their research. These observations bring the debate back to earth and bring about awareness that the research process and the data are the most important factors here and not whether a qualitative or quantitative design is employed. Perhaps it should be about which design best



suits the researcher's epistemological position? Mason (2002:1) writes about exploring a:

wide array of dimensions of the social world including further understanding of those we study, of their experiences and stories of everyday life, the way society see and react to them, relationships and how these affect us, and the significance of the meanings they generate.

Her position resonates with me in relation to my research with young autistic students. The students are individuals with their own ways, their own views of the context in which they live and learn, and their own experiences which they can bring to the research. The resulting reactions, interactions and relationships are what make the research exciting and interesting for me.

In undertaking this study I shall need to consider that the understanding and experience young people have of the world is different to that of adults and the ways in which they communicate their views and experiences may be challenging (Prout and James, 2007; O'Kane, 2008). In addition there is the further challenge of them being autistic and since an understanding of the world and communication are two of the main differences between those with and those without autism (Wing, 1996; Jordan, 1999; Frith, 2003) this challenge consequently becomes much greater. It is interesting how views of research around autism and indeed disability have changed over the years; it seems to me that as the years have gone by we, as a society, have realised that these individuals have more rights than perhaps previously where a child with low functioning autism might be locked away into an institution for most of his or her life. Goffman (1974) may be considered an instigator for using ethnography to research these unfortunately ostracised individuals.

Thirty years ago, Boucher and Scarth (1977), emphasised that for research concerning children with autism to be reliable, it needed to concentrate on groups of autistic children as a whole rather than individual cases. Moreover they suggest research was more about what could be observed, rather than on what the

children's own experiences and thoughts were (e.g. Cowan et al., 1965, cited in Boucher and Scarth, 1977:147). In addition, to guarantee reliability, it was expected that the same research be carried out by many different researchers on many different groups of children. It was very much quantitative rather than qualitative research. Similarly in the environment of sport, since the 1940's, much research on disabled athletes has been positioned 'within a positivist paradigm and adopts quantitative methods of data collection' (Fitzgerald, 2009:147). In contrast she poses the question 'how can we ensure the experiences and views of young disabled people are captured within youth sport research in ways that reflect and recognise their social agency?' (Fitzgerald, 2009:149). Her experience shows that many researchers assume that young people with disabilities, possibly including those on the autism spectrum, are not capable of being included in research. Fortunately there are many instances where this is not the case and in particular participatory approaches are being used increasingly (Mertens and McLaughlin, 2004; Christensen and James, 2008; Goodley, 2011).

## **POSITIONALITY**

I am already a part of the community of participants, albeit not in the same age group; this of course gives me a personal interest in the study topic, and a resulting desire to bring about positive changes, which according to Clough and Nutbrown (2007) is ultimately a common goal for most researchers. I must take into account my own position, that of being a professional working in the field but also an autistic adult and to this end I shall indulge in autoethnography and self-reflection as a critical methodology throughout the thesis.

Epistemologically I shall reject positivist approaches and explore the concept of interpretivism which has, for the past forty years, been seen by many as an alternative to the positivist view that life needs to be defined in measurable terms and 'can exclude choice, experience, individuality and moral responsibility' (Cohen et al., 2007:18). There is also an ontological distinction between objectivity and subjectivity and according to Searle (1995) it is crucial that both ontological and

epistemological senses of the distinction are considered. While positivism purports to give structure and quantification, as a researcher in the field of autism I need to remember that positivism denotes human behaviour as passive and thereby does not take into account individualism which, when researching around young people with autism, is imperative. Baron-Cohen (2008) indicates that autism is a spectrum of behaviours, traits, and characteristics, and each individual has any number and combination of these; and I discussed in Chapter 2 the heterogeneity of autistic individuals. Positivism also fails to take account of our ability to interpret our own experiences (Giddens, 1976). I would not go as far as agreeing with Byrne's view (cited in Robson, 2002:26) that 'positivism is dead. By now it has gone off and is beginning to smell'; but the view, if not the expression of it, seems to be widely accepted as a grounding for research, especially social research. Indeed surely there would be no post-positivism if positivism were suitable for all research? For instance post-positivists accept that the experience, tacit knowledge, values and so on, may influence what is observed although they also argue that there is still a commitment to objectivity albeit recognising that bias may be likely (Robson, 2002).

Interpretivism has history in Weber's approach to social science as an 'interpretive understanding [what he called 'Verstehen'] of social action in order to arrive at a causal explanation of its course and effects' (1947:88) as well as being influenced by phenomenology which is about individuals making sense of the world around them and not conceding to any preconceptions (Bryman, 2008). Schutz, influenced by, amongst others, Weber, has made clear his position:

the observational field of the social scientist – social reality – has a specific meaning and relevance structure for the beings living, acting, and thinking within it. By a series of common-sense constructs they have pre-selected and pre-interpreted this world which they experience as the reality of their daily lives.....

Schutz (1962, cited in Bryman, 2008:16).

It is the researcher's role to listen to what participants say and to see the social world from their point of view. A further influence of interpretivism is the theoretical

tradition of the Chicago School; symbolic interactionism, a term coined and further developed by Blumer (1986). Symbolic interactionists maintain that during interaction, an individual continually interprets the symbolic meanings of what is around him including the actions of others and uses these meanings to act further. Blumer sees 'meanings' as a symbolic interactionist as 'social products... [resulting from] the defining activities of people as they interact' (1986:5). However, the crucial element to these results is that people go through a 'process of interpretation' of the meanings in order to reach the end products, and do not simply take already established meanings as the truth. This process involves engaging in some self-interaction. I shall return to this premise during my discussion of autoethnography. For now I wish to merely note that for autistic people this self-communication and self-interaction is likely to be something which happens naturally. Because of the difficulties with communication with others, in my experience, there is a tendency for autistic people to internally rehearse words and interpret other's words and meanings, before opening up to others or going public with opinions and actions. However, this also means that interaction where one individual responds to another or 'in relation to one another' (Blumer, 1986:7) in the formation of a 'society' may be more demanding for those with autism. In order for a person with autism to engage in this theoretical perspective of society, the *symbol* needs to be understood in terms of symbolic communication which, according to Mead (cited in Charon, 2007:111), is about sharing messages with others, 'intentionally and meaningfully', that is the symbols are understood by both parties. The potential issue for a person with autism is one of different sensory processing (Grandin and Barron, 2005) and particularly if the communication is with a non-autistic person, a lack of shared understanding is common.

Epistemologically, using an interpretive stance for research is a triple process: 'the researcher is providing an interpretation of other's interpretations... [and these] have to be further interpreted in terms of the concepts, theories, and literature of a discipline' (Bryman, 2008:17). This latter stage of interpretation, brings into play the inductive strategy of developing theory from data, influenced by grounded theory as many qualitative research methodologies are (Corbin and Strauss,



2007). It should be mentioned here that grounded theory was considered for this study. Although the phases of my methodology built layers of data, rather than snowballing from each other as data was produced, my phases were all conducted concurrently. There were similarities however that the data created emerging themes.

Constructivism is the ontological position which I consider to be closely aligned to my research and which is often seen as a joint paradigm with interpretivism (Mertens, 1998). It implies that social phenomena and their meanings are produced through social interaction and are constantly being revised; that the researcher presents her own 'constructions' of social reality (Grix, 2001; Smith, 2010). Many social phenomena are considered to be social constructions. Of relevance to this study 'childhood' for instance (Prout and James, 2007:1) and 'sport' (Smith, 2010:1) are both considered social constructions. It was also discussed in Chapter 1 the possibility of 'disability' being a social construction, as considered by some including Green (2008). This would support the premise of the social model of disability.

Constructivism places great importance on the values of the researcher. I value the benefits of teaching sport and physical activities to young people with autism. It is important to me as a researcher, and indeed as a person with autism being involved in these areas, that I utilise academic research and find the methodologies best suited to gaining the most valuable data in order for me, and the young people concerned in the research, to gain the most benefit both in the short term and even more importantly I believe in the long term.

Constructivism grew out of hermeneutics 'which is the study of interpretive understanding or meaning' (Mertens, 1998:11) and Habermas who is a major influence of hermeneutics formed his 'communicative action' which 'relies on a co-operative process of interpretation in which participants relate simultaneously to something in the objective, the social and subjective worlds...' (1989:120). Speaker (participant) and hearer (researcher) may use these three worlds to discover their



common definitions. Their mutual understanding is the 'intersubjective recognition of validity'. Guba and Lincoln (1989, cited in Mertens, 1998:14) on hermeneutics, note that it is important to identify multiple perspectives from the participants, in order to get more reliable interpretations of meanings and then for the researcher to compare and contrast by amalgamating the various ideas, and then 'forcing reconsideration of previous positions'.

## **METHOD AND METHODOLOGIES**

With my research focusing on the learning experiences of young students including interactions between student, teacher and peers, it is clear to me that methods involving field work and working closely with the students themselves play an important role in the data collection. Indeed, in order to get the most accurate picture, using the normal learning environment is crucial to ensure reliability and validity of data, especially since these students are likely to be vulnerable, both in age and learning needs, and taking them out of their usual environment may prove stressful and potentially difficult. For example, in researching social interaction between young people, it may be less likely that they would be able to accurately describe how they interact, in addition to the fact that they are also autistic, and may find it difficult to put what they are thinking or feeling into the correct words. Mayall (2008:110) makes an even stronger point that 'much research... has been carried out... based on the assumption that children, compared to adults, are incompetent, unreliable and developmentally incomplete'. Also 'as an unobtrusive researcher, [I] would be less likely to influence their behaviour in any way' (Gratton and Jones, 2004:160-161). As a researcher with autism, I really wanted very much to be part of the research process, rather than looking in from outside but I must prioritise the needs of the students first and foremost and do what will be better for them. This has been a contentious issue throughout the planning of this study, but after much debate and research, and consultation with the students, teachers and parents, a conclusion was reached that methods must be flexible enough to allow for differences in student reactions to situations. At the start of the empirical research stage, it was

clear that some students were not happy to participate with just one method as it did not suit them, so the need for additional methods was necessary on a practical level as well as to ensure robust and valid data.

Traditional research on 'disability', generally underpinned by the individual model of disability, treated those being researched as 'objects' (Barnes et al., 1999:217). Oliver (2009:108) outlines three reasons why previous disability research has failed: firstly it does not reflect the experiences of the disabled people from their perspective with any accuracy; secondly it has not contributed to policy making, thus improving lives; and thirdly it has not recognised that disability can be a political issue. All approaches to disability research, I am sure, will contribute to the knowledge and insight of disability issues, perhaps more so in circumstances where research is mainly for medical or rehabilitation purposes. However, I am confident that it is not ideal for this study. It must be remembered that while traditional research methods may work in informal education, more flexibility is needed here. For example, in my experience spectators are usually found in perhaps eighty percent of informal education activities' classes.

With my research involving young people from the age of five years I also have to consider other issues. For instance, I need to construct any questions carefully – for example, to take into consideration how they are worded and eliminate underlying meanings. How will I understand a child's experiences? Will the child's view of his experiences be part of a socially constructed ideal, one constructed by adults, and therefore how valuable will it be? Add to this the fact that the young person has autism and my considerations increase again. However, what is clear to me is that the research needs to be *with* the participants and not *on* them. I need to be able to hear the voices of the young people as they tell the stories of their own lives. The research approach I have chosen is crucial to how effectively this will come about and how I interact with them in a meaningful way. It is my responsibility to pay attention to their practice, language and attitudes, and to be conscious of myself as an adult, as an adult with autism and as a researcher. By working alongside these young people, it will be easier to really listen to them and

to represent their voice later on. Reflexivity, a key component to the process of this representation, is a dual process and it will be a position taken by the young people who take part in the research as well as by me. It is likely that the young people will be conscious of the importance of their part in the research and as a result will want to do their best when reflecting on their experiences (Christensen and James, 2008). In order to keep the dialogue open it is essential to form good relationships with the young people so that they will trust me with what they say and want to continue to participate throughout the process. One more issue to consider as the young people have autism, is that they may not all be able to communicate well verbally, and I may need to have ready other options for communication. For instance, a child may not speak fluently or be able to understand the way I am asking a question and therefore I need to be prepared with alternatives. When I am looking at interactions between student and teacher, for example, the use of photographs and pictures may prove valuable as they are able to capture expressions which might reveal more than simply words. By using a varied and flexible approach which, depending upon the participating student, includes observation, interview, the 'diary' method and the 'secret box' for both students and teachers; I am allowing myself an opportunity to gather rich and beneficial data and allowing the students to have a 'voice' in their preferred way without pressure or limitations. The use of the online 'walls' will additionally encourage a more global and free 'voice' where autistic individuals of all ages can share their experiences and their ideals. While this approach may be more complex to analyse, I believe it is worth the effort, to gain such data which in time will be more of high value.

Additionally by encouraging the 'voice' of autism more globally to gain a further insight into learning experiences within informal education throughout the generations, and in different countries and cultures, a more widespread perspective prevails. This information can then be built upon with more localised research as outlined.

I plan to shelve generational and status differences in an endeavour to understand the young people's (participants') views and experiences of their learning experiences. It is important that this will involve, among other methods, observation of the young people and encouraging them to engage with each other and with me to see first hand how learning and interactions within that learning manifest, in addition to how these experiences alter according to the environment they are in. Young people with autism enjoy structure, in fact need structure, a point made by Peeters and Gillberg that the 'chaotic inner experience of a child with autism...needs...a very clear and predictable environment' (1999:49), and structural influences are likely to affect their interactions.

Recent developments in disability research have taken two divergent trajectories: emancipatory research and participatory (interpretive) research (French and Swain, 1997; Goodley, 2011); and in order to select the most effective methodology for this study I have considered the principles behind each and how they might work for me before moving onto other options which may be useful in the field of autism and with young people. I have also considered why and how autoethnography will be used in the study, both from my perspective as an adult with autism, and from the young people's perspectives, by revealing their own 'stories' and letting their voices be heard. I must bear in mind during this exploration that all research methodologies are imperfect and have limitations, and adaptations are likely to be necessary to be suitable for my research needs.

### **Emancipatory and Participatory**

I shall discuss the merits of using both emancipatory and participatory methodologies within the same sub-heading rather than as separate entities as they are both discussed within disability research and they share many common characteristics, despite having very different social and historical roots. Emancipatory research's roots are within the development of the social disability model and the belief that a 'disability is socially created by... barriers which exist within society' (French and Swain, 1997:26). Its main premise is that the research



should be controlled by the participants from the development of the questions to the analysis of the data and the production of the conclusions (Turmusani, 2004), and that it tends to be politically motivated. Participatory research 'challenged the controlling assumptions of traditional research and its role in reinforcing the dominant interests in society' (Ledwith and Springett, 2010:22) and was largely shaped by Freire's influential work *Pedagogy of the Oppressed* which had an instantaneous impact, in the seventies, on how oppression was understood. It has developed from the qualitative research paradigm by researchers who are keen to change the usual hierarchy between researchers and those being researched. It is more about letting participants tell their stories, their views, their feelings, and their life experiences. Zarb (1992, cited in French and Swain, 1997:27), is optimistic about participatory methodology although emphasises that participants still need to be involved in the 'design, conduct and evaluation of the research' and that researchers should be answerable to them, i.e., work *with* them. Oliver (1997:25) argues that participatory research may be used to resolve the difficulty that 'research can only be judged emancipatory after the events...one can only engage as a researcher with those seeking to emancipate themselves'. There is concern that participatory research emphasises existing struggles of oppressed groups rather than seeking to change and improve upon them. Abberley (1992, cited in French and Swain, 1997) believes that the cause of oppression for most disability research is the individuals' view 'that the problems they experience spring from their own inadequacies'. My research is concerned with seeking out individuals' perspectives on their learning experiences including their motivation, teacher/student relationships, and other influencing factors. I do not see this research data as a way to change policies necessarily but to develop a different pedagogical strategy in an attempt to improve the learning experience and consequently improve the quality of life for these young students including but not limited to the participants.

I see my epistemological position to be individualistic and therefore my chosen methods should be to use the most effective ways to collect my data to achieve these goals. This may be by using me as a 'research instrument' as it is for Pahl



(1995:14-15). He takes the view that his research 'is as much about my own life as it is of others', a view shared by Clough (1995, cited in Oliver, 1997). However I must agree with Oliver (1997:28) that we must study our research practice in the context of current 'oppressive social and material relations of research production' and this is why I am examining more than one method before making choices.

The emancipatory research paradigm is mainly associated with disability although it can be used with other groups where there are generally socio-political issues, for example, homosexual or racial groups, populations that have been traditionally marginalised. A fundamental purpose is to create opportunities for the researcher together with people within the groups to engage in social action (Robson, 2002) for positive change, mainly by removal of barriers and by empowerment especially for the groups (Barnes, 2003). Some key characteristics of the emancipatory paradigm, in addition to its expansion from the social model of disability are: accountability, empowerment and dissemination of the outcomes, choice of methods, and the need for rigor (French and Swain, 1997; Barnes, 2003; Oliver, 2007; Hodge, 2008).

Accountability is a consideration which raises concerns for social research (Barnes, 2003), the most important being accountability of the researcher to the participants (in this case autistic individuals) and their organisations (for example, the National Autistic Society). A researcher could never be accountable to the entire population of autistic people, nor the supposedly vast number of undiagnosed people (Baron-Cohen and Scott, 2009) or taking into account those who may have a different perspective on whether autism is a disability.

There is also the issue of who should carry out research with such socio-groups. Writing about how his personal experiences influenced his professional thinking, Oliver (2009:16) notes that 'if disabled people left it to others to write about disability, we would inevitably end up with inaccurate and distorted accounts of our experiences...'. There has been much debate about the disabled versus non-disabled disability researcher (Swain et al., 2003; Barnes et al., 1999;

Fitzgerald, 2009; Oliver, 2009). Goodley (2011:25) asks the question 'can you carry out disability research if you are not disabled'? While the positivist would almost certainly answer yes to this question on the basis that research should be completely objective so as to measure reliability and repeatability, epistemologically the interpretivist may have a different perspective. Indeed he might suggest that research relating to groups such as those with autism, most definitely should be carried out by a researcher who identifies with their differences, experiences and potential difficulties. Aspis (1997, cited in Goodley, 2011:27) is very 'outspoken' in her argument for research on people with learning difficulties to be carried out by researchers 'with intellectual disabilities'. However in contrast Barnes (2003:8) makes a valid point that 'having a designated impairment does not automatically give someone an affinity with people with similar conditions or disabled people generally'. My own position as a researcher then, while seeming an advantage, may be considered a liability, and I must therefore take steps to ensure transparency of my research process, data analysis, and presentation of the outcomes. In order for this to happen I need to be clear at the outset where I stand ontologically and epistemologically and I have already discussed this. It is important that the choice of methods used within the emancipatory paradigm is 'logical, rigorous and open to scrutiny' (Barnes, 1992, cited in Barnes, 2003:11-12).

Theoretically, emancipatory research has a potential weakness in that it is more concerned with political engagement and may not be as concerned with experience and the feelings of the participants during the process (Turmusani, 2004). One further drawback to this type of research, is that by politicising the research findings, there may be a tendency to over-marginalise the groups and force more disability issues on society thus creating 'a feeling of resentment among members of the public towards disabled people' (Turmusani, 2004:6).

It has become very clear that emancipatory research, while having many of the characteristics of suitability for my research, is unsuitable as it is, mainly because of the emphasis on relinquishing power to the supposed oppressed group; in this

case autistic individuals, although once again this remains contentious. While it is important for me to include the participants in the research and for them to benefit from the outcomes, the political or power issue is not so relevant here.

Reason and Heron (1986, cited in French and Swain, 1997) trust that participatory research invites people to 'participate in the co-creation of knowledge about themselves'. I shall identify the main differences between the emancipatory and participatory paradigms. The first issue relates to empowerment. Whereas emancipatory researchers will allow full empowerment over the research process from design to dissemination of results, the participatory researcher will not give full control and the participants whilst fully involved in the research process, are unlikely to have empowerment over the entire production from start to finish. The second issue is the deciding factor for the research. The emancipatory researcher might allow the participant group to make the decision about what needs to be researched as they are the 'experts' in the field whereas participatory research is usually decided externally, whether locally, nationally, or even as an international issue needing investigation. A third difference relates to the role of the researcher in that an emancipatory researcher's role is more neutral than the participatory researcher allowing the participants to be the experts of the research process.

Both methodologies incorporate similar data collection methods using the researcher as a facilitator rather than having complete control, and both encourage participation of those being researched. They use methods based on everyday narratives allowing participants to have a voice through a variety of mediums including dialogue, poetry, photographs, stories and drawings. Inspired by these two types of research and bringing them together under the title of 'Inclusive Research', Walmsley and Johnson (2003) use this 'new methodology' to research learning disabilities. Principles within this methodology dictate: 'the research problem must be owned by disabled people'; 'it should further the interests of disabled people'; 'it should be collaborative'; 'people with learning disabilities should be able to exert some control over the research'; and the 'research question, process and reports must be accessible to them' (2003:64). I

had first thought that inclusive research might be the way forward for this study, but on further reflection, it seems that this is more a collaboration of other qualitative methodologies bringing out the best in each, an example of methodological pluralism.

As a researcher, using any of these methodologies, I must be aware that there are many ethical dilemmas likely to surface. Young people with autism may be particularly vulnerable, especially if their communication skills are lower than the norm, and I shall need to create a safe environment for any one-to-one research, for example, an interview. This can also be a potential ethical dilemma in itself as it can put both me, as the researcher, and the participant in a vulnerable position. The use of parents or other trustworthy adults as 'chaperones' may be necessary but then will the young person open up and express themselves as freely as they might otherwise? With my research in part looking into interactions I also need to think carefully about the interaction between researcher and young person. Christensen (2004:172) outlines implications of being an adult studying children, emphasising incidents of 'being let-in on secrets, particular games...are of crucial value for developing understanding and give rise to new insight...'. Ethical values such as confidentiality and trust are vital when forming relationships with children. These ethical issues and potential dilemmas, especially when the research includes autistic children, give rise to the notion that participant observation may be deemed inappropriate by some, while working in the 'field' may be a better option, and give more accurate data, which may then be used in conjunction with interview data.

Therefore I shall now explore a third option of ethnography incorporating autoethnography which builds on previously mentioned notion of myself as a potential 'research instrument' and again following the 'disabled versus non-disabled researcher debate'.



## **Ethnography and Autoethnography**

Ethnography usually describes and interprets a social group or culture (Ellis, 2004). The research takes place in a natural setting over a long period of time by the researcher who aims to become an accepted member of that social group. The crucial point is that 'the researcher is fully immersed in the day-to-day lives of the people being studied' (Robson, 2002:187). Sport has its own culture and 'to this end, ethnography is well suited for investigating sporting cultures acted out on real-life settings' (Smith, 2010:9). Research questions and foci will emerge and develop as the research progresses. In the symbolic interactionist tradition, Blumer (1986) discusses using ethnography to dig deeper into a community to uncover the truth and Goffman, a key figure in the field of social interaction is famed for using ethnography widely in his work (1967; 1974). Ethnography is closely aligned with anthropology where humans are studied in their own community. In simplistic terms, within this study the social group is that of young autistic students, and their community is that of one or more specific informal education activities, for example gymnastics. Much ethnography takes place over many years (Robson, 2002; Alvesson and Sköldbberg, 2009). However for this particular study, and because I am a researcher within both the group and the community of informal education, and have also been a student in the same environment, a shorter period of time may be feasible, since I would have knowledge of the general context of the study. This is known as micro-ethnography (Bryman, 2008). Strength of ethnography may be that it offers a chance to gather richer and more substantial data as the variety of what can be used is greater; and the researcher is right there with the participants and can modify the collection methods as the research progresses as necessary. The researcher should also get to know the community well and in return the participants are likely to be more open and honest as the process moves on. Goffman points out that 'any group of persons... develop a life of their own that becomes meaningful, reasonable and normal once you get close to it' (1961, cited in Punch 2005:152). The ethnographic researcher must unearth the meaning, while remaining sensitive to the insider's perspective. It takes time to access the



deeper and more significant levels of the perspectives. It is also important that ethnography uses an eclectic mix of flexible methods especially since the participants are young autistic individuals. There may be particular issues either because they are young, because they have autism, or both, which may affect how the process progresses, and it is imperative that there is flexibility to change direction if this is what is required.

One potential weakness in this type of ethnography is that the researcher becomes so involved with the group or community that the researcher may 'go native' (Robson, 2002:187) and perhaps move 'from the role of researcher to that of advocate' (ibid). Although this latter idea is potentially a weakness of traditional ethnography, it might be argued that this premise, in some way, describes the concept of autoethnography and Ellis (2004:38) refers to David Hayano as the 'originator of the term' at least two decades ago in his discussion of 'going native'. That said, however, in this traditional ethnography it is essential that I manage to be 'objectively subjective' (Gratton and Jones, 2009:187) about assessing any conflict between my role as participant and researcher. I can never become a full participant due to me being an adult within a young person's class environment so that should go some way towards solving this conflict. A further potential problem is the ability to gain access to a particular setting (Hammersley and Atkinson, 1995) although my professional position within informal education, outside that of being a researcher, will go a long way to gaining me access.

Ethnography is valuable for research concerning children as it allows for them to be heard and to participate in the production of data. According to Mayall (2008:110) 'a central characteristic of adults is that they have power over children', although I would argue that in the case of adults working alongside children with autism this is not necessarily the case. The children may be, certainly at some level, 'experts' in the condition, or at least in their own experience of it and therefore does this not make them somewhat powerful? Christensen (2004:165-166) agrees that 'issues of power, voice and representation have been central to discussions of children's participation in social and political life' and that these

issues are 'reflected in the growing methodological literature on research with children' (Veale, 2005; Greig et al., 2007; Curran and Runswick-Cole, 2013). By taking an ethnographic approach to research with young people, the researcher is able to observe and interact with them within an environment in which they feel comfortable, thus being more likely to collect valid and reliable data, which according to Gratton and Jones (2004:85) are 'key concepts by which the quality of research is assessed'. Power is not so much about 'adult' and 'child' but more about the 'social representations of these' (Christensen, 2004:167). Such positions will have to be negotiated within the particular groups of young people who take part in my research and these positions will no doubt change as the research progresses and relationships become more established. I intend to 'draw on the views of one group [the young students with autism] in order to stimulate the thinking of others [teachers and instructors]' as suggested by Fitzgerald (2009:150). There is an issue with autistic individuals that their *self* can often be influenced by the actions and words of others; if I were to use methods such as group interviews or forums, their perceptions may be unreliable. Paradoxically many have strong rigidity in their opinions and therefore may be very focused and unmoving with their views. This paradox has methodological implications, and necessitates a multi method approach to facilitate the range of needs. It is essential that I consider this as the data is collected and analysed.

Methodologies may be modified through the research experience as a result of these relationships, of entering their lives and becoming more familiar with the young people's understanding. Although I may remember my own childhood, I will have forgotten a great deal. At that time I was unaware I had autism and therefore perhaps accepted any difficulties I may have had and seen them as the norm. Childhoods vary and have no doubt changed in the past few decades, and the greater awareness of autism will probably have had an impact on the young people now as well. This said, for me the use of autoethnography as a methodology for my study is an inspiring concept and one which will potentially bring an additional layer of richness to the data, both from me as an autistic adult and the young participants. Ellis (2004) describes two forms of autoethnography;

one as a form of autobiography and another as an interpretive or narrative ethnography, where the researcher studies a group or culture and utilises own experience within the culture. Reflexivity is used to study interactions between researcher and participants at a deeper level and also the self-interaction discussed earlier within the symbolic interaction framework. The reflexion of the ethnographer's lens moves from focusing on the others' social and cultural experiences; to looking inward 'exposing a vulnerable self that is moved by and may move through, refract and resist cultural interpretations'. As the lens moves from one to the other, the boundaries 'between personal and cultural become blurred' and thus we have a genre which keeps the 'boundaries blurred and inclusive' (Ellis, 2004:37-39). I find this idea fascinating and one which would incorporate me as the researcher with autism working with the autistic students, both within informal education. A diagnosis of autism is often a 'climactic moment' in a person's life 'and becomes a turning point in his or her personal development' (Brown, 2010:205). Others in these circumstances have written autobiographies (Grandin, 1986; Williams, 1992; Willey, 1999). The students taking part in the study can also form their own autoethnographies as they tell me their stories.

## **PILOT STUDY**

As a consequence of this exploration of methodology the pilot study was based upon two of my research questions: 1. what part does personal motivation play in effective learning for the young student with autism? 2. how does the relationship between student and teacher affect the learning? It contained three young people aged 9-12, who were interviewed once each in a semi-structured way and observed once in a typical class activity. The interviews used a variety of elicitation techniques including games, drawings and traditional questions and were selected based on age, comfort and needs of the young student. I chose to vary the order in which interviews and observations were carried out, i.e., using the interview data to make observations, and using what I observed as a basis for interview. Alternatives to these methods considered were a longitudinal study concentrating for a longer period of time on three students, and the use of video

diaries following learning sessions. I decided that due to the limited time to undertake this pilot study<sup>3</sup>, neither method was suitable as both required a longer research period. Ethical issues were considered and resolved, for example, informed consent and confidentiality. Another issue for this pilot study was a potential power issue, that being the researcher and in most cases the teacher as well. Although I concluded that this had not affected the data, I made the decision to separate the two for this study as far as possible. I was aware that due to the participants being young and autistic, communication may be problematic, and this was the main reason I wanted to pilot interviews as a method in advance of this main study. This problematic communication may have also applied to me as an autistic adult and I wanted to be sure I felt comfortable in the one to one situation.

Both interviews and observations were recorded, so as not to miss any important detail, and to allow easier transcription and analysis. This proved to be very useful, especially in the interview situation. At times when there were slight distractions, I found myself zoning out, and missing the smaller details, or taking longer than some might to process what I hear. These are recognised traits of autistic individuals (Jordan, 1999). Playing back the audio recording later helped me to capture the missing data.

During analysis of the data, I realised that I had too much for the limited pilot study, and I chose to save the data for one participant for this main study where I could expand on the collection and make more use of it. I had informed consent from participant and parent to do this.

I undertook the data analysis using a robust process, influenced by the discussion of Miles and Huberman (1994). This process contained:

1. Typed transcription of each interview from the audio recording;

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<sup>3</sup> The pilot study was undertaken as a module paper for the EdD and therefore the time available to carry out the research was limited. The actual data collection was over a period of one month.



2. Second listening of audio recording, checking, and adding omissions and initial comments;
3. Typed transcription of observation field notes with any initial comments;
4. Initial data reduction and summaries of data, into matrices;
5. Third listening of audio recording, checking against matrices;
6. Further data reduction and analysis of individual matrices into one thematic case summary matrix – aligned to research question and autism specific issues;
7. Matrix coded with specific issues further explored in analysis and discussion.

Validity of the data was checked by inviting the participants to review the transcripts and matrices. Further sampling and examination were not possible in a study with such limited time. The data within the matrix was then analysed in detail, with reference to autism related traits and behaviours, and against two main themes, i.e., personal motivation and student/teacher relationships.

I agree with Phillips and Pugh (2000) that a pilot study is clearly a necessary undertaking to precede a major research project and its value is unmistakable. However careful planning and design will not prevent the inevitable highs and lows, and surprise elements surfacing which they certainly did with this study. For instance, one participant continually postponed his interview and failed to turn up to lessons, when observation was planned. This was not his fault, simply circumstances. I also had some misgivings about interview being the main method of data collection, as it clearly did not suit everyone, to some extent including me. One conclusion which I shall try to take forward into this main study, is that it was more useful to use observation prior to any interview, thus supporting Freeman and Mathison's suggestion that one should 'use participant observation to get a fuller picture of context and build rapport before interview' (2009: 101). It was also useful to use what I had observed as a basis for getting to know the participant and to start discussion. Another issue I encountered during the use of interview was my tendency to fill silent periods with generic chat or words of encouragement. This tendency was painfully clear on listening back to the audio recordings and may have been quite off-putting for the young participants. I

should take note of the advice of Westcott et al. (2002, cited by Westcott and Littlejohn, 2005:152) that interviewers should 'not be frightened of silences', although knowing my personality this will be a challenge in itself and perhaps I should consider a more structured script in case of a repeat of this scenario.

A tool I used during interview which proved very valuable were 'traffic light stress level indicators' which were a way of the young students letting me know how high their stress levels were at times throughout our discussion. Autistic individuals particularly are prone to anxiety, often severe, during scenarios which are new to them (Roth, 2010), and if they are experiencing particularly high levels of anxiety during an interview, the data may be considered unreliable. I also chose to use a range of elicitation techniques including games, word cards, and spider diagrams which can assist 'co-construction of understanding and meaning' (Freeman and Mathison (2009:99) and seemed to calm and comfort the participants. I recognise however that these may not suit everyone.

In addition to the specific areas mentioned, I learnt from this study the importance of bringing together a theoretical framework with the chosen methodologies. I also realised that the proposal cannot be 'set in stone' although in this study the only change was the number of participants.

Following this pilot study, I am certain that the methodology of ethnography is correct here and fulfils my positionality of social constructivism and interpretivism. Indeed I maintain that researching children and young people falls within this paradigm succinctly and the result of the data analysis so far, indicate the requirements of social constructivist research discussed by Freeman and Mathison (2009:1) that:

Requires an awareness of competing meanings and assumptions... and are the result of a unique set of dynamics created when particular individuals (researchers and participants) interact in particular settings.

It is clear however that autistic individuals are unpredictable and all react in different ways to research situations, and this was never clearer than during the interview process. It simply was not right for some individuals; perhaps for the young man who continually postponed his, and for me as an autistic researcher, interview was not the easiest method either. A lot depended on the participant, how comfortable I was with him or her, and how he or she interacted with me. It was essential then that I reconsidered my methodology and methods within this paradigm to allow more flexibility for both the participants and myself as a researcher. Without this flexibility I fear the data would not be as valid and reliable as it needs to be; and the process of collecting it would be complex.

## **MOVING FORWARDS**

The overarching method of autoethnography will be fundamental to my interpretivist stance, and review of the literature against my aims, as well as evaluation of the pilot study; all fit within this method. I had initially thought it would just be *my* autoethnography, reflecting as an autistic adult and professional within the field alongside the research with young participants, but what is clear to me now is that the central autoethnographical input is actually from the young autistic individuals themselves. To this end, I have chosen to use a completely flexible three pronged approach to my methods, all bound by the ethnography concept, and indeed autoethnography. These chosen methods follow an extensive exploration of relevant literature, including that which covers research with children and disabled individuals as well as my pedagogical experience. The three *phases*, all of which can actually be undertaken simultaneously, are in my opinion ethically sound, clearly participatory, and allow the young individuals agency and the ability 'to play a central role in revealing their own priorities and interpreting meanings with adults' (Clark in Lewis et al., 2004:160). In order to get as much useful data as possible, it was essential to collect a wide variety of perspectives to work with, ensuring participants were given the opportunity to vocalise their stories and experiences, and rather than dwelling on any perceived 'inadequacies', focus on positive changes which will benefit their individualities.

Fraser (in Fraser et al., 2004:16) indicates that this multifaceted approach as a process of discovery can 'lead to tangible and immediate benefits for children' and clear insights for the researcher. Furthermore the three methods work in harmony extracting data from varying participant sources thus enabling me to critically reflect as an 'expert' in the field and as an autistic adult in an attempt to achieve the research aims. In addition they lend themselves well to research with young disabled participants allowing flexibility for ages and differences in disability, as well as allowing them to remain at the centre of the research.

### **On-line or Virtual Ethnography (a.k.a. Netnography)**

The first method will be to use an on-line bulletin board called 'Wall Wisher' (since renamed 'Padlet') to collect initial data and 'themes' surrounding issues based on my research questions. Autistic individuals of any age are able to simply 'post' a message of any length they choose. I have built three 'walls' each with a separate but related subject area to make it easier to collate the comments at the end of the 'posting' period. These areas are:

1. What motivates you to take part in this/these activity(ies) – what do you enjoy, what makes you go there and take part?
2. What has made the learning experience difficult/unpleasant/uncomfortable/upsetting for you?
3. How important is your relationship with the teacher? What would make the ideal teacher for a good learning experience?

Participants will be asked to give their perspectives on their childhood learning experiences. A potential weakness of this method is getting the responses to start with; this will take a lot of patience and determined effort in spreading the word about these walls within the autistic communities. However I have confidence that the benefits outweigh this potential challenge. Firstly the 'postings' are easily left; it is simply a case of clicking onto the site, double clicking onto the wall, and typing. Secondly it is a completely anonymous way to participate; no registration is required, and participants can choose what name to use on their posting. Informed consent is gained by the participants choosing to post their comments



since there is no pressure and participation is completely their choice (Kozinets, 2010).

This is a relatively new method for this type of research, utilised here to gain a large number of responses from a wide audience. Participants have been sought from autism websites and magazines, autism trusts and on-line autism communities, for example, *Aspie Village* and *Wrong Planet*, as well as within my own professional network of physical activities, clubs and associations. Word has spread via social media such as *Facebook*, *Twitter*, *MySpace* and *Linked-In*. Many autistic individuals use computers and social media as a way of communicating comfortably without having to endure face to face meetings, or know physical social rules (Wing, 1998). This is a flexible and easy way for them to give their 'stories' and experiences without being uncomfortable or revealing themselves. Personally I find Linked-In, for example, an indispensable network media facility which allows me to undertake essential professional networking, without having to enter a room of hundreds of people, with its associated noise, bright lights, and social expectations (Roth, 2010).

Netnography is a relatively recent neologism created to describe ethnography undertaken with the fast growing on-line communities or 'cyberculture' (Kozinets, 2010:11). Of course the process of qualitative research via the internet is not completely new; for many years researchers have found ways to adapt traditional research methods including interviews, focus groups and observation of linguistic behaviour within the computer-mediated communication manner (Mann and Stewart, 2000) but methods such as these on-line bulletin boards, have more recently been trialled (Correll, 1995, cited in Kozinets, 2010; Schreck et al., 2004); and as a method within research with disabled participants, is an imaginative alternative to less user friendly and more demanding methods.

The data is easily analysed into themes which can then be explored within the other two methods.

## **Mosaic Approach**

This is the more detailed phase of my research involving nine autistic individuals between the ages of five and seventeen, who take part in informal education activities. Individuals were chosen based on willingness to take part, age, and allowing a mix of boys and girls, although less than a third was female. This follows the suggestion that the male-to-female ratio of people with the diagnostic label of autism is 4:1 on average (Frith, 2003). Interestingly more recently it has been acknowledged (Gould and Ashton-Smith, 2011) that a possible reason for these statistics is that girls tend to present differently and are less likely to be diagnosed. In my experience during the selection of participants, many girls either do not know about their diagnosis or do not want to risk anyone else finding out, and in one case a mother pulled her teenage daughter out of the study part way through, citing that her daughter would hate it; this was despite her daughter volunteering and both parents, the father also being autistic, initially giving informed consent. However, later she chose to participate in the 'secret box' element of the research.

This phase uses the Mosaic approach (Clark and Moss, 2011) first used in 2004 (Clark, 2004:143) developed with three and four years olds and adapted for two year olds, and based on the assumption that children are 'experts in their own lives' (ibid). However, I have adapted the approach even further; to fulfill the needs of older children and teenagers with a range of autistic diversities, an adaptation I have thus far named the 'auto-puzzle technique'. This name has served twofold; it refers to the multitude of methods adapted from the original mosaic approach with additions more suited to older children and teenage needs, forming the overall picture of their 'personal story'; their autoethnography. It also refers to the autistic needs and the universal symbol of autism; the jigsaw puzzle piece, and the young participants seem to identify with it as it alludes to them finding their place in informal education. Originally the research design indicated students keeping a mosaic style 'diary'. In reality this was a large scrapbook which the students would fill with their perspectives of learning experiences by

using a variety of artifacts of their choice which might comprise of diary entries, narrative, poems, pictures, photos, maps and drawings. This method also paid homage to Freeman and Mathison's method of journaling (2009:137), which they advocate on its strengths of 'fostering a sense of ownership and control over the data' and being easily integrated into a normal routine. However some of the children in the study saw this as additional homework and not necessarily enjoyable, so in order to encourage participation it was necessary to find a suitable adaption, which still fitted the mosaic approach, but expands further to include other methods of eliciting valuable data from these young people. After reading more on the Mosaic approach, and talking to my target participants: young autistic students, I made the decision to offer a flexible alternative: to allow them to keep video diaries, to undertake participant and non-participant observations, and to offer informal interviews if they preferred this option. While it may appear to be a mismatch of methods, it is actually adapting a range of methods suitable and familiar to young people, and allows enough flexibility to take into consideration their autism as well which is absolutely crucial for this study. The diversity of autistic individuals, calls for flexible methods and this adapted approach is an ideal coupling. I strongly advocate this as a major benefit to the study, matching the diversity of methods with the diversity of the spectrum.

Much of the literature around pedagogy of disabled or young people for instance, champions the use of interview as a way to elicit their views (Christensen and James, 2008; Freeman and Mathison, 2009). I argue, especially following the pilot study, that this method is not suitable for everyone, but I concede that for some, this is the easiest, quickest and most comfortable option of participating and getting their voice heard. Observation is also a method I used during my pilot study and one I was keen to use again. For informal education especially I consider that this is one of the most natural methods for young people, allowing data to be gained with minimal interruption to their normal learning environments. Indeed Tudge and Hogan (2005:116) suggest that while 'interviews with children involve a host of difficulties' observations allow them to have a 'voice' 'through action observed'. In my experience informal education activities, for example,

swimming, martial arts, and dance, often allow spectators at classes, and the students are used to people watching them. It could be argued, and it certainly was vehemently at the start of my research design process by the rapporteur overseeing the research proposal, that these students are disabled and vulnerable and that watching them is ethically wrong; the rapporteur's argument was that it would put additional pressure on already vulnerable individuals by observing them. Bearing in mind my professional experience, I must, however, disagree and reiterate that observation allows natural data to be collected. Furthermore Fine et al. (1988) argue that by school age, an average child may have 'developed techniques of impression management...to avoid disapproval or reprimand' when being observed, and I suggest that autistic individuals are unlikely to be consciously manipulative (Roth, 2010) and consequently behaviours during observation may in fact be *more* natural. Of course I must concede that from an observation, I cannot hear the young person's 'voice', although Tudge and Hogan (2005) argue you can, but there are other benefits including watching interactions with peers and between student and teacher, and looking out for reactions and the themes which have been highlighted in the 'on-line' ethnography. An example of this may be the environment – colours, lights, noise, distractions, and how the student's demeanour or behaviour is affected by this. It allows a comparison for use later in the study, against the 'diary' or interview. For those individuals who choose to be observed only, perhaps just one or two of my questions may be answered, but the data will certainly be of enough value to add to the rich layer of data gained by other methods, and worth the effort.

### **'Secret Box'**

The 'secret box' method (Greig et al., 2007:161) is a real or virtual 'box' where participants in this case both students and teachers can 'post' their perspectives about learning and teaching experiences anonymously. The 'box' is only opened at the end of the research period and therefore individual comments cannot be linked to any particular person, club or organisation. The fact that the individuals choose to 'post' assumes automatic informed consent, thus there are no ethical



issues or additional paperwork to be concerned with. This method was chosen to gather data from those individuals who were less confident about coming forward with their views but wanted to be heard. It allows a 'voice' without consequences or reprisal. It was particularly useful for autistic individuals, as it would not involve any interaction, communication or social niceties and no-one need know that the individual had been a part of the study. The perspectives could either be 'posted' literally into the 'box' during classes within various clubs and activities, or 'posted' by mail or via another source in a sealed and anonymous envelope thus allowing time for writing or typewritten comments. On its own as a method, it would be limited by virtue of the necessity to encourage participants to 'post' but in addition to the other methods; it adds another layer of perspectives and a way by which 'postings' can be made anonymously. In terms of analysis, this would be a way to triangulate the data collected by the other methods, and further confirming any recurring factors impacting on the informal education learning experience.

## **ETHICAL CONSIDERATIONS**

There are many ethical concerns in this study, especially considering it involves working with a twofold vulnerable community, that is, autistic children and young people. Many of the issues relating to methodological choices and access to participants have been covered within those particular discussions, but here I shall just address some of the more practical issues.

Very clear documentation was produced at the start of the study, outlining the aims with full details about what was needed from the participants and how the research would go forwards. Documents outlined each phase of the study, how to participate, and outlined the option to withdraw at any time should this be their choice. There were also additional contacts for the participants to check the authenticity of the study. Phases one and three of the study allowed participants simply to volunteer information, thus giving their informed consent by doing so. For phase two, informed consent was given via forms completed and signed by parents, participants and teachers of the activities observed. The documentation,

advertisements for the research and sample consent form are available in the Appendices.

I have discussed anonymity issues previously and in Chapter 5. One additional issue however is that if the participants in the mosaic phase of the study read the finished paper, they will be able to identify themselves as they chose their 'pseudonym' names. They may or may not have chosen to reveal these names to immediate family. While the raw data and its presentation will be what they have told me, my interpretation as a researcher is clearly not and I acknowledge this may be, in some cases, a little uncomfortable for them or their parents. However I addressed this at the start and gave the participants and their parents an opportunity to debrief both after the research period and after the final study to clear up any outstanding questions they might have. I have consequently been careful during discussion of the data to achieve a balance between not making presumptions which would later affect the participants or their families adversely, while maintaining my integrity as a researcher.

## **SUMMARY**

I believe my chosen methods work in harmony eliciting data from varying participant sources thus enabling me to critically reflect as an 'expert' in the field and as an autistic adult, in an attempt to achieve my research aims and answer my questions. The pluralistic approach lends itself well to research with young disabled individuals, allowing flexibility for ages and differences in disability, as well as allowing the young people to remain at the centre of the research. I shall use my 'expertise' to reflect throughout the research process to question professional and personal development (Bolton, 2010). I shall use a thorough process of data collection which will need to be systematic and objective; and analyse this data by thematic coding with an adapted set of analytic steps suggested by Miles and Huberman (1994), and highlighted during the pilot study review. I shall need to be careful about possible occurrences of misunderstanding; either of meaning, or of perspective. By considering concepts

of context, content, agency and subjectivities (Freeman and Mathison, 2009), I shall endeavour to avoid these occurrences as far as possible.

I shall corroborate the process by using the data collected and cross referencing it at each stage, so that the data is multi-layered thus fulfilling Mason's qualitative paradigm (2002) and allowing a voice for teachers as well. This multi-method approach will allow several ways to gauge perspectives and experiences and allow communication in various ways, and will really embed the data so that the research questions can be answered more easily and the data can be considered valid, consistent and reliable, as well as valuable. Collation and analysis of the detailed phase of the research may prove more difficult as I will need to analyse each component and bring it together with the other phases, but I consider that the benefits of this technique will outweigh any complexities and this may become an additional innovation of the research study.

Research with young autistic students may at times challenge assumptions about their ability to communicate and how this will affect the quality of the research data. It may also threaten the traditional research formats for 'disability research'. The role of me as a researcher may be less important at times during the research process or it may play a pivotal part. All of these issues may be a paradox of methodological discourse which dictates research to follow certain parameters including a particular structure, validity, reliability and so on. Research involving these young people should be celebrated rather than frowned upon and society is often too quick to judge people who are different. Often the focus is on what they are unable to do, of limitations and help which they may need, rather than on their unique qualities which can make them interesting, insightful, full of ideas, and in my experience a pleasure to teach and to be around. Apart from this, in my role as a researcher, it is my role to ensure that these young people are given a chance to have a say, to make changes in society for future generations and complexities aside this makes it worthwhile.

‘Children learn what it means to be a child...by comparing experiences, discussing emotional responses to events, and debating values’ (Christensen and James, 2008:122). Never has this been so true than when discussing children with autism. Personal experience indicates that these comparisons to others and discussions about what is expected are, in some ways, helpful for the person with autism to get an understanding of others and how society accepts people, while at same time giving them a sense of empowerment to be themselves and challenge who society expect them to be.

I believe that gaining first hand experience of working with young autistic students is truly the best way to research them, and interactions between researcher and participants are critical to a successful research outcome. Lee sums this concept up in her legendary novel *To Kill a Mockingbird* (1960:24) ‘you don’t have to learn much out of books that way – it’s like if you wanta learn about cows, you go milk one, see?’



## **CHAPTER FOUR – DATA COLLECTION AND ANALYSIS**

In this chapter I shall explain in depth how each phase of data collation was undertaken, and issues which arose, for example, of an ethical nature, as well as any reflections and resolutions. I shall later expand upon the participant profiles to give a clear idea of the potential expanse of data.

The preparation required for the chosen research methods was extensive and time consuming, demanding many processes suitable for the various audiences and allowing flexibility necessary for the complexity of different autistic communities. The research was ‘advertised’ by way of specialist and academic websites and newsletters, social media, blogs, and a press release; in order to meet the participant requirement I adapted each advertising medium to the particular audience, for example, the *National Autistic Society* website demanded more detailed information on the study than a simple facebook page; The *Lonely Planet* website wanted the information to be geared towards the autistic user but was not concerned about academia. A list of sources used to recruit participants can be found in the Appendices. The multi-method approach also required unending patience as I was relying to an extent on others to ‘post’ the information, at least in phase one, and data collection therefore took longer than I initially estimated. The resulting data that was ‘posted’, however, made the effort worthwhile, and gave a good foundation upon which to layer the remaining data. Reliance of others to ‘post’, despite the aforementioned weakness, also became a benefit of the method to me as a researcher. Because it was out of my control, it allowed the autistic ‘voice’ to take control over the data, something which I would suggest is not commonplace in research with vulnerable communities (Liamputtong, 2007). The matrix below shows the data collection schedule. Although there was not complete consistency in the type of data collected from each child in the mosaic phase, this did not reduce the validity of the data. I would reason that each layer supplemented the next, adding strength to the resulting themes which would eventually answer the research questions. More importantly this flexibility was necessary to allow for the different needs of these autistic children.

DATA COLLECTION SCHEDULE				
Month 1	Month 2	Month 3	Month 4	Month 5
Online Data Collection				
118 postings over 3 walls				
		Diary Data Collection		
		36 entries over 3 diaries		
		Interview Data Collection		
		Observation Data Collection		
		28 observations over 9 participants and 5 activities		
	Secret Box Data Collection			
	31 entries			

## ON-LINE OR VIRTUAL ETHNOGRAPHY

The website used for the on-line ethnography was developed over the period of time I was using it for data collection, changing its identity from *Wallwisher* to *Padlet*, and introducing many new features so that when the research period ended I could simply save the 'walls' as they appeared and print off the data. This made coding a relatively easy process in which I:

1. Printed off data for each of the three 'walls';
2. Highlighted text relevant to research questions and autism;
3. Coded the raw data into themes which commonly occurred and might impact the learning experience;
4. Transferred the data themes onto the main thematic matrices according to the research questions. This was not always easy as some of the themes crossed over the questions, and therefore they cropped up on more than one matrix. As the discussion of results will show, thorough analysis including the reality of simply staring at the matrices for some time until themes 'jumped out' revealed an overriding argument throughout the data results across the questions;

5. Checked back from the matrix to the original data print outs for accuracy and validity and mark out examples to be used in writing up the data.

This on-line methodology fits well with my ontological position; the internet is the epitome of a social construction, and one of its major benefits is to bring people together as a community where each individual can participate without being judged in the same way as perhaps joining a community group in reality. All my methods by the essence of being qualitative are interpretative, perhaps this one being less so in that rather than trying to interpret what participants are saying, it is more about selecting the relevant themes of what they have posted; most of the postings being fairly short and precise. This was not the case for some postings however and these took more interpretation using my experience as a researcher. As with all methods, there were some more challenging issues worth acknowledging. The walls had to be opened for a longer research period than the other methods used, as they relied on others to firstly read the recruitment 'adverts' (sources in Appendices as mentioned previously), and then to post at their convenience. Secondly, it might have been better to have shorter, more specific questions to assist the participants who were less sure of their views. Although I considered this, it was important to me that I did not influence their answers in any way, and the more general questions/topics seemed the best way to gather richer data. I must concede in hindsight however, that there was potential for some participants to have been influenced somewhat by other answers on the wall and at the time I had not considered this possibility.

### **MOSAIC APPROACH (INCLUDING INTRODUCTION TO PARTICIPANTS)**

The second phase of this project featuring nine young individuals was easier to set up and manage but was not without its challenges. As discussed in Chapter 3, the mosaic approach had to be revisited during the research period as the originally planned methods were incompatible with some of the participants. The resulting pluralistic adaptation of this approach was improved for the changes and better suited to the rich diversity of the spectrum. I am confident this was a major

benefit for the study and highlighted the necessity for flexibility for individuals on the spectrum.

My target was ten young people, but as outlined in Chapter 3, one teenage girl dropped out of this phase of the study. The pluralism of the mosaic approach was necessary to enable young individuals with varying presentations of autism, and it turned out varying levels of confidence to be able to participate and have a voice. Some were keen to take part in all aspects: the diary, interview and observations; others were happier to simply be observed in their normal classes. Although this method was contested in the early stages of my research design process; as one of many methods within the mosaic approach, it proved invaluable to eke out subtle nuances in student/teacher relationships for instance, or repeated actions or behaviour by the student, not necessarily revealed during interview or diary collection. Indeed Dey (1993:98) suggests that observation is often employed in a bid to draw distinctions by the data which are not 'recognised explicitly or even implicitly by the subjects themselves'.

Recruitment of potential participants initially was by 'advertising' the research via websites, classes and professional bodies (see list of resources in Appendices). Access to the actual participants was not problematic as they were all contactable via my professional connections – two were my own students, two were students of other teachers within a local group of classes, three were students of other classes within my professional sporting network, one joined the study after her mother enquired about classes and we started talking about my research; and the last one was the son of a professional contact of my husband, who was keen to take part. Therefore prior to the study I knew four out of the nine of the participants, although only two as a teacher. It was made clear to these participants that while I was the 'researcher' they were to assume I did not have prior knowledge of their learning experiences and when they generally referred to teachers, they used other teachers within the classes as benchmarks. One of the participants was not able to understand this concept and therefore chose to talk about me at times. I recognised this parallel and potential conflict between me as teacher and



researcher as I analysed the data in this case (Stenhouse, 1975). It should be noted that due to the variables surrounding these participants, i.e., different activities, some had more than one teacher, differing abilities and so on, the diversity of data will be evident. However, it should be remembered that autistic children are all different and even if there were no variables, i.e., all participated in karate, all had the same teacher, all had trained for one year, there would still be diverse data. The heterogeneity of the participants is what makes gathering the data so interesting; and the study's premise is all about individuals' perspectives.

All of the participants chose 'fantasy names' to be used in the study. Written consent was obtained from each participant, from their parents and from teachers of the classes which were observed, prior to any research being undertaken. Those interviewed all chose their homes as the interview venue. Parents were in the home at all times although not in the same room. Each interview was audio-recorded, and during observations I took copious field notes. The observations were undertaken in their normal activity classes, in familiar surroundings, when they were taught by their usual teachers within mixed ability classes, consisting of autistic and non-autistic individuals between the ages of five and seventeen years. Most of these classes were used to spectators and therefore my presence was not intimidating or distracting. It is common in sports and dance for friends and families to watch classes; this may seem somewhat strange to formal educators, and challenges have been made on a number of occasions about this.

'Malthus', an eleven year old boy with Asperger's Syndrome, chose to be interviewed, put together a diary, and be observed during his karate classes. He also undertook drama and singing classes and had previously taken swimming classes. 'Malthus' came across as very confident, but data suggested otherwise.

'Bob', a fifteen year old boy with Asperger's Syndrome chose to be interviewed and be observed during his karate and football training. He had agreed to collect a diary, but at the end of the research period had changed his mind. He was also

involved in the Duke of Edinburgh Award Scheme with various activities. 'Bob' was a quiet and serious young man and very committed to his activities.

'Sid', is a six year old boy, and he and his parents chose for him to be observed during his usual karate classes. It was the only activity he enjoyed attending having tried a few others and not been happy with his teachers. 'Sid' has Attention Deficit Hyperactivity Disorder (ADHD) and some language delay as well as being autistic, and has a myriad of behavioural issues. Many of these are caused by sensory issues and observations revealed some interesting data.

'Joe', a thirteen year old boy with Asperger's Syndrome took part in the pilot study and asked to be involved in the main study. He chose to be observed over several karate classes. 'Joe' was quiet and tended to be 'invisible' at times.

'Olivia', a ten year old girl was interviewed and observed in her normal karate classes. She was very quiet and friendly. She has Asperger's Syndrome as does one of her brothers.

'Albert', a nine year old boy was simply observed in karate classes at his own request. He was a friendly child who had strict routines from the moment he walked into the room. If one of these was interrupted or changed for some reason, it would affect him for the hour. He had a tendency to get bored easily and find ways to get attention. He loved to show his knowledge which was extensive but struggled with the physicality of his activity.

'Simon' a twelve year old boy was quiet and rarely spoke unless asked a question directly. In this case he always knew the answer. He agreed to be observed during karate classes. His mother told me it was pointless interviewing him as he 'had nothing to say'. His younger sibling has ADHD and talks endlessly, and on reflection I wondered whether this may be an underlying reason for his quietness.

'Jonathan', a ten year old boy waiting for autism assessment was interviewed, and observed during a kung fu class. He also completed a diary. I did not know 'Jonathan' well prior to the study; I only met him once. We met to discuss the study at his home and he was keen to take part. His parents had been talking to him about it prior to my visit. At his request, I interviewed him and then he took me to his class to observe him. We discussed his other activity, a church club, but observation at this activity was unlikely to have been of benefit as it was more social than structured educational activity.

'Abigail', an eleven year old girl joined the study after her mother enquired about my classes and we chatted about the research. She was keen to take part, and we got to know each other a little during email exchange (copied to her parents). I undertook three observations, of classes in ballet, gymnastics and swimming. She was also interviewed and she kept a diary. 'Abigail' was an outwardly confident young lady, very chatty and bubbly in character, but data revealed she has underlying difficulties and insecurities she is not necessarily aware of. Her recent diagnosis is of autism with mid severity.

The matrix below summarises the participants:

<b>'NAME'</b>	<b>DETAILS</b>	<b>AUTISM STATUS</b>	<b>METHODS</b>
<b>'MALTHUS'</b>	11 years Outwardly confident but underlying need for reassurance	Asperger's	Diary, Interview, Observations
<b>'BOB'</b>	15 years Quiet, serious	Asperger's	Interview, Observations
<b>'SID'</b>	6 years Selectively friendly, quick to exhibit behavioural issues	Autism, ADHD, language and behaviour issues	Observations
<b>'JOE'</b>	13 years Quiet, 'hides away'	Asperger's	Observations (interviewed during pilot)
<b>'OLIVIA'</b>	10 years Quiet, friendly	Asperger's	Observations (interviewed during pilot)
<b>'ALBERT'</b>	9 years Friendly, speaks to selected people, his routine is crucial	High functioning autism	Observations
<b>'SIMON'</b>	12 years Quiet, Speaks only when questioned directly	Asperger's	Observations
<b>'JONATHAN'</b>	10 years Friendly, chatty, focused on activities	Waiting for diagnosis	Diary, Interview, Observation
<b>'ABIGAIL'</b>	11 years Outwardly bubbly, confident and chatty with underlying need for reassurance	Autism with mid severity	Diary, Interview, Observations

The process of analysis used consisted of:

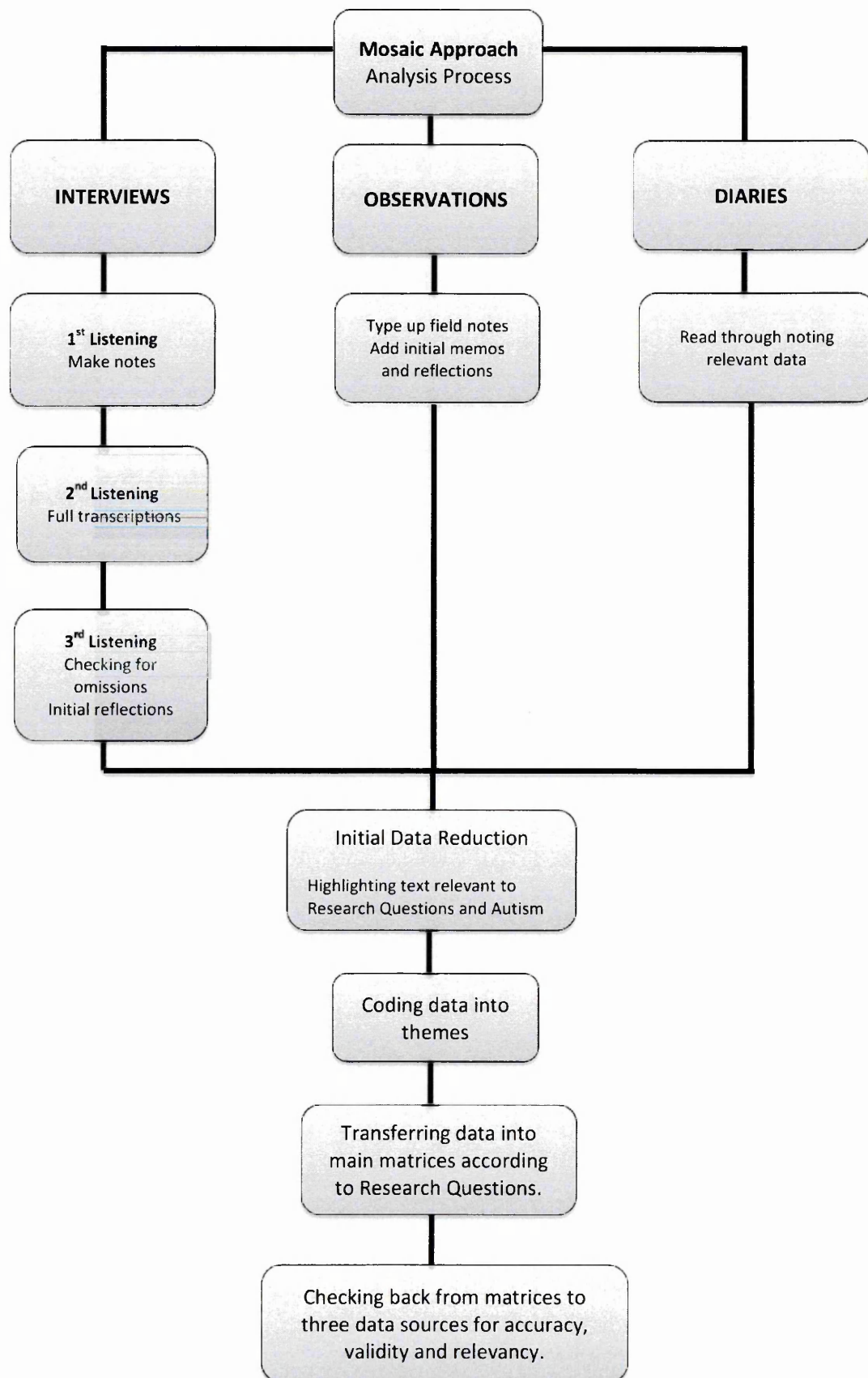
1. Listening back to the interviews immediately afterwards making any pertinent notes (for example, hesitations, long silences or discomfort during particular questions) while still fresh in my mind;
2. Typed transcription of each interview from the audio recordings. I chose to do this myself so that I could fully immerse myself in the data and be able to interpret the atmosphere, the intonations and any other sounds which were likely to be relevant, for example, any noises or visual distractions;



3. Third listening of each interview recording, checking and adding anything I might have missed and initial reflections relevant to the research questions and specifically the learning experience;
4. Typing up of observation field notes, adding any initial memos relevant to the research questions and initial reflections. My only rationale for taking field notes, was to note anything I considered to be relevant to the learning experience;
5. Highlighting text on transcriptions, field notes and diaries (by way of *post-its* as students wanted the diaries back after the study) relevant to research questions and autism: initial data reduction;
6. Coding the data into themes (assigning categories);
7. Transferring the data themes onto the main thematic matrices (used for all three phases) according to the research questions;
8. Checking back from the matrices to the interview recordings, field notes and diaries for accuracy and validity and abstracting examples to be used in writing up the data;
9. Referring to the raw data on many occasions during analysis and writing up.

The diagram below summarises the mosaic approach analysis. The numbers of participants taking part in each method were:

Interviews:	5/9
Observations:	9/9
Diaries:	3/9



This mosaic approach was very much about interpreting the data and therefore was ideal for the research epistemologically. The very nature of the approach produced layers of rich data which, analysed together using the aforementioned rationale, allowed me to really dig deep into the meanings within the raw data and listen to the 'voices' of the participants. As a researcher I value the opportunity to hear these young people, to find out what they really think and feel about their learning experiences. As a professional I believe it is my duty to find ways to improve the experiences of my students, and of the teachers I train in order to make this happen. This approach really enabled me to get into the minds of the individuals who matter.

### **'SECRET BOX'**

The third research phase; the 'secret box' method (Greig et al., 2007:161) added the final layer of data: it was another flexible method and used in various ways. Firstly, an actual sealed box was taken to various classes where students and teachers could 'post' their views. Secondly the research was 'advertised' on autism websites, blogs, social media pages and via my professional contacts for teachers; and participants could send in their views relating to advertised topics (the same topics used in both previous phases). The sealed envelopes were 'posted' into the box and the box was only opened at the end of the research period. All 'postings' were anonymous removing ethical complications and any possible bias and enabling individuals to have a 'voice' without fear of being recognised. This was especially useful for those young students who wanted to contribute but in a more anonymous way and in their own time.

The process for analysis was the same as for the on-line ethnography.

This method of data collection was a further way to allow individuals to have their say, and enabled teachers to be a part of the research as well for another viewpoint. It fitted my positionality in much the same way as the other methods in that postings would need to be interpreted or simply themes would be selected

depending upon the conciseness of the prose. It would not have been a method suitable by itself but as an addition it worked well.

I chose to analyse my data throughout manually, and used simple text and table processing as my only nod to computerised analysis. Despite the widely available software to transcribe, code, theme, and analyse, I really wanted to immerse myself in my raw data, to understand it and be involved at every stage of its transfer to results. As an autistic adult, I tend to be very methodical and visual, and by using manual methods such as mind maps, simple column tables and notes, I find it easier to see emerging themes. Many would argue that this is an ineffective means of data management, and to an extent I would agree, but as an interpretivist I am adamant that the physical process of trawling the data, making annotations and sketching data maps draws in the researcher allowing reflections to assist the interpretation of the richness of the 'voice'. From a more practical point of view, it allowed me to work with the data around me from all three methods without having to keep switching programmes and screens.

For all three phases the same topical areas were explored; each building upon the previous to give various layers of data and allowing triangulation of the results coming through to demonstrate reliability and validity. Phase two took the themes from the virtual 'walls' further and elicited more detail, and phase three collected any excess data as well as allowing a different perception of the same areas to add another dimension.

The matrix below shows more detail about the three phases used to answer the research questions.



RESEARCH QUESTIONS	DATA COLLECTION METHODS	NUMBER OF PARTICIPANTS
<b>RQ1</b> What part does personal motivation play in the informal learning experience for the young autistic student?  <b>RQ2</b> How might teacher qualities impact the informal learning experience for the young autistic student?  <b>RQ3</b> How does the relationship between student and teacher affect the informal learning experience?  <b>RQ4</b> Are there other issues that may affect the informal learning experience for the young autistic student?	<b>Online or Virtual Ethnography</b> Using 'Padlet' walls  All walls included 'think about your childhood learning experiences in informal educational/outside school hours/school curriculum'.  Wall 1: What motivates you to take part in this/these activity(ies) – what do you enjoy, what makes you go there and take part?	54
	Wall 2: What has made the learning experience difficult/unpleasant/uncomfortable/upsetting for you?	51
	Wall 3: How important is your relationship with the teacher? What would make the ideal teacher for a good learning experience?	63
	<b>Mosaic Ethnography</b>  Diaries	3/9
	Interviews	5/9 (2 pilot)
	Observations	9/9
	Instructions/Questions used found in Appendices <b>'Secret Box'</b>  Students	21
	Teachers	10
	Instructions used found in Appendices	

Except for the transference of data in the order of the phases described above, the data was not analysed using any sort of sequence and data from participants was

not necessarily analysed in the order it was extracted. This was not a conscious decision, but an advantageous co-incidence as Dey suggests that 'bias can arise simply from continually encountering some data more frequently because it is located first in some arbitrary... order' (1993:120).

It could be argued that there was potential for bias during analysis of the data in that as an 'insider' my role as a teacher of informal education may have influenced my interpretation. Of course I am bound to have more direct interest in the data than a researcher outside of this area, and it is recognised that most researchers are biased in some way, given their own experiences and interest in the research, but the actual analysis of the data involved recording themes rather than actual interpretations. It was only in the discussion of the data that my interpretations came into play. I acknowledge however that it might have been valuable for some of the original data, for example, the transcripts or diaries, to be read and coded by another person using the same system to check agreement.

## **CHAPTER FIVE – DATA PRESENTATION**

This chapter will present matrices which were developed using the data from the three phases of data collection by a process of abstraction. This abstraction was a powerful tool which enabled clarity and precision in the quest to compare the data from each phase across a range of themes or categories which have been based on the research questions and my position as a researcher. This recontextualisation of the data allowed me to present the data by themes, which is not only significant to my research questions, it enables a better flow of the data allowing the themes to develop across the data sources so that I may attempt to make useful connections and comparisons between the themes. This will help me to understand any evolving theories. Whilst I am not working with grounded theory (Corbin and Strauss, 2008) per se, it is probably inevitable that there will be at least a nod to it as developing pedagogies emerge from the data analysis. Indeed Bryman and Burgess (1994) question whether researchers employ grounded theory in its entirety and suggest its popularity may be more because of the researchers' desire to create theory from data. Of course all qualitative analysis uses techniques suggested by various theorists. For example two key analytic tools: the use of questioning, and making comparisons are used by theorists including but not limited to Blumer (1969), Becker (1998) and Corbin and Strauss (2008). I am simply recognising here that although I do not align this study with every research theory, links to some may be noticed and questions asked about my choices.

The data has been presented by themes rather than by individual cases as this not only makes it easier to answer the research questions, but facilitates the comparison of data between sources and allows common themes to be acknowledged and analysed together. Each matrix is based on a research question.

The significance of the chosen themes will be shown by headings and subheadings, and these themes will be dependent on criteria chosen to

differentiate between included and excluded data observations; the main criterion will be in relation to the number of occurrences throughout the data collection. I have included specific examples along the way to illustrate pertinent points.

The first column of this and all other matrices shows the main theme to come out of the data. In the other columns the specific themes offered by the research participants are detailed.



## Personal Motivation

<b>RQ1 What part does personal motivation play in the informal learning experience for Young Autistic Students?</b>	<b>Virtual Walls (Broad Range) <i>Autistic Voice</i></b>	<b>Mosaic Ethnography (Nine Students 5-15) <i>Autistic Voice</i></b>	<b>Secret Box Students (Broad Range) <i>Autistic Voice</i></b>	<b>Secret Box Teachers (Broad Range) <i>External Perception</i></b>
<u>ENJOYMENT</u>	New Skills Knowledge Prevents boredom Enjoy Learning	New Skills Knowledge Like language and questions Enjoy Learning	Fun Like repetitive movements Rewards	Fun Feel good
<u>PROVE SELF TO OTHERS</u>	Prove not stupid Prove strength not weakness Can be the best / ambition To aim high, eg, Olympics	Likes to impress and show off knowledge Crave positive attention	Able to 'fit in'	Recognition of having done well and gradual rewards Ability to achieve
<u>CONFIDENCE BUILDING</u>	Stop bullying Self / personal confidence Place of safety Comparison to perceived hero Prove to Self: 'Can Do'	Stop bullying Positive thing like to do Prove to Self: 'Can Do'	Stop bullying Personal confidence Self discipline	Safety and comfort in class
<u>EXTERNAL INFLUENCES</u>	Parents / friends / siblings Television / Olympics Peer pressure 'to be same'	Sister Brothers and Sister (Twin)	Friends	Parents
<u>SPECIAL INTEREST</u>	Good at it Love it	Favourite thing Love it Makes me happy		
<u>CONTROL</u>	Physicality / mentality Behaviour Anger Autism Socialise in own way	Physicality Own choice / responsibility Rewards: grade / belt / sticker / medal / certificate Makes friends safely Socialise in own way Anxieties		Music promotes calmness Structure and discipline Not to be different

Responding to questions about personal motivation gave a whole range of answers, and these were categorised into just six main themes. Across the range of sources, similar categories came up repeatedly.

### Enjoyment

It was apparent that all participants enjoy learning; some said that learning was fun for them. The reasons for this enjoyment were broken down by many; learning new skills was a priority, as was gaining new knowledge. Several stated that they joined the class to prevent boredom. For the young people who were interviewed and kept diaries it was clear that they enjoyed learning new skills – ‘Malthus’ and ‘Abigail’ physically showed me technical skills they had learned during their classes while I was interviewing them. They were keen to ‘show off’ what they had learned. Although difficult to ‘observe’ motivation it was easy to observe young people enjoying themselves. ‘Albert’ in particular clearly loved to show off his knowledge of Japanese language during his classes and ‘Joe’ enjoyed the informal games used to teach skills at the start of his class. ‘Jonathan’ wrote in his diary ‘The activitie [sic] makes me feel happy because it makes me learn new moves’. On the wall, ‘CT’ wrote ‘learning an activity makes me feel alive’ and ‘Arnie’ wrote ‘it makes me feel happy and joyful’.

### Prove Self to Others

All aspects of the mosaic phase demonstrated how the young students wanted to prove themselves to others in various ways. Observations revealed how much ‘Jonathan’, ‘Malthus’, and ‘Abigail’ liked to impress anyone who was watching: spectators or teachers. They seemed almost deflated when they were not attracting attention. However this changed rapidly if they struggled with an aspect of their class, or they did a wrong move and to me they visibly seemed to hide within themselves. ‘Sid’s’ behaviour changed dramatically if he was not getting the teacher’s attention, so much so that the entire class dynamic was altered. Proving their strengths was clearly important to some including mental strength for ‘Amy’

who wrote on the wall 'I started karate because people at school said I was weak – I'm not I'm strong and I am going to prove it to them'. 'Anon' explained his motivation 'to prove to people I have strengths and am not useless. People assume my autism means I can't learn. It's really frustrating'. A high ambition was also evident; 'Freddie' wrote on the wall that he 'wanted to do the Olympics'.

### Confidence Building

As many of the young people in this study participate in martial arts, a motivation to stop bullying was probably inevitable. However this was an area mentioned by non martial artists as well. Other activities were chosen to improve personal confidence, and thus reduce the chance of the individual becoming a victim outside the class. 'Jonathan' wrote in his diary 'I like Friday club because I make new friends...having responsibility of my own money and choosing my own tuck'. 'Micky' wrote on the wall 'I just want to do something where I won't be bullied and that's what I get from my tennis club'; and 'EV' wrote 'I can try out talking to others and not feel embarrassed'. Using the class as a place of safety was common. 'Anon' posted in the secret box 'I started karate for self defence. I was bullied at primary school and needed a way out in a place which was safe'. Aleks wrote on the wall 'I like to learn new things in a place I feel safe. My club feels like I am at home'.

### External Influences

These were not as common as other motivations but due the age of the participants it was always likely that parents, friends and siblings would play a part in why a young person takes up an informal learning activity. Peer pressure is present wherever there are young people, and for the autistic individual perhaps more so, although not always acted upon. Television or film also played a part, especially for younger children. 'jj' wrote on the wall 'my favourite film is karate kid'; and 'Dangermouse' wrote 'TV influenced me a lot as a kid and I wanted to be dangermouse, a superhero. Whatever was shown on tv [sic], is what I wanted to

do'. 'Malthus' wrote a lot in his diary about superheroes and even depicted his karate teacher as one. I would also guess that one participant who posted on the wall was influenced by television as his or her 'name' was 'Prof Yaffle: a character in the television show *Bagpuss*.

### Special Interest

With the participants being autistic, it was expected that personal motivations would include special interests as these are a key indicator for autism (Jordan, 1999; Frith 2003). The notion of being good at something is clearly motivation in itself (McLean, 2009) and participants were forthcoming with their thoughts and perceptions on this topic. The aforementioned 'Prof Yaffle' wrote 'I enjoy playing tennis as I don't have to rely on others and I am good' and 'LB' confirmed this insight by writing on the wall 'I just did what I was told... As it happens I was really good at it and this motivated me'. While discussing her love of ballet 'Abigail' explained in her interview 'gym gives me a positive energy and it helps me keep fit, and it's also linked in with my ballet because you have to point your toes...' Some activities perhaps then are taken up as they fit in with and complement an individual's special interest? The final example here must surely be a special interest of 'LB' who wrote an incidental at the end of his posting about rugby '... I quite enjoy getting bumps and bruises so I can watch my skin change colour'.

### Control

Control was a key influence in the personal motivation to undertake particular activities. There were a variety of ways this was demonstrated and many came back to autism. Control of physicality or mentality was a common motivator among participants. 'Bob' revealed during interview that he took up martial arts initially because he felt 'fat and wanted to lose weight'; and 'Jack D' wrote on the wall that learning his particular activity made him 'feel strong'. Argentine tango has given 'SW' control of various issues including 'better social contacts [sic], self awareness and communication'. 'Marie' wrote on the wall 'dance has given me confidence,



discipline, motor skills improvement, taught me how to follow instructions'. Behavioural and anger issues somewhat common for autistic individuals also feature here: 'pm' wrote 'it helps me to control my angry episodes', and 'Sam' on discussing experiences which make him angry and how he resolves these wrote 'I would not be surrounded by idiots but by people who really wanted to learn'.

Repeated observations of 'Sid' revealed a different and fascinating type of control; that of performing or behaving for reward. At first my observation was that his somewhat erratic behaviour was affected by others; if another child was misbehaving or causing a distraction 'Sid' would reciprocate by mimicking the actions. During one particular class he behaved impeccably and at the end his teacher complimented him. He asked why he hadn't received a medal for this. According to the teacher, the week before he had given a medal at the end of the class to the most focused student. Speaking to Sid after the observation, he told me he had behaved so that he would win a medal. During the following observation, another child was given a medal and 'Sid' tried to take the medal from him. During the rest of the class, his behaviour spiraled out of control and despite best efforts he refused to take part or listen to anyone including his parents who were watching. At another class, the teacher instigated a reward system using stickers which at first 'Sid' agreed to, but when he became aware he would not get medals as well, he rejected it. Chatting to his parents, I realised that from a very early age, they had offered him rewards as motivation for performing tasks and behaving well. It seems this may have backfired and I shall explore this issue further during Chapter 6.

### Teachers' Perception

While a teacher may find it hard to know what personally motivates the autistic student, the secret box revealed a few insights which might be valuable. A music teacher for example revealed that for her autistic students, learning music is a calming influence and may curb anxieties which are common in autism. Another teacher perceives structure and discipline to be motivators; one wonders whether

this is more so for the students or their parents? Another believes that his or her activity enables students to 'be the same' and not to 'feel different'.

## Teacher/Student Relationship

<b>RQ2 How might teacher qualities impact the informal learning experience for the Young Autistic Student?</b>	<b>Virtual Walls (Broad Range) <i>Autistic Voice</i></b>	<b>Mosaic Ethnography (Nine Students 5-15) <i>Autistic Voice</i></b>	<b>Secret Box Students (Broad Range) <i>Autistic Voice</i></b>	<b>Secret Box Teachers (Broad Range) <i>External Perception</i></b>
<u>ESSENTIAL</u>	Ability to recognise student needs Patient Understanding Ability to give clear explanations Respectful Kind Happy	Ability to recognise student needs Patient Understanding Supportive Encouraging On time Reliable Kind	Patient Understanding Kind	Knowledge Teaching experience Learning together
<u>IDEAL</u>	Knowledge of autism Good at activity Enjoys teaching Encouraging Funny but serious / strict Fair Good listener Reliable: on time, always there, consistent Caring Flexibility / adapt to needs Nice Follows the rules	Trust Positive Passionate Loyal Caring Lots of ideas Fun / jolly Not biased to individuals	Focused Funny and serious Smart / clever Honest Friendly Caring Helpful	Fairness and equality Trust Allowing student time to process without interruption Awareness of overload To know individual needs Patient Understanding
<b>RQ3 How does the relationship between student and teacher affect the informal learning experience?</b>	Important: Yes 80% No 10% No answer 10% Try harder for good teacher	Important: Yes 100% Like to impress teacher Try hard for teacher who is liked	Important: Yes 90% No 10%	Important: Yes 85% No 5% No answer 10%

The issue of the relationship between student and teacher was seen as a central topic within this study, and consisted of two areas: that of the actual relationship or connection between student and teacher and whether this was important to the young autistic student; and the second being teacher qualities and the impact of these on the learning experience. In the main it seems that this relationship is of the utmost importance. To some of the young students it was deemed not particularly important but I must take into consideration here, the commonality for many autistic individuals to be lacking in self-awareness (Roth, 2010) although to some of course it will simply not be relevant. In the matrix, RQ3, the yes/no answers relate to a question asked of the participants 'is the relationship between student and teacher important'.

The matrix presents the qualities as being essential, that is, those which were discussed by the majority of the participants across the range of data collection sources; and those which are ideal for one or a few of the participants.

Even at this stage in the discussion it is clear that an ideal teacher for autistic individuals must have an assortment of skills and qualities to satisfy a whole range of needs. This once again demonstrates the need for flexibility to suit the spectrum of autistic individuals.

### Essential

At the top of the list for most participants was the ability of a teacher to *recognise a student's needs*, to be *understanding* and willing to be *flexible*. 'Scarlett' wrote on the wall 'I don't need special things to do – just someone to understand my difficulties and be sympathetic towards them...I think an understanding teacher is essential to my learning experiences.' 'Richard' also thought it would be beneficial to have 'a teacher that understands, and helps accommodate for my different learning style and autistic ways'; while 'Molly' wrote 'the teacher needs to realise I may take longer than others to digest instructions'. 'Jake' explains 'the teacher got to know my strengths and weaknesses' and is clear that 'the relationship between



teacher and student is paramount to the learning experience'. Another example of the need for understanding is from 'David' whose teacher and fellow students are familiar with autism, and who writes 'I can let out my frustrations without embarrassment and without other kids freaking out'.

Another virtue of the ideal teacher echoed by most participants was that of *patience*. 'Bambi' elaborates 'my ideal teacher is patient, serious, able to give clear explanations, not using sarcasm, willing to repeat and answer lots of questions'. 'TG' agrees and wrote on the wall 'I believe a teacher needs a variety of teaching methods to keep my attention, lots of patience, a sense of humour (as a child I was very blunt with my views) and lots of flexibility'.

Qualities discussed by several people, during interview and diary collection, were those of *support* and *encouragement*. 'Abigail' describes her gym teacher 'she always has a positive kind of smile when she sees me and that gives me a good feeling'. This joy was echoed upon observing her with her gym teacher. About a swimming teacher she remembers 'Caron' as being 'patient, so if I can't do something at the beginning she always encourages me to try again' and if she has 'trouble with it, they (the teachers) come over and pat you on the back and tell you 'you can do this 'Abigail''. Observation of her classes revealed her need for positive attention. She seemed almost embarrassed when she made mistakes or struggled with a technique or move but practically glowed when she impressed her teacher. The difference in her facial expression was clear, even to me as an autistic adult (Jordan, 1999). She was also ecstatic when she received stickers at her gym class for good effort. Alex wrote on the wall 'my ideal teacher...needs to be warm and supportive and able to spot a potential problem'.

One word which came up continually across the range of data elicitation was *kind*. 'Abigail' told me during interview 'I think that a good teacher should always be kind and smile but be strict if they have to'. She went on later in the interview to tell me about her perfect teacher:

kind, slightly firm, discipline that they sort it out quickly..., passionate, care about the way you move and help you and care about what you are doing... and patient and they don't explode at you if you get a little bit touchy with them...oh and always jolly, full of sunshine.

### Ideal

Other requested qualities which came out of the data were *funny, caring, honest, friendly* and *helpful*.

When the participants were asked whether it was important for their teachers to know about autism and that their students are autistic, there were a whole range of views. 'Malthus' during his interview told me it is 'quite important because they understand how the child actually operates, what his comfort zone is, what his least comfortable position is, how he can do things without straining himself'. He continued a little later 'It is a good idea for teachers to have a connection with their students, especially if a child is autistic and doesn't function exactly the way other children do'. 'Abigail' on the other hand disagreed somewhat 'if I'm doing quite well in an activity and they don't know I think it's probably best to keep it quiet unless the progress gets bad'. 'Bob' during interview was sceptical 'I find it important that they actually know that I have it [autism]. Whether they know how to deal with it is a different story'.

On discussing the question of how important the relationship between student and teacher is to the learning experience, answers were varied as one would expect but in the main positive. The wall attracted plenty of comments on this subject: 'I try harder when I like my teacher' wrote 'ana' and 'KD' has the view 'if a teacher has no respect for the way I am, I have no respect for what they try to teach me'. 'Joe' put it simply 'if I hated my teachers, I would simply quit' and 'Abbey' wrote 'for me the teacher student relationship has to be the most important thing in how I learn'. She also is of the opinion that 'nowadays teachers need to be flexible or not

teach'. Posted in the secret box 'James' wrote 'yes it is important I like the teacher and 'Tom' posted his view that 'the relationship is very important – a teacher must be honest...'. During observations I noted that 'Albert' watched his teacher constantly and if her attention was taken away, he would try to find a way to bring it back; often by bringing to her attention to the behaviour of other students. During interview 'Jonathan' was discussing his favourite teacher of kung fu 'he's a great teacher, and he's loyal to his students'. On further questioning it was clear that *loyalty* is important to him as is *reliability*. He was of the opinion that a teacher he once had was bad because he had finished lessons ten minutes late and once he didn't turn up. Reliability was also cited by others; 'Abigail' on discussing a swimming teacher told me 'I didn't get on very well with her. She was always turning up late for a lesson because our lesson started at four o'clock and she was always ten minutes late...'. 'Poppy' wrote on the wall 'if my teacher is away one week, I refuse to learn and my mum has to take me home again'.

There seems to be a theme developing here of possible *over reliance* on the teacher. It was evident during observations of 'Sid' who tended to play up when his favourite teacher was not at a lesson. 'Justin' revealed 'I have an amazing relationship with my teacher'. 'Malthus wrote in his diary about his teacher, 'she understands me unlike anyone else'. He also wrote 'for me the relationship is very important, as stronger friendship or understanding with the teacher could make the lessons easier or more understandable'. Observation strengthened this position and he clearly strived for praise and attention throughout his classes. 'cj' wrote a powerful statement on the wall about his or her teachers: 'they are the most important adults in my life except for my parents'. Discussion around this area will be undertaken further during Chapter 6.

'Bob' explained his perception of the teacher relationship during interview in his 'matter of fact' way typical of an autistic individual (Wing, 1996):

Honestly, I think teachers should just teach...instead of like getting good relationships with certain people and bad relationships with others. Cos, otherwise, that's when biased things happen. Good relationships with certain people are basically getting the upper hand on other people. So I think it's good for, er [sic] you to be on the good side of your teacher but I don't think it should change their decisions in any way.

One interesting issue which came up across the range of data was that the young autistic students liked to impress the teacher and in some cases other people watching as well. In fact many said they would try harder for a good teacher. While observing, this was certainly the case and as I discussed earlier this was a personal motivation for some. Remarkably there were other students observed, who did not seem to be influenced by the teacher at all. In some cases, for example, 'Simon' whose performance was unchanged no matter who taught him, or how he was taught or interacted with. He continued to do the minimum possible to remain in the class regardless of what happened around him. 'Joe' also appeared to be unaffected by the teacher and despite attempts at correction of techniques his performance remained unchanged.

#### Teachers' Perception

The teachers who responded in the secret box were less concerned with knowledge of autism as a priority but knowledge of their students was more important to them. For two however, knowledge of autism was thought to be crucial to the experience and success of their students. All agreed that teaching experience was important as was learning together, thus the relationship between them was a key factor to the learning experience. It was reassuring to see some awareness of autism issues such as sensory overload and allowing them time to process information without interruption, as well as the issues important to the students such as patience and understanding.



### **Other Issues Affecting Learning**

Other issues affecting the informal learning experience could easily be split into two categories: negative and positive. There were more negative issues given but one of the walls was focused on this aspect. Potentially, knowing what these issues are will help to address the second aim of the study and help to create a more positive learning experience within informal education. Some of the issues in this section cross over various issues, for example, people causing distractions.

## Negative Issues

<b>RQ4 Are there other issues that may affect the informal learning experience for Young Autistic Students?</b>  <b><u>NEGATIVE ISSUES</u></b>	<b>Virtual Walls</b> <b>(Broad Range)</b> <i>Autistic Voice</i>	<b>Mosaic Ethnography</b> <b>(Nine Students 5-15)</b> <i>Autistic Voice</i>	<b>Secret Box Students</b> <b>(Broad Range)</b> <i>Autistic Voice</i>	<b>Secret Box Teachers</b> <b>(Broad Range)</b> <i>External Perception</i>
<u>DISTRACTIONS</u>	Other students Noise (mainly sudden) Mirrors and windows Others' behaviour	Other students Others' behaviour: tendency to imitate	Distractions Other students' behaviour	Distractions for autistic student and equally for autistic teacher
<u>PEOPLE</u>	Bullying Cause interruptions Not listening Teacher not explaining well Making noise Making judgements Teamwork	Patronising people Lack of encouragement Sibling / friend rivalry Interfering with routine Not explaining / demonstrating well Lack of clarity Conflicting instructions		Autistic students can upset other students Other students can find repetition boring Other students understanding
<u>PHYSICALITY</u>	Co-ordination Space: people too close, breathing People touching Struggle with activity Frustration: unable to 'x'	Struggle with activity People touching Lack of self awareness Inability to focus or stand still Sensitivities eg sore feet Dislike hurting others	Lack of self confidence Tiredness causes upset — need rest	

## Distractions

The most commonly discussed issue causing distractions was the behaviour of others; mainly other students. There did not seem to be a distinction between other autistic or non autistic students. This issue arose across the range of data sources. 'Poppy' wrote on the wall 'other children annoy me – they are noisy and don't be good [sic]'. 'Albert' had his own reason for others being a distraction: 'I hate it when others try to interfere or keep interrupting the trainer while I am trying to listen'. 'Malcolm' recalled his childhood informal learning experiences 'I am serious when I learn and I think others should be too. Other children ruined my experiences of learning swimming and I hate them for it even now'. For 'Abigail' it seemed to be about fairness and justice: during her interview she told me 'if one (a student) is misbehaving it kind of makes me feel uncomfortable because sometimes if the teachers turn their back, and they sometimes try to guess who it is and sometimes they get their guesses wrong, and then punish someone who's really innocent...they're basically blaming somebody and that's not right'. 'LB' regales his swimming training experience '...the teacher asking how many of us had remembered to breath [sic] on alternative sides on the warm up, and I knew I had. He then berated all of us for not doing so – I was SO angry (still am, as a matter of fact). I wasn't showing off at all, I was just telling the truth'. A sense of justice is often very important to the autistic individual (Frith, 2003) and clearly these incidents have affected their learning experience. It may be irrelevant here but it is interesting that these three examples are all in connection with swimming; perhaps related to the teacher not being in such close proximity to the students, that is, not in the water with them? Certainly as an autistic adult, I have had swimming lessons but have no confidence in a teacher who is not in the water with me. It may also be about swimming pool etiquette which is not always followed. I believe this is worth pursuing with further research outside the boundaries of this thesis.

Another issue involving the other students is the tendency for some autistic individuals to imitate others (Peeters and Gilberg, 1999). Therefore if another

student is misbehaving, an autistic student may follow as he or she believes it is normal behaviour in the class. During observation this was evident with 'Albert'. If the other students had difficulties in focusing themselves, he would imitate their behaviour and this would start a whole new round of behavioural issues. 'Sid' was another student affected by this but in a more complex way: 'Sid' had a tendency to make animal noises rather than talk, and other children in the class started to copy him. This made him angry, and lose concentration which worsened his behaviour, and he then started to lash out, either hitting out or getting 'in the faces' of others and making louder noises. When he had no distractions, he had better experiences within the classes.

### People

One issue discussed across the range of sources was lack of clarity: teachers not explaining properly or giving bad or no demonstrations. During his interview 'Malthus' was asked what would make a difficult lesson for him: 'one in which the instructions are unclear and demonstrations not provided... then you are expected to do that perfectly, or perfectlyish [sic] ie [sic], 90 percent, and you don't really know what's going on. That's just hell for me'. 'Abigail' told me a story during her interview about how instructions can be conflicting from different teachers 'my early morning swimming I do one, two, three, four, five and then breathe; but some other teachers they put me doing one, two, three, and they actually confuse me because I can breathe more under water'. 'rs' wrote on the wall 'it is difficult unless things are repeated over and over. I need this before I take it in'. 'AB' wrote 'she was bad at explaining and it was annoying'.

The other issue which came up time and time again especially within the study of the nine young people, was sibling or friend rivalry. The rivalry or competition was not necessarily conscious – when asked directly about issues relating to others who were close, nothing was confirmed. However during questions when they were not focusing on it specifically, or during observation it became clear. Lack of self awareness, common for autistic individuals (Frith, 2003), is likely to be a



reason for this. ‘Malthus’ for example, during observation often looked over at his twin brother to see what he was doing. When his twin won a medal for good work, he congratulated him but looked very sad and asked his teacher whether he was good during that class. ‘Abigail’ clearly had issues about her sister’s performance during the activities they both attended. During interview especially it was noticeable that she became very sad and even upset when she was talking about this. She tended to revert to a younger persona, talking in a different and higher voice. ‘...well I have always been the one who does things first...and now she is catching up’. Later on asked if she will carry on with gym ‘yeh, because I know I’m almost there and the more I keep going the more chance that I might just be able to progress enough to catch up with ‘Susie’’. Another related issue was that she tended to be put in groups with younger children than herself ‘...every week someone comes up to me and says ‘why aren’t you over there?’. So I just say it’s ability not age. That makes me feel really bad, as if I’m not good enough’.

Another issue which came up was the way autistic individuals feel they are being judged whether or not they are. ‘Scarlett’ wrote on the wall ‘the most difficult thing is when people assume I’m stupid and cant [sic] take part’. This was also an issue for ‘Micky’ who wrote ‘I hate others thinking they are better than me just because they are not autistic’. For ‘Bob’ the issue was that potential judgment meant that he was uncomfortable ‘showing my work and stuff...unless I know I’m really good at it’ and because of that he disliked ‘being soloed out from everyone else’.

### Physicality

Space and people being too close was brought up often: ‘Freddie’ wrote about his judo class ‘people kept touching me and when close started breathing on me which I hated so I gave it up’. Experience indicates perhaps judo is not the best activity to learn if you have spatial or touch issues. ‘Verity’ wrote ‘I like to have lots of space around me especially if I have had a difficult day’. During interview ‘Jonathan’ spoke in great detail about the space around students at his kung fu class. ‘We all have to line up and there’s only 2cm between us’. When asked if

that small space made him feel uncomfortable he told me 'yeh... so there's one there and then 2cm and one there'. This explanation was accompanied by a demonstration.

Another issue here was struggling with the activity and feeling frustrated about this. This was seen on several of the observations. One in particular was 'Abigail' who clearly became annoyed with herself if she could not do a particular step in ballet. I saw on several occasions that she practised the step on her own several times and talked herself through it before executing it as part of the class. This was also evident with 'Jonathan' who, during partner work, became clearly annoyed with his partner who was doing it wrong, thus causing 'Jonathan' to be unable to carry out the technique properly. In contrast, 'Simon' struggled with various techniques but did not seem to be concerned by this at all and it appeared as if he hadn't even noticed. 'Albert' also struggled with various physical aspects of his learning including difficulties in standing still.

Sensitivities were also an issue with some. During observations I noticed that 'Sid' continuously played with his feet and stroked them. Asked about this afterwards he told me that they hurt a lot. His dad told me that when he started karate he would not wear the uniform due to it being rougher than clothing he would normally favour. It had to be soaked in softener for hours and hours until it was acceptable for him. 'Tyler' wrote in the secret box it was 'uncomfortable touching my toe'. 'Malthus' told me 'if we work too hard I get so tired and achy I might cry'. He also said of background noise 'if it's too loud I might get confused'.

## Negative Issues (continued)

<b>RQ4 Are there <u>other</u> issues that may affect the informal learning experience for Young Autistic Students?</b>	<b>Virtual Walls (Broad Range) <i>Autistic Voice</i></b>	<b>Mosaic Ethnography (Nine Students 5-15) <i>Autistic Voice</i></b>	<b>Secret Box Students (Broad Range) <i>Autistic Voice</i></b>	<b>Secret Box Teachers (Broad Range) <i>External Perception</i></b>
<b><u>NEGATIVE ISSUES</u></b>				
<u>ENVIRONMENTAL</u>	Size of room / groups Noise } sensory Lights } overload Dirty floor Too hot / too cold Mirrors and windows	Sensory issues Tired and hot Lack of space Loud and sudden noises		Mindful of over-stimulation
<u>EXPECTATIONS</u>	Rules: changes for and against Socialising Choices: not easy to decide That autistic student needs things different Competing Of teacher: should understand difficulties Creativity expected Same physicality as other students Teacher needs flexibility Pressure to do well Pressure to fit in	Lack of guidelines Rules: changes Biased to or against an autistic student Made to feel 'small' Teacher to punish correct student rather than everyone	Sometimes bored Slow progress	Not understanding 'autistic reality' Speed of class: autistic students sometimes get lost and confused. Teaching may need to be changed Parents don't take my autism into consideration (as a teacher)
<u>RESPITE OR 'GET OUT'</u>	Need to get away Time out Sensory overload: respite <u>before</u> meltdown	Time out needed Respite	Need time out when tired and achy	
<u>EXTERNAL INFLUENCES</u>		Can cause good or bad learning		

## Environmental

Many of the environmental issues have been discussed under different headings; space for instance and to a degree sensory issues. Other data in this category included too much noise and light. Interviews revealed most of the participants were affected by sudden loud noises including 'Bob', 'Malthus' and 'Abigail' and for some 'wall participants' including 'Tom' who wrote 'too much noise is annoying, other children shouting' and 'Scarlet' who was also affected by 'sudden loud noises'. 'Dangermouse' wrote about the bright lights of the sports centre which were 'the worst thing for me. If I was having a bad day, it would make it far worse'. 'George' was affected by 'dodgy halls used...either too hot or too cold, bright lights...'; while 'anna' was not happy 'when the floor is dirty and we have to sit down to ask and answer questions'. 'Alex' disliked 'rooms with mirrors' which is 'off putting and I can also see other people'. Some other individuals cited mirrors and windows as *distractions* as well.

The other issue cited by individuals across the range of data sources was size of the room or size of the group within the room. 'Jonathan' desired a bigger hall for his class 'because we don't have much room'; and 'Malthus' told me about his preference for a larger room because there 'is a bit more space to move around in and you can also practise your techniques without the fear of hurting a person'. This fear was echoed by others even though some were undertaking a martial art, which potentially could even accidentally hurt someone. During her interview 'Olivia' cited 'hurting other people and myself' as a discomfort; and I noticed during observation that 'Albert' had a tendency to say sorry every time he kicked his opponent during fighting sessions.

## Expectations

Many of the issues already discussed previously could also come under this category. One of the most common expectations to come out of the data is the expectation that attending the class would promote socialising. As difficulties with



social interaction are common for autistic individuals (Wing, 1996), it is often assumed that attending out of school activities is useful to encourage such interaction. However the expectation for the young person tends to be high and they can often feel pressured into fulfilling these expectations. Individuals may be able to select particular activities and classes based on their preferences but younger students may have to do what parents tell them to do. 'Prof Yaffle' wrote on the wall 'I learn tennis because I don't have to talk to anyone except my coach and that's the way I like it'. 'Lynda' writing on behalf of her young son wrote 'he doesn't like to socialise much with them but wants to dance so badly'. 'Crazy Black Cat' wrote about Brownies 'I didn't know how to fit in with the other children. After going a few times, and feeling left out, isolated and rejected by peers I began to dread going, so refused to go...' 'LB' wrote 'the organising of any social activity would just put me off altogether'.

Changes to rules; for and against were another issue for participants. Autistic individuals tend to like rules and stick rigidly to them (Frith, 2003). However, often teachers of informal education adapt the rules to suit these individuals and their particular needs. While for some, this is welcomed: 'Abbey' wrote about the difficulties with 'a teacher who is not willing to adapt and be flexible, not listen to the needs of the student'. However for others, this flexibility of the rules goes against everything they expect or indeed want. It either makes them feel isolated or stand out, or confuses them. On the wall 'LB' discussed the rules and swimming strokes which were adapted for him 'so when the gun went off and everyone else swam off doing butterfly I just stood there crying, because I should be following the same rules as everyone else. Why did they do that to me?' During his interview 'Bob' talked about possible changes for his autism 'but I don't think the rules should be bended [sic] too much. Like, I think everything should be the same but slightly more help'. Like 'Bob', 'Abigail' talked during her interview about her autism and how it can be an excuse 'I think that's kind of bad in a way because I don't want to blame the things I am doing on my autism because that's not really my autism's fault that's me'. 'Scarlett' wrote on the wall 'I don't need special things to do – just

someone to understand my difficulties and be sympathetic towards them when I appear to be having difficulties’.

According to some participants a key expectation is pressure to do well, be the best, be the same as others; pressure from parents, teachers, friends and often self pressure. ‘Pickle14’ wrote I also hated it when they would put pressure on you to do well, and then moan at you if you didn’t – it just makes you feel really stupid and like you can’t please anyone with what you do’. ‘Jake’ enjoyed his classes but ‘didn’t want the competition aspect of it all’. ‘JJ’ hated ‘being forced to do team games – others relying on me to do well’. ‘Abigail’ told me ‘sometimes I used to run out of my ballet classes because of something I thought was too hard, or I couldn’t get it at all...’

### Respite or ‘Get Out’

During observations I noticed repeatedly that the autistic students would sometimes ask to leave the class, or would need to sit out. When questioned about these breaks, I was told that they were feeling overworked and needed time out. ‘Sid’ was a clear example of how this *respite* was necessary at times and ‘time out’ sitting quietly with his parents was effective most of the time. During one session both ‘Malthus’ and ‘Albert’ were affected by the change of hall to a very small room with a myriad of distractions. Both needed to leave the room part way through and ‘Malthus’ sat out for a lengthier period.

### External Influences

As with any activity or learning situation, external influences may sometimes impact what goes on during a class. For one student ‘Albert’ during an observation I noticed a ‘frisson’ between him and another child. They were both spoken to by the teacher and it turned out that the other child and his friends had been teasing ‘Albert’ at school about a particular sensitive subject to him. It had apparently continued at the start of the karate class and was now spilling into this activity. It

was affecting 'Albert's' behaviour, his concentration and his overall performance. 'Sid' was another child whose learning was affected by what happened outside training and how he was in class was largely dependent on what had happened that day at home or school. During interview 'Olivia' told me that if she had a tiring or upsetting day at school, she didn't want to go to karate and in turn being pressured to attend affected her learning experience.

## Positive Issues

<b>RQ4 Are there other issues that may affect the informal learning experience for Young Autistic Students?</b>  <b><u>POSITIVE ISSUES</u></b>	<b>Virtual Walls (Broad Range) <i>Autistic Voice</i></b>	<b>Mosaic Ethnography (Nine Students 5-15) <i>Autistic Voice</i></b>	<b>Secret Box Students (Broad Range) <i>Autistic Voice</i></b>	<b>Secret Box Teachers (Broad Range) <i>External Perception</i></b>
<u>TEACHER</u>		Getting attention for being good at something Lots of encouragement Rewards Teacher noticing good work Trust teacher Inspiring teachers	Amazing teachers Good communication	Working together with the student Watching the student develop See progression See student achieve goals
<u>LEARNING METHOD</u>	Movement, Shape and Colours Tactile way with basic language	Variety of activities Clear instructions		Challenging questions Often pick up the new techniques quicker Visual commands useful Structure to accommodate autistic student
<u>COMFORT AND SAFETY</u>		Comforting to have siblings / friends with you Being comfortable with peers in a safe place Supportive peers Good atmosphere Trust friends	Being able to defend myself Improving confidence Making friends	
<u>ENJOYMENT</u>		Love subject	Enjoyment of class Learning new things Feeling motivated Being inspired	Joyful personality is inspiring



## Teacher

Although much of the discussion around teachers came earlier, there were a few issues seen specifically as positive issues and not necessarily about the relationship that warrant additional dialogue. Getting attention for being good at something was clearly a positive issue for the participants within the mosaic study. 'Malthus' told me during interview he liked to 'exceed their expectations' so that they would appreciate him. 'Abigail' told me 'I like it when someone congratulates me. I like it if a teacher notices how I am doing the work; that I'm actually getting better...' To many of these young people a good teacher is crucial to how they respond and learn. 'Malthus' wrote in his diary about his teacher 'she makes the lesson fun, educational and most of all, inspiring'.

## Learning Method

The wall drew comments relating to specific learning including movement and colours, but other impacting issues appeared to be more important to the learning experience. During interviews, most participants talked about their favourite parts of the lessons; particular techniques or dances, or swimming strokes. However having a class with a variety of activities seemed to be the most positive learning experience. Observations of 'Jonathan', 'Albert' and 'Sid' in particular demonstrated that regular changes of activity kept interest and maintained focus and better performance. Observation of others including 'Bob' and 'Abigail' proved that this is not always the case and too many changes during a lesson may cause confusion and anxieties. Discussion around these areas will be expanded in Chapter 6.

## Comfort and Safety

Although as I discussed earlier in this chapter sibling and friend rivalry can be negative, for others it can have a positive effect. For 'Olivia' the presence in her class of her twin sister and two brothers had a calming effect. I observed a lesson

in which her twin was not present, and she was not so focused and performed less well. For 'Joe', playing a game of football at the start of his karate class allowed him to socialise in a safe place with people he knew well. Informal educational activities give the students a safe place to meet others who have the same interests.

### Enjoyment

The main positive issue to come out of the data is that informal education means that young individuals can choose their activities by favourite subject, what inspires or motivates them, or simply because their friends go as well, and it is largely their choice. 'I go to ballet because I love doing ballet' ('Abigail'). 'Karate is currently one of my favourite things' ('Malthus').

### Teachers' Perception

Teachers who are experienced in teaching autistic students are clearly aware of some of the negative issues which may affect their students, for instance, distractions. For one teacher who is autistic, distractions can work for both parties and this is an interesting issue, and one which I shall discuss to a degree during my personal reflection. In addition the teacher highlighted an issue with students and parents understanding him or her as an autistic individual. An issue which was brought up was of other students' understanding and any teacher who takes autistic students into classes, may need to address this in some way? One teacher wrote that autistic students can upset other students, but does this not presume to prioritise non-autistic students. This reflects the inclusive versus separate class debate and will be discussed further in Chapter 6. It was recognised by some that teaching may need to be adapted to accommodate the autistic students' needs.

The teachers who took part in the 'secret box' mostly took pleasure in teaching autistic individuals. Positive factors included watching students develop, seeing

progression and achievement of goals. They also saw them to be effective learners with some producing challenging questions, and abilities to learn more quickly in some cases than non autistic students. About one student 'anon' wrote 'seeing his joyful personality is inspiring'.

## **BRIEF OVERVIEW**

This research has not been without its challenges but I am more than happy with the data it has produced. It has allowed the young participants to have a 'voice' which can be utilised to create a more positive learning experience for many students in the future. This chapter has presented the issues which have resulted from the data, as being those which impact the informal education learning experience as seen by the very students who are central to this learning. This has gone a long way to answering the research questions set out in Chapter 1. I recognise that many of the issues discussed here may have occurred even if autism was not brought into the mix. However it is clear that many impacting factors on the learning experience are magnified because of the autism, and many are solely in relation to autism. Moving forwards, Chapter 6 will expand on these issues by discussing the data results, aligning them as far as possible to autism theory. In addition I shall reflect on the research design, what happened 'backstage' and how the study affected me as a researcher and as an autistic adult.

## **CHAPTER SIX – DISCUSSION**

This chapter will allow me to discuss the data provided by the autistic ‘voices’; to reflect upon what they have told me, and to demonstrate that I have listened to them. Along the way I shall reflect upon the autistic characteristics, tendencies and theory which may have impacted their learning experiences as well as search for themes which have arisen across the data sources. The discussion is influenced by autoethnography, more so here than in the rest of the paper. Reflection is key to discussion (Etherington, 2004), and as a researcher, professional and autistic adult, I have been affected by the study more than I had initially anticipated.

Throughout the research study, I have self-reflecting in two main ways: firstly in a private journal in the same way as the young participants in phase two of the study; and secondly via an on-line blog. This blog was started for two reasons: (1) to record the doctoral process including promoting and discussing the research; and (2) to reflect upon my Asperger’s Syndrome diagnosis and subsequent feelings and actions. This self-reflection has recorded facts and details but more importantly my own ‘voice’ about autism and the research.

The following blog extract demonstrates my perceived value of listening to the ‘voices’ of these young autistic individuals; and to some degree justifies the value of this research (Ellis, 2013):

On Sunday evening, I finished my interview transcriptions - the last one of which took many hours. I remember the interview well; it was a young lady I did not know prior to my research, but I have got to know her more and more during the past couple of months. Listening to the interview again, I heard things I didn't really hear at the time: the excitement in her voice when she was talking about the activities and the people she loves, and at times the sadness in her voice regaling stories of particular teachers, other children and the way her autism has shaped her young life so far. I smiled, laughed and came close to tears at various points throughout the transcription. In many ways she reminded me of myself at a similar age.



As adults how much do we really listen to what the children around us actually say? Yes of course we hear them, but do we really take time to understand what they actually mean? For me as an adult with Asperger's, it is not always easy for me to understand the underlying meanings, but sometimes I think I should try harder if I can...

I find it a great privilege that these young people have trusted me enough to tell me about their lives. All of my interviewees (and parents) invited me to their homes to undertake the interview, to encroach on their personal lives, to welcome me into their private domain. That is an honour.

My virtual walls are filled with autistic individuals opening up to me - telling me about when they were bullied, how ballet gives them such confidence, what has influenced their lives. I have not yet opened my secret box, hopefully filled with the teachers' perspectives of what it is like to be in the lives of these special individuals as well as other youngsters who did not feel so confident with their views and beliefs.

Each and every one of these individuals has trusted me with their information, and has made me feel special for doing so...

### **Personal Motivation**

For me as an autistic adult, motivation is absolutely essential to any learning experience I have had, and I was interested to see whether the data proved that to be the case for others. However I had not expected such a wide range of issues to arise from the data.

As I analysed the data it became clear that these young people have a desire for learning and reasons for undertaking an activity including learning new skills, acquiring knowledge and preventing boredom, were at the top of the list for most of them. During observations and interviews, what struck me was their enthusiasm for the activity. For many of them, they could not wait to show me what they do: according to parents they got excited for days waiting for me to come and watch their classes. 'Malthus' and 'Abigail' in particular during interviews repeatedly stood up to demonstrate a move, or series of movements

from their activities. 'Malthus' burst into song on a number of occasions while he was trying to illustrate a point he was making. 'Albert's' love of learning a language while at karate classes, was clear to see during observations. He tried to show off this skill at every given opportunity. Experience working with autistic children as a teacher backs up the data in that for most of them, showing off their knowledge or skills is important to them. Often in question time it gets quite competitive. As an autistic adult when I undertake an activity, I am always keen to get constructive tuition; I find it uncomfortable and annoying to be told to have a go and left to practise without lots of detailed instruction first. This was evident for others who posted on the virtual walls; often they felt that an activity was being treated more as a social event rather than a structured learning experience. This frustration is not surprising as a trait of autism is that individuals like to follow *structure* (Wing, 1996). Lack of structure can be uncomfortable and even disorientating and can cause extreme anxiety or anger. 'Richard' clearly participated in his particular activities, music and bell ringing, as they had focus and worked with his *obsessions*, another trait of autism I shall later expand upon. A further posting on the wall revealed that 'Sam' was motivated by the structure of classes, believing that the discipline would eke out 'idiots' who did not really want to learn.

Many participants it seemed were keen to prove their worth to others. Goffman (1959:17) might suggest that an individual is behaving in a certain way in an attempt 'to evoke from them a specific response he is concerned to obtain'. There were likely a variety of underlying factors here, one of which was the desire to 'fit in' with the non-autistic students. This confirms much of the literature including Shore and Rastelli (2006:73) who note the common 'desire to have friends' within social and educational situations. In contrast, some participants clearly wanted to stand out and be noticed and this might, in their own mind, be a way to make friends. Often a difficulty for autistic individuals is that while they may yearn for friends, they have no idea how to make or keep them and this 'social conflict' (ibid) can often lead to unusual or inappropriate ways to attract attention. From personal experience I would agree that for a number of autistic individuals,

these difficulties at some stages of their lives often drive them to become extraverts as a result, perhaps consciously exaggerating their differences to become more accepted. Autistic individuals within this description are often referred to as 'eccentric' or 'quirky'; the latter description one I have always used for myself even prior to diagnosis. Triggers for individuals wanting to prove themselves include being teased or bullied including name calling, peers getting ahead of them in some way or thinking they are better than them, and for one interviewee, keeping up with a sibling who has a tendency to be better at most informal education activities. This situation caused more upset than the young person admitted to but was clear to me during both interview and observations. Teachers recognised that many of these young students thrive on recognition for a job well done and enjoy receiving rewards, both material and emotional in the form of praise. Of course this does not just apply to autistic individuals, but it was clear from observations that praise and formal recognition is crucial to their learning experiences and in some cases is the difference between continuing an activity and giving up. Some individuals aim for heights which may seem unreachable, for example, winning the Olympics, but the focus, determination and obsession of the activity, fuelled in part by their autism, keep pushing them. Paradoxically they can also be the causes of a negative learning experience if a teacher is not encouraging and supportive; or if they perceive they are not doing a good enough job. Often an autistic individual will have very exacting or high standards to be achieved and be demotivated if they perceive they are not reaching these. As an autistic adult I recognise this and I have given up many informal educational activities for this reason.

Personal reflection during the Paralympics in 2012 concerned the language used and the ethos behind it and how it affected personal motivation (Ellis, 2012):

I am currently fascinated by the Paralympics, and it has really got me thinking about disabilities – in fact it is not about disability but all about ability... Perhaps a 'disability' motivates a person to do better, make their life count – personal motivation then is key to a more positive learning experience...

A further motivation which came out of the data was related to building confidence and proving their worth to others was clearly related to this. For many it was a way to stop bullying, something positive which would build their confidence and enable them to deal with certain situations. Many of the informal learning situations were chosen by them and in some ways, it was more about proving their self-worth – allowing themselves the confidence to take control, to learn in a safe place. ‘Abigail’ talked a lot about enjoying positive experiences which made her feel better about herself. As several of the study participants were learning martial arts, achieving physical and mental self-confidence was also a clear motivation. Vulnerability is common for autistic individuals as they deal with uncertainties around them, and the ability to feel self-confident is important for them to handle the pressures they may feel. Many participants talked about the classes being a place where they feel safe, somewhere they want to be; and teachers also pointed out that safety and comfort in the class were important to a positive learning experience. One of my reflections concerned a class I was teaching with mainly autistic individuals in it:

One of the lads with ASC, who I will not name, said something poignant to me. He said he is confused all the time, especially at school. The only place he is not confused is at the karate class. That was definitely an 'it made my day' moment. (Ellis, 2011)

It was unsurprising that external influences featured as motivators for participating in certain activities and to some extent impacting on the learning experience. The first reason here is that the participants are young and parental influence is still a contributing factor. Secondly, autistic individuals often show *echopraxic behaviour*, that is, they tend to copy the behaviours and actions of others, especially those who they admire or aim to emulate, or that of their siblings or friends (Attwood, 1998). This is often in an attempt to ‘fit in’, or to encourage others to ‘like them’. It can also be simply because they are unsure how to behave or react to circumstances, and copying others allows them ‘control’. The data revealed that television and film also played a part in this influence. The Olympics



and Paralympics in London were held just before the research started and these were mentioned by several as motivators for learning sport. Younger children were clearly motivated by television such as ninja turtles, Karate Kid, Kung Fu Panda and so on. This is more child behaviour rather than specifically autistic, but it is important here to remember that autistic children are potentially more impressionable than their non-autistic peers because at a young age they rely on others to show them what to do. A characteristic of autism however is that of *taking what people say literally* (Bogdashina, 2005) and if a form of media has promoted a particular skill or activity in a way which captures the autistic individual's attention, he or she might actually take it on board without question. Appropriateness would have no place in this circumstance. This literal understanding of language can be illustrated by many autistic individuals having difficulties in 'understanding metaphors, irony and jokes' (Roth, 2010:73) and they may get confused if these are used within their learning experiences. Additionally other children may tease or bully them for misunderstanding or getting confused with language used in socially interacting.

Behaviours which affect most autistic individuals are *obsessions* or *special interests* (Grandin, 1992; Wing, 1996; Baron-Cohen, 2008). Preoccupations with particular interests can reach such a level, that all other activities including normal day to day tasks are ignored or excluded. The data within this study clearly shows that special interests are a particularly strong personal motivator. Postings on the wall reveal some cases where special interests clearly take over a person's life. 'KD' turned his teenage obsession of dancing into a business and talks about how it has shaped his life, continuing even now in his sixties. He writes 'I would hate not to be learning... I will never give up because I will never be old'. As a child of four years I started to dance. I remember dancing every evening after school, and at weekends competing. There was a period six years later when I had serious health issues, but I continued to dance at the same level and got angry and upset if others tried to stop me. I would simply *shut down* if I could not dance. This *inflexibility* when interests or routines are interrupted or stopped is common and individuals react in various ways, one of which is to go very quiet and stop

interacting with others, often appearing to hide away, finding a place where no-one will disturb them.

As a learning experience these special interests can sometimes cause an individual severe anxiety if things go wrong, or the level of achievement is not considered high enough. Frustration at not being able to get a particular skill right can send the autistic individual into various sensory states: anxiety, shut down, inexplicable rage. At a deeper level it could also lead to obsessive compulsive disorder (Kutscher, 2005).

The last personal motivator to come out of the data and for me the most interesting and insightful one is that of control. Control is achieved in many ways and for some it was simply literal. A music teacher wrote that her autistic students are calmed by music which brings them control of their anger or anxiety. Others spoke about physical activities controlling their balance or co-ordination difficulties. Another common concept was that of controlling the way in which they socialise; being around others with the same interest in an environment which is safe and comfortable. For many it was their choice to participate in a learning activity and this gave them control over an aspect of their life. 'Abigail' explained that at school they are told what to do, which subjects to learn, but outside school she can go to ballet classes because she wants to. If she doesn't want to go to a swimming lesson one week, it is her choice. 'George' agreed with this idea 'It was my choice to do them and I was more motivated than with school subjects which I was made to do whether or not I liked them'.

The fascinating action of control is one which was not expected, and it would not have necessarily come from the data if observations had not been used. It is one of those motivators which a person may be largely unaware of; certainly for an individual as young as six. Even if he was aware of it, he was unlikely to tell me about it as it was certainly used to his advantage. This control used by 'Sid' was that of performing or behaving for reward. As I discussed in Chapter 5, his parents told me that they had offered him rewards as motivation for performing tasks and

behaving well, and I wonder whether for him at least this may have backfired. Watching him in classes, he was very conscious of what was happening around him although to a general spectator without autism or teaching experience, this may not be evident. His demeanour would change if another child was praised; he would often ask to leave the class for a short time if the teacher was not paying him some attention. However for 'Sid' praise was not nearly enough; rewards needed to be tangible and in his classes nothing short of a medal would appease him. To start with he was happy with stickers and certificates, but as soon as he realised medals were on offer, this was all he wanted. This 'reward inflation' (McLean, 2009) can be dangerous as there is no impact of these rewards if they are not continually upgraded and McLean argues that 'reward-based motivation is not sustainable or healthy'. Building upon Gilbert's theory discussed in Chapter 2 (Gilbert, 2002), Deci and Ryan (1985) suggest that this continued dependency on rewards may have long term negative effects on intrinsic and self-motivation. This is supported by research that suggests while rewards may give immediate learning gains, paradoxically they are likely to lower motivation for continued learning (Eliot and Dweck, 2007). In the autistic child this can become another obsession, and I agree with Puckett and Diffily, that learning is ideal if the child learns that positive interactions and good behaviours enable a better experience (2003). Certainly this is easier to control in the learning situation, but if the autistic children are used to this culture at home, they will often expect it in in classes or activities as well. For the younger child especially it may be difficult for them to distinguish between the two. Praise for continued effort however is essential, as I discussed earlier that autistic individuals like to be recognised for a job well done. I can identify with this myself and get quite upset or disheartened if I have been working hard on a project and get no positive feedback. It is not about boosting the ego, but about being encouraging and supportive. Autistic individuals have a certain lack of confidence and can easily become despondent and depressed. Dweck (2000:143) argues that more vulnerable children have 'a different set of beliefs' and that 'beliefs about the self... play a central role in their motivation'.

This issue of control is one which to me seems to be central to motivation for autistic individuals. Each theme which has arisen from the data has an element of control about it: controlling the choice of activity or learning, controlling how they are perceived by others, building their self-confidence, controlling their environment and to an extent who they socialise and learn with, and controlling negative tendencies: rage, anxiety, frustration, lack of confidence; all of which are often associated with autism although are not characteristics per se.

What follows is a personal reflection via an on-line blog (Ellis, 2012) concerning my own learning experiences:

With the learning experience being so central to my research and my thesis, I thought I would reflect upon my own learning of recent weeks. I am not usually much of a sport spectator, but this year I watched a lot of Olympic and Paralympic action. Although I teach karate, it made me realise that I have not learnt a new activity for many years, and I had forgotten how it felt. I wanted to feel that excitement again.

I remember years ago, a martial arts instructor on a coaching course teaching some basic skills of fencing, and I thought at the time it looked fun. We've all seen swashbuckling films and the sword fighting. I am also drawn to things with uniforms as it means I look the same as the others and don't stand out. So, I did what I do best - research - lots and lots of research, trawling the net for a recognised, safe and relatively local club. I sent an email to an instructor and asked about fencing lessons. After some time he came back to me and to cut a long story short, I have now been fencing for just five weeks.

My first lesson was nerve racking, I had the usual anxieties of starting something new, meeting a new group of people, would I be able to do it? I was given a lot of strange clothing, a fencing mask which was an experience in itself - like looking through a colander - with lots of little squares in front of my eyes (it didn't help that it was far too big) and a foil (blunt tipped weapon). To start with I felt like I had been given the equipment and told to get on with it which really I had. It seems fencers fence and along the way teach each other. Not what I am used to at all and pretty frustrating for me if I am honest. Later in the lesson a guy came over and said you look lost - do you want some help? I am so glad I said yes because since his intervention I have been able to learn a lot and I left that



first lesson exhilarated. I spent the next few hours on the internet looking up equipment, clothing, YouTube videos of fencing...

A few weeks later and I still love it - of course I have bought the equipment - there is only so much I can stand of communal clothing and mask and I wanted a foil of my own to practice with.

But... this is a danger zone for me. I start my learning process full of enthusiasm, do well initially, buy into the experience, and then I get frustrated if I don't start getting better. I am competitive and hate to not understand or not learn and improve. So time will tell if I can fight these frustrations and keep calm and learn at a steady pace rather than my usual pace of 'it must be now'. I hope so. Of course if it wasn't for my age, I would already have the Rio Olympics in my sights!!!

### **Student/Teacher Issues**

There are two research questions to be answered here; firstly about teacher qualities and their impact on the informal education learning experience; and secondly about the actual relationship between student and teacher. As I mentioned in previous chapters, it was important in my study to allow as much flexibility as possible to collect the data; not only because the participants were young and arguably disabled, but also because the range of questions to be answered relied upon a flexible approach. Some of the issues sought could not be resolved from simply using one method. Although the participants' 'voices' were central to this study, one question in particular about the student teacher relationship relied to an extent on an outsider's view. Often it is the case that the people within a relationship are not always the best ones to see what is going on. I would argue that the additional use of observation as a method was the right decision and one which has been valuable in collecting the data. Similarly Jones (2002:91) argues for observation via video by colleagues of teaching sessions in schools as a 'valuable' way to 'identify positive features and aspects which might be done differently'. An on-line blog entry made as part of my self-reflection during the study supports this:

Although I am not using observation as my main method, it is part of my pluralistic approach to methodology and I am finding it so useful.

Many of the youngsters in my study are shy, inward and loathe to speak to many around them, especially adults. Many of them of course, are the absolute opposite and these are the students I am also interviewing and collecting more varied data from in my study. The former group though seem to be the ones providing me with some fascinating observation data - perhaps because they are less aware of themselves than others, the data is more real in some way? There is no act, they are not playing up to me, for the most part, they seem not to care that I am taking notes or even there

Ellis, 2013)

I found during the initial research period when I was seeking participants, many potential candidates did not necessarily want to be interviewed or collect a diary. For some it was too much like more school work and took effort on their part. Some asked if I could simply watch them during their lessons and it seemed that for two parents at least, they were more comfortable with that method than the planned alternatives. Further reflection and exploration into the mosaic approach enabled me to adapt it slightly to take these young people into consideration and take into account their heterogeneity. Ethically I was given informed consent by the young people, parents and teachers and other students within the class were used to spectators being present, so for them it was not different to any other class. There were clear benefits to using this method together with other methods, the main one being the opportunity to see the interactions between students and teacher and reactions of the student to both the teaching methods and the activities themselves. This was supported by questions during interviews: some of the participants gave me answers to questions which were often polar opposites of what I had observed. This was possibly due to subconscious actions during the activities or a lack of *self-awareness*, common in autistic individuals. Of course during an observation, I would not be able to see an action as 'subconscious' but ensuing conversation with participants sometimes supported this. For example, one participant was observed to lack rapport or engagement with some children he was asked to teach a particular skill to. During interview he told me that he was

very good at interacting with and teaching other children and that they responded well to him.

For the majority of the participants, the relationship between the teacher and the student was thought to be important. On average across the range of data collection methods 88.75% agreed this was the case. Just 6.25% thought the relationship was not important and 5% did not answer the question. Several participants said that it was important to them that they tried hard for a good teacher and liked to impress him or her. It was significant to see that the teachers agreed with the students that the relationship between the two had a large impact on the learning experience. For 'Jake' the 'relationship between teacher and student is paramount to the learning experience'.

One interesting issue which came out of the data here, presented briefly in Chapter 5, was a somewhat over reliance on the teacher from some participants. 'Poppy' wrote on the wall 'if my teacher is away one week, I refuse to learn and my mum has to take me home again'. This was also the case for 'Jonathan' who told me how he left one club because the teacher left and he followed him to another club. 'Sid' also struggled with changes of teacher and would often not attend one week because the previous week his favourite teacher was away. From personal experience in a learning situation I know this can be common; I have similar issues myself and once I get to know and trust a teacher, will panic if someone else takes a class. I have left dance schools for this reason and similarly changed fencing clubs for the same. This may be in part due to the *resistance of change* common with autism. It can take some time for individuals to get used to a situation or a person, and if it suddenly changes this can cause great anxiety. Golding (1997:47) discusses 'well-behaved' students' reliance on particular adults as *excessive dependency* where being 'without adult cues, the students did not have the confidence to initiate or even carry out familiar tasks and thus appeared as passive or lazy'. They suggested work on confidence and self-esteem to develop aspects of personality as well as developing a suitable environment.

As far as these students are concerned, one way around this, especially if classes are taken by more than one teacher, is to engage one or two peers within the class who can be 'go to' individuals if a student is feeling anxious or needs someone else to confer with. They will need to be individuals the student feels comfortable with. It can be a way to ward off any difficulties before they escalate and can also be useful to encourage a degree of socialising without the expectation that they actually become friends thus removing any pressures.

A whole range of issues came out of the data to explain how teacher qualities might impact the learning experience. Qualities which were deemed essential came up across the range of data collection methods. At the top of the list for most individuals was the ability to recognise student needs as well as patience and understanding. For many autistic individuals it can be frustrating when people assume they are all the same; that them being autistic means they will struggle with a particular activity or will need help in a specific area. On the other hand I have observed learning situations where the teacher pays no attention to the fact that a student is autistic and expects them to react in the same way to instruction as other non-autistic students. For example, a complex combination of techniques are demonstrated once and then students are sent away to practice. For many students this is not a problem, but for students who might have issues with *processing information* and the speed in which they can do so, common in autism, this is likely to be bewildering, confusing, at best frustrating and at worst may cause an attack of anxiety or even rage. It is important for a teacher to get to know students and take into consideration the ways in which they process and learn new skills or knowledge. Often for an autistic student the key is to learn one new idea at a time before moving on (Jordan and Powell, 1995). If a physical skill is being taught, several demonstrations of the skill may be needed plus lots of practice and individual explanation in between before the skill can then be reproduced effectively. 'Molly' explained 'the teacher needs to realise I may take longer than others to digest instructions'. 'This of course may not be the same with every student and it is crucial that the teacher gets to know individual student's preferences of learning. While this is not necessarily possible immediately,



especially in a larger class, simply the willingness of the teacher to adapt a teaching method to take the student's needs into consideration would be ideal from the student's point of view. 'Richard' requested of his ideal teacher one that 'understands and helps accommodate for my different learning style'; and 'Abigail' wrote in her diary that it upset her when a particular teacher taught her swimming as she didn't understand her instructions.

Paradoxically some students have also had experiences of teachers making assumptions that because of their autism, they need to repeat instructions over and over, and teach them as though they are much younger than they are. 'Abigail' pointed out in her interview 'she seemed to treat me as if I was kind of you, you know, a toddler or something. Some teachers do that, if you can't do something the first time... I am going to be a teenager next year and that's really annoying'.

What comes out repeatedly here is the need for teachers to be patient and learn to understand the individual students:

... I have been teaching this morning and have been watching the children in true ethnographer style. They are all so very different and among them is a myriad of characteristics - each one unique to the child, some more pleasant than others admittedly, but all unique. There is one little girl, not a student but a sister of one, who always chats to me while I am packing up at the end of a session. She is only 4 but she is so intelligent, she asks lots of questions, and notices everything. I am looking forward to teaching her later in the year when she turns 5  
(Ellis, 2011)

An issue which came up time and time again was the need for sensory awareness. *Sensory issues* affect the majority of autistic individuals in one way or another (Bogdashina, 2010). The theory behind these was discussed in Chapter 2, but there are many issues which occur in the informal education environment. One common issue is the room in which the students are taught. In many such activities, the room is a large bright sports hall, or large community hall where there is often bright lighting; usually fluorescent lights which can be painful for the

autistic individual both with the type of light they emit and often with the high pitched buzz which comes from them. To the non autistic student or teacher this may not even be noticed but to someone who is hypersensitive this can be excruciating. In addition lots of people talking at once, music, and sometimes other activities in the same hall, for example, badminton in the courts next door, and the senses are overloaded. Add in the instruction from the teacher, other children chatting, and the frustrations of learning new skills, and you have an unsatisfactory learning situation. While there may not be much a teacher can do to change the actual environment, at least being aware of the way it affects the autistic student and being a little more patient and understanding will certainly help in some way. I would argue however that there are little things that can be done to change the forced environment although resolutions are outside the scope of this study and will form part of a future project to inform a teacher development programme. I shall come back to specific sensory issues later in the chapter.

Participants also saw a supportive and encouraging teacher as essential to their learning experience as well as one who was kind. 'Dangermouse' wrote that his teacher 'encouraged me... to be the best. He helped me into adulthood and I am far more confident than I would have been otherwise'. 'Maggie' agreed that a teacher 'should push you to do your best or even better'. 'Abigail' during her interview talked about the importance of encouragement and kindness from her ideal teacher on many occasions: 'they come over and pat you on the back, and tell you, you can do this 'Abigail', you can do this'. Positivity is clearly associated with a good learning experience and 'Abigail' sums up her ideal teacher as someone who is 'always jolly...needs to be full of sunshine'.

The last essential quality to come out of the data is for a teacher to be respected and respectful of an individual's autism and indeed of that student's individuality. 'KD' explains 'if a teacher has no respect for the way I am, I have no respect for what they are trying to teach me'. This view was supported by others including 'Maggie' who said the teacher should be 'respectful of you, your views and your abilities'; and 'Damian' who agreed that an ideal teacher should 'treat people with

respect and work mutually with the person's motivations'. For any person who is deemed different from the norm, who has an atypical physical appearance, a condition which makes them unique or a distinctive personality; *self-esteem* issues may be prevalent. This need for respect is a way for them to seek control of their situation, of the people in their lives, and I would argue is a right for humanity. Sadly for these people who may be a bit different in some way, this right may not always be fulfilled.

An ideal teacher quality which had an impact on several of the participants was reliability. Autistic individuals place a great deal of importance on *routines* and *predictability* (Frith, 2003). If there is any likelihood that there may be a change to the normal routine or an interruption of a given schedule; it would ideally be discussed in advance to prepare the individual. If someone makes an autistic individual a promise and then breaks it, this can cause great anxiety or even meltdown (Shore and Rastelli, 2006). To the non-autistic person small changes may seem trivial but to the autistic person, these are often blown up into a major event. The autistic reality is not the same as for non-autistic people. Understanding of language and intent is different: naïve and literal (Bogdashina, 2005). Autistic individuals do not realise that this reality is not the same for others; they typically lack the capacity to understand how others will react or feel (Bogdashina, 2010). The need for predictability was supported by both 'Jonathan' and 'Abigail' as they both discussed in their interviews ways in which teachers caused a negative learning experience. 'Jed was so bad I had to leave cos [sic] he kept on like, we usually finished at quarter to eight, and he finished at five to eight' ('Jonathan'). 'I didn't get on very well with her. She was always turning up late for a lesson because our lesson started at four o'clock and she was always ten minutes late which upset me' ('Abigail'). Autistic individuals may take a long time to trust another (Willey, 2003). For me as an autistic adult, it is all about being able to be myself with someone, not feeling awkward or that I am being judged in some way; and feeling that I can ask anything if I do not understand without embarrassment. However it can only take one small act to lose that trust, and it is often difficult to get it back again completely. If an autistic individual

perceives that the trusted person has let them down, this can be of great detriment to the relationship. Often it is minor but to the autistic individual it is huge (Willey, 2003). Autism causes the brain to perceive events in very different ways from the 'norm' and it is difficult for non-autistic people to understand why they often react in such a dramatic way.

It was interesting to see the difference of opinion on whether a teacher should know about autism or indeed whether they are autistic. It seemed in most circumstances that they were happy that their teacher knew about their autism, but I found it was often the parents who did not want the teacher to know. At the start of my own experience of teaching an autistic child, it took the parent a year of my teaching him for her to reveal the diagnosis to me. I am unclear whether this was because she did not feel it was relevant or perhaps it took her that long to trust me with the information. Perhaps it is simply a need for the parent to protect her child reducing any possible unfair treatment or teasing in the class. For most of the young people within the mosaic stage of the research they were happy for their teachers to know about their autism and perceived it as essential knowledge. I am of the opinion that while some do not want the autism to be public knowledge, they still expect consideration of their needs. 'Molly', for example, wrote 'the teacher needs to realise I may take longer than others to digest instructions'. 'Butterfly73' 'wished the teacher would have recognised that (her sensory issues)'. 'Pickle14' clearly appreciated her teacher understanding about her autism and discusses the ways in which her teacher adapts for her needs '...she knew when to give me my own space...'. If the autism is not made known to a teacher how can she be understanding and flexible? Surely this puts up a barrier to the learning experience immediately. The other issue here which impacts the learning experience is with parents who choose for the child not to know about the diagnosis. How then does the teacher fulfil the needs of the child without appearing as though she is singling the child out either in a positive or negative way? I have had experience of this and it can cause some difficulties within the learning environment. I taught one young man from the age of nine to seventeen and in that time he had no idea of his Asperger's Syndrome. He often asked me



why he found learning so difficult, why he reacted in different ways from others in the class. It put an immense pressure on me as a professional, trying not to give him special attention while needing to adapt the way I taught. As I teach so many young people with special needs and especially autism, other students are very 'autistic aware', and I was lucky that many of them took it upon themselves to help this young man, to support him when he seemed stressed or anxious. Peer assisted learning can be very helpful in these situations but not all young people are so lucky within their learning situations; and the question of whether a child should be told of their diagnosis remains a contentious issue and one which is clearly outside the remit of this study.

Despite the views of a minority of participants within the study that the relationship between student and teacher is not important or relevant to the learning experience; the majority clearly value this relationship and thrive on positive qualities of a good teacher.

'Lisa' sums up the ideal teacher as 'someone who understands the unique gift of someone with autism, cultivates an environment that fosters acceptance...'; 'Abbey' is insightful 'there is so much diversity nowadays that teachers need to be flexible or not teach'; and 'Matt' puts it simply 'teachers should be lovely, playful, fun and happy'.

### **Other Issues**

There are various issues which the data revealed as impacting the learning experience and these have been categorised under negative and positive. Some of these affect all students, both autistic and non-autistic, and some clearly affect autistic students predominantly. What must be understood however is that the degree to which the students are affected by these factors. Remembering the earlier discussion around reactions to certain events or situations and the autistic reality, the autistic student may react far more intensely to what may seem minor details. For example, the feel of a karate suit on the body may be a little

uncomfortable as it is made of canvas which is not particularly soft. An autistic person with hypersensitivities relating to touch may find this so bothersome it will affect every other aspect of the learning; it may cause loss of focus, irritability, anger or anxiety. Another person with autism may not be affected by it at all.

It is important to reiterate here the heterogeneity of the autistic community and the fact that these issues will not affect all autistic individuals. Schultz (cited in Waterhouse, 2013: no pagination) notes 'If you've seen one child with autism, you've seen one child with autism. Autism's like a snowflake'. In the same way no autistic individual is ever the same, follows that no educational 'recipe' for pedagogy will ever be the same. During the extraction of the data for analysis I took into consideration issues which affected many of the participants and discarded some which arose infrequently. In addition I used my experience both as an autistic adult and professional within the field of autism to make decisions relating to relevancy.

While there was a lot of discussion around distractions, this is not new information. Every learner is likely to be affected by distractions in some way, but it is worth focusing here on the ways and to the extent some of these distractions are likely to affect an autistic individual. One example of a distraction that might affect all students is having other students standing too close to them. For non-autistic students this might simply cause the other student not to have enough room to move properly and practise the activity. For the autistic student, this may cause several difficulties. 'NN' explains her discomfort of 'other children touching me or standing too close – I like my own space to breathe'. For 'Scarlet' the issue was with others touching her unexpectedly, 'I feel upset when others get too close to me or try to touch me without me letting them – like if someone put their hand on my shoulder suddenly'. Autistic individuals can be affected deeply by having their personal space invaded: often it is due to sensory issues, for example, if someone gets too close, their breath may be felt on their skin, and this can often cause actual pain for some; or the fact that another person is so close may create a change in the temperature around them thus causing discomfort. Others have

co-ordination and/or balance difficulties and physical activities may cause them to wobble or fall or need more space than a non-autistic individual. Claustrophobia-like feelings are common if there are lots of people in a small space; this is why autistic individuals have a tendency to avoid busy places if possible, such as crowded pubs, theme parks or even airports. My own places to avoid are shops at sale time or Christmas; and beaches at the height of summer, both of which send me to the edge of sensory overload. The nearest non autistic individuals get to a situation that is anywhere near similar 'seems to be rush hour' (Sainsbury, 2000:101). If autistic individuals reach sensory overload in any given situation, they have a tendency to shut down or '*zone out*'. They would do literally anything just before this stage to get out of the situation. Recently I heard from a colleague of a man who stole an item from a supermarket just to get arrested and removed from the situation. From my experience sensory overload can cause an autistic child to misbehave in a learning situation if he has learned that he will be removed from the class for a period of time. Discipline for an autistic child has to be judged on an individual basis as what might be considered appropriate for a non-autistic child, can potentially be a reward for an autistic child. Once again, the autistic individual learns ways to control the situation to make it more comfortable and bearable.

Some distractions may sound trivial to a non-autistic individual, but to an autistic individual they may be distractions of gargantuan proportions as Anna explains 'I don't like it when the floor is dirty and we have to sit down and answer questions. I don't like dirt. Perhaps they should sweep the floor before the lesson starts!' With this obviously disturbing distraction 'Anna' is likely to have difficulties concentrating on the questions putting her at a disadvantage to other students.

Other people can often be the cause of discomfort for autistic individuals and this was certainly evident within this study. For the children, it was often the behaviour of other children which was of concern – they could be off putting by making noise, constantly talking, or interrupting the teacher during explanations. This would distract the autistic individual. As far as the teacher was concerned, lack of clarity

and conflicting instructions confused and caused anxiety for the students. Several participants also talked or wrote about issues with teachers grouping students together to reprimand. This is a tactic for teachers who want to admonish students for misbehaving or because their performance is not as good as it could be, but do not want to single individuals out. Autistic individuals have a *strong sense of fairness* and would consider it inappropriate to be reprimanded for no reason, and would likely feel anger towards the other students and possibly the teacher. It could actually cause the student to perform less well next time if they perceive they will be told off regardless of what they do. At worst if it happens again, they might just give up the activity. For the younger child, it might encourage him or her to copy the bad behaviour just so that the potential admonishment would be fairer.

The other theme here which came out of the research especially at the mosaic stage is friend or sibling rivalry. This was especially clear with 'Abigail' who talked about her sister's progress time and time again, and also about friends who had started activities after her but progressed more quickly. I have to confess I identify with this. I often try to compete with others in a class if I am learning and get frustrated if they seem to be learning quicker or are better. In fact I have always used this trait as a motivator and have found it helps me to focus. It can have negative side effects however, and causes a great deal of anxiety if I perceive I am not 'measuring up'. Common in autistic individuals is a tendency to 'socialise' with or be drawn to others of an extreme age, either younger or older. I have many students who tend to 'hang around' and talk to me before the class rather than mix with their peers. Others like 'Abigail' have friends in classes who are several years younger than themselves. This age issue may be to avoid being judged by their peers and not having to 'fit in' with them; 'Dave' explains that he 'struggles when comparing himself to others his age'. I certainly remember at college having two friends who were ten years older than me and feeling really uncomfortable with people of my own age.

Another issue impacting the learning experience was categorised as physicality. Some of the themes from the data have been discussed within previous issues, for



example, space between students and some sensitivity experiences. Other issues discussed by participants included struggling with the activity, often due to co-ordination, balance or body awareness issues. These are common in autism. There was also mention from some participants of frustration at being unable to grasp the technical aspects of the activity, often due to the previously mentioned physicality problems. Autistic individuals can often get tired very quickly (Bogdashina, 2010). This may be due to the intense concentration needed for tasks, or to the sensory overload which often accompanies informal education learning situations: bright lighting, teachers speaking loudly, spectators chatting, music playing and so on (Bogdashina, 2010). This tiredness can result in the student needing time out to rest or get away from the environment. Failure to take these needs into consideration may cause the 'overloaded' individual to panic or get angry, or simply to 'fade out'; it is common for an autistic individual to suddenly appear detached or 'in his own world'. It is usually a coping mechanism (ibid).

One category which encompassed data from many participants and was quite varied was expectations. These were from student to teacher and vice versa. One expectation seemed to be that teachers expected all autistic students to be the same, to need the same type of teaching, to react in the same way, to need changes in the class. This came from teachers in the 'secret box' element of the research, and from autistic individuals in all research phases. The students were particularly frustrated by these assumptions as, quite rightly so, they wanted to be treated as individuals in the same way as non-autistic students would be. Just because one autistic student may need more help with the physicality of playing the violin for example, did not mean another would have the same difficulties. He may be particularly good at this skill but struggle with understanding good breathing posture. The activity or skill here is not relevant, but the problem is the assumption that all autistic students will be the same. They will no more be the same than two girls or two boys. This is one of the reasons that when students were describing their ideal teacher, understanding their needs was near the top of the list. Another area here was around the rules and expectations of students. There was distinct confusion from some individuals: most clubs and activities had

rules, what to do, what to wear, how to behave and so on. However, there were occasions when the teacher would make allowances for students, in particular those with autism, and would allow the rules to be flexible. For example, a piece of clothing normally worn for an activity causes sensory distress for an autistic student so he is allowed to wear something different. For some participants these flexibilities were necessary for comfort or autistic need. For others, they were distressed or angered at the rules changing for any reason. Strict adherence to rules and predictable structure is important to most autistic individuals, and changes to these may cause upset. This supports the need to consider the heterogeneity of the autistic community, but makes it difficult for a teacher to 'get it right'.

It is evident here that many of these impacting issues cross over into various categories. When the participants were asked about issues which impacted their learning experiences, mainly they revealed negative issues; of course they had expectations that the issues they discussed would be turned into positive learning experiences, which at a basic level is the notion behind the research. However some participants especially those who were interviewed did talk about positive experiences and it is worth discussing a few of these in terms of autism.

Many of the positive issues revolved around their teachers and it was encouraging to see them talk so enthusiastically about them. 'Jonathan' enjoyed his teacher's classes so much he followed him from one club to another. He talked about how much he liked his kung fu teacher on several occasions and was especially keen to tell me how loyal he was to his students. 'Malthus' talked heartily about one of his teachers explaining the importance of a connection with a student enabling him to read his movements. He was always keen to impress his teacher and got disheartened if he perceived his teacher was not noticing his efforts. His diary was also full of praise for his teachers. 'Abigail's' comments about her teacher, both during interview and in her diary, were also full of enthusiasm, especially when it came to being rewarded for good work. She loved praise and rewards including stickers and certificates for recognition of good effort. During observations I noted

her getting quite excited when a teacher noticed how well she was doing or gave her lots of praise; her face just lit up.

Discussions around learning methods split the participants into two preferences. Many of the participants enjoyed classes which provided a variety of activities and moved on quite quickly to prevent them getting bored. This was especially evident during observations with the younger children, and may simply be due to the lack of focus prevalent in young children. This is not necessarily the case however, as for some young people who may struggle with particular aspects of the class, moving on quickly between activities may be a way to avoid aspects they dislike or find difficult. For other students, lessons with too many activities are simply confusing and can cause overload of information. In my professional experience the key to a class suitable for all students is to have a variety of activities but for them to flow from each other so there are connections which makes sense but allow enough of a change for a bored student to remain motivated. Certainly as an autistic adult, I like a little variety, but if there are too many disjointed aspects to a class I get tired, confused and overwhelmed, not to mention frustrated. One aspect here to consider is the tendency for autistic individuals to need a structured routine. Many will join a particular activity, for example a martial art, because there is usually a routine to the way a class is run: warm up, basics, patterns, fighting, cool down, for example. If a teacher adds in a variant on this, to aid motivation or reduce misbehaviour or lack of focus in some students; the autistic individual then has to cope with this change of direction in some way. Often they will become anxious or upset by the change; a lack of spontaneity is common in autism (Jordan and Powell, 1995).

Other positive issues discussed focus around comfort and feelings of safety; e.g. learning within an environment with others who enjoy the same activities. Often individuals are dressed the same: dance, scouts, sport, and autistic individuals will not necessarily stand out as being different. With a good class, and a good teacher, the students will often support each other to do well and help each other. This increases the autistic individual's self-confidence.

## REFLECTION AND AUTOETHNOGRAPHIC MEMOIRS

As an overall experience the study has been demanding for a variety of reasons. Firstly, the planning and marketing necessary to encourage participants was far more intense than I ever realised it would be. It required much persistence and patience; luckily I have plenty of the former but sadly not so much of the latter, and for me as an autistic adult this has proved extremely tiring. At one point about a month into the research period, I doubted the methodology and considered whether it was worth persisting, or reviewing the specifics. I reflected:

It seems the potential participants do not want a 'voice'. Perhaps they would prefer me to extract information in other ways – certainly some I have spoken to would prefer me to make the notes, watch and learn... One parent told me he wouldn't want to write anything but could 'talk for England' even if it didn't make sense. Another told me simply 'he doesn't really have an opinion'... She said he just does what he's told to do. I would love to know what he really thinks. So I am trying to give these young people a 'voice', but I am starting to think that perhaps they don't really want one...  
(Ellis, 2013)

Rather than waste valuable time, I decided it was worth reviewing and spent time rereading the literature on the mosaic approach to ethnography to enable me to find a solution to my problems of some young people simply finding it too much pressure to keep a diary of their experiences. I chose to add observations into the mix as well as conduct some interviews with the participants who were happy to take part in this way. This subtle change in methodology still fitted the chosen mosaic approach but in a more varied way, allowing for the diversity of autistic individuals. In fact it worked out far better than I ever thought possible. This multi method approach has given me rich, multi-layered data, and has allowed these young individuals to be a part of research which may help to influence the learning experience for future generations:

Just an overall look at the data spread before me justifies the use of mixed methods; just one would simply not have been enough. By using various methods of extracting data, I have a rich mix of themes jumping out...  
(Ellis, 2013)



I found that as I was collecting the data, especially during interviews and observations, my own experiences as an autistic adult regularly came into play; not to influence what I was noting or questioning my integrity as a researcher, but in that I identified with the participants. This was especially so with a female participant who was a dancer, possibly as it was an informal educational activity which heavily influenced my own life. As a child I had some of the same struggles: finding friends who she could trust to be herself with, learning without others' negative judgements, always wanting to be the best. It was quite an emotional time for me as I observed classes, and the teacher in me, as well as my personal experience of autism, sometimes wanted to give an opinion on ways to make learning more positive or offer advice. This was an inner struggle and one in which the researcher won mostly. The advice can wait until the data is utilised in a more practical way for future teaching.

From the point of view of being autistic myself, several issues came up as I observed and interviewed. Some of the issues which came up in the data affected me as well. For instance during one interview with 'Bob' we were in his house, and at one point during the questioning there was a sudden loud screech. 'Bob' did not even notice until I jumped and he told me it was his guinea pig. This made me lose focus for a few minutes, and it took some general conversation to get me back on track again. In another interview with 'Malthus', we were sitting in the kitchen/diner talking, and half way through a tap started dripping. At this point I lost focus and continuously looked over to the tap wishing it would stop. I had planned for the possibility of losing focus as it happened during my pilot study, and the interviews were audio recorded by two mediums in case one failed. In 'Abigail's' interview, it was she who lost focus when she heard the boiler make noises every few minutes, and it meant she stopped from time to time. This began to affect me as well but my having to draw her back stopped my own loss of concentration.

These issues could perhaps have been avoided if we had not used their homes for interviews, but I wanted to make the interview environments as comfortable and

familiar for the young people as possible and they all chose their own interview venue. Their needs had to be considered as a priority over mine.

Observations also instigated a few sensory issues for me. During 'Jonathan's activity, we were in a small room with low ceilings and fluorescent lights. There was also a group of parents in the corner of the room, chatting. The combination of the chatting parents, noises of children dropping on mats, and the instructor shouting affected my concentration. As the class went on, I was also affected by the very bright lights as they were within sight. I was glad when the class ended as I was affected by sensory overload. I left the hall for 5 minutes so that I could refocus in natural light and used a scheduled break in the class to ensure I did not miss anything. During an observation with 'Sid' I found myself distracted a couple of times by music coming from a room above the hall we were in. I had to push through this and concentrate for the rest of the lesson.

The observations were not difficult for me to set up, and there was no issue with consent as the teachers of the activities involved had already signed the informed consent forms along with parents and participants. However because I had added the observations to the method mix at a later stage in the research for reasons already outlined, it meant I had lots to do in a relatively short space of time. My biggest concern as an autistic adult, which impacted on me as a researcher, was information overload within this period:

So, here I am in the midst of my research...I am finding it tiring; an overload of information is affecting me as a researcher and more so as an adult with autism. I had to cancel an observation, or more accurately postpone it. I couldn't take any more information...

(Ellis, 2013)

The benefits of adding in the observations, however, as discussed earlier, far outweighed any personal effects. My experience as a teacher and an autistic adult enabled me to see the classes from an insider point of view, while allowing objectivity as a researcher; most of the classes I observed I had never visited before in any capacity. I must add though that one difficulty with being an autistic

observer was the inclination to give constructive feedback to both participants and teachers on how to improve the learning experience. I even wrote little notes at the top of my notepad, that I was in the class as a researcher to remind me; battling with my own autistic reality was challenging at times.

As an autistic 'insider' there was the benefit of a 'shared experience' with the participants. I was very aware of the sensory issues which may affect them, of the degree to which distractions may impede their focus and in turn their learning. I was also aware that my own experiences may not be the same as the children's and I had to be careful not to assume anything based on my own perceptions. Gair (2011:134) writes that empathy is often 'understood to be an indispensable ingredient in perceiving the lived experience of another person' and that the shared experience can therefore be an advantage for a qualitative researcher. Here is a slight conflict in that 'empathy' is a quality often lacking in autistic individuals (Wing, 1996). Taking into consideration Harris and Foreman-Peck's view that researchers may be at danger of over-empathising (2004, cited in Gair, 2011:135), being an autistic researcher then may actually be ideal for this research. It is also worth noting that autistic participants are not necessarily comfortable with new people; knowing that the researcher is autistic and in many ways understands them goes a long way towards settling them enough for them to open up and 'be themselves' in the research situation. In some ways it takes away the *outsider access to vulnerable participants* issue which is commonly discussed (Oliver, 2009); indeed Liamputtong (2007) advocates the sensitive or insider researcher working with vulnerable groups, although also recognises the need for some degree of distance to prevent becoming too involved in the participants' experiences thus removing any kind of objectivity.

I encountered a 'backstage' issue I had not expected; that of a participant's behaviour escalating so much, I considered pulling him out of the study. Another child joined his class and the two children seemed to enable each other's difficult behaviour. This does indeed follow the data discussed at the start of this chapter, but for me as a researcher this left me with a dilemma. He was close to being

asked to leave the classes as it was affecting several other children, and it would therefore affect my research with him. I decided to seek professional advice and after much contemplation, I chose to be persistent and use the experience as a tool for reflection. After all, potentially the more issues a participant has, the more interesting the data. As he was only six, I spoke to the child's parents to ensure they were still happy for me to record his experiences; I did not want to take advantage of a clearly vulnerable child.

This experience made me realise that research is not all about finding positive outcomes, but about discovering opportunities for further development. This child's case certainly provided those.

In Chapter 2 I briefly touched upon the possibility of developing an autism specific learning environment with various informal educational activities, to enable the differences of autistic students. While the data would support this to a degree especially bearing in mind the distractions discussed, it also reveals numerous benefits by activities remaining inclusive, not least of which is the potential for increasing, and indeed improving socialisation in a controlled environment. Professionally though over the past few years during the doctoral process, I have encountered children who quite clearly cannot cope in an inclusive environment and need more intensive help in a much smaller class of children; perhaps even with parents joining in. These specific classes are certainly something I will research further outside of this study.



## **CONCLUSION**

'Scarlett' featured at the start of Chapter 1 where she expressed her frustration at assumptions made about her being autistic. It was important to me and to the integrity of this study that the autistic 'voice', my own included, was considered of the utmost importance and central to the thesis. The concept of working with the autistic 'voice' suited my interpretivist epistemology and my own professional background dictated the underlying motivation for focusing on the learning experience within 'informal' education. Additionally much research previously had addressed 'formal' school education and I was determined to prompt more of a balance. In doing so I hoped to bring about a change where informal education is not an afterthought; but considered a valuable supplement to school education. By listening to a vast array of young autistic students who are being informally educated, and analysing their experiences, along with teacher perspectives, I have taken a positive step toward informing the professional development of teachers; which will in turn aim to improve the overall learning experience for these young people.

Before I could consider the aims and research questions of the thesis, it was important to explore the underlying issues. Thus I began with an exploration of autism language which would arise throughout the thesis. Any writer or researcher discussing areas concerning vulnerable communities is acutely aware of the need to be honest with language yet considerate of issues which may be highly sensitive to both research participants and their families, and readers who may be personally affected by the content of the thesis. Despite many researchers preferring the term 'person with autism' or more recently 'person with the label of autism' (Hodge and Chantler, 2010), I chose to remain true to my own convictions in my use of the term 'autistic person' as this is the way I refer to myself; being a member of the autistic community. In addition, I have chosen to describe those who are not autistic as 'non-autistic' rather than use the term 'neurotypical' which I dislike. I also explored the term 'disability' alongside autism as well as the Social Model of Disability which was necessary from an ontological perspective. Finally

in Chapter 1 I took on the concept of self and identity, as the way people perceive autism is varied and much depends on whether one sees autism as a condition or a being. Recent research from Waterhouse (2013) takes autism discussion to a new level, considering it as a series of symptoms which accompany primary underlying conditions, for example, fragile X syndrome with autism symptoms.

The literature review was an opportunity to explore and critically analyse the theory behind the research context, to find out what has previously been written and eke out any gaps which the research within this thesis could potentially fill. The questions to be answered within the thesis, outlined in Chapter 1 were all around the informal education learning experience, and concerned issues which impacted this experience. Specifically issues around the autistic individuals' motivation, the student/teacher relationship and teacher qualities; and any other issues, both negative and positive, which were considered by the autistic 'voice' to be relevant. I explored the autistic mind and the growing number of academic and literary works written on autism. Bearing in mind the autoethnographic aspect of this thesis, I chose to include many autistic authors who have become as well known for their writing as the 'professional experts' on autism. I highlighted the work of Friere, an educationalist and Vygotsky, a psychologist, both of whose work, I suggest, drew parallels with this thesis and with my epistemology and ontology. The review also covered aspects of pedagogy especially within the context of my professional work and that of this thesis. The review revealed clear gaps in the literature around the area of informal education.

The methodology chapter began with an assessment of traditional methods of research for children and in particular those with disabilities. Consideration of my epistemology together with the research aims led me to explore interpretivism within the tradition of symbolic interactionism. This drew me to the methodology of autoethnography and influenced my decisions from thereon. Closely related to this was constructivism and this formed my ontological position for the empirical research which would surely incorporate interpretations of meaning considering both researcher and participants' values. The need to be working with the young

people and enabling their 'voice' to be heard was paramount in the methodology choices and by using the overall methodology of ethnography, I was able to customise the methods to suit the heterogeneity of the autistic community as well as take into account the various ages of the participants. I expanded the use of the mosaic approach to use with older children and midway through the initial data collection stage recognised the need to expand this even further to accommodate the needs of the participants, and ensure that they were not improperly affected by the methods of extracting data from them. Thus the auto-puzzle technique was born using autoethnography to enable the autistic individual 'audience'. By using the supplementary on-line ethnography and the 'secret box' method, I enabled a wider net from which to catch the autistic 'voices' who sought to participate in a less interactive way. I had not anticipated the work it would take to gather the data in these supplementary methods as I was relying on people I did not know to 'post' their perspectives. This was somewhat frustrating and on reflection, perhaps I should have posed more specific questions for the on-line participants rather than giving them 'carte blanche' on three topics. For some autistic individuals, language can be confusing and exact questions may have been easier for some to answer. However, I chose not to do this from the start as I wanted to allow them to say what they wanted rather than being confined to my specific questions. I stand by my decision but it was important to acknowledge.

Chapter 4 introduced the young participants of the more detailed phase of the study, and additionally outlined the processes used for data analysis. I used a simple process for extracting the data, applying the research questions as a basic rationale for selection. The themes were then put into simple table matrices which were then used for more detailed analysis. This visual method was in keeping with the way in which I process information as an autistic individual, and enabled transparency of the data themes.

Chapter 5 presented the data within these matrices, and the themes were then explored further by using examples of the autistic 'voice' throughout. These themes undoubtedly answered the research questions, but it was in the discussion

chapter that these were studied further in order to achieve the aims of the thesis. Further examination and reflection enabled the data to be compared to autism theory; thus enabling me to evaluate whether the learning experience was affected by students' autism and how classes might be adapted for a better experience. The data also revealed that there are issues impacting the learning experience which affect all students, whether or not they are autistic, although this was not unexpected. The issue here is the differences in the way it is handled and developed to provide a more positive learning experience.

Chapter 6 was also very reflective, both of the participants' experiences and by my writing autoethnographic memoirs of the research experience from my perspective as a researcher and as an autistic adult. It was somewhat of a challenge to provide a true autoethnography here, while remaining true to the academic requirements and indeed expectations of a doctoral thesis. I included many of my own reflections along the research journey and considered these supportive of many of the research design decisions. Once again the data was discussed by topics relating closely to the research questions, and the themes within them which came from the data. One aspect which came from the data was the issue of control: many of the participants revealed aspects of control under many different guises. For instance, under the first research question concerning the part personal motivation plays in the learning experience, issues included improvement, self-confidence, controlled socialising, changing others' perceptions, and an opportunity to choose for themselves. There was also a strong issue of control for one participant whose behaviour relied on controlling his teachers, other students, and even his parents. He had, it seemed, developed his own methods to gain control; for a child of six years old I would argue this is conscious control rather than a coincidence. While it may be argued that it is purely a coping mechanism and subconscious, I am of the opinion that there is something more here, and as an autistic adult, I recognise that control is an issue I easily identify with.



Looking back to the research questions, I suggest that the data has fulfilled what the research set out to achieve. To summarise the analysis has shown that personal motivation plays a part in the learning experience in a variety of ways and other issues both negative and positive certainly impact the experience. It seems from the majority of participants that the relationship between teacher and student is important in a variety of ways, and there are a myriad of qualities either essential or ideal that a student like in a teacher.

I have examined autistic individuals' perspectives across a range of data collection methods, using a visual process staying true to my autistic preferences, but achieving robust and valid data as a researcher. I then critically reflected on how this data could be built upon to create a more positive learning experience for young autistic individuals in informal education. This thesis was not about creating new teaching methods per se, but by using the data analysis robustly and applying the results to teacher development programmes, I would hope that a more inclusive curriculum for informal education can be advanced and expanded across a whole range of activities. In this way the learning experiences of future young people might be changed for the better and the heterogeneity of the autistic community recognised and respected.

My intentions are to take the data and resulting discussion and design some guidelines for teachers of informal education activities. Clearly there is no right and wrong way to teach these young people based on their heterogeneity discussed at length, but with the insight this study has enabled by listening to the very people the classes are to benefit, the learning experience can only be improved. The guidelines will inform the national teacher training programme of which I am responsible within informal education activities including martial arts. This programme covers a whole range of coaching issues and topics are similar to traditional teacher training programmes. These include planning sessions, programmes of work, development of syllabi, use of resources, assessment, evaluation, specific groups including children, disabled students and vulnerable adults, and teaching methods as well as more specific modules including equality,

health and safety, physiology and safe exercise. I have been developing an autism specific module and this research will play a part in the content of this module. In addition I aim to design a range of classes to be taught along these guidelines.

What follows are some of the key aspects of the research which I aim to develop for inclusion in the training programme and classes:

- Students tend to enjoy constructive and detailed teaching with structure to the classes,
- Many students like to impress – to prove their worth or try to fit in. They may come across as extraverts or confident but awareness is needed to realise that internally this may not always be true,
- Students like recognition and praise for a job well done. For autistic individuals this is even more so; they are often lacking in confidence and have low self-esteem,
- Students have high expectations and exacting standards, of themselves and their classes. This can lead to frustration, anxiety and rage,
- Students have a tendency to copy behaviour. Especially in younger students, this tendency may result in unwanted behaviour simply because others exhibit unwanted behaviour,
- Students often have a literal understanding of language; therefore accurate and careful instructions are necessary, with the addition of reasons for them. This helps the student understand,
- Teachers may need to allow more time for autistic students to learn new activities or skills,
- The student/teacher relationship is paramount to the learning experience. Trust takes a long time to build and is easily lost,
- Students tend to become over-reliant on a teacher. Using named peer support in addition is useful,
- Teachers need to remember that all autistic students are different – it is essential to get to know students' needs and to be flexible and patient,

- Teachers need to be aware of sensory overload in students – something which seems minor may in fact affect the student in a major way. For example, an itchy label on clothing may seem insignificant but may ruin an hour's learning experience for the student,
- Teachers should never make assumptions based on autism.

## **FINAL REFLECTIONS**

This study has been a steep learning curve taking on a myriad of perspectives from a wide range of people of all ages. The thesis began with a young autistic person purposefully as this group of people were really at the core of what I wanted to achieve. Along the way I 'listened' and 'engaged' with theorists, psychologists, philosophers, sociologists, researchers and educators, all of whose perspectives have been valuable; but of most importance to me throughout has been 'the autistic voice'. As an autistic adult myself, I have learned a great deal from this study, from the professionals certainly, but even more from the young people and the autistic advocates. The information I can take back to informal educators is vital to develop classes which will be enjoyed and create more positive learning experiences for many. As a researcher I must ask myself: what would I do differently if I was given the opportunity? I would probably allow more time for the research and indeed the preparation prior to it. For example, I would spend longer publicising the research and be bolder with organisations and individuals about the importance of encouraging individuals to take part. This may have provided me with more choice for the participants involved in the mosaic stage of the research. Ideally I would have had 12 participants – more of a boy/girl mix, and perhaps 3 of each age group; 5-7, 8-10, 11-13, 14-17. It would have been easier to compare data and note the differences in issues which were important to these ages. It might also have been interesting to add in young people who had left informal education to find out whether issues relating to their being autistic were the reason. This might actually make a fascinating follow up micro-study perhaps for a journal article. Overall I was happy with the study and

the choices I made. Along the way I discovered autoethnography and this will undoubtedly shape the way my research and writing progresses for future work.

I am grateful and honoured to everyone who shared their 'voice' with me.

'You never really know a man until you stand in his shoes and walk around in them' (Lee, 1960:283).



## REFERENCES

- Alvesson, M. Sköldberg, K. (2009). *Reflexive Methodology: New Vistas for Qualitative Research*. 2<sup>nd</sup> Edition. London: Sage.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (text revision)*. 5<sup>th</sup> Edition. American Psychiatric Association: Washington DC.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders (text revision)*. 4<sup>th</sup> Edition. American Psychiatric Association: Washington DC.
- Arnold, L. (2006). *Whichever Way You Look At It, It's Still Autism*. [DVD]. National Autistic Society. <http://www.autism.org.uk/products/dvdmedia-or-software>. [Last Accessed: 19.07.11].
- Attwood, T. (2008). *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley Publishers.
- Attwood, T. (1998). *Asperger's Syndrome: A Guide for Parents and Professionals*. London: Jessica Kingsley Publishers.
- Attwood, T. Grandin, T. (2006). *Asperger's and Girls*. Texas: Future Horizons Inc.
- Autism Europe. (2011). *About Autism*. Available at <http://www.autismeurope.org/about-autism> (Accessed: 05 June 2011).
- Baker, D. L. (2006). 'Neurodiversity, Neurological Disability and the Public Sector: Notes on the Autism Spectrum'. *Disability & Society*. 21,1,15-29. [Online] DOI: 10.1080/09687590500373734. Routledge. [Last Accessed: 30.04.12].
- Barnes, C. (2003). 'What a Difference a Decade Makes: Reflections on doing'emancipatory' disability research'. *Disability & Society*. 18,1: 3-17.
- Barnes, C., Mercer, G. (2003). *Disability: Key Concepts*. Cambridge: Polity Press.
- Barnes, C., Mercer, G., Shakespeare, T. (1999). *Exploring Disability: A Sociological Introduction*. Cambridge: Polity Press.
- Baron-Cohen, S. (2010) *Concepts of Autism*. Seeing the Light...or ticking the box? Conference. 02.11.10.
- Baron-Cohen, S. (2008). *Autism and Asperger Syndrome*. Oxford: Oxford University Press.
- Baron-Cohen, S. (2004). *The Essential Difference: Forget Mars and Venus and Discover the Truth About the Opposite Sex*. London: Penguin Books.

- Baron-Cohen, S. (2000). 'Is Asperger Syndrome/High-Functioning Autism Necessarily a Disability?'. *Development and Psychopathology*. 12:489-500. <http://www.journals.cambridge.org.lcproxy.shu.ac.uk>. [Last accessed 05.06.11].
- Baron-Cohen, S. Scott, F.J. (2009). 'Prevalence of autism-spectrum conditions: UK school-based population study'. *The British Journal of Psychiatry*. 194:500-509. <http://www.bjp.rcpsych.org>. [Last accessed 13.01.2011].
- Barton, L. (2004). The Disability Movement: Some Observations. In Swain, J. French, S. Barnes, C. Thomas, C. (2004). *Disabling Barriers – Enabling Environments*. 2<sup>nd</sup> Edition. London: Sage.
- Beadle Brown, J. Murphy, G. Wing, L. Gould, J. Shah, A. Holmes, N. (2002). 'Changes in Social Impairment for People with Intellectual Disabilities: A Follow up of the Camberwell Cohort'. *Journal of Autism and Developmental Disorders*. 32, 9: 195-206. [Last Accessed 01.09.13].
- Beale-Ellis, S. (2009). *Celebrating Talent: An Autobiography*. [Keynote speech to Bromley Autistic Trust AGM]. 12 November.
- Beardon, L. (2010). Email to Sandra Ellis, 27 July.
- Beardon, L. (2008). *Asperger Syndrome and Perceived Offending Conduct: A Qualitative Study*. EdD thesis. Sheffield Hallam University. [Online]. <http://shura.shu.ac.uk/7155>. [Accessed: 7 September 2009].
- Becker, H. S. (1998). *Tricks of the Trade: How to Think About Your Research While You're Doing It*. Chicago: The University of Chicago Press.
- Berger, P.L. (1963). *Invitation to Sociology*. New York: Doubleday.
- Block, M. E. (2000). *A Teacher's Guide to Including Students with Disabilities in General Physical Education*. 2<sup>nd</sup> Edition. Maryland: Paul H Brookes Publishing Co.
- Blumer, H. (1986). *Symbolic Interactionism: Perspective and Method*. London: The University of Chicago Press Ltd.
- Bogdashina, O. (2010). *Autism and the Edges of the Known World: Sensitivities, Language and Constructed Reality*. London: Jessica Kingsley Publishers.
- Bogdashina, O. (2006). *Theory of Mind and the Triad of Perspectives on Autism and Asperger Syndrome: A View From the Bridge*. London: Jessica Kingsley Publishers.
- Bogdashina, O. (2005). *Communication Issues in Autism and Asperger Syndrome: Do we speak the same language?* London: Jessica Kingsley Publishers.

Bolton, G. (2010). *Reflective Practice: Writing and Professional Development*. 3<sup>rd</sup> Edition. London: Sage Publications Ltd.

Boucher, J. Scarth, L. (1977). Research and the Teaching of Autistic Children, in Furneaux B, Roberts, B (eds). *Autistic Children: Teaching, Community and Research Approaches*. London: Routledge & Kegan Paul Ltd. pp 140-159.

Brewster, S. Coleyshaw, L. (2010). 'Participation or Exclusion? Perspectives of Pupils with Autistic Spectrum Disorders on their Participation in Leisure Activities'. *British Journal of Learning Disabilities*. 39:284-291. [Online]. <http://www.onlinelibrary.wiley.com>. [Last Accessed: 28.08.12].

Brown, J,S. Collins, A. Duguid, P. (1989). 'Situated Cognition and the Culture of Learning'. *Educational Researcher*. 18 (32):32-42. <http://www.er.aera.net>. [Last Accessed: 05.08.11].

Brown, J. (2010). *Writers on the Spectrum: How Autism and AS have Influenced Literary Writing*. London: Jessica Kingsley Publishers.

Bruner, J. (1996). *The Culture of Education*. Massachusetts: Harvard University Press.

Bryman, A. (2008). *Social Research Methods*. 3<sup>rd</sup> Edition. Oxford University Press.

Bryan, A. Burgess, R,G. (1994). Reflection on Qualitative Data Analysis, in Bryan, A and Burgess, R,G. (1994). *Analyzing Qualitative Data*. London: Routledge, pp 216-226.

Campbell, S. (2010). Email to Sandra Ellis. 27 July.

Carpenter, L, A. Soorya, L. Halpern, D. 'Asperger's Syndrome and High-Functioning Autism'. *Pediatric Annals*. 38,1:30-35. [Online]. <http://www.search.proquest.com.lcproxy.shu.ac.uk>. [Last Accessed: 29.12.12].

Chandler-Olkott, K. Kluth, P. (2009). 'Why Everyone Benefits from Including Students with Autism in Literary Classrooms'. *Reading Teacher*, 62 (7):548-557. [Last Accessed: 21.11.11].

Charon, J, M. (2007). *Symbolic Interactionism: An Introduction, An Interpretation, An Integration*. 9<sup>th</sup> Edition. New Jersey: Pearson Prentice Hall.

Child, D. (2007). *Psychology and the Teacher*. 8<sup>th</sup> Edition. London: Continuum.

Christensen, P and James, A. (2008). (Eds). *Research with Children: Perspectives and Practices*. 2<sup>nd</sup> Edition. London: Routledge.

Christensen, P. (2004). 'Children's Participation in Ethnographic Research: Issues of Power and Representation'. *Children and Society*. 18:165-176.  
<http://www.interscience.wiley.com>. [Last Accessed 07.12.10].

Clark, A. (2004). The Mosaic Approach and Research with Young Children, in Lewis, V. Kellett, M. Robinson, C. Fraser, S. Ding, S. *The Reality of Research with Children and Young People*. London: Sage Publications Ltd. pp 142-161.

Clark, A. Moss, P. (2011). *Listening to Young Children: The Mosaic Approach*. 2<sup>nd</sup> Edition. London: NCB.

Clough, P. Nutbrown, C. (2007). *A Student's Guide to Methodology*. 2<sup>nd</sup> Edition. London: Sage.

Cohen, L. Manion, L. Morrison, K. (2007). *Research Methods in Education*. 6<sup>th</sup> Edition. Oxon: Routledge.

Coldron, J. (2010). *Approaches to Reading*. (Lecture to EdD Cohort 6: Module 1). 13 March.

Coombes, P, H. Ahmed, M. (1974). *Attacking Rural Poverty: How Non Formal Education Can Help*. Baltimore: John Hopkin University Press.

Corbett, J. Norwich, B. (1999). Learners with Special Educational Needs, in Mortimore, P (ed). (1999). *Understanding Pedagogy and its Impact on Learning*. London: Paul Chapman Publishing. pp 115-136.

Corbin, J. Strauss, A,C. (2008) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 3<sup>rd</sup> Edition. London: Sage. Kindle version accessed 26 October 2010 from <http://www.amazon.co.uk>.

Coyne, P. (2004). in Coyne, P., Fullerton, A. (2004). *Supporting Individuals with Autism Spectrum Disorder in Recreation*. USA: Sagamore Publishing.

Coyne, P., Fullerton, A. (2004). *Supporting Individuals with Autism Spectrum Disorder in Recreation*. USA: Sagamore Publishing.

Creswell, J, W. (2009). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. 3<sup>rd</sup> Edition. Sage: London. Kindle version accessed 9 November 2010 from <http://www.amazon.co.uk>.

Crisp, R, J. Turner, R,N. (2007). *Essential Psychology*. London: Sage.

Crosby, J. (2009). 'Why Asperger Syndrome is a Legal Disability'. [Online]. <http://www.ageofautism.com/2009/07/why-asperger-syndrome-is-a-legal-disability.html>. [Last Accessed 23.01.11].



Curran, T. Runswick-Cole, K. Eds. (2013). *Disabled Children's Childhood Studies: Critical Approaches in a Global Context*. Basingstoke: Palgrave Macmillan.

Dale, M. Bell, J. (1999). 'Informal Learning in the Workplace'. DfEE Research Report 134. London: Department for Education and Employment.  
<http://www.voced.edu.au/content/ngv23047>. [Last accessed: 07.08.11].

Dance Oolites Inc. (2013). Available at: <http://www.danceoolites.com> (Last Accessed: 13.11.13).

Dattilo, J. Williams, R. (1999). 'Inclusion and Leisure Services Delivery', in Jackson, E, L. Burton, T,L. (eds). *Leisure Studies: Prospects for the 21<sup>st</sup> Century State College*. PA: Venture Publishing. pp 451-463.

Deci, E, L. Ryan, R,M. (1985). *Intrinsic Motivation and Self Determination in Human Behaviour*. New York: Plenum.

Deer Richardson, L., Wolfe, M. (2001). (eds). *Principles and Practice of Informal Education: Learning through life*. London: Routledge Falmer.

Denzin, N, K. Lincoln, Y, S. (Eds). (2008). *Collecting and Interpreting Qualitative Materials*. 3<sup>rd</sup> Edition. London: Sage.

Dey, I. (1993). *Qualitative Data Analysis: A User-Friendly Guide for Social Scientists*. London: Routledge.

Donaldson, M. (1978). *Children's Minds*. London: Fontana Press.

Dowty, T. Cowlshaw, K. (2002). *Home Educating Our Autistic Spectrum Children: Paths Are Made By Walking*. London: Jessica Kingsley Publishers.

Dweck, C, S. (2000). *Self Theories: Their Role in Motivation, Personality and Development*. New York: Psychology Press.

Dyson, B. Griffin, L,L. Hastie, P. (2004). 'Sport Education, Tactical Games, and Cooperative Learning: Theoretical and Pedagogical Considerations'. *QUEST*. 56: 240. [Online]. <http://www.sirc.ca>. [Last Accessed 25.5.11].

Edmonds, G, Beardon, L. (2008). *AS and Social Relationships: Adults Speak Out About AS*. London: Jessica Kingsley Publishers.

Elliot, A, J. Dweck, C, S. Eds. (2005). *Handbook of Competence and Motivation*. New York: Guilford Press.

Ellis, C (2004). *The Ethnographic I: A Methodological Novel about Autoethnography*. CA: Altamira Press.

- Etherington, K. (2004). *Becoming a Reflexive Researcher: Using Our Selves in Research*. London: Jessica Kingsley Publishers.
- Fine, G.A. Sandstrom, K, L. (1988). *Knowing Children: Participant Observation with Minors* (Qualitative Research Methods No. 15). Sage: London. Kindle version accessed 23 April 2012 from <http://www.amazon.co.uk>.
- Fitzgerald, H. (2009). Are You a 'Parasite' Researcher? Researching Disability and Youth Sport, in Fitzgerald, H (ed) *Disability and Youth Sport*. Oxon: Routledge. pp 145-156.
- Flick, U. (2009). *An Introduction to Qualitative Research*. 4<sup>th</sup> Edition. London: Sage.
- Foley, D. (2003). Starting From Scratch: Being Innovative in Finding Interventions for your Adolescent with Asperger Syndrome, in Willey, L, H. (2003). *Asperger Syndrome in Adolescence: Living with the Ups, The Downs and Things in Between*. London: Jessica Kingsley Publishers. pp 227-242.
- Foley, G. (1999). *Learning in Social Action: A Contribution to Understanding Informal Education*. USA: St Martin's Press Inc.
- Fontana, D. (1995). *Psychology for Teachers*. 3<sup>rd</sup> Edition. London: Macmillan Press.
- Fraser, S. (2004). Situating Empirical Research, in Fraser, S. Lewis, V. Ding, S. Kellet, M. Robinson, C. *Doing Research with Children and Young People*. London: Sage Publications Ltd. pp 15-26.
- Freeman, M. Mathison, S. (2009). *Researching Children's Experiences*. New York: The Guilford Press.
- French, S. Swain, J. (1997). 'Changing Disability Research: Participating and Emancipatory Research with Disabled People'. *Physiotherapy*. 83,1:26-32. [Online]. <http://www.sciencedirect.com>. [Last Accessed 25.11.10].
- Friere, P. (1996). *Pedagogy of the Oppressed*. Translated by Myra Bergman Ramos. London: Penguin Books.
- Frith, U. (2003). *Autism: Explaining the Enigma*. 2<sup>nd</sup> Edition. USA: Blackwell Publishing.
- Frith, U. (2008). *Autism: A Very Short Introduction*. Oxford: Oxford University Press.
- Furneaux, B. Roberts, B. (eds) (1979). *Autistic Children: Teaching, community and research approaches*. London: Routledge and Keegan Paul Ltd.

- Furneau, B. (1979). Working with the younger children in Furneau B, Roberts, B (eds). *Autistic Children: Teaching, Community and Research Approaches*. London: Routledge & Kegan Paul Ltd. pp 91-120.
- Gair, S. (2011). 'Feeling Their Stories: Contemplating Empathy, Insider/Outsider Positionings, and Enriching Qualitative Research'. *Qualitative Health Research*. 22, 1:134-143. Sage. [Online]. <http://www.qhr.sagepub.com/content/22/1/134>. [Accessed 18.01.14].
- Ghaziuddin, M. (2010). 'Brief Report: Should the DSM V Drop Asperger Syndrome?'. *Journal of Autism Developmental Disorders*. 40:1146-1148. Springer Science & Business Media:USA. [Online]. <http://www.link.springer.com.lc.proxy.shu.ac.uk>. [Accessed 29.12.12].
- Giddens, A. (1976). *New Rules of Sociological Method*. London: Hutchinson.
- Gilbert, I. (2002). *Essential Motivation in the Classroom*. Oxon: Routledge Falmer.
- Gindis, B. (1999). Vygotsky's Vision: Reshaping the Practice of Special Education for the 21<sup>st</sup> Century. *Remedial and Special Education*. 20, 6:32-64. [Online]. [http://www.bgcenter.com/Vygotsky\\_Vision.htm](http://www.bgcenter.com/Vygotsky_Vision.htm). [Last Accessed: 05.08.11].
- Gindis, B. (2003). Remediation Through Education: Sociocultural Theory and Children with Special Needs, in Kozulin, A. Gindis, B. Ageyev, V, S. Miller, S.M. (eds) *Vygotsky's Educational Theory in Cultural Context*. Cambridge: Cambridge University Press. pp 200-222.
- Goffman, E. (1959). *The Presentation of Self in Everyday Life*. London: Penguin Books.
- Goffman, E. (1967). *Interaction Ritual: Essays on Face-to-Face Behaviour*. New York: Doubleday.
- Goffman, E. (1974). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. London: Penguin.
- Golding, M, M. (1997). Beyond Compliance: The Importance of Groupwork in the Education of Children and Young People with Autism, in Powell, J. Jordan, R. (1997). *Autism and Learning*. London: David Fulton Publishers. pp 46-60.
- Golubock, S. (2003) Different on the Inside in Kearns Miller, J. *Women From Another Planet?: Our Lives in the Universe of Autism*. USA: 1<sup>st</sup> Books. pp 63-71.
- Goodley, D. (2011). *Disability Studies: An Interdisciplinary Introduction*. London: Sage.
- Gould, J. Ashton-Smith, J. (2011). Missed Diagnosis or Misdiagnosis? Girls and Women on the Autism Spectrum. *Good Autism Practice (GAP)*. 12, 1:34-48(8).

Grandin, T. (2009) *Thinking in Pictures*. Bloomsbury. Kindle version accessed 26 October 2010 from <http://www.amazon.co.uk>.

Grandin, T. (1992). An Inside View of Autism, in Schopler, E. Meisibov, G.B. Eds.(1992). *High-Functioning Individuals With Autism*. New York: Plenum Press. pp 105-126.

Grandin, T. (1986). *Emergence: Labelled Autistic*. New York: Warner Books.  
Grandin, T. Barron, S. (2005). *Unwritten Rules of Social Relationships: Decoding Social Mysteries Through the Unique Perspectives of Autism*. Texas: Future Horizons Inc.

Gratton, C. Jones, I. (2004). *Research Methods for Sport Studies*. Oxon: Routledge.

Greig, A. Taylor, J. MacKay, T. (2007). *Doing Research with Children*. 2<sup>nd</sup> Edition. Sage: London.

Green, K. (2008). *Understanding Physical Education*. London: Sage Publications Ltd.

Grix, J. (2001). *Demystifying Postgraduate Research: From MA to PhD*. Birmingham:University of Birmingham Press.

Gutstein, S, E. (2003). Can My Baby Learn to Dance?: Exploring the Friendships of Asperger Teens in Willey, L, H. (2003). *Asperger Syndrome in Adolescence: Living with the Ups, The Downs and Things in Between*. London: Jessica Kingsley Publishers. pp 98-127.

Habermas, J. (1989). *The Theory of Communicative Action: The Critique of Functionalist Reason*. Vol II. Cambridge: Polity Press.

Hall, K. Murphy, P. Soler, J. (2008). *Pedagogy and Practice: Culture and Identities*. Milton Keynes: The Open University.

Hammel, A, M. Hourigan, R, M. (2013). *Teaching Music to Students with Autism*. Oxford: Oxford University Press. Kindle version accessed: 0 November 2013 from <http://www.amazon.co.uk>.

Hammersley, M. Atkinson, P. (1995). *Ethnography: Principles in Practice*. 2<sup>nd</sup> Edition. Oxon: Routledge.

Happé, F. (2011). *Why Fold Asperger Syndrome into Autism Spectrum Disorder in the DSM-5?*. [Online]. <http://www.sfari.org/newsandopinion/viewpoint>. [Last Accessed: 8.1.13].



- Happé, F. (1994). *Autism: An Introduction to Psychological Theory*. London: UCH Press. Kindle version accessed 16 October 2012 from <http://www.amazon.co.uk>.
- Happé, F. Frith, U. (2010). *Autism and Talent*. Oxford: Oxford University Press.
- Harris, P, L. (1989). *Children and Emotion*. Oxford: Blackwell Publishing.
- Harris, R. Foreman-Peck, L. (2004) in Gair, S. (2011). 'Feeling Their Stories: Contemplating Empathy, Insider/Outsider Positionings, and Enriching Qualitative Research'. *Qualitative Health Research*. 22, 1:134-143. Sage. [Online]. <http://www.qhr.sagepub.com/content/22/1/134>. [Accessed 18.01.14].
- Hart, C. (1998). *Doing a Literature Review: Releasing the Social Science Research Imagination*. London: Sage.
- Healy, S. Msetfi, R. Gallagher, S. (2013). 'Happy and a Bit Nervous: The Experiences of Children with Autism in Physical Education'. *British Journal of Learning Disabilities*. 41,3:222-228. [Online]. <http://onlinelibrary.wiley.com.lcproxy.shu.ac.uk/doi/10.1111/bld.12053/full>. Wiley. [Last Accessed: 10.11.13].
- Hodge, N. (2008). 'Evaluating Lifeworld as an Emancipatory Methodology'. *Disability & Society*. 23,1:29-40. [Online]. <http://www.shura.shu.ac.uk/6095>.
- Hodge, N. Chantler, S. (2010). 'It's Not What You Do; It's The Way That You Question: That's What Gets Results'. *Support For Learning*. 25, 1:11-14. [Online]. <http://www.onlinelibrary.wiley.com/doi/10.1111/j.1467-9604.2009.01433.x> [Last Accessed 15.9.13].
- Ireson, J. Mortimore, P. Hallam, S. (1999). The Common Strands of Pedagogy and Their Implications, in Mortimore, P. (ed) (1999). *Understanding Pedagogy and Its Impact On Learning*. London: Paul Chapman Publishing. pp 212-232.
- Iovannone, R. Dunlap, G. Huber, H. Kincaid, D. (2003). 'Effective Educational Practices for Students with Autism Spectrum Disorders'. *Focus on Autism and Other Developmental Disabilities*. 18,3:150-165. [Online]. <http://www.foa.sagepub.com/lcproxy.shu.ac.uk/content/18/3/150>. [Last accessed 01.04.2011].
- Jackson, J. (2004). *Multicoloured Mayhem: Parenting the Many Shades of Adolescents and Children with Autism, Asperger Syndrome and AD/HD*. London: Jessica Kingsley Publishers.
- Jackson, L. (2002). *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence*. London: Jessica Kingsley Publishers.
- Jeffs, T. Smith, M,K. (2005). *Informal Education: Conversation, Democracy and Learning*. 3<sup>rd</sup> Edition. Nottingham: Educational Heretics Press.

- Jones, G. (2002). *Educational Provision for Children with Autism and Asperger Syndrome*. London: David Fulton Publishers.
- Jones, G. Attfield, E. (founded 2000). (current eds). *Good Autism Practice*. Worcestershire: BILD Publications.
- Jordan, R. (1999). *Autistic Spectrum Disorders: An Introductory Handbook for Practitioners*. London: David Fulton Publishers Ltd.
- Jordan, R. Powell, S. (1995). *Understanding and Teaching Children with Autism*. Chichester: Wiley & Sons Ltd.
- Kamins, M. (2011). The Keeper: A Tale of Late-Childhood Asperger's Diagnosis, in Des Roches Rosa, S. Byde Myers, J. Ditz, L. Willingham, E. Greenburg, C. (eds). (2011). *Thinking Person's Guide to Autism: What You Really Need to Know About Autism: From Autistics, Parents and Professionals*. CA: Deadwood City Publishing. pp.187-191.
- Kamins, M, L. Dweck, C,S. (1999). 'Person Versus Process Praise and Criticism: Implications for Contingent Self-Worth and Coping'. *Developmental Psychology*. 35,3:835-847. [Online]. [http:// www.psycnet.apa.org/journals](http://www.psycnet.apa.org/journals). [Last Accessed: 31.1.13].
- Kaweski, W. (2011). *Teaching Adolescents with Autism: Practical Strategies for the Inclusive Classroom*. London: Corwin.
- Kearns Miller, J. (2003). (ed) *Women From Another Planet?: Our Lives in the Universe of Autism*. USA: 1<sup>st</sup> Books.
- Keegan, M. (2011). 'Inspirational Teacher to be Honoured by the Queen for Helping Disabled Children Take Up Cycling'. *Manchester Evening News*. [Online].<http://www.manchestereveningnews.co.uk/news/greater-manchester-news/inspirational-teacher-to-be-honoured-by-the-queen-for-helping-862270>. 3.6.11.
- Koegel, R, L. Koegel, L,K. (1995). *Teaching Children with Autism: Strategies for Initiating Positive Interactions and Improving Learning Opportunities*. Maryland: Paul H Brookes Publishing Co.
- Kozinets, R, V. (2010). *Netnography: Doing Ethnography Research Online*. London: Sage.
- Kozulin, A. Gindis, B. Ageyev, V,S. Miller, S,M. (2003). (eds). *Vygotsky's Educational Theory in Cultural Context*. Cambridge: Cambridge University Press.
- Kutscher, M, L. (2005). *Kids in the Syndrome Mix of ADHD, LD, Asperger's, Tourette's, Bipolar, and More! The One Stop Guide for Parents, Teachers, and Other Professionals*. London: Jessica Kingsley Publishers.

- Lave, J. Wenger, E. (1991). *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.
- Lawrence, C. (2012). *Autism and Flexischooling: A Shared Classroom and Homeschooling Approach*. London: Jessica Kingsley Publishers.
- Lawson, W. (2011). *The Passionate Mind: How People with Autism Learn*. London: Jessica Kingsley Publishers.
- Layder, D. (1992). *New Strategies in Social Research: An Introduction and Guide*. Cambridge: Polity Press.
- Ledwith, M. Springett, J. (2010). *Participatory Practice: Community-Based Action for Transformative Change*. Bristol: The Policy Press.
- Lee, H. (1960). *To Kill a Mockingbird*. London: Pan Books.
- Leekham, S, R. Libby, S, J. Wing, L. Gould, J. Taylor, C. (2002). 'The Diagnostic Interview for Social and Communication Disorders: Algorithms for ICD-10 Childhood Autism and Wing and Gould Autistic Spectrum Disorder'. *Journal of Child Psychology and Psychiatry*. 43, 3: 327-342. [Online]. <http://www.onlinelibrary.wiley.com>. [Last accessed 28.06.11].
- Lewis, V. Kellett, M. Robinson, C. Fraser, S. Ding, S. *The Reality of Research with Children and Young People*. London: Sage Publications Ltd.
- Liamputtong, P. (2007). *Researching the Vulnerable: A Guide to Sensitive Research Methods*. London: Sage Publishers. Kindle version accessed 17 July 2013 from <http://www.amazon.co.uk>.
- Lord, S. (1997). Dance and Drama, in Powell, S. Jordan, R. (eds). *Autism and Learning: A Guide to Good Practice*. London: David Fulton Publishers. pp 79-99.
- Macalister Brew, J. (1946). *Informal Education Adventures and Reflections*. London: Faber and Faber.
- McLean, A. (2009). *Motivating Every Learner*. London: Sage.
- McLean, A. (2003). *The Motivated School*. London: Paul Chapman Publishing.
- Magnusen, C, L. (2005). *Teaching Children with Autism and Related Spectrum Disorders*. London: Jessica Kingsley Publishers.
- Mann, C. Stewart, F. (2000). *Internet Communication and Qualitative Research: A Handbook for Researching Online*. London: Sage.
- Masilamani, A. (2003). The Personas. in Kearns Miller, J. (ed). *Women From Another Planet?: Our Lives in the Universe of Autism*. USA: 1<sup>st</sup> Books pp 111-114.

- Mason, J. (2002). *Qualitative Research*. 2<sup>nd</sup> Edition. London: Sage.
- Mayall, B. (2008). Conversations with Children: Working with Educational Issues, in Christensen, P and James, A. (eds). *Research with Children: Perspectives and Practices*. 2<sup>nd</sup> Edition. London: Routledge. pp 109-124.
- Mead, G H. (1967). *Mind, Self & Society*. London: The University of Chicago Press Ltd.
- Melber, L.M. Brown, K.D. (2008). 'Not Like a Regular Science Class': Informal Science Education for Students with Disabilities. *The Clearing House*. 82,1:35-39. Taylor & Francis Inc: Washington, USA. [Online]. <http://www.search.proquest.com.lc.proxy.shu.ac.uk/docview/196844743>. [Last Accessed 28.08.12].
- Mertens, D. M. (1998). *Research Methods in Education and Psychology: Integrating Diversity with Quantitative & Qualitative Approaches*. London: Sage.
- Mertens, D,M. McLaughlin, J,A. (2004). *Research and Evaluation Methods in Special Education*. CA: Corwin Press.
- Miles, M, B. Huberman, A, M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*. 2<sup>nd</sup> Edition. London: Sage.
- Mortimore, P (ed). (1999). *Understanding Pedagogy and its Impact on Learning*. London: Paul Chapman Publishing.
- Murphy, G,H. Beadle-Brown, J. Wing, L. Gould, J. Shah, A. Holmes, N. (2005). 'Chronicity of Challenging Behaviours in People with Severe Intellectual Disabilities and/or Autism: A Total Population Sample'. *Journal of Autism and Developmental Disorders*. [Online]. <http://springerlink.com>. 35,4:405-418.
- Murphy, P. (2008). Defining Pedagogy in Hall, K. Murphy, P. Soler, J. Pedagogy and Practice: Culture and Identities. Milton Keynes: The Open University. pp 28-39.
- Murray, S. (2008). *Representing Autism: Culture, Narrative, Fascination*. Liverpool University Press.
- National Autistic Society. (2011). *What is Autism?*. <http://www.autism.org.uk/about-autism.aspx>. [Last Accessed 05.06.11].
- Norwich, B. Lewis, A. (2001). 'Mapping a Pedagogy for Special Educational Needs'. *British Educational Research Journal*. 27,3:313-329. [Online]. <http://www.jstor.org/stable/150898>. [Last accessed: 21.04.11].
- O'Kane, C. (2008). The Development of Participatory Techniques: Facilitating Children's Views about Decisions Which Affect Them. in Christensen, P and



James, A. (Eds). *Research with Children: Perspectives and Practices*. 2<sup>nd</sup> Edition. Oxon: Routledge. pp 125-152.

Oliver, M. (2009). *Understanding Disability: From Theory to Practice*. 2<sup>nd</sup> Edition. Hampshire: Palgrave Macmillan.

Oliver, M. (2004). In Swain, J. French, S. Barnes, C. Thomas, C. (2004). *Disabling Barriers – Enabling Environments*. 2<sup>nd</sup> Edition. London: Sage.

Oliver, M. (1997). Emancipatory Research: Realistic goal or impossible dream? in Barnes, C. Mercer, G (eds). *Doing Disability Research*. Leeds: The Disability Press. pp 15-31.

Ortiz, J.M. (2008). *The Myriad Gifts of Asperger's Syndrome*. London: Jessica Kingsley Publishers.

Oxford English Dictionary. (2006). Oxford: Oxford University Press.

Pahl, R. (1995). *After Success: Anxiety and Identity*. Cambridge: Polity Press.

Pan, C, Y. (2009). 'Age, social engagement, and physical activity in children with autism spectrum disorders'. *Research in Autism Spectrum Disorders*. 3:22-31. [Online] <http://www.sciencedirect.com/science/article/pii/S1750946708000263>. Elsevier. [Last Accessed: 01.12.12].

Pan, C.Y. Frey, G.C. (2006). 'Physical Activity Patterns in Youth with Autism Spectrum Disorders'. *Autism Developmental Disorders*. 36:597-606. [Online] <http://researcher.nsc.gov.tw/public/9301903/Data/771214371271.pdf>. Springer. [Last Accessed: 08.10.12].

Peeters, T. Gillberg, C. (1999) *Autism: Medical and Educational Aspects*. 2<sup>nd</sup> Edition. London: Whurr Publishers.

Phemister, A. (2005). 'Reaching Kids with Asperger's Syndrome'. *The Education Digest*. 71,2:58-63. [Online] <http://mandysinquiry.wikispaces.com/file/view/Article5.pdf> ProQuest Education Journals. [Last Accessed: 11.12.13].

Phillips, E, M. Pugh, D,S. (2000). *How to get a PhD: A Handbook for Students and their Supervisors*. 3<sup>rd</sup> Edition. Buckingham: Open University Press.

Popkewitz, T, S. (1998). 'Dewey, Vygotsky, and the Social Administration of the Individual: Constructivist Pedagogy as Systems of Ideas in Historical Spaces'. *American Educational Research Journal*. 35,4, 535-70. [Online] <http://www.aer.sagepub.com>. [Last Accessed: 01.07.11].

Powell, S. Jordan, R. (1997). (Eds). *Autism and Learning: A Guide to Good Practice*. London: David Fulton Publishers.

- Premack, D. Premack, A. (2003). *Original Intelligence: Unlocking the Mystery of Who We Are*. New York: McGraw-Hill.
- Prior, M. Leekam, S. Ong, B. Eisenmajer, R. Wing, L. Gould, J. Dowe, D. (1998). 'Are There Subgroups within the Autistic Spectrum? A Cluster Analysis of a Group of Children with Autistic Spectrum Disorders'. *Journal of Child Psychology and Psychiatry*. 39,6:893-902. [Online] <http://www.onlinelibrary.wiley.com>. [Last Accessed: 28.06.11].
- Prout, A. James, A. (2007). *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*. 2<sup>nd</sup> Edition. Taylor and Francis. Kindle version accessed 4 December 2010 from <http://www.amazon.co.uk>.
- Puckett, M,B. Diffily, D. (2003). *Teaching Young Children: An Introduction to the Early Childhood Profession*. 2<sup>nd</sup> Edition. New York: Delmar Cengage Learning.
- Punch, K, F. (2005). *Introduction to Social Research: Quantitative and Qualitative Approaches*. 2<sup>nd</sup> Edition. London: Sage.
- Ratnesar, N. Mackenzie, J. (2007). The Quantitative-Qualitative Distinction and the Null Hypothesis Significance Testing Procedure, in Bridges, D. Smith, R. (Eds). *Philosophy, Methodology and Educational Research*. Oxford: Blackwell Pubs. pp 107-115.
- Recours, R, A. Souville, M. Griffet, J. (2004). 'Expressed Motives for Informal and Club/Association-based Sports Participation'. *Journal of Leisure Research*. 36,1:1-22. ProQuest Education Journals. [Online] <http://www.search.proquest.com.lcproxy.shu.ac.uk/docview/201122750/fulltextpdf>. [Last Accessed: 28.8.12].
- Robson, C. (2002). *Real World Research*. 2<sup>nd</sup> Edition. Blackwell Publishing.
- Rogoff, B.(2008) in Hall, K. Murphy, P. Soler, J. (2008). *Pedagogy and Practice: Culture and Identities*. Milton Keynes: The Open University.
- Roth, I. (2010). *The Autism Spectrum in the 21<sup>st</sup> Century: Exploring Psychology, Biology and Practice*. London: Jessica Kingsley Publishers.
- Rubio, R. (2008). *Mind/Body Techniques for Asperger's Syndrome: The Way of the Pathfinder*. London: Jessica Kingsley Publishers.
- Sacks, O. (1986). *The Man Who Mistook His Wife for a Hat*. London: Picador.
- Sainsbury, C. (2000). *Martian in the Playground: Understanding The Schoolchild with Asperger's Syndrome*. London. Paul Chapman Publishing.
- Schatz, M. Walker, R. (1995). *Research as Social Change: New Opportunities for Qualitative Research*. London: Routledge.
- Searle, J, R. (1995). *The Construction of Social Reality*. London:Penguin.

- Shore, S, M. Rastelli, L, G. (2006). *Understanding Autism for Dummies*. New Jersey: Wiley Publishing Inc.
- Shreck, K, A. Mulick, J, A. Smith, A, F. (2004). 'Sleep problems as possible predictors of intensified symptoms of autism'. *Research in Developmental Disabilities*. 25,1:57-66. [Online] <http://www.dx.doi.org/10.1016/j.ridd.2003.04.007>. Elsevier. [Last Accessed: 16.11.13].
- Sinclair, J. (1993). 'Don't Mourn for Us'. *Autism Network International*. 1,3. [Online] [http://www.autreat.com/dont\\_mourn.html](http://www.autreat.com/dont_mourn.html). [Last Accessed 19.07.11].
- Smeltzer, B. (2011). Through A Father's Eyes. *The Autism File Global*. Issue 39, 37-40.
- Smith, M, F. (2010). *Research Methods in Sport*. Learning Matters. Kindle version accessed 29 November 2010 from <http://www.amazon.co.uk>.
- Smith, M,K. (1999). 'Informal Learning'. *The Encyclopaedia of Informal Education*. [Online] <http://www.infed.org/biblio/inf-Irn.htm>. [Last Accessed 07.08.11].
- Stenhouse, L. (1975). *An Introduction to Curriculum Research and Development*. Oxford: Heinemann.
- Swain, J. French, S. Barnes, C. Thomas, C. (2004). *Disabling Barriers – Enabling Environments*. 2<sup>nd</sup> Edition. London: Sage.
- Swain, J. French, S, Cameron, C. (2003). *Controversial Issues in a Disabling Society*. Bucks: Open University Press.
- Szalavitz, M. (2010). Study: Some Autistic Brains Really Are Wired Differently. [Online] <http://healthland.time.com/2919/11/03>. [Last Accessed 21.07.13].
- Tammet, D. (2006). *Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant*. New York: Free Press.
- Tashakkori, A. Teddlie, T. (1998). *Mixed Methodology: Combining Qualitative and Quantitative Approaches*. Thousand Oaks, CA: Sage.
- Tinning, R. (1997). Performance and Participation Discourses in Human Movement: Toward a Socially Critical Physical Education in Fernandez-Balboa, J. (Ed) *Critical Postmodernism in Human Movement, Physical Education, and Sport*. USA: State University of New York Press. pp 99-121.
- Tomney, P. Ed. (1999-2014). *The Autism File Global*.
- Tudge, J. Hogan, D. (2005). An Ecological Approach to Observations of Children's Everyday Lives in Greene, S. Hogan, D. (Eds). *Researching Children's Experience*. London: Sage pp 102-122.

Turmusani, M. (2004). 'An Eclectic Approach to Disability Research: A Majority World Perspective'. *Asia Pacific Disability Rehabilitation Journal*. 15,1:3-11 2004. [Last Accessed 30.11.10].

Twachtman-Cullen, D. (1998). Language and Communication in High-Functioning Autism and Asperger Syndrome in Schopler, E. Mesibov, G.B. Kunce, L.J. Eds. (1998). *Asperger Syndrome or High-Functioning Autism?* pp199-225

Veale, A. (2005). Creative Methodologies in Participatory Research with Children in Greene, S. Hogan. (2005). *Researching Children's Experiences*. London: Sage Publications.

Vygotsky, L. S. (1993). The Collected Works of L S Vygotsky. Vol 2: The Fundamentals of Defectology (Abnormal Psychology and Learning Disabilities). (Jane E Knox and Carol B Stevens trans). (R W Rieber and A S Carton, Eds). New York: Plenum Press.

Vygotsky, L. S. (1997). *The History of Development of Higher Mental Functions*. NY: Plenum Press.

Vygotsky, L. S. (1978). *Mind in Society: The Development of Higher Psychological Processes*. Cambridge MA: Harvard University Press.

Wakefield, A. Stott, C. (2010). 'Regular Review'. *The Autism File*. 37:110-118.

Walmsley, J. Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present, and Futures*. London: Jessica Kingsley Publishers.

Waterhouse, L. (2013). *Rethinking Autism: Variation and Complexity*. USA: Elsevier.

Watkins, C. Carnell, E. Lodge, C. (2007). *Effective Learning in Classrooms*. London: Sage.

Watkins, C. Mortimore, P. (1999) Pedagogy: What Do We Know? in Mortimore, P. (Ed) *Understanding Pedagogy and its Impact on Learning*. London: Paul Chapman Publishing. pp 1-19.

Weber, M. (1947). *The Theory of Social and Economic Organisation*. Trans: A M Henderson and T Parsons. New York: Free Press

Wenger, E. (1999). *Communities of Practice: Learning, Meaning and Identity*. Cambridge: Cambridge University Press.

Westcott, H.L. Littleton, K. S. (2005). Exploring Meaning in Interviews with Children in Greene, S. Hogan, D. (Eds). *Researching Children's Experience*. London: Sage. pp 141-157.



- Wilde Astington, J. (1994). *The Child's Discovery of the Mind*. London: Fontana Press.
- Willey, L. H. (2003). (Ed). *Asperger Syndrome in Adolescence: Living with the Ups, the Downs and Things in Between*. London: Jessica Kingsley Publishers.
- Willey, L. H. (1999). *Pretending to be Normal: Living with Asperger Syndrome*. London: Jessica Kingsley Publishers.
- Williams, D. (1992). *Nobody Nowhere: The Extraordinary Autobiography of An Autistic*. New York: Avon.
- Wing, L. (1998). The History of Asperger Syndrome in Schlopler, E. Mesibov, G.B. Kuncze, L.J. (Eds). *Asperger Syndrome or High Functioning Autism?* New York and London: Plenum Press. pp 11-28.
- Wing, L. (1996). *The Autism Spectrum*. London: Constable and Robinson Ltd.
- Wing, L. Gould, J. (1979). 'Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification'. *Journal of Autism and Childhood Schizophrenia*. 9:11-29. [Online]  
<http://www.springerlink.com.lcproxy.shu.ac.uk/content/q17600t265712jl>. [Last Accessed 28.06.11].
- Wing, L. Gould, J. Gilberg, C. (2011). 'Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV?'. *Research in Developmental Disabilities*. 32, 2: 768-773. [Online] <http://sciencedirect.com>. [Last Accessed: 22.9.13].
- Wood, R. (1996). Interview quoted in Campbell, J. and Oliver, M. (1996). *Disability Politics: Understanding Our Past, Changing Our Future*. London: Routledge.
- Wolbring, G. (2008). 'The Politics of Ableism'. *Development*. 51: 252-258. [Online]  
<http://www.sidintorg.development>. [Last Accessed: 20.9.13].
- Wright Mills, C. (1967). *The Sociological Imagination*. Oxford: Oxford University Press.

## **APPENDICES**

**Informed Consent Form**

**Phase One Advert**

**Phase Two Leaflet for Participants, Parents/Carers, and Class Teachers**

(outer and inner views)

**Phase Three Advert**

**Phase Two Diaries – Participant Guidance**

**Phase Three Sample Questions to be answered**

**List of Places Used for Recruitment for Participants**

**Questions used for Interviews**

**IDENTIFYING FACTORS IMPACTING THE INFORMAL EDUCATION LEARNING EXPERIENCE FOR  
YOUNG AUTISTIC STUDENTS**

**Phase Two: 'Diary Collection' 2012-2014**

**RESEARCH ETHICS: CONSENT FORM**

I (name)..... give permission to allow my child (name).....  
to take part in the above named study.

- ☐ I confirm that I have read and understood the leaflet about the study and have had a chance to ask any further questions.
- ☐ I understand that my/my child's participation is voluntary and that I/my child is free to withdraw at any time without any repercussions.
- ☐ I am happy that my child understands what is involved in the study and is happy with the arrangements.
- ☐ I understand that I/my child's real name will not be included in the study report or any subsequent papers.
- ☐ I understand that any data collected for this study from me/my child will be used only for the study and it will be seen by the researcher, the supervisory team and the doctoral examiners. When it is no longer needed, it will be destroyed.
- ☐ I understand my child will be given a 'diary pack' to enable data to be collected and that he/she will be allowed to keep any leftover materials from this pack.

Name of Participant	Date	Signature
.....	.....	.....

Name of Parent/Carer	Date	Signature
.....	.....	.....

I/we the undersigned teacher(s) agree for the above named child to collect data relating to his/her own experiences in our classes/activities. We understand names and places will remain anonymous.

Name	Date	Signature
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....

**Researcher Details:**

Sandra Ellis MAEd PGCertAS  
Sheffield Hallam University, Doctoral Student/Researcher  
Tel: 01227 376181 / 07966 403271 Email: [sandra@challengeautism.co.uk](mailto:sandra@challengeautism.co.uk)  
Director of Studies: Dr Luke Beardon Tel: 0114 225 4548 Email: [l.beardon@shu.ac.uk](mailto:l.beardon@shu.ac.uk)

May 2012

**WANTED:**  
**Individuals with Autism**  
**(Intellectually High Functioning)**  
**Ages 5-Adult**

**WOULD YOU LIKE TO SHARE YOUR EXPERIENCES/VIEWS OF  
YOUR CHILDHOOD LEARNING EXPERIENCE  
(WITHIN INFORMAL EDUCATION/PHYSICAL ACTIVITIES)?**

**As part of my doctoral thesis I shall be attempting to  
Identify Factors Impacting the Informal Education  
Learning Experience for Young Autistic Students**

Phase one of this research study aims to collect  
as many perspectives as possible based on three questions relating  
to the learning experience, via on-line bulletin walls. The answers/  
comments will be anonymous and on closure of the walls, will be collated  
into themes to use for phase two of the research study.

**WHAT TO DO NOW:**

- 1 Visit [www.wallwisher.com/wall/autismresearch1](http://www.wallwisher.com/wall/autismresearch1)
- 2 Visit [www.wallwisher.com/wall/autismresearch2](http://www.wallwisher.com/wall/autismresearch2)
- 3 Visit [www.wallwisher.com/wall/autismresearch3](http://www.wallwisher.com/wall/autismresearch3)
- 4 The 'walls' will be open between 1st October and 31 December 2012 for 'postings'
- 5 No registration needed—just choose a name for yourself
- 6 Post your views/answers/comments to each wall
- 7 Use more than one 'sticky' if you need to or follow the link for longer messages
- 8 At the end of the study, towards the end of 2014, the results/summary will be published on my website <http://www.challengeautism.co.uk>

'Postings' on the walls automatically give your consent for the 'posts' to be used for this research study. No names will be used. The research has been approved by Sheffield Hallam University Research Degrees Sub-Committee and the Faculty Ethics Committee.

For more information:  
Researcher/Doctoral Student: Sandra Ellis MAEd PGCertAS, Sheffield Hallam University  
[sandra.j.ellis2@student.shu.ac.uk](mailto:sandra.j.ellis2@student.shu.ac.uk)  
Director of Studies: Dr Luke Beardon [l.beardon@shu.ac.uk](mailto:l.beardon@shu.ac.uk)



#### **Will I know the research results?**

I shall give you a summary of the results at the end of this study. This study will form my Doctorate in Education Thesis. You are welcome to see any papers I write containing this research. The research has been approved by Sheffield Hallam University Research Degrees Sub-Committee and the Faculty Ethics Committee.

#### **What consent is needed for me to be involved in the study?**

If you agree to take part in this research study, I shall ask you and your parents/carers to sign a special form allowing me to collect information from you. Your teacher(s) will also need to consent to you collecting information relating to your learning in their classes/activities.

#### **About me**

I am an experienced karate and dance teacher, having been teaching for over 20 years; 13 of which I have been teaching individuals with autism. I am also responsible for a national coaching programme for physical activities coaches/teachers. I am in my third year of a Doctorate in Education. I have also been clinically diagnosed with Asperger's Syndrome (a presentation of autism).

#### **Further questions**

If you have any further questions or would like to be considered to take part in this study, please contact me on the telephone or email below. You are also welcome to contact Dr Beardon for further clarification. I hope you will agree to work with me and help other young people with autism. You will be helping to make a difference.

Sandra Ellis MAEd PGCertAS  
Sheffield Hallam University  
Tel: 01227 376181 / 07966 403271  
sandra@challengeautism.co.uk  
www.challengeautism.co.uk/mywork/current research  
Director of Studies: Dr Luke Beardon  
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July 2012 2

## **Identifying Factors Impacting**

## **the Informal Education Learning Experience for Young Autistic Students**

**2012-2014**

**- Doctoral Research Study -  
Phase Two: Mosaic Collection**

**This leaflet is for young people, their  
parents/carers and class teachers**

**This leaflet gives some details about the study. I  
have offered some questions you may have, with  
my answers, so you can talk about them  
together before you decide whether you would  
like to take part.**

### What is the research for?

All young people on the autism spectrum are special and unique individuals, sometimes with special requirements for learning or with unique skills which need to be supported and developed. This detailed research study will take place over the next two years and will aim to identify factors which impact the learning experience for young people with autism, within activities outside the normal school curriculum eg, dance, martial arts, football, scouts, brownies, swimming and so on.

It is important for this research that I hear individuals' childhood experiences of these activities and also involve young people in collecting information which I can use, but will also benefit them and be fun. I shall write reports on what I see, hear, read and learn.

Examples of what I would like to know:

- What makes you decide to take up an activity outside the school curriculum?
- How important is it for your teacher to know about autism?
- How important to you is the relationship between you/your teacher?
- What kinds of difficulties do you have in your classes?
- How do you think these may be resolved?
- What would make the learning experience more positive for you?
- What makes the ideal teacher to suit your needs and help you enjoy your classes?

### What does the study involve?

This phase of the study (phase two) involves you helping me to answer some of the questions above by keeping a 'diary' of your experiences, thoughts, feelings, likes, dislikes, wishes. This 'diary' is really a big scrapbook which you can fill exactly as you want to. You can use stories, diary entries, pictures, cartoons, photographs, maps, poems, whatever you like. You can be as creative as you like or not at all. You can handwrite or use the computer. Spelling and grammar is not a priority so don't worry if this is a difficulty. The 'diary' is all about your learning in activities and classes outside school, eg, martial arts, dance, football, swimming, scouts, brownies, army cadets, Duke of Edinburgh scheme, tennis, gymnastics, or whatever else you do. I can also watch you in your classes and take notes, or ask you questions in an informal interview type situation. You may choose how you want to help me.

### What will I be given?

You will be given a 'diary pack' which will consist of:

- Guidelines
- Scrapbook
- Coloured pens
- Disposable camera
- A variety of stickers and craft materials

### How long will I have to complete my 'diary'?

You will have about two months to complete the 'diary'. This will include any observations or interviews I do in addition to or instead of the 'diary'.

### Who will be involved?

This phase of the study will be 'advertised' to lots of young people who take part in informal learning classes/activities. Ten individuals will be selected with a variety of ages and a mix of boys and girls. No-one else needs to know you are involved in the study.

### Do I have to take part?

It is your choice whether you take part. If you say yes, you can drop out at any time if you feel uncomfortable or for any other reason. Any information you have already collected will be destroyed and no-one will be annoyed.

### Will doing the research help me?

I hope you will enjoy the project but my main aim is to make the learning experience more positive for young people in similar situations as you and you will be helping them as well. It will be a real chance to make your views, whatever they are, known and an opportunity to have some fun.

### Who will see the information?

The information you give me will be seen by me and colleagues at Sheffield Hallam University, your teachers and your parents/carers will see a summary of the research at the end of the study. Your name will not be used in the study. The information will be kept by me in a lockable cabinet, and when the information is no longer needed, it will be destroyed.



**'SECRET BOX'**  
**Individuals with Autism Ages 5-15**  
**Teachers of Young Autistic Individuals**

**WOULD YOU LIKE TO SHARE YOUR EXPERIENCES/VIEWS OF  
YOUR TEACHING / LEARNING EXPERIENCES  
(WITHIN INFORMAL EDUCATION\*/PHYSICAL ACTIVITIES)?**

**As part of my doctoral thesis I shall be attempting to  
Identify Factors Impacting the Informal Education  
Learning Experience for Young Autistic Students**

The 'SECRET BOX' will be available at classes for you to 'post' your views, experiences and wishes. Only I will see the 'postings' and will not be able to identify who they come from. This is your opportunity to say exactly what you think and perhaps change the future learning experiences of you, your peers and your students.

**WHAT TO DO NOW:**

1. A worksheet with research 'topics' will be available at classes or on my website:  
[http://www.challengeautism.co.uk/current research/secret box](http://www.challengeautism.co.uk/current%20research/secret%20box)
2. You may 'post' your views directly into the box at a class
3. You may 'post' your views by putting into a sealed envelope addressed as 'secret box' and either give or send to me.
4. The box will not be opened until the end of April 2013 (research period)
5. At the end of the study, towards the end of 2014, the results/summary will be published on my website <http://www.challengeautism.co.uk>

'Postings' in the box automatically give your consent for the 'posts' to be used for this research study. No names will be used. The research has been approved by Sheffield Hallam University Research Degrees Sub-Committee and the Faculty Ethics Committee.

For more information:

Researcher/Doctoral Student: Sandra Ellis MAEd PGCertAS, Sheffield Hallam University  
[sandra@challengeautism.co.uk](mailto:sandra@challengeautism.co.uk)

Director of Studies: Dr Luke Beardon [l.beardon@shu.ac.uk](mailto:l.beardon@shu.ac.uk)

\* For this study defined as an 'organised educational activity outside the school curriculum, where the teacher has appropriate experience and/or qualifications'

## DOCTORAL RESEARCH - PHASE TWO 'DIARIES'

### PARTICIPANT GUIDANCE (and for parents for younger children)

Thank you for taking part in my study. I hope you enjoy this diary (scrapbook) collection.

I want to know what you think and feel about your learning outside the normal school curriculum. **IMPORTANT - THIS IS NOT ABOUT YOUR SCHOOL LEARNING OR SCHOOL TEACHERS**

- ☺ Please try to include all activities you do. For example, karate, dancing, football, netball, scouts, brownies, swimming, basketball, army cadets, gymnastics or whatever else.
- ☺ You may use all or some of the materials I have provided in your diary pack. Keep everything in your 'diary' - you can write or draw in it directly, or on paper and stick it in using glue or sticky tape.
- ☺ Spelling and grammar are not so important, so don't worry if you struggle with this for any reason.
- ☺ Just use first names or pretend names in your diary so that other people do not get upset. The information you give me will only be seen by me and some people who read my work at Sheffield Hallam University.
- ☺ You may use a computer to type out what you want to say and then stick this in the 'diary'.
- ☺ Please use the camera to take photos of your activities, of your favourite teachers, of your favourite halls or rooms for learning, or whatever else you wish. You may either ask your parents to get the photos developed or you may return the camera to me and I will do it, and return the photos back to you to stick in your 'diary'. If you want to use your own photos that is fine too.
- ☺ Consider some of the following to help you fill your 'diary':
  - ✓ What made you take up the activity (s) (MOTIVATION)?
  - ✓ How important is it for your teacher to know about autism?



- ✓ What makes a good or not so good teacher for you?
- ✓ How important is the relationship you have with your teacher?
- ✓ If there was a perfect teacher what would he or she be like?
- ✓ What would be your ideal lesson/class?
- ✓ What makes an activity difficult or uncomfortable for you?
- ✓ What makes the learning experience positive for you?
- ✓ How do your activities make you feel?
- ✓ Show me some of your favourite things in a lesson?
- ✓ What is the ideal hall/room for you to learn well?
- ✓ How do you think your autism affects how you learn?
- ✓ Anything else you want to tell me

☺ You can use:

- ✓ Stories
- ✓ Diary entries
- ✓ Poems
- ✓ Pictures
- ✓ Photographs
- ✓ Maps
- ✓ Spider diagrams
- ✓ Charts
- ✓ Drawings
- ✓ Labels
- ✓ Posters
- ✓ Stickers
- ✓ Leaflets
- ✓ Anything else you would like to use.

If you would prefer I can have a chat with you (interview) and record your answers, or I can simply watch you during classes and take notes. These can be instead of the diary or as well as the diary.

If you get worried about your diary at any time or have a question you can contact me. You can either email me at [sandra@challengeautism.co.uk](mailto:sandra@challengeautism.co.uk) or call me on 01227 376181 or 07966 403271. I would like you to tell your parents or guardian before you call me.

## DOCTORAL RESEARCH - PHASE THREE 'SECRET BOX'

### POTENTIAL TOPICS for students and teachers

You are welcome to either write or computer generate your views and comments and bring them back to a class where the 'secret box' will be available, or give/post to me in an envelope (Secret Box, PO Box 262, Herne Bay, Kent, CT6 9AW). DO NOT INCLUDE YOUR NAME.

#### Students

- What made you take up the activity (s) (MOTIVATION)?
- How important is it for your teacher to know about autism?
- What makes a good or not so good teacher for you?
- How important is the relationship you have with your teacher?
- If there was a perfect teacher what would he or she be like?
- What would be your ideal lesson/class?
- What makes an activity difficult or uncomfortable for you?
- What makes the learning experience positive for you?
- How do your activities make you feel?
- What are some of your favourite things in a lesson?
- What is the ideal hall/room for you to learn well?
- How do you think your autism affects how you learn?
- Anything else you want to tell me

#### Teachers

- Talk to me about the relationships you have with your autistic students and issues surrounding the teacher/learner situation
- What difficulties do you have?
- What do you find positive and enjoyable or rewarding?
- Anything concerning the student topics listed above

## **PLACES USED FOR RECRUITMENT OF PARTICIPANTS**

Websites of:

- Challenge Autism
- National Autistic Society
- National Association of Karate and Martial Art Schools
- Kent Karate Schools
- Talk About Autism
- Autism Community
- Wrong Planet
- Communities for Autism
- Autism Speaks
- The Autism Trust
- Autism File
- Kent Autistic Trust
- Autism Education Trust
- Autism Support Network
- AS Support Group Online
- Burgess Autistic Trust

Sport and Recreation Alliance: leaflets to members and representation at meeting

Linked-In

Facebook

Twitter

Martial Arts Illustrated & Combat Magazines

Press Release from Sheffield Hallam University

Personal Blog

Laleham Gap School

## QUESTIONS FOR INTERVIEWS

These were adapted as necessary for ages and appropriateness, and were supplemented by additional questions based on answers given.

1. Tell me about the activities you take part in.
2. Why did you start these activities?
3. What do you enjoy about ... (activity)?
4. What has ... (activity) given you?
5. Do you get days when you don't want to attend a class?
6. Why?
7. How important do you think it is for your teacher to know about/understand your autism/Asperger's?
8. Do you tell people you are autistic?
9. What makes a good teacher for you?
10. What makes a teacher not so good for you?
11. How important is the teacher/student relationship for you?
12. What might make a class better for you?
13. What might make a class uncomfortable or difficult for you?
14. What makes a learning experience really positive for you?
15. Do you find that the learning environment, ie, the hall, affects your learning?
16. What makes the environment good for you?
17. What issues about it affect your learning negatively, if any?
18. Is anything likely to distract you?
19. How do you think your autism affects your learning?
20. Tell me anything else you can think of which relates to your learning experience which you think would be useful?