

The Construction of the Autistic  
Individual: Investigations in Online  
Discussion Groups

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## **Abstract**

This project investigates the construction of the autistic individual through the use of Internet methodologies, drawing on the social model of disability and critical psychology as epistemological resources. Four asynchronous online discussion groups were studied, whose membership comprised of people with autism, parents of people with autism, and professionals working within the field of autism. The group discussions yielded diversity of discourses surrounding autism, and through critical discourse analysis, I prioritised three key issues that are examined through the empirical chapters of the thesis.

The first major theme to be analysed is identity and highlights strong alternative discourses surrounding autism. It is shown that these alternative discourses led some contributors to the discussion groups to construct an empowered identity, which frequently contradicts and challenges 'expert' views of people with autism and their abilities, and resists the regulation of autistic identities by professionals working within the psy-complex.

The second major section of the analysis details discussions of the diagnosis of autism. This chapter reflects the powerful position held by psy-professionals with regards to the diagnosis of autism and the importance of identified norms of childhood which serve to identify normal and abnormal behaviour.

The final empirical chapter reflects complex negotiations surrounding the label of autism. The chapter includes an examination of the construction of the autistic individual within the therapeutic relationship and the goals of therapeutic interventions. In addition, attention is given to an influential position within some of the discussion groups which rejects 'therapeutic improvement' in favour of negotiating a place for a person with autism within society that is dominated by the 'neurologically typical' who lack autistic characteristics.

In the concluding chapter I reflect on my position as a neurologically typical researcher and examine my role within the research process. I discuss the ways in which my analysis contributes to theoretical debates and the applications of the thesis.

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I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed: 

Dated: 18<sup>th</sup> October 2007

# Chapter 1: Introduction

## 1.1 The methodological approach

I first considered the methodology employed in this thesis and the research questions posed after reading an article in the New York Times by Harvey Blume, which discussed the potential that the Internet may have for self-advocacy among people with autism. I had previously worked with both autistic adults and children, who were rarely accorded a voice in decisions made about them, and I became interested in some of the self-advocacy literature within disability studies in light of this. Initial Internet searches identified numerous online groups discussing issues surrounding autism. In exploring the construction of the autistic individual I have employed online qualitative research methodologies, which complement the key theoretical influences in the work.

The methodology employed in the thesis uses the Internet as a research tool. This is in line with recent work carried out using online methodologies in other research areas such as researching interactions between breast cancer survivors (see for example Sharf 1999). Research also highlights an increasing use of the Internet by people with autism (see for example Dekker 2000, Blume 1997). It has been shown that people are more likely to display higher levels of self-disclosure in computer mediated communication as compared to face to face situations (Joinson 2000). People can therefore be encouraged to speak openly, and in some instances are able to show a resistance to positioning imposed on them in the 'real' world (Joinson 2000). This is particularly important for my research population, as the use of computer mediated communication enables researchers to contact populations who may have difficulty in interacting in traditional face to face situations, as people with autism have been characterised in traditional literature (please refer to the literature review for a fuller discussion). The Internet

is therefore considered to be a useful tool in enabling individuals with autism to share their experiences and perceptions of the label 'autism'.

## **1.2 The theoretical approach**

The thesis draws upon a number of epistemological resources in order to understand the rich data collected. One key influence is the social model of disability. The social model was initially primarily focused on people with physical impairments, but in more recent writings its scope has been widened to include people with intellectual and sensory impairments (Barnes and Mercer 1996). The model was initially developed by a group of disabled activists in the late 1960s and early 1970s as a reaction to the dominant medical approach to disability (Barnes and Mercer 1996). Traditionally psychology has employed a strong focus on an individual's impairment, presenting such impairment as a 'personal tragedy' view of people with disabilities (Lawthom and Goodley 2005). The social model is mainly located within British disability politics (Shakespeare and Watson 1997), and the focus is on the impact of disabling barriers in societies and a rejection of the conception of disability as an individual problem stemming from a person's impairment (Barnes and Mercer 1996). In chapter 3 I review literature discussing the social model of disability and its application to learning difficulties. This thesis presents an application of the model to autism, and the fit of the theory to autism with respect to the findings presented in the thesis will be reflected upon and discussed in chapter 8: Critical Reflection.

In addition to a strong influence from the social model of disability the thesis also draws upon a critical approach in order to enable me to examine social and political influences on the construction of autism, and allows an examination of power, which is a key theme prioritised in the analysis. The theoretical underpinnings of the work are also reflected in the choice of analytical methodology, critical discourse analysis. The approach complements the theoretical influences as, in addition to studying the ways in which language creates meaning, critical discourse

analysis enables an examination of how various forms of language serve a range of social, ideological and political interests (Parker 1997a).

### **1.3 Definition of key terminology**

In introducing the thesis I would like to briefly outline some of the terminology used in the work. Attention must firstly be paid to my use of the label 'autism' to refer to some of the contributors to the project, rather than 'Asperger syndrome'. The literature review presents work which discusses the differences between Asperger syndrome and autism, and the clinical differences between autism and Asperger syndrome are both complex and unclear. Indeed Kugler (1998) comments that a lack of reliable research findings does not enable many definitive conclusions to be drawn regarding a specific differential diagnosis. The complex clinical picture results in disagreements concerning the differences between the two labels in the non-professional population. Some activists within the autism rights movement argue that the distinction between autism and Asperger syndrome is not clear enough for them to be taken as separate entities, and therefore people with a label of Asperger syndrome should be able to identify with the broader label of autism spectrum (see for example Siedel 2004/2006). In contrast other writers controversially reject Asperger syndrome as part of the autism spectrum on the basis that it constitutes a separate entity (see for example Schafer 2005). My research has taken the lead from contributors to the online discussion lists contributing data to the thesis, and includes Asperger syndrome within the general term 'autism'. The discussion lists presented in the thesis typically use the term 'AS' to refer to the autism spectrum, and hence include people at all levels of autism and Asperger syndrome. The terminology used by contributors is also interchangeable between autism and Asperger syndrome, with posters referring to themselves as 'Aspies' but also as part of the autism spectrum. Such interchangeable use of terminology reflects the lack of agreement among professionals as to the diagnostic uniqueness of the characteristics of autism and Asperger syndrome.

The terminology that I have used to refer to the non-autistic population has also taken the lead from the writings of people with autism, and such a population is referred to throughout the thesis as 'neurologically typical' or 'NT'. Dekker (2000) traces the origins of the term 'NT' to a self-advocacy organisation run by people with autism called Autism Network International. Dekker notes that in order to avoid having to use the term 'normal' to refer to people without autism, the founders of Autism Network International invented the new term of neurologically typical to refer to people without neurological conditions such as autism. The use of NT is now commonplace within the autism community online, and is a term widely recognised by people with autism, parents and some professionals working within the field of autism.

Another key term used throughout the thesis is 'people with learning difficulties' rather than 'people with learning disabilities'. This follows the discussions of Sutcliffe and Simons (1995) who reported that most respondents in their research project preferred the label 'people with learning difficulties' as it offered a potentially positive self-definition. The use of people first language characterises much of the label use in the thesis, although this is an area for debate within disability theory. For example Barnes, Mercer and Shakespeare (1999) advise to avoid using the term 'people with disabilities' as this implies that a person's impairments defines the identity of that individual, and may blur the important conceptual distinction between impairment and disability, both key concepts guiding the social model of disability. Similarly Harmon (2004) prefers the term 'an autistic' or 'an autistic person' rather than 'person with autism', due to the important self-definition attached to a label of autism. Harmon highlights the central role that autism plays in an individual's identity by arguing that it would also appear strange to refer to someone as 'a person with femaleness' rather than 'female'.

The use of labels is a key issue explored in chapter 5: Identity, and the use of the term 'autistic' reflects the political strategy of a positive construction of an autistic identity. In the thesis I therefore use people first

language in some instances, particularly when reviewing academic literature, and alternative terminology when a statement is being made by individuals concerning the differences between autistic and non-autistic people. For example in chapter 5 when I discuss the differences between autistic and non-autistic people in terms of being social I refer to 'autistic people'. In contrast, when discussing dominant constructions as presented in academic and professional literature I refer to 'people with autism'.

#### **1.4 The structure of the thesis**

Chapters 2 and 3 provide a review of literature concerning autism, the Internet and key epistemological resources informing the thesis. This outlines the context in which the work rests, enabling chapter 4 to detail the methodological approach of the thesis in light of this. Chapter 4 discusses the use of online methodology as a research approach, and details the strategy used in the thesis with regards to selecting the online discussion groups for inclusion in the study, and the analytical methodology employed.

Chapters 5, 6 and 7 represent the three key themes prioritised as being important in the e-mail contributions and focus discussions on issues relating to identity, diagnosis and the negotiation of a label of autism. Chapter 8 is titled 'Critical Reflection' and represents a critical examination of my role as an NT researcher in the field of autism. This chapter also includes a general review and discussion of the thesis, including a presentation of the practical applications of the thesis.

#### **1.5 Research aims and objectives**

The research aims and objectives are detailed below, with a brief commentary indicating where each will be met within the analysis presented in the thesis. A fuller discussion of the research aims and

objectives and how these have been met in the thesis can be found in Chapter 8: Critical Reflection.

The principal aim of the research is to investigate the construction of the autistic individual. Five main objectives have been identified: -

1. *To explore how the perspectives of individuals with autism can be heard through investigations using new technologies.*

Four online discussion groups were joined for the research. Membership for two of these groups consisted primarily of people with autism, supplemented by membership to a list dominated by parents and a list dominated by professionals in their membership status.

2. *To examine the implications of accepting the construction of autism as a singular 'disorder'.*

The methodological approach to the thesis has led to the identification and sampling of a diversity of discourse surrounding autism. Such diversity has been identified both within and between discussion groups, with a range of discourses drawn upon by people with autism, parents and psy-professionals, which at times can appear contradictory. This fits with a focus in the thesis on valuing neurodiversity, which does not necessarily make assumptions that all people with autism or all psy-professionals will construct an identical portrait of autism, and similarly, the groups will not necessarily differ in their discourse in uniform ways. The acceptance of a particular construction of autistic individuals is therefore brought into question.

3. *To examine the relationship between 'normality' and 'abnormality', and consider how autism as a specific 'impairment' has been constructed within this framework.*

The concepts of 'normality' and 'abnormality' are explored in Chapter 6: Diagnosis. Here I discuss the psychological resources used by psy-professionals in the diagnosis of autism, and explore the powerful position that they maintain in such a discourse. The powerful discourses of professionals are also reflected upon in discussions of the pervasive nature of the professionally identified norms of childhood, and the use of such benchmarks by parents in identifying 'normal' and 'abnormal' behaviour.

4. *To examine similarities and differences between constructions of autistic and neurologically typical individuals.*

The constructed differences between autistic and neurologically typical individuals is a recurring theme throughout the thesis. It is examined in particular detail in Chapter 5: Identity, where a discussion and analysis of the constructed differences are presented.

5. *To examine the powerful position accorded to psy-discourse within discussions of autism.*

An examination of power is evident in all of the empirical chapters of the thesis. Discussion of power differentials is however particularly prevalent in Chapter 6: Diagnosis and Chapter 7: Negotiating a label of autism. Chapter 6 discusses the powerful position that psy-professionals hold with regards to diagnosing autism, and the powerful role that they play in establishing the norms of childhood. Chapter 7 extends this analysis and discusses the dominant position maintained by professional discourse in interventions with people with autism, and presents an examination of the dominant construction of the autistic individual within therapeutic discourse as having a *deficit* rather than a *difference*.

## **Chapter 2: Literature Review – Autism and the Internet**

In reviewing the literature I have chosen to discuss three key areas, and the structure of the review reflects this. My aim in the review is not to provide a completely comprehensive account, particularly of literature discussing autism, as the material in this area is wide in its scope and numerous in volume. Rather I am aiming to introduce the reader to the key issues outlined in the literature that are relevant to my current thesis. The review is separated into two chapters: this first chapter details a review of literature concerning autism and the Internet, and the second discusses the epistemological resources drawn upon in the thesis.

The first part of the review in chapter 2 will consider literature relating to autism. In discussing the material related to autism I will focus primarily on the key characteristics of autism as defined by professionals and researchers working within the field, issues concerning the diagnosis of autism including a review of discussions concerning the diagnostic independence of the labels 'autism' and 'Asperger's syndrome', and approaches to therapeutic intervention and the explicit goals of therapy. In reviewing the literature in the field of autism the review will focus on a traditional viewpoint of autism spectrum disorders. This is important because traditional psychological accounts construct autism in particular ways and in doing so present an account as to the 'impairments' of people with autism. The dominant scientific accounts of autism which serve to construct the reality of autism will be critically examined in later parts of the thesis.

The second part of the review in chapter 2 will consider literature relating to the Internet and research carried out through an online medium, reflecting the methodological choices made with regards to the current thesis presented here. I will review discussions of the type of communication interactions that take place through Internet technologies,

and issues surrounding the concepts of 'cyber-communities'. I will also provide a review of material detailing the use of the Internet by people with disabilities generally and autism specifically and the implications of this. A discussion will also be provided concerning issues of identity and specific questions that are raised regarding identity presentation through communication via an online medium.

The discussions of identity will lay the basis for the theoretical approach of my thesis which will be detailed in chapter 3 where I will discuss epistemological resources for the thesis. Within this chapter I will present current literature in disability theory, including the social model of disability and its application to learning difficulties generally and autism specifically. Also within this chapter I will present wider theoretical tools which I will use to frame my analysis of the material from the online discussion groups. Here I will discuss the historical and cultural production of knowledge which serves to frame our understanding of autism in particular ways. I also draw upon the work of critical commentators in discussing the ways in which experts are in powerful positions in both the identification and diagnostic testing of autism, and the interventions provided by professionals. These discussions guide the analysis of the material in the thesis.

## **2.1 Autism**

### *2.1.1 Characteristics of autism*

The term 'autism' was first introduced in 1911 by Eugen Bleuler but was initially considered to be a branch of schizophrenia. Thirty years later autism was 'discovered' almost simultaneously by two psychiatrists working independently. Kanner (1943) working in USA made observations in his paper 'Autistic Disturbances of Affective Contact' of children he considered to be autistic. Hans Asperger (1944) working in Austria made independent observations and also chose to use the label 'autism'. The research of Kanner became the predominant work in the

field, largely due to Asperger's work not being translated into English until the 1980s, and also the geographical location of the work being carried out: Kanner working mainly in the USA and Asperger predominantly in Austria.

### *Leo Kanner*

Kanner's influential 1943 paper highlighted a series of key impairments that he associated with autism. These key features were presented from detailed clinical accounts of a group of children with common features subsequently labelled as autism. While Kanner acknowledged individual differences in the cases presented, he emphasised a number of common characteristics in the eleven cases, and proposed that such characteristics formed a 'unique syndrome'.

The first feature highlighted by Kanner is that of an inability to relate to people and social situations. Kanner proposed that this was evident from the beginning of life and manifested in an 'extreme autistic aloneness' in which no social reciprocation was evident in relating to others in social situations. Like Asperger, Kanner noted that this lack of social interaction was different from the aloneness characteristic of some people with schizophrenia, because for people with schizophrenia, relationships are often evident but deteriorate over time. In contrast, people with autism have an 'extreme autistic aloneness' from the start of life.

A key area focussed on by Kanner related to the management of social situations was that of speech. From his clinical population, Kanner reported that eight out of the eleven children acquired the ability to speak either at the appropriate level or with some delay, and of those who did acquire speech, most did not use speech in a socially communicative way in order to convey meaning to others. Common to Kanner's clinical population was a literal understanding of language, and a failure to generalise between situations. In addition, several features of language were also reported to be common in children with autism, for example

pronoun reversal and echolalia, with either the immediate or delayed repetition of words or phrases.

A further key feature of Kanner's syndrome was that of a desire for the maintenance of sameness. This often manifested into an anxiously obsessive desire for routines and aspects of the child's environment to remain the same and become ritualised. Changes for example in the order of events for a daily routine led to anxiety for the children and often despair. Kanner argued that such a desire for the maintenance of sameness led to a narrow range of interests, despite the children with autism in his population displaying good cognitive potential.

Physically Kanner believed that the children were not unusual, but proposed that they did come from highly intelligent families, indicating a genetic link in the manifestation of autism. In most of the cases focussed on by Kanner, the children come from successful middle class families, often with eccentric ancestors, as shown in the example of Donald: "The father, whom Donald resembles physically, is a successful, meticulous, hard-working lawyer who has had two "breakdowns" under strain of work." (Kanner 1943 p.218). Kanner's final thoughts examined parenting styles more closely, and he commented that "In the whole group, there are very few really warm-hearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people. [...]The question arises whether or to what extent this fact has contributed to the condition of the children." (p.250). This view would in subsequent years have important implications for future theories concerning the nature of autism and its link to parenting styles.

### *Hans Asperger*

Asperger's 1944 paper also presented work detailing clinical case studies, this time from a group of four boys. Asperger's focus in his research population was on the use of social contact and this was considered by Asperger to be the 'fundamental disorder', which affected all aspects of their personality, therefore purporting to explain difficulties and deficits as well as any special abilities that the children may display (Asperger 1944 p.39). Such a core impairment in social contact resonated in a lack of socially interactive gestures and expressions and this focus by Asperger on expression leads to a scrutinisation of the use of the pragmatics of language by children with autism and the conveyance of meaning in language, by, for example, the management of lies, genuine meaning and tone of voice. In observing the problematic use of the pragmatics of language by children with autism, Asperger observed that autistic language is not always directed at the listener, an element which is echoed in more contemporary characterisations of autism, (for example Folstein 1999; Frith 2003). However, Asperger does cite some examples of children with autism developing adult-like speech at an early age, highlighting the diversity of speech patterns among his clinical population. Speech for Asperger then is not necessarily absent in children with autism, but may be accompanied by some expressions of echolalia or repetition of words or phrases, and is frequently accompanied by an inappropriate use of eye contact and expression.

The second key feature highlighted by Asperger was that of intelligence. His clinical case study observations describe a series of problematic encounters with children with autism when employing standard intelligence tests. Obtaining a true measure of intellectual abilities was proposed to be particularly problematic by Asperger due to the reluctance of children tested to focus and respond to questions, particularly those that were not interesting to the child. As a result of this, Asperger describes the outcomes of intelligence testing as 'highly contradictory'. If the child's attention could be focused on the task however, Asperger reported some high achievements, particularly in the area of mathematics.

Asperger refers to the concept of 'autistic originality' and felt this to be particularly evident with respect to mathematical tasks. He proposed that children with autism can only produce original ideas, and mechanical learning is hard for them. This was evident in the use of original methods for solving mathematical problems, rather than the ones conventionally taught in the education system. These novel methods were however often more complicated than more conventional methods, which frequently led to errors being made in calculations. In spite of this, Asperger comments that such areas of talent often impress teachers, who find it hard to understand why children with autism fail to learn on a more general level in an educational environment.

The third key area of difficulty highlighted by Asperger as central to children with autism is that of behaviour in a social group. This reflects his belief that the core deficit in autism is a limitation in social relationships. Expectations from others such as parents regarding behaviour in social situations may lead to aggressive and negative behaviour. Such conduct problems are described in several of the clinical case studies presented by Asperger along with several clinical case study depictions describing 'mischievous' behaviour. However, while discussing such problems that children with autism may have in social groups, Asperger did comment that children with autism do not necessarily remain isolated from all social relationships. Particularly with reference to the case study on Fritz, Asperger noted that while it may seem initially that Fritz avoided social interactions where possible, Fritz was skilled in seeking relationships with key people with whom he reciprocated affection on occasions.

Asperger proposed that issues relating to a lack of social reciprocation manifest themselves in often stereotyped activities such as monotonous play or rhythmic rocking. In describing several case studies he refers to the children as 'precise', with certain things having to be done in certain ways. Frith (1991) comments that this is similar to Kanners insistence in sameness. However, while Asperger notes this characteristic, he does

not necessarily focus on this symptom, unlike Kanner who viewed it as a central feature of autism, (Frith 1991).

The fourth characteristic highlighted in Asperger's clinical picture is that of drive and affect. However, he notes that the picture is far from uniform. Within this broad bracket, Asperger discussed hypersensitivity to certain tactile sensations, and an obsessive relationship to objects. The clear difference for children with autism however, is not to make the objects representative of an animate being, but the relationship is more that of a collector. Also linked to issues of affect is the inability of children with autism to demonstrate a sense of humour. Asperger proposed that such children do not understand jokes, particularly if the joke is on them.

The fifth feature focused upon by Asperger was that of genetic and biological factors of autism. Asperger maintained that autistic traits were usually found in families of children, and his detailed focus on the family histories of children reflects this. Asperger proposed that children often display hereditary traits of intellectuals who are characterised as deep in thought and unaware of things around them. He notes that "If it is the father who has transmitted the autistic traits, then he will in most cases have an intellectual profession. If one happens to find a manual worker among them, then it is probably someone who has missed his vocation. In many cases the ancestors of these children have been intellectuals for several generations and have been driven into the professions by their nature." (Asperger 1944 p.84). Asperger can therefore be argued to present his distinct syndrome as more readily attributable to the middle classes, something that resonated in the thinking of later work.

The final feature highlighted by Asperger in his clinical description is that of questioning the social value of people with autism. Again he notes that the picture is far from uniform, with some 'able autistics' getting good employment positions and have the potential to do particularly well in some employment arenas because of their ability to focus on one aspect

of a situation, enabling them to ignore everything else and attend solely on one area.

Despite working with independent clinical cases, there are clearly some similarities between the key features proposed by the two early influential theorists Kanner and Asperger. However, it is important to note that each theorist prioritised certain key features as being central to their clinical picture at the expense of others. The importance of historical influence on the development of Kanner and Asperger's theories has been discussed by Alderson (1999), who focuses on the very different political environments in which Kanner and Asperger were researching. Alderson comments that decades later their work was revived without any reference to their political origins and influences, as if both had developed in a cultural and political vacuum.

Several commentaries have been written comparing the two early accounts of Kanner and Asperger, and Frith (2003) usefully summarises the key points of shared commonalities and differences. One key feature highlighted by Frith (2003) as being common to both early accounts is the focus on communication and social adaptation, which play important roles in both theories, as well as a focus on stereotyped activities and an uneven performance on intelligence test scales. One of the key differences summarised by Frith is the definition that each theorist approached their syndrome from. Asperger's definition of autism was much broader than Kanner's, enabling an inclusion in his clinical picture of children who displayed signs of brain damage and those who displayed high intelligence patterns, and could therefore be considered to shade into normality due to the subtlety of their symptoms, (Frith 2003).

*Characteristics of autism in contemporary research materials:*

*Wing's (1997) 'Triad of Impairments'*

The initial foundations for conceptualising autism rested on the early influential papers by Kanner (1943) and Asperger (1944). While some contemporary constructions of autism echo such early descriptions, for example inappropriate use of eye contact and speech difficulties, there are some differences in contemporary prioritised characteristics, for example a questioning of the average IQ proposed by Kanner (Mesibov, Adams and Schopler 2000). Some contemporary descriptions of autism have been reported with reference to Wing's (1997) 'triad of impairments'. The key features of the triad largely echo the earlier work of Kanner and Asperger and will be briefly detailed here due to their influence on the field of autism and the important role they play in shaping our understanding of autism and focusing our gaze on specific characteristics.

The first criteria of the triad focuses on the social development of the individual, the second on impairments in communication, and the third on the repertoire of behaviours expressed by the individual. Such diagnostic criteria were conceptualised by Wing (1997) as a "Triad of Impairments" due to the nature of the impairments not necessarily being separate entities, but occurring together (Frith 2003). Wing (1997) proposes that such a triad is common to all people with autism and includes areas of social interaction, communication, imagination and a narrow and repetitive pattern of behaviour. Each of these areas will now be presented more fully.

*Social Development*

Folstein (1999) argues that developments in social behaviour for non-autistic children are evident from early infancy, particularly with respect to the use of eye contact and a desire to be physically close to a caregiver. In contrast, some children with autism do not appear to be interested in their parents, and may actively avoid physical contact with them. However, this is by no means a pattern true for all children with autism and the picture of social development is complex and diverse. Frith

(2003) notes that such early signs of sociability are not necessarily absent in all children with autism, with some showing patterns in socialisation which are similar to children without autism such as smiling at their parents. However, such patterns of social development typically do change for the child with autism, who becomes more withdrawn socially, with preferred isolation at its height at around three to five years old (Frith, 2003).

In later childhood, many autistic children do develop a close relationship with their parents, but may remain largely uninterested in other children, particularly failing to develop friendship networks (Folstein, 1999). Folstein observes that this may diminish into adolescence, with many adults with autism wanting to establish relationships with others, but lacking the social skills required to form these such as eye contact and small talk, with chat very often being restricted to a narrow range of topic areas. Frith (2003) further comments that such developments in socialisation, particularly after five years, are displayed in a general improvement in social skills and general adaptation to life circumstances. However, such developments are typically slow due to the inability to appreciate others' thoughts leading to the behaviour of others remaining confusing to them, (see later for a discussion of Theory of Mind Hypothesis).

Such problems in social development can be highlighted with reference to the use of eye contact by people with autism. Generally, people without autism use eye contact in subtle ways to communicate intent and understanding in situations. People with autism have been shown to be unable to use eye contact for this purpose and pay little attention to other people's facial expression or direction of gaze (Trepagnier et al 2006). Frith (2003) argues that if children with autism cannot automatically decode the meaning of eye gaze, then silent messages sent by peers and parents are likely to be ignored or mistaken, further compounding problems in social communication.

### *Language Development*

Folstein (1999) discusses a variety of impairments in language development, with some people with autism never developing speech, while others may acquire speech, but this may vary from a few phrases to a 'normal' construction of language. If people with autism do acquire speech, they may exhibit several characteristics such as echolalia (the repetition of words or phrases which may be delayed or immediate) and problems with the pragmatics of speech and the social aspects of language, with speech often being used to communicate specific needs or information, rather than the purpose being to chat or socialise. Competence in communication has been positioned as a key feature in determining an individual person with autism's abilities to develop relationships with others and engage in social interactions (Woods and Wetherby 2003).

The majority of speaking children with autism display echolalia, which may be either immediate or delayed (Woods and Wetherby 2003). Frith (2003) notes that while this does occur in the speech of children without autism, this only occurs at a very young age and fades with development, as language skills improve. This is also true for children with autism but to a lesser extent. Frith argues that such echolalic speech often occurs in place of ordinary communicative speech, and in some instances, echolalic utterances may have a specific purpose, such as requesting something from another person. However, in many instances, such utterances are thought to be stereotypic in behaviour with no communicative purpose. However, as with all of the identified 'impairments' in people with autism there are a range of abilities.

In contrast to communication in face to face situations, Frith (2003) notes that the use of written language can often be highly sophisticated, with many people with autism preferring to communicate in a written form. Frith comments that this is because such individuals find face to face conversation stressful at times, and feel that they are under less pressure and can therefore think better when they read or write. This observation is

drawn upon in the current thesis which employs a new methodology when researching with people with autism, by focusing on non face to face communication channels. The novel methodology that I am employing in my research with people with autism will also serve to enable an examination of the commonly stated impairments in social interaction and question the constructed lack of interaction between people with autism. The contributors to the discussion lists posted interesting and insightful comments, frequently dealing with complex issues and discussions in sophisticated ways without the need for reliance on non-verbal cues to guide behaviour.

### *Rigid and Repetitive Behaviours*

Rigid and repetitive behaviour are one of the diagnostic criteria highlighted in contemporary descriptions, again drawing upon the earlier work of Kanner and Asperger. Folstein (1999) proposes that this category includes hand flapping, the need to ritualise behaviour, such as always taking the same route to school, and the overly focused interest that children with autism sometimes have in specific topics or objects. Such interests may consume all or a significant proportion of their time, and may be the main/only topic of conversation, even if the listener does not know about or has no interest in the topic. Frith (2003) notes however that such behaviours are not unique to autism and may occur with other diagnostic conditions such as schizophrenia and brain stem dysfunction.

One area not addressed specifically by Wing's triad of impairments but which is central to the current thesis is that of 'intelligence'. The measurement of intelligence has occupied a central position in psychological theory, enabling the categorisation of individuals according to statistically standardised norms (see for example Rose 1989a; Richards 1996; Burman 1994). The powerful position that this accords to psy-professionals will be further discussed in the section detailing the epistemological resources of the thesis. What will follow is a discussion of the dominant contemporary thinking concerning the relationship between IQ and autism.

The relationship between autism and IQ is complex, and researchers frequently find that results from IQ tests reflect a level of intelligence which does not match the observed pattern of behaviour in an individual with autism. As noted earlier, the work by Kanner and Asperger highlighted this incongruence, with some children with autism performing above average on certain sub-scales of IQ tests and below average on others. Such abilities in certain areas may leave teachers and parents confused as to the general lack of performance across a range of tasks, including those of a daily routine, which was in stark contrast to a proficient ability in others.

When testing is carried out using intelligence tests such as the Wechsler scales of intelligence, it is assumed that a calculation of average performance for the 'normal' child can be made, and that such children will perform equally well across a series of sub-scales. However, testing of children with autism often leads to a profile of peaks and troughs in sub-scale measurements, with children performing well on some measures and below average on others. Taken together, this can skew any calculations of a child with autism's IQ level. Frith (2003) comments that such a test profile is specific to autism and not found in any other clinical group, and although not every child with autism will display exactly the same profile, typically performance is worst on areas requiring communication abilities, and best at those tests involving visio-spatial abilities.

Further complicating discussions of intelligence in people with autism is literature pointing to the identification of 'islets of ability' found in people with autism (see for example Happe 1991, Thioux et al 2006). Typical examples of such 'islets' in people with autism are rote memory skills, where individuals can remember impressive sequences, which are outside the normal range of abilities, or mathematical calendar calculation skills. Frith (2003) estimates that such areas of excellence can be found in approximately ten per cent of people with autism, a figure in contrast to popular media representations of autism such as the film 'Rainman'.

Alderson (1999) reflects on the plentiful discussions of the characteristics of autism and argues that there are so many characteristics proposed in the literature that it is unlikely that a single person will have all of them, and others may have none of them at some points in time. Selfe (2002) echoes this conclusion and reflects on the frequently observed gap between the picture presented in textbooks and the experiences of people with autism, highlighting the complex issues involved in defining and diagnosing autism. Selfe argues that the literature very often presents autism as a distinct and homogenous group of people, playing down the important differences between autistic individuals. Alderson (1999) further argues that the context in which observations and diagnoses are taking place can further affect the behaviours and consequent judgements about a child. Alderson proposes that certain environments such as a highly structured and segregated educational system may actually enforce the characteristics associated with autism, such as isolation and self-absorption, onto the pupils.

The triad of impairments has had an important influence on both academic literature and clinical professional practice. It serves as a basis through which to conceptualise the 'impairments' typically associated with autism, and has important links to the diagnosis of autism.

### *2.1.2 Diagnosis*

Wing's (1997) triad of impairments has had important influences on the diagnostic procedure and criteria for the diagnosis of autism. Diagnosis is also an important issue for many contributors to the discussions lists which are detailed in the current thesis, with postings ranging from wanting to secure an 'official' diagnosis, to a reliance on self-observation and self-diagnosis. In the following section I will describe some of the key features of an official diagnosis in order to facilitate later discussions of diagnostic experiences in the chapters of analysis.

The identified characteristics associated with autism have led to guidelines concerning the diagnostic criteria for autism. The two primary classificatory systems for diagnosis are the Diagnostic and Statistical Manual (DSM) and International Statistical Classification of Diseases and Related Health Problems (ICD), with the DSM system being the most commonly used. It was not until the DSM –III (American Psychiatric Association, 1980) that autism was recognised as an ‘official’ and distinct diagnostic category (Volkmar 1998). In the DSM-III autism was included in a new ‘class’ of disorders termed the Pervasive Developmental Disorders, and all criteria had to be satisfied before a diagnosis could be made. Since its original inclusion, several revisions of its specific categorisation are evident. The first notable change was in the revised version of the DSM (DSM-III-R) where the early onset of the disorder was dropped as a necessary diagnostic criterion (Volkmar 1998). Bishop (1989) notes that the DSM-III-R defined Pervasive Developmental Disorders as encompassing all disorders in which there is a qualitative impairment in reciprocal social interaction, communication and imagination. Autism is defined as a severe form of Pervasive Developmental Disorder, with ‘less severe’ cases diagnosed as Pervasive Developmental Disorder not Otherwise Specified (PDD-NOS).

This revised edition led to concerns that clinicians were ‘over-diagnosing’ autism, and discrepancies were highlighted between the two classificatory systems of DSM and ICD with respect to the diagnosis of autism (Volkmar 1998). The creations of the DSM-IV (1994) and ICD-10 (1992) have seen a convergence in agreement of diagnostic categories and criteria. Also notable is the inclusion in the DSM-IV and ICD-10 of Asperger syndrome as a ‘new’ and distinct disorder. (Literature reviewing the distinctions between autism and Asperger’s syndrome will be presented in a later section of this review.)

However, despite guidelines for diagnosis, there remains much debate concerning the diagnosis and criteria for autism and Aspergers. One of the major debates is the cut off point between Aspergers and normal

eccentricity (e.g. Wing 1981). Wing proposes that all features which characterise Aspergers can be found in varying degrees in the general population in terms of people differing in their social skills and ability to read non-verbal cues. While she is confident that a 'typical' case of Aspergers can be easily recognised by a professional working in the field, there are cases which lead to confusion with 'normal eccentricity' and other clinical diagnoses. As a result, Wing (1981) proposes that any diagnosis must be made based on a full clinical picture and individual history and not solely on the absence or presence of individual items in a diagnostic sheet.

Bishop (1989) further discusses diagnostic issues and proposes three main reasons for the lack of agreement over the diagnosis of autism. The first of these is the use of different diagnostic criteria by different clinicians. This is compounded by the subjectivity of the symptoms used in such diagnostic criteria. Finally, the diagnostic procedure can be complicated by the changes in the clinical picture of autism with age.

The lack of agreement between the different diagnostic criterion for autism and Aspergers will be discussed in a later section in this chapter. However, Radda (2001) writing for the Medical Research Council, summarise that the distinction between autism spectrum disorders and 'normal eccentricity' can be defined in terms of clinical need. They propose that while one person may manage well without a diagnosis, and may find a niche in life, others may benefit from a diagnosis through the understanding of a person that a diagnosis may give.

### *Parental Experiences of diagnosis*

As previously stated, the importance of diagnosis is reflected in discussions on the online lists contributing to the current thesis. For many individuals posting to the forums, issues surrounding diagnosis pose central questions. However the diagnosis of autism also has important influences which resonate beyond the individual and pose questions for family members and partners of the individuals diagnosed. This wider

influence of diagnosis is also reflected in the postings to the discussion lists, and I would now like to briefly examine some of the empirical literature addressing such questions, particularly of parental experiences of diagnosis, due to one of the discussion lists largely comprising of this population.

Morgan (1988) stresses the bi-directional nature of the relationship between the child with autism and their family, and consequently the family's reaction to the diagnosis is an important feature of the diagnostic process. Avdi, Griffin and Brough (2000) interviewed three sets of parents in eleven semi-structured interviews and found that parents frequently welcomed a firm diagnosis as once a label had been given, it could act as an "antidote to uncertainty" (p.248). A diagnosis could therefore transform a problem that was vague and not well understood to a definite 'thing', that had implications for causes to be hypothesised and treatment programmes which could be employed to change behaviour. Avdi et al found that parents frequently constructed autism as an 'enemy from within', which could, once labelled, be analysed and challenged. Avdi et al propose that in constructionist terms, diagnosis can be seen as the point in which the condition is reified, and a search for causes can begin. Avdi et al found that once a diagnosis had been made, parents "...were found to be actively involved in constructing their child's problem and their own role in it and in this process they were found to draw from available discourses around normal development, medical knowledge and disability." (Avdi et al 2000). Avdi et al's analysis of how some parents expressed a feeling of relief when given a label provided a pointer to the analysis of themes identified in the discussion list exchanges in my research.

Midence and O'Neill (1999) conducted a qualitative piece of research using Grounded Theory to investigate parents' perspectives and experiences of diagnosis. Through their research they identified several core categories in the reporting of such experiences. One core category was behaviour development in which all parents in the study reported that

their child's development was not as they expected and that there was something 'different' in the way that they behaved. This was accompanied by feelings of confusion in not being able to understand why their child behaved in the way that they did. That is, while the parents could identify that there was a problem, they did not know what the problem was. This finding formed the basis for an analysis of the issue in parental postings to the online groups studied in this thesis.

A third significant category was that of incorrect diagnosis, where despite seeing professionals, many parents felt that the diagnosis given to their child was wrong. In contrast, and similar to the findings of Avdi et al (2000), if a 'correct' diagnosis of autism had been given (in the eyes of the parents) feelings of relief were expressed by some parents. Indeed the parents in this study highlighted the need for a label to be given to their child. Once a label had been given, parents often reported feeling more supported, although they highlighted the need for practical help and support to be made available to them following diagnosis. The final category identified by Mindence and O'Neill (1999) is that of acceptance and adaptation. Here, once a diagnosis had been given, parents placed a firm importance on accepting their child's condition, and stressed the importance of leading a 'normal' life and including the child in every day activities. Parents also reported the importance of accepting that autism is part of their child and they would not necessarily want to change it.

In addition to the acceptance and understanding of parents of autism, Gray (2002) highlights the important effects of stigmatising reactions from other members of the public. Gray notes that autism is not a disability that is obvious to the public; however it can have strong effects on encounters with the public due to its low visibility. This can lead to stigmatising reactions from others in light of the absence of more obvious explanations of disablement that other conditions can draw upon. The reactions of communities and the consequent acceptance or rejection of difference has important effects on people with autism in their everyday interactions with other individuals.

### *The question of difference between autism and Asperger's syndrome*

One important area of controversy regarding the agreement of definitions and diagnosis of people with autism is the relationship between autism and Asperger's syndrome and the questions regarding their similarity and differences. As previously stated, Asperger's syndrome became recognised as a distinct category in its own right in the DSM-IV (1994) and ICD-10 (1992) revisions. What follows will be a brief account of current literature discussing the distinctions between autism and Asperger's syndrome, with a position statement with regards to my own use of terminology in the thesis in light of the literature.

There are a range of diagnoses proposed to overlap with autism; however, the main debates are those surrounding the similarities and differences between autism and Asperger's syndrome, and whether the two can be conceptualised as separate entities. Such debates have been evident from early classifications of the two, with Wing (1981) commenting that Hans Asperger acknowledged the similarities between his own syndrome and Kanner's infantile autism. However, Wing notes that Asperger did consider the two to be separate as he regarded autism as a psychotic process, but his own syndrome as a stable personality trait.

More contemporary research has proposed that a label of Asperger's syndrome is used to describe a group of individuals who do not appear to strictly fulfil the diagnostic criteria of autism (Eisenmajer et al 1996). Such a label of Asperger's has been used almost interchangeably with other labels such as atypical autism, residual autism, PDD- not otherwise specified, at one time or another to describe such a group of individuals (Eisenmajer et al 1996). Eisenmajer et al comment that the description of Asperger's in DSM-IV has criteria which are almost identical with those for autism, therefore suggesting that there is not currently any clear boundary between the two diagnoses. The authors note however, three main differences in the diagnostic criteria of the two. With respect to Asperger's, no communication and imagination impairment criteria are highlighted, in contrast to autism. Secondly, no delay is identified in a

diagnosis of Asperger's with respect to cognition or self-help skills other than social skills. Thirdly, Asperger's is not associated with a clinically significant delay in language development. Such differences in criteria, particularly with regards to cognitive potential and language development are generally agreed on by researchers (see for example Prior et al 1998, Folstein 1999). Eisenmajer et al note that these criteria are in agreement with those originally proposed by Asperger (1944), who emphasised the main areas of impairment to be social and not language or cognitive delays.

McLaughlin-Cheng (1998) notes that while there are no specific diagnostic criteria for children with high functioning autism (HFA), many studies when making a comparison between autism and Aspergers, select participants who are regarded by them as high functioning autistics. For example, in their study detailing structured interviews with 48 parents of children and adolescents with high functioning autism and 69 parents of children and adolescents with Asperger's syndrome, Eisenmajer et al (1996) found that few clinical differences existed in categorisation by clinicians between Asperger's and the group labelled as having high functioning autism. Eisenmajer et al did however highlight some key characteristics which may influence a clinician's choice of labels. The desire for friendship was considered to be one such key characteristic. If the individual had a stronger desire for friendships, then they were more likely to be labelled as Asperger's, even though both groups displayed problems in attaining and maintaining friendships. Parents from both groups were interviewed and were unable to report a strong friendship with others as commonly displayed by non-autistic people. Eisenmajer et al propose that the view of the person with autism as being socially aloof is incompatible with the desire for friendships. Therefore in displaying such a desire, individuals were more likely to be labelled as having Asperger's syndrome rather than as being autistic.

Other issues arose in the study with respect to impairments in communication. The authors proposed that clinicians were more likely to

diagnose Asperger's, even if they displayed a delay in language, if they were less socially impaired. Eisenmajer et al comment that a lack of language delay is taken by both DSM-IV and ICD-10 as traits in Asperger's not autism, but clinicians in the study were still diagnosing Asperger's even when language delays had been evident. This provides further evidence as to the complex nature of differentiating the two labels. Eisenmajer et al also noted that clinicians were less likely to label a less 'retarded' group as having Asperger's syndrome.

Eisenmajer et al comment that it is significant to note that the two groups were not different on many of the 'classic' autism impairments, such as imagination, imitation, non-verbal communication, literal understanding of language, awareness of social rules and presence of routines and resistance to change. They comment that while factors such as accurate reporting by parents, and clinicians mis-classifying, or indeed no real difference being evident between the two groups, may influence diagnosis, there remains the issue that even though the children were fulfilling the diagnostic criteria for autism, clinicians were selecting the label of Asperger's for some. They propose that this may reflect the differences in cognitive ability between the two groups. Further complications in diagnosis were highlighted with respect to the changing clinical picture over time in individuals, with some children with high functioning autism becoming more 'Asperger-like'.

Ozonoff, South and Miller (2000) conducted a study comparing 23 children diagnosed with high functioning autism with 12 children diagnosed with Asperger's syndrome. The children were matched for chronological age, gender and intellectual ability, with the authors investigating possible differences in cognitive function, current symptomatology and early history. Few group differences were found in current presentation and cognitive functioning, but they did find differences in early history. Such differences reflected more impairments in language ability in the high functioning autism group as reported by parents. The authors propose that this indicates a difference in the

developmental pattern of the two disorders, with high functioning autism beginning with more severity of impairments than Asperger's. The pre-school age differences between the two groups were also seen to diminish in adolescence, taken by the authors as indicating that the high functioning autism group 'caught up'. Ozonoff et al conclude that due to similar cognitive profiles identified between the two groups, Asperger's syndrome can be seen to be on the same spectrum as other autistic syndromes, but differs primarily in the degree of impairment.

Other studies support the proposal of a distinct difference between the two diagnostic classifications of autism and Asperger's syndrome. McLaughlin-Cheng (1998) compiled a meta-analytic study reviewing the differences between autism and high functioning autism and Asperger's syndrome. The findings suggest that children and adolescents diagnosed with Asperger's syndrome perform better on cognitive measures and adaptive behavioural measures. McLaughlin-Cheng proposes that such findings support clinical research that maintains a difference between the two groups on such measures and ultimately supports the proposal that the two are distinct clinical entities.

Work by Ziatas, Durkin and Pratt (1998) reinforces this claim. Ziatas et al investigated potential differences in the theory of mind of children with autism and Asperger's syndrome. They propose that despite many similarities arising between the two groups, particularly with respect to communicative features, there are differences between the two groups that relate specifically to the development of a theory of mind and belief terms. Such differences were particularly evident with respect to social-cognitive and communicative functions, therefore suggesting an important distinction between the two groups in these areas.

The studies discussing the differences between autism and Asperger's syndrome take several different forms as shown above, although many rely on a quantitative approach to methodology, with some form of statistical analysis of the differences (see for example Ozonoff, South and

Miller 2000; Eisenmajer et al 1996). Such an approach fails to incorporate the voice of people diagnosed with autism and Asperger's syndrome, and may not fully encapsulate the complex issues surrounding the acceptance of a diagnostic label, and in doing so fail to consider the implications of accepting such a label, and the importance of the label to an individual. A literature search shows that much research effort is placed in discussing the differences between autism and Asperger's syndrome and the consideration as to whether they form distinct clinical entities; however, no agreed conclusions have been reached within this literature. Kugler (1998) comments that a lack of reliable research findings does not enable many definitive conclusions to be drawn regarding a specific differential diagnosis.

The discussions of clinical difference between autism and Asperger's syndrome therefore draw upon a particular frame of reference, and the arguments become circular when considering the exclusivity of the two diagnoses. This complex picture painted by professionals has important effects on the understandings of non-professionals with regard to the differences between autism and Asperger syndrome, and important influences on the effects of labelling on individuals. Some activists within the autism rights movement argue that the distinctions between autism and Asperger's is not clear enough for them to be taken as separate entities and hence people with Asperger syndrome should be able to identify with the broader concept of the autism spectrum (see for example Siedel, 2004/2006). In contrast, other contributors to the autistic advocacy debate controversially reject the inclusion of Asperger syndrome as a part of the autism spectrum, constructing it as a separate entity with specific needs that are quite separate from the needs of people with autism (see for example the Schafer 2005).

My research will take the lead from the contributors to the online discussion lists and include Asperger syndrome within the discussions of the general term 'autism'. The discussion lists presented in the current thesis use the general terminology of 'AS' to refer to the autism spectrum,

and hence include people at all levels of autism and Asperger syndrome. The terminology used by contributors is also interchangeable between autism and Asperger's with posters referring to themselves as 'Aspies' but also as part of the autism spectrum. Such interchangeable use of terminology is also reflected in the lack of agreement among professionals as to the diagnostic uniqueness of the characteristics of autism and Asperger syndrome.

### *2.1.3 Adults with Autism Spectrum Disorders*

Much of the research literature focuses upon children with autism, often to the neglect of adults with autism. Adults with autism form the main group of contributors to the current thesis, and consequently literature examining the conceptualisation of autism in adults will now be addressed. Bishop (1989) argues for the importance of adopting a life-span approach to autism. Bishop argues that a lack of such a perspective can be confusing for parents who are told that their child has an incurable condition, and may consequently believe that they can expect no change in their child's behaviour and abilities, when in reality the picture is far more complex.

The highlighted lack in social awareness has been an area frequently studied when research is carried out with adults with autism. Folstein (1999) discusses how a lack in such social abilities can become particularly problematic once people with autism are sexually mature. Folstein argues that like other adolescents, people with autism have sexual desire but are unsure as to the appropriate releases for it. Folstein further proposes that more able adolescents with autism will become increasingly aware that they are different to others and do not 'fit in'. Folstein proposes that such a lack in social abilities leads to many adults with autism being under-employed relative to their measured intelligence, a premise reflected in several postings to the discussion lists contributing to the current research.

These points are echoed by Barnard, Harvey, Potter and Prior (2001) who comment that people with autism or Asperger's have very little choice in where they live, what work they can do, and who, if anyone, looks after them. Barnard et al cite that only 2% of adults at the lower end of the autism spectrum and only 12% of high functioning autistic adults are in full-time employment, with 24% not in education or employment. Barnard et al further discuss points of advocacy and cites that only 19% of adults in their study had access to any sort of advocacy when their future was being decided upon in order to help them express their views about their choice of care, housing and activities.

In a recent study Portway and Johnson (2005) researched life stories of 25 young adults with Asperger's and their parents. The study explored the expressed feelings of the group in that they appeared to be 'normal' but did not quite 'fit in'. The authors raised important questions concerning the reasons for this perceived 'lack of fit' – did the experience arise solely from the attitude and behaviours of others towards the young adults, or did the individual feel different regardless of the behaviour of others? Or some possible interaction between the two? Portway and Johnson cite two risk types associated with the experiences of people contributing to their research. Everyday risks were those arising from the perception of others, and included being misunderstood, teased, ridiculed and ostracised. Longer term risks were cited as including underachievement, risks to emotional well being and over dependence on their parents.

Reflecting on the stories of parents of the young adults, Portway and Johnson (2005) found that parents often felt accused by professionals of being overprotective, but felt that it was only them that understood the true extent of their offspring's dependency and vulnerability. Addressing the accusations of over protectiveness they cited their offspring's vulnerability towards exploitation from others as a primary concern in addition to an inability to cope with independence.

Increasingly literature is also turning to autobiographical accounts from people with autism in order to better understand the challenges faced by adults with autism (see for example Barrett 2006). Such personal narratives can highlight the complexity of issues faced by people with autism and restate the individual experience of various challenges (Barrett 2006), rejecting the construction of people with autism as one homogenous group. The use of autobiographical accounts has led to important insights, for example, into how individuals with autism experience emotions. Barrett for example details a student, Chris, who discusses his experience of emotions. For Chris, emotional understanding was a complex issue, with some emotions being more easily understood than others. The accounts provided by Chris concerning his emotional understanding also related to his behaviour in social situations in which he experiences anxiety when he is expected to rely on cues from other people.

Similarly, emotions are highlighted as a central concern for Edgar Schneider (1999) in his reflective autobiography:

“First, as far as being able to connect with other live human beings, male or female, I am an emotional idiot. (That last phrase is mine; the phrase commonly used in psychology is ‘emotional deficit’.) It seems that, just as some people have an important physical component missing (eyes, limbs, etc.), I have an important component of the human psyche missing: the ability to connect emotionally with other human beings.” (Schneider 1999, p.25)

The richness of such autobiographical accounts and the sophisticated reflections that many make on autism make them an important resource for both people with autism and their families and professionals. Indeed, Barrett (2006) proposes that the understanding of the personal experience of autism should be a key concern for professionals in their work practices. First hand accounts can also potentially play an important role in informing debate concerning the theories proposed to explain autism, although in practice the influence of such accounts on academic literature remains marginal.

#### *2.1.4 Theory of Mind*

Numerous theories propose to explain autism and range from a series of psychologically focussed theories to those influenced by biology and neurology. All theories of autism share the common assumption that there is a deficit in people with autism which should be researched, classified, and ultimately modified if the hypothesis suggests that this may be possible. The common link between the theories is therefore an assumption that there is something 'wrong' with the person with autism. Some theories occupy a more influential position than others within the autism literature, for example theory of mind, while some such as the debate concerning the links between the MMR vaccine and autism are given high visibility in the media despite a rejection by Radda (2001) as to epidemiological evidence to support the links between the vaccination and autism. Such media portrayal is never the less highly influential and high priority is given to parental voices in such a debate (O'Dell and Brownlow 2006).

One highly influential theory purporting to explain the impairments in autism is that of theory of mind. This will be focussed on here due to its influence within the professional field and the powerful position that it holds in constructing an image of the person with autism. The theory of mind hypothesis will also be revisited when discussing the epistemological resources drawn upon by the thesis, and challenges to the hypothesis by both academics and people with autism will be discussed.

Tager-Flusberg, (1999) defines theory of mind as referring to "the ability to attribute mental states, such as desire, knowledge, and belief, to oneself and other people as a means of explaining behaviour" (p.326). People with autism are therefore thought to be impaired in the ability to appreciate their own and other peoples mental states (Baron-Cohen 1998). It is proposed that theory of mind develops as the child matures, with the ability first emerging towards the end of the first year when

infants begin to view people as having intentions in their behaviour patterns (Tager-Flusberg, 1999). By 3 years the child can understand desires and simple emotions in themselves and others, and are able to discuss a person's actions in terms of the mental states that cause them. This ability improves by 4 years whereby children can understand more complex mental states, notably the concept of beliefs, and the understanding that people may hold beliefs that conflict with reality (Tager-Flusberg, 1999).

A landmark study investigating theory of mind was carried out by Baron-Cohen, Leslie and Frith (1985) which examined the hypothesis and the assertion that children with autism could not understand that other people may have beliefs that differ from their own. This study adapted the methodology of Wimmer and Perner (1983) to create the Sally-Anne experiment. In the experiment Baron-Cohen et al compared children with autism, children with Down's syndrome and typically developing children on their understanding of false belief. In the experiment the researchers introduced the children to two dolls, Sally and Anne. Sally has a basket and Anne has a box. The researchers then acted out a short sequence for the children involving the two dolls. In the sequence Sally has a marble and places this in her basket, she then goes for a walk. Unknown to Sally, Anne takes the marble from the basket and places it into the box. The children are then asked to predict where Sally will look for the marble when she returns to the room. In order to give the correct answer, that Sally will believe that the marble is still in the basket where she left it, the children will have to understand the concept of false belief and an appreciation that another person could have a belief which contrasts with their own. The child must therefore disregard their own knowledge of the true position of the marble in the box, and respond that as Sally did not witness Anne move the marble, she will believe that the marble is still in the basket where she left it.

In their study, Baron-Cohen et al (1985) found that 80% of the children with autism failed to give the correct answer to this question, although

they could answer control questions concerning where the marble was originally and where it was moved to. The results for the children with autism were in contrast with those for the other two groups of children who gave more correct answers to the false belief question despite the fact that the mental age of the children with autism was higher than the other two groups of children on both non-verbal and verbal scale measurements. Baron-Cohen et al (1985) conclude that the results of the experiment show that the children with autism did not appreciate the difference between their own and the doll's knowledge. They further argue that such a failure by the children with autism in their experiment constitutes a specific deficit. They propose that it cannot be attributed to the general effects of cognitive ability, since the children with Down's syndrome performed well on the task, and were at a lower measured cognitive level. They therefore propose that they have identified in their experiment a specific cognitive impairment that is largely independent of general intellectual level and has the potential to explain both the lack of pretend play and the social impairment often witnessed in children with autism.

The Sally-Anne experiment is an example of a first order theory of mind tests as it involves understanding that someone can hold false beliefs about the world. Second order theory of mind tests have also been developed and require the participant to hypothesise what another person may think that a third person is thinking, and therefore are more complex in their demands.

Bowler (1992) Replicated first and second order theory of mind experiments with adults with Asperger's. Bowler found that young adults with Asperger's could solve problems requiring a second order theory of mind. However, when asked to justify their answer they failed to make use of mental states. Bowler proposed that this lack of appreciation and use of mental states can make the behaviour of adults with Asperger syndrome appear 'odd' in everyday social interactions. Bowler proposed that due to the cognitive skills of people with Asperger's being relatively

unimpaired, they can get around their lack of intuitive knowledge of social situations and perform well in such test situations. However, they fail to replicate this in real life situations. This is something that Hermilin and O'Connor (1985) refer to as a "logico-affective state".

Peterson and Siegal (1999) characterise theory of mind research as falling into two camps. The nativist approaches, for example, Baron-Cohen (1992), propose that neurobiological factors are responsible for the development of theory of mind in children without autism, and it is therefore a specific deficit in children with autism. The cultural or environmental accounts, for example Lillard (1997), propose that the understanding of mind develops through social interactions. It is through observing others and engaging in conversations, that children come to construct representations of mental states, (Peterson and Siegal 1999 p.126). Peterson and Siegal feel that their work falls into the latter camp. They highlight the importance of theory of mind in deaf children's development, and highlight several studies which have found that despite only including deaf children with typical intelligence in studies, researchers have found that children who are deaf displayed a lower performance on theory of mind tasks than hearing children. This is true only for those children brought up in families where there are no native signers. Although Peterson and Siegal acknowledge that biology and culture may not be necessarily mutually exclusive, they propose an important cultural effect in the development of a theory of mind.

Guajardo and Watson (2002) also propose that children's understanding of mind is linked to their participation in conversations with others about feelings and mental states. To test this they developed training involving naturalistic social interactions using children's storybooks as a way of manipulating exposure to social discourse. In the sessions they discussed mental states and the concepts of false belief and deception in relation to the stories. They hypothesised that children embarking on the social training would perform better on theory of mind post-tests than a control group who did not receive such training. They failed to find such

an effect in their experiments, but went on to modify methodology and in light of this did subsequently find improvements in performance following training. In the later experiments both groups of children improved on subsequent theory of mind tests, but training accelerated improvement.

Several discussions focus on the problematic nature of such tests for theory of mind. Tager-Flusberg (1999) proposes that one of the main problems associated with such tests is that some people with autism can complete the tasks. Tager-Flusberg also notes that there are developmental inconsistencies with the theory in that theory of mind should develop in children by 4 years of age, but by then, there are already many signs of autism. However, despite such reservations, Tager-Flusberg does endorse a connection between a theory of mind hypothesis and social impairment in people with autism. Tager-Flusberg argues that the social world is complex for the person with autism as they have difficulty in understanding and predicting other peoples actions. However, this may be less true for people who they know well and in situations that they are familiar with, as a more structured routine can be established which makes interaction with these significant others less uncertain for the individual and hence a close and affectionate social interaction can be evident.

The theory of mind hypothesis is also proposed to be important in explaining difficulties in language and communication, which is cited as a core deficit in the diagnosis of autism. Tager-Flusberg (1999) proposes that people with autism have specific problems in understanding that language is a means of interacting with others and for sharing perspectives and ideas. Tager-Flusberg argues that people with autism at all ages have difficulty in taking into account the listener's perspective, which affects engagement in conversation. Tager-Flusberg concludes that such language and communicative deficits evident in people with autism can be directly attributed to an impaired understanding of others' minds.

Andrews (2002) discusses two main strands to objections to taking false belief tasks such as Baron-Cohen et al's (1985) as the criterion for a theory of mind. First is the claim that a theory of mind is best understood as a continuum. Therefore if children fail a task, they may have a less developed theory of mind, and hence a theory of mind may not be necessarily absent completely (Fodor, 1992, cited in Andrews 2002). Secondly criticisms focus on the additional skills that children need in order to pass the false belief tasks, such as language, and memory skills.

Dyck, Ferguson and Shochet (2001) question the specific role that a theory of mind may have in the explanation of autism. Dyck et al argue that because of the varying abilities on theory of mind tasks by children with autism, it is not necessarily specific to such a spectrum of disorders. Dyck et al therefore propose that theory of mind ability should be seen as a disability dimension affected by a range of factors, and not necessarily as a marker for a specific disorder. Dyck et al argue that participants in studies have emotional empathy impairments in addition to theory of mind impairments, and that both emotional empathy and theory of mind deficits are not unique to autism spectrum disorders but can occur in a variety of children. However, despite such concerns, the theory is still very influential in current research approaches to autism.

### *2.1.5 Therapeutic intervention*

Numerous interventions have been proposed to be effective when working with people with autism. What I would like to introduce here is not a comprehensive account of all available approaches to therapies which pertain to change and improve the behaviour of people with autism, but rather outline some of the key ideas upon which such therapeutic intervention rests. I will begin by introducing some of the more common therapeutic approaches and the key ideas that underpin these. It must be noted however that theorists and professionals generally guard against specific advice for all people with autism based on the general principles of the approaches due to the large individual differences found in the

population of autism and the changing needs through the life-span (see for example Frith 2003). Interventions must therefore be tailored to meet individual needs.

Happe (1994) proposes a useful division of therapeutic interventions into two main areas: biological treatment and behavioural therapies.

Behavioural intervention can be considered an umbrella term that covers a range of techniques including Lovaas method, discrete trial training, operant learning and applied behavioural analysis (Shea, 2004). While these approaches are not necessarily interchangeable, and each has important distinctive features, they can be considered to fit within this broad bracket. The outcomes of biological treatments are not always consistent and no drug has been identified as effective in helping all people with autism (Happe 1994). Behavioural therapies, and in particular educational programmes, have received more favourable evaluations (Happe 1994; Frith 2003; Shea 2004; Baker 2006). Baker (2006) notes that Applied Behavioural Analysis has been cited as the most 'scientifically proven' treatment for autism. Such an approach requires full-time intensive treatment with the explicit goal of intervention being to teach the individual child with autism to act as if they were neurologically typical, that is non-autistic. Baker (2006) highlights that this form of intensive behavioural therapy may not be suitable for all people with autism, particularly those with high functioning autism who may view this form of intervention as oppressive.

Within this thesis I would suggest that the experiences of people with autism should be central in a discussion of therapeutic interventions, and several biographies and autobiographies detail such experiences. For example, Schneider (1999) discusses his experiences with various drug treatments:

“...I went from one psychiatrist to another at the county mental health clinic. Each would see me approximately every three months for about fifteen minutes, ask how I had been doing, and write new prescriptions for my medications.”  
(Schneider 1999)

Schneider discusses how such a relationship resulted in him being prescribed anti-psychotic drugs which affected his intellectual and aesthetic faculties. He then moved area and found a new psychiatrist who changed his drug prescriptions, which have restored his functioning and enabled him to write his autobiography.

Similarly Klein (2002) reflects on behavioural techniques and questions the morality of such interventions due to their identification of autistic behaviours as 'undesirable'. For example, Klein discusses 'stimming' behaviour (an abbreviation of self-stimulation) as being one area singled out by professionals as undesirable behaviour and therefore in need of change. Klein however argues that such hand-flapping etc. serves as a means of providing the autistic person the stimulation that they need at a specific moment in time. To target such behaviours as undesirable and hence in need of change is not appropriate.

However, one of the fundamental principles common to therapeutic approaches is the concern for the need to change 'undesirable' behaviour and replace this with more 'desirable/acceptable' behaviour. For example, reflecting on behavioural approaches to intervention, Safran, Safran and Ellis (2003) noted that students undertaking behavioural therapy must be specifically taught to be able to discriminate between socially acceptable and socially unacceptable behaviours, learning appropriate alternatives to unacceptable behaviour. Here the clear implication is that people with autism must change in order to accommodate the non-autistic world. In a further example of the requirements for people with autism to change in order to fit a 'less autistic ideal' Safran et al (2003) discuss the use of technologies by people with autism. It is proposed in the current thesis that technological advances mark an important development for people with autism and this is reflected in their online exchanges and advocacy enterprises. In this way, new technologies can be an important link in the communication chain for people with autism. Safran et al however warn of the potential dangers of using such new technologies. While they acknowledge the appeal of new technologies for people with Asperger's

syndrome particularly, they propose that there needs to be a balance between online and 'real-time' interactions, given that the student with Asperger's may choose cyberspace interactions over the more energy demanding interactions in the 'real world'. The researchers here are therefore prioritising 'real' face to face interaction over the possibility of people with autism taking ownership of an effective communicative style which may be appropriate for them. This again reflects the presupposition in therapeutic interventions that it is the individual with autism that is required to change rather than engage in a more accommodating interactional environment.

While influential theorists and professionals working in the field such as Francesca Happé and Uta Frith propose that there is not a cure for autism, and in as much, autism is not a condition that can be eliminated from a person, they do highlight therapies that can be used to 'improve' people with autism. The key issue for these theorists however is that the fundamental neurological condition underlying autism remains untreatable and hence unchangeable. This appeal to neurology is echoed in the discussions presented by many of the contributors to the discussion lists presented in this thesis, and also has a wider use in online autistic communities more broadly; however, the argument is used to serve a very different purpose, as can be seen in the discussions in Chapter 4 surrounding issues of identity. In citing the distinctive features of people with and without autism, professionals undertaking therapeutic intervention highlight and value more positive attributes in non-autistic behaviour, and hence autistic behaviour resulting from the neurological make up is considered deviant and must therefore be changed through professional interventions.

Billington (2006) has provided a fresh examination of therapeutic intervention with people with autism and highlights the dependence of traditional interventions on the 'triad of impairments' (Wing 1997). Billington proposes that a rigid adherence to such a triad can reflect in an inability of services to meet the needs of people with autism and their

families. Due to the reliance of the models on the *impairments* of people with autism and not the *differences* of such a group, the experiences of individuals are largely lost in the therapeutic exchanges. Billington argues that such individual experiences and accounts can be an important resource for professionals. This remains unexplored due to the focused interventional approach, and the views of people with autism should be heard and respected within the professional discourse. Billington therefore highlights the need for professional practice to focus on the assets rather than deficits of people with autism by engaging in a new way of talking about and conceptualising autism, thereby placing the onus of change not just upon the person with autism, but also on the wider social network, including parents and professionals. This view is very much in line with one of the theoretical influences of this thesis, the social model of disability and its focus on self-advocacy. The implications for such alternative assumptions about therapy will be explored in the context of the current thesis.

The review of literature thus far has focused on dominant traditional approaches to the study of autism. While such approaches command a powerful position in psychological literature, I want to examine through the current thesis the role that such dominant constructions play for people with autism. One of the impairments in Wing's triad is that of social interaction and the difficulties of interaction with others in a face-to-face setting. My research has employed the use of Internet technologies to examine interactions of people with autism in non-face-to-face situations facilitated via an asynchronous discussion list. It is to the literature surrounding such methodologies that the review will now turn.

## **2.2 The Internet**

### *2.2.1 The Internet as a means of communication and conventions in Internet communication*

The Internet provides several avenues for the exchange of information. These can generally be grouped into two main types: synchronous and asynchronous exchanges. Synchronous exchanges are performed in real-time, with all parties contributing to the exchange online at the same time. These interactions are characterised by frequent exchanges of information, with responses received as soon as the reader has read, digested and typed their reply. In contrast, asynchronous exchanges are characterised by frequent time lags between the initiated conversational point and the response to it. In asynchronous interactions all members do not have to be online at the same time, and consequently there may be many hours or even days between the posts and replies. Both types of communication are however characterised by a range of conventions and rules. It is these conventions, often specific to Internet communication, that make such interactions unique and therefore they will be briefly detailed here. My research employed the use of asynchronous interactions, and I have discussed the reasons for this choice in the methodology section (chapter 3). However, what will follow details commonalities to both synchronous and asynchronous communication exchanges, and many of the conventions are evident in the data gleaned from the current thesis.

The absence of non-verbal cues may pose problems for some populations engaging in online interactions with others. Suler (1997) has noted that when reading transcripts of online exchanges, particularly synchronous interactions, it can sometimes be quite difficult to follow the development of the conversation. Suler highlights however that when read as the exchanges develop, there is relatively little confusion, with most parties understanding what the other intended. Suler proposes that this is due to the delay between posts and comments, which inevitably

arise as the reader reads the message, digests the comments, and creates their reply. Reading the printed record of such exchanges does not allow for such pause, and is often read quickly, increasing the likelihood of confusion. This is however less of a problem with asynchronous exchanges as each posting is a stand alone post, intended to be read and responded to at some point in time in the future rather than immediately.

A common source of confusion however for both synchronous and asynchronous interactions are messages employing humour and sarcasm. Suler (1997) notes however that this confusion does appear to be relatively low level and can usually be rectified with the use of a smiley : ) ☺ or winky ; ). This symbolic language appears to be used across a range of Internet communications including asynchronous discussion lists such as those studied in this thesis. Any potential confusion in the discussion lists was preceded by a smiley or winky, and with any confusion subsequently arising, the reader was pointed to the use of the smiley or winky in order to convey the intentions of the writer. This common use of symbols appears to be an important resource for Internet users in the absence of the non-verbal cues and voice tones which can be used to guide interactions in face to face settings. Seymour and Lupton (2004) stress the importance of being as clear and accurate as possible when interacting online, and stress that there are still many misunderstandings in online exchanges even when emoticons are used due to the reliance on the reader reading your message to understand your intentions without the aid of supplementary information.

Suler (1997) comments that several acronyms are also in use on discussion lists such as BRB (be right back), IMHO (in my humble opinion) and LTNS (long time no see). However Suler notes that the use of these can vary across lists. One common acronym used across most online exchanges however is LOL (laugh out loud), again highlighting the importance of conveying humour in interactions which otherwise are without non-verbal cues. The widespread use of such terminology, which

may cut across several discussion lists covering a variety of areas, or be more localised to particular topics such as NT to indicate 'Neurologically Typical'/non autistic as found in the discussion lists accessed for my thesis, indicate the cultural understanding shared by members of such online communities as reflected in their common use of terminology. The shared cultural understandings by group members of a specialist discussion list can be highlighted by example of the use of the term 'NT' among the autistic community online. The act of using 'NT' to refer to people that are not autistic is significant not only for its use in downplaying the value of a label of 'normal', but also for its ability to enable the bolstering of a group identity among people who are not NT. Such a shared understanding of terminology is in contrast to the widespread lack of knowledge of the meaning of the term 'NT' among the NT population.

The final convention frequently witnessed across discussion lists is the use of capital letters and asterisks. Netiquette conventions lend to only using capital letters in a title or when trying to highlight a particular point. Capitalising whole words is generally termed SHOUTING and is not encouraged (Rinaldi 1996). Writers are encouraged to use asterisks if they want to make a \*stronger\* point in their exchanges. The use of capitals can be met with a range of responses from list members depending on who is doing the 'shouting', and whether they are perceived to be experienced in internet communications.

### *2.2.2 Web Accessibility*

A wide range of people use the Internet for a whole host of reasons such as researching topics of interest and shopping as well as contributing to online exchanges through discussion lists. At this point it would therefore be prudent to discuss various issues that influence and limit people's use of the Internet through consideration of issues of web accessibility. Burks, Pardos, Waddell and Nakane (2000) conceptualise accessibility as enabling the largest audience possible to use a specific website

regardless of (dis)ability. The inventor of the World Wide Web Tim Berners-Lee envisioned his creation as a universal tool: "The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect." (Berners-Lee). However, several issues have emerged which do not embrace Berners-Lee's vision, and as web designers have become more elaborate and sophisticated in their designs, certain sectors of the population have been excluded from the full use of certain pages on the web.

Burks et al (2000) comment that people with disabilities use the Internet in much the same way as people without disabilities, for example to shop, find information, converse with others and present personal blogs, but may face specific difficulties with some web pages due to their design. Burks et al highlight that such difficulties are complex and diverse because of the wide variety of disabilities that may occur in a population. However Burks et al stress that the most important challenge to people with disabilities when using the Internet is not being able to access the content of a website due to the way that it has been presented. This is a particularly important issue for people with visual impairments who may employ the use of a screen reader to translate written text into spoken words. If the website design is not compatible with the technology used to access it, the result will be a random collection of words and poorly labelled images that are hard to make into a comprehensive understanding of the text. This issue of inaccessible design occurs across a range of Internet functions such as web pages, mailing lists and chat rooms, and Burks et al note that several of these functions are devoted to disability issues and yet are not accessible for the very population that they are aimed at.

Much of the research and development of web accessibility is pioneered by the Web Accessibility Initiative (WAI) division of the W3C (Burks et al 2000), which has as its director Tim Berners-Lee. The WAI have produced a series of guidelines outlining good practice for web designers in the production of accessible websites, which have been important in

the development of the Disability Discrimination Act of 1995, which includes under its regulations that all government websites should be accessible in the United Kingdom (Burks et al 2000). Burks et al also highlight that sections of the act came into force in October 1999 that require service providers to make adjustments for people with disabilities, including Internet service providers. Burks et al argue that such measures could eventually force accessibility across the board on all websites hosted in the United Kingdom.

The WAI highlight a number of different issues for user groups, each with very specific needs in web design. The WAI propose that common problems for people with visual difficulties include unlabelled graphics and undescribed video and poorly marked tables. These issues make the compatibility with a screen reader difficult as the reader will read out “graphic” or “video” but offer no information with regarding content. Similarly, poorly marked tables will lead to the screen reader reading in a fashion not necessarily consistent with the table layout in order for the information to make sense. Waddell (1998) comments that “When blind people use the Internet and come across unfriendly sites, we aren’t surfing, we are crawling... Imagine hearing pages that say, ‘Welcome to ... [image].’ ‘This is the home of...[image].’ ‘Link, link, link.’ It is like trying to use Netscape with your monitor off and the mouse unplugged. See how far you’ll get.” (quote cited from NY Times Cybertimes 1<sup>st</sup> December 1996). People with hearing difficulties may have problems with videos that are not captioned or do not have a text transcription. People with physical difficulties may find the control of a mouse difficult if the link to be clicked on is quite small. In these cases there should be an option for the navigation of the webpage through keyboard commands. Finally, people who have cognitive or neurological difficulties may find barriers with a lack of consistent structure for navigating through the website and the use of over complex presentation or language. The use of flickering or strobing may also present some difficulties for this population. All of these issues can be overcome by accessible web design and in many instances the requirements to overcome such barriers are not cumbersome for web

developers, and sophisticated sites can be designed and maintained following the WAI guidelines.

Bohman (2003) reflects on discussions that propose that the Internet has had the biggest impact on society since the invention of the printing press in the mid 1400s. Bohman sums up the importance of the Internet and the need for accessible web design in the following quote: “Now, at the click of a mouse, the world can be ‘at your fingertips’ – that is, if you can use a mouse... and if you can see the screen... and if you can hear the audio – in other words, if you don’t have a disability of any kind.”, (Online webpage). Bohman argues that it is possible to create web pages that accommodate a range of abilities and disabilities, but this relies on the creativity and dedication of web developers. Bohman stresses that there needs to be a firm commitment to accessibility if a significant proportion of the population do not become alienated from potentially useful technology due to the barriers presented by designers.

### *2.2.3 The use of the Internet by people with disabilities and people with autism*

Provided that web pages are constructed appropriately, the Internet offers a potential new way to shop, find information and partake in exchanges and interactions for a range of people both with and without a disability. It can be a particularly valuable tool for sectors of the population who may otherwise feel isolated due to physical or social constraints. For example, Seymour and Lupton (2004) discuss how societal constraints such as inaccessible environments exclude many people with physical disabilities from participation in some aspects of public life, and the authors discuss whether the Internet can potentially offer an alternative solution to such issues. Seymour and Lupton cite one example from a participant who highlighted the importance of the Internet in enabling him to remain in paid employment through remote working rather than having to make the physically difficult journey into the workplace. The authors conclude that such technologies may offer several opportunities for people with physical

difficulties, but the cost and availability of the equipment must remain critical issues. As Cromby and Standen (1999) note disability and poverty are closely associated, and therefore issues surrounding the digital divide must remain pertinent when considering such debates. The following section will introduce in more detail the use of the Internet by people with disabilities, and then specifically people with autism as a way of exchanging information with other people and interacting with others online.

Seymour and Lupton (2004) conducted an online qualitative interview and found that many of their participants used the Internet as a way to make friends and interact with others. Their participants highlighted the importance of being able to interact with others who were perceived as being in a similar situation to themselves, and consequently are perceived as being able to understand fundamental personal and wider social situations and issues. Such exchanges were characterised as a valuable way of exchanging support and advice through shared understanding. In addition to the valuable exchanges with people perceived as similar, Seymour and Lupton also found that their participants highlighted a positive in the anonymity that the Internet offers. Several examples cite the importance of being able to exchange information online without the influence of preconceived ideas based on how a person looks. Their participants felt that they could be judged therefore on what they typed rather than how they looked, and the need to reveal information regarding individual (dis)ability was a personal decision. "The body is represented by one's own textual description; you can be what you want to be" (Seymour and Lupton 2004, p. 292). This is also reflected in the work of Bowker (1999) who argues that exchanges in such online media offer people with disabilities the possibility of constructing more empowering identities online due to the alternative pool of discourse surrounding identities from which people can build.

These findings were echoed in the work of Guo, Bricout and Huang (2005) who found that 54% of their respondents agreed that there is less

discrimination towards people with disabilities on the web (35.3% neither agree nor disagree; 10.6% disagree). Guo et al propose that such a reduced perceived discrimination is not due to the elimination of discrimination online, but rather that such discrimination is suppressed due to the choice that people with disabilities have as to whether to reveal their disability. Guo et al argue therefore that the Internet's potential to eliminate discrimination may be limited due to its lack of influence on change in 'real world' social attitudes. Similarly Seymour and Lupton (2004) comment that while a person may choose to represent their body in a variety of ways online, the pain and discomfort in the non-online world will remain, leaving the 'virtual' and 'real' world inseparable. Seymour and Lupton further note that their participants reported not being confident that they knew the 'real' person that they were exchanging with online, and so even though anonymity was highlighted as a potential benefit in online exchanges, several participants reported exchanging photographs with good friends who they had met online in order to get a better feel for who they were 'talking' with.

Bowker and Tuffin (2002) highlighted in their work the potential that the Internet offers for presenting images of the self and evaluating others when visual cues for assessment are typically not available. Bowker and Tuffin propose the potential importance that the Internet offers in challenging the traditional notion that an identity is necessarily stable and permanent, but may change to reflect the specific interaction a participant is engaged in. They were particularly interested in whether and how people with disabilities would disclose or choose to conceal their impairment. Bowker and Tuffin's participants highlighted the choice that an individual has as to whether to disclose their impairment online, which Bowker and Tuffin note is in contrast to the perceived lack of control over identity construction in the 'real' world. The authors highlight that the availability of different discourses online from which to construct an identity which does not solely rest on the perceived physical deviation from norms may lead to empowering outcomes for the individuals concerned.

Bowker and Tuffin (2002) do however raise important points concerning the choice not to disclose an impairment and the potential impacts that this may have on disability politics. They propose that trying to 'pass as non-disabled' may further marginalise the voices of people with disabilities. This point is echoed in the discussions of Seymour and Lupton (2004) who question the impact of the Internet on disability politics for this very reason. Seymour and Lupton propose that talking with people perceived as like-minded on the Internet may serve to 'ghettoise' disability discussions rather than presenting them as a challenge to the wider society. Such discussions may provide comfort and support for an individual but they do not challenge the fundamental issues that arise in the physical world. The authors question whether such private discussions isolate issues raised to become issues of the 'special world' of disability, rather than issues that society at large needs to address. Such discussions are proposed by Seymour and Lupton to fragment the political voice of people with disabilities, and it is the very anonymity that the Internet offers that Cromby and Standen (1999) argue undermines the potentials for political action that computer mediated communication provides. However, Avery (1998) proposes that there may be an influence on wider society from discussions online, but only if these are focused on empowerment and emancipatory goals. Avery proposes that interactions that solely focus on medical or emotional experiences will focus discussions on the circle of membership, and may consequently remain 'special issues'. Once members begin actively constructing new roles and identities for themselves which may pose challenges to traditional images, larger and more diverse audiences can be tapped into, and the talents and issues of the online community can be recognised more widely.

Previous sections have focused on the use of the Internet by people with disabilities generally and the potential political implications of this. I will now turn my attentions specifically to the use of the Internet by people with autism and the growing body of literature concerning this. Dekker (2000) neatly stresses the importance of the Internet for people with

autism: “The Internet is for many high functioning autistics what sign language is for the deaf.” (Dekker 2000, p. 1) That is a crucial means of communication that filters out non-verbal cues which can appear confusing for some people with autism, thus enabling new opportunities for social exchanges, (Blume 1997b). Blume (1997a) proposes that using the Internet enables people with autism to challenge one of the defining ‘triad of impairments’, that of the impairment of social interaction with others. Blume cites interactions with people with autism online as lively and interesting, with the absence of face-to-face interaction and the non-verbal cues that go with such exchanges as having a positive effect on interactions. Strickland (1996) notes that discussions as to the potential importance that computer mediated communication may play for people with autism is not a new idea. Strickland cites studies dating back as early as 1968 where computers were used to assist in the teaching of language to children with autism (for example, Colby 1968). The advent of Internet technologies builds on this and has enabled much more complex interactions with a wide range of people.

Dekker (2000) notes several features that differentiate the communication styles of people with autism from neurologically typical (NT), non-autistic people. The first is the use of a different rhythm to communication. NTs frequently attempt to fill in silences in a conversation with ‘small talk’ as their experience such silent pauses as uncomfortable. In contrast Dekker argues that people with autism are comfortable with such silences and are happy to remain silent while waiting for a reply from another person. This leads to a different pace in communication, with NT exchanges characterised as fast paced with frequent exchanges in contrast to the slower paced exchanges by people with autism. Also notable in exchanges as highlighted by Dekker is the emphasis of communication by people with autism through words rather than the appeal to body language and facial expressions. This also manifests in a directness of exchanges, with a person with autism usually meaning exactly what they say rather than expecting the recipient to ‘read between the lines’. This is mirrored in a literal interpretation by people with autism of what another

person has uttered. Dekker proposes that people with autism rarely re-interpret what the other person has said according to how they believe things should be, instead taking the persons words literally. This may make the communication style of people with autism ideal for taking advantage of Internet technologies, due to their direct nature, expectation of literal meanings and no need to supplement exchanges with non-verbal cues, areas that have been highlighted as challenging for people interacting online (see for example Suler 1997).

Jones, Zahl and Huws (2001) discuss the Internet as a major resource which can enable people with autism to express their ideas and share their experiences. By examining websites written and maintained by people with autism, Jones et al highlighted the complexity of the emotional lives of people with autism which are often in stark contrast to more stereotypical views. Jones et al discuss the generality of their findings and while they acknowledge that not every person with autism would be able to construct a website and write such detailed web pages of emotional experiences and therefore to generalise their findings would be inappropriate, they propose that such reports are important first-hand accounts from people with autism and their experiences. This important point of challenging stereotypes has been taken up by Blume (1997b) who argues that people with autism have historically been spoken for by others, notably parents and professionals. Blume argues that this is partly due to the prevailing stereotypes of the person with autism as a child who is unable to speak for themselves, or similar to the character portrayed by Dustin Hoffman in the film 'Rain Man' (Blume 1997a) and consequently requires interpretation, intervention and advocacy from others. Blume (1997b) argues that the use of the Internet is enabling this myth to be challenged, with many adults with autism finding their voice online through effective communication using new technologies. Blume (1997a) proposes that this has led to many people with autism doing what their syndrome supposedly prevents them from doing – communicating with others. Such interactions are believed by Dekker (2000) to be an important step in the self-advocacy movement of people with autism, with

the first stages being the recognition by parents and professionals that adults with autism can communicate their experiences of autism.

However, the self-advocacy movement of people with autism is still in its infancy when compared to the wider disability movement (Dekker 2000). Dekker argues that a culture and a community for people identified as being on the autism spectrum remains in its infancy, although it has witnessed rapid developments since the wider availability of the Internet. This again highlights the fundamental position that the Internet may hold in enabling effective communication between people with autism. Dekker proposes that one of the greatest strengths of the Internet has been to enable the uniting of small groups of similar people who may be spread across different geographical locations. Dekker proposes that this has enabled the empowerment of such groups of people. Dekker further notes that high-functioning people with autism who are not famous and therefore not in the public eye often go unnoticed and their experiences not heard. The Internet provides a medium for their voices to be heard even if they are not consistent with the dominant established views of autism held by many parents and professionals. In a position similar to that of Dekker, Blume (1997b) suggested that if the voice of people with autism gathers force online, this will have reflections in the 'real' world as well due to the connections and support it enables.

#### *2.2.4 Cyber-communities and identities*

The many positive experiences that the Internet may enable and facilitate do highlight interesting questions regarding the nature of the lists and groups formed on the web. Members of lists and groups frequently identify themselves as belonging to a 'community', and I have previously discussed the various benefits with regards to an alternative discourse which can be generated by such 'communities' which can be key in constructing an identity for participants. The current thesis will highlight a strong alternative narrative surrounding autism and the strengths of people who identify with an autistic spectrum label. Such discussions

often lead to an empowered identity which frequently contradicts and challenges the more traditional 'expert' view of people with autism and their abilities. The availability of such alternative discourses brings into question the traditional notion of identity being a stable and consistent entity. This is reflected by studies that I have previously discussed which highlight the complex interactions that take place between people online and the decision as to whether to disclose certain facts about yourself, including details relating to impairment. In a sense, you can be whoever you want to be on the Internet. Robins (1995) highlights this point and argues that if we accept the concept of a virtual world being socially constructed, identity may become a matter of choice; a concept in stark contrast to more traditional theories of identity.

Traditionally within psychology the concepts of 'self' and 'identity' have been viewed as entities which are primarily the property of individuals (Kitzinger 1989; Wetherell and Potter 1989). Such entities may be stable and coherent as represented in Eysenck's psychological trait theory, or changing and adaptable as represented by Darendorf's role theory (Wetherell and Potter 1989). An examination of identity from a critical perspective questions the notion that self and identity are personal properties of an individual, and rather proposes that they develop in accordance with dominant political interests of the social order (Kitzinger 1989). Within such a critical theoretical framework, accounts of self may be more usefully examined with reference to the position they maintain within various socio-cultural contexts.

The importance of such socio-cultural contexts are evident in the work of Archakis and Tzanne (2005) in their study of the identity formation of a group of young people in Greece. Archakis and Tzanne propose that different identities are presented according to the linguistic, social and physical context, with speakers narratively portraying a particular picture of themselves which does not necessarily reflect an exact mirror image of past experiences, but rather its purpose is to design a particular picture for a specific end. Archakis and Tzanne also highlighted the co-

constructive nature of identity by examining the young people's identification with a particular sub-culture and drawing on this common culture through discussions positioning the collective 'we' as central to experiences rather than the individual 'I'. The use of 'we' and 'them' served to highlight group differences, and is a strategy observed in the interactions of people with autism in the current thesis.

In adopting such a theoretical position, identity becomes something that a person does in a particular social setting, rather than something that they are (see for example Archakis and Tzanne 2005). However, in the creation of such identities, individuals do not have the freedom to create whatever identity they choose, but rather are restricted by a range of possibilities which are constructed within the dominant framework. Such dominant frameworks encourage the creation of particular identities for certain groups in order to maintain the social status quo (Archakis and Tzanne 2005).

Directing discussions specifically to the identity of people with disabilities, new issues need to be addressed with regards to identity presentation. Frequently a person's disability is taken as the single most important defining feature of an individual, which may render other important aspects of an individual's identity as 'invisible' (Vernon 1999); Gordon and Rosenblum 2001). Indeed Gordon and Rosenblum (2001) propose that the term 'people with disabilities' is presented as a term for those who can be considered heterogeneous in race, sex/gender, sexual orientation and their experiences of the nature and extent of their disability. This then requires the individual to assess the significance of their membership to a variety of groups. Ferri (2000) highlights the complex nature of identity formation with reference to people with learning difficulties. Ferri argues that the very experience of having learning difficulties is mediated by a range of differences in class, age, gender and culture, and because of the diverse experiences within such a socio-cultural presentation, there is no universal experience or identity associated with individuals with learning difficulties. Drawing on previous

critical literature examining dualisms, the use of dichotomies may serve a useful purpose of erasing group membership ambiguities by setting up the binary processes through which to understand identity group membership (see for example Gordon and Rosenblum 2001). For example, sexual orientation becomes 'gay' or 'straight', sex becomes 'male' or 'female', and people are either 'disabled' or 'normal'. In each case, one side of the dichotomy is stigmatised and the other is valued. Gordon and Rosemblum propose that identification with a disabled identity is different from other stigmatised identities because people can be afraid of becoming disabled. This has important implications for the formation of an autistic identity as demonstrated by investigations into the media portrayal of the links between the MMR vaccination and the development of autism (O'Dell and Brownlow 2006). Such work demonstrates the fears that parents have concerning their child becoming autistic and the negative images that are associated with such a diagnosis. The theoretical discussion of dualisms will be revisited with regards to an 'autistic' or 'neurologically typical' identity later in the thesis.

The consideration of online identities or 'cyberidentities' may further complicate the discussions surrounding identity and self-presentation. Drawing upon theories which position identity as a non-static and multi-voiced entity, researchers investigating online identities frequently portray online identities as being performed and negotiated in accordance with other members of the community (Talamo and Ligorio 2001; Nguyen and Kellogg 2005). Talamo and Ligorio (2001) cite that the first important step of online identity development is choosing a name. The user is in a unique position as to whether to remain anonymous or to identify themselves, and may therefore choose to give their own name, or choose a new nickname for online purposes. The choice of nickname may be significant in that it may express some characteristics of the self, even if these are not evident necessarily in the offline world. In a similar manner, users may also choose avatars or icons to represent themselves.

Future interactions once a self-signifier has been created will largely be dependent on what each person chooses to reveal about themselves, and the cultural context of the group within which the interaction is taking place (Talamo and Ligorio 2001). The group will have various influences on the possible presentations of the self and may serve to guide and model possible choices. In as much it can be argued that identity is not a static property or characteristic of individual contributors to groups, but rather is negotiated through interactions with other members of the group (Talamo and Ligorio 2001). Such negotiations may serve an important purpose of widening the possible resources and discourses through which to create an identity by presenting an individual with alternatives to the positioning imposed on them by others such as professionals working within the psy-disciplines. Siddiquee and Kagan (2006) demonstrated that e-mail communication was a central tool for their participant population of refugee women in shaping more empowering identities, as well as internet technologies more broadly acting as an important information source through which to maintain up to date information about for example their former country of residence.

The current thesis will approach identity from a theoretical position influenced by critical theorists. I will propose that the identity of the 'neurologically typical' is the dominant one and as a result autistic identities are compared to this 'benchmark'. Drawing on the work of writers such as Nikolas Rose (please see discussions of epistemological resources), I will propose that professionals working within the psy-complex regulate such identities. The thesis examines discourses of a group of people who either have been identified by professionals, or who identify themselves as autistic, and who in their interactions challenge the dominant negative perception of an autistic identity. In doing so they present an autistic identity as equal to a neurologically typical identity, drawing on political dimensions of identity formation common to other groups. It is through the use of internet technologies that the autistic population contributing data to the present thesis, can explore alternative constructions of autism, with the potential to create more empowering

identities which may serve to challenge some of the professional constructions regarding the (in)abilities of people with autism as outlined in some professional and academic literature.

Such discussions of identity and identity formation also raise important questions concerning the place in which such exchanges are taking place, and whether such an arena can be considered a 'community'. People contributing to such discussions frequently characterise themselves as belonging to a community, and Rinaldi (1996) has noted that people using the Internet sometimes refer to themselves as 'netizens' (network citizens), highlighting their perceived belonging to a distinct population. As previously discussed, Rinaldi highlights that such communities are characterised by certain customs and guidelines that need to be followed in order for the group to remain a cohesive and functional whole.

However, can these groups of people be thought of as belonging to a *community*? Fernback (1999) discusses such issues in detail and begins an examination of the complex processes involved in defining 'community'. Fernback proposes that the complexity involved in such a definition is due to the fact that community has both symbolic and functional elements. Community is not just about physical, geographical location, but is also concerned with the relationships between members of the community. Fernback notes that traditional sociological literature presupposes that a community requires a physical place as a central component in its definition, such as a neighbourhood. However, competing interpretations of community emphasise the symbolic elements: community as a place to interact with like minded others, and a place in which to create and develop your identity. Such a symbolic interpretation of the concept of community enables local meanings of ideas to be emphasised, often at the expense of more dominant ones found in wider society. However, such symbolic constructions of community do not necessarily preclude the existence of a structured physical community within which participants can interact.

The two simplified definitions of community cited above have important implications for discussions of a 'cybercommunity'. Clearly, if the emphasis is on a physical location for a community then online groups and lists can not be considered a community in this sense as there is no physical location for interactions. However, if a symbolic emphasis is placed on community definitions then such groups can be considered a community. Indeed the focus on the emphasis on local rather than dominant meanings fits very well with the current thesis.

Fernback (1999) concludes her discussion by focusing on the particular attributes of cybercommunities. Fernback proposes that such communities are characterised by common value systems, rules and norms in much the same way as physical communities. If Fernback's argument is accepted, the online lists in the current thesis can therefore be considered to be communities. Robins (1995) echoes similar points and highlights that the Internet affords the possibility of the creation of communities that are not bounded by geographical location, but whose defining factor is common interest. Sharf (1997) highlights the similarities between online communities and physical communities by reflecting on their development. Sharf proposes that like any other community, an online community will reflect and develop in accordance with the major life events of its members. Online communities can therefore develop in a complex way that can exist without the boundaries of geography, something highlighted by members of the discussion lists in the current thesis.

The theoretical debates evident within such discussions of identity will be further explored in the next chapter which details and discusses the epistemological resources drawn upon in the thesis.

## **Chapter 3: Literature Review – Epistemological Resources**

The second section of the literature review will position my work within theoretical influences and orient the work within the theories and methods of analysis drawn upon in the thesis. One of the key influences has been that of the social model of disability, the main aspects of which will be reviewed before discussing wider theoretical presuppositions.

### **3.1 The Social Model of Disability**

The social model of disability was initially developed by a group of disabled activists in the late 1960s and early 1970s as a reaction to the dominant medical approach to disability (Barnes and Mercer 1996). Traditionally psychology has employed a strong focus on an individual's impairment, presenting such impairment as a 'personal tragedy' view of people with disabilities (Lawthom and Goodley 2005). The social model is mainly located within British disability politics (Shakespeare and Watson 1997), and the focus is on the impact of disabling barriers in societies and a rejection of the conception of disability as an individual problem stemming from a person's impairment (Barnes and Mercer 1996). Bury (1996) proposed that through such new thinking, disability can be conceptualised as a product of terminology defining those individuals who deviate from the norms of the able bodied. Disability is therefore not conceptualised as an individual attribute but rather, something that was created through social exchanges and social practices. Individuals are therefore categorised by their position in society and their relation to the dominant values within such a society (Bury 1996). In developing a social focus to disability, the debate surrounding disability became politicised. Barnes and Mercer (1996) propose that through debates, 'disablism' has become a political term which is on par with the political issues concerning sexism and racism.

Barnes and Mercer (1996) highlight that initially, the social model primarily focused on people with physical impairments, but report that the model has since been extended to include people with intellectual and sensory impairments. The model is built on the definition originally set out by the Union of Physically Impaired Against Segregation (UPIAS), which proposed the original distinction between the concepts of 'disability' and 'impairment' as defined in their 'Fundamental Principles'.

Impairment: Lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.

Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream.

(UPIAS, 1976: 3-4, Quoted in (Hughes and Patterson 1997)

The central tenet of the social model of disability is therefore its rejection of the conception of disability as an individual problem, placing the onus of change firmly within society (Pinder 1996; Begum 1996; Llewellyn and Hogan 2000; Lawthom and Goodley 2005). The difficulties therefore that an individual may have are the result of a 'disabling environment', rather than a result of any deficiencies of people as individuals (Pinder 1996; Lawthom and Goodley 2005). Such a disabling society excludes people with disabilities and prevents them from participating as full and equal members (Begum 1996). Tregaskis (2000) argues that when guided by a social model the problem of disability is therefore not located within the individual, but within the relationships between people with impairments and society. Such relationships are socially constructed in that people within them are constructed as 'dependent', 'disabled' or 'other'. In placing the emphasis on society rather than the individual, social model theorists reject medical definitions of disability.

Such a model and definitions are therefore in stark contrast to the more traditional medical approach to disability. Oliver (1983) was the first to talk about the distinction between the individual and social models of

disability. Oliver (1990) proposes that an individual model of disability encompasses the medicalisation of disability, and sees disability as an individual problem. Within such a model, Oliver proposes that a 'personal tragedy theory of disability' emerges, which constructs disability as a chance event that happens to unfortunate individuals. In contrast, the social model of disability places the problem of disability firmly within society. It is society's failure to provide appropriate services to individuals that is the disabling factor rather than some inherent problem resting within the individual. Oliver (1990) argues that because of this, the medicalisation of disability is inappropriate as disability is a social problem rather than a medical condition. Llewellyn and Hogan (2000) further such discussions by commenting that such a medical focus is led by the disease model used in medicine. The use of such a model leads practitioners to think of disability in terms of a condition, which consequently needs appropriate treatment. Llewellyn and Hogan propose that this focus on the individual and the quest to find appropriate treatment for that individual creates a picture of society as fixed and unalterable, with an emphasis on the need for the individual to adapt to their environment. Such concepts are rejected by those guided by a social model of disability.

There are several positive aspects associated with removing the focus from the individual and firmly locating the problem within society, such as highlighting the oppressive nature of society and questioning the socially excluded and marginalised position that people with disabilities occupy within society. Such questions emphasise the political nature of disability and disablism. However, despite the increased political awareness accorded by the social model, several commentators have questioned the neglect of the individual experiences of disability by social model theorists, (for example Marks 1999; Morris 1991). Morris (1991) argues that theorists need to recognise the importance of the experiences of individual disabled people, as minimising the importance of these runs the risk of missing a vital part of the overall picture of the experiences of people with disabilities. Such issues concerning the individual voice in

disability politics and the call for the re-alignment of the concepts of impairment and disability in order to make such experiences visible will now be discussed.

### *3.1.1 The Social Model of Disability and constructions of impairment and disability*

The challenges to the social model of disability by arguments to re-align the concepts of disability and impairment are met with opposition from researchers accepting the more 'orthodox' version of the social model of disability, who claim that by including impairment in accounts of disability, the political force of the social model may become undermined (Barnes and Mercer 1996; Shakespeare 1992; Marks 1999). In addition to such calls for a re-alignment with impairment, other writers have argued for the incorporation of other experiences such as sexism, racism and other exclusions which affect people both with and without a labelled disability (see for example Begum, Hill, and Stevens 1994; Morris 1991).

Proponents for a re-alignment argue that the social model of disability is not attentive to multiple impairments and because of its lack of focus on issues such as sexism and racism, an over-simplified version of events may be presented by the model. This inclusion (or exclusion) of impairment and personal experience within the social model form the main critical discussions of the approach (Shakespeare and Watson 1997). A call for the examination of the construction of impairment is therefore voiced, with so called 'second wave' British disability theorists becoming increasingly concerned with the discursive production of disability, rather than the materialist/structural production (Rapley 2004).

In a landmark paper, Abberley (1997/1987) discusses the proposition of a socially produced concept of impairment. Abberley argues that such an examination of the concept of impairment does not aim to reduce biological phenomena to attitudes or reactions by society. Such an examination does not deny biology, but instead examines the effects of biological phenomena in social and historical context, thus highlighting

the importance of historical and socio-cultural influences on the production of knowledge. By undertaking such an examination of the concept of impairment, criticisms levied against the social model for ultimately reducing an individual's experience to biology by not addressing the experiences of impairment, can be examined. Hughes and Patterson (1997) further this argument and propose that the social model ultimately understands impairment in terms of medical discourse. They argue that impairment is not ahistorical and asocial, rather it is embedded in culture and meaning. "Impairment is more than a medical issue. It is both an experience and a discursive construction." (Hughes and Patterson 1997, p.329). Goodley (2001) likewise stresses the importance of an examination of impairment without the assumptions of biology commanding the analysis. Goodley warns of the dangers of accepting naturalised impairment on the part of people with learning difficulties, largely ignoring their experiences and cultures, which may arise as a consequence of the lack of examination of the construction of the concept of impairment. In developing a discursive focus, Rapley (2004) argues that what counts as 'impairment' is culturally relative, and so too are the responses to it. Rapley asserts that by conceiving of impairment and disability as two separate entities there is the risk of oversimplifying the issues through the use of dichotomous terms. In our conceptions of 'disability' we should not exclude the ways in which it is a cultural, moral and discursive formation as well as theorising about marginalisation in economic and social terms, as would be the focus of more traditional approaches within the social model of disability. Such theoretical consideration of autism with regards to the discursive formation of impairment is central to the current thesis, and an investigation of the socially constructed nature of autism will be investigated through the use of techniques of critical discourse analysis.

Hughes and Patterson (1997) propose that the re-alignment of disability and impairment is vital for the disability movement. Hughes and Patterson argue that the important turn to examine the socially produced nature of disability changed the focus from bio medical agendas to issues raised by

politics and marginalisation of individuals in a society. Such discussion now needs to turn to the concept of impairment. Hughes and Paterson warn however, that such an examination runs contrary to the key distinctions between the concepts of disability and impairment laid down in the original (UPIAS, 1976) vision, which detailed the original important change of focus from constructing disability discourse as a medical problem to a political emancipatory issue.

The debates surrounding the social construction of disability will be revisited following an examination of the social model of disability's application to people with learning difficulties. However, it is important to note, as Corker (1999) has highlighted, that a constructionist examination of disability does not necessarily lead to a rejection of the social model of disability. Corker argues that it is important to look at the relationship between the individual and society rather than placing the focus on one or the other. She argues that by doing this, marginalised voices may be brought to the forefront of discussions. Such an argument is developed by Marks (1999) who defines disability as "the complex relationship between the environment, body and psyche, which serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs." (p.611). Marks argues that disability is not something that resides in a particular body or environment, but rather is an 'embodied relationship'.

### *3.1.2 The Social Model of Disability and Learning Difficulties*

The social model of disability has not been specifically applied to autism, and consequently the focus of this review will be the model's application more generally to people identified as having learning difficulties. A critical discussion of the place occupied by autism within the social model can be found in the discussion in chapter 8.

With reference to the inclusion of people with learning difficulties in the social model, several writers have questioned the coverage of learning

difficulties by the social model of disability (see for example Goodley 2001; Marks 1999; Chappell 1998). Chappell (1998) proposes that the disability movement comprises of people with learning difficulties and mental illness as well as people with physical impairment, and so questions why the social model has neglected learning difficulties. Chappell highlights that much of the disability literature has a tendency to define the concept of impairment in terms of the physical body. However, she asserts that there is nothing intrinsic about the word impairment to suggest a physical rather than an intellectual difficulty, providing a firm place for learning difficulties within such a model. Chappell further questions the terminology used in disability studies: the opposite of disabled being able-bodied. Such use of language, Chappell proposes, presupposes a physical disability and serves the purpose of neglecting the experiences of people with learning difficulties.

Chappell, Goodley and Lawthom (2001) further these discussions of the neglect by the social model of disability of people with learning difficulties, and argue that due to this exclusion, an individualised model of disability is frequently applied to people with learning difficulties. Further, Goodley (2001) argues that such an exclusion of people with learning difficulties and their placement in an individual model of disability leaves people with learning difficulties in an isolated position, with their voice not clearly represented within the disability movement. Goodley proposes that this positioning of people with learning difficulties can lead to the recognition of their experiences as a 'naturalised impairment', something that falls within the gaze of 'experts' working within the psychological sciences.

Goodley (2001) argues that the experiences of people with learning difficulties, particularly those who are members of self-advocacy groups, can be drawn upon to provide an important body of knowledge in the understanding of learning difficulties. The acknowledgment of the importance of such knowledge was proposed thirty years ago by Bogdan and Taylor (1976), who highlighted that people who are labelled as 'retarded' have their own understandings about themselves, which are

often very different from those of the professionals working with them. Despite this, people with learning difficulties are still not fully incorporated in the social model. Bogdan and Taylor (1976) highlight that in literature, people with learning difficulties are studied as a separate category of human beings, people who are very different from 'us'. As such, these people need to be explained by special theories, which are distinct from theories that are designed to explain 'normal' people.

Broadening the debate and returning to the issues raised earlier concerning the construction of disability and impairment, learning difficulties poses some interesting and important challenges to the social model of disability. As Marks (1999) discusses, while the medical model considers learning difficulties to be the result of some organic brain damage, the social model argues that the measurement of intelligence is never value free and is influenced by cultural, social and economic factors. This feeds back into earlier arguments by Chappell (1998) concerning the conception of impairment as a physical bodily issue. In the case of people with learning difficulties, impairment is intellectual, and the social model of disability needs to re-examine its conception of the term impairment if learning difficulties can be embraced fully into the model.

### *3.1.3 Self-advocacy*

Self-advocacy is a key feature of the social model of disability and the potential links with self-advocacy offered by Internet technologies fits well with the ethos of researchers informed by the social model (see for example Barnes and Mercer 1996; Goodley, Armstrong, Sutherland and Laurie 2003). Such researchers reject the 'personal tragedy' view of disability (Oliver 1990) in favour of a more emancipatory construction of disability. While material questions the inclusion by the social model of learning difficulties (see for example Chappell 1998; Chappell, Goodley and Lawthom 2001; McClimens 2003) and autism, there is a strong focus in literature on issues of self-advocacy by people with learning difficulties and autism. The self-advocacy movement is founded on the assumption

of the competence of individuals, rather than a focus on what a specific group of individuals cannot do (Chappell, Goodley and Lawthom 2001).

Ward and Meyer (1999) propose that the self-advocacy movement for autism has grown since the development of Internet technologies due to the unique uptake of such tools by this population. Ward and Meyer argue that able adults with autism or Asperger's syndrome have employed new technologies to frame a new identity which sets themselves outside the remit of medical discourse of 'disordered', and have moved toward the development of a shared group understanding of an autistic identity. Dekker (2000) notes that a discourse has developed from such groupings, where members avoid using the term 'normal' to refer to people who are not autistic, preferring instead to use the term 'neurologically typical'. However, Dekker (2000) notes that an autism self-advocacy movement is still in its infancy when compared to the self-advocacy groups of people with physical disabilities, which he comments have a strong disability culture operating. Dekker advocates more collaboration between self-advocacy movements in order to facilitate the success of self-advocacy movements for autism. While positively outlining the growth in self-advocacy amongst the online community, Dekker highlights that there are self-advocacy movements for people with autism which do not have a strong online focus. Such organisations also play an important role in the definition of human rights for people with autism.

Ward and Meyer (1999) provide a detailed history of the emergence of self-advocacy groups and comment that large scale self-advocacy by people with autism did not begin formally until the publication of the diagnostic criteria by Gillberg and Gillberg (1989). Ward and Meyer propose that this publication provided a turning point for some who felt that they could now gain a good understanding of themselves through the definitions of professionals, and begin on the path of self-advocacy. Other groups however were not as influenced by such academic classification and felt that they knew who they were already, and were not prepared to

wait until professionals had settled their academic debates on definitions (Ward and Meyer 1999).

In tracing the history of autism self-advocacy, Ward and Meyer (1999) detail how autism advocate Herbert Lovett founded the Autism National Committee (AUTOCOM) in 1990. AUTOCOM was an organisation consisting of parents of adults with autism, advocating on behalf of their adult children. A difficult relationship followed between parents of people with autism and their willingness to provide an equal footing in discussions for able adults with autism advocating for themselves. Consequently, Autism Network International (ANI) was started in February 1992 by three adults with autism. This organisation was very different from AUTOCOM in that parents of people with autism were welcome to join the organisation, but were not allowed to 'run' things (Ward and Meyer 1999). Dekker (2000) comments that ANI is a unique organisation due to its management solely by people with autism. As an organisation it runs yearly conferences in which the positive aspects of autism are exploited as well as discussing the negatives.

As with many self-advocacy movements, the autistic self-advocacy movement has had people questioning how representative the individual self-advocates are within the wider population of people with autism. Kitchin (1998) comments for example that when people with disabilities live independently they are frequently characterised as the 'plucky hero/heroine' who defies their impairment and natural biological condition. Wong (2000) takes up the argument with reference to self-advocates with Down syndrome. Wong notes that within the Down syndrome self-advocacy movement, there are several individuals who attend conferences, give speeches and have proved themselves capable of taking charge of their own lives. While Wong acknowledges that such individuals tend to come from family backgrounds that remain very supportive and have the financial resources at their disposal to make such appearances possible, she questions the assertion that these individuals are not representative of people with Down syndrome in

general. Wong argues that people are generally happy for Albert Einstein to represent Jewish male scientists and Michelangelo to represent Italian male artists, so she questions why an important Down syndrome self-advocate such as Chris Burke who has written a book and appears on television, should not be accepted as representing (male) people with Down syndrome.

In summary, the advent of Internet technologies represents an important facet in the self-advocacy movement for people with autism. Cromby and Standen (1999) reflect on the importance of computer mediated communication generally and propose that it serves to reduce all participants to the same level of textual representation, and in doing so raises unique possibilities for identity construction. The technologies facilitate for example the creation of online groups, as is the focus of the present study, which may serve to construct more empowering identities through which challenges can be posed to some professional constructions of autism, and some resistance made to the positioning of autistic people.

### **3.2 The theoretical position of the thesis**

Thus far the epistemological resources reviewed have focused on the social model of disability. I would now like to turn attention to the broader theoretical presuppositions of the thesis, firmly placing autism at the centre of these. In reviewing the literature in the field of autism the review has so far focussed on a traditional viewpoint of autism spectrum disorders. This is important for several reasons. By examining traditional psychological constructions of autism, the dominant scientific account of autism can be examined. Traditional scientific interpretations of autism are presented as fact and construct an account of autism as an enduring entity (see Waltz 2005). Despite the presentation of such conceptualisations as 'real' and unchanging, a critical historical reading of the literature shows that there are changes in the understanding and interpretations of concepts. This point will be further discussed drawing

on work by for example Rose, Richards and Bogdan and Taylor who provide critical readings of the history of psychological measurement in order to examine the use of statistical models to enable the classification and standardisation of concepts such as intelligence, and the consequent creation of categories of the 'normal' and 'abnormal' range. The diagnosis of autism creates the binary of non-autistic/autistic, with professionals placing value in the behaviours associated with the non-autistic side of the binary as reflected in the goals of diagnosis and therapeutic intervention. This raises important points concerning the theoretical underpinnings of the thesis which are in conflict with the focus of more traditional approaches to the understanding of autism which serve to problematise the individual. The analysis of contributions to the discussion groups studied in this thesis will explore how the participants used a binary distinction between NT and autistic and what value or priority they set on each.

My position and approach to my work stems from a concern regarding the scientific explanations and understandings of people with autism, in which the voice of people with autism is typically absent from descriptions, in contrast to the dominant third person distanced voice of expert authority (see Waltz 2005). My approach is that in addition to the focus on language I am also interested in the wider social and political influences that accepting or rejecting a label entails. This is reflected in my choice of the analytical method of critical discourse analysis influenced by the work of Edley and Fairclough. An examination of social and political influences will enable an examination of the historical and cultural production of knowledge at specific periods of time and how autism is understood in light of this. This echoes writings within community psychology who argue for the need for a reflexive and historical practice which can serve to challenge the status quo and work towards empowerment (Kagan and Burton 2001, Kagan 2002). An influence of the writings of Rose and Foucault will be evident with regards to an examination of the power that experts have to test for and diagnose autism, as reflected in the chapters of analysis which portray a tension between expert knowledge and

experiential knowledge and the conflict regarding which should be prioritised. My work therefore draws on social constructionism, critical psychology and the social model of disability in its theoretical positioning and analytical approach.

### **3.3 The Power of Psychology**

It is to the powerful position that psychology occupies with regards to identifying, explaining and performing interventions with individual behaviour that the focus of the literature review will now turn. The development of such a powerful discipline has important implications regarding the categorisation of individuals. The history of psychology as an academic discipline has been well documented in texts (see for example Stainton-Rogers, Stenner, Gleeson and Stainton Rogers 1995; Richards 1996; Rose 1979; Kanner 1972). Rose (1979) notes that the emergence of psychology as a theoretical field is generally accepted as being in a period between 1875 and 1925. This 50 year span saw the development of psychology as a coherent field both in Europe and the United States. Rose discusses how this important period saw not only the development of psychology as a discipline, but also the establishment of what he terms a 'psychological complex' or 'psy-complex'. This complex reflects the regulated practices of discourses and agents working within the field, which produce specifiable goals and outcomes. It covers the variety of theories and practices and the ways in which people are observed by and regulated by psychology and related fields (Parker 1997b). Reflecting on the work of Michel Foucault, Rose (1990) notes that all the sciences that have the prefix psy- or psycho- have important relationships embedded in them between social power and the human body, and consequently both psychology and psychiatry can be discussed in terms of the psy-complex.

With a strong lead from Euro-American thinking, a discourse of individual psychology has developed, (Kanner 1972; Rose 1989a) and Rose (1979) argues that such an individual approach has led psychology to play a key

role in establishing the norms of childhood. Rose asserts that by individualising children, psychologists can categorise, calibrate aptitudes and ultimately invent technologies for the cure and normalisation of individuals. Variability in individuals can therefore be managed and governed appropriately through the psy complex.

Rose (1989a) argues that with the advent of psychometrics and the focus on the individual, psychology could develop its position as the appropriate authority to govern the lives of the individual. This rise of psychology to a powerful position led to a normalising vision of childhood and development. Rose argues that the newly developed scales were not just a means of assessing children's abilities, they provided new ways of thinking about childhood with the development of milestones of achievement. Such milestones led to the regulating of ideas of a variety of groups including parents and health workers. Burman (1994) proposes that this new position adopted by psychology was so powerful in its impact on the everyday lives of people that its ideals became taken for granted expectations about children's development, and had broader reaching implications concerning the role of parents and families in fostering the development of the 'normal' child.

Rose (1990) argues that the powerful position of psychology has emerged due to its centrality in the discussions between agencies such as politicians, business and the general population. Rose proposes that we have convinced ourselves that we must live our lives in terms of 'set psychological terms of adjustment'. In doing this, Rose believes that we have embraced the expert knowledge of matters, and their assertions to guide us down the path of fulfilled 'normal' development. Indeed De Swaan (1990) has commented that everyone in today's advanced and affluent societies lives under some sort of psycho-medical supervision. We do not have to search very far for comprehensive manuals and guides concerning how to be a good parent, and how to lead our children down the most successful road of development. Developmental

milestones as set out by psychologists have become common place in the discussions of psychologists, health visitors and parents alike.

Indeed Rose (1989a) has argued that childhood is the most intensively governed area of personhood, with agents monitoring to ensure 'normal' development and actively promoting certain attributes such as intelligence, education and emotional stability. Disguised by a 'cloak of apparent humanity', Rose argues that the focus on childhood served to increase the surveillance which could be made of the family. Such observation however, was best suited to professionals who claimed particular expertise in the area – psychologists therefore came to hold a powerful position in the new focus on the individual.

With the goal of measuring and regulating behaviour while monitoring any deviations from prescribed norms, came the important marrying of the concepts of human variability and the statistical concept of the normal distribution. Rose (1989a) highlights the importance of such a relationship in the work of Galton. By employing the concept of normal distribution, human variability could be presented in simple visual form, with the assumption that human attributes varied in a predictable manner. Such patterns of behaviour therefore became governed by the statistical laws of large numbers (Rose 1989a). Intelligence for example could now be quantified and intellectual abilities could now be presented as a single dimension, with an individuals aptitude plotted on the distribution (Rose 1989b; Burman 1994; Richards 1996; Rapley 2004). This then enabled the appropriate action to be taken by the expert psychologists. Intellect and its variations had therefore become manageable and the transformation of ability into a numerical form could then be used in political and administrative debates (Rose 1990). Rose (1990) therefore debates that the power of psychology rested in its promise to scrutinise troublesome individuals such as criminals, lunatics and school children, and categorise types of individuals in order that evaluations and assessments could be made. Subjectivity was therefore replaced by the promise of being able to classify individuals in a rational and objective

manner. Such subjective and moral judgements underpinning the descriptions of individuals thus become invisible through the appeal to the apparent impartiality of statistical norms and the power of the institutions of the psy-complex who develop and enforce such descriptions.

Such a focus on measurement and classification of individuals is particularly evident with respect to the classification of learning difficulties. Carrier (1983) notes that during the 1960s 'learning difficulty' rose from a previously obscure name to a widely recognised clinical category, which was consequently applied to over 1 million American school children (Carrier 1983 p.948, citing U.S Office of Education 1973, p.2). Carrier argues that the growth of a theory of learning difficulties involved the acceptance of learning difficulties as a real condition with real causes and effects. Such a theory required certain attributes of children to be recognised as signs or symptoms of a disordered thought process, brought about by neurological malfunction. Carrier therefore argues that such a theory became an explanatory model for behaviour which attempted to account for certain attributes in people highlighted as in some way curious or different. Rapley (2004) however warns against conceiving that IQ curves necessarily 'created' a group of people. Rapley argues that before the advent of IQ tests and standardised approaches to measurement, people were still assigning others to a category reflecting ability, but based on other measures such as unwanted moral conduct. The formalisation of group membership could however be established.

Carrier (1983) further comments that researchers working in the field of learning difficulties in the late 1960s asserted a neurological basis for the labels they constructed and sought to explain. However, the link between neurology and behaviour became problematic as researchers were typically using behavioural and educational criteria in order to identify children who displayed what they asserted was a neuropathology. A lack of firm neurological evidence was blamed on their tools not being sophisticated enough in order to test for and be able to present neurological evidence for a variety of conditions. This has parallels with

the diagnostic testing for autism which is presented by psy-professionals as a neurological disorder, although the diagnostic procedures largely rely on behavioural criteria.

New developments in perspectives within the psy-complex reflect the growing interest in genetics, and the quest to identify genetic markers for various 'conditions'. Novas and Rose (2000) propose that this new focus on genetics means that life is now investigated, explained and sometimes intervened on at a molecular level. Geneticists are attempting to construct DNA sequencing maps that will enable them to identify the chromosomal location of mutated genes. Such an approach is viewed by Novas and Rose as an individualising tactic, which serves to draw attention away from the social solutions to social problems. Viewed through such a genetic lens, it is the individual rather than society that are seen to require intervention leading to change; a view in sharp contrast to the ethos of the social model of disability.

The power of the psy-disciplines has particular resonance with people with autism. One example of this is in the methodologies selected by psy-professionals in their investigations aimed to categorise, diagnose and ultimately treat people with autism, with the principal goal being to normalise the behaviour of the population under study. Waltz (2005) for example discusses such issues in relation to the use of case studies as a methodology to single out people with autism as needing special attention and ultimately special treatment. Waltz notes that certain case studies hold particularly powerful positions in the discussions surrounding autism, and she argues that the predominant discourses surrounding autism refer to a relatively small set of well known cases. Waltz highlights that such studies are frequently written from a position of power, employing a distant, third-person authoritative voice, which effectively constructs an 'official discourse' about autism that has the conspicuous absence of the views of people with autism themselves. Due to the authoritative style adopted and the lack of personal experiences documented, Waltz proposes that such texts can effectively present themselves as factual

accounts despite the lack of grounding in the experiences of the population that they purport to encapsulate.

Waltz (2005) provides Kanner's case studies as an example and notes that Kanner's own voice is rarely heard in the writings as he approaches the descriptions and analysis from a third person narrative. In contrast, Kanner does include observations from parents as first person text, but these are presented as distinct sections, effectively distancing them from Kanner's more authoritative account of autism. This example given by Waltz neatly highlights the position adopted by science in its approach to the study of people, and to the study of autism specifically. Scientific discourse aims to distance itself from subjectivity in its striving for objectivity, and in doing so presents some of its observations and hypotheses as 'fact'. Such a distant and authoritative approach is also evident in more contemporary research. Waltz notes that more contemporary work further removes itself from the individual under study, instead appealing to diagnostic assessment and test scores, frequently resulting in the use of several acronyms (for example PDD, AD, AS). Such use of acronyms serves to further maintain the powerful position that psy-professionals maintain in the discourses surrounding autism through the employment of specialist language. I will return to the issues surrounding the use of such specialist language in the chapters of analysis reflecting experiences of diagnosis, where I will provide a further commentary on its importance. However, Waltz further draws our attention to the important use of such acronyms in shifting the gaze away from the individual with autism and placing it firmly on an homogenous group of people all identified as having similar traits through the process of diagnosis. Waltz proposes that early studies presented an individual for comment on by professional, however more recent studies do not incorporate information specifically about the individual, further removing the important voices of people with autism from the scientific discourses surrounding autism.

### *3.3.1 The boundaries of 'normality' and 'abnormality'*

As previously stated, my theoretical position is that of a general critical perspective due to my concerns about science and the scientific explanations and understanding of people with autism. It is influenced by social constructionism but has broader concerns in that I am also interested in wider social and political influences. In a classic early paper which has remained influential in contemporary critical thought, Gergen (1985) summarised social constructionist inquiry as that which is concerned with identifying the processes by which people come to account for the world, including themselves. In doing this, social constructionism emphasises the central role of language, interaction and culture in the understanding of situations (Danforth and Navarro 1998). Beliefs and understandings that are taken to be factual in an interaction are constructs, where certain constructs are prioritised over others. As such, social constructionism strives to challenge the objective basis portrayed by conventional knowledge (Gergen 1985). Gergen therefore proposes that the terms by which we understand the world are not objective realities, but rather are social artefacts, which are produced and modified by historical influences and interactions between people. An interaction between language, politics, history and culture is therefore central in the understanding of human behaviour in various contexts (Danforth and Rhodes 1997).

As an example we can highlight the work of Danforth and Navarro (1998) and their discussions of the concept of mental retardation. They highlight that the term mental retardation and various synonyms of it, have become casually spoken about by both professionals and lay persons, thereby highlighting the 'taken for granted' nature with which the terminology and concepts is approached. They note that while there has been much debate concerning the precise definition of the term, the word and related concepts are generally accepted as 'real'. In doing so, the population diagnosed as mentally retarded is constructed as really bearing the

condition. Such discussions have strong links with questions concerning the construction of 'normality' and 'abnormality'.

Bogdan and Taylor (1989) question what mental retardation is. They propose that as a concept, people tend to believe that mental retardation is something that people have and do not question this assertion. Bogdan and Taylor propose that instead of this absolute conception of mental retardation, the classification of people as mentally retarded depends on organisational and societal values. As such, Bogdan and Taylor argue that a person may appear to be mentally retarded at some times or in some situations but not in all situations. This is further explored in Rao's (2006) work on the cultural construction of 'mental retardation', which highlights the importance of locating constructions of normality in a cultural context. In focussing on the cultural context and its importance on the constructions of normality, Rao found that the norms used by families in their perceptions of intelligence and consequently mental retardation, were much broader than those used by professionals, frequently extending beyond 'mere' academic performance and IQ levels.

In light of the need to identify the expected norms of behaviour in a discussion of normality, mental retardation can therefore be considered an arbitrary classification, which is ultimately defined by the measurement of intelligence (Bogdan and Taylor 1989). In similar arguments to Rose (1989b), Bogdan and Taylor discuss the assumption of the normally distributed nature of intelligence and the consequent measurement of a proportion of individuals at the lower (and upper) ends of the scale. Bogdan and Taylor argue that an individual's placement on the scale is not a reflection of their ability or competence, but due to the design of the test. Further, the determination as to who should be classified as mentally retarded will depend on exactly where the cut-off point is placed on the continuum. Once a cut-off point has been agreed, the division of the two groups of 'normal' and 'retarded' is complete (Bogdan and Taylor 1989).

The debates concerning the concept of 'normality' and its measurement which are common in contemporary work are entrenched in a history surrounding the construction of abnormality and consequently normality. This is not to say that contemporary psychology ignores history. Indeed as Parker et al (1995) have highlighted, once a new concept or classification is described, experts then 'discover' cases of it in the past; for example the neurologist Oliver Sacks proposes that Henry Cavendish who discovered hydrogen was most likely autistic (Harmon 2004). This serves as a way of warranting the real nature and truthfulness of the concept being described. In doing so, Parker et al (1995) believe that experts very often ignore discontinuities in history and that words may have very different meanings in different historical contexts. The meanings attached to such 'problems', evaluations made about them and the consequences of such evaluations cannot be isolated from the specific cultural, social and historical situation in which they are made. The resulting diagnoses are therefore not neutral labels but rather are a reflection of the directive gaze of professionals within the psy-complex that focuses attention on certain issues and reduces others to the periphery.

We have seen in earlier sections the important role played by the introduction of psychometric tests and the development of the psy-practitioners and their increasing power over individuals. Rose (1989a) also highlights the importance of the concept of normality. Such a focus by psychologists, psychiatrists and medics on the identification and treatment of individuals labelled as 'abnormal' has led to clear, implicit guidelines regarding what is acceptable as 'normal' behaviour. Rose discusses three aspects to the concept of normality. Normality can represent that which is taken as natural and hence healthy; normality can be used as a measure against which other acts can be judged and found unhealthy; and as a goal to be reproduced by intervention programmes. Rose therefore argues that the concept of normality can be used to simultaneously construct an image of the natural child and family, and to provide a set of instructions to those involved as to how to behave in a

normal fashion, and also to provide a means for identifying abnormality. Such an identification of abnormality through the comparison with that which is constructed as normal further rationalises intervention as a means of combating the discrepancy identified between normal and abnormal.

So pervasive is the influence of psychology in constructing the images of the natural family that Burman (1994) has proposed that mothers have become a primary focus of intervention by psychologists. It is this shifting of emphasis that reflects the wider themes of regulation by psychology through its tools of investigation. It is through such regulation that psychology can ensure that women subscribe to dominant psychological accounts of child development and the required behaviour of parents in providing what is 'best' for their children.

Rose (1989a) further argues that such concepts of normality are not gleaned solely from our experiences with 'normal' children, but instead such normality definitions are developed by experts on the basis of their claims to scientific knowledge. Such claims are based not on the study of 'normality' but also draw on the study of 'abnormality' or cases deviating from the prescribed norms in a given situation. The relationship between normality and abnormality is therefore symbiotic: it is the normalisation of individual development that enables the abnormal developmental patterns to become visible, and vice versa (Burman, 1994). Rose (1989a) concludes that normality is therefore not an observation of a group of individuals, but a valuation. In similar arguments to Rose, Burman (1994) proposes that the construction of normality is so powerful that it becomes naturalised into psychological descriptions of children's behaviours through appealing to biology and evolution. Burman notes that such descriptions of children's behaviour are then drawn upon across a range of developmental areas such as attachment theory and language development.

Because of the powerful position that the concepts of normality and abnormality occupy, Rose (1989a) argues that childhood, parenting and family life can be rigorously governed and regulated in new ways. Rose proposes that mothers govern their own children according to psychological laws, in partnership with psychological experts. Burman (1994) highlights the work of North American psychologist Arnold Gesell as being particularly influential in the creation of 'norms' and 'milestones' of development that underlie many contemporary developmental health checks. Gesell was particularly influential in promoting the view that development is a natural process of maturation and growth which will unfold given the appropriate supports and circumstances. It is this naturalisation of child development and developmental goals and milestones that regulate the behaviour of parents and mothers in particular. Indeed Urwin (1985) provides a detailed discussion documenting the experiences of a group of new mothers. Urwin's research includes discussions of the role of service providers in normalising goals and achievements, and the handing out of pamphlets and other written material on developmental milestones. Many of the mothers in Urwin's research referred to such material and kept a record of their child's progress in light of these. These mothers were therefore concerned with the normalised goals developed by psychological experts, and whether their child met the specific criteria of normality within them. Walkerdine (1999) has highlighted that models of childhood from within developmental psychology privilege a particular model of normality. Children who do not meet this standard of normality are frequently 'Othered', and become the object of pathologisation. The process of 'othering' reflects modernist thinking in the production of binaries, for example, male/female, normal/abnormal non-autistic/autistic. Implicit in such binaries is a valued end of the dualism, singled out as preferable.

Scientific writings about autism remain firm in their belief that autism can be considered to be a disorder which can be reliably measured, diagnosed and treated. Frith (2003) is clear in her discussions surrounding the history of autism that autism is not a modern

phenomenon despite being recognised only relatively recently; a position held by previous researchers of autism such as Bettelheim (1959). Frith cites and discusses several cases from history which have been retrospectively considered to be cases of autism. One such example is that of the wild boy of Aveyron, whose case was notably documented by Itard (1932). In her discussions of the boy, Victor, Frith cites evidence from historical documents written about him which she believes exemplify commonly agreed impairments associated with autism in contemporary research. A second example from history is that of Hugh Blair of Borgue, a case which Frith has written extensively about (Houston and Frith 2000). It is when discussing this case that she is firm in her assertion that a retrospective clinical diagnosis of autism can be given to Hugh Blair, confirmation that a condition of autism indeed does predate its 'discovery' in the 1940s.

Such an historical examination of autism can be criticised by drawing upon the work of Graham Richards (1996). Richards argues that histories that serve to 'prove' an author's theoretical position incorporate several important errors notably that they aim to construct the present perspective as the final authoritative account. The account therefore presupposes the possibility of an objective examination of the past through the benefit of modern scientific tools and methods of assessment. The presentation of a history of autism such as that by Houston and Frith (2000) can therefore be seen as an attempt to rationalise the presented 'truth' of present theory, with history being used as a story of how such 'truths' were arrived at.

Hacking (1999) discusses the socially constructed nature of childhood autism, and questions the effects of identifying an aetiology for autism. Hacking discusses what effects identifying a biological marker will have on children and families previously diagnosed with autism, if such a marker is absent in a sub-set of these individuals. Such individuals would be excluded from the diagnosis of autism without such a marker. This raises the question as to whether such individuals who had previously

been labelled and had accepted a diagnosis of autism would be given a 'new' label. Similarly Novas and Rose (2000), referring more generally to genetic research, reflect on the importance on the discovery and linking of a genetic marker to a specific condition. Novas and Rose propose that once a specific marker has been associated with a condition, the illness or condition then becomes a 'family matter', with the possibility of the 'cause' of the individuals 'problem' resting with a family member of a previous generation. This means that the diagnosis in one individual necessarily has implications not only for the individual but for their relatives as well. The identification of a genetic marker for autism would therefore have important implications with regards to the way that individuals with autism construct their identities, their relationships to their families, and the course of intervention embarked on by psy-professionals. Questions of genetic screening may be raised in light of the identification of a genetic marker, further serving to construct an image of the autistic person as 'damaged', rather than drawing on discourses that celebrate differences.

### 3.3.2 *'Othering'*

A questioning of the boundaries of 'normality' and 'abnormality' can be increasingly seen in the literature, and the specific importance this has for actions and interventions to change individuals (for example Oliver 1990). Oliver (1996) comments that increasingly people with disabilities are rejecting notions of 'cure' and have become critical of therapeutic interventions. Such thinking is informed by the growing self-advocacy movement and the culture of disability that is based upon pride. Oliver proposes that within these assertions, ideas concerning normality are increasingly coming under attack. However, despite the growing self-advocacy movement, the construction of normality, and consequently abnormality, remains entrenched in powerful discourse, and an examination of the history of such concepts is important in discussions. Kitchin (1998) echoes such claims by highlighting that people with disabilities have a long history of being labelled as the deviant 'Other'.

Kitchin proposes that their position in society as such 'Other' is perpetuated by cultural representations and myths which are dominant in a given society. It is through such cultural representations and myths that disability is constructed as a medical and individual problem, with people with disabilities being the victims of their biological fate. In such constructions of disability, social model theorists propose that society removes itself from any blame or guilt for disablist practices.

In discussing the theoretical arena of 'Othering' I will draw on specific examples from the autistic community in order to more effectively illustrate my theoretical position. In the current thesis, the binaries operating in the discourse are those of non-autistic and autistic. People with autism frequently reflect the use of such binaries in their own discussions of the differences between people with and without autism, but the terminology is slightly different. (See the introduction for a fuller discussion of terms). For the population contributing to the current thesis, the binary is constructed as the difference between 'neurologically typical' (NT, non-autistic people), and people with autism, frequently referred to as 'AS'.

Drawing on earlier work highlighting the duality of modernist thinking, Aitchison (2000) proposes that othering is characterised by dualisms, which inevitably define norms and deviants. Drawing on such dualisms, defining the 'other' is a particularly important concept in the current thesis. In this way people with autism are defined as 'deviant' and 'other' by the dominant non-autistic 'NT' population. It can be argued that NT is the normal/natural way and does not therefore require a label (and consequently a theory) outside the AS community. NT traits are taken to be positive by the dominant majority, and something to strive for by non-NT people. This is being inverted in some pockets of the autistic community, with an increased scrutiny of some of the negative traits associated with being NT, and a consequent development of the study of NTs. This assertion is in line with work by MacCallum (2002) who proposes that "a group is defined not necessarily by those who are in it

but by those who are excluded from it “ (p. 87). A theory or definition of NT is therefore not required as the focus of the dominant group is on people with AS, with NT taken as the default majority. NT is taken to be the norm and therefore there is no need to investigate them as a specific study; in contrast people with autism are seen as ‘special’ and therefore specific attention is warranted to this group of people. While psy-practitioners spend considerable time focusing on ‘normal’ development, the primary reason with respect to autism is in order to highlight the potential ways in which people with autism can vary or deviate from this norm, by for example studying the use of eye contact by people with autism and comparing this to the typical population.

If we take NT to equate to typical development, then this has been ‘normalised’ by professionals, particularly with respect to child developmental milestones, where ‘normal’ development has been mapped out partly in order to identify the ‘abnormal’ behaviours and enable the regulation of development (see for example Rose 1989a; Burman 1994). Drawing on the discussions of theorists such as Foucault, Rose and Burman, NT can therefore be seen as an implicit goal in developmental psychology, maintained by close checks made by regulating bodies such as health visitors. These bodies can highlight any differences (and by definition problems) early in order to increase the chances of the maintaining normal/NT behaviour. The AS community, particularly online, are inverting this assumption by creating a group of ‘others’ as NTs, who are as a consequence of their new definition, worthy of study. This is a strategic practice evident in other research areas such as feminist research and gay and lesbian literature. Kitzinger, Wilkinson and Perkins (1992) argue for example that accepting the label of ‘lesbian’ is an act of self-naming in which a label frequently constructed in negative terms is claimed by an individual as a political action. In a similar vein, people with autism may be politicising the label of autism and claiming it for themselves despite the negative constructions of the label presented in the wider society.

Psychologists and psychiatrists have the power to define autism as Other. However, the autistic community are politicising the label and inverting the Othering to give a syndrome of NT, constructed in a similar manner to DSM descriptions and suggested therapeutic interventions for AS. This remains a marginalised voice though due to the power of the medical model of disability, particularly with specific reference to autism. Therefore the construction of the 'other' group consisting of non-autistic people remains largely unrecognised due to the overarching power of the dominant group, that is, NTs who have the avenues through which to construct and maintain autism as 'other'. I will return to discussions of theorising the (NT)other in chapter 8 of the thesis.

### **3.4 Theory of Mind revisited**

I will now return to theory of mind in order to illustrate my theoretical position more clearly with regards to this thesis. Theory of mind is felt to be a cornerstone in understanding and explaining people with autism due to its perceived ability to underpin the 'triad of impairments'. I am choosing to focus my discussions of it here due to the explicit way that people with autism are constructed within this framework.

Theory of mind was a term originally coined by Premack (1978) to describe the intentions of primates (Leuder, Costall and Francis 2004). It has since been developed and is now applied across a range of disciplines within psychology, notably developmental psychology, and specifically studies investigating 'abnormal' behaviour. Theory of mind is presented as an ability which develops as the child matures, and an ability to appreciate one's own and other people's mental states is presented as an ability that is in some way lacking in people with autism.

While the theory of mind hypothesis is not specific to autism and not linked to intellectual attainment specifically, literature proposing explanations for behavioural characteristics in autism draw heavily on the hypothesis. For example impairments in theory of mind have been drawn

upon to explain a lack of pretend play amongst children with autism and may be important in explaining communication difficulties (see for example Guajardo and Watson 2002). The focus of the theory of mind hypothesis is therefore on an inability which has important consequences in a variety of situations and may influence several aspects of social interaction. The arguments that there are impairments in the ability to understand feelings and mental states has been challenged by Jones et al (2001) who propose that people with autism can express emotions, particularly online using internet technologies.

The online exchanges between such groups frequently call for the conceptualisation of alternative theories of mind. The use of theory of mind by psy-professionals is dominated by scientific thinking that presents theories as objectively researched 'facts' and hence while theory of mind remains a hypothesis, it is frequently presented by writers as an explanatory 'thing'. While there is no acknowledgement in dominant traditional psychological literature of an alternative theory of mind, a body of research is emerging which discusses alternative theories of mind (for example Costall and Leuder 2004; O'Dell and Brownlow 2004).

#### *3.4.1 Alternative Theory of Minds*

Theory of Mind has been proposed as a core element explaining the 'deficits' frequently outlined in people with autism (for example Baron-Cohen 1985; Tager-Flusberg 1999; Guajardo and Watson 2002). Recent material from both people with autism and academics has led to a questioning of the concept of theory of mind. Such discussions are in line with the work presented in this thesis, which questions the construction of autism in a predominantly negative light.

Klein (2002) proposes that theory of mind explanations reflect the dominant way of thinking in society in that it favours neurotypicality. Klein argues that implicit in discussions of theory of mind is the assumption that the neurotypical way is the only way, and as such people with autism are

at fault because they are not like neurotypical individuals. Klein reflects on the theory of mind hypothesis and the way that it characterises autistic and non-autistic individuals:

“If one of my kind cannot figure out what a normal person is thinking, it is a theory of mind error... it is the fault of the autistic for not being like the NT. If a normal person cannot figure out what one of my kind is thinking, it is because we are not using the proper means to tell you. Again it is the fault of the autistic for not being like the NT.”  
(Klein 2002 webpage)

Klein (2002) therefore argues that within the theory of mind hypothesis, individuals, and specifically people with autism, cannot be different. If they do not behave in a similar manner to neurotypicals, they are ultimately classified as being impaired, and ‘failing’ the test. Smukler (2005) echoes this point and argues that theory of mind theorists ultimately define autism in terms of an insufficiency in skill that constitutes a problem and therefore must be fixed. Such individuals are rarely constructed as being different by such theorists and hence accommodated, but rather traditional literature constructs such individuals as being impaired and requiring specific intervention.

Reflecting on the concept of theory of mind, Smukler (2005) observes that autism is viewed as a unitary phenomenon, arising from a single core disability, rather than a multi-faceted entity. The basis for such an assertion is provided through science which ultimately maintains the professional ‘expert’ voice as the authority with which to explain autism, marginalising the voices of people with autism themselves. Such representations Smukler argues, present autism as a deficiency rather than a difference. Such ‘damaged’ individuals therefore require specialist help in order to function in society. Smukler argues that these depictions of people with autism have become the dominant perspective, and hence normalised and not questioned.

Much work has examined the concept of theory of mind, and Costall and Leudar (2004) comment that rather than appearing as a new and

dominant theory, many of the assumptions of the theory of mind hypothesis were visible in psychology several years before the hypothesis came to adopt its dominant position. Indeed Costall and Leudar (2004) argue that the hypothesis amalgamated these assumptions, and came along at the right time in order to climb to such a dominant position due to developmental psychologists at the time needing a theory which would hold up to close experimental scrutiny. Within experimental psychology the accessibility of the hypothesis to experimental testing contributed to the acceptance that psychological experiments could represent the situations in which people have to understand other's minds generally (Costall and Leudar 2004). Smukler (2005) argues that it is this acceptance that maintains the position of scientific experimentation as a powerful tool for examining human beings. Smukler, in line with other critical theorists, however, warns that decisions about what aspects of individuals and society more broadly to consider are never neutral, scientists are never value-free. This relates to Klein's (2002) earlier point regarding the ideals of the theory of mind hypothesis being non-autistic/neurologically typical traits.

Smukler (2005) cites the example of the contrasts between how theory of mind is defined and how it is tested in order to illustrate the differences in choices made by theories concerning representations of elements of theory. Smukler observes that theory of mind is defined in a very broad way, as an ability to understand the intentions of others, their emotional states etc. However, Smukler notes that in contrast, it is evaluated in very specific ways, primarily through the design of various false belief tasks. Making a similar point to Klein (2002) earlier, Smukler argues that the employment of such tests gives rise to a group of individuals who do not complete the test as expected (that is, like neurotypical individuals would), and are therefore labelled as deficient.

Smukler (2005) further develops this argument with the observation that some professionals take the concept that people with autism are mindblind as uncontroversial. However, such a group of experts

vigorously debate the details of the hypothesis in every other regard. The concept of the lack of theory of mind in autistic individuals could therefore be argued to be hegemonic. Smukler reflects on the literature written by people with autism which began to emerge in the late 1980s as evidence for this. Smukler notes that the publication of first person accounts of autism by people such as Donna Williams and Temple Grandin led to the questioning as to whether or not these individuals could be 'really' autistic (see for example Haslem 1996 for a review of the controversy). The insight expressed by such authors as to the experiences of living as an autistic person in a non-autistic world was incompatible with the unquestioned assumption that people with autism could not offer such insights due to their lack of a theory of mind. Indeed Leuder, Costall and Francis (2004) argue that the hypothesis has become so widely accepted in developmental and cognitive psychology that it is often confused with the phenomena it was introduced to explain. Leudar et al (2004) also note that in contrast to the vast amount of books and papers published by proponents of theory of mind hypothesis, there is only a small body of literature criticising the concept.

At this point in my discussions on the concept of theory of mind I would like to introduce and draw upon some papers written by people with autism and published online. The papers hold particular importance in the discussions for several reasons: firstly because they reflect a voice of people with autism on a topic about which discussions are normally dominated by psy-professionals, and secondly because they provide an important challenge to the scientific concept of theory of mind as a means of constructing people with autism as deviant or deficient rather than different. The papers cover various aspects of the theory of mind hypothesis, but I would like to focus attention primarily on the questioning of the concept of a theory of mind, the testing for theory of mind and the tools used by psy-professionals, and the conclusions and assertions drawn from the observations of individual performances on such tests.

Perkons (1998) presents a theory of social delusion, and within it questions whether there is really such a thing as a theory of mind.

Perkons makes the notable observation that:

“...a theory is usually something that can be written down or explained to another person, yet the people who supposedly have it, don't ever explain it. This makes me wonder if it exists at all... before I buy into a “Theory of Mind” as something other people have, but I don't, I want to know what it is.” (Perkons 1998; webpage)

Perkons develops the argument that people without autism or ‘normal’ people do not tend to consider the possibility of people living in separate worlds and hence having very different outlooks on the world. Perkons argues that people with autism have a very good theory of mind, but that this is a different theory from that of non-autistic people.

Perkons (1998) also reflects on the very specific tests devised by psychoprosessionals to test the concept of theory of mind, and describes a classic theory of mind test where sweets are put in box A and then when a person is out of the room transferred to box B. The question posed to participants is where will the person look for the sweets on their return? Perkons notes that it is generally observed that both autistic and non-autistic children will say box B at around 3 years, but argues that their rationale for doing so might be very different:

“I think the NT kids were assuming that the “person” was the “same” as they were, an extension of their own mind and emotions, and therefore would think the candy was in box B, just as they knew it was... The autistic kids would have been baffled, as I would have been. From my experience adults and older kids knew a lot of things that I didn't. In fact, they could do a lot of things that were “magical” to me – they could drive cars, they knew where the cereal was without looking for it... etc. So how can a sensible child possibly imagine what on earth the adult or older kid might or might not know? For all he knows adults might have x-ray vision.” (Perkons 1998; webpage)

Perkons summarises the findings from the assessment tests by highlighting important differences between people with autism and neurologically typicals:

“The basic difference seems to be:  
NT Theory of Mind = Everyone thinks like me, except when shown to be otherwise.  
Autistic Theory of Mind = Everyone thinks differently from me – vastly and mysteriously – expect when shown to be otherwise.” (Perkons 1998; webpage)

However, despite the different strategies and possibly theories of theories of mind as proposed by Perkons (1998), the findings from theory of mind research typically characterise the impaired performance of people with autism on such tests as deviant or impaired rather than different. This view of proposing challenges to the dominant theory of mind has become characteristic of a more general move within academia and by autistic people.

### **3.5 Summary**

The chapters presenting the literature review have examined several main areas, beginning with an examination of more traditional scientific explanations of autism which remain an important focus due to their powerful position in shaping our understanding of people with autism and the various characteristics proposed to be associated with the autistic spectrum. The discussion of internet technologies and communications through the use of such media brought to light the important question regarding an individual’s identity and a rejection of the notion of identity necessarily being a stable and enduring entity. This literature will be drawn upon in the chapters of analysis which discuss the concept of an autistic identity and the complex issues which surround the development of an individual’s identification with the label of autism.

The review then moved on to discuss the epistemological resources that the thesis will draw upon, detailing particularly the social model of disability and influences from critical psychological theory. The lack of literature specifically addressing the position that autism adopts with regards to theorising by the social model was acknowledged and will be revisited following the chapters of analysis of material from the discussion lists that contributed to the thesis. Questions were also raised regarding

the specific inclusion of learning difficulties generally into the social model of disability, by drawing on the work of several writers such as Chappell and Goodley.

The influential position maintained by psychology was discussed with particular reference to the powerful nature of the psy-complex and the maintenance of its dominant position by constructing psy-practitioners as best placed to govern the 'rules' and 'norms' of development. Focussing on the individual has enabled psy-practitioners to employ standards of statistical measurement which play a key role in establishing the norms of childhood. It is these established norms that enable psy-practitioners to identify individuals who fall outside of 'normal' criteria and can therefore be identified as requiring special attention and intervention. This identification of 'normal' and 'abnormal' has particular impact for individuals identified as having learning difficulties and specifically to this thesis, autism. The power of the psy-disciplines has particular resonance with people with autism. One particular example of this is in the methodologies selected by psy-professionals in their investigations aimed to categorise, diagnose and ultimately treat people with autism, with the principal goal being to normalise the behaviour of the population under study.

The theory of mind hypothesis provides a good example of the power of the psy-disciplines to define and categorise 'others', i.e. people with autism. The hypothesis also provides a good example of people with autism providing alternative theories of mind where autism is characterised as a difference rather than a deviance. Challenges are also presented by people with autism through drawing on the concept of dualisms prevalent in modernist theories and inverting the dominant group who has the power to define the 'other'. This has led to a creation of a neurologically typical group who are available for study in their own right, and not necessarily an ideal for people with autism to become. This is inline with other political subversions, for example Kitzinger and her work surrounding the construction of lesbian identities.

## **Chapter 4: Methodology**

The previous review has outlined key areas of influence for the thesis, and I would like to now focus more specifically on the methodological approach adopted for the thesis. I will begin by outlining the aims and objectives of the research, then focus on the research approach, citing examples of previous discussions regarding the use of online methodologies, and building on the review of literature previously presented. The nature of the data collected will be discussed before detailing the specific methodological approach of my work. Finally the method of analysis adopted in the thesis will be discussed before a brief outline is given of the four groups contributing to the data in the thesis.

### **4.1 Research aims and objectives**

The principal aim of the research is to investigate the construction of the autistic individual. Five main objectives have been identified: -

- To explore how the perspectives of individuals with autism can be heard through investigations using new technologies.
- To examine the implications of accepting the construction of autism as a singular 'disorder'.
- To examine the relationship between 'normality' and 'abnormality', and consider how autism as a specific 'impairment' has been constructed within this framework.
- To examine similarities and differences between constructions of autistic and neurologically typical individuals.
- To examine the powerful position accorded to psy-discourse within discussions of autism.

## 4.2 The research approach

The primary method employed in this research has been to use the Internet as a research tool. This is in line with recent work that has been successfully carried out using such methodology in other research areas (see for example Sharf 1999; Coomber 1997; Siddiquee and Kagan 2006), and takes account of the increasing use of the Internet by people with autism (see for example Dekker 2000; Blume 1997a). (Please refer to the literature review for a full discussion of previous work.)

It has been shown that people are more likely to display higher levels of self-disclosure in computer mediated communication as compared to face to face situations (Joinson 2000). People can therefore be encouraged to speak openly without fear of embarrassment and in some instances, are able to show resistance to positioning imposed on them in the 'real' world (Joinson 2000). This may be particularly beneficial to my research as computer mediated communication enables researchers to contact populations who may have difficulty in interacting in traditional face to face situations. This is important in the current thesis because the participants in the project are people with autism who have been characterised in traditional literature as having difficulties in face to face communications.

It is however recognised that the Internet may not be an appropriate tool for all group research. As with all interactions in an online environment the question arises as to the confidence one can have in the 'true' identity of the participants given the opportunity for anonymity which the Internet offers. This has developed into a major discussion point for researchers using the Internet as a research tool. Mann and Stewart (2000) however question why there is a tendency to associate deception more closely with computer mediated communication and the Internet than more traditional research approaches. They raise the argument that in other methodologies such as questionnaire research, the researcher also does not necessarily have direct contact with the participants, yet deception is

not usually considered to be a major problematic factor. Horn (1998, in Mann and Stewart 2000 p.91) contributes to these important discussions by making the following point: 'You don't have any more guarantees that someone is who they say they are just because you can see them. We are often as fooled by appearances as we are informed by them.' This argument is further developed by Mann and Stewart (2000) who comment that if the key requirement of the study is that participants have an informed knowledge of a specific area, then individual identity may not be so crucial.

The question as to the 'true' identity of research participants was not felt to be a major concern in the current research, given its focus on questioning the construction of autism and the diagnostic processes and power given to 'experts' in the field. The participants in the current project ranged from those with an 'official' diagnosis, to those self-diagnosed, and non-autistic members of the lists. All participants did however share the common view of being interested in AS and promoting self-advocacy and celebrating neuro-diversity, and due to the closed nature of the discussion lists joined, a degree of knowledge of autism is required in order to gain membership. What was important for the current research was that participants identified themselves as belonging to a particular group. Please refer to section 4.7 of the methodology for a fuller description and characterisation of the discussion groups studied in the thesis, and the general membership of the lists.

The predominant construction of autism as a stigmatised identity also increased confidence in the identity of the participants on the discussion lists. It has been previously demonstrated in the literature review that people with autism are considered to be a group of people characterised by 'impairments' in certain abilities and a 'lacking' in certain cognitive functions such as the ability to understand concepts of false belief. It is therefore felt that it is unlikely that a person without autism would take on the identity of a person with autism online.

The Internet is therefore considered to be a useful tool in enabling individuals with autism to share their experiences and perceptions of the label 'autism', and have these perceptions and experiences recognised within a professionally dominated discourse of autism.

#### *4.2.1 Online methodology*

Research through computer-mediated communication can take various forms, and can include an adaptation of traditional methodologies such as questionnaires, interviews and focus groups. However, a distinction in its broadest terms can be made between synchronous and asynchronous interactions and several methodologies can be adapted to take either a synchronous or asynchronous form. Synchronous interactional patterns online require all members of the interactional sequence to be online at the same time, and can appear to most closely resemble a conversation in written form. Questions posed and replies are often immediate, and can be confusing for the beginner as many participants appear to be 'talking' at the same time. Specific examples of this form of communication include Internet Relay Chat, and some forms of online conferencing. In contrast, asynchronous interaction online does not require all members of the interaction to be present at the same time, and here there can be significant elapses of time before question and responses are delivered and read. Specific examples of this form of communication include discussion lists and private e-mail interaction between two or more people.

I decided to focus my research on asynchronous methodology, specifically employing the use of discussion lists. Discussion lists are characterised by several individuals joining a discussion group usually specifically created to focus on one particular topic. Discussion lists have a list owner, who is usually the creator of the group, and may be open access where people can subscribe themselves, or closed access where the list owner approves individual membership. Individual members post messages to the group via an e-mail address for the group which sends

the message to all members of the list via their individual e-mail in boxes. This can then be responded to at a time convenient to the receiver by posting a reply to the group, or in some instances, sending a personal reply to the creator which will not be seen by the wider group.

Using asynchronous methodologies had several advantages in the current research project. It has been noted by Mann and Stewart (2000) that when employing synchronous discussion methodologies it is often the participant with the most proficient typing skills who may have the most power to 'say' the most in the online interactions. The specific aim of my research was to enable the examination of the construction of autism from a range of participants. A key concern therefore was to ensure that every member of the discussion list had equal access to make contributions to the discussions. The use of asynchronous discussion lists ensured that all messages had equal weighting in the contribution to the general discussion no matter how long or short the message was or how long the message took its creator to post.

A second key advantage of the use of asynchronous discussion lists in the current research was that all participants and the researcher did not have to be online at the same time. This enabled participants from several time zones to contribute to discussions, providing a range of discussions and comments.

#### *4.2.2 CMC as a hybrid communication*

The question as to the type of data generated from an asynchronous discussion list will now be addressed. Computer mediated communication has been likened to a variety of modes of communication and debate exists in the literature concerning the similarities of online exchanges to both written and verbal communication. For example, Giese (1998) likened both synchronous and asynchronous computer mediated communication to conversation, with claims that people do not 'write' to their friends online, they 'talk' (Mann and Stewart 2000), while Morrisett

(1996) characterised computer mediated communication as writing, particularly asynchronous computer mediated communication which is the focus of the current thesis. This form of computer mediated communication allows the reader and writer time to reflect, check what is intended for communication, and formulate thoughts to be made into further communications. However, as regular users of e-mails may argue, e-mails do not wholly resemble traditional written text, as mistakes are common and grammar rules are not always applied. Trietler (1996) has therefore challenged this likening to written forms of communication and has suggested another analogy in telephone communication. Trietler suggests that people 'grab' a keyboard for a quick transmission of thoughts (Mann and Stewart 2000). The complexity in characterising the nature of online exchanges has led commentators to propose that electronic discourse can be characterised as a hybrid form of communication, showing features of both spoken and written language, resulting in a text that is unique and formulated as a medium that has never existed before (Ferrara, Brunner and Whittemore 1991).

This 'hybrid' style of communication which computer mediated communication has developed into can offer both positive and negative features in style. With regard to the features likened to spoken language above, which include 'grabbing' the keyboard for a quick transmission of thoughts, data collected has been criticised for being unfocused and 'faulty' (Sproull and Kiesler 1991), which may form superficial exchanges due to users being able to quickly construct and send messages before reflection of the content has been fully achieved. However, unlike spoken language, computer mediated communication has also been criticised for being 'deliberative, stilted, and formal' (Denzin 1999), characteristics which may be amplified due the absence of the usual turn-taking and non-verbal processes which operate in face to face exchanges.

However, computer mediated communication also visibly adopts some of the more positive features which are often attributed to written and spoken discourse. Particularly with regard to asynchronous

communication, like written text, e-mails allow the creator and reader time to create, reflect and analyse messages, controlling the interaction pattern with respect to time taken for response creation and consumption. This reflexive nature which is offered particularly by asynchronous communication can be seen to increase the accuracy of the data (Mann and Stewart 2000). However, as well as the opportunity to reflect on thoughts, computer mediated communication also allows thoughts to be transmitted in a manner similar to oral communication. The conventions of a relaxed attitude to grammar, spelling etc. may aid the communication of thoughts and feelings which may otherwise be difficult to express. This may be particularly beneficial for my research.

The unique patterns of exchange provided by asynchronous discussion lists particularly are therefore embraced by contributors to the online discussion lists in this thesis, where exchanges are often characterised by sophisticated exchanges of information and ideas.

### **4.3 Group selection**

Now that a broad theoretical and methodological basis has been discussed for the current work, I would like to focus more specifically on my strategies for selecting the discussion groups that contribute to the data in this thesis. Several host sites facilitate online discussion groups such as Google and Yahoo. Due to the large number of discussion lists hosted by such sites I decided to focus my research on just one host. On investigating the discussion lists hosted by the sites, Yahoo was considered to provide a potentially representative sample for the discourse of autism spectrum disorders at the time the research began due to its hosting of a variety of discussion lists ranging from professionally dominated to those owned by people with autism.

Within Yahoo there were two types of potential online communication – Yahoo clubs and Yahoo groups. The club includes an online chat room where synchronous exchanges can take place between participants. All

participants in the interaction are required to be online at the same time and question and response scenarios are immediate. To become a member of this type of online interaction, an individual becomes a member of Yahoo clubs generally and then is permitted to enter any club discussion of their choosing.

Yahoo groups consist of closed discussion lists to which members must join, and be approved for membership by individual groups. Here interaction is asynchronous. A decision was taken to research asynchronous interaction online for a number of reasons. Due to their nature, asynchronous discussion lists do not require participants to be online at the same time, this enables a participant pool from a wide geographical area to take part in discussions. Questions and responses are frequently delayed by a number of hours and in some cases, days. Due to these characteristics, everyone has a more equal 'voice' in discussions, as the individual concerned can control their participation in 'conversation'.

Initially a search was conducted within the Yahoo group host, and all groups focusing on autism spectrum discussions were examined. This yielded a potential sample pool of 430. Selection was further tailored to only include groups which were based on general discussions, excluding from the study groups which were very specific in their nature. These included for example, groups against applied behavioural therapy, dietary discussion lists, and those looking at specific proposed causes such as mercury. Initially 9 clusters of groups were identified:-

- Groups for people with autism/Asperger's
- Groups for parents of people with autism/Asperger's
- Groups for professionals
- Groups for professionals and parents
- Groups for siblings of people with autism/Asperger's
- Groups for spouses of people with autism/Asperger's
- Groups for wider family and friends

- Groups advocating for people with autism/Asperger's
- General interest groups welcoming everyone

These groups varied in size and number, with the most dominant groups being those for parents and those for people with autism/Asperger's. In accordance with the initial aims of the study which were to analyse discourse from people with autism/Asperger's through employing new technologies, a decision was made to join groups mainly consisting of people identified as having autism/Asperger's. These discussions were to be supplemented through membership of professional and parent groups.

A second criterion for group selection was evidence of recent posting activity within the group and the number of members of the discussion list. Groups were therefore initially selected and approached for inclusion in the study if they firstly comprised of members predominantly consisting of people with autism/Asperger's, and displayed evidence of recent exchanges on the discussion list, and comprised of more than 5 members in order to maximise the opportunity for exchanges to be made between participants in the course of the research period. Based on these criteria, 16 groups were initially contacted to take part in the research.

In addition to my own priorities in selecting discussion groups, the list owners ultimately had the power to permit my membership to the group. Some list owners denied access to the groups on the grounds of myself being a non-autistic researcher, and such a purpose would therefore be in conflict with the aims and ethos of the group; others chose not to respond to the initial e-mail and were therefore not contacted further. Other list owners requested more information about the research. For example, one of the list owners that did ultimately permit me to become a member was initially quite cautious about the research, and responded to my initial e-mail with concern, saying that if I wanted to know what makes people with autism 'tick' I should read one of the many excellent autobiographies written by people with autism as a start to my research. I

replied with more information about the research and its aims, and membership was granted to the group for the time period of the proposed research.

The discussion group largely consisting of professionals working within the field of autism was selected due to its large membership (350 members at the start of the research process), and the broad range of theoretical discussions that it hosted. The broad range of topics that were covered reflected the broad professional membership base, which consisted of therapists from a range of schools of thought, researchers and parents of people with autism. Gaining approved membership to this group was straightforward.

The final sample that contributes to the data in the thesis is therefore a combination of group identification and selection by myself in accordance with the aims and objectives of the research, and self-selection by the list owners.

#### **4.4 Data collection**

##### *4.4.1 Joining the discussion groups*

Discussion list owners were approached individually via e-mail, detailing what the research entailed and a proposed time period for group membership (please see Appendix 1). By indicating a limited time period of 4 months, it was hoped that the list owners would be more encouraged to allow 'lurking' for short periods in their groups as the group would then know the definite time period of the researcher's presence. The research period would also impose time restraints on the research process, which could otherwise have been infinite in its length. A four month time period for membership was anticipated to be appropriate given the number of postings in previous months to the discussion lists.

Initial technical problems were encountered when trying to contact several list owners in a short period of time. The Yahoo service appeared to treat multiple postings to list owners as junk mail, and the initial batch of e-mails was returned undelivered. A spacing of several hours was therefore required in order to contact all 16 list owners identified as potentially useful contributors to the research project.

Membership was eventually gained to five groups. Three of these groups predominantly consisted of adults with autism/Aspergers, one predominantly parents of people with autism/Aspergers, and one predominantly professionals. During the research period, one discussion group of people with autism/Aspergers were not very active in their postings to the discussion list, and did not contribute to the discussions under the research focus and hence were excluded from the final analysis.

Once approval had been gained from the list owners, a full introduction was announced to each group by myself, detailing the research, and the intention to remain a silent member of the group following the initial posting. The introductory e-mail also encouraged members to contact me privately (i.e. not by posting a message to the group), if they had any further queries regarding the research. This was designed to encourage members to express their concerns with myself as a group member, which they may have been reluctant to do in the public forum, due to the list owner approving membership. This also ensured that group discussions were not dominated by talk of the current research – the study was designed to investigate naturally occurring discourse. During the initial stages of research I received several personal e-mails from members of the discussion lists, most being friendly enquiries about the research, some seeking further clarification about specific areas of the research. All such enquiries were responded to promptly and no members subsequently contacted me about either the purpose of the research or my status as a group member. In all of this correspondence, no list members explicitly objected to the research being proposed.

#### *4.4.2 Ethical considerations in the research process*

Ethical considerations are a major concern in this field of work, and guidance surrounding researching vulnerable groups has therefore been taken into account. The code of conduct of the British Psychological Society has been followed, and its principles applied to the new context of internet-based research.

Specific measures have been built into the research process in line with current ethical debates surrounding researching online (see for example Brownlow and O'Dell 2002). The proposed research was clearly introduced to the discussion lists at the time of membership enquiry, and permission was sought to continue with the membership in light of this. In this initial posting I introduced myself as a non-autistic researcher interested in the perceptions and experiences of people with autism. This made the research process more transparent, and ethical issues of 'lurking' in discussion lists for research purposes reduced. A strict time limit was imposed and agreed by the groups for the period of membership to ensure that all list members were aware of the time of research membership, and the departing from the groups was clearly announced via a posting. The time period identified spanned 4 months between August and November 2001. An extension of research membership was requested for one group who had been 'quieter' than the others in the initial time identified; this was granted and agreed until January 2002.

The second major ethical concern for the research was that of gaining consent to use materials contained in the postings to the groups. The nature of online discussion groups means that information is exchanged frequently and freely by members of the groups. While this is not unique to online group interactions, additional potential problems can arise due to the ease of forwarding messages posted to the groups to outside sources, and the obtaining of consent from individuals prior to doing this. All of the groups contributing to the current research had group mandates requesting that such forwarding of messages did not occur without first

obtaining the individual consent of the post creator. Following such guidelines, my initial posting to the groups made it explicit that quotes may be taken from the group as examples of discussions, but that no quote would be used without the researcher contacting the individual creator of the post. Additionally in the final write up, all quotes were to remain anonymous, with neither the individual creator nor the discussion list being identified. All participants whose quotes contribute to the data in this thesis were contacted individually. Where the e-mail account was no longer in use, a decision was taken to include the quotes in the final write up due to the transparent nature of the research process and the creator being aware at the time of posting that the researcher was present and quotes may be potentially used to highlight group discussions.

Further concerns surrounding anonymity and future identification of the origins of quotes and groups contributing data to the thesis rest with the possibility of third parties 'Googling' quotes in order to determine the original source. This does not apply to the current research. Three of the discussion lists (A,B and C) all had closed archives for messages in that they were only available to be viewed by members of the group. Such closed archives are not indexable by Google and therefore can be considered secure as an individual would need a login and password to access Yahoo groups who host the list. Discussion list D had archives that were available to the public, although only members were able to post to the group discussions. Such quotes could only be Googled if someone had previously linked to that exact page containing the posting, and that linking page had previously been indexed by Google. Given the etiquette in the groups concerning not forwarding other peoples messages this was felt to be unlikely. A final check on anonymity was to give all contributors a pseudonym.

Ethical problems faced by researchers in online environments do therefore raise some salient issues, but are not dissimilar to those encountered when conducting qualitative research in face-to-face settings. In addition to important issues of gaining informed consent from

participants, ethical problems faced by researchers in both media include the power of the researcher to interpret the data collected. The danger of 'speaking for' others is particularly key for people with autism, who have traditionally been denied their own (autonomous) voice. Blume (1997a) has suggested that this is changing and adults with autism are finding their own voice, notably in online environments.

#### **4.5 Data analysis**

In total 994 e-mails were collected from the groups during the membership period, and all e-mails from the membership period for the final four groups which were selected for analysis were printed and saved electronically. Within each of the four groups, a large number of individuals contributed to the final corpus of data, and while this figure was not as large as the total group membership (some members preferring to be silent, while some members contributed regularly to discussions), it did constitute a large sample. This provided a large and rich corpus of data to work with. More details regarding the four groups and their membership can be found in section 4.6, where the characteristics of each group is discussed in addition to details concerning the number of members and the average number of postings per month. Due to the vast number of postings to the groups during the membership period, a sample of postings from one day across all four of the discussion lists has been provided in appendix 2.

Initially, all the e-mail discussions from the groups were kept in chronological order and read several times, noting the themes to emerge in each group. The e-mails were then transferred into Atlas ti, where I could develop a more rigorous coding framework.

#### *4.5.1 Methods of data analysis*

The method of analysis chosen was critical discourse analysis and was informed by Edley (2001) and Fairclough (1992, 2001). Like other forms of discourse analysis, critical discourse analysis goes beyond perceiving language as just a tool for communication, instead viewing language as actively constructing what is understood (Scior 2003). Potter and Wetherell (1987) propose that discourse therefore does not only reflect and express meanings, it constructs them. It is these constructions which are shared and therefore enable a shared understanding of events. Discourse is therefore not necessarily the product of a single individual, but rather a social activity with shared understandings.

In addition to highlighting the central issue of constructing meaning through language, discourse analytic techniques also raise key questions concerning claims to 'truths'. Keen (1997) for example comments that truth claims occur within a given discourse and consequently can only be seen to be true or false within that discourse. Such discourses are also operating within a particular historical, cultural and socio-political environment, and an analysis of discourse cannot be isolated from such influences. Stenner (1993) therefore cautions against asking whether or not a given story is 'true', but instead advises that attention should be focussed on what is achieved through the use of such a story, that is, what are its constructive effects.

Theorists have proposed a division of approaches to discourse analysis into two broad camps: 'critical' and 'non-critical' (for example Fairclough 1992, Wetherell 1998). The non-critical approaches can be thought to encompass ethnomethodological and conversation analytic traditions, while the critical approaches follow post-structuralist or Foucauldian lines (Wetherell 1998). In common with other forms of discourse analysis, critical discourse analysis identifies underlying themes in texts. However, the critical method further explores these themes by undertaking an examination as to the meanings of accepting such constructions to

individuals identified in the discourse. It is therefore concerned with the position discourse maintains in the negotiation of social relations, social identities, and cultural values (Fairclough 2001). Critical discourse analysis also seeks to show how discourse is shaped by relations of power and ideologies (Fairclough 1992). Van Dijk (1998) therefore proposes that the research focus of critical discourse analysis tends to be on social problems and political issues rather than on current paradigms and fashions. This focus allows an investigation into the ways in which discourses legitimate or challenge issues of power and dominance in society.

Issues of power are often central to researchers guided by critical discourse analytic techniques. This is particularly evident with respect to what constructions are 'available' for speakers to use. Edley (2001) argues that there may be numerous options from which the speaker can draw upon in exchanges, but the options are not always equal in that some are more 'available' than others. Edley argues that this is because some ways of understanding the world become culturally dominant or hegemonic. In doing so, some discourses become taken for granted and accorded factual status as a true or accurate description of events. Edley proposes that one of the key foci of critical work is to investigate such issues of normalisation/naturalisation and to enquire whose interests are best served by the prominence of different discourses.

The method therefore fits well with the current research's focus on self-advocacy and emancipatory challenge to the dominant constructions of autism. The method of analysis that I have adopted has followed a macro level of analysis as the research is focused on issues of power, dominance and inequality between groups rather than specific language use and communication styles and patterns. While the latter is an interesting avenue, the research is primarily focused on how communication styles and patterns operate within social structures. As previously discussed, power is an important concept in critical discourse analysis, and is a key theme running through my analysis, with a focus

being placed on the power to define, diagnose and treat/modify autism. The analysis also examines challenges to more powerful others and the potential power shifts that would be required for such a challenge to become a dominant discourse.

While discourse analysis has been applied to a range of research areas, it remains underused in research with people with learning difficulties (Scior 2003). Research informed by critical discourse analysis is particularly scarce in such an arena. Scior (2003) notes that there are examples of people using discourse analysis with people with learning difficulties but such research tends to draw upon the use of case notes etc. and rarely does it use the descriptions of people with learning difficulties in their own words. Booth and Booth (1996) propose that the use of narrative/discourse methods may provide access to perspectives and experiences of oppressed groups who may otherwise lack the power to make their voices heard through the use of more traditional research approaches used in academia.

My research therefore makes novel use of methodology to tap avenues of research which may otherwise remain inaccessible through other research methodologies. The research seeks to provide an arena whereby people with autism can express their experiences and opinions about a label of autism and have these recognised within a professionally dominated discourse.

#### *4.5.2 Rationale for organisation of analysis*

The organisation of the analysis has taken the form of a focus on the dominant themes prioritised, rather than the four discussion lists themselves. The need for this became evident when a preliminary analysis identified common themes that spanned all the lists, with several list members from different groups contributing to constructions of particular concepts. In order to allow a fuller examination of a particular concept and theme, the analysis has drawn upon divergent voices, which

serve to construct and negotiate meanings. A thematic organisation further allows a detailed examination of the voices of people with autism in the context of other more dominant voices, notably professionally dominant constructions of autism. This allows an examination of the singularity of the concept of autism, by a contrast of the similar and dissimilar constructions of autism through each list.

The main themes that I have identified as being important in the analysis form the chapters of analysis. These are discussions of Identity, Diagnosis, and Negotiating a label of autism.

#### *4.5.3 The agency of the researcher*

The analysis is grounded in discussions of the power of the researcher in the identification and analysis of specific themes identified from the text, (Parker and Burman 1993), and recognises the agency of the analyst in the research process. This follows Bannister, Burman and Parker (1994) who highlight that discourses are not hidden in texts waiting to be discovered, they are produced through the analytical techniques of the researcher. Goodley (1996) therefore highlights the need to reflect on the role of the researcher when accounts are collected from participants, and on the researcher's role in interpreting and presenting accounts.

One area of concern for researchers has been biases in the transcription of data collected. The data collected for this thesis did not require transcription because the data was collected in an electronic form. Mann and Stewart (2000) propose that the data occurring already as a digital record eliminates error or bias during the transcription process. In order to further maintain the original text, all quotes used in the thesis are reported verbatim, and therefore typos and grammatical errors are presented as in the original texts, eliminating the 'correction' of postings. However, this does not eliminate bias when organising text into categories, and the write up that follows. Marks (1993) notes that the identification, definition and labelling of discourse enables academics to exert their power in the

control and classification of discourses and thus reify meaning. An examination of the researcher's position within the research and analytical process is therefore important in the current thesis. Indeed Van Dijk (1998) proposes the focus of theorists following a critical discourse analytic technique is often placed on the importance of their own position in society and the research process specifically.

The role of the researcher is a key debate in disability studies. Oliver (1996) discusses the importance of prioritising experience in research, and including such individual experiences within research designs. Similarly, Walmsley (2004) reflects that proponents of the social model argue that people with disabilities should be active researchers in their own right rather than passive subjects of research by others. This leaves a questionable role for the non-disabled researcher. A full discussion concerning my position in the research and the implications of this can be found in Chapter 8: Critical Reflection where I reflect specifically on my position as a non-autistic researcher.

#### **4.6 The discussion groups**

In the following section I would like to discuss the four online lists contributing to the research data in more detail. While the four lists have a common tie in their primary discussion topic of autism, they vary quite significantly, particularly with regards to their membership. I became a member of all four groups in August 2001 and withdrew from the groups in November 2001, with the exception of discussion list B where I negotiated an extension to my time in the group due to the low frequency of postings made by the group in the initial four month period. Despite there being few postings in discussion list B the postings that were made were considered to contribute important data to the research topic, and hence the decision was made to request an extension of group membership, which was granted until January 2002.

All four groups were moderated by a list owner, who approved new memberships (with the exception of discussion list B, please see below for more details) and provided additional information about the groups concerning netiquette. Such charters concerned not forwarding private list messages to outside parties and no 'flaming' or hostility towards individual members being tolerated. Due to the list owners individually approving new members, all four of the lists had a restricted membership, with only members of the discussion lists being able to post messages to the group, and the message archives could only be accessed by approved members of the groups, with the exception of discussion list D where archives were made public. Once group membership had been approved, the lists were unmoderated in that any member could post a message to the group without it being approved by the list owner as containing material suitable for discussion. This led to a diverse range of discussion topics raised by the groups during the membership period. All discussions in all four groups took place in English despite a geographically diverse population contributing to discussions.

#### *4.6.1 Discussion list A*

This list was created in April 2001 by a group of people who had met previously on a different online discussion list. The group was initially formed as a reaction to the previous list owner who the group considered did not allow them enough free expression of thoughts and ideas on the discussion list, especially if such thoughts and ideas did not match those of the list owner. The founding members of discussion list A therefore created the list as a space to express concerns without being heavily moderated in their message content. This ideology is reflected in the group's self description where it describes itself as 'non-judgemental' encouraging the 'free exchange of ideas', but with an emphasis on respecting the values and belief systems of other members.

The membership is primarily comprised of adults with Aspergers/autism (termed jointly AS by the group) and is conceptualised as a place for

them to 'connect with each other'. The list also welcomes those who are closely involved with a person with AS, such as partners, family and friends. Such people who have a close relationship with a person with AS are referred to as 'autistic cousins' (AC). This population are considered to know significantly more about AS and AS issues than an average non-autistic, 'neurologically typical' (NT) person. The list discussions therefore reflect the different categorisation of individuals with regards to their position in autism, and the model of autism generally adopted by members of this group is that of a neurological *difference*, with some focus on issues of self-advocacy.

At the start of the research membership to the group there were 39 members, and at the time of disengagement from the group there were 49 members. During the period of the research membership some members were more vocal, with others choosing to remain silent in their contributions to the list, although the pattern of engagement with group discussions varied for individuals over a period of time. During the time of my membership to the group 23 members contributed to group discussions regularly, and within this population some individuals posted more messages than others. The total number of postings made to the group in the period August – November 2001 varied, and reflected the intensity of the group discussions at particular periods of time (August 122, September 137, October 14, November 11).

My membership of the group was gained through contact with the list owner, who identified herself as AS. I made a request to join the group as detailed earlier in section 3.4.1. The initial response from the list owner was cautious about the research process and the purposes of the research:

Hi Charlotte,

If you want insight as to what makes an autistic person 'tick'  
You would be better reading some books or articles written by adults with autism.  
Bella, List A.

Following this I sent further information about myself and my position in the research to the list owner and membership of the group was approved. I then posted a message to the group introducing myself as a non-autistic researcher and gave some details concerning the nature and purpose of the research, inviting any questions regarding the research to be posted to me privately, that is not as a general message to the list, (please see section 3.4.1. joining the discussion groups for a fuller rationale for this decision). Some members e-mailed to request further details concerning the study, and these were dealt with via personal e-mail correspondence. One member e-mailed me privately to share with me his own observations about discussion lists and was concerned that his observations would disturb my study and so invited me to delete the message before reading his observations.

hi charlotte -

my comments concern my observations, so perhaps you may wish to delete this for the sake of your study. or cursor down. in either case, good luck with your studies!

...

...

Fred, List A.

The individual highlighted several important observations with regards to communication by people with autism on the internet, particularly a general approach of the categorisation by people with autism of “us vs. them”. The message creator also felt that important challenges that people with autism face in face to face interactions are not necessarily apparent in e-mail exchanges due to the population using such online media being comfortable with the medium before joining the lists. The final important observation provided concerned the culture of people with and without autism:

the most significant thing i've seen is a distinct difference in culture of parents who consider themselves NT (neurologically typical) but rearing kids in the spectrum. there you'll find the differences expected when talking about children as well as a dramatic difference in attitudes toward "treatment".  
Fred, List A.

This important observation is reflected in the current research approach where I have joined four online groups, who while having a common tie of focussing discussions on autism, vary in their characterisation of autism, particularly in terms of whether autism is considered a 'difference' or a 'deviance' that necessarily requires specialist intervention.

Only one query was posted to the group and again this was dealt with via personal e-mail with the option given to the recipient to forward the response to the group, or request that I formulate a response for the group. This was not requested, and my participation in the group was not mentioned in the group discussion forum again.

examining what language? Our foreign alien language or intelligence?  
Our understanding of the world around us and within us? sorry if I am being abnoxious...just in a shit mood tonight. I had my blood taken today so I am a little edgy till Monday...then who knows what I will be....??????? probably back on lots of vitamins...is my guess.  
Tracy, List A.

The themes that are to follow in the analysis were evident in postings to the group, with some themes being more predominant than others at certain times.

#### *4.6.2 Discussion list B*

This discussion list was created in November 2000 for people who are self-diagnosed with Asperger's syndrome or autism. The membership is therefore comprised of people who have not received an 'official' diagnosis of autism from a professional, but rather have self-diagnosed. The group description reflects the general position adopted by contributors to the list, of people with autism being the experts with

regards to knowledge about autism, and professionals knowing less about autism than the people who deal with it on a daily basis.

The group consisted of 12 members when research began, and this remained consistent throughout the research period. During the time of my membership of the group, some members were more vocal than others, although the pattern of engagement with group discussions varied for individuals over a period of time. During this time 7 members contributed regularly to group discussions, and within this population some individuals posted more messages than others.

The membership procedure for discussion list B is slightly different from the other three groups in that it has an open membership, with new members not needing to be approved by the list owner. Despite this, and in accordance with the ethical steps identified in the design of the research project, the list owner was contacted privately as with all the other groups, prior to gaining membership to the group, in order to seek their approval. In common with the other discussion lists contributing data to this thesis, only members of the list may post to the group discussions, and the archives remain accessible by members only.

The number of members of discussion list B was quite low when compared to the other three lists, and this was reflected in the number of postings made to the list each month. However, as previously described, despite there being few postings in discussion list B, the postings that were made were considered to contribute important data to the research topic, and hence the decision was made to request an extension of group membership after the November deadline initially agreed with the group, which was granted until January 2002. The total number of posts to the group varied each month: August 0, September 2, October 10, November 13, December 11 and January 3.

On approaching the list owner for membership approval, they were concerned about the quiet nature of the group and the suitability of the group based on this for the research that I was proposing:

Well, that sounds really nice, but unfortunately, my group is rather, well, non-talkative...you might be better served to find a more active group? But if you would like to join, be my guest :)  
Mike, List B.

I replied to the list owner that I was still keen to join their group despite the low number of postings, and posted a message introducing myself and my research to the group, again inviting and questions regarding the research to be posted to me privately. Only one member expressed queries concerning the research at this time:

Dear Charlotte Brownlow,  
I would like additional information on what you want to do or hope to accomplish. This is one of the quietest listservs I belong to. I don't know any of the other members. I am being passive and so are the others from what I see.  
Ronald, List B.

I provided the individual concerned further information about the research, and this individual remained positive about the research throughout the period of group membership. Only one other member commented on the research at this period, and they posted the message to the group, expressing concerns about the low activity on the list:

Ms. Brownlow,

Well, seeing as there has been little activity on the message board this summer, I certainly hope you weren't relying on this group for all of your research data!!...Your research sounds worthwhile. Good luck.  
Evan, List B.

No further queries regarding the research were voiced until I contacted the group towards the end of my agreed membership time, requesting an extension of my membership until January 2002. This prompted the following response from one group member:

charlotte,

now that you posted i think i recall you saying something about being a silent member. but if i remembered throughout the whole time, I think i would have posted differently or in private. too late now, and i don't blame you, since it was i who forgot. but i don't like to be watched like a bug. it's not up to me to end your stay here since i am not the list coordinator, but i for one would like it to end.  
Hannah, List B.

Another group member who initially requested further information concerning the research from me at the start of my membership to the list responded to the message:

Charlotte, I remember that your e-mails to the group. I have no problem with your continuing presence. [Hannah], if it you want to e-mail me privately. I have no problem with that.  
Sincerely yours,  
Ronald, List B.

It was decided that no individual intervention from myself was needed at this point, and no further concerns were expressed about my status as a group member, and the individual concerned continued to make regular contributions to the group discussions. The data in the current thesis therefore draws upon postings made to discussion list B for a 6 month membership period.

#### *4.6.3 Discussion list C*

This list was founded in September 1999 and the membership mainly comprised of parents of people with autism and Asperger's, with some additional posts from adults who identified themselves as autistic/Asperger's, and some children whose parents were also members of the list. The group describes itself as a forum for support and understanding, with no prohibited topics of discussion, although all postings needed to be suitable for viewing by children. The discussions on the lists were however largely dominated by parents of people with autism, and the list owners and the list moderator identified themselves as parents of a person with autism. Due to the personal experience of autism through the eyes of a parent, the discussion list portrayed itself as an arena for similar people to share experiences and know that 'they are

not alone'. The group charter presents a positive picture of Asperger's/autism and questions the labelling of such individuals as 'disabled'; it also highlights that an 'official' diagnosis is not required by list members, with self-identification and understanding being more important, and highlights the importance of parents and professionals listening to the views of people with autism.

The group comprised 88 members at the start of the research period and 92 at the end of the research time. As in the other discussion lists contributing to the thesis, some members of discussion list C were more vocal than others, although again the pattern of engagement with group discussions varied for individuals over a period of time. During the time of my membership to the group 27 members contributed to group discussions regularly, and within this population some individuals posted more messages than others. The total number of postings made to the group in the period August – November 2001 varied, and reflected the intensity of the group discussions at particular periods of time (August 139, September 30, October 6 and November 9).

My membership to the group was gained through contact with the list owners who individually approved all group membership. The list owners were positive about the research proposed and encouraged me to introduce myself to the list members. As with the introduction to all of the discussion lists that contribute to this thesis, I invited members to contact me personally rather than via the list if they had any queries concerning the proposed research. This prompted three posts from group members, the first post making positive comments about the proposed research and highlighting the importance of the voices of people with autism when discussing issues surrounding autism.

It has been said, more than once, that the best sources on what autism is all about are autistic people themselves who are able to communicate, one way or another.

Boris, List C.

The poster identified themselves as having Asperger's syndrome which they categorised as "...the highest-functioning form of autism...", and directed me to read an autobiography that they had published which was rich in personal perspectives on autism.

The second two posts from individual members sought clarification regarding the proposed project:

Hi Charlotte,

I thought this list was for parents and relatives. Please send me details of the project you are involved in.  
Lisa, List C.

Charlotte, [Shelly] to be a person with HFA and is not sure of what you are wanting to research. She to wonder if you could clarify in your words what it is you will be researching? Her to be curious is all. Her to post on many list and so her to wonder why you choose this list as on this list most are parents who post, some to be adults with AS like [Shelly] but most of the parents to be posting about their children. She to wonder if you to be researching children, or parents comments about such children?  
Shelly, List C.

Further information was provided to the individuals answering their specific queries, to which they gave their approval to the research, and no further personal contact was made with members of the group.

#### *4.6.4 Discussion list D*

The list was created in September 1998 and the membership mainly comprised of professionals working within the field of autism and some parents. The list owner identified themselves as a Facilitated Communication practitioner who has advocated for people with autism on the internet since 1995. The postings to the list therefore reflected a mixture of foci on a range of therapeutic interventions, and issues surrounding advocacy of and for people with autism. The list owner described the list as unmoderated for members' posts, but with the list owner closely monitoring the suitability of some posts. This led to some concerns during the period of research membership surrounding the list owner individually moderating messages sent to the group. In contrast to

the other three discussion lists contributing to the thesis, the archives are available for public viewing, although only members may post to the list.

At the start of the research membership to the group there were 350 members, and at the time of disengagement from the group there were 521 members. Discussion list D therefore comprised the largest membership pool of all of the discussion lists contributing material to the thesis. As would be expected from such a large group, some members were more vocal than others, and during my time as a member of the group 53 members posted regularly to the list, and within this population some individuals posted more messages than others. The number of posts to the list each month was quite high, again reflecting the number of members to the list (August 245, September 112, October 219 and November 114).

Despite the availability of the archives for public viewing I contacted the list owner for approval to join their group in accordance with the ethical steps outlined in section 3.4.2. The list owner approved my membership and was positive about the research highlighting in their post that "...people with autism are very bright and have a whole lot to say to those willing to listen." I then introduced myself to the group, again encouraging individual members to contact me personally with any concerns or queries about the research rather than via the list. No personal queries were received and no postings were made to the group concerning the proposed research, and I remained a silent member until my disengagement from the group in November 2001.

#### **4.7 The process of analysis**

Once the period of agreed membership had come to an end I announced my intention to leave the groups by posting an e-mail to the discussion lists. I then began my analysis by initially immersing myself in the politics of disability discussed in the disability theory literature. This enabled me to think about my position within the research process, and my agency within the analysis through my decisions to prioritise certain themes over others. I then read the work of researchers drawing on critical discourse analysis, particularly Edley and Fairclough. A basic analysis was then conducted, firstly on paper and then using Atlas ti in order to organise my ideas. The process of analysis then went forward and back between theory and analysis in order for my ideas and discussions to become more fully formed and to enable me to produce a rigorous and considered critical discourse analysis. The following three chapters present the three themes that I prioritised in my analysis: issues surrounding identity, diagnosis and the implications of living with a label of autism.

## Chapter 5: Identity

A key theme that I have prioritised in the analysis of the texts is that which reflects discussions of identity. An important theoretical influence in the thesis is that of critical psychology, as outlined in the literature review. An examination of identity from a critical perspective questions the notion that self and identity are personal properties of an individual, but rather develop in accordance with the dominant political interests of the social order (Kitzinger 1989, Atchakis and Tzanne 2005). This chapter of analysis examining identity highlights strong alternative discourses surrounding autism, and the availability of alternative discourses brings into question the traditional notion of identity being a stable and consistent entity. Such alternative discourses have led in some cases to an empowered identity which frequently contradicts and challenges 'expert' views of people with autism and their abilities, and resists the regulation of autistic identities by professionals working within the psy-complex.

Professional and academic texts dominate explanations and discussions of autism, and Waltz (2005) highlights a conspicuous absence of the voice of people with autism in such texts. Such texts frequently adopt an authoritative style and lack details of personal development and experience, and present themselves as factual accounts despite the lack of grounding in the experiences of the population that they purport to encapsulate. This chapter reflects on some of the key characteristics outlined in academic texts and positions these within discussions by people with autism, parents of people with autism and professionals working in the field of autism who contributed to the online discussion lists.

Discussions drawing on more empowering identities of people with autism are reflected in the second section of the analysis which highlights

the constructed differences between autistic and non-autistic people. Such discussions frequently highlighted the positive characteristics associated with an autistic identity and positioned these against the negative features attributed to a non-autistic identity. In doing so the dominant view of 'normal' (i.e. non-autistic) characteristics are no longer prioritised and valued by contributors to the lists.

The positioning of the two groups of autistic and non-autistic people as mutually exclusive groups is challenged by discussions of contributors to the lists by the creation of an 'AC' (autistic cousins) identity, which offered a potential identity for contributors that was somewhere in between autistic and non-autistic. An AC identity however was a controversial term on the lists and there remained inconsistency regarding the use of the term.

The final section of the analysis forming this empirical chapter focuses more broadly on an autistic identity, particularly concerning the question as to whether autism is constructed as an integral or separate part of an individual's identity. The conceptualisation of autism as a separate entity from the individual has been identified in discussions by Smukler (2005) who reported that adults frequently refer to a 'real' (i.e. non-autistic) child within an individual which can be released given sufficient professional intervention. Some resistance to this construction is presented from contributors to the discussion lists.

In presenting the analysis, this chapter seeks to address research objective 4: to examine similarities and differences between constructions of autistic and neurologically typical individuals.

## 5.1 Characteristics of autism

Until recently descriptions of autism have largely been reported with reference to Wing's (1997) 'triad of impairments', which has been influential in organising academic and professional conceptualisations of autism. The key features of the triad largely echo the earlier work of Kanner (1943) and Asperger (1944), and play an important role in shaping contemporary understandings of autism and focussing our gaze on specific characteristics. By highlighting salient characteristics that can be considered evident of autism, psy-professionals can categorise individuals and identify those as requiring a special focus of attention, and develop appropriate interventions with the goal of normalising behaviours. While the following two chapters consider issues of diagnosis and the consequences of living with a label of autism, I would like to focus attention in this section of analysis on the characteristics purported to be typical of autism, and the reflections by contributors to the online discussion lists on this. For a fuller discussion of the triad of impairments please refer to the literature review.

### 5.1.1 *Impairment in social interaction*

Characteristics typically associated with impairment in social interaction with respect to people with autism include an inappropriate use of eye contact and a failure to develop close relationships with others, particularly a failure to develop friendships.

Impairments in social interactions were highlighted in the postings of parents as a particular concern, and several reported that their child "struggles with socializing related to her AS" (Abigail, List C.) A failure to operate in a social setting was therefore frequently highlighted as a focus of intervention and an important goal for many parents was that their children should develop a friendship network. For example:

I found this extremely helpful with my son's first experience with preschool. His support teacher modelled behavior appropriate for socializing and it doesn't happen overnight but by the end of the school year Evan had made lots of friends.  
Liz, List C.

He actually has friends that he can talk to and play with...one of the kids even came up to us after camp and asked for Matt's phone number so they could get together!  
That's never happened before!  
Barry, List C.

Given the strong emphasis placed on these skills in everyday interactions and practices, these skills are considered to be something that the person with autism should strive to achieve.

A sense of the importance of social interaction and a desire for emotional closeness without having the resources to achieve this was also reflected in some postings from people with autism. For example:

For myself, I'll say that it's damn frustrating to want to have emotional contact with people, but to be unable to think of anything to say to people that would help to make this happen.  
Evan, List B.

Throughout the group discussions it therefore remained clear that an outcome of increased social interaction was valued, particularly by parents and professionals. However, this immersing of a person with autism into the social world was not necessarily a goal of all contributors who identified themselves as autistic. For example:

If you are Adult with Autism Diagnosis you have to have experience with medicine. Applied Behavior Analysis is a way to bring you completely into the social world and I do not want to go. I want to stay in my world and just visit the social world.  
Ronald, List B.

Therefore while social interaction is cited as a central issue for both people with autism and parents and professionals, there is some conflict in the implications and interpretations of this, highlighting the complexity of the issue. When considered solely within the professional discourse of academic texts, a failure to interact socially can be highlighted as a

problem that fundamentally requires professional interventions. The dominant non-autistic society that formed the background of many of the parents of people with autism also values social skills, both in a working environment that relies on social networking, and with regards to developing a basis for personal friendships. Parents of people with autism therefore frequently cite social interaction as a suitable point for professional intervention.

The discourses of some people with autism do however challenge such an assertion. While acknowledging that social interaction is a key issue for people with autism, they resist the construction that it is people with autism who necessarily have to change in order to become more social. The shift in attention for behavioural change is therefore placed on a difference in abilities to operate in a social world for autistic people and a difficulty in operating in a non-social world for non-autistic people. For example:

When I was the kid the comforting quiet around me was scary to the social ones  
Ronald, List B.

The experience of difference with social interaction is therefore considered to be a key feature that defines people with autism, but different discourses surround the understanding and implications of this.

### *5.1.2 Impairment in communication*

Communication difficulties are reported to range considerably amongst people with autism, with some people with autism never developing speech, while others do develop speech but experience problems with the pragmatics and social aspects of language, (Folstein 1999). Frith (2003) notes that in contrast to communication in face to face settings, written communication can often be highly sophisticated. This sophistication in communication through written means is reflected in the postings by people with autism on the discussion lists. The postings reflected interesting and insightful comments, frequently dealing with

complex issues and discussed in sophisticated ways without the need for a reliance on non-verbal cues to guide behaviour.

While contributors to the discussion lists did not specifically reflect on the ease of computer mediated communication compared to face to face interactions during the period of group membership, this was raised via a private email to me at the start of the research when I introduced myself to the discussion groups.

i think the major problem is that the sort of things that affect autistics in conversation just don't really show up in an email list. By the time people arrive here, they've often had some experience with email and have become as comfortable with the medium as anyone else.  
Fred, List A.

Computer mediated communication is therefore positioned as removing some of the nuances that occur in face to face interactions that people with autism find challenging.

However, while acknowledging some of the challenges faced by people with autism with respect to communication, some contributors to the lists reject the idea that autistic communication is in some way inferior or lacking. This is reflected in contributions to the discussion lists that examine the communicative interactions of neurologically typical individuals, and position such exchanges as 'illogical'. For example:

Humans, even NTs, possess the linguistic ability to express concepts, ideas, and emotions verbally with clarity, but the NT brain seems incapable of actually doing so. They rely heavily on the animalistic means of body language. It's primitive and unnecessary, I think. Further, NTs can't seem to express thoughts completely. They use an irritating form of verbal shorthand, where significant gaps are left to be filled by the listener. It's absurd!  
Archie, List A.

This quote questions some common assumptions surrounding the traits of autism and specifically impairments in communication and social interaction. Here the much researched 'impairments in social interaction' commonly associated with people with autism are positioned as being a consequence of the illogical behaviour of NTs (non-autistic people).

While there is therefore a strong focus in professional and academic literature on the inability of people with autism to communicate, there is a competing conceptualisation of people with autism communicating in a more direct manner, where no 'reading between the lines' is necessary. The predominance of a non-autistic society however ensures that face to face communication which uses non-verbal as well as verbal cues is the benchmark of communicative abilities. Communication online removes the use of non-verbal cues and has been cited by Dekker (2000) as being highly suited to the communicative styles of people with autism, due to their tendency to be direct, expect literal meanings and not need to rely on non-verbal cues to supplement words – all areas that have been highlighted as challenging for non-autistic people interacting online (see for example Suler 1997).

### *5.1.3 Impairment in imagination*

Impairment in imagination is typically characterised in academic literature by rigid and repetitive behaviours which may manifest in hand flapping, ritualised behaviour and an overly focussed interest in a particular topic or object. Such behaviours were cited by parents as evident in their children. For example:

my eldest son is 3 & 1/2yrs & has just begun assessment for asd. he had problems at birth but seemed 2 develop normally til about 2yrs. obsessive rituals began, speech probs, violence etc.  
Jennie, List D.

He had also almost completely stopped doing autistic things, like head banging, hand banging, spinning, word repeating, arm flapping, etc. He was almost a normal child for several months.  
Natalie, List D.

Such characteristics are presented by these parents as characteristics of autism and as such are clearly attributed solely to autism, with a 'normal' child not expected to engage in such behaviours.

The characteristics of autism constructed by some parents often take on a 'cause and effect' nature to consequent behaviour displayed by their offspring. That is autism has certain characteristics which consequently affect and influence the behaviour of an individual. Such characteristics are often reified through such discussions.

My AS kid seems to like to fight with his siblings all the time. I mean to extremes. Does anyone else have this problem? I do not know what to do about it. He is fine outside the home with others but his sisters or brother it is another story.. He just goes on and on. Any suggestions please?  
Hope, List C.

The implication of this mothers message is that the brother and sisters are not autistic and consequently the problem of 'inappropriate behaviour' is not attributed to them, but solely the 'problem' of the child with autism, that is the behaviour pattern is attributable to the characteristics of autism and not to any circumstances in which the child may find their interaction patterns with siblings.

However, some postings by parents serve to challenge popular conceptions of the characteristics of autism with regard to a proposed impairment in imagination. For example:

He had 2 suns and 2 moons in it, almost symbolic. Of course with autism, we assume that it is simply concrete. He has always been fascinated with drawing the sun and usually rainbows. He also has a fascination with how night is dark, and in daytime is light. The issue of his spirituality came into my mind. For him, what is important is these things in the sky that represent the passing of time day into night, etc. whether he is contemplating this is another question. what is important to him is some aspect of nature he can relate on some level. I guess he cherishes the things that we take for granted. Or perhaps he does have deep thoughts about how this phenonoma of nature occurs.  
Rhia, List D.

Here a parent is challenging the popular conception of the person with autism having very concrete thoughts, and hence a lack of imagination and creativity.

The proposition that rigid and focused behaviours should necessarily be considered problematic is also questioned on the discussion lists. Equally, repetitive behaviour is presented as evident amongst the non-

autistic population, but this is largely regarded as unproblematic. For example:

They often have the pasttime of watching TV soap operas with repetitive storylines where they perceive unbelievable storylines but still insisting on watching all the same  
Edward, List A.

While rigid and repetitive behaviours are cited by parents as evident in their autistic children's behaviour, there are resistances to the presentation of behaviour being solely concrete in children with autism, which strictly follows a rigid behavioural pattern. Further challenges to an impairment of imagination being the sole property of people with autism is also presented by focussing the attention on the repetitive behaviours of people without autism. The characterisation of the 'strange' behaviours of the NT population is discussed later in this chapter and in chapter 8, where the 'syndrome' of NT is reflected upon.

#### *5.1.4 Autism as a spectrum*

Academic literature discussing autism frequently refers to a spectrum of autism, (see for example Wing 1981). The conceptualisation of a spectrum of abilities/disorder is a pervasive one and is reflected in contributions to the discussion lists. Such postings draw upon the differences proposed between the various categories or points on the spectrum such as the differences between autism, Asperger's syndrome and high functioning autism. Differences highlighted in a range of positions on the proposed spectrum are evident in postings to all four discussion lists.

Throughout the discussions on the lists participants use a series of terms inter-changeably, notably AS, HFA (high functioning autism), autism, and Asperger's Syndrome. The group definitions for common abbreviations cites AS as meaning Asperger's Syndrome and autistic spectrum, although several references are made to a distinction between Asperger's syndrome and high functioning autism, for example:

That brings me to Andrew, the high functioning autistic (he wasn't high functioning enough to be asperger, but was higher functioning than the severe autistics).  
Tom, List D.

Distinctions are also made regarding the 'severity' of autism by conceptualising autism as being on a continuum of severity with some individuals more seriously 'affected' than others.

OUR SON, ANDREW, IS 4 1/2 YEARS OLD. HE WAS DIAGNOSED TWO MONTHS AGO BY HIS PEDIATRICIAN WITH MILD AUTISM  
Tracy, List A.

Once differences between positions on the spectrum are identified, different value is attached to various points. For example in addition to the classification differences between autism and high functioning autism, there is a view expressed which suggests that high functioning autism is 'better', and the child has 'moved along' the spectrum, and hence become more 'normal', through exposure and interaction with 'normal' children. For example:

...yes my son does benefit from the exposure from normal children. That is why he is now high functioning.  
Natalie, List D.

This section has reflected on characteristics typically associated with autism and the construction of autism as resting on a continuum ranging from 'normal' to 'severely autistic'. The construction has important implications as to how autism is viewed and is reflective of much professional and academic literature. The contributors to the discussion lists do not all accept the construction of autism as a spectrum and conceptualise two groups of people: those with and those without autism. It is to this alternative construction of autism that discussions will now turn.

## **5.2 Differences between people identified as autistic and non-autistic**

A key issue highlighted in the analysis is the distinction between people with and without autism and reflects the importance placed by members of the discussion lists on identifying with one particular group. This thread of discussions therefore does not assume a spectrum of autism as presented in the dominant psychological literature and also evident in quotes presented from the groups in the previous section of analysis. In the analysis that follows, contributors to the lists draw upon a different conceptualisation of autism, one which constructs people identified as autistic and those identified as non-autistic as two separate and mutually exclusive groups. The distinction between viewing autism as a spectrum or as two separate distinct groups reflects the divergent voices and positions adopted by individual contributors to the discussion lists. The complexity of the conceptualisation of autism as a spectrum or a group separate from people without autism is reflected in postings from individual contributors who are not necessarily consistent in their position. While examples of this conflicting position will be presented, it is not uncommon for posters to discuss autism in terms of a spectrum in one contribution to discussions, and highlight the separateness of autism as a group of people in a subsequent post.

I have identified in the data two primary ways that contributors to the lists discuss group differences. The first is a comparison between the groups of AS (people with autism) and NT (Neurologically typical, non-autistic people), and the second a creation of a different dualism of non-social (people with autism) and social (people without autism).

### *5.2.1 Constructed differences between NT and AS*

Despite the complexity in distinguishing between terminology referring to people with autism and Asperger's Syndrome (please refer to the literature review for a fuller discussion of this), there remains a strong

thread of contributions to the discussion lists that construct people with AS as a group as significantly different from people who do not have AS. This difference is constructed as real, and weight is given to the position by reference to neurology. This is reflected in the choice of terminology for people who do not have AS – Neurologically Typical (NT). Such presuppositions about neurological differences are evident throughout the discussions.

The first two quotes presented below exemplify common occurrences of the voiced differences between NT and AS group members:

The hunger is intense, and this is where the AS brain makeup can cause a lot of worry to the Aspie  
Abigail, List C.

I know they are all individuals, and that we shouldn't blame every NT for the action of every other NT... but there is a common thread that ties them together, and it is at the core of their being. It is more than cultural; it is how they are hardwired from the factory.  
Archie, List A.

As can be seen, both quotes serve to highlight the very real differences constructed between the two groups of AS and NT members, and while the quotes are from two different contributors, both appeal to neurology as the basis for a justification of the constructed differences. The quotes also exemplify that such a reliance on neurological explanations is applied to both groups, with the common presupposition being the neurological origins of the exclusiveness of each group.

Discussions specifically contrasting the two groups of NT and AS were more commonly found on Discussion list A which was dominated by people with AS and provided important insights concerning the characteristics associated with autism. However, rather than focusing on the characteristics commonly associated with autism as evident in professional psychological literature, discussions on this list focus more on the anomalies of being NT rather than the salient characteristics of AS, further strengthening the assumption that the two groups are

mutually exclusive. In focussing on NT characteristics rather than on AS characteristics the list contributors are able to challenge the dominant position that non-autistic characteristics hold the valued position in the dualism set up between NT and AS individuals, and therefore throughout these discussions, AS is predominantly constructed in a positive light, with NT being constructed in a negative light. Several examples are evident across the four lists constructing positive images of AS individuals. For example:

Notes: There does exist groups of people who do not, or cannot make deceit. Please visit [www.autism.org](http://www.autism.org) for more information.  
Edward, List A.

AS children are such treasures with their pure logic.  
Patty, List C.

More anecdotal (better than scientific in many cases) proof the autistic mind is a step up the evolutionary ladder.  
Frank, List D.

When AS is characterised, particularly by people who identify themselves as AS, it tends to be done in a 'tongue in cheek' manner:

Well I think this so called professor is VERY RUDE and SELF ABSORBED...more than the average aspie!  
Tracy, List A.

He does seem completely self-absorbed and just does not care. I am glad that most aspies are not like that at all.  
Sarah, List A.

Here the contributors demonstrate that they are familiar with the characteristics attributed to people with autism in psychological literature, particularly highlighting qualities associated with a narrow focus of interest. They do however reject the construction of such behaviours as being representative of people with autism generally. This is in line with analysis presented in section 5.1 which examines the challenges posed to characteristics of autism as framed by the triad of impairments (Wing 1997).

The differences between AS and NT groups are further highlighted in discussions referring to 'NT strangeness'. Again, these discussions tend to be more closely associated with postings to groups whose membership is dominated by people identifying themselves as AS. For example as previously quoted:

Humans, even NTs, possess the linguistic ability to express concepts, ideas, and emotions verbally with clarity, but the NT brain seems incapable of actually doing so. They rely heavily on the animalistic means of body language. It's primitive and unnecessary, I think. Further, NTs can't seem to express thoughts completely. They use an irritating form of verbal shorthand, where significant gaps are left to be filled by the listener. It's absurd!  
Archie, List A.

In addition to serving the purpose of highlighting the strange behaviour of NTs, the quote also questions some common assumptions surrounding traits of AS. Here the much researched 'impairments in social interaction' commonly associated with people with autism are positioned as being a consequence of the illogical behaviour of NTs. This is further supported in the following quote.

now that I have come to realize how bizarre and illogical the NTs really are, I have found that their comments and insults have greatly reduced effect.  
Archie, List A.

Throughout these reflections on NT lifestyle, the diagnostic labels are inverted to create a syndrome of NT. This is supported more widely when examining pages displayed by people with AS on the World Wide Web, by for example on-line NT tests to give a full diagnostic break down as to the severity of the syndrome. This inverted construction of diagnosis is an area that will be further examined and discussed in chapter 8.

The postings also pose challenges to the dominant scientific position of studying autism as an 'oddity' by highlighting the potential research material that an NT society offers. However, despite the potentially rich area of research in the curiosity of NT traits, the author below rejects the desire to become NT in light of all the negative traits identified as being associated with being NT.

In conclusion, one would find it good curiosity to study the NT society, but not to live in it. The NT lifestyle appears either totally incoherent or rather primitive, and NTs in general, remain slaves to their own genetic codes than master of them.  
Edward, List A.

In light of these often negative perceptions, opinions were commonly expressed which rejected the desire for a cure for AS that would lead to becoming NT ('normal'). It is recognised that some people with AS would like to be different, but this is largely discouraged:

I can't blame the people that are afflicted with neurotypicality, but that does not mean that I am obligated to change my views to see value in traits I dislike. I am not trying to get them to be anything they are not... my diatribes are directed toward aspies that hate their affliction and would give anything to be normal.  
Archie, List A.

As can be seen from the quote above, the writer holds a negative view of NTs and those AS people who want to be like them. This view of the undesirable qualities of a 'normal' NT life is further expressed by a desire not to change through losing some of the positive features of being AS:

Knowing one could never, and perhaps should never, wear the same "clothes" of the other species, then why should those gifted with special abilities and talents choose to abandon the chance to stand tall among the knowledgeable and the wise in exchange for the life of a number among millions?  
Edward, List A.

Here AS is constructed as a special talent, which should be celebrated. By referring to the two groups as different "species", the writer highlights the differences between AS and NT, reinforcing the assumption that AS and NT are distinct groupings. In keeping with the construction of AS in a positive light, the postings also reflect a consistent rejection of constructing AS as a disability:

I won't use the term 'disability' to describe AS... I do not feel disabled or impaired. I am not broken and I do not need to be fixed or cured. If I were to become NT, I would not be 'me' anymore, and a lot of my good qualities would disappear.  
Archie, List A.

It remains clear throughout the discussions had by the groups that labelling was a key issue and self-identification with a specific label was a

central feature in many of the interactions. This remained important whether the label under discussion was 'AS' or 'NT'. The use of the labels 'AS' and 'NT' are common across all four of the discussion lists, and provide a way for individuals to identify themselves and their group membership to the rest of the list. However, the discussions surrounding these labels can be considered quite specific depending on who is using and discussing the labels. As can be seen in the previous section of analysis, most of the quotes presented as examples are drawn from discussion list A whose primary membership is that of people who identify themselves as AS. Given the dominance of this group to the discussions, more reflections are provided on the differences between AS and NT people, particularly focusing on some of the negative qualities associated with being NT in contrast to highlighted positive aspects of being AS. The other discussion lists contributing data to the thesis have a different membership, particularly groups C and D, which mainly comprise parents of people with autism and professionals working within the field of autism respectively. Due to the membership make up in these groups, the differences between AS and NT as reflected in psychological literature may be less problematic and less political as the dominant membership core of the group align with the generally accepted more positive side of the dualism, that is NT. The taken for granted distinction therefore between NT and AS people does not need to be examined in light of the idiosyncratic behaviours associated with the core members of the group, people without autism.

Section 5.4 further develops these discussions where I will introduce postings by NT members of discussion lists who question their membership status to particular groups based on the negative construction of neurologically typical's and the dominance of discussions by people with AS.

### 5.2.2 *Constructed differences between social and non-social/autism*

In a similar way to the comparisons made between NT and AS characteristics, there are also dualisms constructed between social and non-social people, that is, people with and without autism. This is an alternative way of conceptualising differences between people with and without autism, and again, the two categories are constructed as mutually exclusive entities.

In the following example, autism is considered to be a communication disorder, and hence the differences between people with and without autism are attributed to their being social or non-social in nature.

I believe that autism is a communication disorder and I have social deficits. I do not process social information well. Most people do not perceive that I have a communication problem. Can't do and won't do are too different things. You respond differently to them. I am scared when I am not understood especially when others assume understanding.  
Ronald, List B.

The message creator in this example neatly highlights the differences between social and non-social people. It raises an important point concerning social people, that is, people without autism, assuming understanding of the communications by others.

The importance of such social factors in achieving in a social world is highlighted in the quote below:

Some aspies are downright smart, downright insightful, but there are many (most) aspies who are not and who struggle with day to day coping. I know a handful of adult aspies who are talented, competent, presentable, college trained, and adequately sociable, yet un(under)employed due to the social factor nuances  
Edward, List A.

Here, despite individuals having knowledge about a particular skill or job role, they are still disadvantaged in the workplace due to social issues arising. This highlights the central position accorded by the creator of the message that the key differences between people with and without autism are social in nature.

One area that the non-social nature of people with autism is highlighted as problematic is in a work place setting.

A lot of ACs try to use the "networking" methods used by NTs without much problems, or walking in lots of interviews. They don't seem to realise that such methods often prove futile as they don't have the social abilities as NTs. Hence, ACs\* should take employment advice with a barge load of salt...With the "New Economy" now sweeping us, the NTs had made a come-back with the "New Age" employment tactics, including making a work place extremely sociable. This gives ACs\* an extremely troubling headache.  
Edward, List A.

In both of the above examples, the social world is targeted as 'the problem', not the fact that people have AS which may be a more common assertion among NT employers and researchers. Such insights echo the position of the social model of disability where impairment is only considered to be a disability because of society's reactions to it and lack of accommodation of an individual's needs. Given the proliferation of internet technologies in recent years, an individual can work remotely outside of the workplace depending on the requirements of their occupational role. A non-social/AS person should therefore be able to function efficiently and effectively in such a working re-organisation if the social demands of the role are reduced or removed.

The differences between social and non-social people are therefore highlighted and attributed to the processing of 'social information' in various postings to the discussions. A potential problem in interaction is highlighted by the failure of social people (people without autism) to interact with non-social people (people with autism), particularly when they assume that they understand the intentions of a non-social person by 'reading between the lines', but in the event, misunderstand the intentions of the person with autism.

The perceived differences between social and non-social people are highlighted on several occasions in the discussion lists. In a similar vein

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\* AC is a controversial term with regards to whom it refers. The term is discussed in section 5.3. In this posting it is taken to be indicative of people with autism/Asperger's syndrome

to the discussions surrounding the differences between AS and NT members, it is the non-autistic social people who are typically constructed as having a 'problem' with (non)social situations.

When I was the kid the comforting quiet around me was scary to the social one

I don't try to hold onto people like the social people do  
Ronald, List B.

The people with autism are therefore positioned as being more flexible in their approach to the social world in enabling an environment through which non-autistic social people can operate.

We can trade a comfortable silence for a comfortable conversation that social people might join.  
Ronald, List B.

The constructed differences between social and non-social people are therefore highlighted with the 'problem' of sociability often being inverted by the autistic, non-social group members. This leads to a perceived lack of social skills not necessarily being identified as 'the problem'. In keeping with the argument that autistic people are more flexible in their approach to the two worlds, it is proposed that it is the social non-autistic people who need help in interpreting the world. This line of argument is reminiscent of the negotiations between NT and AS identities, with the problem firmly resting with people who do not have autism and are consequently social. For example:

My personal vision statement is: I want to create a world where people with autism can live on their own terms. As social interpreter could interpret that for social people. If the world was filled with only people with autism how could a social person cope  
Ronald, List B.

At times the social people are not open to an autistic interaction.  
Ronald, List B.

The quote below highlights the perception that the differences between the social and non-social world are real, and a person can be thought to operate in two separate worlds. While there is an acknowledgement for the social world and the path which can be taken to cross between the two, there is also a rejection to being completely emerged in the social world and hence not being autistic.

If you are Adult with Autism Diagnosis you have to have experience with medicine. Applied Behavior Analysis is a way to bring you completely into the social world and I do not want to go. I want to stay in my world and just visit the social world.  
Ronald, List B.

In addition to highlighting the differences between non-social and social people, this quote also provides important insights with regards to the need for change and the broader goals of therapeutic intervention reflecting a position of normalising people, and therefore making autistic people less autistic and more closely aligned with the more acceptable behaviours of NTs. This important theme of normalising people with autism and bringing them out of 'their world' and into a more social world of non-autism will be further discussed in chapter 7 which discusses the implications of identifying with a label of autism.

The distinctions made between AS and NT and non-social and social people parallel each other in both serving the purpose of creating and reflecting dualisms which highlight the differences between autistic and non-autistic individuals. Where the dualisms drawn upon in the exchanges on the discussion lists differ from more traditional contrasts between people with and without autism reflects the valued position accorded in the dualism. Professional literature typically values non-autistic traits, and therapeutic interventions have the goal of normalising and hence making individuals less autistic. This is in contrast to the binary set up by some contributors to the discussion lists, where it is the non-social/AS position that is frequently valued, presenting challenges to the dominant understandings of autism.

### **5.3 Challenging the boundaries between the apparent mutually exclusive categories of AS and NT: Construction of the AC group identity**

The dualisms of AS/NT and non-social/social discussed in the previous analysis present autistic and non-autistic people as mutually exclusive groups. However contributors to the discussion lists also reflect the complex issues involved when attributing a particular group membership to an individual and reflect competing and divergent voices in a multifaceted debate. The challenge presented to the binaries created takes the form of an 'AC' group identity.

The group referred to as AC (autistic cousins) is particularly complex to define. On some occasions AC is used to refer to a whole range of similar terms, encapsulating several diagnoses, including high functioning autism, Asperger's etc, while on other occasions it refers to a distinct group of people without a specific diagnosis of AS, but who have a close relationship with someone who has AS. However, despite the seemingly flexible use of terminology, there remains a strong distinction between the group who can collectively be referred to as AC, and the NTs, that is, neurologically typical people who do not have Asperger's or autism.

The group definition of AC from discussion list A interprets the category as comprising of autistics and 'cousins' who are friends of autistics. This implies that the boundaries between NT and AS are more fluid than would first appear. This is particularly evident in the following quote:

Some NTs have experience with one of us, and they suppress their innate rule enforcement protocols. We call these people Acs, and we elevate them to a higher status than the run-of-the-mill narrow-minded NT. The fact is, though, that NTs don't become Acs easily. Like I said earlier, we Ass do not go out and force our ways on others... it is not part of who we are. NTs, with the exception of Acs, do, and it takes special knowledge to make an NT into an AC.  
Archie, List A.

This interpretation of AC is in agreement with the general definition as set out by the group charter, that is, NTs can become ACs, and hence the

differences between the two categories are not as rigid as would first appear. Such a definition of ACs also creates a hierarchical structure to category membership, with NT being the least valued, and AS the most valued, with a few deserving NTs promoted to a point midway between the two. This forms an inversion of the implicit, dominant view that 'normal' and therefore NT is best.

With any luck, she will soon be eligible for promotion to AS cousin, or whatever term you would rather use to describe an "enlightened" NT :)  
Archie, List A.

However, this is by no means a generally accepted definition of AC, as is demonstrated below:

I think AC's are those with disabilities similar to Auties and AS like PDDNOS's.  
Sarah, List A.

The above quote conceptualises the category of AC as comprising of those with related diagnoses, not NTs. Such a construction of an AC group serves to maintain the very 'real' differences presented as evident between autistic and non-autistic people.

The importance of membership of categories and how they are defined is highlighted throughout discussions, particularly by those members of the list who were felt labelled as NT, but did not fit the stereotypical NT which was being constructed throughout discussions. It was quite common for the wordings of postings to construct people with NT in a negative light, with the perceived negative features of being NT highlighted, and contrasted with the positive attributes of being AS, (see for example section 5.2). Such NT members of the list felt that they were becoming victims of 'NT bashing' (words of list owner).

I feel that I live in two worlds. The "NT" but I don't especially care for that term, and the AS b/c of my son...Do you think I belong on this list? I'm NT and I'm just not sure if I'm in the right place.  
Thea, List A.

We take a lot of flack as NT's from the aspie community even though we know and accept far more then the average NT.  
Sarah, List A.

The category of AC ('Autistic Cousins') was used to refer to NT members who felt that they did not fit into the stereotypical NT bracket. Membership of the category of AC therefore addressed some of the concerns voiced by NT list members, which again highlights the hierarchical structure of labelling created by the group.

I don't consider you guys to be full NTs... you're honorary semi-aspies if you can at least understand that we aspies are not just weird idiots :) Just as we can try to learn how you guys think, you try to learn how we think, and that is a lot more than the vast majority of NTs ever will.  
Archie, List A.

And [...], if you are an empathetic person/mom to your child's AS, then you are not merely NT. You are a cousin, which is AC; am I correct in this everyone? NT's are pretty much blind/oblivious/don't care about AS, which is definitely not you. Anyone who is either related to someone AS or has good insight/empathy is, at least in my understanding, AC, or autism cousin.  
Elizabeth, List A.

However, despite these concerns, some participants in the list felt that the discussions were not aimed at 'NT bashing', but rather an expression of views in a safe environment to empathetic others. Here the main rationale was that in order to accept ourselves as AS, we need to know how we differ from NTs. For example:

This is supposed to be a pro-AS list, and part of accepting AS is to know how we differ from regular folks.  
Archie, List A.

This argument for the highlighting of group differences, often by portraying NTs in a negative light, was further strengthened by the argument that the list is aimed at people with AS and empathetic others.

I don't intend, per se, to put down NTs... primarily I am attempting to show that AS is not a curse or a terrible flaw. There are many good things about being AS, and there are a lot of things that are not good about being NT... so aspies should not be unhappy to be what they are. There is tremendous pressure to make us think that AS is horrible, and NT is the only way to be. Think of the flack you get from the AS community... we get that from the NT community, and the NT community is a lot bigger.  
Archie, List A.

And what is to worry about the possible hurt feelings of NTs? They don't care. They just simply do not care  
Elizabeth, List A.

The construction of group labels and group attributes and characteristics is therefore complex, and conceptualisations of group membership vary between individuals and often differ depending on the group to which a particular individual has been assigned/identifies with. The discussions presented in the analysis also reflect competing discourses and challenges to the dominantly prioritised traits of an individual. As previously commented, it was more common for groups whose primary membership consisted of people with autism to highlight positive features associated with AS and contrast these with negative characteristics associated with being NT. In such lists people with autism were the dominant group, in contrast to being a minority group in the wider society. Being the dominant group enabled individuals to question the valued position accorded by society more widely, and invert the dominant understanding surrounding the negative traits of autism.

Such discussions led to some NT list members questioning their position on the lists and rejecting the negative label of NT due to their more empathetic approach to autism. While many of the NT members identified more readily with the label of AC, the use of the label still firmly reflected the dominant constructions of hierarchy within the groups: NT being the least valued, AS being the most valued, with AC somewhere in between. This poses important challenges to the dominant professional view that 'normal' and hence NT traits are necessarily the goals for an individual to attain.

#### **5.4 An AS Identity**

The final section of analysis in this chapter will focus on issues of an AS identity and draw upon some of the discussions and analysis previously presented. The section will reflect issues of group membership with respect to identifying with a label of autism, and hence the development of an AS identity. The development of such an identity is however complex and questions are raised amongst the contributors to the lists concerning whether autism is considered to be a separate or integral part

of an individual's identity. The postings echo the work of Smukler (2005) who found that when adults describe an autistic child they commonly refer to a 'real' (non-autistic) child who they know is in the child and can be released given appropriate professional intervention. Such constructions of a non-autistic person within a person with autism are reflected in the postings to the discussion lists, but are also challenged by some autistic people.

#### *5.4.1 Developing an AS identity*

Adopting an autistic identity can be a complex process, particularly because part of such an identity involves the embracement of many characteristics constructed by professionals as negative in nature. An autistic identity also requires the individual to become a member of a minority and often stigmatised group. Developing and accepting an identity of AS can therefore be a gradual process, as the example posting below highlights.

I've just started considering myself AS within the last year or so. But I've known about it for some time now.  
Bethany, List B.

Sometimes for parents, accepting an AS identity can be a move from seeing the characteristics of AS as part of an individual's make-up, to seeing the individual as part of a sub-group of 'disordered' individuals. For example:

We don't feel she is too badly affected, but realise that we saw the AS traits as ["Ellaisms"], she is my 1st born, so to us, she is "normal"!  
Anna, List C.

Once parents have received a label of autism for their child, characteristics that were previously considered to be unique to their individual child now acquire a new meaning. Such characteristics are now presented as evidence for their child's new group membership, highlighting the similarities between their individual child and other people also identified as autistic. The identification with other people with autism therefore requires the adoption and identification with an autistic identity.

Such an identity is often stigmatised in wider, non-autistic society and the individual adopting such an identity will be faced with mainly negative views from other, mainly non-autistic, people. For example:

So, as you can see, I have managed to adapt well in spite of being "disabled". It was not always that way. During childhood and early adolescence, my family and teachers were not at all optimistic.  
Boris, List C.

The posting raises important questions as to the effects that the negative views that may be held by wider society have on self-identity. The individual contributor above rejects the construction of being necessarily disabled because they are autistic, and presents a picture of an individual who is managing well in society despite the pessimistic views of family and teachers. Such negative conceptualisations of the abilities of people with autism tend to be a reflection of the negative traits associated with autism in professional and academic literature, which remain pervasive in the understanding of autism.

The importance of the perceptions of wider society with regards to the abilities of people with autism is highlighted in the following quote. This quote exemplifies some of the problems which may be created by wider society when developing a positive self-identity based on AS.

[Shelly] does feel issues need to be resolved. I think the issues many to face is the negative feedback from everyone and the inability to gain self.  
Shelly, List C.

The influential position that society maintains with regards to what is valued and what is held negatively is highlighted in the post. Given the dominant position of non-autistic individuals in society, non-autistic traits are more likely to be positioned as the most valued, making the adoption of an autistic identity a minority and undervalued position.

In addition to posts reflecting the negative construction of an AS identity there are numerous examples across all four discussion lists of an AS identity being constructed in a positive manner by people with AS. The

various positive constructions of AS are often found when contrasting with Neurologically Typical. The earlier section examining the constructed differences between these two groups highlighted some examples of a positive construction of AS. This section will examine such constructions in terms of accepting an identity.

As shown in previous quotes, there are positive constructions surrounding discussions of AS and an AS identity. This is something supported by a rejection of sympathy from NTs. People with AS do not need sympathy and are not charity cases to be adopted to make the NTs feel better about themselves. For example:

i have met some GREAT people on this list, and one of my now amazingly close friends. but, unfortunatley, i have met a couple of inconsiderate, self centred pricks, that don't really care about autism.. they only care about themselves and how their CHARITY makes them look, \* awwwww, your helping he POOR, HELPLESS, autistic society,\* thats exactly how other see it, im not naming any names, but youd have to be a damned idiot not to know who you are.  
Nadine, List D.

Previous posts highlighting the positive characteristics of autism and the post above rejecting sympathetic concern from non-autistic people present an identity of autism as a positive attribute, equal to that of an NT identity.

Although previous discussions have portrayed largely positive attitudes to AS and consequently an AS identity, there are some negative references to autism, both by people with autism and parents and professionals.

I do not like my autism. I do not like not understanding others or others not understanding me. Why don't I like not understanding others or others not understanding me? I am stuck at this point. I agree that I am frustrated by not being able to do what I want. Sometimes I am frustrated by not being able to please others.  
Ronald, List B.

She don't like having AIDS like I don't like having autism  
Ronald, List B.

The two quotes above reflect the complexity of adopting an autistic identity in a society dominated by non-autistic values. While groups

dominated by people with autism generally construct autism in a positive light as shown in the previous sections of analysis, there are several competing discourses evident on the discussion lists reflecting the many divergent voices contributing to the construction of autism.

The adoption of an autistic identity can therefore be seen as a complex process where an individual balances the development of a positive self-identity that embraces autism which is constructed by wider society as a negative characteristic. A positive self-identity of autism is evident in quotes presented earlier which examined the positive attributes associated with autism in contrast to the negative attributes positioned as characteristic of the non-autistic population. Such an engagement with a negative identity in a positive manner reflects self-advocacy challenges to dominant views within a culture.

#### *5.4.2 AS as an integral part of self or a separate identity*

Linked to discussions concerning the development of an AS identity, are questions concerning whether AS is an integral part of self or should be considered a separate part of identity. When autism is constructed in a negative manner by parents, it is often done so in a way which separates the 'thing' that is autism from the self of the child. Here the individual retells the concerns of the parents:

My mother was worried that I was "becoming Autistic again".  
Tegal, List D.

Autism is hence seen in a negative manner, something which should be moderated and changed, but also as an external body which engulfs the individual from time to time. The quote implies that a person can 'become autistic', and presumably become non-autistic in a similar manner, with the latter being the preferred state.

This theme of autism being a separate part of the person arises in several discussions across the lists.

I'm concerned that people will just see the AS and not [Ella]. I'm concerned that teachers will "make allowances" for [Ella], and so not encourage her to reach her potential. I'm concerned that [Ella] might learn to use AS as an excuse for not trying, because I realise she will have to try much harder than her peers just to get by.

Anna, List C.

I still live with my Dad. My Dad doesn't understand autism, but he understands me. He is disappointed that I haven't used my intelligence to get a white collar job. He accepts me without understanding

Ronald, List B.

AS here is being constructed as separate from an individual's identity. This highlights the important effects that a diagnosis has. In the second example, the father is positioned as having a lack of understanding of autism, but in contrast, a good understanding of his offspring who has autism. Having autism is therefore not positioned as the sole defining attribute of an individual, but rather highlights that having a diagnostic label of autism is a powerful attachment to self – the individual is separating the label from self, and constructing the lack of understanding of the diagnostic label, but good understanding of person behind it.

In contrast to this construction of autism being a separate entity from the self, a more integral discourse is also evident in discussions. For example:

I LIVE AUTISM! It's not my \*hobby\* or my \*work\* or my \*mission\*, it's my LIFE. I don't get a break from it. I don't WANT a break from it.

Susan, List D.

Here autism is constructed as a central feature of an individual's identity and embraced positively in accordance with this.

Issues concerning autism being a central defining characteristic of an individual are also reflected more broadly outside of the discussion lists contributing data to the current thesis, with regards to the terminology used to refer to people with autism. Harmon (2004) for example prefers 'an autistic' or 'an autistic person' rather than 'person with autism' due to the terms more effectively reflecting the central position accorded to autism in an individual's identity. Harmon argues that referring to a

‘person with autism’ is as strange as referring to a ‘person with femaleness’.

The complexity in defining terms is also reflected in the acceptance of constructing autism as an integral part of identity, but some rejection of it becoming the sole defining entity of self and identity. For example:

I am more than my autism and other people are more than their social natures.  
Ronald, List B.

Such discussions of identity therefore reflect the competing discourses surrounding aspects of an individual’s identity and the prioritising of one part of an identity over others. Autism is a complex part of identity but operates in conjunction with other key features of an individual’s identity make-up such as ethnicity and gender. For example Gordon and Rosenblum (2001) propose that the term ‘people with disabilities’ is presented as a term for those who can be considered heterogeneous in race, sex/gender, sexual orientation and their experiences of the nature and extent of their disability. Similarly Ferri (2000) highlights the complex nature of identity formation with reference to people with learning difficulties and argues that the very experience of having learning difficulties is mediated by a range of factors such as class, age, gender and culture. The same arguments can be applied to autistic people. Identity is not therefore necessarily a stable entity but a series of interconnected features, some of which will be prioritised at one time over others.

Drawing on the work of (Braidotti, 1994) individuals can be conceptualised as having nomadic and disjuncted selves, where many facets of an individual occur simultaneously intersecting and interacting with each other. The prioritising of certain facets remains however embedded in political and power relations. This can be considered particularly pertinent to autistic people who are typically identified and defined by others.

## 5.5 Discussion

It is clear that throughout the discussions had by the groups, labelling was a central issue and self-identification with a specific label was a key feature in many of the interactions. The analysis has demonstrated competing discourses evident in the construction of autism and the values attached to autistic characteristics, with a positive construction of an autistic identity presented by several list contributors, mainly dominated by people who identify with the label of autism. In constructing a positive identity the 'other', i.e. NT group is created. This is done by inverting the implicit dominant view that 'normal' and therefore 'neurologically typical' is best. This is in contrast to the descriptions and discussions of people with autism in professional and academic literature where people with autism are defined as 'deviant', requiring specialist intervention by psy-professionals.

Outside of the autistic community non-autistic people form the dominant population, and consequently the neurologically typical is taken for granted as the normal/natural way. Such a population therefore does not require a label outside of the autistic community, as the focus of attention is placed on the deviance from the norm by people with autism. In a change in position from being a minority group to the dominant group in some of the discussion lists, members identifying themselves as autistic do not need to examine the idiosyncrasies typically associated with autism, as the dominant group of NTs traditionally do in an academic arena. The traditional thinking surrounding the boundaries of normality and abnormality are hence questioned, and often inverted in light of this, with autistic members of the groups positioning themselves as different from and often better than the 'other' group of NTs.

The construction of autistic and non-autistic people as two mutually exclusive groups is however one of many voices found on the discussion lists. The complexity in constructing autism is reflected in a competing discourse surrounding autism as a spectrum of disorders, ranging from

‘normal’ to ‘severely affected’. However it can be considered more politically challenging to conceptualise autism in terms of dualisms rather than a spectrum on which everyone rests, as by positioning autism as a distinct group an individual can align their self-identity with a clear set of values. Frequently in the discussion on the lists such values position autistic traits as positive in contrast with negatively positioned non-autistic traits. This enables a minority population to challenge the dominant position of neurologically typical which is accorded to them in professional and academic psychological literature.

The debates evident on the lists surrounding identity contribute to discussions surrounding the negotiated nature of identity formation. The contributors to the discussion lists are enabling more empowering identities to be constructed by highlighting the positive characteristics associated with autism, and rejecting the negatively constructed characteristics attributed to NTs. This is in accordance with the work of Butler (1990) who questions whether identity can be considered more of an imposed ideal rather than a description of an individual’s experience. Identity can therefore only be formed with reference to regulatory practices operating which reflect ‘cultural intelligibility’ (Butler 1990), with only certain identities being acceptable and possible in accordance with the dominant cultural rules and understandings. Online interactions enable a wider scope of identities to become available to people with autism, in addition to the ‘identity of impairment’ prioritised in professional literature, and the variants on it that are often imposed by family members. This is reflective of the work of Braidotti (1994) who conceptualises identity in terms of a ‘nomadic’ experience, where individuals shift in their understanding of self-identity as they discover the linked understandings and implications of labels such as age, gender, class etc. By adopting a shifting and flexible state of identity Braidotti proposes that an individual can therefore realise the potential for the positive renaming of features, which may in turn open up new possibilities and present challenges to the hegemonic state. A positive identity of autistic can therefore be made available.

In line with new empowering identities, the problems of communicative and social misunderstandings are removed from being the sole property of an individual, and placed within the social realm. This is very much in line with the principles of the social model of disability where impairment only becomes a disability through society's reaction to and lack of accommodation of a specific trait or ability. The 'problem' of autism is therefore removed from the individual and placed within the social realm.

There remain however important questions to be considered concerning the challenge of new empowering identities and a refocus of impairment present outside of the online community. This issue of a minority voice 'ghettoised' online will be discussed in chapter 8. However it raises issues concerning the challenges posed to the wider professional and academic community by such discussions. As previously highlighted Waltz (2005) has discussed the lack of voice given to people with autism in academic literature, with a professional third person voice being adopted to portray an authoritative factual style to descriptions and explanations of people with autism. While there are numerous examples of texts written by people with autism, these are not typically positioned as challenges to more scientific conceptualisations. The posts contributing data to this thesis consistently convey sophisticated thoughts and insights by people with autism, which raise important questions concerning the conceptualisation of people with autism as defined by the pervasive 'triad of impairments' (Wing 1997). The fluency in exchanges poses particular challenges to the constructed deficits in impairments in communication and social interaction, and highlights the important role that computer mediated communication may play for people with autism.

This chapter of analysis which prioritised discourses of identity in the discussions contributed to the lists has investigated the importance and meanings associated with particular labels. How an individual becomes labelled will be the focus of the next chapter examining issues surrounding diagnosis.

## Chapter 6: Diagnosis

Discussions of diagnosing autism were evident in postings to all four of the discussion lists contributing to the current thesis. Such discussions drew on competing discourses, highlighting the complexity of issues surrounding diagnosis. The critical approach taken in this thesis has particular strengths in examining such negotiations and competing discourses. Rapley (2004) comments with respect to learning difficulties that it is often understood as an ahistorical, clinico-medical entity that can be reliably diagnosed. This has importance when exploring the discussions on the four online lists as challenges to diagnostic tools and labelling was voiced by some members of the discussion lists, and the analysis presented seeks to explore the historical production of autism. In doing so the discussions and analysis of diagnosis remain linked to discussions of identity presented in the previous chapter, due to the important implications and influences that receiving and accepting a label of autism have for an individual's identity formation.

The first section of the analysis reflects the powerful position that psy-professionals hold with regards to diagnosing autism. Such a powerful position is also important in establishing the norms of childhood, and consequently the ability to define and identify normal and abnormal behaviour (for example Rose 1979a, Burman 1994, Richards 1996). The developmental milestones set out for children as a result of this have been influential in the discourses surrounding child development outside of the professional community. This chapter of analysis will demonstrate their pervasive nature by citing examples of parents adopting the professionally constructed normal/abnormal framework and using this to compare their children who are perceived to be abnormal against the idealised prescribed normal benchmark.

The framework of normality and abnormality can be maintained within the psy-complex due to the role played by psychometrics and the standardisation of abilities (Rose 1989a). By employing the concept of normal distribution, human variability can be presented in a visual form, enabling appropriate action to be taken by expert psychologists for any individuals falling outside of the 'normal range'. Such use of psychological resources enables psychology to maintain its position as the most appropriate authority to govern the lives of the individual (Rose 1989a). The use of diagnostic tools of assessment form a key theme in the discussion list threads, and are accompanied by a frequent mastery of professional specialist language through people with autism and parents of people with autism adopting elements of the professional discourses surrounding the use of such psychological resources.

The second section of the analysis examines challenges posed to professionals within the discussion list exchanges. Some of the contributors to these discussions construct professionals as one homogenised group, without necessarily acknowledging the different positions adopted by a range of psy-professionals in their interventions. A key element in these discussions is the prioritisation of either experiential or scientific knowledge and a questioning therefore regarding who should be considered the 'experts' with respect to autism. In a related thread of discussions is the question of self vs. official/professional diagnosis, where one discourse prioritises experiential knowledge and therefore highlights an individual's self knowledge and understanding as being key in diagnosis, while the competing discourse prioritises scientific and professional knowledge as the appropriate basis for an 'official' diagnosis of autism.

In presenting the analysis, this chapter seeks to address research objective 3: to examine the relationship between 'normality' and 'abnormality', and consider how autism as a specific 'impairment' has

been constructed within this framework, and objective 5: to examine the powerful position accorded to psy-discourse within discussions of autism.

## **6.1 The Power of the professionals**

The literature review has drawn upon discussions regarding the powerful position that psychology occupies with regards to identifying, explaining and performing interventions with individuals. The first theme prioritised from the e-mail discussions reflects such a dominant position of the psy-disciplines with respect to autism, and within this the powerful position of the professionals will be examined. Professional approaches to interventions with people with autism are very different, but some of the contributors to the discussion lists characterise all professionals as being one homogenous part of the psy-discipline. Within this construction the 'problem' to be identified is an intra-psychic problem that remains an issue of the individual. Such 'problems' once identified can be resolved through psychological intervention. The position maintained by psy-professionals in the discourses of autism therefore enable them to define and identify (ab)normal behaviours, and adopt a dominant position in parent-professional interactions. Their expertise enables the development of specialist psychological resources to aid the identification of individuals who fall outside of the 'normal' range, who can then be discussed by drawing upon specialist discourses shared by agents working within the field of autism. These ideas will be examined under the broad theme of 'The power of the professionals'.

### *6.1.1 Defining (ab)normality*

An important feature of the power of professionals is the ability and authority to define what is 'normal' and therefore what is 'abnormal' behaviour, resulting in psychology playing a key role in establishing the norms of childhood (Rose 1979a). The advent of psychometrics led to the development of scales that clearly identified 'normal development'

through identifying a series of milestones of achievement to which the progress of individual children could be compared (Rose 1989a). Burman (1994) proposes that this has been so pervasive in its influence on the everyday lives of non-professionals that such norms and milestones have become taken for granted expectations about children's development.

The powerful position of such a normalised vision of development is evident in many of the discussions by parents in their comparisons of their children with autism to 'normal' children. Parents often report suspecting their child may have AS long before an 'official' assessment has taken place. This assertion is commonly made by the parents comparing the behaviour of their child to what they expect 'normal' children to be doing at this stage. For example:

My daughter [...], is now 11 years old, and diagnosed with Asperger's Syndrome.

Since [...] is an only child, we really didn't notice some of her behavior differences until preschool. She was not a baby who liked to be hugged. She preferred to be carried around and to look at things. She would quickly lose interest in her bottle or food and was always underweight. She spoke at 9 months, didn't walk until 15 months and wasn't potty trained until almost 4! But she knew all the letters in the alphabet before she was two!  
Rosie, List C.

The comparison by parents of the behaviour of their child to what is portrayed as being 'normal' is a common theme, which highlights the strong influence of the common assumption of the 'universals' of childhood (see for example Burman 1994). Burman (1994) proposes that the adoption of developmental goals by parents has served to regulate their behaviour, particularly that of mothers. In charting the experiences of a group of new mothers Urwin (1985) discusses the role of service providers in normalising goals and achievements and the distribution of written materials to new mothers concerning developmental milestones. Such written guidelines of expected progress enable the comparison by the parent of their child to a 'normal' idealised child, as reflected in the posting above where the contributor clearly cites various milestones such as walking and potty training as being delayed in their child. Close

observation of behaviours is further strengthened in the UK by professionals requesting developmental checks on children at various stages of development in order to assess skills such as fine motor control, language development and gross motor skills. Each skill can be compared against a standardised norm, with the focus of such observations on identifying abnormalities and deviations from the norm rather than embracing individual differences. This emphasises the assertion that a child with autism is different and consequently constructed as 'other'. This construction echoes Walkerdine's (1999) discussions which propose that models of childhood from within developmental psychology privilege a particular model of normality, and children who fail to meet this standard of normality are frequently 'othered' and become the object of pathologisation.

The important distinction between normal and abnormal behaviour in broader terms is also evident in the following example:

my eldest son is 3 & 1/2yrs & has just begun assessment for asd. he had problems at birth but seemed 2 develop normally til about 2yrs. obsessive rituals began, speech probs, violence etc. he had mmr vaccine b4 this btw ... he went downhill a while, then slowly improved & in last month speech has become almost normal & only aggression when annoyed & hyperactivity remain! surely that's not autism!?  
Jennie, List D.

In the first part of the posting, the parent reports initially being confident that her son was developing 'normally' until around his second year, at which point a series of 'abnormal' behaviours are highlighted as developing. Again the parent highlights normality in the second half of the posting which refers to more recent behaviour of the child, whose speech has become 'almost normal'. Implicit in this is that children with autism are excluded from this construction of normality.

Discussions surrounding normality are also evident in parental reactions to a diagnosis of autism for their children. Their response has sometimes been described as an initial grief reaction, which could be characterised

as possibly mourning for the 'loss' of their 'normal' child (see for example Case 2000; Konrad 2005). Within the framework of what they expect from their child's developmental pattern, a strong separation of the concepts of normality and abnormality is created, with clear guidelines associated with each concept. Within the framework of normality, a child's development is a natural process of maturation and growth which will unfold given the appropriate supports and circumstances which creates a taken for granted construction of child development. The framework of abnormality is called upon if the child does not meet the taken for granted pattern of development. Once abnormal development has been identified, the parent may look for a cause for the identified deviant behaviour, which is often constructed as not natural, and therefore some salient entity is at fault for this abnormality. For example:

No one around me knew what AS was and brushed it off as if I was talking about the common cold. I felt lost, useless and drained. I kept saying to myself what did I do that made my son this way? Carefully going over my pregnancy and thereafter. Did I not pay enough attention to him? Maybe I should have held him more or nursed him longer.  
Liz, List C.

Such an identification of a child's behaviour as being abnormal invokes the need to find a salient reason for this perceived un-natural developmental pattern, and hence find the reason for the 'abnormality'. Such discourses therefore draw heavily on the constructed differences between normal, natural development, and abnormal, un-natural development. The creation of such a binary forces autism to be positioned within the abnormal/un-natural half of the dualism, rejecting the construction of autism as a difference, which was a key feature in the discourses surrounding identity by people with autism in the previous chapter.

A strong focus on normality and abnormality is therefore evident in the contributions to the discussion lists. The pervasiveness of the milestones of normal child development is evident in the adoption of such concepts by parents in their descriptions and comparisons of their autistic children.

The powerful discourse of the psy-professionals therefore creates an important binary that is drawn upon in discussions, and excludes alternative constructions of autism as a difference rather than a deviance or deficit. The important relationship between parents and professionals embedded within such constructions will be further explored in the following sub-theme.

### *6.1.2 Parent-professional 'partnerships'*

The constructions of normal and abnormal behaviours have been incorporated into taken for granted constructions of development, and this is reflected in some parental discourse. I would now like to examine in further detail the relationship between parents and professionals, specifically with regards to the diagnostic journey undertaken. Parental involvement in intervention programmes has been identified as an important contributor to successful outcomes, and the parent-professional relationship is an area widely researched (see for example Soodak and Erwin 2000). Citing the DfEE (1997; 1998) Tissot, Bovell and Thomas (2001) comment that the goal of parent-professional partnerships is one highlighted by parents, professionals and government; however, in practice the parties are often working to different agendas, with different priorities.

With respect to the current thesis, while both parties in the relationship may draw upon similar constructions regarding behavioural goals and norms, it remains clear in contributions to the discussion lists that such a 'partnership' formed between parents and professionals on the diagnostic journey is not necessarily equal as one partner has more power and influence than the other.

Such a disproportionate distribution of power is evident in several posts where parents express that their views are being dismissed by the professionals that they have come into contact with. For example:

I always knew something was amiss with [...] and fought with the School as well as her pediatricians, etc. I was dismissed as being nuts, or an over-protective mother. When we finally received [her] most recent diagnosis, I have to say I had a mixture of emotions.

Alice, List C.

Contributions to the lists where parents cite feeling misbelieved or doubted by those diagnosing their children is a common thread running through the discussions. Such parents commonly display a resistance to being positioned by the professionals as an over-protective parent, challenging professional knowledge as to 'who knows best' about their child. Parents are particularly resistant to propositions by professionals that postulate the child 'growing out' of any difficulties that they are displaying.

We always knew there was something different about [...]. He entered Catholic elementary school and breezed through Kindergarten and Grade 1, but we noted he had little friends and seemed never to be happy. In 2nd grade we received communication from his teacher that he was having problems socializing, but he did not seem to have academic problems. He saw a child Psychiatrist for a time but she told us he would outgrow it... We had been to doctors after doctors and no one had a clue... I became a very militant advocate for my son.

John, List C.

However, despite such verbal challenges, even if directed at a specific professional, the power imbalance remains concerning assigning a diagnostic label. Such imbalances have been discussed elsewhere in academic literature, and the importance of bringing the subjective voice to professional awareness highlighted (see for example Konrad 2005). If the experience and voice of parents is not acknowledged, the trust placed in the professionals is questioned which can lead to parents becoming disconnected and dissatisfied with the diagnostic relationship (Konrad 2005). The disconnection of parents from the relationship has been highlighted in research which demonstrates the control that professionals have in the relationship, assuming the position of 'expert' within the dialogue, failing to integrate parents in decision making processes (Case 2000). Reflecting on previous literature, Case (2000) proposes that the service provision for disabled children typically reflects the needs and

agendas of professionals, rather than those of disabled children and their parents.

The parent-professional partnership is an implicit theme evident in much of the following analysis, and will be drawn upon again explicitly in the general discussion at the end of this chapter, where a further examination of the nature of such a partnership and the implications of this will be addressed.

### *6.1.3 Psychological resources*

Psy-professionals draw heavily on psychometrics and standardised tests through which behaviours and abilities can be portrayed in a scientific manner by reference to the principles of normal distribution. Through this psy-professionals have developed an 'objective' assessment process in which individuals can be identified as not fitting with the 'normal' range of development. For example a professional contributor to list D reflects on a particular individual's centile placing on the WISC III:

some of his responses on the wisc III did indicate difficulty understanding appropriate behavior in social situations... and serious weakness 16%tile inferential thinking and social cognition may have difficulty comprehending concepts and determining correct behavior in social situations.  
Charlene, List D.

Such psychological resources are created and owned by professionals, and their specialist use maintains the position of professionals as best placed to monitor and evaluate the development of individuals. It is to these psychological resources that the analysis will now turn.

The diagnostic tools of the professionals are frequently reflected on in threads of the discussion lists by professionals, parents and people with autism. One common thread surrounds challenging the use of tests which are based on the ability to communicate effectively. For example the

following extracts are from discussion list D and are posted by two professionals working within the field of autism.

The school wants to evaluate him using the Stanford Binet IV. I do not know much about this instrument. Is anyone familiar with it? Have any of you had this test done on your child? Is it appropriate for an autistic child??... What I'm looking for are parents who's children have been administered this test. Is it appropriate for a child with Fragile X/Autism? A child that does not communicate very well? A child that doesn't write?

Sandra, List D.

I agree with you [Sandra], The problem with these tests is that they are based on the ability to communicate, which is the impairment in autism, which means that you are measuring someone with the one factor that you already know is the problem....thus they are not valid.

Gemma, List D.

In the above examples, the validity of the tests are questioned due to their reliance on communicative abilities – an area highlighted by professionals as being impaired in people with autism. In raising issues concerning the effectiveness of such tests, the scientific tests developed as diagnostic tools are therefore questioned. Such questioning may be more freely mooted in a computer mediated environment due to the potential anonymity that such exchanges can provide. Such exchanges are evident across all four of the discussion lists and highlight the unique role that the lists play for individuals. In the example exchange above, the two contributors are both professionals working within the field of autism who use the lists as a way of discussing diagnostic tools with others via computer mediated communication as well as/rather than face to face discussions with colleagues.

The questioning by parents of the behaviours of professionals again serves to highlight the unique position that the discussion lists adopt in the exchanges of individuals. For example:

i was just wondering if anyone can tell me why the doctor needed to know my sons head circumference(hescurrently being assessed for autism)

Jennie, List D.

The parent in the above example is using the group as an important resource for assessing the behaviour and decisions made by

professionals that they interact with in face to face settings. This highlights the important role of the groups as an arena for expressing concerns without having to directly question a professional perceived as holding a position of authority in the face to face interaction. While the parent is clearly questioning expert judgement as to the type of tests carried out in order to achieve a diagnosis, it remains unclear why this parent felt that they could not question the doctor at the time of test performance. This highlights the perceived status of scientific knowledge over experiential knowledge and the difficulties many parents have in resisting professionals.

However, despite questioning the use of existing tests with children with autism due for example to their heavy reliance on communication skills, there is still an implicit belief in developing standardised tests with which to assess children. The discussions focus on the problematic nature of many of the tests, but ultimately their use generally is still endorsed. This reflects the importance placed in professional discourse on the 'scientific' categorisation and standardisation of abilities in individuals.

In addition to professionals questioning the appropriateness of some tests for children with autism, there is also a thread of discussions that focus on parental experiences of the tools of diagnosis. Through these postings parents present a challenge to professionals by questioning their tests and resources. For example:

The school is a joke on the assessments. They don't work with him enough to get to know him, before they do the test. They take him to a strange place (to him) to do the test and is always uncooperative. I took him one place on my own to get him tested, and that was a joke. She didn't get to know him or let him get used to the new place either. Done all the test in 3 one hour visits. She told me that I need to take some parenting classes and learn how to raise my child. She also told me there was something wrong with his brain in the same breath. I got a good mad laugh out of her. But anyway the school used her testing to write one years IEP.  
Natalie, List D.

Here the main focus of questioning is on the procedure with which the assessment takes place, not necessarily the actual tests used. The

validity of the test results is therefore questioned due to their inappropriate administration but the parent is not however questioning the constructs underlying the tests. The role of professionals in the identification and management of (ab)normal behaviours through the employment of standardised tests developed within the professional scientific community therefore remains unquestioned. The importance of the individual's 'performance' on such tests is also reflected in the inclusion of the 'results' in the child's individual education plan which will form the basis of the individual's educational experiences. This again highlights the credibility accorded to professionals and their administration of psychometric tests through their important place in the writing of IEPs.

In addition to raising issues regarding the tools and the procedures adopted when carrying out the assessments, discussions also raise important questions regarding the specific terms of reference used by professionals when devising their diagnostic tools. For example:

After looking at this I have a question. It says it is an Australian scale for Aspergers Syndrome. Of course my question is why? What is so different about the Australian person with AS that the US or UK (or whomever) that has AS?

Other than being written by Tony Attwood (per Australia – and he's actually born, educated and trained in the UK) – so is that relevant???

Bella, List A.

I was just thinking the same thing...so now I wonder if the assessment scales are different in each country, and if so how? Say, amybe in Australia you have AS but in China you don't???

Emma, List A.

Both contributors used as examples above identify themselves as being autistic. Their exchanges represent an examination of professional discourse, notably questioning possible cultural differences which may be important when considering a diagnosis of AS. In doing this, the creators of the messages are questioning the professional scientific knowledge drawn upon when devising such tests, and ultimately questioning the stability of the professionally defined construct of AS. However, the next contributor addresses this questioning with a proposal to explain such

differences by comparing the professionals creating and using the tests rather than comparing people with AS, hence changing the focus of the central differences with respect to autism.

It's not the people with AS that are different, it's the doctor's.  
Terry, List A.

Here people with AS are clearly grouped as being alike regardless of geography or culture, serving to construct AS as a stable entity. The differences in diagnosis and language are therefore attributed solely to the experts using the diagnostic tools, enabling the maintenance of the conception of people with autism as a group of individuals who exist outside of the tools that professionals develop to measure and define them. To reinforce this argument, the lack of agreement in professional literature regarding the nature of autism is also highlighted, for example:

They can't even agree on what the condition is, or the terminology to use.  
Terry, List A.

Such discussions position the experts/professionals as being unable to agree coherent terminology with which to refer to people with autism, as reflected in the debate concerning the distinctions between autism and Asperger syndrome. The contributors to this discussion thread however present a coherent body of individuals by setting themselves apart from such academic debates. The language used in such academic debates will be focus of the next section of analysis.

#### *6.1.4 The use of professional/specialist language*

Part of the position of power maintained by psy-professionals is evident in a specialist discourse adopted by members of the profession, by for example referring to psychometric terminology when presenting assessments of people with autism. Such a discourse utilises terminology that is not commonly found in lay/non-scientific language. The use of such discourse maintains specialist knowledge and confirms

professionals working within the field as best suited to govern individual behaviour through the identification of 'problem' behaviour and subsequent interventions. The lack of mastery of such jargon also precludes certain groups from having an equal voice and therefore equal power within the diagnostic relationship. However, contributions to the discussion lists by people with autism and parents of people with autism demonstrate a sophisticated understanding of professional discourse and a fluency in its use. For example

The legal definition for a child to qualify for Learning disabilities placement is any child who displays a "significant discrepancy (usually one standard deviation or greater) between ability and performance, combined with an associated processing deficit...

...Typically what one sees in a child with Learning Disabilities is a high degree of what we call "SCATTER" -- meaning that her verbal reasoning skills may be very HIGH, but say, her spatial reasoning may be low. The differences between the subtests pinpoint areas of relative strength and weakness.

John, List C

Wow! a 57 point difference between verbal and non verbal IQ. That is something. My sons school district was shocked to see a 35 point difference between his verbal and non verbal IQ. Yet I am still having trouble getting them to do anything to assist him.

Hope, List C.

This fluency in jargon is an important element in the therapeutic relationship, as it places the lay person on a more equal level with the professionals, by enabling them to have access to terminology and concepts. The power differentials operating in such a setting may therefore be adjusted. However it remains at the judgement of the psy-professional to decide which tests to administer and ultimately what label to give to the individual in the diagnostic assessment.

The use of such terminology also highlights the important and pervasive influence of the standardisation of abilities through scientific quantification. The central importance placed on such standardisations of behaviour and abilities is particularly reflected in discussions surrounding intelligence and measured IQ. For example:

Our [son] is AS, ADHD and his IQ seems to bounce all over the place.  
Derrick, List C.

Well, I don't think we will ever get valid IQ scores on [our son]. He has the common Swiss Cheese profile that many AS kids have ~ better verbal than performance (I think a 30 point difference, just going by memory), and huge highs and lows in subscores ~ from 70 to 138!  
Suzanne, List C.

Parents commonly cited measured IQ as a central feature in their offspring's developmental description which reflects the importance placed on such tests by psy-professionals, albeit not as a core diagnostic tool for assessing autism. The powerful position accorded to such tests is reflected in the parental mastery of jargon associated with the discussions of IQ. Such discussions by some parents also serve to maintain the importance of the concept of IQ and the tools for measuring such ability despite a rejection of finding a 'valid' IQ score for an individual with autism.

Throughout this sub-theme concerning the power of professionals, several challenges have been presented regarding the tools of professionals and diagnostic practices. However, throughout the debates the dominant position of psy-professionals is maintained through the lack of direct challenge to the fundamental assumptions underpinning the tests. The central role that psychometrics plays in the diagnostic process reflects such a dominant position due to it being developed and maintained by some groups of professionals working within the field, notably psychologists.

While some questions are raised concerning the applicability of tests cross-culturally, positioning the professionals as the factor of variability rather than the people with autism, it remains the professionals who have the power to 'officially' diagnose autism and hence make available a whole series of services to individuals and families.

The dominance of professional discourse and its pervasive nature outside of the academic arena is further highlighted in the adoption of the

milestones of development by parents and their consequent focus and comparisons of normal and abnormal behaviour. Such milestones have become taken for granted expectations about children's development and have important implications concerning the role of parents and families in fostering the development of the 'normal' child (see for example Burman 1994).

The current section of analysis has therefore highlighted the powerful position given to psy-professionals working within the field of autism. The next section of analysis will present some challenges to the power of professionals with regards to the diagnosis of autism.

## **6.2 Challenges to professionals**

The second theme that I have prioritised within the main area of diagnosis is that of challenges posed to professionals. Due to the dominant position that psy-professionals adopt in the diagnosis of autism, presenting challenges to such individuals can be difficult to voice and may be ultimately reduced to a marginal position in discourse. However, important challenges are posed to psy-professionals through threads of the discussion lists. Such challenges are presented in a number of ways, and I have grouped and labelled these as experiential vs. scientific knowledge, and discussions of self-diagnosis and the contrasting need for an 'official' diagnosis, although the two sub-themes remain intrinsically related.

### *6.2.1 Experiential vs. scientific knowledge*

A key theme in posing challenges to professionals is the questioning as to who are the experts with regards to autism, and consequently a contrast between experiential knowledge held by people with autism and scientific knowledge held by professionals. In questioning the position, and sometimes the usefulness of scientific knowledge and research, a

clear distinction is made between NTs who are officially recognised by academia as being experts in autism and people who have autism, who should be considered the 'official experts'. Members of the discussion lists, particularly people who identified themselves as autistic and parents of people with autism, commonly prioritised their own (and others') first hand knowledge over the scientific knowledge held by academics.

For example, many of the discussion list members are based in Australia, and are consequently familiar with the work of Tony Attwood. While this particular individual is given credit for his knowledge of autism, there is still a strong challenge to him being more of an expert than people who have autism, thereby prioritising experiential knowledge over scientific knowledge.

Now, this whole thing about Tony Attwood being THE expert is I agree total tripe. I've heard the man speak here in [place name], and yes he's very entertaining, and knows a lot, but hey, he's only one man who knows about AS. I'm sure glad we have him here in Australia, but everywhere else has an "expert" on AS as well. Namely, anyone who lives with it every single day of their life. Tony is an NT person who knows a lot about AS and I respect him for that, but he's no Saint!  
Barry, List A.

This theme is further highlighted in the following quote in which a member attends an academic conference (presumably run by recognised experts in the academy). Here, the conference speakers were constructed as being unhelpful in their presentations of autism and unwilling to have their positions challenged by inviting discussion from floor members.

I have attended a conference for AS adults. It was held at [place name] UK last year. It was about as much use as a chocolate fire guard. We were told that to fit in we had to become more like normal people. Quite how we were supposed to do this remained unsaid.

There were some interesting talks by people with AS, but the experts would not answer questions, no time apparently.

The AS people there were treated like children too, the attitude was "we know what's best for you."  
Robert, List A.

From these discussions, a clear theme begins to emerge surrounding who should have the status as expert in their knowledge about AS. The consensus from the quotes used as examples above, and generally from groups A and B whose membership was dominated by people who identified themselves as autistic, was that the people who have the most knowledge about AS and, hence, who should be considered the experts, are people with AS themselves. This demonstration of the conflicting position which is constructed between experiential and scientific knowledge is a thread running through many discussions on the online lists.

A challenge to scientific knowledge was also evident in exchanges that employed the use of satire when discussing academic research at a respected British University. For example:

A team at [place name] University claims it has found that children with the disorder tend to have unusually long ring fingers, compared with their index fingers. It seems this research will be extremely valuable in fulfilling the dissertation requirements required to give these morons their PhDs.  
Bella, List A.

Oh brother! Now I've heard everything. BTW, my son's fingers are perfectly normal so I guess, according to these Einsteins, he doesn't have autism after all, eh?  
Emma, List A.

LOL He's cured!  
Bella, List A.

The claim that children with autism tend to have long ring fingers compared with index fingers is dealt with directly and satirically, serving to challenge the position of the expert in autism.

The suggestion that the contributor's son no longer has autism by definition of the new expert research again highlights the conflict between experiential and scientific knowledge. Such satire makes light of the science being drawn upon in the research and in the present situation serves to disempower the scientific theory. The scientific theories

surrounding the new research are therefore implied to show a lack of understanding as to the 'true' nature of autism.

The importance of experiential knowledge was also evident in exchanges which prioritised the direct and personal experience of people with autism over the 'scientific evidence' for the effectiveness of professional tools and interventions. For example:

How is it feel if someone "train" you like - sorry - a dog, like in ABA does is it hurt ? is it noisy ? is it make you upset ?  
Michael, List D.

The importance of the direct experiences of people with autism in a variety of therapeutic interventions will be explored in the next chapter, where again the prioritising of experiential knowledge over scientific reports of effectiveness is evident in some discussion threads from the groups. This however runs along side professional debates regarding the effectiveness of various interventions and the evidence base for such assertions, clearly drawing on and prioritising scientific knowledge.

The theme of experiential vs. scientific knowledge was an important element running through several threads on the discussion lists mainly dominated by people with autism. Such a prioritising of experiential knowledge serves to challenge the position that scientific knowledge holds with regard to autism. By questioning scientific discourse, the position adopted by psy-professionals can be challenged, and repositioned as less knowledgeable about autism than people who have vast experiential knowledge. This challenge may however remain a marginalised voice in the academic debates surrounding autism, as the experiences of people with autism remain conspicuously absent from academic literature (Waltz 2005). In contrast however, certain debates such as the debate concerning the links between the MMR vaccination and autism make parental voices highly visible in the media, and in doing so experiential knowledge is emphasised. However, the voices of

individuals with autism largely remain silent in such reports, with autism largely constructed in a negative manner (O'Dell and Brownlow 2006).

In a theme linked to issues raised regarding experiential and scientific knowledge the following discussions will turn to issues of self vs. official diagnosis which draws heavily on the prioritisation of one type of knowledge over another.

### *6.2.2 Self-diagnosis vs. an 'official' diagnosis*

A second challenge to professional scientific knowledge and the consequent construction of expert status are discussions surrounding self-diagnosis and the need for an officially recognised diagnosis provided by a psy-professional. Here, the focus was on how individuals know themselves best and, therefore, are able to self-diagnose. Individuals contributing to such discussions positioned themselves as being as much of an expert as the professionals traditionally recognised by academia as being so, and therefore are able to self-identify with a label of autism without the need for an 'official' diagnosis. For example:

I have Asperger's Syndrome, the highest-functioning form of autism, and only found out in the spring of 1995, as a result of reading an article in "The New Yorker" by Oliver Sacks.  
Boris, List C.

The process of self-diagnosis is commonly reported to emerge through experiences with people with autism and parents of people with autism and can be a gradual process. For example:

I am 48 and self-dxed ... I got a grassroots confirmation of my self-diagnosis by being around parents of autistic children  
Ronald, List B.

Such a process of self-diagnosis draws heavily on and prioritises the experiential knowledge of people with autism and their families rather than the scientific knowledge of the professionals working within the field. Self-diagnosis can therefore be seen as a challenge to the status and

knowledge of professionals in diagnosing autism. However, despite this challenge, there is still recognition of the power of a person able to give an 'official' diagnosis, and hence a recognition of the importance of an 'official' diagnosis. This is reflected in the postings by some individuals who have self-diagnosed, but who are currently seeking an 'official' diagnosis. For example:

I had confirmed that I fit into the spectrum after a dx.

This means I can remove "self-dx" from my description. Maybe it calls for a quick celebration, but I don't count on it. Ever heard of AC parties, anyone?  
Edward, List A.

I know that you know yourself well enough to self-dx but it always seems to be a great relief when it becomes official.  
Sarah, List A.

Throughout the discussions there were unresolved issues as to who truly "knows best" about AS. The people positioned by academia traditionally as experts were not always recognised as such by contributors to the discussion lists. However, although discussions frequently circled around the argument as to who displays the most important knowledge about people with AS, it remained clear that obtaining and accepting a diagnosis was important to individuals. Similarly as with many self-diagnosed people with autism who strive to acquire an 'official' diagnosis, so too do parents for their children. This again demonstrates the power and importance that an 'official' diagnosis holds for individuals. This importance may be in the provision of a framework with which to better understand themselves and others, and also because of the access to resources which become available once a label and diagnosis has been gained and accepted. For example:

we did not have an Asperger's diagnosis at the time, so none of us really knew how to handle some of her problems.  
Rosie, List C.

Parents therefore may use the diagnosis as a means of better understanding their children, and as a resource for receiving guidance as to the most appropriate interventions with their children. However Hodge

(2005) proposes that receiving a diagnosis of autism can have a negative effect on family interactions through the disempowerment of parents by causing them to question their own parenting skills and perceive the need for interactions to be based on professional interventions with specialist training. Hodge proposes that the label itself may become more significant than the individual child, particularly in the label-led climate of the UK and US where parents and people with autism need to first be given the label of autism before gaining access to resources and advice from professionals. Reflecting on the position of parents within such a diagnostic journey Hodge comments that the individuals given the label rarely have their voice heard within the diagnostic process, and the voices of parents are frequently marginalised. This reflects a notable power imbalance within the parent-professional partnership ideal. The lack of visibility, particularly of the people given the label is a concern for professional practice due to the acceptance of a diagnosis of autism having important implications for an individual's identity as discussed in chapter 5, and requires the adoption of a minority and often stigmatised identity.

Such an adoption of a label and consequent influence on identity construction is however accompanied by the important contribution that an official diagnostic label may have in acting as a tool through which to gain a better understanding of self. For example:

I gave up long ago at finding the "truth" in anyone else's eyes but my own. AS and ADD have been useful in gaining a better understanding of myself.  
Terry, List A.

The scepticism with which the contributor approaches the ultimate truth with respect to diagnostic categories provides a direct challenge to the fundamental principles of the scientific basis for diagnosis. Science, and the diagnostic process developed from its principles, assumes that there is a single truth that can be demonstrated objectively and hence diagnosed. While truths can be considered multiple, within the psy-

complex one version, i.e. one truth, is more likely to be prioritised and consequently remain dominant in diagnostic exchanges.

The complexity concerning the need for an official diagnosis is reflected in the competing discourses surrounding such discussions. There are many threads on the lists questioning whether an 'official' diagnosis is necessary for an individual, as the example below highlights. This example also demonstrates how members use discussion lists to empower themselves and acquire knowledge through creating networks with others, as discussed earlier with respect to the power of professional discourse.

I am a 31 year old self diagnosed Aspie. I was wondering if it was really necessary to go back and get a professional diagnosis. Whata is every one else's experiences in this matter.  
Gemma, List D.

There is also a questioning as to the purpose of an official diagnosis once it has been obtained with respect to what will change as a result of the label being made 'official'. This is shown in the following quote from a parent of a person with autism.

whilst I accept(happily?!!) the diagnosis,I wonder if there will be any benefits to [Ella] in making it "official"  
Anna, List C.

This questioning is sometimes accompanied by a rejection of an 'official' diagnosis, in favour of a self-diagnosis. In these discussions, self-diagnosis can therefore pose a challenge to professional constructions of AS, by rejecting the dominance of scientific knowledge.

I am not currently seeking a doctor diagnosis  
Ronald, List B.

An 'official' diagnosis is therefore not always constructed as something which individuals should necessarily aim to achieve.

The challenges posed to professionals that I have identified in discussions on the online lists reflect the competing discourses surrounding who should be accorded expert status with regards to issues about autism. Such complex discussions frequently separate experiential and scientific knowledge and prioritise one over the other depending on the individual accorded with the expert status. The importance of the different types of knowledge are further developed in discussions surrounding the self-diagnosis of individuals versus the need for an official diagnosis from professionals working within the psy-complex. While challenges are posed by individuals and groups on the lists, the power of the professionals remains evident and secure as reflected in the ultimate ability to decide on the diagnostic tests to administer and the diagnostic label assigned to an individual. Such labels and tests may go on to occupy a central position in an individual's experiences due to the important influences that such a label will have on identity formation, and the services and provisions available for an individual and their family if a diagnostic label is accepted.

### **6.3 Discussion**

The prioritisation of issues concerning diagnosis as a main theme in the research reflects the importance placed on diagnosis by people with autism, parents of people with autism and professionals working within the field of autism in their contributions to the four discussion lists. The powerful position adopted and maintained by psy-professionals is reflected in a series of areas including the definitions and identification of normal and abnormal behaviours. The discourse of psy-professionals creates an important binary which clearly identifies normal and abnormal behaviour, and is drawn upon in discussions presented on the online lists. In presenting a framework for understanding behaviour, autistic and non-autistic traits are clearly identified with each half of the dualism. The identification of autism with abnormal behaviour that deviates from prescribed norms, excludes alternative constructions of autism as a

difference rather than a deficit. Such an identification of normal and abnormal behaviour is based on a NT world view and reflects the powerful position that the NT ideal holds. AS is not in an equal position to NT, and therefore is not constructed as a difference in the diagnostic process, but rather a behavioural pattern that deviates from the taken for granted natural course of normal child development. This is in contrast to discussions presented in the previous chapter in which people with autism construct autism as a difference which is equal to, and in some cases considered preferable to, the NT majority. However the prevailing discourse of professional psychology is dominated by an NT benchmark, and consequently people with autism can be identified and singled out for special attention and intervention from psy-professionals.

The diagnostic tools developed, owned and administered by professionals working within the psy-complex further serve to maintain the exclusive position of psy-professionals as best placed to manage individuals. The control over such tools excludes the full embracement of parents and people with autism as equal partners in the diagnostic relationship. The mastery of specialist language used in professional discourse by parents of people with autism and people identifying themselves as autistic may give an impression of a re-evaluation of the power imbalance within the diagnostic and therapeutic relationship due to both parties drawing on the same discourse pool, and non-professionals having access to professional constructs. However it remains at the judgement of psy-professionals to decide which tests to administer, and ultimately what label to give to the individual in the diagnostic assessment.

Such power imbalance brings into question the position of stakeholders in the parent-professional partnership, and the partnership between people with autism and professionals. Goodley (2005) has highlighted an important barrier to a meaningful co-operative relationship between practitioners and people with learning difficulties being the creation of the

partnership agenda being set by professionals rather than their clients. Similarly, Ward and Meyer (1999) comment on the resistance by professionals to relinquish their power to self-advocates and parents of people with autism. Such resistance has the potential to marginalise individual advocates' voices in the wider pool of academic literature. Indeed Todd (2006) comments on the lack of evidence pointing to any real and extensive involvement of children or parents in service provision and delivery. This lack of active involvement is proposed by Todd to open up the possibility of identities being fashioned for individuals through professional practices, which may not necessarily be identities that such labelled individuals would construct for themselves.

The powerful position maintained by professionals is also reflected in the reluctance of some parents to question professionals in person regarding their choice of assessment tools or manner of administration, preferring instead to voice concerns and ask for advice from other people contributing to the discussion lists. Such an appeal to the experiential knowledge of individuals on the lists can form the basis for a challenge to professional scientific knowledge by choosing to prioritise experiential knowledge over scientific knowledge. By questioning scientific discourse, the position adopted by psy-professionals can be challenged and repositioned as less knowledgeable about autism than people with autism who have vast experiential knowledge (Brownlow and O'Dell 2006). This challenge may however remain a marginalised voice within professional literature due to the absence of reported experiences of people with autism from much academic literature (Waltz 2005).

Further challenges to professionals were evident in the discussions by contributors to the online lists with respect to the need to obtain an official professional diagnosis, or the rejection of this in favour of a self-diagnosis. The two diagnostic pathways clearly prioritise one type of knowledge over the other and have strong implications concerning who should be considered the 'expert' with regards to autism: people who

have direct experience of autism, or professionals who claim scientific knowledge through the use of objective tools of assessment. However, despite this challenge the power of the professionals is maintained in the label-led service provision of UK and US societies. An individual can choose to self-diagnose but if they subsequently want to gain access to services they have to first obtain and accept a recognised label given to them by a psy-professional. Accepting a label of autism has clear implications for the construction of an individual's identity where they are required to accept a label that signifies an often stigmatised identity in a wider society dominated by NT ideals. The two issues of diagnosis discussed here and identity formation as explored in the previous chapter are therefore intrinsically linked.

The meaning of a diagnosis of autism and the consequent identification label attached to an individual can have different implications for different people. Access to services can only be maintained through entering into a diagnostic relationship with a professionally recognised individual who ultimately holds the balance of power in the diagnostic relationship through being the person with the ability to administer diagnostic tests and consequently assign a diagnostic label to an individual. Both parents and people with autism cite in their contributions to the discussion lists that having a label of autism may provide a framework through which to better understand themselves or others. For parents of people with autism a label may increase their understanding of their children, but will also provide greater access to services and advice from professionals. Parents expressing concern that their views have been dismissed by professionals as over-protective when they raised the possibility of something not being 'quite right' with their children, may embrace a diagnostic label as a way to prove to others that they were right to have concerns about their child and their child's behaviour (Hodge 2005). However, Hodge cautions of the power inherent in a label which may result in the parents seeing the label as more significant than the individual child. With a label parents may begin to rethink their child's

potential and become fearful of the future due to the constructed implications implicit in the diagnosis.

This chapter of analysis which presented discourses of diagnosis in the discussions contributed to the lists has investigated the importance of diagnostic labels and the power imbalances inherent in the diagnostic relationship. The acceptance of a label of autism, and the negotiated consequences of living with such a label will be explored in the next chapter.

## Chapter 7: Negotiating a Label of Autism

A key theme that I have prioritised in the analysis of the texts is that which I have termed negotiating a label of autism. While the theme draws on important discussions of therapeutic intervention following diagnostic classification, its elements stretch wider than the intervention proposed by psy-professionals, and include an examination of the construction of the autistic individual within the therapeutic relationship and the goals of therapeutic interventions, in addition to a rejection of change and the negotiation of a place for a person with autism in an NT dominated society. The theme therefore reflects the negotiation of a label of autism throughout an individual's life-span, engaging in a continual renegotiation exploring what autism means both to self and others. Drawing on Rapley (2004, 1998), the often taken-for-granted understanding of an individual comprising of fixed entities in an unchanging social world will be questioned and the active negotiation of identity as an autistic person will be discussed.

An important element in such a negotiation is the key role played by therapeutic interventions and the central role of psy-professionals within such interventions. Numerous interventions have been proposed to be effective when working with people with autism and the goals underpinning interventions will be examined. Applied Behavioural Analysis has been cited as the most 'scientifically proven' treatment for autism (Baker 2006), and discussions on the online lists reflect its dominance within therapeutic discourse. Such an approach requires full-time intensive treatment with the explicit goal of intervention being to teach the individual with autism to act as if they were neurologically typical, that is non-autistic. Safran, Safran and Ellis (2003) noted that students undertaking behavioural therapy must be specifically taught to be able to discriminate between socially acceptable and socially unacceptable behaviours, learning appropriate alternatives to

unacceptable behaviour. Here the clear implication is that people with autism must change in order to accommodate the non-autistic world. The presupposition of therapeutic interventions is therefore that the individual with autism is required to change rather than engage in a more accommodating interactional environment.

Such presuppositions lead to the dominant construction of the autistic individual within therapeutic discourse as having a *deficit* rather than a *difference*, and the goal of therapeutic interventions is therefore to seek to change and normalise individual behaviour. The therapeutic relationship can be examined in light of this construction, particularly the powerful position accorded to professionals as best placed to identify and consequently manage autistic behaviour. Such a powerful position adopted by professionals is reflected in the marginalisation of the voices of people with autism within this debate.

The dominant position maintained by professional discourse regarding interventions is linked to previous discussions in chapter 6 concerning the identification of normal and consequently abnormal behaviour and the pervasive nature of such classifications as reflected in the assumptions of the universal pathways of normal development for children. It is through this identification of normal and abnormal behaviour that explanations for behaviour identified as deviating from the taken for granted construction of normal behaviour are deemed necessary. The propositions of explanations for autism in the discussion lists contributing data to this thesis reflect this assertion, and the postings cited as examples concern the prevalent media debate concerning the links between autism and vaccinations.

The final section of analysis draws upon an alternative construction of autism and presents autism as a *difference* rather than a *deficit* or *deviance*. This final section concerns the management of lifestyles for adults with autism, particularly reflecting their position within an NT

socially dominated workplace, and the value attributed to individual skills in light of this.

In presenting the analysis, this chapter primarily seeks to address research objective 5: to examine the powerful position accorded to psy-discourse within autism research.

## **7.1 Therapeutic intervention**

Parents and professionals dominate discussions surrounding therapeutic intervention, with the goal of 'normalising' people with autism through therapeutic intervention. One of the fundamental principles common to therapeutic approaches is the concern for the need to change undesirable behaviour and replace this with more desirable/acceptable behaviour. The clear implication of such interventions is that people with autism must change in order to accommodate the non-autistic world. The competing discourses of deficit and difference will be reflected in the following discussions surrounding therapeutic intervention, where two conflicting constructions of autism are drawn upon in the discussions of intervention and change.

### *7.1.1 'Normalisation' through therapy*

A strong theme in discussions surrounding the use of therapy with people with autism is the goal of 'normalising' people with autism through therapeutic intervention. This is related to issues discussed in chapter 6 when examining the broad theme of diagnosis and the conceptualisation of 'normality' and 'abnormality', with non-autistic/NT traits clearly aligned to the normality half of the dualism, rendering 'autistic traits' within the domain of abnormality. Echoed again in discussions of therapeutic intervention is a strong separation of the concepts of normality and abnormality, with clear expectations of behaviours associated with each concept. Once a person has been identified as 'not normal' and hence

straying from the path of 'natural/normal' development, therapy can be utilised to seek the 'fault' and change an individual's behaviour in order to make them more 'normal'. The goal of therapy is therefore often to change a person's behaviour by making them resemble the more acceptable behaviours of NTs.

The importance placed on NT traits and their value in wider society is reflected in postings to the discussion lists. For example:

I will not discredit any therapy because while it may not be good for one child, it may be doing a wizz-bang job for another, giving that child a chance at a maybe normal life. Isn't that the whole reason why people became professionals in the first place? To help people with Autism and their families?  
Tegal, List D.

The goal of changing the behaviour of people with autism in order to more closely reflect the dominant construction of normality, mirroring non-autistic traits is therefore an often explicit assumption within the therapeutic process. The quote used as an example above also reflects a predominant discourse surrounding the nature of help provided within the therapeutic relationship. The professionally dominated discourse of therapeutic intervention clearly positions help as a means of making an individual more 'normal' and therefore implicitly 'less autistic'. Intervention is therefore not concerned with celebrating individual neurological differences and helping to negotiate a means with which people with autism can embrace difference, yet still maintain a positive identity and position within society.

The importance and potential achievement of the goal of making an individual's behaviour more normal is highlighted in postings citing examples of people with autism 'recovering', as for example in the reference to the famous individual below:

Raun K Kaufman is a 26 year old diagnosed as severely autistic when he was 2. He now bears no traces of the affliction thanks to the Son-Rise Program.  
Kim, List D.

The use of terminology of the above contributor is interesting, particularly the term 'affliction'. This highlights the construction of autism as a negative trait, and consequently something that has to be changed in some way, to become more 'normal'. The 'success' of the process of change for the particular individual cited in the posting is clearly attributed to the type of intervention undertaken rather than the individual's ability to manage and negotiate difference. This serves as a clear example of the position accorded to specialists as most appropriately placed to identify and manage the behaviour of people with autism.

In addition to discussions concerning broad behaviours aligned with normality and abnormality, postings also reflect specific individual behaviours. Such postings often reflect behaviours identified as 'autistic' by the triad of impairments (Wing 1997). For example:

I have a question I am posting for a friend with a 3 ½ year old son diagnosed Autism (hyperlexic). This little guy is fixated on light switches. The first thing he does when he enters any room is look for the light switch and then repeatedly turns the lights off and on. This is something he does wherever he his private homes or public areas.

Does anyone have any advice on how to deal with this?  
Janet, List D.

The focus is therefore on the behaviours that have been deemed inappropriate and undesirable by the parents and professionals, and interventions with the individual will largely focus on change, and the elimination or reduction of the identified inappropriate behaviour.

However, one posting replying to the above request had a different focus:

IS IT THE SWITCH ITSELF OR WATCHING THE LIGHT GO ON AND OFF. IF IT IS THE SWITCH, THEN MAYBE THE PARENT CAN ATTACH A SWITCH TO A PIECE OF WOOD, DECORATED WITH THE CHILD HELPING AND HE CAN TAKE WHEREVER HE GOES.  
Charlie, List D.

In the above posting, the message creator suggests that the parent may try alternative switches, thereby enabling the child to maintain their

behavioural interest, but channel such interest into more acceptable avenues. The poster is therefore concerned that intervention should help the person with autism and the family live with the behavioural difference, and the focus is not necessarily on a complete change of behaviour. The emphasis of this suggested intervention is therefore on enabling an individual and their family to live with a difference rather than trying to completely change an individual's behaviour. Such a voice however largely remains marginal within the professionally dominated discourse of therapeutic intervention.

The discussions above reflect the broad aims of therapeutic intervention as presented in the literature review. The dominant focus in such a discourse is on help by therapeutic intervention providing a channel through which to change the autistic traits and behaviours of an individual in order to make individual behaviours more closely reflect the dominantly approved construction of normality which is more closely aligned to non-autistic/NT traits. The negative perception of autistic traits reflects the dominant construction within professional discourse of autism as a deficit or deviance rather than a difference. Reflecting this is the position accorded to professionals to clearly identify individuals who deviate from the prescribed norm and intervene where it is deemed necessary and appropriate. The voice of individuals with autism largely remains silent in such debates on the discussion lists. This voice often reflects an alternative construction of autism and will be examined in the next section.

### 7.1.2 *Rejection of change*

A rejection of change as prescribed by dominant therapeutic interventions is the next sub-theme that I have identified as being important within the contributions to the online discussion groups. Such discourse draws on an alternative construction of autism and autistic traits to that prioritised in the previous section. The dominant construction among these contributors was that of autism as a *difference* rather than a *deficit*.

In line with this alternative construction of difference, the goals to make people with autism more 'normal' through therapy are countered by a rejection of the desire to change and become less autistic. For example:

There is no pill to make you more social and I am not sure that I would take one if there were...

...This medicine is mostly for behavior control. The Applied Behavior Analysis is mostly for behavior control. I don't want to pretend to be normal. I want to be me Ronald, List B.

The contributor draws on the social/non-social dualism as discussed in chapter 5. In rejecting the desire to become more social they are rejecting the construction of autism as necessarily being a deficit/deviance which needs to be changed. Rather, autism is positioned as a difference, constructed as part of an individual, where any changes would be a reflection of an individual masking their own sense of self.

Such discussions are intrinsically linked to notion of a 'cure' for autism. Discussion of cure is a thread that recurs through discussions on several of the lists, with a rejection of a cure dominated by lists A and B whose contributors primarily consisted of people with autism. For example:

If we agree that even if an instant "cure" existed, we would not want it, right? Archie, List A.

The rejection of a cure is often positioned alongside a rejection of being NT, and therefore a rejection of embracing NT traits at the loss of AS

ones. This is related to discussions presented in chapter 5 surrounding the constructed differences between the two groups of AS and NT, where the implicit value placed on the halves of the binary challenge the professionally dominant ones, and autistic traits are positioned as valued rather than non-autistic/NT traits. In professional therapeutic discourse NT is typically constructed as representing 'normality' and in a challenge to this, some contributors to the discussion lists present a negative construction of NTs as part of their rejection of change through therapeutic intervention. For example:

Given my views on neurotypical syndrome, you can see why I am unwilling to make any effort to appear NT.  
Archie, List A.

A rejection of becoming NT is further highlighted by a dislike of people with autism who voice negative assertions about their AS, and in doing so express an implicit desire to be more NT. For example:

I have talked to so many fellow aspies that HATE their condition, HATE who they are, and would give everything they had to be normal. That's an unrealistic, and tragic, expectation. It's those people I am the most interested in. I aim to show tht being NT isn't necessarily so great, and that there are things to be happy about.  
Archie, List A.

Within the AS community online there is therefore a powerful discourse privileged where an individual embraces their autism and therefore their differences and rejects the less valued non-autistic traits. In such a discourse, change is positioned as not desirable and not necessarily an achievable goal.

The rejection of the normalisation goal of therapeutic intervention is given weight by the construction presented of autism as a neurological difference and not a neurological deficit. By constructing autism as a difference, the need for a 'fix' is removed. This construction of autism may also explain the lack of voice of people with autism in discussions regarding appropriate therapeutic interventions on the discussion lists.

The resistance to constructing autism as a deficit removes the need for a change and consequently a therapy through which to facilitate this change. However, the lack of voice must also be discussed in light of the possible power differentials in the therapeutic relationship, which will be examined later in this chapter.

In constructing an alternative positive autistic identity, some of the discussion list contributors are rejecting the valued NT identity, and in doing so are not only showing that they are aware of the meanings attached to an autistic identity by some psy-professionals, but are resisting such a construction (cf. Rapley 2004). However, the adoption of an alternative positive autistic identity still presents important negotiations for an individual, by for example their participation in the workplace, an area that will be discussed later in this chapter.

### *7.1.3 The AS world*

A theme related to the goal of 'normalising' people with autism through therapeutic intervention and a rejection of such change are discussions of an 'AS world'. One proposed goal of therapy is to bring people with autism out of their AS 'other' world, into the 'normal' world. Achievement of this would constitute a positive result for therapists and parents working within a normalising therapeutic intervention model. Such a focus on a subtle yet complex aspect of the differences between people with and without autism reflects the complex nature of autism and presents challenges for therapeutic interventions when trying to manipulate such an intricate and sensitive area.

A common discussion thread reflected a rejection by people with autism to fully immerse themselves into the NT/social world. However contributors were largely positive about the possibility of employing a social interpreter to negotiate between the two 'worlds'. A social interpreter could facilitate interaction with others, but the onus of change

is not placed solely on the individual with autism as in a traditional therapeutic environment. A social interpreter would act as a mediator to the social world, hence not requiring the person with autism to adapt/change completely and fully immerse him or herself in the social world. Intervention as a means of making individuals more normal and less autistic is therefore rejected, and help here is to enable individuals to live with/negotiate a difference. The role of such an interpreter is quite clearly defined. For example:

My vision of a social interpreter is someone who will allow me to communicate with other adults with autism.

The difference between a social interpreter and a social worker is social worker presupposes that you have social abilities and a social interpreter would not. A social worker helps you fit in. As social interpreter would express your world view to others and explain their world in ways that you understand.  
Ronald, List B.

The importance of a social interpreter is highlighted in the next quote, with the writer drawing parallels to people who are blind and deaf and their use of interpreters.

They are required by law to provide interpreters for the visually and hearing impaired.  
Ronald, List B.

This need for a social interpreter adds weight to arguments proposed in chapter 5 on identity regarding the constructed differences between social and non-social people in explaining the differences between people with AS and NTs. It is the complexity which surrounds social situations which are difficult for an autistic person to manage, which is why a social interpreter is so important. It is through a social interpreter that the autistic person can mediate with the social world. The use of a social interpreter therefore rejects the concept of bringing autistic people out of the AS world and into a more acceptable social world. Instead an interpreters role is about facilitating interactions between the AS and NT worlds, and enabling individuals to live with and manage a difference. For example:

I don't want to live in a high social world all the time----I can't take it in fast enough. I want to experience some of that through the eyes of an interpreter and I want to share some of the experience with other social and nonsocial people.  
Ronald, List B.

The important links between therapeutic intervention and the AS world are eloquently reflected in the following quote:

If you are Adult with Autism Diagnosis you have to have experience with medicine. Applied Behavior Analysis is a way to bring you completely into the social world and I do not want to go. I want to stay in my world and just visit the social world.  
Ronald, List B.

This individual does not want to change through ABA and completely enter the social world, but rather preserve his AS/non-social behaviours and at the same time maintain a way with which to mediate with the social world. The goal of professional therapeutic intervention is therefore constructed as removing the individual from the AS world and changing their behaviours in order to make them a full member of the social world. Such a change rejects the positive embracement of AS traits in favour of more dominant NT traits.

The value attached to social interpreters serves to highlight the important differences constructed between the social and non-social world. Both sets of contributors to discussions who are AS and NT construct the difference between the two worlds as real, but both have different goals with respect to negotiating these. The NT therapists largely have a therapeutic goal of bringing the person with AS out of their world and into the 'normal' world of social NTs. In contrast, the people with AS largely hold positive views about 'their world', and embrace the use of a social interpreter which would enable them to remain in the AS world, but still negotiate to some extent in an 'NT world'.

The goals of therapeutic intervention are therefore often explicit in their aim to change the behaviour of people with autism in order to make them 'less autistic' and more closely aligned to the dominant construction of

normality. While there is a challenge to the goal of change voiced by people with autism, this largely remains a marginalised voice within the professionally dominated discourse surrounding therapeutic intervention. The marginalisation of the voices of people with autism reflects the power imbalances inherent in the therapeutic relationship, and it is to the question of the nature of the therapeutic relationship and the power imbalances inherent within it that the analysis will now turn.

## **7.2 The therapeutic relationship**

A second key issue that I have prioritised in the analysis of the main theme of negotiating a label of autism is an examination the therapeutic relationship. An examination of such a relationship and the power differentials played out within this is important as it has overlaps with the previous analysis concerning therapeutic intervention. For example, the powerful position accorded to psy-professionals enables a particular construction of autism as a deficit, deviating from the normal path of development to be prioritised in professional discourse over an alternative construction drawing upon a discourse of difference. Such a view of people with autism thus enables some professionals and parents to legitimately speak for people with autism, marginalising voices that draw upon experiential rather than scientific knowledge. Such a construction further influences therapeutic intervention in the provision of help and its goals. Due to the dominant construction discussed above, help in a therapeutic relationship typically aims to change the behaviours identified by professionals as deficient or deviant rather than enabling an individual to negotiate differences. The uneven distribution of power in such therapeutic relationships will be further examined in this section of analysis.

### 7.2.1 *'Appropriate' therapeutic interventions*

Much discussion was evident on the forums that highlighted a professional split between therapists as to the most appropriate treatment programmes for people with autism. The quotes that reflect this thread are dominated by discussion list D whose members largely consisted of therapists and some parents. This domination highlights the absence of the views of people with autism within professional debates who often have vast experiential knowledge of such programmes. The therapists generally appeared to be split on this particular list between two camps of pro behaviour therapy and pro facilitated communication. What is important for this analysis however are the influences that theoretical presuppositions have as to how people with autism are viewed in the therapeutic relationship and the types of interventions proposed. Both behavioural therapy and facilitated communication have been the subject of critical discussions; (see for example Shea 2005; Duchan 1993). What is presented in the following section reflects the discussions had by contributors to the online discussion lists. The critical discussions presented here of the two approaches are therefore not necessarily balanced, but represent the discourses drawn upon in the lists.

The construction of the person with autism within each professional domain has important implications for the distribution of power within the therapeutic relationship. For example, those who were Facilitated Communicators (FC) were keen to construct FC in a positive light, respecting the rights of the person with autism. For example:

Underlying cornerstones of FC are justice, free expression, equal rights-- All of which we see in the disability rights movement.  
Pennie, List D.

Implicit in such descriptions of the foundations of FC is the construction of a particular version of autism which views autism as a difference rather than a deviance, with a key focus on equal rights and self-advocacy through drawing on the disability rights movement. In contrast, Applied

Behavioural Analysis (ABA) therapists are constructed as having a negative view of people with autism and their abilities. For example:

If you have believed that people with autism are incapable of learning and you have built your whole career on that belief, it is very difficult to step back and admit that you are wrong, and see the people you are dealing with in a whole new light.  
Gemma, List D

The following post from a FC practitioner attempts to discredit the claims of success by ABA therapists, and constructs ABA as a controlling domain, which goes against the principle of self-advocacy, unlike FC.

Oh get off it [Sandra]...the "poor girl". You get paid damn well and have been highly supported in your behaviourist profession while doing jack for us who are being persecuted by that same profession.

Any studies or conclusions that the behaviorists have done to discredit FC can be applied to behaviorsim who's only success is getting clients to tie their shoes...sometimes. With FC we have adult clients, who long ago haven't responded to behaviorism, who now can talk and type independently, not to mention the millions who could use this method just to communicate.

What has happened to all of us that we have reached such a low level of cynicism that we support mental retardation advocates (behaviorists) who use fascist methods and have all the power instead of supporting those who hold a clients hand and communicate with them?  
Tom, List D.

In addition to reflecting on the power imbalances between the person with autism and the professional within ABA interventions, the quote also serves as an important pointer towards imbalances of power within the grouping of psy-professionals.

The majority of the discussions that surround the most appropriate therapy for people with autism, and the underlying principles of the techniques, largely exclude the views of people with autism who have experienced the various methods, irrespective of the approach being discussed. This further highlights the exclusion of the voices of people with autism from such debates. However, the discussions between therapists concerning the most appropriate interventions for people with autism were often supplemented and developed by parents on the list. The contributions by parents frequently drew upon experiential

knowledge of methods of intervention in order to add weight to scientific claims. For example:

Tom, come to my house ANY TIME and see what ABA has done for my son. He is regaining language skills he lost at 15 months, and learning new skills he had never acquired! ABA is not phony.

I can understand why Tom promotes FC. I think it is great for those who are nonverbal. But ABA is real, and it works, and it really pisses me off, Tom, to hear you say otherwise. I've seen it work for more than just my own child.  
Susan, List D.

Such postings provide important evidence as to the perceived effectiveness of interventions due to their clear success in a specific case study, rather than appealing to broader scientific claims such as statistical evidence. The postings have the effect of making the benefits of interventions 'real' and concrete rather than abstract and academic. However, the power in the therapeutic relationship is firmly placed with the therapist, who can initiate changes in behaviour; the person with autism is largely not constructed as a key voice in such a relationship. The complexity in the debates surrounding what constitutes appropriate intervention is reflected in the rejection of the use of ABA by some parents. For example:

[My daughter] will never be able to consistently do the tasks/tricks behaviorists teach. But she can go to Yankee Doodles (a sports bar) with friends and enjoy the moment. As a result of FC and a "circle of support (friends)" she can smile, relax and enjoy the pleasures behaviour modification could never have taught her.

Anne Donnelan stated that the only result of demanding eye contact was to create a generation of people with autism who stared at you.  
Frank, List D.

ABA is constructed by this parent as a form of compliance by a person with autism to learn tasks which are not useful in day to day activities. In contrast, FC is positioned as being a central feature in enabling a person to have a social life, and is consequently portrayed in a more positive light. Such examples reflect the construction of autism at the core of therapeutic interventions and whether autism is presented as a deficit to be changed or a difference to be negotiated and managed. For example,

by focusing on eye contact the parent is reflecting on one of the core features associated with a diagnosis of autism – a qualitative difference in the use of eye contact. Once such an ‘abnormality’ has been identified, the therapist must consequently strive to change and ‘normalise’ this.

The lack of voice of people with autism despite their often vast experience with a range of interventions (see for example Waltz 2005), reflects the power imbalance in the therapeutic relationship, enabling both parents and professionals to speak for people with autism and resist self-advocacy by people with autism within the therapeutic setting. This important aspect of the therapeutic relationship will be examined in the next section of analysis.

### *7.2.2 Speaking for people with autism*

The absence of voice of people with autism both in the discussions presented above and in wider academic and professional literature reflects the marginalisation of direct experiential knowledge in favour of scientific or professional knowledge, an area drawn upon in the analysis presented in chapter 6 concerning diagnosis. For example with respect to discussions of therapeutic intervention:

How is it feel if someone "train" you like - sorry - a dog, like in ABA does is it hurt ? is it noisy ? is it make you upset ?  
Michael, List D.

The post was replied to by a therapist rather than a person with autism, reflecting their dominance in number of list membership.

It's aggravating to the autistics, but they understand that we mean well and are trying to help. When they are young it is hard for them to rebel against it, but as they get older they make it clear how much they will tolerate. If it is intensive like the Lovass variety of ABA, I have reason to beleive they will be more prone to acting out when they are older.

You ask excellent questions. [Tony] is lucky to have you as his parent.  
Tom, List D.

The reply serves as a good example of people with autism being spoken for by others.

The prioritisation of professional and scientific knowledge further reflects the power dynamics in the therapeutic relationship, where professionals and some parents speak for people with autism.

One of the few examples of people with autism speaking for themselves concerning a specific therapeutic intervention is presented below. This posting was in response to a thread of parental discussions concerning possible therapeutic interventions for their children, including the introduction of drug therapies.

I was put on desperado as an adult and it caused great weight gain in a few short months. It did help me to be some what more aware of my environment, but nothing drastic. [Shelly] do not discredit the medication as each person is much different and it to not always work for some while working miracles in others.  
Shelly, list C.

An important element in the quote is the focus on the person with autism as an individual. Implicit therefore in the argument is that there is not only one type of person with autism, but rather, every person should be regarded as an individual and therapeutic interventions need to reflect this. Such individualising of people with autism resists the construction of a homogenous group of 'the autistics' who are necessarily all the same and will therefore respond in a similar manner to therapeutic interventions

The importance of individual experiential knowledge is reflected in some postings to the discussion lists where challenges to professional scientific knowledge are made. For example:

I'm an independent woman thanks to whatever therapy they used and my parents' willingness to fight for me and try everything they could to help me. I'm glad they did not only stick to one thing or fall for what the "professionals" said...I may not be where I am today.

I work, I drive, I've come farther than any of the "professionals" my parents fought with said I ever would. I'm not in an institution like they said I would be. Tegal, List D.

Here the individual positions herself as an 'independent woman' and attributes this to the therapy received earlier in life, thus acknowledging the importance that therapy may have to individuals. However, the use of quotation marks surrounding the description of 'professionals' highlights the possible rejection of such scientific knowledge in favour of the more accurate experiential knowledge that her parents had regarding her behaviour and development. The poster is thus highlighting that therapy can 'work' for individuals, but knowledge and experience of a person can and should guide therapeutic choice.

While there are examples of individuals with autism speaking about therapeutic interventions this largely remains a marginal voice in an area of debate dominated by professional discourse. The powerful position adopted by professionals in the therapeutic relationship is maintained by the prioritisation of the construction of the person with autism as in some way deficient and who can therefore be spoken for in the therapeutic exchanges.

In a linked theme to the therapeutic relationship and the powerful position of professionals within that, the analysis will now turn to the focus in professional discourse of the deviation that autism presents from the identified normal and natural path of development.

### **7.3 Constructing the (un)naturalness of autism: seeking aetiologies and explanations**

The representation of autism as an unnatural path, deviating from the path of normal development outlined by psy-professionals draws upon the construction of autism as a deficit that is in some way deviant from the prescribed path of ideal normal development. I have already presented discussions in chapter 6 examining the powerful role that professionals play in charting the path of normal development and the pervasiveness of such ideas outside of the professional community as reflected in the discourses of parents comparing the behaviour of their child to taken for granted universal milestones of development. The powerful position accorded to the assumptions of the universals of childhood (see for example Burman 1994) is further reflected in the need to find reasons for behaviours identified as abnormal. It is to the presentation of explanations for autism that the analysis will now focus.

Autism is often discussed on the lists in terms of assigning ‘fault’ and maintaining the biological naturalness of autism as a ‘problem’ which consequently requires intervention from professionals. In doing this, autism is not seen as a neurological difference, but a deficit, deviating from the prescribed path of normal development. Due to the individual’s constructed deviance from normality rather than constructed difference, an explanation for autism is frequently presented.

For example, the linking of autism to previous vaccinations is a common thread which runs throughout discussions on the lists and is an issue that has been given high visibility in the media (O’Dell and Brownlow 2003, 2006). For example:

There is a strong family history of immune related illness in my family as well as my husbands, thus your genetics, and by the time my son had the MMR his immune system was simply pushed! over the edge.  
Eileen, List D.

Such parental voices linking the onset of autism to vaccinations is often prioritised over scientific evidence rejecting the links, particularly in media debates. The rejection of a link can also be seen on the discussion lists, particularly among professionals. For example:

There is no scientific evidence that the vaccines cause autism though autism symptoms sometimes get worse around the time vaccines are given. There's no scientific correlation however.  
Tom, List D.

In addition to rejecting the proposed relationship between autism and vaccinations, this therapist calls on expert/scientific knowledge in order to substantiate this claim. Here scientific knowledge and research of the possible links is prioritised over the experiential knowledge proposed by parents which claim to give evidence of behaviour change following immunisation. By prioritising the scientific knowledge of professionals over the experiential knowledge of parents, the powerful position of professionals is again asserted.

On examining the wider implications of the debates linking or rejecting the link between vaccinations and autism it is clear that a fault-finding process surrounds the identification, diagnosis and consequent therapeutic intervention with people with autism. Due to the predominant construction of autism as a deficit, being autistic requires an explanation of fault. In contrast, the dominant NT position does not require an explanation due to it being constructed as the norm to which others are compared.

In this section I have prioritised a presentation of a discussion thread on the lists that links autism to just one aetiology: vaccinations. Others were evident such as the appeal to genetics and abnormal brain size, but given the wide coverage both in academic discussions and the visible presence in media reporting linking the MMR vaccination to autism, I chose to focus on this. However, the important point that underpins all of these debates is the need to find an explanation for people with autism and behaviours

that do not fit the dominantly approved model of normal development. This strongly reflects the dominant professional construction of autism as a problem that therefore warrants specialist professional intervention. Appealing to a different construction of autism, the following section celebrates neuro-diversity and focuses on the positive contributions autistic traits may have for an individual if managed appropriately.

#### **7.4 Adults with Autism and Career Opportunities**

The final theme prioritised from the discussion list contributions reflects the question of what happens following a diagnosis (either professional or self-diagnosis) and possible interventions, an important component to the negotiation and renegotiation of a label of autism. While much professional and academic literature focuses on achievements through therapy in detailed situations, I would like to view the broader picture concerning how an individual identified as autistic manages life situations. The turn to the perspective of individuals in the wider negotiations with life issues is in line with discussions following Kagan (2002), who argues that research needs to turn to ways in which people identify themselves and overcome barriers to inclusion. In doing this I have used as an example the management of career opportunities and the negotiation of a place in the workforce when faced with the problem of a socially demanding environment.

There is some advice posted to parents from adults with autism regarding the educational and future possible work environments which might be beneficial for their children. For example:

If you have an AC child, you better make sure to help him or her to learn what he or she wants to learn. Getting them interested in "meta-subjects", such as Sociology, Digital Physics, Accelerated Learning and general Computer Science could help. However, sometimes the AC children just needs to know that they can get what they want, for instance, by learning to program, and they will learn to do so willingly.  
Edward, List A.

Parents are therefore encouraged to adopt an 'autism as difference' construction of individuals by enabling their children to follow their interests. The often narrow range of interests typically identified as a problem in professional literature is thereby reconstructed as a positive asset in providing focus for individuals. Such a positive focus on autistic traits can lead to disbelief that people with such positive talents and abilities should ever be omitted from work opportunities. For example:

When I first heard of HFA and AS unemployment I almost didn't believe that. I thought, why would people with such unusual talents and abilities have to suffer such a fate?  
Edward, List A.

Such difficulties in AS employment are attributed to the domination of the workplace by NTs and the consequent insistence that it become a social domain. For example:

With the "New Economy" now sweeping us, the NTs had made a come-back with the "New Age" employment tactics, including making a work place extremely sociable. This gives ACs an extremely troubling headache.  
Edward, List A.

It is therefore not the abilities of people with autism that are at fault with regards to employment opportunities, but rather the domination by NTs of the workplace and its consequent social nature. This echoes debates common in the social model of disability where an individual could be considered to only be disabled by their 'impairment' of autism because of the socially demanding nature of the workplace created by NTs. Autism traits can therefore be valued and channelled into important employment and lifestyle opportunities for people with autism if they wish, providing that the wider ethos of society generally and the workplace specifically values diversity and difference. The dominant majority of NTs create a working environment that is more suited to social NT ways rather than non-social AS ways. People with autism will therefore find it challenging to operate in such an environment if they cannot adequately negotiate a channel of effective communication within an arena. With adequate supports people with autism may be able to use their unique skills

effectively and make important contributions to the workforce. This has been shown by employers such as Goldman Sachs, who have formalised a programme for workers with autism, where positions do not require a focus on communication skills, and the importance of working as a team, (Dosani 2006). Such programmes value the specialist knowledge that autistic individuals may have in a narrow range of fields, and address the issues faced at the interview, which frequently rely on a competence in social skills in addition to competencies in the key skills demanded of the job.

## 7.5 Discussion

It remains clear in discussions contributed to the list that a central powerful position is maintained by therapists in evaluating and determining the outcome and goals for people with autism. Such a powerful position accorded to professionals in therapeutic relationships has important links to their position with regards to the diagnosis of autism and the development and maintenance of the specialist resources used in such assessments as discussed in chapter 6. The dominance of psy-professionals is further reflected in the marginal position of people with autism with regard to speaking about therapeutic interventions and the goals of such interventions, resulting in people with autism being spoken for by both professionals and parents. It is largely other people who define and determine 'appropriate' behaviour rather than people with autism, and such 'appropriate' behaviour largely reflects the professionally dominant construction of autism as a deficit which consequently requires some form of professional intervention in order to more closely match the NT ideal predominant in society.

Indeed the dominance of professionals in therapeutic interactions has been reflected upon in academic literature (see for example Todd 2006). Todd comments that in therapeutic relationships, professionals need to understand the important role that they may play in shaping the identities

of their clients: in the analysis presented in this thesis, the important role that they play in constructing autism as a deficit. Drawing on Morgan (2000), Todd argues that an alternative role is possible for professionals to adopt, which engages in practices that assist people to develop their own preferred identities. In the case of the present thesis, such alternative identities may support the construction of autism as a *difference* rather than a *deficit*. However, Todd highlights that professionals draw on a range of discourses, and most of these will run counter to the goal of collaboration with clients. Todd argues that such discourses draw upon the professional being the 'expert', and consequently the half of the relationship who can define the problem, drawing on objectivity and rationality. Such 'expert' knowledge needs to be addressed in combination with 'popular knowledge' in order to further understanding (Kagan and Burton 2001). This conflict between experiential and scientific knowledge was an area highlighted and discussed in chapter 6, and a fuller understanding of the experience of therapeutic interventions and wider lifestyle negotiations needs reconciliation between the two knowledges.

At the core of discussions relating to therapeutic interventions and the goals of such interventions is the construction of autism as either a *deficit* which consequently requires professional intervention in order to normalise and change the behaviour of the individual, or as a *difference* where individuals can learn to negotiate differences in a supportive environment. The construction prioritised in competing discourses has important implications for views on interventions necessitating change. While influential theorists and professionals working within the field of autism such as Francesca Happé and Uta Frith propose that there is not a cure for autism, and in as much, autism is not a condition that can be eliminated from a person, they do highlight therapies that can be used to 'improve' the lives of people with autism. The key issue for these theorists is that the condition is fundamentally neurological in nature, and as such remains unchangeable. Such an appeal to neurology in order to explain

the differences between people with and without autism is echoed in discussions presented from the online lists in chapter 5. However the important difference between the two discourses regards the implications of the neurological condition. If the condition is constructed as a neurological deficit then interventions are aimed at modifying behaviour in order to make an individual's behaviour more socially acceptable. Such an approach may mean that people's experiences become a set of pathologies, and interventions focus on doing things to people rather than with them (Burton and Kagan 2005). If the condition is constructed as a neurological difference, then change has a different meaning and the focus is on enabling individuals to manage their difference through for example the use of social interpreters which can facilitate negotiated interactions between the social NT world and the non-social AS world.

The construction of autism as a deficit remains predominant within professionally dominated discourses, and this has important implications for the development of a positive identity for people with autism, given the focus on changing behaviour in order to more accurately reflect a dominant NT world view. Such a world organised around NT values places a strong emphasis on social skills, which have been highlighted by both professionals and people with autism as areas of difficulty. Due to the importance accorded to social skills in areas such as employment, the traits and skills of people with autism largely remain undervalued, as reflected in the discussions presented concerning AS unemployment.

A further important issue related to the under-valuing of people with autism reflects the socially prescribed nature of acceptable behaviour. Professional interventions frequently explicitly state the goal of removing an individual from their AS world and into the 'normal' world, more accurately reflecting approved social norms. Cloaked in the professional discourse of science and objective measurements, psy-professionals formalise assessments and interventions.

The dominance of professionals has important links to issues of self-advocacy amongst people with autism, with adults with autism rarely having a voice within the therapeutic relationship. The lack of voice can be linked to the competing assumptions between professional constructions of autism and the assumptions of the self-advocacy movement where the focus is on the competence of a group of people rather a focus on their deficits and failure to meet an expected defined norm. Ward and Meyer (1999) have proposed that the self-advocacy movement for autism has grown since the development of Internet technologies due to the unique embracement of such tools by this population. Through such use Ward and Meyer argue that many adults with autism have employed new technologies in order to frame a new identity that sets themselves outside of the medical discourse of 'disordered', and moved towards the development of a cultural grouping understanding of an autistic identity. However, the uneven distribution of power within the therapeutic relationship means that such self-advocacy can be resisted by psy-professionals within the face to face therapeutic relationship. Indeed, referring to intellectual disabilities more generally, Rapley (2004) comments that while identity can be conceived of as a negotiated process of interaction between people, the negotiations do not always take place from positions of equality.

The lack of self-advocacy by adults with autism as represented in professional discourse is further reflected in the frequent neglect of adults with autism and their specific concerns within academic literature. Bishop (1989) argues for the importance of adopting a life-span approach to autism, but highlights that this can be confusing for parents who are told that their child has an incurable condition, and may consequently believe that they can expect no change in their child's behaviour and abilities. Such a construction predominantly focuses on the negative characteristics associated with autism, rendering the positive attributes as discussed by contributors in for example chapter 5 invisible. This has important implications for the lifestyle choices presented to adults with

autism, who need to challenge the negative construction of their abilities if they are to develop a positive self-identity and successfully negotiate their differences within an NT dominated world. For example, Folstein (1999) proposes that a lack in social abilities can lead to many adults with autism being under-employed relative to their measured intelligence, a premise reflected in several postings to the discussion lists contributing to the current research. These points are echoed by Barnard (2001) who comments that people with autism have very little choice in where they live, what work they do, and who, if anyone, looks after them. Barnard further cites that only 19% of adults in their study had access to any sort of advocacy when their future was being decided on in order to help them express their views about their choice of care, housing and activities.

The negotiation of a label of autism is therefore complex, and an individual may negotiate several times throughout their life span. Important constructions of autism are presented through professional interventions, and these serve largely to construct autism as a deficit rather than a difference. A renegotiation of this construction, and the focus on the individual differences of autism and the positive traits that these may offer, makes available a different construction of autism. In this alternative construction, the potential value of people in a workplace are highlighted, and a position adopting neurodiversity can be maintained. The importance of celebrating neurodiversity will be further reflected on in the following chapter.

## Chapter 8: Critical Reflection

This final chapter presents a review of the analysis detailed in the thesis, and a critical discussion of this, including the contributions that my research makes to new knowledge and possible applications of the thesis. In providing a review and discussion of the thesis, I will reflect on my aims and objectives as outlined in Chapter 1, and discuss how each of these has been met through the analysis and discussions presented in the thesis.

In addition to providing a review of the thesis, this final chapter also seeks to explore the position of myself as a neurologically typical researcher researching autism. In doing so I will begin with a short review of literature which examines the role of the non-disabled researcher in disability research generally, and then focus more specifically on my role within the research carried out for this thesis. As part of this critical reflection I will provide a discussion on the creation of 'NT syndrome', and the commentary provided by members of the autistic population on an inverted construction of the dominant diagnostic classificatory system, the DSM.

A critical review is considered necessary for several reasons. The research has been approached using qualitative research methodology, and in doing so it embraces key aspects broadly associated with such an approach. The practise of a reflexive discussion as part of the research method is an important aspect of qualitative work (see for example Parker 2005), and therefore a critical reflection on my role as a researcher and on my status as neurologically typical fits well with my methodological approach to the work.

An examination of NT syndrome is also important for theoretical reasons. The key focus of the thesis has been one of investigating the construction

of autism, and a critical reflection is a further instance of such questioning. Linked to this is the theme of binaries that runs through the analysis in the thesis. Within the analysis in this thesis, and in wider academic literature, autism and autistic traits are scrutinised in detail. However the supposed binary opposite of neurologically typical is not generally examined, other than as a means of portraying a 'normal' individual, with which to compare behaviour identified as 'abnormal'. The powerful end of the binary may therefore remain invisible and unaccounted for. Many of the people with autism contributing data to my thesis employ a strategy in making a syndrome of NT, and therefore an examination of this syndrome and strategy is important as this fits with the approach of the thesis, a focus on the political and cultural implications of discourse.

Finally, a specific examination of my role as an NT researcher is important as the thesis looks critically at the production of autism through science. To fail to examine my own position within the research exercise would serve to replicate existing power relations, as the NT individual would remain a 'taken for granted' exemplar of 'normality'. My critical reflection is therefore part of an academic, theoretical and political strategy.

### **8.1 The research aims and objectives**

The principal aim of the research has been to investigate the construction of the autistic individual, with five key objectives identified. These research aims and objectives will now be reflected upon and addressed in light of the analysis presented.

*Objective 1: To explore how the perspectives of individuals with autism can be heard through investigations using new technologies.*

The methodological approach of the thesis has employed the use of online asynchronous discussion lists. Four online groups were joined for the research: membership of two of these groups consisted primarily of people with autism, supplemented by membership of a list consisting

primarily of parents and a list dominated by professionals. The analysis presented in the thesis has not only portrayed the online voice of people with autism, but has also placed this within the context of the online voices of parents and professionals. Earlier work by Dekker (2000) and Blume (1997) highlighted the potential benefits that online technologies may hold for people with autism, and the postings to the online lists reflect a sophisticated interactional pattern between people with autism that capitalises on the lack of face to face interaction, and consequently the elimination of non-verbal cues in exchanges. My methodological approach has therefore been effective in sampling online discourses of people with autism as well as parents and professionals.

The analysis presented in chapters 5, 6, and 7 uses verbatim extracts from postings to the lists as exemplars. The extracts demonstrate a sophisticated interactional style between people with autism, challenging the dominant construction of the abilities of some people with autism. The varying perspectives of people with autism, and in addition parents and professionals, have therefore been demonstrated through the use of new technologies throughout the three empirical chapters.

*Objective 2: To examine the implications of accepting the construction of autism as a singular 'disorder'.*

The methodological approach to the thesis has led to the identification and sampling of a diversity of discourse surrounding autism. Such diversity has been identified both within and between groups, with a range of discourses drawn upon by people with autism, parents and psy-professionals, which at times can appear contradictory. This fits with a focus of the thesis on valuing neurodiversity, which does not necessarily make assumptions that all people with autism or psy-professionals will construct an identical portrait of autism. Similarly the groups will not necessarily differ in their discourse in uniform ways. The singularity of a construction of an autistic individual has therefore been brought into question.

A questioning of the acceptance of the conception of autism as a singular 'disorder' is also reflected in discussions of competing discourses surrounding autism used on the online discussion lists. Chapter 5 details parallel discussions on the lists which present autism as a spectrum and also as a distinct entity in contrast to NTs. Such constructions are frequently used interchangeably, however the use of the two discourses are drawn upon in different ways and for different purposes. The autism as a spectrum discourse is drawn upon by contributors when discussing traits as a range of abilities, with arbitrary cut off points presented to outline the normal and abnormal range. However the NT/autism dualism discourse is important when making a political statement to be different. Both discourses serve different purposes and are used in different ways, yet despite their seeming incompatibility, they exist effectively together. If autism was accepted as one single construction, the range of discourses would not necessarily capture the complex political and personal construction of autism.

*Objective 3: To examine the relationship between 'normality' and 'abnormality', and consider how autism as a specific 'impairment' has been constructed within this framework.*

The psychological resources employed by psy-professionals and their importance in defining the concepts of 'normality' and 'abnormality' were explored in Chapter 6: Diagnosis. The discourse of psy-professionals creates a binary which clearly identifies normal and abnormal behaviour, and this binary is drawn upon in discussions presented in the online lists, with several parents using professionally defined benchmarks of development in order to highlight and discuss 'abnormal' behaviour. The powerful presentation of (ab)normality provides an important framework for understanding behaviour, with autistic and non-autistic traits clearly identified with each half of the dualism. The identification of autism with abnormal behaviour excludes alternative constructions of autism as a difference rather than a deficit. This powerful binary was deliberately set aside by those members of the discussion lists who wanted to embrace a position for autism and autistic traits as an example of neurodiversity.

The discourse of psy-professionals is however accorded a powerful position in the construction of autism, and the identification of normal and abnormal behaviour with respect to autism remains central in debates and is based on the dominant NT world view, further reflecting the powerful position maintained by an NT ideal. Within this discourse, autism is not constructed in an equal position to NT, and therefore is positioned as a behavioural pattern that deviates from the taken for granted 'natural' course of normal child development. The discourse on the lists that espouse a different position was shown to grapple constantly with tensions arising from the dominance of the conventional view.

*Objective 4: To examine similarities and differences between constructions of autistic and neurologically typical individuals.*

The construction of differences between autistic and neurologically typical individuals was a recurring theme throughout the thesis. It was examined specifically in Chapter 5: Identity, where a discussion and analysis of the construction of differences between the two identified groups was presented.

It was clear throughout the groups' discussions that labelling was a central issue, and self-identification with a specific label was a key topic of discussion in many of the exchanges, with traits associated with autistic and NT individuals frequently discussed. However, discussions presented on the lists whose membership mainly comprised of people with autism presented an important challenge to the taken for granted nature of normal development, where NT traits are presented as the ideal benchmark. Outside of the autistic community non-autistic people form the dominant population, and consequently the neurologically typical is taken for granted as the normal/natural way. Such a population therefore does not require a label outside of the autistic community, as the focus of attention is placed on the deviance from the norm displayed by people with autism. In a change in status from minority to majority position within the discussion lists due to their membership composition, and in a supportive and 'safe' environment, autistic members chose not to

examine the idiosyncrasies typically associated with autism, but rather focussed discussions on the idiosyncrasies associated with NT behaviour. The traditional thinking surrounding the boundaries of normality and abnormality were therefore questioned, and often inverted in light of this, with autistic members of the groups positioning themselves as different from and often better than the 'other' group of NTs.

*Objective 5: To examine the powerful position accorded to psy-discourse within discussions of autism.*

Discussions of power were an important element that ran through the analysis in all of the empirical chapters. The powerful position accorded to psy-discourse was however most specifically addressed in Chapters 6 and 7. Chapter 6 detailed discussions surrounding diagnosis, and reflected upon the diagnostic tools that are developed, owned and administered by professionals working within the psy-complex. It was argued that the control over such tools serves to maintain the powerful position of psy-professionals as best placed to manage individuals, and excludes the full acceptance of parents and people with autism as equal partners in the diagnostic relationship. In addition to diagnostic assessment tools, the powerful position of psy-discourse was also shown to be evident with respect to the identified 'norms of childhood' and the pervasive nature of such taken for granted norms of child development, as reflected in their use by parents of people with autism to identify and discuss 'abnormal' or autistic behaviour.

Chapter 7 extended this analysis and examines the negotiation of a label of autism by individuals. As part of this discussion the dominant position maintained by professional discourse in interventions with people with autism was analysed and an examination of the dominant construction of the autistic individual within therapeutic discourse as having a *deficit* rather than a *difference* was presented.

## **8.2 General review of the thesis**

Through the analysis in the thesis I have prioritised three main themes in the discourse of participants contributing to the asynchronous discussion groups: issues relating to identity, diagnosis and negotiating a label of autism. Each of these themes has been individually discussed in separate chapters; what follows therefore is a more general discussion of the thesis, focusing on wider issues arising from the thesis approach and analysis. In the review I will focus discussions on my methodology and the diversity of discourse identified in the discussion groups, the sophisticated reflections on NT syndrome and the potential challenges that these pose to broader hypotheses of theory of mind, and finally, in light of the theoretical importance of the social model of disability in the thesis, the place of autism within such a model.

### *8.2.1 Methodological and analytical reflections*

The methodological approach of the thesis has been to employ new technologies in order to access a variety of discourses surrounding autism from a range of contributors. I feel that this method is particularly applicable to research with people with autism as research using computer mediated communication enables researchers to contact populations who may have difficulty in interacting in more traditional face to face situations. This approach is therefore an important tool in enabling their voices to be heard, and in employing such tools I used the form of communication that is most appropriate for the population under study, following previous discussion by Dekker (2000) and Blume (1997a, 1997b), (see literature review for a fuller discussion).

Online methodology is also important for the current project as it samples groups of participants who are members of discussion groups which are comprised of a distinct membership population. Such dominant membership groupings may be particularly important for the groups mainly comprising people with autism, as it enables free discussions and

commentary on psy-professionals and their approaches, presenting important challenges to academic constructions of autism in a supportive environment. The supportive environment is further maintained by the closed nature of several of the groups, where only approved group members can post messages to the lists and read archived discussions. The final corpus of data collected during the period of membership to the groups was therefore rich in its scope and large in its postings.

While the methodology employed has been important in enabling me to sample discourse from my research participants using the tools to most effectively reflect discussions, using online methods raises important questions concerning the digital divide. Miniwatts Marketing Group reported on 18<sup>th</sup> September 2006 a number of statistics relating to the general use of the Internet in populations. They summarised that 49.5% of the world usage of the Internet is by people living in North America and Europe, and while not a large contributor in terms of world usage (1.7%), Australia/Oceania boast 54.1% of its population as Internet users. This is in stark contrast to Internet users living in Asia, who account for 56.4% of the world population, yet only 10.8% are Internet users. These statistics are reflected generally in the current thesis, with the main contributors to the discussion lists based in North America, Europe and Australia/Oceania. While there are some contributors from other parts of the world, these remain few. The data collected using such methodologies therefore is largely dominated by contributors from certain parts of the world, and discourses identified will therefore be largely dominated by Euro-American constructions. The demographics are further compounded by biases in the age and gender of participants (see for example Kendall 1999; Reeher 2006), and socioeconomic bias within the societies where internet usage is high.

Such biases may have important implications for the sampling procedures of research projects, particularly if the key issues of interest centre around gender, language and cross-cultural research. While these are important issues in the current thesis, the overriding importance of

using the most appropriate methodology in order to fully access discussions by people with autism outweighed the questions concerning biases in sampling; these are issues for Internet research generally, and not something that can be resolved in the current thesis. Indeed Mason and Hacker (2003) have reflected that rather than endlessly debating the biases in Internet usage in world populations, researchers should acknowledge that some people are online and some people are not, and focus their gaze instead on the consequences of this difference.

The rich data collected from the discussion lists was analysed using techniques of critical discourse analysis (see for example Fairclough 1992). Central to this approach is an examination of the implications of maintaining the dominant discourse in a particular context. Therefore rather than describing the discourse practices occurring in the discussion lists, critical discourse analysis enables an examination of these in light of the wider social interactions and social structures (see for example Edley 2001). The sampling of a range of discussion lists comprising of people with autism, parents and psy-professionals enabled the analysis and discussion of key themes prioritised to be examined within a wider context of largely professionally dominated discourse and literature, and the power differentials operating within such contexts to be examined. This technique has been useful in enabling an examination of power in the shaping of discourses, and has enabled me to examine autism as a product of history by, for example, drawing on theoretical debates surrounding the political production of measuring what is normal and abnormal and the pervasive way in which such ideas of normality and milestones of development have become commonplace in non-professional discourse surrounding child development. In Chapter 6 the powerful position of a professionally constructed vision of normal development is evident in many of the discussions by parents in their comparisons of their children with autism to 'normal' children, commonly by citing comparisons to milestones of development such as walking and speech development.

Critical discourse analysis has also enabled an examination of thinking that prioritises NT traits over autistic traits, and the implications that this may have for an individual. As previously discussed, the public discourse on autism is produced and maintained largely by professionals, who are typically NTs, and who prioritise NT ways. It is an aim of the thesis to contribute to this knowledge base an alternative construction of autism which draws on alternative discourses of autism, and some of these discussions have been published in academic journals (see for example Brownlow and O'Dell 2006).

The methodological approach to the thesis has therefore led to the identification and sampling of a diversity of discourse surrounding autism. Such diversity has been identified both within and between groups, with a range of discourses drawn upon by people with autism, parents and psy-professionals, which at times can appear contradictory. Such complexity in discourse and the challenges that this may make to the commonly accepted version of understanding autism fits with a focus of the thesis on valuing neurodiversity. As part of valuing neurodiversity I am not making assumptions that all people with autism or psy-professionals will construct an identical portrait of autism, and similarly, the groups will not necessarily differ in their discourse in uniform ways. The singularity of a construction of an autistic individual has therefore been brought into question.

### *8.2.2 The construction of 'NT syndrome' and challenges to the theory of mind hypothesis*

The analysis has enabled an examination of power relations within autism constructions, and the important role that professional discourse plays in the understanding of autism. However, the powerful position of professional discourse has been challenged throughout the thesis by the frequent postings by people with autism presenting sophisticated challenges to expert knowledge bases. The challenge has often taken a political form in the inverting of the construction of diagnosis and the

creation of an NT syndrome (see later discussions). The creation of a syndrome of NT fits well with the political strategy of constructing the two groups of AS and NT as mutually exclusive groups, based on neurological differences as identified in chapter 5: Identity. However in parallel discussions by the groups, autism is also constructed as a spectrum, with several contributors drawing upon discourses of spectrum and dualism interchangeably. Such seemingly competing discourses are used in very different ways, and because of this can be complementary. In certain discussions it is useful for contributors to draw upon the autism as a spectrum discourse, for example when discussing traits as a range of abilities, with cut off points between identifiable normality and abnormality presented as arbitrary. However the NT/autism dualism discourse is important and is drawn upon when it is important to make a political statement about being different, and challenge the negative constructions of autistic individuals. The identification of the NT syndrome fits within this second approach.

In discussing an NT syndrome a sophisticated inverted construction of diagnosis is drawn upon, and the complex reflections and observations made serve to make important challenges to the theory of mind hypothesis. Tager-Flusberg (1999) defines theory of mind as referring to “the ability to attribute mental states, such as desire, knowledge, and belief, to oneself and other people as a means of explaining behaviour” (p.326). People with autism are therefore thought to be impaired in the ability to appreciate their own and other people’s mental states (Baron-Cohen 1998). The theory of mind hypothesis is proposed to be important in explaining difficulties in language and communication, which are cited as a core deficit in the diagnosis of autism (see for example Tager-Flusberg 1999).

While the theory of mind hypothesis is not specific to autism, literature proposing explanations for behavioural characteristics in autism draw heavily on the hypothesis. For example impairments in theory of mind have been drawn upon to explain a lack of pretend play amongst children

with autism and may be important in explaining communication difficulties (see for example Guajardo and Watson (2002)). The focus of the theory of mind hypothesis is therefore on an inability which has important consequences in a variety of situations and may influence several aspects of social interaction including the ability to understand feelings and mental states.

The literature review presented in Chapter 3 detailed critical discussions of the hypothesis. For example Klein (2002) proposes that theory of mind explanations reflect the dominant way of thinking in society in that it favours neurotypicality. Klein argues that implicit in discussions of theory of mind is the assumption that the neurotypical way is the only way, and as such people with autism have a deficit because they are not like neurotypical individuals. By accepting the traditional theory of mind hypothesis a certain construction of people with autism is presented. Smukler (2005) argues that such representations present autism as a deficiency rather than a difference. Such 'damaged' individuals therefore require specialist help in order to function in society. Smukler argues that these depictions of people with autism have become the dominant perspective, and hence normalised and not questioned.

While there is therefore literature that questions the theory of mind hypothesis, I would argue that further light is thrown on the traditional hypothesis through the analysis presented in the current thesis. One of the key areas of focus for theory of mind researchers is the influence that an inability to appreciate others' thoughts and intentions has for an individual in social interactions with others. Various experimental investigations have been devised in order to test this assertion. However, such tests commonly require an individual to interact in face to face settings, an area highlighted as a potential challenge for people with autism. When interacting via an online medium people with autism frequently display a sophisticated communicative interaction, in which complex reflections concerning the position of people with autism in relation to NTs are voiced.

This is reflected in contributions to the discussion lists that examine the communicative interactions of neurologically typical individuals and position such exchanges as 'illogical'. For example:

Humans, even NTs, possess the linguistic ability to express concepts, ideas, and emotions verbally with clarity, but the NT brain seems incapable of actually doing so. They rely heavily on the animalistic means of body language. It's primitive and unnecessary, I think. Further, NTs can't seem to express thoughts completely. They use an irritating form of verbal shorthand, where significant gaps are left to be filled by the listener. It's absurd!  
Archie, List A.

This extract questions some common assumptions surrounding the traits of autism and specifically impairments in communication and social interaction. Here the much researched 'impairments in social interaction' commonly associated with people with autism are positioned as being a consequence of the illogical behaviour of NTs.

While there is therefore a strong focus in professional and academic literature on the inability of people with autism to communicate, there is a competing conceptualisation of people with autism communicating in a more direct manner, where no 'reading between the lines' is necessary. The predominance of a non-autistic society however ensures that face to face communication which uses non-verbal as well as verbal cues is the benchmark of communicative abilities. Communication online removes the use of non-verbal cues and has been cited by Dekker (2000) as being highly suited to the communicative styles of people with autism, due to their tendency to be direct, expect literal meanings and not need to rely on non-verbal cues to supplement words – all areas that have been highlighted as challenging for non-autistic people interacting online (see for example Suler 1997). The thesis has drawn on the above in order to demonstrate the positive way some people with autism can communicate using internet technologies.

The impairment in theory of mind of people with autism as reflected in an inability to communicate effectively in social situations may be a reflection on the method of interaction rather than the abilities of people with

autism. Once an appropriate channel of communication has been established, which in the case of the participants in the current thesis is via asynchronous online discussion lists, complex reflections and discussions are detailed in exchanges between autistic individuals. Some of the posters critically discuss the concept of 'NT' in ways that not only appreciate that others may have thoughts different from their own, but present these thoughts by reflecting on complex constructions of the characteristics of autism and neurotypicality.

One of the main challenges presented to the theory of mind hypothesis by some of the participants in this research has been that of challenging the construction of people with autism as having some deficit as identified by a failure on a theory of mind test. Many of the commentators in the discussion lists inverted such a construction and positioned the NTs as the illogical group in their communicative style, highlighting autistic communication as direct, with no 'reading between the lines' necessary in order to understand the intentions of others.

### *8.2.3 The place of autism within the social model of disability*

The final reflections on my thesis in light of the above are those concerning my theoretical perspective, and specifically the place for autism within the social model of disability. The use of the social model of disability has enabled an examination of the social and cultural implications of disability and a disabling society. In order to more fully understand the complex constructions of autism and provide an examination of the social and cultural production of knowledge, I have also drawn upon debates surrounding intelligence testing and the constructions of normality and abnormality. This marriage of influences has been particularly applicable to my research area as the social model of disability has not been specifically applied to autism before. This has allowed me to draw upon a range of influences, which theoretically all fit together well and complement each other.

There has, as previously discussed in chapter 3, been some questioning in the literature concerning the application of the social model of disability to learning difficulties (see for example Chappell, Goodley and Lawthom 2001), and a call for an examination of the construction of impairment rather than understanding this purely through biological means (see for example Hughes and Paterson 1997; Abberley 1987). This is particularly important when examining autism due to a lack of agreement concerning autism and its aetiologies.

The 'Fundamental Principles' of the social model of disability as set out by the Union of Physically Impaired Against Segregation (UPIAS), proposed the original distinction between the concepts of 'disability' and 'impairment'.

Impairment: Lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.

Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream.

(UPIAS, 1976: 3-4, Quoted in Hughes and Patterson, 1997)

The separation of the two concepts has mixed implications for the understanding of autism. The concept of disability as defined by the UPIAS raises important questions concerning why being autistic should necessarily be a disability. Rather the difficulties encountered by people with autism are the result of an unaccommodating NT world, which focuses heavily on social systems. This is reflected for example in the analysis presented in chapter 7, where individuals negotiate their understanding of a label of autism through their experiences. Here postings to the discussion lists reflect on the underemployment of people with autism due to the social nuances operating within the workplace. Employment is therefore not solely a reflection of skill, but also an ability to master the social interactions operating within a specific arena. Being autistic is therefore not necessarily a disability unless an

unaccommodating environment creates barriers. Many occupations could be performed remotely in contemporary workplaces with the employment of Internet technologies, which in theory should improve the working potential for some people with autism.

The separation of impairment may however present some difficulties when applied to autism. If a position of valuing neurodiversity is adopted, then the core neurological issues present a neurological *difference* rather than *deficit*, which consequently does not constitute an impairment. The construction of autism as a difference rather than a deficit therefore draws upon wider arguments concerning the scientific model and the production of knowledge, with the pervasive framework of understanding normality and abnormality at the centre of discussions. Such dominant frameworks largely reflect psy-discourse and have also had a considerable impact on non-professional constructions of normality and abnormality, and consequently autistic and non-autistic people. The important influence of the powerful discourse of psy-professionals must therefore be acknowledged when discussing specific impairments in people with autism due to their prioritisation of NT ways.

Following critical writers such as Bogdan and Taylor (1976, 1989) and Hughes and Paterson (1997), an examination must be made with respect to the construction of impairment if the social model of disability is to be effectively applied to the understanding of autism. Rapley (2004) comments that intellectual impairments frequently fall outside the remit of discussions which present an understanding of 'impairments' as a socially constructed category, with the focus on the biological nature of the fundamental impairment. I am suggesting that discussions regarding the constructed nature of autism must be engaged with if important understandings of autism are not masked by a veil of biological and neurological explanations. In discussing autism as a socially constructed entity, I am in no way denying the experiences of people with autism, who construct their own identities based around an understanding of autism. I am therefore not seeking to definitively question whether or not autism

exists, but rather I am questioning the positioning and construction of autism in relation to the professionally defined concepts of normality and abnormality. An engagement with the socially constructed nature of autism enables an engagement with important presentations of the characteristics of autism as a *deficit* or a *difference*, and enables a more empowering identity to be constructed by individuals through drawing on alternative constructions of autism.

With respect to understanding autism, the social model of disability may therefore have some limitations, and the separation of the concepts of impairment and disability may not necessarily be a useful framework. While the concept of a socially defined disabling environment fits well with a focus on neurodiversity, the concept of impairment may need to be broadened in order to focus on the powerful discourses surrounding the identification of ability and measured deviations from this. The applications of the social model of disability to autism, in light of the findings presented in this thesis, may be a useful model to follow if a critical reflection on the understanding of impairment is employed, while still maintaining the political activist ethos of the approach.

In addition to a critical reflection on the use of theoretical tools throughout the thesis, it is also important to reflect on my role as a researcher within the research process. It is to my position as an NT researcher researching autism that the focus of my discussions will now turn.

### 8.3 The Role of the researcher

The role of the researcher is a key debate in disability studies (see for example Oliver 1996; Duckett 1998; Chappell, Goodley and Lawthom 2001; Sullivan 2006), and a brief discussion will be presented here followed by a specific examination of my role as an NT researcher researching autism.

Walmsley (2004) reflects that proponents of the social model argue that people with disabilities and learning difficulties should be active researchers in their own right rather than passive subjects of research by others. Such a prioritisation of experiential knowledge within the design and implementation of research projects leaves a questionable role for the non-disabled researcher.

Walmsley (2001) discusses the role of the non-disabled researcher in learning difficulties research. Walmsley postulates that in the case of learning difficulties, the debates surrounding the inclusion of non-disabled researchers may be more problematic. She argues that apart from Simone Aspis, a well known self-advocate, it is hard to find researchers with learning difficulties who can complete a piece of research on their own, from question proposition, to field work and finally to analytical write up. This is unlike those (physically) disabled academics working within disability studies. Similarly Chappell (1998) has reflected on the differences between research possibilities by people with physical disabilities and people with learning difficulties. While Chappell is not arguing that people with learning difficulties are unable to theorise and reflect on their experiences, she notes that such issues are not explored in disability studies to the same extent as the reflections and theorisations of people with physical disabilities or sensory impairments. Chappell also notes that when such reflections do occur in the literature, they are rarely done without the involvement of a non-disabled researcher as an ally, supporter or facilitator. In light of such observations Walmsley (2001) rejects the blanket response that people with disabilities should control

and conduct research projects. She argues for a need to examine the power relationships within the disability movement, with some sectors of the disability movement wielding more power than others. Walmsley proposes that people with learning difficulties are particularly disadvantaged and argues that until research processes are changed in order to engage people with learning difficulties as equal partners, the role of an academic advocate in order to carry out the research will remain necessary.

The complex issues raised concerning the control of research projects and the role of the non-disabled researcher within this will now be focused on my position as a neurologically typical researcher researching autism.

### *8.3.1 My role as an NT researcher*

Throughout this thesis, issues of group membership have been a central concern. This initially became apparent when I first began to contact discussion list owners regarding the possibility of my membership of their lists for my research. As previously documented in chapter 4, in order to present the research to the list owners and discussion list members in as transparent a manner as possible, I chose to identify myself as a non-autistic researcher. My alignment with the label of NT met with some resistance by list owners to me joining their groups, and suspicions by members as to my role and purpose from several list members. While I chose to self identify as non-autistic for ethical reasons, the question could be posed as to whether I would have been met with such resistance had I been an autistic researcher, researching the same material. I suspect that my alignment with an NT label raised questions and concerns regarding what 'version' of events I would be presenting in my work, and the consequent construction of people with autism.

Group identification has been shown to be a key issue for group discussions as presented in chapter 5: Identity, and power differentials

between groups has been a theme running throughout the thesis, with NTs frequently adopting the powerful position in discourse. The closed nature of many of the discussion lists reflected this power differential, with many of the groups being formed to comprise membership solely of people with autism and not academic researchers investigating 'curiosities'. Weight was given to experiential knowledge over scientific /expert knowledge, and therefore an NT researcher would not be approved for group membership in such groups. This was evident despite the e-mail detailing the research proposed as an opportunity for people with autism to have their voices heard amongst other academic voices which are traditionally constructed as being the most powerful. My position as a NT researcher therefore meant that I was not freely able to access all discussion lists equally.

The powerful position generally accorded to NTs in the research processes surrounding autism also needs to be addressed with respect to my work. Much of the literature in disability studies concerning the role of the non-disabled researcher focuses on the comparisons between emancipatory and participatory research. My research rests somewhat uneasily in these debates as it does not fall into either of the categories as ultimately it is not controlled by the participants in the research. However, I propose that my work constitutes a different kind of research approach in that I am not interviewing people or asking specific questions, and therefore not controlling the research in a traditional sense. Rather, the discussion lists were formed independently of my research and therefore were not formed solely for the purpose of research, and members of the lists were free to discuss whatever issues they choose, albeit guided by the overarching ethos and charter of the group. At no point during my membership of the groups did I pose questions for the lists to address or otherwise try to guide discussion topics. To that extent it could be said that group members set the agenda for some aspects of the research, though I clearly retained ultimate control through prioritising and selecting within their material.

My research also follows a model of valuing diversity whereby the skills of people with autism are presented, drawing upon positive constructions of autism, rather than prioritising NT characteristics and comparing people with autism against such a benchmark. Indeed, in several places throughout the thesis, AS characteristics are prioritised over NT characteristics, challenging the group to which I myself as a researcher is aligned, and later sections of the current chapter present a critical examination of NT as a syndrome. In doing so, my work presents challenges to some academic constructions of autism by questioning some of the perceived competencies of such a labelled group.

### *8.3.2 The role of the academy*

In any research project, power may rest heavily with the researcher, whether they are disabled or non-disabled, which leads to the question as to whether any research can be truly emancipatory, particularly for research which contributes to some form of academic assessment as in the current thesis. While my work seeks to enable people with autism to speak for themselves and have their voices heard within the academic arena, I as a researcher also benefit from the work. With respect to the power held by the researcher, I ultimately have control over which themes to prioritise and what quotes to use as examples in the final write up. In doing so however, I have tried to address some of the power inequalities in that I am not speaking for people with autism, or indeed presenting my version as necessarily representative of all people with autism, just as, it could be argued, a disabled researcher cannot speak for all disabled people. In selecting the methodological approach for the thesis I am however opening up the 'expert' voice for questioning (Kagan and Burton 2001; Brownlow and O'Dell 2006).

In adopting this approach to my research important links can be made between autistic activists and the academy, echoing previous work from the discipline of community psychology (see for example Kagan, 2007; Goodley and Lawthom, 2006; Kagan and Burton, 2000). Drawing on

community psychological approaches, my work is concerned with the focus on the diversity of skills, constructing autism as a difference rather than a deficit. However, this alternative construction of autism is discussed in relation to the powerful psy-discourse of autism. The critical commentary of autism can be made more visible through collaboration with the academy, and such collaboration may provide a route for the challenge to psy-constructions of autism, making space for alternative, more positive constructions of an autistic individual.

#### **8.4 NT syndrome**

The identification of 'neurologically typical' as a distinct group and the associated 'NT ways' has been a recurring theme throughout the thesis. It has been most explicitly addressed in chapter 5 in the creation of the AS/NT dualism. The idea of a clinical and critical examination of NTs as a population ripe for study was raised by Edward on discussion list A where he presented a summary of what he termed 'NT strangeness'. In his posting he provided a lengthy and sophisticated reflection on the lifestyles of NTs, which were considered strange by people with autism, and a 'beginners guide' to understanding such strange behaviour. In presenting such a commentary, the critical examination falls on the population of NTs rather than people with autism, challenging the traditionally powerful end of the dualism, as previously reflected upon in chapter 5.

Edward presents his commentary in several key areas singled out as depicting strange behaviour among NTs. At several points in the commentary autistic traits are implicitly highlighted as being superior to NT ways. For example:

A good number of them also immerse themselves in sports, such as watching people kick a durable rubber sphere around a green grass field towards one of the two "goal-posts". They seem to delight in such passive participation even though this does not contribute to their intellectual ability that they can use in other areas.

Edward, List A.

Edward is therefore questioning the usefulness of such behaviours which are identified as strange by him and consequently not something that people with autism would engage in due to it having no obvious intellectual purpose. Further reflections on the 'primitive' ways of NTs are presented when commenting on NT social hierarchies. For example:

NTs often play a game of comparison with each other. They compare their processions, qualifications, status, influence or whatever material items they take a fancy to with each other. Like preening peacocks, these games often end with NTs establishing some kind of "pecking order" where the person with the most of the compared item stays at the top with the second-most person below him or her and so on.

Often, some of these NTs "bluff" their way to a higher level in the social hierarchy via some deceit that comes at considerable cost to themselves...Their logic justifies this because they value their place in the social hierarchy more highly than their own financial problems. Again, in nature, you can see some of such behaviour with animals wanting to attract more mates to propagate their genes, and thus a study of animal mating behaviour and evolution will greatly aid your survival in NT society.  
Edward, List A.

Here the primitive behaviour of NTs is highlighted by a call for comparison to the animal kingdom.

The final area depicted as strange by Edward is that concerning communication and information networks. For example:

My most amazing discovery lies with the fact that NTs often execute frequent queries (i.e. gossip) over their social network systems that try to discover more data about other nodes and networks.

Like the CIA, they keep a huge mental database and inventory of who does what, who goes where, and everything you can think about a person's relationships with another... Carrying the CIA analogy further, they often have a rather good ability in providing misinformation, especially if such misinformation can please others. Apparently, some of them do this under perceived duress that the other person will take offense at their words and reduce their relationship strength. This comes at a cost because they have to maintain an internal database of misinformation which they must look up on demand at very rapid speeds.

More amazingly, they can somehow use non-standard high speed transmission protocols, which psychologists had only partially deciphered, requiring the coordination of many part of the human body or the shifting of frequency ranges and other aspects of the human voice in subtle manners to establish the rules of their social network, synchronize with each other and thus avoid offending each other. An AC cannot hope to develop such transmission speeds and scope

unless he or she receives an extraordinary amount of training, and even with this imperfections can still exist.  
Edward, List A.

The traditional impairments in communications highlighted by professionals as being associated with autism are questioned and inverted in order to present the NT communicative styles as the ones that are illogical and impaired.

Influenced by the interesting idea of a syndrome of NT and the inverted use of diagnosis in such a sophisticated manner, I carried out further investigations of 'NT syndrome' on the World Wide Web. My search yielded several sites which also drew upon and developed this theme. The following examination presents material from two websites.

#### *8.4.1 An inverted construction of diagnosis*

An important discussion strand featured on the two websites is one presenting a challenge to dominant ideas concerning what is considered to be normal and abnormal, and consequently what behaviour is singled out for a clinical diagnosis. The ideas presented in the websites challenge dominant academic thinking by constructing NT ways as the ones that should fall under the clinical gaze and presenting material in a way that echoes some traditional literature about autism. For example:

Definition of NT: "Neurotypical syndrome is a neurobiological disorder characterised by preoccupation with social concerns, delusions of superiority, and obsession with conformity...Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one...NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical is typically smaller than that of an autistic individual and may have overdeveloped areas related to social behaviour."

How common is it?: "Tragically, as many as 9625 out of every 10,000 individuals may be neurotypical...There is no known cure for Neurotypical Syndrome. However, many NTs have learned to compensate for their disabilities and interact normally with autistic persons."  
Institute for the Study of the Neurologically Typical (1998)

Similarly website two reflects on neurotypicality and parodies the influential triad of impairments to create a syndrome of NT.

“Neurotypicality is a pervasive developmental condition, probably present since birth, in which the affected person sees the world in a very strange manner. It is a puzzle; an enigma that traps those so affected in a lifelong struggle for social status and recognition. Neurotypical individuals almost invariably show a triad of impairments, consisting of inability to think independently of the social group, marked impairment in the ability to think logically or critically, and inability to form special interests (other than in social activity).”  
Klein (2002)

The writer of the above text identifies himself as autistic and also has an ‘official’ diagnosis, yet is still reflecting in sophisticated ways on the concepts of NT and AS, something that traditional theory of mind researchers question that a person with autism could do.

The importance of the construction of groups of people as forming distinct clinical populations is reflected upon by website two, where the individual reflects on the construction of autism as a clinical entity and the resonance this has for an individual. For example:

“Can you imagine what it would be like if, every time that one of your own kind was born, the parents of that child typically responded in shock and horror, as if a terrible tragedy had happened? That is typically what happens when a parent finds out that their child is one of my kind... in other words, that the child is autistic...The message here is perfectly clear: Being autistic is like a prison sentence. Being autistic is something so horrible that it should be soft-pedalled, like an inoperable malignant brain tumour.”

“It does not end there. These parents, in an attempt to reverse the tragedy that is the birth of one of my kind, immediately begin investigating all sorts of therapies, training programs, nutritional supplements, special diets, and drugs, in the interest of “fixing” their poor, damaged child. Can you imagine what it would be like if expectations of you were so low that it was considered heroic to teach you the most basic of self-care skills?..If a normal kid improves, it is development; if one of my kind improves, it HAS to be the result of some heroic action from a normal person.” (Caps in original)  
Klein (2002)

Such a sophisticated discussion of NTs and the impacts of diagnostic isolation to people with autism is further investigated in parallels of diagnostic categorisation for the syndrome of NT. For example the following is a summarised version of the DSN-IV classification of Neurotypic Disorder.

'DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders'  
666.00 Neurotypic Disorder

The essential features constitute a severe form of Invasive Developmental Disorder, with onset in infancy or childhood.

- A. Qualitative impairment in independent social interaction  
e.g. extreme or abnormal seeking of comfort at times of distress
- B. Qualitative impairment in verbal and non-verbal communication and imaginative play  
e.g. blatant overuse of all modes of communication, such as communicative babbling, facial expression, gesture, mime, or spoken language. Excessive imaginative irrelevant activity, such as playacting of adult role, fantasy characters, or animals, lack of interest in computers or other logical fulfilling pastimes.
- C. Markedly restricted repertoire of activities and interests  
e.g. persistent lack of awareness or inability to perceive parts of objects, or has an attachment to unusual objects (e.g. insists on driving around in a BMW, wearing Rolex watches, carrying a cellular phone or briefcase). Unreasonable insistence on sameness in others in precise detail, e.g. insisting that exactly the same social behaviour always be followed when shopping.
- D. Onset during infancy or childhood  
Institute for the Study of the Neurologically Typical (1998)

The diagnostic identification of NTs is supplemented by advice concerning intervention strategies which could be adopted for use with NT children in order to make them less NT and more 'normal'. It is to this second theme of discussions that the focus will now turn.

#### *8.4.2 Interventions with neurologically typicals*

Several aspects of the websites focused on intervention strategies for use with NT children, designed to reduce the occurrence of NT ways. For example:

What to do if you suspect your child has NT  
"Nowadays due to diagnostic advances, early intervention and carefully tailored behavioural management techniques, there is no reason why your child can not grow into an independent social being, develop a TOOM (Theory of Others Minds), and in time, even develop some special interests and abilities to contribute to society...Rote drills such as Applied Behaviour Analysis with their easily understood regimen of repetitiveness and punishment will do wonders with common NT behaviours such as lying, teasing and faddishness."  
Institute for the Study of the Neurologically Typical (1998)

In addition to such satirical examinations of interventions, there are also comments concerning intervention programmes designed for people with autism. For example:

“The biggest problem with most programs designed to assist autistic children is, as far as I can tell, that they were designed by NTs, and for NTs.... They are, after all, the ones that will be paying the considerable bill for these programs, and it is their wishes that are catered to with regard to goals of that program...The goal should be to help the autistic child develop in a way that will make a relatively decent life possible, not to make him into an NT clone. That’s not real; a cat trained to fetch and wag his tail when happy is a trained cat, not a dog.”

Klein (2002)

The creator of website two further comments that:

“While there are a lot of resources that aim to educate normal people about how autistics think, there really are no resources at all that serve to explain to autistics how normal people think.”

Klein (2002)

The concepts of change associated with such intervention programmes are also questioned in website two, where the concept of constructing autism as a disability is challenged, in favour of the construction of autism as a difference. For example:

“The single biggest “disability” we have is being such a small minority... so small that we can be mostly ignored by the populace at large, and so misunderstood that we can be written off as mentally incompetent.”

“...I am particularly bothered by the self-loathing attitude that many of my fellow aspies have. It saddens me to see so many good, intelligent, wonderful people hurting so because they see themselves with NT eyes.”

“I question the motives of any person that thinks that a cure or an amelioration of a child’s autism is a good thing. This includes the parents that wish for a cure for their child. What that says to me is that they wish that their child would go away, and be replaced with a new, better, improved, less defective child – one that acts and thinks more like they do.”

“Please do not buy the sales pitch that the autism is “overcome”, “cured”, or anything like that. It cannot be cured; it can only be hidden. Please don’t make your child live a lie just so his existence is more acceptable to you.”

Klein (2002)

The postings on discussion list A and the two websites singled out as examples here present eloquent and challenging arguments concerning

the unusual behaviour of neurologically typicals, which can consequently be marked out for special interest. Such commentary contributes to the dominant theme in the thesis concerning the construction of the autistic individual by examining the traits traditionally associated with autism that are considered to be impairments in the individual and investigating these by positioning them against the equally impaired portrayal of NT traits, which are generally accepted by wider society as the norm. Such debates raise issues concerning the valuing of diversity and the celebration of neurodiversity – a position in which one half of the dualism is seen as not necessarily better than the other, with both having positive and important contributions.

The commentary also provides several sophisticated reflections of autism and NT syndrome by some people identified as autistic, which presents challenges to some mainstream theory of mind research, which would question a person with autism's ability to reflect on concepts of mind. A strong example of this is by the poster to discussion list A, Edward, who self-identifies as being autistic, but who also receives an 'official diagnosis' by a psy-professional in the course of his group membership, which prompts the other group members to have a celebration (see chapter 5: Identity), demonstrating an understanding of others beliefs and feelings.

## **8.5 Unique contributions to knowledge**

The thesis has presented several unique contributions to knowledge, which will be summarised here. With respect to the theoretical resources drawn upon in the thesis it is, as previously discussed, the first time to my knowledge that the social model of disability has been applied specifically to autism. The previous section has reflected on the embracement of autism within the social model. While at times there may be an uneasy relationship between the social model and learning difficulties generally, and autism specifically in this thesis, the novel application of the model has enabled me not to be constrained solely within the remit of the

social model's theoretical embrace and to draw upon supporting theoretical resources such as those from critical theory more broadly and discussions of the history of psychology and the appeal to the scientific model.

This unique application of theory has led to a fresh consideration of autism, in light of the alternative (positive) constructions of autism presented by some members of the discussion lists. The analysis surrounding issues of identity has built on ideas in the autistic community which contrast autistic and non-autistic traits, and has presented a formal critical discussion concerning the attributes of both autistic and non-autistic individuals. This final chapter has supplemented such discussions by drawing on wider discussions of neurologically typical individuals in order to make the powerful end of the constructed binary visible, rather than focusing research attention primarily on the autistic end of the binary as has been the case in the majority of academic and professional research.

Throughout the discussions of diagnosis a lens informed by critical psychological theory was adopted, which enabled the examination of the powerful position accorded to professionals within the therapeutic relationship. It was through this critical lens that a questioning of the ontological nature of diagnosis could be posed, which was used to inform the debates surrounding the social model of disability, and specifically for this thesis, its applications to autism, an area to which the social model of disability has not formally been applied to before.

The final chapter of empirical analysis engaged with the socially constructed nature of autism at its most relational through an examination of the negotiations undertaken by an individual in accepting or rejecting a label of autism. In common with the analysis in the rest of the thesis, this chapter drew on contributions by professionals, parents and, crucially, people with autism engaging in their active construction of identity. In such a negotiation the positioning of autism as a deficit common to much professional literature was questioned in favour of a position of

neurodiversity, where autism was constructed as a difference. Through my empirical work I have demonstrated and stress this position of neurodiversity.

In presenting my analysis of these three core themes that I identified, my work makes several possible contributions to professional practice, and focuses on the importance of making alternative versions of autism visible, from which alternative constructions of a positive autistic identity become possible.

With respect to the methodology adopted for the thesis several areas are novel. The use of online methodology in order to conduct research with people with autism is not a new idea, and the benefits of computer mediated communication have been highlighted by several researchers (see for example Blume 1997a, 1997b, Strickland 1996). However, computer mediated communication and online research methodologies remains important in enabling researchers to contact populations who may have difficulty in interacting in traditional face to face situations, such as people with autism, and is therefore considered in the present thesis to be an important tool in enabling their voices to be heard amongst more dominant psychological literature.

My research is unique in its use of the online methodology. In researching within online discussion groups that exist independently of the research, the contributors to the discussion lists are therefore in control of the topics and pace of discussions, due to my being a silent member of the groups. In doing so my work enables adults with autism to speak for themselves rather than have others speaking for them and describing them. My work therefore documents people with autism speaking to each other, rather than answering questions posed by a researcher.

The second methodological issue that arises in my work is the population under study. The focus of my work is adults with autism due to their membership of the online lists and my work therefore documents how

adults with autism construct their identity rather than the main focus being on the study of children, which has dominated more traditional autism research. The examination of such constructions of autism by the contributors to the lists contributes to debates surrounding the dominant theory of mind hypothesis. Adults contributing to the research frequently discuss and reflect on complex issues such as the theory of mind hypothesis in sophisticated ways, and make complex comparisons between the two populations of NT and AS. In making comparisons complex discussions are engaged in concerning the differences between the two groups, frequently challenging professionally identified deficits in people with autism and positioning these as a consequence of the illogical behaviour of NTs, or drawing upon an inverted construction of diagnosis whereby neurologically typical is reconstructed as a syndrome in its own right. The challenge posed to much autism research concerning the perceived competencies of people with autism is an important application of the thesis, to which my discussions will now turn.

## **8.6 Applications of the thesis**

My research has focussed on valuing diversity and in doing so has demonstrated that people with autism can have sophisticated conversations with others in an online environment. This challenges stereotypes concerning the capability of people with autism. Also in valuing diversity it examines the positive attributes associated with autism which are traditionally constructed in a negative light. This challenges ideas raised in debates such as the links to MMR which frequently imply a position of people with autism forming a group of people that are less valued than their NT counterparts, and a group whose numbers we should strive to minimise (see for example O'Dell and Brownlow 2006).

My work highlights the many positive attributes associated with autism. The thesis therefore presents an argument for a more visible presence of the voice of people with autism within professional discourse and the diagnostic process and an examination of the implications for individuals

given the label of autism on their identity construction. By including the wider views of people with autism in professional constructions a less negative and stigmatised construction of autism can be presented. Drawing on discussions from community psychology (see for example Kagan and Burton 2000; Burton and Kagan 2005) my work is therefore useful in providing a critical analysis and commentary, often by people with autism, concerning the construction of autism. In doing so it draws on the voice of individuals with direct experience of autism, who are frequently positioned as less powerful in debates, and suggests a new agenda with which to discuss autism. This alternative construction of autism can feed into a more enabling vision of practice, as highlighted by Todd (2005), where the focus on the individual is moved from a source of change through professional interventions once labelled, to the individual as being positioned as an important co-constructor in any solution proposed.

However, with respect to a more positive and therefore potentially more empowering construction of autism, we need to be cautious in linking giving voice to empowerment, and issues of empowerment through research have led theorists to reflect on how this might arise. Zarb (1995) draws on the work of Oliver, and highlights that empowerment is not something that can necessarily be given through research; rather, it is something which people with disabilities must claim and own for themselves. Bhavnani (1990) notes that empowerment is not the same as 'giving voice'. According to Bhavnani, silences can be as empowering as 'giving voice'. Bhavnani further highlights that merely giving voice to a population in a given piece of research does not necessarily lead to empowerment. Bhavnani asserts that careful reflection must be given to the reasons for the silencing of particular voices in the first place. By not addressing such issues, the inclusion of certain voices in research outcomes assumes that they have an equal weighting in the debates with other more dominant voices.

Issues of empowerment raise important questions concerning the impact of online social movements in the non-virtual world. As previously discussed in the literature review, Seymour and Lupton (2004) question the impact of the Internet on disability politics, due to the anonymity that the Internet offers, and with it the opportunity to 'pass as non-disabled'. Seymour and Lupton propose that talking with people perceived as like-minded on the Internet may serve to 'ghettoise' disability discussions rather than presenting them as a challenge to the wider society. Such discussions may provide comfort and support for an individual but they do not challenge the fundamental issues that arise in the physical world. The authors question whether such private discussions isolate issues raised to become issues of the 'special world' of disability, rather than issues that society at large needs to address. Such discussions are proposed by Seymour and Lupton to fragment the political voice of people with disabilities.

While the ghettoisation of the online voice of people with autism is a concern, this research has highlighted a strong alternative discourse surrounding autism that is drawn upon by autistic people, who construct an alternative positive identity based on this. Some of the contributors to the online discussion groups studied for this piece of research crafted a strong AS identity with which they identified, frequently favourably positioned against an NT identity. In as much, these contributors were not seeking to 'pass as non-autistic', and appear neurologically typical; indeed quite the opposite goal was espoused, with some list members voicing a rejection of the dominant NT ways in favour of autistic understandings. While many of these discussions did occur between 'like-minded individuals', the collective positive acceptance of an alternative autistic identity was embraced by the majority of members of such lists, which also included several parents. The possibilities for an individual through constructing a more enabling version of autism may provide the leverage for influencing wider society, and the discourse pool for enabling an alternative construction of a more empowering identity must draw on a

range of discourse which can only freely operate and foster within such a group of individuals.

My research is therefore in line with that of Avery (1998) who proposes that there may be an influence on wider society from discussions online, but only if these are focused on empowerment and emancipatory goals. Avery proposes that interactions that solely focus on medical or emotional experiences will focus discussions on the circle of membership, and may consequently remain 'special issues'. Once members begin actively constructing new roles and identities for themselves which may pose challenges to traditional images, larger and more diverse audiences can be tapped into, and the talents and issues of the online community can be recognised more widely. By presenting an alternative construction of autistic traits (see for example discussions of neurologically typicals in chapter 5, and employment opportunities for adults with autism in chapter 7), the talents and positive contributions made by autistic people can be celebrated in the non-virtual world.

With respect to the applications of the work presented in the current thesis this raises important debates concerning how this celebration of neuro-diversity will be achieved. While the voices of people with autism are persuasive, and in certain groups where the membership is dominated by people with autism, more powerful than psy-professionals, this is not necessarily true in the wider psychological community operating outside of the discussion groups. The debates voiced and the positive constructions of autism must therefore be heard and seen within the context of the more dominant deficit model of autism prevalent in most autism research. As discussed in the literature review in chapter 3, the historical construction of normality and abnormality privileges the voice of psy-professionals in constructing the seemingly homogenous grouping of people with autism and the impairments associated with this. However through the publication of work drawing upon a more positive construction of autism in academic journals, such a voice can become more visible, and may inform mainstream debates concerning the

position of autism and the constructed competencies of people with autism. Kagan and Burton (2001) comment that a key task for community psychology is one of establishing a dialogue between people. The work presented in this thesis begins a dialogue between practitioners and people with autism, which involves constructing autism in an alternative and more positive light, and seeks to open up debates around valuing diversity. In doing so my work can inform critical pedagogy and encourage practitioners to reflect upon their own practices and engagement with people with autism, possibly employing alternative forms of assessment which make effective use of computer mediated communication, which this thesis has demonstrated that some people with autism embrace. In doing so people with autism could play an active role in strategies designed to assess their needs, and be a central role in discussions concerning the provision and support that may be offered to them.

## References:

- Abberlery, P. (1987). The concept of Oppression and the development of a Social Theory of Disability. *Disability, Handicap and Society*, 2(1), 5-19.
- Abberlery, P. (1997). The concept of Oppression and the development of a Social Theory of Disability. In L. Barton and M. Oliver (Ed.), *Disability studies: past, present and future* (pp. 160-178). Leeds: The Disability Press.
- Aitchison, C (2000) Poststructural feminist theories of representing Others: a response to the 'crisis' in leisure studies' discourse, *Leisure Studies*, 19, 127-144.
- Alderson, P. G., C. (1999). Autism in special and inclusive schools: 'there has to be a point to their being there'. *Disability & Society*, 14(2), 249-261.
- Andrews, K. (2002) Interpreting autism: a critique of Davidson on thought and language, *Philosophical Psychology*, 15(3), 317-332.
- Asperger, H. (1944). 'Autistic psychopathy' in childhood. In U.Frith (Ed.), *Autism and Aspergers Syndrome*. Cambridge: Cambridge.
- Atchakis, A. and Tzanne, A. (2005). Narrative positioning and the construction of situated identities. Evidence from conversations of a group of young people in Greece. *Narrative Inquiry*, 15(2), 267-291.
- Avdi, E., Griffin, C. and Brough, S. (2000) Parents' Constructions of the 'Problem' During Assessment and Diagnosis of their Child for an Autistic Spectrum Disorder, *Journal of Health Psychology*, 5(2), 241-254.
- Avery, D. M. (1998). Electronic Parenting or, It Takes A (Listserv) Village to Raise Families with Disabilities. *CMC Magazine*.
- Baker, D. L. (2006). Neurodiversity, neurological disability and the public sector: notes on the autism spectrum. *Disability and Society*, 21(1), 15-29.
- Bannister, P. Burman, E. and Parker, I. (1994) *Qualitative Methods in Psychology. A Research Guide*, Buckingham: Open University Press.
- Barnes, C. and Mercer, G. (Ed.). (1996). *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press.
- Barnes, C., Mercer, G. and Shakespeare, T. (1999) *Exploring Disability. A Sociological Introduction*, Cambridge: Polity Press.
- Barnes, M. and Shardlow, P. (1996). Identity Crisis: Mental Health User Groups and the 'Problem' of Identity. In C. Barnes and G. Mercer (Ed.), *Exploring the Divide* (pp. 114-134). Leeds: The Disability Press.

Barnard, J., Harvey, V., Potter, D. and Prior, A. (2001) *Ignored or ineligible? The reality for adults with autism spectrum disorders*, London: The National Autistic Society.

Baron-Cohen, S. Leslie, A. M. and Frith, U. (1985) Does the autistic child have a "theory of mind"?, *Cognition*, 21, 37-46.

Baron-Cohen, S. (1992). The theory of mind hypothesis of autism. History and prospects of the idea. *The Psychologist*, 5, 9-12.

Baron-Cohen, S. (1998) Does the Study of Autism Justify Minimalist Innate Modularity?, *Learning and Individual Differences*, 10(3), 179-192.

Barrett, M. (2006) "Like Dynamite Going Off In My Ears": Using autobiographical accounts of autism with teaching professionals, *Educational Psychology in Practice*, 22(2), 95-110.

Begum, N. (1996). General practitioners' role in shaping disabled women's lives. In C. Barnes and G. Mercer (Ed.), *Exploring the Divide* (pp. 157-172). Leeds: The Disability Press.

Begum, N., Hill, M. and Stevens, A. (1994). *Reflections: Views of Black Disabled People on their Lives and Community Care*. London: Central Council for Education and Training in Social Work.

Berners-Lee, T. W3C Director and inventor of the World Wide Web. Retrieved 30th June 2006

Bettelheim, B. (1959) Feral Children and Autistic Children, *American Journal of Sociology*, 64(5), 455-467.

Bhavnani, K. (1990) What's Power got to do with it? Empowerment and Social Research. In I. Parker and J. Shotter (eds) *Deconstructing Social Psychology*, London: Routledge, 141-152.

Billington, T. (2006). Working with autistic children and young people: sense, experience and the challenges for services, policies and practices. *Disability and Society*, 21(1), 1-13.

Bishop, D.V.M. (1989) Autism, Asperger's syndrome and semantic-pragmatic disorders: Where are the boundaries?, *British journal of disorders of communication*, 24, 107-121.

Blume, H. (1997a). Autistics are communicating in cyberspace. Retrieved 6th July 2000, from <http://www.nytimes.com/library/cyber/techcol/063097techcol.html>

Blume, H. (1997b). "Autism & the Internet" or "it's the wiring, stupid". Retrieved 27th June 2000, from <http://media-in-transition.mit.edu/articles/blume.html>

- Bogdan, R. and Taylor, S. (1976). The Judged, Not the Judges. An Insider's View of Mental Retardation. *American Psychologist*, 31, 47-52.
- Bogdan, R. and Taylor, S. J. (1989). Relationships with Severely Disabled People: The Social Construction of Humanness *Social Problems*, 36(2), 135-148.
- Bohman, N. (2003). Introduction to Web Accessibility. Retrieved 2nd December 2005, from <http://www.webaim.org/intro/>
- Booth, T. and Booth, W. (1996) Sounds of Silence: Narrative Research with Inarticulate Subjects, *Disability and Society*, 11(1), 55-69.
- Bowker, N. (1999, 5/10/99). Online Resources for People with Disabilities and their Potential Impact on Disability Identity: A preliminary analysis. Retrieved 5th June, 2001, from <http://bath.ac.uk/students/learning-support/webb/bowker.htm>
- Bowker, N. and Tuffin, K. (2002). Disability Discourses for Online Identities. *Disability and Society*, 17(3), 327-344.
- Bowler, D. M. (1992) "Theory of Mind" in Asperger's Syndrome, *Journal of Child Psychology and Psychiatry*, 33(5), 877-893.
- Braidotti, R. (1994). *Nomadic Subjects*. New York, Chichester West Sussex: Columbia University Press.
- Brownlow, C. and O' Dell, L. (2002). Ethical Issues for Qualitative Research in On-Line Communities. *Disability and Society*, 17(6), 685-694.
- Brownlow, C. and O'Dell, L. (2006) Constructing an autistic identity: AS voices online, *Mental Retardation*, 44(5), 315-321.
- Burks, M. A., P. Pardos, J. L., Waddell, L. and Nakane, M. (2000). The internet and people with disabilities: Expanding horizons or barrier to information and services. Retrieved 5th June, 2001, from [http://www.ISOC.org/inet2000/cdproceedings/5c/5c\\_1.htm](http://www.ISOC.org/inet2000/cdproceedings/5c/5c_1.htm)
- Burman, E. (1994). *Deconstructing Developmental Psychology*. London: Routledge.
- Burton, M. and Kagan, C. (2005) Marginalization. In G. Nelson and I. Prilleltensky *Community Psychology: In pursuit of wellness and liberation*, London: Palgrave MacMillan, pp. 293-308.
- Bury, M. (1996). Defining and researching disability: challenges and responses. . In C. Barnes and G. Mercer (Ed.), *Exploring the Divide* (pp. 18-38). Leeds: The Disability Press.
- Carrier, J. G. (1983) Masking the Social in Educational Knowledge: The Case of Learning Disability Theory, *American Journal of Sociology*, 88(5), 948-974.

- Case, S. (2000) Refocusing on the Parent: hat are the social issues of concern for parents of disabled children?, *Disability and Society*, 15(2), 271-292.
- Chappell, A., Goodley, D. and Lawthom, R. (2001). Making connections: the relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities*, 29(2), 45-50.
- Chappell, A. L. (1998). Still Out in the Cold: People with Learning Difficulties and the Social Model of Disability. In T. Shakespeare (Ed.), *The Disability Reader. Social Science Perspectives*. London: Cassell.
- Colby, K. M. (1968). Computer aided language development in non speaking children. *Archives of General Psychiatry*, 10, 641-652.
- Coomber, R. (1997) Using the Internet for Survey Research, *Sociological Research Online*, 2(2).
- Corker, M. (1999) New Disability Discourse, the principle of optimization and change. In M. Corker and S. French (Eds) *Disability Discourse*. Buckingham, Philadelphia Pa: Open University Press, p. 192-210.
- Costall, A. and Leuder, I. (2004). Where is the 'Theory' in Theory of Mind? *Theory and Psychology*, 14(5), 623-646.
- Cromby, J. and Standen, P. (1999). Cyborgs and Stigma: Technology, Disability, Subjectivity. In A. Gordo-Lopez and I. Parker (Ed.), *Cyberpsychology* (pp. 95-112).
- Danforth, S. and Navarro, V. (1998). Speech Acts: Sampling the Social Construction of mental Retardation in Everyday Life. *Mental Retardation*, 36(1), 31-43.
- Danforth, S. and Rhodes, W. C. (1997). Deconstructing Disability. A Philosophy for Inclusion. *Remedial and Special Education*, 18(6), 357.
- De Swaan, A. (1990). *The Management of Normality. Critical Essays in Health and Welfare*. London: Routledge.
- Dekker, M. (2000). On Our Own Terms: Emerging Autistic Culture. Retrieved 12<sup>th</sup> April 2007, from <http://autisticculture.com/index.php?page=articles>
- Denzin, N.K. (1999) Cybertalk and the Method of Instances. In S. Jones (ed) *Doing Internet Research. Critical Issues and methods for Examining the Net*, London: Sage, p. 107-127.
- Department for Education and Employment (DfEE) (1997) *Excellence for all children: Meeting special educational needs*, London: HMSO.
- Department for Education and Employment (DfEE) (1998) *Meeting special educational needs: A programme of action*, London: HMSO.

- Dosani, S. (2006) Special Intelligence, *The Guardian*, 18<sup>th</sup> November 2006, Work Section, 1-2.
- Duchan, J. F. (1993) Issues raised by facilitated communication for theorizing and research on autism, *Journal of Speech and Hearing Research*, 36(6), 1108-1119.
- Dyck, M. J., Ferguson, K. and Shochet, I. M. (2001) Do autism spectrum disorders differ from each other and from non-spectrum disorders on emotional recognition tests?, *European Child and Adolescent Psychiatry*, 10, 105-116.
- Edley, N. (2001) Analysing Masculinity: Interpretative Repertoires, Ideological Dilemmas and Subject Positions. In M. Wetherell, S. Taylor, and S.J. Yates (eds) *Discourse as Data. A Guide for Analysis*, London: Sage, p. 189-228.
- Eisenmajer, R., Prior, M., Leekam, S., Wing, L., Gould, J., Welham, M. and Ong, B. (1996) Comparison of Clinical Symptoms in Autism and Asperger's Disorder, *Journal of the American Academy of Child and Adolescent Psychiatry*, 35(11), 1523-1531.
- Fairclough, N. (1992) *Discourse and Social Change*, Cambridge: Polity Press.
- Fairclough, N. (2001) The Discourse of New Labour: Critical Discourse Analysis. In M. Wetherell, S. Taylor, and S.J. Yates (eds) *Discourse as Data. A Guide for Analysis*, London: Sage, p.229-266.
- Fernback, J. (1999). There is a There There. Notes towards a Definition of Cybercommunity. In S. Jones (Ed.), *Doing Internet Research. Critical Issues and Methods for Examining the Net*. Thousand Oaks, California and London: Sage, p.203-221.
- Ferrara, K, Brunner, H, and Whittemore, G. (1991) Interactive Written Discourse as an Emergent Register, *Written Communication*, 8(1), 8-34.
- Ferri, B. (2000). The Hidden Cost of Difference: Women with Learning Disabilities. *Learning Disabilities: A Multidisciplinary Journal*, 10(3), 129-138.
- Fodor, J. A. (1992). *A theory of content and other essays*. Cambridge MA: MIT Press.
- Folstein, S. E. (1999) Autism, *International review of Psychiatry*, 11, 269-277.
- Frith, U. (2003). *Autism. Explaining the Enigma* (Second ed.). Oxford: Blackwell.
- Gergen, K. (1985). The Social Constructionist Movement in Modern Psychology. *American Psychologist*, 40(3), 266-275.

Giese, M. (1998) Self without body: Textual self-representation in an electronic community, *First Monday, A Peer Reviewed Journal on the Internet*, 3(4). Available: [http://www.firstmonday.dk/issues/issue3\\_4/giese/index.html](http://www.firstmonday.dk/issues/issue3_4/giese/index.html). Accessed: 4th January 2007.

Goodley, D. (1996) Tales of Hidden Lives: A Critical Examination of Life History Research, *Disability and Society*, 11(3), 338-348.

Goodley, D. (2001). 'Learning Difficulties', the Social Model of Disability and Impairment: challenging epistemologies. *Disability and Society*, 16(2), 207-231.

Goodley, D. (2005) *Self-advocacy: Forming reliable alliances*. Paper presented at the ASSID 40<sup>th</sup> Annual Conference, 10<sup>th</sup> October 2005, Auckland, New Zealand.

Goodley, D., Armstrong, D., Sutherland, K. and Laurie, L. (2003) Self-Advocacy, "Learning Difficulties", and the Social Model of Disability, *Mental Retardation*, 41(3), 149-160.

Gordon, B. O. and Rosenblum, K. E. (2001). Bringing Disability into the Sociological Frame: a comparison of disability with race, sex, and sexual orientation statuses. *Disability and Society*, 16(1), 5-19.

Gray, D. E. (2002) 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism, *Sociology of Health and Illness*, 24(6), 734-749.

Guajardo, N. R. and Watson, A. C. (2002). Narrative Discourse and Theory of Mind Development. *The Journal of Genetic Psychology*, 163(3), 305-323.

Guo, B., Bricout, J. C. and Huang, J. (2005). A common open space or a digital divide? A social model perspective on the online disability community in China. *Disability and Society*, 20(1), 49-66.

Hacking, I. (1999) *The social construction of what?* Cambridge Massachusetts and London England: First Harvard University Press.

Happe, F. (1991) Autism: Cognitive deficit or cognitive style?, *Trends in Cognitive Style*, 3(6), 216-222.

Happe, F. (1994). *Autism. An Introduction to Psychological Theory* (2nd edition ed.). Oxford: Blackwell Publishing.

Hare-Mustin, R. T. and Marecek, J. (1997). Abnormal and Clinical Psychology: The Politics of Madness. In D. Fox and I. Prilleltensky (Ed.), *Critical Psychology. An Introduction* (pp. 104-120). London: Sage.

Harmon, A. (2004). How about not 'curing' us, some autistics are pleading. Retrieved 25th April, 2006, from [http://www.co-brass.com/articles/how\\_about\\_not\\_curing\\_us.htm](http://www.co-brass.com/articles/how_about_not_curing_us.htm)

- Haslem, B. (1996) Best-selling author denies she faked autism, *The Australian*, 30<sup>th</sup> July, p.3.
- Hermilin, B. and O'Connor, N. (1985). Logico-affective states and non-verbal language. . In E. Schopler and G. Mesibov (Ed.), *Communication problems in Autism*. New York: Plenum Press.
- Horn, S. (1998) *Cyberville: Clicks, Culture and the Creation of an Online Town*, New York: Warner Books.
- Houston, R. and Frith, U. (2000) *Autism in History. The case of Hugh Blair of Borgue*, Oxford: Blackwell.
- Hughes, B. and Paterson., K. (1997). The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment. *Disability & Society*, 12(3), 325-340.
- Institute for the Study of the Neurologically Typical (1998) Retrieved 17<sup>th</sup> July 2002 from <http://isnt.autistics.org/index.html>
- Itard, J-M-C (1932) *The Wild Boy of Aveyron*, New York and London: The Century Co., translated by George and Murial Humphrey.
- Joinson, A. N. (2000). *Self-disclosure, visual anonymity and self-awareness in computer-mediated communication*. Paper presented at the British Psychological Society London Conference, Institute of Education, 20<sup>th</sup> December 2000.
- Jones, R. S. P., Zahl, A. and Huws, J. C. (2001). First-hand Accounts of Emotional Experiences in Autism: a qualitative analysis. *Disability & Society*, 16(3), 393-401.
- Kagan, C. (2002) *Making the road by walking it*, Inaugural Professorial Lecture, Manchester Metropolitan University, 30<sup>th</sup> January 2002.
- Kagan, C. and Burton, M. (2000) Prefigurative Action Research: an alternative basis for critical psychology? *Annual Review of Critical Psychology*, 2, 1-15.
- Kagan, C. and Burton, M. (2001) *Critical Community Psychology Praxis for the 21<sup>st</sup> Century*. Paper presented at the British Psychological Society Conference, March 2001, Glasgow.
- Kagan, C. (2007) Working at the 'edge'. Making use of psychological resources through collaboration, *The Psychologist*, 20(1), 224-227.
- Kanner, L. (1943). Autistic disturbance of affective contact. *Nervous Child*, 2, 217-250.
- Kanner, L. (1972). *Child Psychiatry* (fourth ed.). Springfield and Fort Lauderdale: Charles C. Thomas.

- Keen, E. (1997) Psychiatric Power and Levels of Concealment, *Journal of Constructivist Psychology*, 10, 125-137.
- Kendall, L. (1999) Recontextualising cyberspace: Methodological considerations for on-line research. In S. Jones (ed) *Doing Internet Research*, Thousand Oaks, CA, and London: Sage, 57-75.
- Kitchin, R. (1998) 'Out of Place', 'Knowing one's place': space, power and the exclusion of disabled people. *Disability & Society*, 13(3), 343-356.
- Kitzinger, C. (1989). The Regulation of Lesbian Identities: Liberal Humanism as an Ideology of Social Control. In J. Shotter and K. J. Gergen (Ed.), *Texts of Identity* (pp. 82-98). London: Sage.
- Kitzinger, C., Wilkins, S. and Perkins, R. (1992) Theorizing Heterosexuality, *Feminism and Psychology*, 2(3), 293-324.
- Klein, F. (2002). Understanding Neurotypicality. Retrieved 19th September, 2002, from <http://home.att.net/~ascaris1/neurotypicality.htm>
- Konrad, S. C. (2005) Mothers of Children with Acquired Disabilities: Using the Subjective Voice to Inform Parent/Professional Partnership, *Journal of Death and Dying*, 51(1), 17-31.
- Kugler, B. (1998) The differentiation between autism and Asperger syndrome, *Autism*, 2(1), 11-32.
- Lawthom, R. and Goodley, D. (2005). Community Psychology. Towards an empowering vision of disability. *The Psychologist*, 18(7), 423-425.
- Leuder, I., Costall, A. and Francis, D. (2004). Theory of Mind: A Critical Assessment. *Theory and Psychology*, 14(5), 571-578.
- Llewellyn, A. and Hogan, K. (2000). The Use and Abuse of Models of Disability. *Disability & Society*, 15(1), 157-165.
- MacCallum, E. J. (2002). Othering and Psychiatric Nursing. *Journal of Psychiatric and Mental Health Nursing*, 9, 87-94.
- Mann, C. and Stewart, F. (2000) *Internet Communication and Qualitative Research. A Handbook for Researching Online*, London: Sage.
- Marks, D. (1993) Case-conference Analysis and Action Research. In E. Burman and I. Parker (eds) *Discourse Analytic Research. Repertoires and Readings of Texts in Action*, London: Routledge, p. 135-154.
- Marks, D. (1999). Dimensions of Oppression: Theorising the Embodied Subject. *Disability & Society*, 14(5), 611-626.
- Mason, S. M. and Hacker, K. L. (2006) Applying Communication Theory to Digital Divide Research, *IT and Society*, vol. 1, issue 5, pp. 40-55.

McClimens, A. (2003) The Organization of Difference: People With Intellectual Disabilities and the Social Model of Disability, *Mental Retardation*, 41(1), 35-46.

McLaughlin-Cheng, E. (1998) Asperger syndrome and autism: A literature review and meta-analysis. *Focus on autism and other developmental disabilities*, 13(4), 234-245.

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

Midence, K. and O'Neill, M. (1999) The experience of parents in the diagnosis of autism, *Autism*, 3(3), 273-285.

Miniwatts Marketing Group (2006) World Internet Usage and Population Statistics, <<http://www.internetworldstats.com/stats.htm>> accessed: 24<sup>th</sup> October 2006.

Molloy, H. and Vasil, L. (2002) The Social Construction of Asperger Syndrome: The pathologising of difference? *Disability and Society*, 17(6), 659-669.

Morgan, A. (2000) *What is Narrative Therapy? An Easy-to-Read introduction*, Adelaide:Dulwich Centre Publications.

Morgan, S. B. (1998) The Autistic Child and Family Functioning: A Developmental-Family Systems Perspective, *Journal of Autism and Developmental Disorders*,18(2), 263-280.

Morris, J. (1991). *Pride against prejudice*. London: Women's Press.

Morrisett, L. (1996) Habits of mind and a new technology of freedom, *First Monday, A Peer Reviewed Journal on the Internet*, 2(11). Available: <http://firstmonday.dk/issues/issue3/morrisett/>. Accessed: 4<sup>th</sup> January 2007.

Novas, C. and Rose, N. (2005) Genetic Risk and the Birth of the Somatic Individual. In M. Fraser and M. Greco (eds) *The Body. A Reader*, London and New York: Routledge.

Nguyen, H. T. and Kellogg, G. (2005). Emergent identities in online discussions for second language learning. *The Canadian Modern Language Review*, 62(1), 111-136.

O'Dell, L. and Brownlow, C. (2004). *Constructing a Theory of Mind: Reflections by people with autism*. Paper presented at the British Psychological Society Developmental Conference, Leeds Metropolitan University, 2<sup>nd</sup> - 5<sup>th</sup> September 2004.

O'Dell, L. and Brownlow, C. (2006) Media reports of links between MMR and autism: A discourse analysis. *British Journal of Learning Disabilities*. Accepted for publication.

Oliver, M. (1983). *Social Work with Disabled People*. Basingstoke: MacMillan.

Oliver, M. (1990). *The Politics of Disablement*. Basingstoke: MacMillan.

Oliver, M. (1996). Defining impairment and disability: issues at stake. . In C. Barnes and G. Mercer (Ed.), *Exploring the Divide* (pp. 29-54). Leeds: The Disability Press.

Ozonoff, S., South, M. and Miller, J. N. (2000) DSM-IV- defined Asperger syndrome: cognitive, behavioural and early history differentiation from high-functioning autism, *Autism*, 4(1), 29-46.

Parker, I. (1997a) Discursive Psychology. In D. Fox and I. Prilleltensky (eds) *Critical Psychology. An Introduction*, London: Sage, p. 284-298.

Parker, I. (1997b). *Deconstructing Psychopathology*. London: Sage.

Parker, I. (2005) *Qualitative Psychology. Introducing Radical Research*, Maidenhead: Open University Press.

Parker, I. and Burman, E. (1993) Against discursive imperialism, empiricism and constructionism: thirty-two problems with discourse analysis. In E. Burman and I. Parker (eds) *Discourse Analytic Research. Repertoires and Readings of Texts in Action*, London: Routledge, p. 155-172.

Parker, I., Georgaca, E., Harper, D., McLaughlin, T., and Stowell-Smith, M. (1995) *Deconstructing Psychopathology*, London: Sage.

Perkons. (1998, 20th September 1998). The Theory of Social Delusion. Retrieved 30th June 2006, from <http://www.autistics.org/isnt/socialdelusion.html>

Peterson, C. P. and Siegal, M (1999) Representing Inner Worlds: Theory of Mind in Autistic, Deaf, and Normal Hearing Children, *Psychological Science*, 10(2), 126-129.

Pinder, R. (1996). Sick-but-fit or fit-but-sick? Ambiguity and identity at the workplace. In C. Barnes and G. Mercer (Ed.), *Exploring the Divide* (pp. 135-156). Leeds: The Disability Press.

Portway, S. M. and Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk and Society*, 7(1), 73-83.

Potter, J. and Wetherell, M. (1987) *Discourse and Social Psychology: Beyond Attitudes and Behaviour*, London: Sage.

- Premack, D. (1978). *Intelligence in ape and man*. Hillsdale NJ: Erlbaum.
- Prior, M., Leekam, S., Ong, B., Eisenmajer, R. Wing, L., Gould, J. and 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.
- Radda, G. (2001) Medical Research Council Review of Autism Research. Epistemology and Causes, December 2001. Available: <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002394>, Accessed: 4<sup>th</sup> January 2007.
- Rao, S. (2006) Parameters of normality and cultural constructions of 'mental retardation': perspectives of Bengali families, *Disability and Society*, 21(2), 159-178.
- Rapley, M. (2004) *The Social Construction of Intellectual Disability*, Cambridge: Cambridge University Press.
- Rapley, M., Kiernan, P. and Antaki, C. (1998) Invisible to Themselves or Negotiating Identity? The Interactional Management of 'Being Intellectually Disabled', *Disability and Society*, 13(5), 807-827.
- Reeher, G. (2006) Log on, Tune off? The complex relationship between internet use and political activism, <<http://www.personaldemocracy.com/node/836>> accessed: 4<sup>th</sup> May 2006.
- Richards, G. (1996). *Putting Psychology in its Place. An Introduction from a Critical Perspective*. London: Routledge.
- Richardson, F. C. and Fowers., B. J. (1997). Critical Theory, Postmodernism and Hermeneutics: Insights for Critical Psychology. In D. F. a. I. Prilleltensky (Ed.), *Critical Psychology. An Introduction* (pp. 265-283). London: Sage.
- Rinaldi, A. (1996). The Net: User Guidelines and Netiquette. Retrieved 19th February, 2001, from <http://www.fau.edu/netiquette/net/index.html>
- Robins, K. (1995). Cyberspace and the World We Live In. In M. F. a. R. Burrows (Ed.), *Cyberspace, Cyberbodies, Cyberpunk. Cultures of Technological Embodiment* (pp. 135-156). London, Thousand Oaks and New Delhi: Sage.
- Rose, N. (1979). The Psychological Complex: Mental Measurement and Social Administration. *Ideology and Consciousness*, 5, 5-68.
- Rose, N. (1989a). Individualizing Psychology. In J. Shotter and K. J. Gergen (Ed.), *Texts of Identity* (pp. 119-132). London, Newbury Park and New Delhi: Sage.

- Rose, N. (1989b). *Governing the Soul. The Shaping of the Private Self*. London: Routledge.
- Rose, N. (1990). Psychology as a 'Social' Science. In I. Parker and J. Shotter (Ed.), *Deconstructing Social Psychology*. London: Routledge.
- Safran, S. P., Safran, J. S., and Ellis, K. (2003). Intervention ABCs for Children with Asperger Syndrome. *Topics in Language Disorders*, 23(2), 154-165.
- Schneider, E. (1999) *Discovering My Autism. Apologia Pro Vita Sua (with apologies to Cardinal Newman)*, London and Philadelphia: Jessica Kingsley.
- Selfe, L. (2002) Discussion Paper - Concerns about the Identification and Diagnosis of Autistic Spectrum Disorders, *Educational Psychology in Practice*, 18(4), 335-341.
- Seymour, W. and Lupton., D. (2004). Holding the line online: Exploring wired relationships for people with disabilities. *Disability and Society*, 19(4), 291-305.
- Schafer, L. (2005) Somewhere over the spectrum: Is Asperger syndrome Autism? Available: <http://lists.envirolink.org/pipermail/sareport/Week-of-Mon-20050103/000347.html>. Accessed: 4th January 2007.
- Scior, K. (2003) Using discourse analysis to study the experiences of women with learning disabilities, *Disability and Society*, 18(6), 779-795.
- Shakespeare, T. (1992). Renewing the social model of disability. *Coalition*, September, 40-42.
- Shakespeare, T. and Watson, N. (1997). Defending the Social Model. *Disability & Society*, 12(2), 293-300.
- Sharf, B. F. (1997). Communicating Breast Cancer On-line: Support and Empowerment on the Internet. *Women and Health*, 26(1), 65-84.
- Sharf, B. F. (1999) Beyond Netiquette. The Ethics of Doing Naturalistic Discourse Research on the Internet. In S. Jones (ed) *Doing Internet Research. Critical Issues and methods for Examining the Net*, London: Sage, p.243-257.
- Shea, V. (2005). A Perspective on the Research Literature Related to Early Intensive Behavioural Intervention (Lovaas) for Young Children with Autism. *Communication Disorders Quarterly*, 26(2), 102-111.
- Siddiquee, A. and Kagan, C. (2006) The Internet, Empowerment, and Identity: An Exploration of Participation by Refugee Women in a Community Internet Project (CIP) in the United Kingdom (UK), *Journal of Community and Applied Social Psychology*, 16, 189-206.

- Siedel, K. (2004/2006). Neurodiversity. Retrieved 25th April 2006, from <http://www.neurodiversity.com/>
- Smukler, D. (2005). Unauthorized Minds: How "Theory of Mind" Theory Misrepresents Autism. *Mental Retardation*, 43(1), 11-24.
- Soodak, L. C. and Erwin, E. J. (2000) Valued Member or Tolerated Participant: Parents' Experiences in Inclusive Early Childhood Settings, *Journal of the Association for Persons with Severe Handicaps*, 25(1), 29-41.
- Sproull, L. and Kiesler, S. (1991) *Connections: New ways of working in the networked environment*, Cambridge, MA: MIT Press.
- Stenner, P. (1993) Discoursing Jealousy. In E. Burman and I. Parker (eds) *Discourse Analytic Research. Repertoires and Readings of Texts in Action*, London: Routledge, p. 114-132.
- Strickland, D. (1996). A Virtual Reality Application with Autistic Children. *Presence. Teleoperators and Virtual Environments*, 5(3), 319-329.
- Suler, J. (1997). Psychological Dynamics of Online Synchronous Conversations in Text-Driven Chat Environments. Retrieved 17th May, 2002, from [www.rider.edu/users/suler/psycyber/psycyber.html](http://www.rider.edu/users/suler/psycyber/psycyber.html)
- Sullivan, H. (2006) The role of the non-disabled researcher in researching disability, *The Psychology of Education Review*, 30(1), 59-65.
- Sutcliffe, J. and Simons, K. (1995) *Self-Advocacy and Adults with Learning Difficulties*, Leicester: National Institute of Adult Continuing Education.
- Tager-Flusberg, H. (1999) A psychological approach to understanding the social and language impairments in autism, *International Review of Psychiatry*, 11, 325-334.
- Talamo, A. and Ligorio, B. (2001). Strategic identities in cyberspace. *CyberPsychology and Behaviour*, 4(1), 109-122.
- Thioux, M., Stark, D. E., Klaiman, C., and Schultz, R. T. (2006) The Day of the Week When You Were Born in 700 ms: Calendar Computation in an Autistic Savant, *Journal of Experimental Psychology: Human Perception and Performance*, 32(5), 1155-1168.
- Tissot, C., Bovell, V. and Thomas, S. (2001) Addressing system failures for children with autism, *Educational and Child Psychology*, 18(2), 63-75.
- Todd, L. (2006) Enabling Practice for Professionals: The Need for Practical Post-Structuralist Theory. In D. Goodley and R. Lawthom (eds.) *Disability and Psychology*, Basingstoke: Palgrave MacMillan, 141-154.

- Townson, L., Macauley, S., Harkness, E., Chapman, R., Docherty, A., Dias, J., Eardley, M. and McNulty, N. Carlisle Research 'Co-Operative' (2004) We are all in the same boat: doing 'people-led research', *British Journal of Learning Disabilities*, 32, 72-26.
- Tregaskis, C. (2000). Interviewing non-disabled people about their disability-related attitudes: seeking methodologies. *Disability & Society*, 15(2), 343-353.
- Treitler, I. (1996) Email for democracy? A commentary on Morissett's habit of mind and new technology of freedom, *First Monday A Peer Reviewed Journal on the Internet*, 1(3). Available: <http://www.firstmonday.dk/issues/issue3/treitler/index.html>. Accessed: 4th January 2007.
- Trepagnier, C. Y., Sebrechts, M. M., Finkelmeyer, A., Stewart, W., Wodford, J. and Coleman, M. (2006) Simulating Social Interaction to Address Deficits of Autistic Spectrum Disorder in Children, *CyberPsychology and Behaviour*, 9(2), 213-217.
- Urwin, C. (1985). Constructing Motherhood: the persuasion of normal development. In C. Steedman, C. Unwin and V. Walkerdine (Ed.), *Language, Gender and Childhood* (pp. 164-202). London, Boston and Henley: Routledge and Kegan Paul.
- UPIAS. (1976). *Fundamental Principles of Disability*. London: Union of the Physically Impaired Against Segregation.
- Van Dijk, T. A. (1998) Critical Discourse Analysis. Retrieved 20<sup>th</sup> June 2001 from <http://www.hum.uva.nl/~teun/cda.htm>
- Vernon, A. (1999). The Dialectics of Multiple Identities and the Disabled People's Movement. *Disability & Society*, 14(3), 385-398.
- Volkmar, F. R. (1998) Categorical Approaches to the Diagnosis of Autism. An Overview of DSM-IV and ICD-10. *Autism*, 2(1), 45-59.
- Waddell, C. D. (1998). *Applying the ADA to the Internet: A Web Accessibility Standard*. Paper presented at the Conference Name|. Retrieved Access Date|. from URL|.
- WAI. <http://www.w3.org/WAI/>.
- Walkerdine, V. (1999). Violent boys and precocious girls: regulating childhood at the end of the millennium. *Contemporary issues in early childhood*, 1(1), 3-23.
- Walmsley, J. (2001) Normalisation, Emancipatory Research and Inclusive Research in Learning Disability, *Disability and Society*, 16(2), 187-205.
- Walmsley, J. (2004) Inclusive learning disability research: the (nondisabled) researcher's role, *British Journal of Learning Disabilities*, 32, 65-71.

- Waltz, M. (2005). Reading case studies of people with autistic spectrum disorders: a cultural studies approach to issues of disability representation. *Disability and Society*, 20(4), 421-435.
- Ward, M. J., and Meyer, R. N. (1999). Self-determination for people with developmental disabilities and autism: Two self-advocates' perspectives. *Focus on Autism and Other Developmental Disabilities*, 14, 133-140.
- Wetherell, M. (1998) Positioning and Interpretative Repertoires: Conversation Analysis and Post-Structuralism In Dialogue, *Discourse and Society*, 9(3), 387-413.
- Wetherell, M. and Potter, J. (1989). Narrative Characters and Accounting for Violence. In J. Shotter. and K. J. Gergen (Ed.), *Texts of Identity* (pp. 206-219). London: Sage.
- Wimmer, H. and Perner, J. (1983). Beliefs about beliefs: representation and constraining function of wrong beliefs in young children's understanding of deception. *Cognition*, 13, 103-128.
- Wing, L. (1981) Asperger's syndrome: a clinical account, *Psychological Medicine*, 11, 115-129.
- Wing, L. (1996) *The History of Ideas on Autism: Legends, Myths and Reality*. Paper presented at the 5<sup>th</sup> Congress Autism-Europe, Barcelona, Spain.
- Wing, L. (1997). The Autistic Spectrum. *Lancet*, 350(9093), 1761-1767.
- Wong, S. I. (2000). At Home with Down Syndrome and Gender. *Hypatia*, 17(3), 89-117.
- Woods, J. J. and Wetherby, A. M. (2003) Early Identification of and Intervention for Infants and Toddlers Who Are at Risk for Autism Spectrum Disorder, *Language, Speech, and Hearing Services in Schools*, 34, 180-193.
- Zarb, G. (1995) Modelling the Social Model of Disability, *Critical Public Health*, 6(2), 21-29.
- Ziatas, K., Durkin, K. and Pratt, C. (1998) Belief Term Development in Children with Autism, Asperger Syndrome, Specific Language Impairment, and Normal Development: Links to Theory of Mind Development, *Journal of Child Psychology and Psychiatry*, 39(5), 755-763.

## **Appendix 1: Introductory e-mail to the discussion groups**

To all,

I have joined your group, with the permission of the list owner, to become involved in discussions of autism and ASD. I understand that your discussion list is mainly aimed at individuals who identify themselves as being ASD. I am a non-autistic researcher whose interests are in enabling the 'voice' of people with labels to be heard in the academic writings about autism spectrum disorders.

My hope is to join your discussion list for the period July until 30<sup>th</sup> November 2001. During this time I intend to be a silent observer. I will be examining the language surrounding the discussions of autism via the messages posted by members of the discussion list.

Confidentiality will be assured at all times, and no quotes will be taken from the group before prior consent by the individuals concerned has been attained. A summary of the main research themes will be sent to the group if requested once the research has been completed.

Please contact me off the list if you have any queries regarding the project. I look forward to working with you.

Charlotte Brownlow  
charlotte.brownlow@luton.ac.uk

## Appendix 2: Sample of raw data

### Discussion list A: people with autism

From: Edward  
Date sent: Fri, 31 Aug 2001 16:40:59 +0800  
Subject: **NT Strangeness**

Just a short note of my pending research...

As one of those struggling with the problems of human relationships, I had realized that NTs have amazingly peculiar lifestyles. I shall provide some of you here with a beginner's guide of their strangeness.

- "Playing Games" with each other

They often prize relational achievements more than intellectual achievements, and perhaps the pinnacle of their achievement lies with the amazing politicians that control their lives that hold as much prominence in them as the amazing scientists such as Albert Einstein holds in ACs.

Their games often unfold in intricate ways, so vast in scope and powerful in calculated effect that if they catch you unprepared you will suffer heavily without even knowing who set you on fire. Some of their games would seem incomprehensible, but from what I do understand, they often consider solutions that ACs would rule out because of "unfairness", that these goes against one's morals or that it violates some rule systems suchas the law.

Often, negative emotions such as anger, unhappiness, jealousy and the like motivate them in the games they play. if you had caused them embrassment especially when they show off stuff to others, then the more devious of these might subject you to difficult situations where they frame you, disseminate nasty gossip about you or do other nasty stuff similar to bullying you but in a non-physical manner. They do this even though it will take them more time and effort while they cannot gain anything back in return, because they want to seek "revenge" against you.

To you, such an (accidental and unknowing) transgression may appear as a non-event, but to them, they may not rest until they see you get back many multiples of what (they think) you had done to them. Even worse, they usually assume that you have the same negative emotions as them so they believe you had intentionally committed the transgression.

#### - Entertainment

They also like to (or unintentionally) play political games with each other, and often these games had hidden factors that will greatly confound an AC trying to get the hang of it. They often have the pasttime of watching TV soap operas with repetitive storylines where they perceive unbelievable storylines but still insisting on watching all the same, at the expense of the ACs trying to concentrate.

A good number of them also immerse themselves in sports, such as watching people kick a durable rubber sphere around a green grass field towards one of the two "goal-posts". They seem to delight in such passive participation even though this does not contribute to their intellectual ability that they can use in other areas.

Some NTs prefer to spend their money with luck as an arbitrator. They may buy lottery or gamble at the Casino, but as any beginning student of the Law of Probability and Economics knows, they actually almost always lose money in the long run. Yet they persist in such a strange behaviour to the extent of contributing a good part of their salary to this endeavor.

A good number of NTs, especially the more affluent and the teenage, like to set up on expeditions to the local shopping district with their favorite peer group. What meaningful things they do there remains a small mystery, but the author assumes that they take this opportunity to strength their social relationships and perhaps to flaunt their material possessions.

Some NT teenage girls, for instance, have the legendary ability to walk around the whole day trying on clothes and not purchasing anything at all.

Meanwhile, these exist groups of NT teens form tightly bonded social groups (i.e. gangs), which claim to rebel against "authority" and which can contribute to crime. One must take care to avoid such groups at all costs, for some of them take offense even if they saw you merely observing them. They use very little reasoning ability and tend to resort to violence to resolve issues.

Again, recall that NTs have a different mode of thinking if you find

yourself confused by such strangeness. Generally, NTs have a wield sense of the meaning of entertainment. One must take great care to differentiate NT and AC entertainment.

#### - Thinking Modes

They think of those with intellectuals who use logic in their discussions as "beyond" them, even though they should have no problems grasping logical thinking. As many other ACs had discovered, they don't "make sense". They can insist on the principle that everyone has equally valid opinions worthy of respect and yet they often insist you comply with their opinions.

Their beliefs seem to originate from from their peers, what they perceive from the limited viewpoints and what they perceive in the media. If the beliefs come from someone they trust or respect, then one will find it almost impossible to convince otherwise since they don't rationalize by true logic but their pseudo-logic built from half-baked arguments repeated ad infinitum by others.

As a result, they have a tendency to stick to their ideas to the bitter end of resulting huge inefficiencies, while remaining obviously unaware of the great disaster they had created for themselves.

We would find it best to understand their thinking in terms of a different logic than actual irrationality. A lot of what they like appearances above actuality (i.e. form above substance), and they think in this manner too.

To some of us we had learnt not to judge a book by its cover, but for NTs, more often than not, they base their decisions on frivolous reasons such as intentionally implementing the opposite advice of someone they dislike, or on what they call a "first impression" based on the initial impressions they get, or on their mood at the moment. Therefore an NT's decision can have significant randomness and one would have some difficulty predicting the actual decision.

#### - Social Hierarchies

NTs often play a game of comparison with each other. They compare their processions, qualifications, status, influence or whatever material items they take a fancy to with each other. Like preening peacocks, these games often end with NTs establishing some kind of "pecking order" where the person with the most of the compared item stays at the top with the second-most person below him or her and so on.

Often, some of these NTs "bluff" their way to a higher level in the social hierarchy via some deceit that comes at considerable cost to themselves. An NT can dress himself or herself to look very rich with a wide range of jewellery and expensive branded goods, even if he or she has the imminent danger of bankruptcy.

Their logic justifies this because they value their place in the social hierarchy more highly than their own financial problems. Again, in nature, you can see some of such behaviour with animals wanting to attract more mates to propagate their genes, and thus a study of animal mating behaviour and evolution will greatly aid your survival in NT society.

NTs often express themselves by appearances, just another step of what we can expect out of their logic. Even though some of these NTs dress, or even distort (such as by tongue-piercing or nose rings), themselves with items of no actual functionality, they intend to present these as their "personality" to others. Obviously, an NT wanting to emphasise his or her independence must choose a unique style of presentation, such as with peculiar hairstyles and rainbow colored hair.

Very soon, such NTs run out of unique configurations and thus appear more homogeneous. How they maintain the claim that their now similar styles set them apart from the "rest" appears as one of the mysteries of NT thinking.

Meanwhile, NTs also simultaneously have a liking for group homogeneity. Members often dress alike in some subtle or not so subtle manner. You could almost distinguish a long established social group from another by observing the similarities in their dress. They also share common beliefs and assumptions such as that a certain sports team always reigns supreme over others that they defend vigorously.

The most powerful expression of their idea lies with their concepts of groups. They have a tendency to treat groups as one entity, for instance of a married couple, a political party, business corporation or even an entire nation as one unified entity even when the individuals of these entities have real differences. Via this, one individual can claim to act for a group and cause massive conflicts, violence and inefficiencies to occur.

Some of them can also irrationally identify in the group even though they do not actually subscribe to the apparently prevalent thinking of that group (such as claiming "patriotism" in conducting a violent, forceful revolution that only they themselves want).

The most important flaw in their logic lies with its restrictive nature.

Their logic only applies to themselves, and they seem more interested with each other than their own self or about others things (especially abstract things like Fermat's Last Theorem).

They can only aspire to greatness among themselves, but not to improving their life's condition fundamentally. Their creativity and skills exist more for the purpose of improving their relationships with each other than for questioning of previous assumptions, discovery of new facts in a systematical manner and applying them.

#### - Information Networks

My most amazing discovery lies with the fact that NTs often execute frequent queries (i.e. gossip) over their social network systems that try to discover more data about other nodes and networks.

Like the CIA, they keep a huge mental database and inventory of who does what, who goes where, and everything you can think about a person's relationships with another. You would almost think that they read too much of George Orwell's "Big Brother" in their quest to find out all of other's relationships' trivia. This resembles an AC's internal "encyclopedia" and shows the ability of humans to use their memory storage systems for many distinct purposes.

Carrying the CIA analogy further, they often have a rather good ability in providing misinformation, especially if such misinformation can please others. Apparently, some of them do this under perceived duress that the other person will take offense at their words and reduce their relationship strength. This comes at a cost because they have to maintain a internal database of misinformation which they must look up on demand at very rapid speeds.

More amazingly, they can somehow use non-standard high speed transmission protocols, which psychologists had only partially deciphered, requiring the coordination of many part of the human body or the shifting of frequency ranges and other aspects of the human voice in subtle manners to establish the rules of their social network, synchronize with each other and thus avoid offending each other. An AC cannot hope to develop such transmission speeds and scope unless he or she receives an extraordinary amount of training, and even with this imperfections can still exist.

From this information network, an NT can derive a lot of power. Their strength lies with this ability to share information rapidly, but this also causes them to suffer from a corresponding weakness of distractibility and also the misinformation that exists on the network.

While an AC can penetrate part of their network with moderate effort, a very bad aspect of this network lies with that one would have to expend a lot of time and computing resources to make sense of it. Like the ultimate peer to peer "Gunella" network, you will have to differentiate valid data from invalid and act upon these, and you have to tap into the network long enough to find what you want. The network can provide you with serious misinformation as well as valuable information about your "allies" and "enemies".

- Conclusion

In conclusion, one would find it good curiosity to study the NT society, but not to live in it. The NT lifestyle appears either totally inconherent or rather primitive, and NTs in general, remain slaves to their own genetic codes than master of them.

This document by no means can cover the entire aspect of NT behaviour. Perhaps only the NTs really understand themselves, or perhaps they don't at all.

From: Bella  
Date sent: Fri, 31 Aug 2001 19:26:50 +1000  
Subject: **Feat News 28-29th August**

August 29, 3000

Search [www.feat.org/search/news.asp](http://www.feat.org/search/news.asp)

Understanding Autism: A PBS News Hour with Jim Lerher - Transcript

[William Walsh, a chemist and senior scientist at the Pfeiffer Institute in the Chicago area, says that his research shows that an imbalance of metals metabolism is at the source of autism and that compensating adjustments in nutrition is an effective treatment.]  
[http://www.pbs.org/newshour/bb/health/july-dec01/autism\\_8-24.html#](http://www.pbs.org/newshour/bb/health/july-dec01/autism_8-24.html#)

RAY SUAREZ: Now, understanding autism, a developmental disorder That afflicts about half a million people in this country. The cause is still A medical mystery, but some progress is being made. Elizabeth Brackett of WTTW-Chicago reports.

JEFF BOSCO: Zach, it's okay.

ELIZABETH BRACKETT: The screams of their unhappy little boy let Tami and Jeff Bosco know that something was wrong with their child.

TAMI BOSCO: Zachary was a difficult baby from the beginning, but

We just wrote it off that he was a stubborn, difficult child. The pediatrician, the doctor said, "you know, every once in a while, you just get a child like that." We couldn't take him anywhere. I mean, we basically just stayed home. He was fine in his home environment, but we couldn't take him to restaurants. I would have to leave the Target or the grocery store, with things still in my cart because he would just go into a complete rage. And I could not... I couldn't control him.

JEFF BOSCO: It was a full blown rage that could last for 20 to 30 minutes. And we did this for about six months to a year. We did this where he would have four or five rages a day. And that's when we knew that something just was not right.

Looking for an explanation

ELIZABETH BRACKETT: The Bosco family sought out Dr. Bennett Leventhal at the University of Chicago to help their son, Zachary. After three days of examinations, Dr. Leventhal gave them the diagnosis they had suspected and feared: Zachary had a form of autism.

JEFF BOSCO: It did feel like the bomb dropped on our house, because what was relayed to us was we've tested, after two and a half days of testing, his IQ is below 70. At that time, he wasn't saying any words. We don't know if he'll ever speak. And then they give you an article that says, well, you know, 80 percent of these kids have to be put into an institution.

TEACHER: Water. Look, it's getting wet.

ELIZABETH BRACKETT: Children in this after-school program outside of Chicago have all been diagnosed with a form of autism. Autism is a complex developmental disability that typically appears during the first three years of life. It affects normal brain development, making it harder for the autistic child to communicate with others and relate to the outside world. There are several types of autism. In the standard psychiatric handbook, they're all grouped under the heading "pervasive developmental disorder."

There have been many theories as to what causes autism. One of the early theories, says Dr. Leventhal, was to blame the child's mother.

DR. BENNETT LEVENTHAL: It was thought that children were, initially when they were first born and the first few weeks or months of life, tended to turn inward, and it was the mother's job to coax the child to join the rest of the world. We now know that is completely untrue.

ELIZABETH BRACKETT: Are there any known causes of autism?

DR. BENNETT LEVENTHAL: Well, I think there is no doubt today that it is an abnormality in the way the brain develops, and there is strong evidence to suggest that at least the predominant cause is genetic, although there is clearly some evidence that other kinds of events can cause the same kind of brain damage.

How to treat autism

ELIZABETH BRACKETT: When the answer is autism, what do parents do? Traditional psychiatry has offered very few answers. But scientists here at the Pfeiffer Institute in Naperville, Illinois, believe they

have identified the cause of autism, or at least its major contributing factor.

WILLIAM WALSH: We may have found a cause of autism.

ELIZABETH BRACKETT: William Walsh, a chemist and senior scientist at the Pfeiffer Institute, bases his new and controversial finding on the study of 503 children who have been diagnosed as autistic by their own physicians.

WILLIAM WALSH: We found they all had the same severe problem. We found that every single autistic that we saw has a rather remarkable really nasty error of metal metabolism. It seems to be inborn and genetic, and... it's an inability of a particular protein to function. A protein that's supposed to be managing our metals-- it's called metallothionein-- that protein is not doing its job. And so you get all these crazy levels of metals in their brain and in their blood, but it also is the very same system that has the job of keeping toxic metal from harming us.

ELIZABETH BRACKETT: Walsh presented the results of the analysis Done in his labs at the American Psychiatric Association meeting in May. But it has not yet been published in a peer review journal. Walsh found the Metal metabolism imbalance by analyzing samples of the children's blood, urine and hair. He says to his surprise, he found problems with the protein metallothionein in all but four of the 503 autistic children, no matter what kind of autism they had been diagnosed with.

WILLIAM WALSH: You find that there is a chemical imbalance in the brain, then it can be changed. One can tinker with the chemistry and hopefully help the patient.

ELIZABETH BRACKETT: Walsh has been studying disorders of metal metabolism for the past 25 years. (Beethoven's Fifth Symphony playing) He garnered national attention last year after determining that Ludwig Van Beethoven had died from lead poisoning.

WILLIAM WALSH: This is Beethoven's hair.

ELIZABETH BRACKETT: He did it by analyzing 170-year-old strands of the famous composer's hair. Walsh began trying to understand what elements in the autistic child's body or brain chemistry had gone awry. This research led to what he saw as a remarkably high correlation between autism and metal metabolism imbalance as a result of the disordered metallothionein proteins.

But Dr. Leventhal remained skeptical.

DR. BENNETT LEVENTHAL: There is a tricky problem here. One is in order to do the kind of studies that are likely to tell us the causes of Disorders like autism, ADHD and others, you have to very, very precisely define the characteristics that make up your diagnosis. So I don't know in this particular study what his diagnostic criteria are. Just to say they have autism isn't sufficient. There's second this always of concern to us, and that is measuring things in the blood is not necessarily measuring anything related to what's going on in the brain. So we always have to be very careful about generalizing from blood measurements to brain functioning.

An unclear search

ELIZABETH BRACKETT: Dr. Robert DeVito is the senior consulting scientist at the Pfeiffer Center. He is the former director of the Illinois Department of Mental Health. He is urging the medical community to test Walsh's theory. Dr. Walsh says he has found the cause of autism. Is that too bold a statement?

DR. ROBERT DeVITO: Well, that's a bold statement and I think he's entitled to say that. I wouldn't go that far, but I would say that he has come up with something that is tremendously important, and I think it should be given a very adequate trial within the scientific community, because

I think a lot of good can come from this. But you want to make sure that you're right because it affects a lot of people, and it affects people in such profound ways that it needs... It needs a real good review.

ELIZABETH BRACKETT: After believing that he had identified metal metabolism problems as a cause of autism, Walsh devised treatment that seeks to balance the autistic child's body chemistry.

WILLIAM WALSH: We give them nutrients that stimulate the production of that protein. We're trying to get the metallothionein protein that's disordered working again. And if that happens, then the toxics that they've accumulated will naturally leave. They will be protected in the future from the environment with the toxics because it will be working, and their brain levels of copper and zinc and these other important meta will normalize.

DR. BENNETT LEVENTHAL: There is no evidence to suggest that there is any dietary intervention that makes a significant difference in any Behaviour disorder -- not just autism. And so one has to be very, very careful until one can look at the study and say, was it appropriately done methodologically and published?

ELIZABETH BRACKETT: Devastated after the autism diagnosis for Zachary, the Bosco family came to the Pfeiffer Clinic for help. The Boscos began working with Walsh to balance their son's body chemistry. The nutrient supplements cost them between \$40 and \$140 each month. A portion of the clinic visits are covered by the Boscos' medical insurance, but the supplements are not. They say they saw the difference almost immediately, and that when Zachary is not taking the supplements, he regresses.

TAMI BOSCO: And once we started on the vitamin and supplements, he was a changed child. A good way to put it is he was in our world now instead of Zach's world. His eye contact was better, his behavior was a lot better. He said "mommy" and "daddy" for the first time.

ELIZABETH BRACKETT: But Dr. Leventhal remains unconvinced that supplements can be credited with improving the behavior of autistic children.

DR. BENNETT LEVENTHAL: All children with autism, as best we can tell, get better over time, almost in spite of what we do to them. The question really is: Can we do things that enhance the amount of getting better? And I think there is plenty of evidence that suggest that speech and language therapy and good educational programming really makes a big difference in the ultimate outcome.

JEFF BOSCO: Most psychiatrists would probably say due to the schooling, due to the speech therapy and the OT therapy you're giving him, that's why he's better. And I don't deny that that's helping. That is only one piece of this puzzle. There is another piece to the puzzle, that biochemically these kids need to be treated and treated with something that balances their body.

ELIZABETH BRACKETT: Walsh and his patients continue to like the results they see from the effort to balance the autistic child's metal metabolism. Walsh hopes to publish his results in a peer reviewed medical journal in the next six months.

[Brief Commentary: Ignoring the mounting chorus of anecdotal Reports of resulting symptom improvements from parents who make a variety of dietary changes for their autistic children, traditional medical clinicians insist there is no evidence that nutritional factors have anything directly to do with the symptoms of autism and so refuse to get acquainted with, much less suggest these treatments (like the practitioner in the above report).

[However, for decades, lack of scientific evidence did not stop The medical profession from the barbaric and incorrect insistance that Autism was the result of emotionally distant mothering practices. Then as now, the medical experts are choosing to ignore the reality of parents of Children with autism (and now choosing instead to safely wait for the results of scientific studies yet to be designed, proposed, funded, reviewed and published, before considering any treatment alternatives). Is it any surprise to find parents turning away from standard medical opinions about autism in droves over the last decade? -LS]

From: Bella  
Date sent: Fri, 31 Aug 2001 19:26:49 +1000  
**Subject: joke**

A man walked into a crowded doctor's office. As he approached the desk, the receptionist asked, "Yes sir, may we help you?"

"There's something wrong with my dick," he replied.

The receptionist became aggravated and said, "You shouldn't come into a crowded office and say things like that."

"Why not? You asked me what was wrong and I told you." he said.

"We do not use language like that here," she said. "Please go outside and come back in and say that there's something wrong with your 'ear' or whatever."

The man walked out, waited several minutes and reentered. The receptionist smiled smugly and asked, "Yes?"

"There's something wrong with my 'ear'," he stated. The receptionist nodded approvingly. "And what is wrong with your ear, sir?"

"I can't piss out of it." the man replied.

From: Bella  
Date sent: Fri, 31 Aug 2001 19:26:59 +1000  
Subject: **Feat News - 29th August**

Success for Ulster Boy's Asperger Book

[By Kathryn Torney in the Belfast Telegraph.]  
<http://www.belfasttelegraph.co.uk/today/aug27/News/5front.shtml>

A child author from Co Down has already sold almost 6,000 copies Of his first book, it emerged today.

Kenneth Hall, from Holywood, wrote the page turner last year based On his experiences of having Asperger Syndrome - a form of autism.

The 12-year-old's book has since been sold throughout the UK and America and will also soon be published in Japanese and Swedish.

The 96-page book - entitled Asperger Syndrome, the Universe and Everything - had to be reprinted just 10 days after its release due to The demand. The youngster, who is a Mensa member, received additional good news this week when he was awarded an A grade in GCSE Information Technology.

He sat the exam at the age of 11 - five years earlier than most of His peers.

Last year, Kenneth was the youngest person in the province to pass A GCSE exam when he received a B for the Maths exam he sat when he was just ten years old.

Kenneth's mum Brenda Boyd said: "We have received a lot of emails And letters from people who have read the book including children and parents. "It is very exciting that the book is now going to be translated into other languages and it is nice for Kenneth that it has had such an impact.

"He has no plans at the moment to do more exams but I think if There was a GCSE in Pokemon he would do that!"

Kenneth said: "I did enjoy writing the book and I hope it will Help people learn more about AS and autism."

Publisher Jessica Kingsley said: "Asperger Syndrome touches a lot Of people's lives, and Kenneth's book speaks very directly to them, which Is why it has sold so well.

"One of the nicest things for us is that we have had so much

Feedback from people who really appreciate the book and the way it has helped them to understand Asperger Syndrome.

"We've heard of lots of parents who have given it to their Asperger children and that child's siblings, and the overriding impression is of delighted understanding, and relief that they are not alone.

The book is available from amazon.co.uk, direct from the publisher's website [www.jkp.com](http://www.jkp.com) or from bookshops.

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August 29, 2001      News Morgue Search  
[www.feet.org/search/news.asp](http://www.feet.org/search/news.asp)

### Study Challenges Vaccines: Pertus., Tetanus, Diph., MMR Cause Seizures

The Risk of Seizures after Receipt of Whole-Cell Pertussis or Measles, Mumps, and Rubella Vaccine

Volume 345:656-661 August 30, 2001 Number 9

<http://content.nejm.org/cgi/content/abstract/345/9/656>

William E. Barlow, Ph.D., Robert L. Davis, M.D., M.P.H., John W. Glasser, Ph.D., M.P.H., Phillip H. Rhodes, Ph.D., Robert S. Thompson, M.D., John P. Mullooly, Ph.D., Steven B. Black, M.D., Henry R. Shinefield, M.D., Joel I. Ward, M.D., S. Michael Marcy, M.D., Frank DeStefano, M.D., Virginia Immanuel, M.P.H., John A. Pearson, M.D., Constance M. Vadheim, Ph.D., Viviana Rebolledo, B.S., Dimitri Christakis, M.D., M.P.H., Patti J. Benson, M.P.H., Ned Lewis, M.P.H., Robert T. Chen, M.D., for the Centers for Disease Control and Prevention Vaccine Safety Datalink Working Group

#### ABSTRACT

**Background** The administration of the diphtheria and tetanus Toxoids and whole-cell pertussis (DTP) vaccine and measles, mumps, and rubella (MMR) vaccine has been associated with seizures.

We studied the relation between these vaccinations and the risk of A first seizure, subsequent seizures, and neurodevelopmental disability in children.

**Methods** This cohort study was conducted at four large health maintenance organizations and included reviews of the medical records of children with seizures. We calculated the relative risks of febrile and nonfebrile seizures among 679,942 children after 340,386 vaccinations

with DTP vaccine, 137,457 vaccinations with MMR vaccine, or no recent vaccination. Children who had febrile seizures after vaccination were followed to identify the risk of subsequent seizures and other neurologic disabilities.

**Results** Receipt of DTP vaccine was associated with an increased Risk of febrile seizures only on the day of vaccination (adjusted relative risk, 5.70; 95 percent confidence interval, 1.98 to 16.42). Receipt of MMR vaccine was associated with an increased risk of febrile seizures 8 to 14 days after vaccination (relative risk, 2.83; 95 percent confidence interval, 1.44 to 5.55).

Neither vaccination was associated with an increased risk of nonfebrile seizures. The number of febrile seizures attributable to the administration of DTP and MMR vaccines was estimated to be 6 to 9 and 25 to 34 per 100,000 children, respectively. As compared with other children with febrile seizures that were not associated with vaccination, the children who had febrile seizures after vaccination were not found to be at higher risk for subsequent seizures or neurodevelopmental disabilities.

**Conclusions** There are significantly elevated risks of febrile seizures after receipt of DTP vaccine or MMR vaccine, but these risks do not appear to be associated with any long-term, adverse consequences.

**Source Information**

From the Immunization Studies Program, Center for Health Studies, Group Health Cooperative, Seattle (W.E.B., R.L.D., R.S.T.); the Department of Biostatistics, University of Washington, Seattle (W.E.B.); the National Immunization Program, Vaccine Safety and Development Activity, Centers for Disease Control and Prevention, Atlanta (J.W.G., P.H.R., F.D., R.T.C.); the Center for Health Research, Northwest Kaiser Permanente, Portland, Oreg. (J.P.M.); the Division of Research, Kaiser Permanente of Northern California, Oakland (S.B.B., H.R.S.); the UCLA Center for Vaccine Research, Harbor-UCLA Medical Center, Torrance, Calif. (J.I.W.); and the Kaiser-UCLA Vaccine Research Group, Southern California Kaiser Permanente, Panorama City, Calif. (S.M.M.). and other authors.

\* \* \*

## Parents Don't Accurately Judge Kid's Intelligence

[Another study to point out just how incompetent parents are when It comes to their kids. This is important information to have if your Agenda is to mitigate flawed, non-progressive parental authority with the Expertise of medical, public health and education experts and their government agencies. Someone has to break the cycle of domestic mediocrity, after all.

It's not automatic that doing this would require the further growing of government, either. It just might be a matter of giving the folks already there something to do. Maybe the GAO can do its own study of the matter.

By

Melissa Schorr via Reuters Health. -LS.]

Parents may be unable to accurately assess their child's intelligence, potentially blaming poor school performance on attention-deficit disorder rather than lack of smarts, according to research presented here Monday at the annual meeting of the American Psychological Association.

"Parents perceptions of their children's intellectual level did Not correspond with the children's obtained intellectual scores, as measured by an IQ test," said study author Jennifer J. Selden, a doctoral candidate in psychology at Nova Southeastern University in Ft. Lauderdale, Florida.

"Where a parent might think, 'My kid is gifted,' the kid didn't confirm that." Selden measured 43 children self-referred for attention-deficit/hyperactivity disorder (ADHD), using scales that measure a child's development, achievement and intellect. Their average age was 10.

Parents, the vast majority of whom were the children's mothers, Were then asked to assess their child's ability using a questionnaire. While the parents were able to accurately assess their child's development and achievement in terms of schoolwork, they were highly inaccurate when it came to assessing their child's intelligence.

"Based on this research, we should be wary of parents' claims About intellect," Selden said. "A parent might come in saying 'My kid is Really bright, but they're not performing well in school, obviously they have ADHD,' blaming it on that. Well, maybe the kid is not that bright after all," she explained.

"Parents have a tendency to label what the problem is," Selden added.

"But in particular with intelligence, they're not reflecting it accurately, so that is good reason to be cautious when they come in making these contentions."

However, not all the parents overestimated their children's intelligence, she noted. Some placed their child's intelligence well below its measured level to explain the child's deficiencies at school. "It works both ways,"

Selden pointed out. "Where the parent says 'My kid is below average,' The kid may really be okay with intelligence, but just misbehaving."

Selden said although there is some possibility the scale measuring intelligence was flawed, this is unlikely because it has been extensively tested for validity in the past. "There's more reason to believe it's the parental end that are skewing things."

The finding may generalize to parents who bring their children in for treatment for other emotional or behavioral problems as well, Selden said.

"When parents are trying to justify...a problem," she says, "that's when they start hypothesizing."

\* \* \*

UK Parents Call For MMR Vaccine Inquiry

[From BBC News online.]  
[http://news.bbc.co.uk/1/hi/english/health/newsid\\_1513000/1513108.stm](http://news.bbc.co.uk/1/hi/english/health/newsid_1513000/1513108.stm)

A majority of parents believe a public inquiry should be held into the safety of the controversial MMR vaccine.

However, the government's deputy chief medical officer says that the issue has already been extensively researched both at home and abroad.

A survey for the BBC Radio 4's Today programme found while three-quarters of parents thought the MMR vaccine was safe, more than six out of 10 said parents should have the option of separate jabs for their children.

MMR is a combined vaccine giving protection against measles, mumps and rubella.

But some research has linked the vaccine to an increased risk of autism and bowel disorders - although large scale studies have failed to find any link between MMR and ill health.

Campaigners say it is wrong that parents in the UK are not given the option of three separate jabs for the different conditions.

In rare cases, measles can kill children or leave them severely disabled.

The Department of Health - which is backed by the overwhelming majority of medical opinion - has stressed the combined vaccine poses no health risk to children.

Studies commissioned by the Department of Health, the World Health Organization and public bodies in America have rejected any link between the MMR and disorders such as autism.

Officials say that children are at increased risk of disease if their parents opt for separate vaccines because of the time lag involved.

They have also warned that if children are not immunised with MMR in sufficient numbers the risk of a measles epidemic is sharply increased.

Repeated assurances

However, despite repeated public assurances about the safety of the combined vaccine, it seems that some parents still continue to harbour doubts.

Gillian Brockley, from Connah's Quay, north Wales, chose to travel 125

miles to Worcester so that her daughter could have separate vaccines.

She said: "It should be the parents' choice. If they want it all in one go then fine, but if they don't feel comfortable with that then they should be able to make the choice.

"At the moment there isn't any choice apart from having to pay extra and having to travel all this way."

Dr Audrey Boucher, a GP from Whitchurch, Hampshire, said she could understand why some parents still harboured concerns.

"There's a constant drip feed of stories in the press and radio and television about MMR and after BSE who can blame anybody for not believing the government?

"But I'm quite sure that MMR is in the best interests of their child."

Dr Pat Troop, deputy chief medical officer, said: "Obviously when

You hear concerns - which we take very seriously - we have gone back and back and back to the research community and all the expert groups to make sure we are offering something that is safe.

"We have had lots and lots of independent inquiries already where everybody's viewpoint, all the evidence has already been reviewed and I'm not sure by going over it all again we would come up with anything different."

Liberal Democrat Health spokesman Dr Evan Harris said: "Scientific research cannot be a slave to opinion polls. Medical research must proceed on the basis of published, properly scrutinised data.

"All the data so far suggests that the MMR vaccine is the safest option."

Rebellious GP

Next month the General Medical Council will hear the case of former GP Dr Peter Mansfield.

Dr Mansfield, 58, was reported to the GMC after he gave children single immunisation jabs instead of the combined MMR vaccine.

He believes families should have the right to choose single vaccinations instead of the MMR jab even though it is recommended by the Department of Health.

Up to 400 children have received the single immunisations from Dr Mansfield at a clinic he runs in Worcester in the past year.

He has also given single jabs to a further 300 children at his practice in Louth, Lincolnshire.

Dr Mansfield was reported to the GMC by a health authority in Worcester, which accused him of putting children at risk.

The survey, carried out by the polling organisation ICM, was based on telephone interviews with more than 1,000 people.

\* \* \*

Poor Visual Processing, Oscillatory Brain Activity In Autism, Williams Syn.

Disordered visual processing and oscillatory brain activity in autism  
And Williams Syndrome

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list>

ui  
ds=11522950&dopt=Abstract

1: Neuroreport 2001 Aug 28;12(12):2697-2700

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University of London, WC1E 7HX, UK.

Two developmental disorders, autism and Williams syndrome, are Both commonly described as having difficulties in integrating perceptual features, i.e. binding spatially separate elements into a whole.

It is already known that healthy adults and infants display electroencephalographic (EEG) gamma-band bursts (around 40 Hz) when the brain is required to achieve such binding.

Here we explore gamma-band EEG in autism and Williams Syndrome and demonstrate differential abnormalities in the two phenotypes. We show that despite putative processing similarities at the cognitive level, binding in Williams syndrome and autism can be dissociated at the Neurophysiological level by different abnormalities in underlying brain oscillatory activity.

Our study is the first to identify that binding-related gamma EEG Can be disordered in humans.

PMID: 11522950 [PubMed - in process]

From: Bella  
Date sent: Fri, 31 Aug 2001 19:26:47 +1000  
Subject: jokes

[\[ Double-click this line for list subscription options \]](#)

After a few days, the Lord called to Adam and said, "It is time for you and Eve to begin the process of populating the earth so I want you to kiss her." Adam answered, "Yes Lord, but what is a 'kiss?'" So the Lord gave a brief description to Adam who took Eve by the hand and took her to a nearby bush.

A few minutes later, Adam emerged and said, "Thank you Lord, that was enjoyable."

And the Lord replied, "Yes Adam, I thought you might enjoy that and now I'd like you to caress Eve." And Adam said, "What is a 'caress?'" So the Lord again gave Adam a brief description and Adam went behind the bush with Eve.

Quite a few minutes later, Adam returned, smiling, and said, "Lord, that was even better than the kiss." And the Lord said, "You've done well Adam. And now I want you to make love to Eve." And Adam asked, "What is 'make love' Lord?" So the Lord again gave Adam directions and Adam went again to Eve behind the bush, but this time he reappeared in two seconds.

And Adam said, "Lord, what is a 'headache?'"

From: Bella  
Date sent: Fri, 31 Aug 2001 19:27:05 +1000  
Subject: **Feat News - 29-30th aug**

August 30, 2001

## Therapies Push Injured Brains and Spinal Cords Into New Paths

[By Sandra Blakeslee in the NY Times.]

[http://www.nytimes.com/2001/08/28/health/anatomy/28REHA.html?page\\_wanted=pr](http://www.nytimes.com/2001/08/28/health/anatomy/28REHA.html?page_wanted=pr)

in  
t

At a growing number of rehabilitation centers, stroke patients Move around with their limbs tightly bandaged, mummy style. Toddlers with cerebral palsy are ensconced in partial body casts.

Paraplegics are slung in harnesses and made to walk on treadmills, with automatic equipment moving their feet. Even the blind are having their brains reconfigured with a special camera that allows them "see" via a device worn on the tongue.

Rehabilitation may never look the same. Like engineers in thrall to A new idea, many of the doctors and therapists who help patients with Brain injuries are using revolutionary insights about the brain to coax the nervous system into rewiring itself.

But even as new approaches show promise, much uncertainty remains about which patients, if any, are likely to benefit from specific treatments. And the amount of rehabilitation time that is covered by Medicare and private insurers is shrinking just as the patients' options Are growing.

The new rehabilitation strategies stem from the realization that The brain makes new neurons in adulthood, and from indications in animals that these cells may be able to migrate to areas damaged by disease or injury.

Moreover, researchers know that activity can keep neurons from atrophying.

The challenge is translating that increasingly dynamic view of the brain into useful therapies, said Dr. Susan Fitzpatrick, vice president of the James S. McDonnell Foundation in St. Louis, which promotes research on the mind, the brain and behavior.

Of the half-million people who survive strokes each year, a third recover spontaneously. A quarter are too severely injured to benefit from therapy.

The rest can be helped to varying degrees by conventional therapy. It is too soon to know how many people may be helped with the new approaches.

Most physicians adopt a wait-and-see attitude after a brain injury because they are pessimistic, said Dr. Jordan Grafman, a neurologist at

the National Institute of Neurological Diseases and Stroke.

"They recommend rehabilitation therapy more out of a sense that something has to be done than a real expectation that it will help the patient," Dr. Grafman said.

To assess where the new therapies are headed, the McDonnell Foundation invited 30 leading research scientists and rehabilitation therapists to Birmingham in July for a two-day meeting.

Dr. Pamela W. Duncan, director of the Center on Aging at the University of Kansas Medical Center in Kansas City, said at the meeting That the new insights should be greeted cautiously. "The insights hold great promise but we must proceed with caution," Dr. Duncan said. "It is Premature to know exactly how beneficial the therapies may be for most patients."

Some patients are very sick and confused, Dr. Duncan said, and nothing much can help them, while others may benefit enormously. So far, she said, there are more questions than answers: Who decides which patients are candidates for the therapies? What is the definition of improvement or recovery? And, more important, who will pay? A few years ago, Dr. Duncan said, stroke patients who qualified for Medicare services got three weeks of rehabilitation care.

Now they get about 11 days.

Medicare is cutting back because the cost of rehabilitation Services rose to \$30 billion in 1996 from \$2.5 billion in 1986.

When patients with brain and spinal cord injuries hear about Seemingly miraculous new treatments, said Dr. Anne Shumway-Cook, an associate professor and rehabilitation therapist at the University of Washington, they pressure therapists to provide them.

Frustrated that ordinary methods — like teaching a patient to get dressed using only one hand — do not do much, especially in 11 days or so, many therapists are offering the new treatments without quite knowing how they work, Dr. Shumway-Cook said. If a method fails, no one knows if it was a problem with the technique or with the way it was being delivered.

The new rehabilitation methods try to kick-start the process of self-repair in the brain or spinal cord. One way to do that appears to be to give amphetamines several weeks after a stroke; that strategy is being tested in a large multicenter trial.

The therapies that rely on restricting or encouraging movement are based on the idea that after a brain injury, a number of brain cells are killed outright, but many cells surrounding the injury are merely stunned. The therapies try to wake up the cells that have been stunned, said Dr. Edward Taub, a neuroscientist at the University of Alabama.

"Right after a stroke, a limb is paralyzed," Dr. Taub said. "Whenever the person tries to move an arm, it simply doesn't work." Even when all the cells that represent the arm in the brain are not dead, he said, the patient, expecting failure, stops trying to move it. "We call it learned non- use," Dr. Taub said.

When the patient relies on the good arm, the recovery of the use Of the bad arm becomes less likely.

One approach, called constraint-induced movement-based therapy, rests on the principle that lots of practice can reorganize the brain, said Dr. Wolfgang Miltner, a neuroscientist at the Friedrich-Schiller University Of Jena in Germany. But it has to be carried out in a specific manner.

"You don't just repeat movements," Dr. Miltner said. "You have to shape them, which means thinking about the elements of each movement." In the therapy, a person's good arm is immobilized in thick bandages so the bad arm must be used. Or a good leg is put in a splint, forcing greater reliance on the bad leg. Patients practice moving the bad limb six to seven hours every day for two to three weeks. They sweep the floor, throw balls, draw, play checkers, or walk to the cafeteria.

More than 150 stroke patients have been treated with this method in Birmingham and in Germany, Dr. Taub said, and all have improved, some regaining a great deal of movement. The improvements appear to be permanent, he added.

Constraint-induced movement therapy cannot work if it is given two hours a day for three days a week for a couple of weeks, Dr. Taub said, which is what most medical insurance plans allow. The therapy must be intensive and almost overwhelming, he said.

The timing of the therapy is important, said Dr. Randolph J. Nudo, the interim director of the Kansas Center on Aging. If an animal begins using an injured limb immediately after an experimentally induced stroke, damage to the brain increases. That is not true in the second week after the injury, Dr. Nudo said, so it is wise to wait several weeks before beginning movement-based therapies.

But Dr. Duncan said it was not clear how many people could be helped by this technique, how many hours of therapy were needed, and how patients should be selected. Until clinical trials involving a large number of patients have been carried out, she said, patients should be careful not to waste their money.

The cost of constraint-induced therapy for a stroke patient at the University of Alabama's new treatment center is \$6,000 to \$13,000, which Medicare will not pay. Five new patients are enrolled each week, and 5,000 are on a waiting list.

Physicians in Birmingham and elsewhere are also offering constraint-induced therapy to some young children with cerebral palsy who have limited movement on one side. To help them overcome that, the children are fitted with casts that immobilize their good limbs.

"Kids that could not move an arm can now bat balls with that arm," Dr. Taub said.

In other stroke centers, a form of constraint-induced therapy — figuratively tying down the tongue — is being tried on stroke patients who have lost some aspects of speech.

In the therapy, said Dr. Thomas Elbert, a neuroscientist at the University of Konstanz in Germany, the patients play card games that force them to use the words they tend to neglect. To prevent frustration, the game pushes each person to perform at the top range of what he or she can do. After 10 days of intense practice, patients who had suffered with aphasia for an average of eight years experienced a 30 percent improvement in

Their verbal abilities, he said.

In other pilot studies in the United States and Germany, writers and musicians with severe finger cramps have been successfully treated with constraint-movement therapies. Because such people intensely use certain fingers together, the borders between the brain areas devoted to those fingers can break down. The treatment involves splints that separate the fingers and exercises that help separate the brain areas.

Similarly, patients with tinnitus, a ringing in the ears, suffer because of a fusion between areas that handle different tones within primary auditory regions of the brain. The ringing can be made to go away when patients are exposed to many hours of different single tones.

Patients who are partly paralyzed from spinal cord injuries are being treated with another type of movement therapy.

"The spinal cord is smart," said Dr. V. Reggie Edgerton, a neuroscientist at the University of California at Los Angeles. If it is not severed, it can relearn many aspects of locomotion. Patients are slung in harnesses over treadmills, and therapists or automated equipment move the paralyzed legs in natural stepping movements. Many patients have regained the ability to get around with a walker or to walk unaided.

In one of the strangest therapies, Dr. Paul Bach-y-Rita, a Biomedical engineer at the University of Wisconsin, has touch substitute for vision in blind people.

"You don't need your eyes to see," Dr. Bach-y-Rita said. "Vision is the process whereby the brain recreates an image from a pattern of nerve pulses.

If we provide the same pattern of pulses through the skin, the brain can see, only with less detail." Each blind patient wears glasses with a tiny camera that translates the visual scene into electronic pulses, which cause vibrations in a device worn on the tongue.

In a recent experiment, Dr. Bach-y-Rita said, six congenitally and totally blind people and six sighted people wearing blindfolds quickly adapted to the tongue pulses, processing those sensory signals in the visual cortex. After they learned to make out patterns, he said, they could recognize faces and could hit slow-moving balls with a bat, a good example of the kind of brain malleability that underlies many of the new rehabilitation therapies.

\* \* \*

Molecular Analysis Of Japanese Patients With Rett Syndrome: Identification of five novel mutations and genotype-phenotype correlation.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list>

ui  
ds=11524741&dopt=Abstract

1: Hum Mutat 2001 Sep;18(3):253

Yamada Y, Miura K, Kumagai T, Hayakawa C, Miyazaki S, Matsumoto A, Kurosawa K, Nomura N, Taniguchi H, Sonta SI, Yamanaka T, Wakamatsu N. Department of Genetics, Institute for Developmental Research, Aichi Human Service Center, Kasugai, Aichi 480-0392, Japan.

Rett syndrome is an X-linked dominant neurodevelopmental disorder that affects females almost exclusively. The recent identification of mutations of the methyl-CpG-binding protein 2 gene (MECP2) in patients with RTT, encouraged us to analyze the gene in 37 Japanese patients divided into classical RTT (14 cases), variant RTT (13 cases), and mentally retarded patients with Rett-like features (10 cases).

Mutations in MECP2 were identified from most of the patients with classical and variant RTT (25 of 27 cases). Six reported common mutations were detected in 17 cases, and rare single nucleotide substitutions were found in 3 patients.

In addition, one insertion mutation (1189insA) and four deletion mutations including one double deletion mutant (451delG, 100del4, 1124del53 and 881del289 plus 1187del8) were newly identified. In the 10 mentally retarded patients with Rett-like features, however, no mutation was detected in the coding region of MECP2.

The finding of MECP2 mutations in 92.5% of patients with RTT indicates that RTT fulfilling the diagnostic criteria are due to genetic alteration. Copyright 2001 Wiley-Liss, Inc.

PMID: 11524741 [PubMed - in process]

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The UCLA Reading And Writing Program: An Evaluation Of The Beginning Stages

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list>

ui

ds=11523953&dopt=Abstract

1: Res Dev Disabil 2001 Jul;22(4):289-307

Eikeseth S, Jahr E. Akershus College and Glenne Center, Sandvika, Norway.

[gssvei@sysedata.no](mailto:gssvei@sysedata.no)

Some individuals with developmental disabilities fail to acquire functional speech despite extensive teaching efforts. To help such individuals develop functional communication skills, a "reading and writing" program was developed.

This study was designed to evaluate early parts of the program. Acquisition, transfer, and maintenance of "reading and writing" skills Was examined and compared with the acquisition, transfer, and maintenance of sign language.

Participants were four children with autism, who scored within the mentally retarded range on standardized tests of intellectual, adaptive, and language functioning, and three 3-year-old non-disabled children. A simultaneous-treatment design was employed to compare the rate of acquisition of "reading and writing" skills to the rate at which the participants acquired receptive and expressive signs. For the participants with autism, acquisition of "reading and writing" was more successful than receptive and expressive signing on all variables assessed.

All non-disabled participants acquired all of the "reading and writing" and sign language skills, but participants with autism did not. However, "reading" was acquired slightly quicker by the participants With autism than the non-disabled participants, and the participants with Autism also showed some evidence of better transfer and maintenance than the non-disabled participants did.

PMID: 11523953 [PubMed - in process]

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#### Clinical And Catamnestic Descriptions Of 240 Children With Infantile Autism

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list>

ui

ds=11523431&dopt=Abstract

1: Vestn Ross Akad Med Nauk 2001;7:7-13

[Article in Russian]

The paper provides clinical and catamnestic descriptions of 240 children with infantile autism; 160 with atypical autism (of them 100 had schizophrenic attacks, 60 presented with mental retardation concurrent with atypical autism (in phenylketonuria, tuberose sclerosis, Down syndrome, Martin-Bell syndrome), 20 with Asperger's syndrome, 60 with Rett's syndrome, 20 with psychogenic paraautism according the Nissen classification. The similarity of autism-like disorders and atypical autism was considered.

Syndromal verifications in accordance with ICD-10 (1994) and ICD-10

(1999) in Russian versions and clinical nosological verifications adopted In Russia were studied in all the examinees. New approaches to treating patients with autistic disorders were developed.

PMID: 11523431 [PubMed - in process]

\* \* \*

Increased Central-Parietal EEG Theta-2 Activity (About 6.5 Per Sec)  
Found

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list>

ui

ds=11523430&dopt=Abstract

1: Vestn Ross Akad Med Nauk 2001;7:48-53

[Article in Russian]

Increased central-parietal EEG theta-2 activity (about 6.5 per sec) was found in children with cognitive disorders (in Rett's syndrome, fragile X-syndrome, infantile autism) and in elderly patients with Alzheimer-type dementia (with prevalence of neuropsychological "frontal" disorders) in the presence of suppressed alpha rhythm.

This theta-activity was closely associated with cognitive deficits and possessed a specific functional topography, namely it focused in the parietal region and suppressed by both visual stimulation and motor tests. The similar EEG pattern was observed in some patients treated with neuroleptics and/or during hyperventilation.

By taking into account the data available in the literature on motor, oculomotor, regional cerebral blood flow and the probability prediction in frontal lobar dysfunction, it is suggested that the theta-activity described appears in the visuomanual coordination system and is a physiological correlate of decreased functional status of frontal lobes.

PMID: 11523430 [PubMed - in process]

### Arizona Early Intervention Program Forced To Close

[This is from Kay Marie King, Director of the Children's Center for Neurodevelopmental Studies in Glendale, Arizona, from their newsletter. Thanks to B. Rimland.]

It is with great sadness - and considerable frustration - that the Children's Center is ending its Early Intervention (E.I.) program. For several years, the Center ~ provided intensive therapy, education and social interaction opportunities for children under 3 year's of age who are "at risk" for developmental delays. A group of no more than six toddlers meets 3 times per week for 2.5 hour sessions in which they receive speech, music and occupational therapy combined with cognitive and social skill development, all provided by trained professionals. The Center's E.I. Program is probably the most intensive available, with a very high staff to student ratio (4 -5 adults with six children).

In Arizona, E.I. is operated by the Arizona Early Intervention Program (AzEIP) and funded through the Division of Developmental Disabilities (DDD), which is a part of the Department of Economic Security. Children can "qualify" for these services as a result of a doctor's

diagnosis, etc. They are then put on a waiting list to participate in one of the local Early Intervention programs approved and funded by DDD. Parents are able to choose the program which best meets their needs when an opening becomes available.

In recent years, the federal push has been toward “natural environments” as a setting for early intervention services. As defined by the IDEA (Individuals with Disabilities Education Act), natural environments are “the settings that are natural or normal for the child’s age peers who have no disabilities. They are the contexts in which families live, work and play. The concept of natural environments includes home and community settings; for example, parks community recreation centers, restaurants, child care settings, libraries and neighborhood gathering places”. Given this definition, one can easily see how center-based programs such as the Children’s Center would be perceived as “unnatural” and therefore unacceptable.

The move toward natural environments became an unavoidable mandate in June when DDD issued a Request for Proposal (RFP) from all organizations currently providing or wanting to provide early intervention services. Normally, RFP’s are an opportunity for DDD to make minor changes in current contracts, raise (or lower) rates paid to providers, etc. In this latest RFP for early intervention services, however, such dramatic changes are being required that it is simply impossible for the Children’s Center to continue its EL Program. Following are examples of the most crippling requirements:

\* “When providing Early Intervention services in a setting where there are more than 2 children, children developing typically (without special assistance) will be the majority.” This means that of the six children in our program, only two would need our special services, while the other four would essentially receive supervised play (babysitting). Is this the Center’s mission? NO! The Center’s mission states: “to enhance the well being of society by improving the quality of educational and therapeutic services available to the neuro-developmentally impaired.”

It goes on to define how this is accomplished. Why would we Utilize highly trained (and paid) professionals to baby-sit while denying Services to children who desperately need our help? Why would parents of “typical” children choose our highly specialized facility and pay higher rates for childcare?

When I asked these questions of Ida Fitch, Children’s Service Specialist at DDD, she asked me if the Center had considered getting its Day

Care License? NO! We are not professional babysitters.

\* “Interventions must support the functional outcomes developed By the IFSP team for the child.. . Such interventions are more likely to utilize equipment and materials found in the child’s natural environment rather than equipment and materials found in a clinic or segregated center-based program.” One of the Children’s Center’s greatest assets is its large therapy room. Therapists can choose from a broad array of

equipment, based on the specific neurodevelopmental needs of each child, ranging from gross motor to fine motor, calming to stimulating, etc. In a natural environment, the therapist can only choose from the equipment he/she can carry.

\* "Provide special instruction year round, without disruption according to supports and services outlined in the Individualized Family Service Plan. Planned time off shall include a system for coverage in order to not disrupt service delivery.. ." The Center follows a school schedule, and so there are times during the year when there is no school. It would be impossible to provide continuous coverage for early Intervention during those times. Staff need the time off and it would be difficult if not impossible to find individuals with the necessary training who would be willing to work only during those breaks.

\* "Schedules are flexible for staff to meet the needs of families, including evenings and weekend hours." Professional Center staff are already stretched very thin - many put in more than 40 hours per week. How could they be asked to work even more hours? Hours would have to be cut from other programs, and it is very possible that the current high quality of work would suffer if staff were not able to spend evening and weekend time with family and friends.

\* Payment: "...If multiple clients are receiving services together, for billing purposes, the payment unit rate shall be divided by the number of children receiving service." This means that our current hourly rate, which does not even cover operating costs, would be divided by 6 (the number of children in the program). We would receive only 1/6 of our current rate. Because the RFP asks providers to calculate their own rate (which is accepted or rejected), I called DDD to make sure I understood correctly. In order to achieve a rate that when divided by six would at least give us our current rate, it is first necessary to multiply by six. When I named that figure. (six times higher than our current rate) the voice at DDD gasped and said, 'Oh, no!'"

I hope this explanation will help parents, professionals and other members of the community understand why the Children's Center feels forced to end its Early Intervention program. Although not a financial 'success', this was more than compensated for by the success of the children and families who participated. We hope that you will join us in continuing to push and hope for the day when the pendulum might swing back the other way- when government agencies realize that there are many children with exceptional needs who can best be helped through a program of intensive therapeutic interaction. A short-term program like this brings long-term and lasting results, but most importantly, joyous new hope for the family and child.

Kay Marie King, Director

[cns@netwrx.net](mailto:cns@netwrx.net)

\* \* \*

More on William Walsh, Metals Metabolism & Dietary Treatments

In an earlier posting today, the FEAT Daily Newsletter ran a piece concerning metal metabolism and autism, "Understanding Autism: A PBS

News Hour with Jim Lerher - Transcript." William Walsh, the scientist who discovered the metabolism dysfunction, is one of the speakers at the Defeat Autism Now! Conference in San Diego, in early October (check FEAT Calendar of events out by the end of this week.) He will be discussing his research.

In a brief commentary made following the article, I referred to anecdotal reports from parents describing their child's improvement on dietary interventions. Dr. Bernard Rimland points out in a fax that quite apart from the anecdotal reports, there are 18 consecutive published studies showing positive results from high dosage vitamin B6 and magnesium in the treatment of autism, including 11 double-blind placebo-crossover studies.

There are also a number of peer reviewed journal reports providing hard evidence that dietary avoidance of gluten and casein (wheat and milk products) in food products produces positive behavioral, biochemical and metabolic changes in autistic children. Rimland, ever the one to ingratiate himself with the traditional medical community, remarks "Of course, none of this will make any difference to the typical mainstream physician of the 'Don't bother me with the facts, my mind is already made up' variety."

For more information on this research, see the Autism Research Institute website [www.autismresearchinstitute.com](http://www.autismresearchinstitute.com).

\* \* \*

#### New PC FEAT of Indiana Gets In Gear

Seventy children within Putnam County, Indiana are presently Diagnosed with a form of autism. The need to enhance services available to the families has inspired the development of a FEAT Program within our community.

Cindi Elkins Executive Director/Project Director of the PCFEAT Program, has dedicated several months research and preparation, for the program to be implemented.

The status of the Program, with an established board of parents educators, and consultants is projected to receive funding and open their offices by November 2001.

Currently a website has been published with the intent to inform The general public of our program and it's mission objectives. PC FEAT Would like to thank the FEAT Organization of Sacramento, for giving Authorization for this worthwhile program to be established within our community.

[All FEAT organizations are independent. The original FEAT, out Of Sacramento, collects no dues and exercises no authority over any other advocacy organization. -LS]

\* \* \*

## New Dad's Autism Email Discussion List Forms

[This announcement comes from Artie Kempner.]

We have formed a Dad's e-group, for fathers who have children with autism.

The group is an extension of the ASA conference presentation, "For Dad's Only." We hope this will be a valuable asset to the autism community, and offer ideas, support and information to all the Dads out there. Please pass this information on to your members, friends, husbands, family members or professionals.

To subscribe, go to: [AutDads-subscribe@yahoogroups.com](mailto:AutDads-subscribe@yahoogroups.com)

To post a message: [AutDads@yahoogroups.com](mailto:AutDads@yahoogroups.com)

Thanks to Cheryl Kelley, Autism Society of Delaware "Web Babe" for setting this up. She says she will not be monitoring the site, only administrating it. We don't have a "No-Babes" rule, but we know that women tend to have more support groups than us XYers.

\* \* \*

## Texas Autism Advocacy List Gets Website

[This is from Michelle Guppy.]

Theresa Madore has set up a website for our Texas Autism Advocacy list! Please feel free to send her any links to put on the website - and please put a link on your website to this one!

Biomedical links, Legislative links, Special Services links - Anything that would be of benefit to parents of Special Needs Children - Especially those with an Autism Spectrum Disorder...

Theresa can be reached at [autismzone@yahoo.com](mailto:autismzone@yahoo.com) - so please send anything to that e-mail that you would like linked on the website!

<http://www.angelfire.com/tx5/autismlist/>  
is the Texas-Autism-Advocacywebsite!

\* \* \*

## Medical Assoc. Spends Drug Co. \$\$ Telling Docs Not To Accept Drug Co. Gifts

[By Lindsey Tanner, Associated Press.]

<http://www.nandotimes.com/healthscience/story/69887p-989881c.html>

The American Medical Association is spending a lot of drug-company money to tell doctors not to accept large gifts from drug companies in a

campaign that critics say is hypocritical.

The AMA is contributing about \$400,000 to the \$1 million effort, But most of the balance comes from payments between \$50,000 and \$100,000 from nine major drug companies.

The AMA says it makes sense to involve the industry in a campaign that's also designed to inform drug makers about what is considered unethical behavior. But critics question that logic.

"How can anyone believe that they're engaging in some kind of Campaign to fight the perception of unethical behavior by engaging in unethical behavior?" Dr. Sidney Wolfe, director of the consumer-oriented Public Citizen Health Research Group, said Wednesday. "It's just outrageous." Some medical ethicists agree.

"It's symbolically endorsing the very behavior that they're trying To caution against," said Dr. John Lantos, associate director of the University of Chicago's MacLean Center for Clinical Medical Ethics.

At issue are the myriad freebies, ranging from pens and notepads To free dinners and trips, that some drug makers shower on doctors. Ethicists say the gifts could encourage doctors to prescribe medications that may not be in patients' best interests.

"Overall they spend billions of dollars trying to influence physicians' prescribing behavior, and it works," Lantos said.

AMA policy suggests a limit of about \$100 on such gifts and says They should not include things like free trips, hotel accommodations and Other personal expenses for doctors attending conferences. Things like work-related pens and notepads are considered acceptable.

"Any gifts accepted by physicians individually should primarily Entail a benefit to patients and should not be of substantial value," the Policy says.

Dr. Randolph Smoak, the AMA's immediate past president, said the campaign was prompted in part by concern that many younger doctors may be unaware of the decade-old policy.

"We're attempting to not only re-educate physicians but also the marketing forces," Smoak said, "so that all those people understand the rules of engagement."

The Pharmaceutical Research and Manufacturers of America, a trade group for most of the nation's brand-name prescription drug makers, supports this.

From: Terry  
Date sent: Fri, 31 Aug 2001 07:48:48 -0500  
Subject: Re: [asperger\_autism\_12up] AC Indecision

I don't understand your point here. Are you being intentionally rude? Why? Or is one of your symptoms not realizing that you sound rude to other people?

-----Original Message-----

>  
 >> ... Although no girl had actually asked me to partner them for reasons  
 >> of liking (from what I perceive) ...  
 >  
 >  
 > From what I've heard, bubble gum and sex before 50 are illegal in  
 >your Singapore. Is this true? And do they really say "to partner" when  
 >they mean screw?  
 >  
 >\*\*\*\*\*  
 >  
 >  
 >On Fri, 31 Aug 2001 14:22:35 +0800 [Edward] writes:  
 >> << He would rather work alone, which is fine with the teacher, but  
 >> was very rude and mean when he told her so. >>  
 >>  
 >> Well, due to a coincidence my father had assigned Eric to my last  
 >> name and I happen to have the age of 18 years, placing me into the  
 >> teenage group.  
 >>  
 >> Although no girl had actually asked me to partner them for reasons  
 >> of liking (from what I perceive) and if so more because how my  
 >> advantageous computer, English and Internet skills would accelerate  
 >> their project progress, I think can speak from an AS perspective. It  
 >> also happens that (at the risk of self-flattering) that I happen to  
 >> have the appearance of the "other" Eric (at least this consists of  
 >> what quite a number of trusted people told me about).  
 >>  
 >>  
 >> I don't have help from aides, "rehearsals" and the like, and I had  
 >> only discovered AC last December. I just went for a dx and it seems  
 >> that I did really have AS.  
 >>  
 >> I can definitely say that there do exist hints that some girls did  
 >> take a liking to me. I did not reciprocate because I have my  
 >> priorities defined already. Generally, I want to devote myself to  
 >> science instead of to the social world of NTs. I think having a  
 >> temporary relationships others can cause problems and distract one  
 >> from one's true purpose in life.  
 >>  
 >>  
 >> As those with AC (or even those with NT), we ought to figure out  
 >> what we want to achieve in life and then base on this to decide how  
 >> we will deal with mundane situations. What does the decision maker  
 >> want to achieve? What future does he or she want to live in? What  
 >> kind of lifestyle does he or she want to live? What role does he or  
 >> she want to play in the development of Humanity? I daresay that if  
 >> you can answer these questions, then your eventual decision would  
 >> now appear much more clearly.

>>  
>>  
>> I had decided to work on the great problem of creating a rational  
>> society and I think I will spend many decades on that. Eventually I  
>> hope to transcend myself and live free from my frail and limited  
>> human body, via the research work of that society. So for now, I  
>> don't need to lead the lifestyle of NTs yet, but should concentrate  
>> on my research.  
>>  
>> I hope this helps.  
>>  
>>

From: Fred  
Date sent: Fri, 31 Aug 2001 22:45:44 -0400  
**Subject: Re: NT Strangeness**

On 31 Aug 2001, [Edward] wrote:

> Just a short note of my pending research...

yeah, short. that is probably the longest dissertation on NTs (as such)  
ever written! pretty funny too!

a few random comments

> Some NT teenage girls, for instance, have the legendary ability  
> to walk around the whole day trying on clothes and not purchasing  
> anything at all.

i don't know, but i'd say that shopping without direct intent to buy is  
also an AS trait. maybe not for long periods with several friends  
looking at fashion, but i've spent over an hour in a hardware superstore  
buying a can of spray lube and a duplex outlet (mains socket). my  
purchase of a ladder was done with the due diligence some use to buy a  
car.

> Their logic justifies this because they value their place in the  
> social hierarchy more highly than their own financial problems.

it looks like you were commenting partly tongue-in-cheek, but (as with  
the rest of the article) there's some truth in that. people set up  
social heirarchies based on a number of things. there are some societies  
where social standing is based on gift giving and the like. i think AS  
people fit in here, although not in the same way.

## Discussion list B: Self-identified people with autism

**From:** Hannah  
**Date sent:** Sat, 29 Dec 2001 14:22:06 -0000  
**Subject:** **social interpreter**

dear [Ronald],

i read that you had a social interpreter with you at the conference. how did you get one? what does he/she do when she's with you? so far, my ex-partner has been fulfilling that role, but i am very thrilled that there's such a thing as an official job of someone to be a social interpreter. how is it different from social worker?

i had an appointment with an AS specialist yesterday. it went fairly well. he didn't dx me straight away, but said i probably have it (AS, and possibly DID). he want to do some more tests, but i don't know if i'm coming back, it costs me quite a bit.

**From:** Ronald  
**Date sent:** Sat, 29 Dec 2001 19:53:11 -0500  
**Subject:** **Re: social interpreter**

Dear [Hannah],

I am working informally with several people on the idea. I talked with one of the organizers of the MAAP Conference about it. They are required by law to provide interpreters for the visually and hearing impaired. I have certain one on one skills. When there are three people, the dynamic changes. My social interpreter for that occasion was an ex-partner, too. I spent nine years trying to figure out someway to become engaged to her. I am still friends with her. She and I share some similar life situations. I am important in her life and she is in mine. My vision of a social interpreter is someone who will allow me to communicate with other adults with autism. I don't try to hold onto people like the social people do. When I go to a conference like that, I find out a lot of information, but I develop few ongoing relationships because I don't know how to do it very quickly. My social interpreter kept me social enough to visit Room 162. I didn't stay at the hotel. I was interested in the person with the Irlen glasses. My social interpreter only worked one way. I access the conference better, but I couldn't socially support my interpreter. When I was the kid the comforting quiet around me was scary to the social ones. My interpreter really wasn't very interested in the people out the conference just the ideas. I think that one adult with autism can act as an interpreter for another. We can trade a comfortable silence for a comfortable conversation that social people might join. I belong to a community service organization that has help me gradually self-interpret simple social situations. It's like "My Fair Lady" the movie. Professor Henry Higgins acted as a social interpreter for Eliza Doolittle. All she wanted was a room, and she ended up with all kinds

of social complications. I am trying to become part of the autistic community. We believe in doing our own thing very quietly and not involving others. I am still developing the idea of social interpreter. I like them at MAAP Conferences. At other conference such as ABA Conference, I wanted to maintain a low profile. How the interpreters for the visually and hearing impaired make a difference in their lives? It is an opening of the worlds between us. I don't want to live in a high social world all the time----I can't take it in fast enough. I want to experience some of that through the eyes of an interpreter and I want to share some of the experience with other social and nonsocial people. The difference between a social interpreter and a social worker is social worker presupposes that you have social abilities and a social interpreter would not. A social worker helps you fit in. As social interpreter would express your world view to others and explain their world in ways that you understand. My personal vision statement is: I want to create a world where people with autism can live on their own terms. As social interpreter could interpret that for social people. If the world was filled with only people with autism how could a social person cope. I can't satisfy the social needs of some of my friends for very long. At times, I am so not there. At times the social people are not open to an autistic interaction. What happens after diagnosis?  
Sincerely yours,

### **Discussion list C: parents and people with autism**

From: Barry  
Date sent: Wed, 29 Aug 2001 14:00:00 -0400  
**Subject: Re: Medications for AS?**

Hi all,

It doesn't look as if [person] responded on the meds question. [My son] takes 75mg of Provigil daily and 2.5ml of Paxil each evening. We started on just Paxil about 1.5 years ago reluctantly, and gradually moved up in dosage but it had a negative effect in terms of irritability. We then switched from a Psychiatrist we did not like to our current med-prescriber, a Developmental Pediatrician who prescribed the Provigil. The plan was to gradually phase out the Paxil altogether and go with the Provigil alone, possibly replacing Paxil with a similar med if needed... but that didn't go over well either and we have sort of reluctantly stuck with the low dosage of Paxil to keep anxiety levels down.

Quite frankly we see very little positive effects from meds. The most dramatic positives come from interactions with the right people. We lucked out with an extraordinary one-on-one aide in the public school even though the entire rest of the school personnel had not a clue. [Person] probably mentioned y son] begins in an out-of-district classroom designed especially for A.S. children run by the Y.A.L.E. school in the fall for fourth grade. He attended their summer camp program this summer

and that had the most dramatic positive effect of anything we've tried so far including medication and therapy.

**From:** Hope  
**Date sent:** Wed, 29 Aug 2001 17:02:23 -0700 (PDT)  
**Subject:** **Re:**

Thanks [Alice]! That will help alot! [Hope]

--- [Alice] wrote:

> [Hope],

> It's been my experience with my daughter [...]

> that it's really not so much the kids that are the probelm believe it or not

> it's the adults!! They have a program called peacebuilders for the

> students. (too bad the adults don't practice what they preach) I will try to  
> get you more info on the program itself.

> Good

> luck, [Alice]

> ----- Original Message -----

> From: Hope

> Sent: Thursday, August 16, 2001 4:07 PM

> Subject: Re:

>

>

> > tell me more details about this peacebuilders  
> program.

> > sounds like something we need here. [HOPE]

> > --- [Alice] wrote:

> > > Hi [Anna]

> > > In response to your message Talk to your doctor  
> he

> > > maybe able to put you in

> > > touch with support groups or recommend other  
> helpful

> > > ideas.The school my

> > > daughter [...] 14yo attends has implimented a

> > > program called peacebuilders

> > > .They hold school rallies and give rewards to

> > > students who practice being

> > > peacebuilders it's really a neat program,good

> luck!!

> > > When and if you

> > > decide to let the school know [Ella's] diagonsis  
> make

> > > sure school staff know

> > > your daughter has enough to deal with without

> > > criticism and judgement from

> > > people who may not have an understanding of AS

> > > suggest that they get

> > > educated and receive support services this can  
> be  
> > > written into her IEP  
> > > ----- Original Message -----  
> > > From: Anna  
> > > Sent: Wednesday, August 15, 2001 6:43 AM  
> > >  
> > >  
> > >  
> > > Hi all  
> > > > Let me introduce myself. I'm [Anna], 35, married with 2 DD's and  
> > > > we live in Scotland. Our girls are [Ella], nearly  
> > > > 6, and [Mandy], 3.  
> > > > After 4 years of tests and assessments, usually  
> > > > 6  
> > > > months apart, I was  
> > > > advised that Aimee has AS, on July 23rd this  
> > > > year. So I am very new to  
> > > > AS, and to computers too, as we just got one  
> > > > this  
> > > > January!  
> > > > [Ella's] diagnosis will not be confirmed til  
> > > > Dec, as  
> > > > we must wait til  
> > > > she turns 6. Any info we have got has been via  
> > > > websites and an NAS  
> > > > leaflet.  
> > > >  
> > > > [Ella] starts school in 10 days, and I am  
> > > > worried  
> > > > how she will  
> > > > settle. She should have gone last year, but we  
> > > > all  
> > > > decided to leave it  
> > > > til this year as she was still experiencing  
> > > > frequent tantrums and a  
> > > > complete lack of concentration. She has matured  
> > > > a  
> > > > lot in the past 12  
> > > > months, and the school is aware of her  
> > > > disordered  
> > > > development. We are  
> > > > not to mention AS as the Dr wants an unbiased  
> > > > report for the panels  
> > > > assessment.  
> > > > At this stage I am not sure how "badly" she  
> > > > will be  
> > > > affected, and  
> > > > whilst I accept (happily?!!) the diagnosis, I  
> > > > wonder

> > > if there will be  
> > > > any benefits to [Ella] in making it "official"  
> > > > .I'm concerned that people will just see the  
> AS  
> > > and not [Ella].I'm  
> > > > concerned that teachers will "make allowances"  
> for  
> > > [Ella],and so not  
> > > > encourage her to reach her potential.I'm  
> concerned  
> > > that Ella might  
> > > > learn to use AS as an excuse for not  
> > > trying,because I realise she  
> > > > will have to try much harder than her peers  
> just  
> > > to get by.This is  
> > > > probably the 1st of many such quandries,and I  
> > > would appreciate any  
> > > > feedback!  
> > > > This summer we took up camping as a family  
> > > hobby.It gave us more time  
> > > > as a family,and a chance for [Ella] to  
> socialise  
> > > with new kids,most of  
> > > > whom she will never see again,We felt that as  
> she  
> > > was keen to make  
> > > > friends,but often can't get it right,that this  
> was  
> > > a good way to  
> > > > observe how she coped,and help show her how to  
> > > cope,without her being  
> > > > judged.Unfortunately,a lot of the kids got  
> bored  
> > > with her,some called  
> > > > her odd,weird and stupid.This upset [Ella]  
> enough  
> > > to tell me,and I  
> > > > explained that she will cope better having  
> been to  
> > > school  
> > > > herself.Deep down,it broke my heart to see her  
> > > being rejected,but I  
> > > > tried to hide my feelings.  
> > > > It makes me worried about the day when SHE  
> knows  
> > > she  
> > > > is "different",and how to explain all the  
> > > implications of her  
> > > > situation.Still,we'll cross that one when we

> come  
> > > to it!  
> > > > Anyway,thankyou for getting through all  
> this,I'm  
> > > sure I am not alone  
> > > > in feeling so lost at this stage.I know the  
> > > constant pain I am  
> > > > feeling will go,I need to be positive for  
> Aimee  
> > > and my family,I just  
> > > > need some time to let this all sink in.I know  
> I  
> > > still will cry  
> > > > sometimes,but the feelings will sink away from  
> the  
> > > surface.  
> > > > I look forward to getting to know you all.I'm  
> off  
> > > to my Mums for a  
> > > > week(she is also devastated,this affects so  
> many  
> > > family members)so  
> > > > I'll get back to you all next Friday.  
> > > > With love and best wishes  
> > > > [Anna]  
> > > > PS It would appear that I too have a lot of  
> Aspie  
> > > traits,as I have  
> > > > discovered on my research.I didn't make  
> friends  
> > > easily as a child,and  
> > > > still find new relationships and situations  
> > > > unsettling.Also,I am  
> > > > prone to being obsessional,which has come in  
> handy  
> > > with the need for  
> > > > personal research.Youv'e got to laugh!!X  
> > > >  
> > > >

From: Rosie  
Date sent: Wed, 29 Aug 2001 20:11:21 -0400  
**Subject: Re: Medications for AS?**

What kind of med is provigil? I have heard of a lot of meds, but never this one.

----- Original Message -----

From: Barry  
Date sent: Wed, 29 Aug 2001 14:00:00 -0400  
**Subject: Re: Medications for AS?**

Hi all,

It doesn't look as if [person] responded on the meds question. [My son] takes 75mg of Provigil daily and 2.5ml of Paxil each evening. We started on just Paxil about 1.5 years ago reluctantly, and gradually moved up in dosage but it had a negative effect in terms of irritability. We then switched from a Psychiatrist we did not like to our current med-prescriber, a Developmental Pediatrician who prescribed the Provigil. The plan was to gradually phase out the Paxil altogether and go with the Provigil alone, possibly replacing Paxil with a similar med if needed... but that didn't go over well either and we have sort of reluctantly stuck with the low dosage of Paxil to keep anxiety levels down.

Quite frankly we see very little positive effects from meds. The most dramatic positives come from interactions with the right people. We lucked out with an extraordinary one-on-one aide in the public school even though the entire rest of the school personnel had not a clue. [Person] probably mentioned y son] begins in an out-of-district classroom designed especially for A.S. children run by the Y.A.L.E. school in the fall for fourth grade. He attended their summer camp program this summer and that had the most dramatic positive effect of anything we've tried so far including medication and therapy.

From: Barry  
Date sent: Wed, 29 Aug 2001 21:01:30 -0400  
**Subject: Re: Medications for AS?**

A web search will pull up many hits on Provigil if you like. It is a Brand name for the drug Modafinil. It is a "schedule IV" drug and is used for the same indications as the "schedule II" drug Ritalin (methylphenidate), both of which are stimulants. Exactly how these drugs help AS, ADD and ADHD children I haven't a clue. It is very difficult to say if it has done us any good or if other factors have given us the most positive results.

From: Barry  
Date sent: Wed, 29 Aug 2001 21:06:10 -0400  
**Subject: Re: Medications for AS?**

On the dietary front, we tried a wheat-free/gluten-free diet for a while (which was very difficult for a child who wants to eat mainly cereal, pancakes, pizza, spaghetti, macaroni & cheese, and peanut butter and jelly) but it had absolutely no effect whatsoever. I'm sure if your child has

any kind of food allergies it would help greatly to identify and remove those foods from his/her diet but I am not aware of any dietary treatments specifically for AS. I would be very interested if anybody knows of any.  
[Barry]

### **Discussion list D: Professionals**

**From:** Kim  
**Date sent:** Wed, 29 Aug 2001 19:12:43 -0000  
**Subject:** **off topic --Paains**

Hello all,  
Just a quick memo to keep you updated at PAAINS . But firstly I would like to take this opportunity to thank you all for visiting paains and sharing your much appreciated information and comments.

PAAINS has just opened a forum at <http://groups.yahoo.com/group/paains> or via the site [www.paains.org.uk](http://www.paains.org.uk) and go to Forum. We would like to invite you all to participate sharing stories, advice and information, anything from Autism related disorders to Interventions. Ask someone a question, share tips that help you through the day, point to some research or request information to be placed on our web site.

A quick reminder. Raun K Kaufman is a 26 year old diagnosed as severely autistic when he was 2. He now bears no traces of the affliction thanks to the Son-Rise Program. Raun K. Kaufman, international lecturer, writer, and teacher for The Son-Rise Program® at the Autism Treatment Centre of AmericaT will be presenting his lecture, "Practical Strategies for Autism and PDD" from September 14-22, 2001 in London, Edinburgh, and Dublin, as well as other areas in and around the United Kingdom. This presentation is free\*\* and open to the public. For more information contact <http://www.son-rise.org/tour.html>

Big thank you for all your kind words and interest on Jack's page. I am sure you can understand that with the summer holidays 100% of my time has been devoted to my wonderful children. So chapter 2 will have to wait until mid September. CHAPTER 2 will contain my emotions, the struggle for family acceptance and support along with my determination to help my special little boy, and make his and my voice heard.

Finally Septembers newsletter is now in progress so any information you have or would like to see please submit by Sept 15th to [newsletter@paains.org.uk](mailto:newsletter@paains.org.uk)  
**KEEP IN TOUCH**

From: Tom  
Date sent: Wed, 29 Aug 2001 15:21:42 -0700  
**Subject: Fwd: New from TASH: Foundations of Inclusive Education**

--

----- Forwarded Message -----

Looking for an incredibly readable composite of the most current research on inclusive education for students with more significant disabilities?? It now exists!

The Foundations of Inclusive Education:  
A Compendium of Articles on Effective Strategies to Achieve Inclusive Education:  
Originally Published in JASH  
JASH is the Journal of TASH: Equity Quality and Social Justice for People with Disabilities  
Douglas Fisher and Diane Ryndak, Editors.  
Foreword by Steve Taylor

Although the importance of inclusive education for preparing students with disabilities to be full participants in their communities (both as children and eventually as adults) is well established, it is hard to put your hands on the research that demonstrates this. Here it is all in one place! This book covers both the conceptual underpinnings of inclusion as well as the strategies that have proven effective across the country both the "whys" and "hows" of achieving true inclusion in today's classrooms.

The book includes articles by the nation's leading researchers in inclusive education articles by Dianne Ferguson, Doug Fisher, Michael Giangreco, Lori Goetz, Pam Hunt, Rachel Janney, Craig Kennedy, Ian Pumpian, Diane Ryndak, Roberta Schnorr, Marti Snell, Steve Taylor and others whose names you know. The book is ready for immediate shipment and quantity discounts are available.

To obtain an announcement and order form (with table of contents) please go to [http://www.tash.org/publications/foundations\\_for\\_inclusion.htm](http://www.tash.org/publications/foundations_for_inclusion.htm) . Feel free to copy and distribute the form to people who may have interest or to call TASH for additional copies or more information. The book can be ordered by returning the enclosed form by mail or fax or by calling 410-828-8274, ext "0" during business hours, Eastern Time. Information about the book and the order form are also available on our web site at

www.tash.org, under "publications".

Sincerely,

Nancy Weiss  
Executive Director

----- End Forwarded Message -----

From: Tom  
Date sent: Wed, 29 Aug 2001 16:42:05 -0700 (PDT)  
**Subject: Re: If behaviorism is getting all the funding, then why this article??**

I'm happy to hear my dogmatic posts are causing some laughs. I always have that big gut laugh in mind whenever I type anything, but try also to keep my nose to the dogmatic grindstone.

You're not any relation to that wonderful man in Syracuse whose last name is Sundberg, are you?

Tom

From: Tom  
Date sent: Wed, 29 Aug 2001 16:44:47 -0700 (PDT)  
**Subject: Re: apology to [person]**

I don't blame your skepticism, but go to one of the FC conferences and come back and let me know how you explain it. I did behaviorism for years with that age group hoping to do what the FC people have done, and didn't get anywehre near it.

Tom