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Developing a social understanding of autism through the 'social model'

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ABSTRACT

The aim of this study is to design an innovative research methodology to engage young people with a label of 'autism', in the research process. Advancement in the creation of a new and innovative research methodology made it possible for 11 young people to communicate with the researcher about what was important to them as they went through adolescence. 'Barriers' to inclusion in the research process were challenged by developing, practical ways to de-code and translate complex communication systems through the design of a 'communication profile'. Engaging young people with a label of 'autism' in a way that enables them to lead and direct the research process is new and challenges traditional research assumptions. It also challenges traditional research methods used with people with a label of 'learning difficulties' and questions the validity of 'researcher led' narrative.

Utilising a more democratic process of 'inclusive' research methodology led to the findings that young people with a label of 'autism' are disabled by 'barriers' within wider society rather than by their perceived 'impairments'. The disabling barriers evident from this research were physical barriers (in relation the physical environment); support barriers (in relation to interpersonal relationships and support); and information barriers (the way information causes disabling barriers if it is not presented in ways that enables understanding).

The findings significantly challenged current and past theories of autism and questioned the 'truth' in the 'knowledge' ascertained from positivist research methodologies. Listening to the collective 'voice' of young people with a label of 'autism', urges a move away from a reductionist explanation of 'impairment', to embrace the wider holistic explanation of autism as 'disability'. To advance the continuation of participation in research, this research study calls for a 'paradigm shift' in research methodology, to move away from 'positivist' research methodologies to advancing an 'emancipatory disability research' agenda. This research also calls for the inclusion of people with a label of 'autism' to become engaged in the wider 'social model of disability' debate and to become included as part of the wider disabled people's movement.

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CONTENTS

INTRODUCTION

AIMS AND SCOPE OF THE THESIS

Autism is defined as a set of 'impairments'. Impairment of communication, social interaction and imagination. This definition of autism now forms worldwide diagnostic criteria with the advantage of the development of 'worldwide' consistency in the understanding and diagnosis of autism. It is, however, argued that there are limitations in the emergence of these criteria, in that it is predominantly based on observations of behaviour *without* significant regard to social context. It will be argued in this study that the history of the emergence of autism as a set of 'impairments' is a direct result of autism being 'medicalised' by psychiatry, and by it being subjected to the dominance of positivist research methodology from the field of psychology.

This thesis sets out to challenge the philosophical notion of 'truth', which is encompassed or steeped in the history and the discovery of 'knowledge' of autism from a particular position of inquiry. This position has predominantly been from a medical/deficit perspective within a positivist research tradition and with the utilisation of quantitative research methods.

Oliver (1990:5) argues that one of the consequences of developing an understanding from a medical perspective is to understand all difficulties solely in relation to proposed treatments. This has been evident in relation to the literature on 'autism' where the tabloid press, broadsheets, as well as academic journals print articles about 'treating autism'. For example: The Lovaas Techniques - 'David Ward on a radical treatment – Quest for a remedy to halt 'retreat' by twin sons' (Ward, 1998:12); the use of diet - 'Thank-you for saving my son from autism' (Moynahan, 1999:35-36); and miracles – 'Saved by her water pistol' (Crickmer, 1998:4-5).

The personal tragedy approach and 'triumph over autism' are major themes in portraying 'autism' in the press. For example 'Tragic computer kid Chloe, 5 finds love at first byte' (Sunday People, July 4, 1999:12). This article refers to 'tragic' tot Chloe who has escaped from a secret world of torment by becoming a whizz-kid on a computer. Such themes perpetuate a sense of 'wonder' or 'surprise' when a person is successful in their achievements, for example employment. A local paper read: 'David Bocking meets a 16 year old overcoming his autism to join the workforce at a local superstore (Bocking, 2000).

The focus on 'impairment' in autism promotes not just the personal tragedy model, or the focus on treatment, but it perpetuates an understanding of autism as an 'illness' as opposed to a disability. For example *'My husband just seemed eccentric. I had no idea that it was an illness which would destroy our entire family'* (Daily Mail, March 9, 1999:50).

Oliver (1990:5) argues that the medical approach produces definitions of disability which are partial and limited and which fail to take into account wider aspects of disability. Articles on 'autism' that explore exclusion and discriminatory attitudes within society are few and far between, however one example is an article that explores, exclusion, bullying and a lack of access to appropriate support services (Beaumont, 2000).

This thesis will argue that there is a need to challenge the fundamental definition of autism as 'impairment', if we are to develop a wider more accurate understanding of disability and those with a label of 'autism'. If we continue to understand 'autism' as 'impairment', then this conserves the notion of 'impairment' as abnormality of

function. It also takes the environment for granted and does not require environments to be scrutinised, rather it seeks out the failings in the individual (Oliver, 1990:4). As this thesis sets out to challenge the fundamental basis by which 'autism' is defined it will be important at the outset to draw upon wider disability theory to explore a socio-politcal understanding of 'autism' as 'disability' as opposed to 'impairment'.

This introduction to the thesis will outline the main tenets of the social model of disability and set the scene for explaining the language used throughout the thesis.

In the 1970's the British Disability movement responded to the dominance of the medical model by proposing the social model as an alternative. More recently the social model has been defined as follows:

> *'The social model of disability represents nothing more complicated than a focus on the economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment. These include inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities and the devaluing of disabled people through negative images in the media – films, television and newspapers'* (Barnes, 2003).

The definition of the social model is based upon differentiating 'impairment' from 'disability'. The Union of the Physically Impaired Against Segregation (UPIAS) defined this as follows:

> Impairment – *a term that refers to the lacking part of 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 impairment and this excludes them from the mainstream of social activities* (UPIAS, 1976:3-4)

The term 'disabled people' rather than the term 'people with disabilities' is the preferred term set out by UPIAS and then later by the British Council of Disabled People (BCODP). The BCODP have forged a collective identity for disabled people with a range of physical and sensory impairments. People with the label 'learning difficulties' were excluded from the debate and the development of the social model up until 1991, but people with a label of 'autism' have been and are still absent. 'People First' a lobbying group for people with learning difficulties argues that its members wish to be seen as 'people first and their disability second'. They do not accept the term 'Disabled people'. Whereas Oliver (1990:xiii) argues:

> 'the term 'disabled people is used in preference to people with disabilities. It is asserted by some that it is the person first and the disability second. Disabled people themselves argue that far from being an appendage, disability is an essential part of the self'.

People with a label of 'autism' have not been part of the debate and have not been included in the wider disability movement. In the absence of this individuals often refer to and explain 'autism' in relation to the framework of 'impairment' positioned by academics, professionals and researchers. When examining the autobiographical accounts, there is little reference to the term 'disabled' or 'disability' and more of a trend to re-claim autism (as impairment) from their own perspective. Jim Sinclair one of the founder's of Autism Network International, positions his understanding of autism:

> 'Autism isn't something a person has, or a shell that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colours every experience, every sensation, perception, thought, emotion and encounter, every aspect of existence. It is not possible to separate the autism from the person – and if it were possible, the person you'd have left would not be the same person you started with'
> (Sinclair, 1993)

Autism Network International prefers to use the term 'autistic people' and the principles set out on the site refers to the term 'autistic people1 (http://ani.autistics.org/intro.htmP It is important for this thesis to position those with a label of 'autism' in relation to the wider disability movement. In the continued exclusion of this group of people with 'impairments', in the wider socio-political debate of the disability movement, I have to be respectful to understanding the position of those with a label of 'autism' in their journey along the way towards self-empowerment, self determination and collective action. It is not for me to refer to people as 'disabled people' if there is no association with this term by this group.

As this thesis sets out to position its inquiry within the social model it is important to use the language of the social model throughout. It is recognised that although people with the impairments of 'autism' do not recognise themselves as part of the wider collective of disabled people, the sentiments and the experiences that emerge from the writings of this group, mirror the issues experienced by disabled people. The focus of this study is then about the barriers that are experienced by those with a label of 'autism' and not about reinforcing a focus on the 'impairment' itself. To concentrate on the barriers and not on the 'impairment', the term children or adults with the label of 'autism' will be used. Where it is evident that reference is being made to the person or people, their pseudonym or the plural 'young people' will be used.

People with a label of 'autism' do need to part of the wider disability movement debate to be able to contribute to the debate on the concepts of 'impairment' and 'disability'. For the debate to start a dialogue is required and a methodology needs to be designed to enable engagement. The barriers of access to the social model also need to be broken down. Dowse (2001) argues that there is as yet no plain English version of the social

model. This she argues precludes most people with learning difficulties to the ideas upon which the collective endeavour is based. She argues that the social model by definition is an abstract representation of a set of ideas. This could be a barrier for many with the label of 'autism' in accessing inclusion into the social model of disability debate.

While the children in this study did not identify with the terms 'impairment', 'disability' or 'deficits', there was evidence that they experienced their life as 'other'. When referring to the term 'normal', they gave examples of how they faced 'disabling barriers' throughout their lives. Within the social model of disability it is proposed that individuals who are different by virtue of an 'impairment', find that they are oppressed by societal views of normality. The social model of disability puts the onus of the problem back into the collective responsibility of society as a whole.

Goodley (2001) argues that there is a distinct lack of focus on 'learning difficulties' when examining 'impairment' and he argues for a further analysis of learning difficulties when exploring the social model. What Goodley and others (Tregaskis, 2002) call for, is that the time has come to develop a social theory of impairment which ceases to ignore the reality of the impaired body. This will reclaim control of discussion of the body from the medical profession who have 'pathologised and individualised impairment' thus ensuring that a person's impairment has usually become an all-encompassing description of his or her identity.

Although the social model is absent in the literature on 'autism' there does appear to be a change and a move away from complete reliance on the 'medical/deficit model'. Where the beginnings of an understanding of autism emerged from the efforts of

individuals in psychiatry and psychology, proponents in the field now appear to support the recognition to break with this dominant viewpoint. Wing (1996:11-12) argues that the advances in knowledge on autism has not led to any great changes for those with a label of 'autism'. The advances she argues have been in the *creation of an environment* that minimises disability and maximises potential, she writes:

> *"The increase in secure knowledge about autistic disorders has not led to any curative methods of treatment. The real advances [in autism] have been in understanding how to create an environment and a daily programme that minimise the disabilities and maximise the potential skills"* (Wing, 1996:11-12)

This thesis will argue that the primary difficulties for people with a label of 'autism' are in relation to understanding a confusing 'social' world. Just as importantly is the way that schools, other services and professionals perpetuate and maintain barriers to access for these individuals. It has often been the experience of children with a label of 'autism', that where schools have not been able to respond to their needs, this has resulted in their exclusion. In a report published by the National Autistic Society *Inclusion and autism: is it working?* (2000) it was found that secondary schools needed to give more attention to social and life skills and that support staff should understand the specific needs of this group of children. These children make up the biggest single group of children excluded from school, with one in five children with a label of 'autism or Asperger syndrome' having been excluded from school. This is nearly 20 times the national average. The reason for the exclusion is frequently the result of the lack of appropriately trained support staff.

There are now more children with a label of 'autistic spectrum disorders' on their statement of special educational needs, in 'special schools', than children with any other impairment label. A report by the National Autistic Society *Autism in schools: crisis or*

challenge? (2002) reveals that one in three children in special schools have needs related to autism, yet 75% of schools in the survey reported that their teachers are inadequately trained. It could then be argued that children with a label of 'autism' are being excluded from mainstream schools, not because of their 'impairment' but because of the barriers in place that continue to deny their access to education. A legal framework has now been introduced to challenge such discriminatory practices. The Special Educational Needs Code of Practice (2001) sets a statutory framework to ensure that as of September 2002:

> *'schools will be required not to treat disabled pupils less favourably for a reason relating to their disability and to take reasonable steps to ensure that they are not placed at a substantial disadvantage to those who are not disabled'* (Special Educational Needs Code of Practice, 2001:V)

In practice, the Special Educational Needs and Disability Act 2001 amends the Disability Discrimination Act 1995, to prohibit all schools from discriminating against disabled children in their admissions arrangements, in the education of its pupils or in relation to exclusions from school. There is a new emphasis in the Special Educational Needs Code of Practice, on the rights of children with special educational needs to be involved in decisions and to be able to exercise choice. There is a whole chapter on 'Pupil Participation' and recognition that the process of communication may well be varied and different for some children, the document argues:

> *'Consultation with young children will necessitate a range of communication strategies, including the use of play, art, audio and video as well as verbal communication'* (Special Educational Needs Code of Practice, 2001:28)

This position places emphasis on the acknowledgement of the different communication styles, which become the starting point for developing pupil participation. It will be the establishment of a means and method of communication that will enable participation

rather than communication difficulties being an excuse for the exclusion of some individuals from such a process. The Special Educational Needs Code of Practice has started to acknowledge the sensory difficulties of children with special educational needs. Although the document does not identify any particular children, there is a sentiment in the following extract that indicates that we may need to understand children in different ways:

> *'It is important to avoid making assumptions about levels of understanding, particularly amongst very young children and older children with learning, communication or sensory difficulties. These children may need additional help to be able to make their views and wishes known and efforts should be made to arrange for this help to be provided where it is needed'* (p.31)

It is only through the *process* of communication that a true picture can be built of the issues and concerns of children and young people with the label of 'autism'.

In the opening of this chapter, it was argued that 'autism' has a history of being defined from a particular position of inquiry - from a psychiatric and psychological field of inquiry with a focus primarily on the cognitive/medical aspects of autistic people. This has resulted in a 'skewed' understanding of autism, one which focuses on impairments, deficits and disorders (from a medical/illness perspective) and one that looks at psychological issues of cognition, behaviour, motive, theory of mind and weak central coherence. This definition of autism is reductionist and understandings of autism emerge from a 'deficit'/'impairment' perspective which sharply contradicts developments in the wider disability movement, which has dispensed with the medical/impairment model and has advocated for an understanding of disability from within the social model.

It will be argued that while 'autism' research to date has contributed greatly to the development of practice in understanding learning styles and creating learning environments, people with a label of 'autism' have been largely absent from actively participating in such research. Qualitative research facilitates working with people in their natural 'setting' and observing them in interaction with others and their environment. There is a need to break with the dominance of positivist research methodology and to explore ways to actively engage people, who have a label of 'autism' in the research process, using 'participatory' and 'emancipatory' research methodologies. This research project hypothesised that, by changing the research methodology and by actively engaging those with a label of 'autism' in the research process, a new definition of autism may emerge.

Chapter 1 presents an analysis of the way autism has been theorised throughout its short history in the professional arena. Each 'theory' or 'understanding' of autism is examined in relation to the model/approach underpinning it. It will be argued that such theories explain more about the professional body advocating the theory than about people with the label of 'autism'. It was only when people themselves started to write their own accounts of their experiences, were others able to identify 'key themes' in common amongst people with the label of 'autism'. Chapter 1 proposes a 'paradigm shift' is required to help move away from positivist research methodologies in autism research and to move towards ways that enable people with a label of 'autism' to have a 'voice' and to ultimately lead the research process. The use of the social model of disability as a fundamental framework in undertaking research with people so labelled, will be examined and critically reviewed in relation to the important question of *why* research is being undertaken in the first place. If, as Wing suggests, the knowledge gathered from research has not made a particular difference to the lives of people with a

label of 'autism', then should we not question the continuation of research carried out in this way?

Lather (1986) argues that it is important for research to be carried out that is 'explicitly committed to critiquing the status quo and building a more just society'. It is essential to start the process of enabling empowerment, control and decision-making of people with a label of 'autism' in the research process. Although this research project never ultimately achieved the use of 'emancipatory' research methods for reasons I will discuss later, it started the process of involving participants in 'participatory' research.

Chapter 2, outlines the research methodology used for this research and proposes some key principles for engaging people with a label of 'autism' in the research process. 'Participatory' and 'emancipatory' research methods are appraised and provide a framework for the development of a research methodology, which enables active participation of the research participants. Lather (1986) argues that emancipatory research 'must operate within a conscious context of theory building'. Because she argues that without this how will the researcher demonstrate that constructs are actually occurring, rather than merely inventions of the researcher's perspective? There must be a respect for the experiences of people in their daily lives to guard against theoretical imposition.

The original aim of this research was to explore the experiences of adolescence from the perspective of young people with a label of 'autism', but initially I thought about the themes that *I* would be interested in exploring. Ideas about the development of a sexual identity, the onset of depression and epilepsy in adolescence (Gillberg and Steffenburg, 1987; Volkmar and Nelson 1990; Gillberg, 1991; Rossi et al 1995) emerged from a

review of the literature, which guided me to think about the development of a quantitative 'check list' assessment schedule. As the principles of emancipatory research started to shape up the research design, the focus of the research moved from exploring 'content' issues and concepts, to devising and developing a research methodology that would enable the inclusion of young people with a label of 'autism' to have a 'voice' in the research process. I was guided by the values of pursuing research as a democratised process of inquiry. Lather (1986:257) argues that such a process is characterised by negotiation, reciprocity and empowerment.

It was never the original aim of the thesis to spend a considerable amount of time on the design of a methodology to engage and 'communicate' with young people with a label of 'autism'. As a novice researcher I was keen to design the research methodology and to start the research process as soon as possible. It soon, however, became apparent that to enable effective communication between the researcher and the research participants a dynamic, reliable and valid research methodology would need to be in place that would have the ability to be flexible and adaptive to the individual communication styles of the research participants.

Once the research became grounded in the commitment to pursue emancipatory research with the young people, this development became an inevitable and central part of the research process. The learning from this research has led me to believe that a commitment to engage people with a label of 'autism' in the research process is not enough on its own. For inclusion to be meaningful, researchers need to seriously reflect on and consider how their own communication style can be changed in order to break down communication barriers and establish a dialogue. Such a dialogue is possible, but it will require meeting the person halfway. If the person needs to talk about his special

interest, for example of cars prior to the formal part of an interview, then the researcher needs to analyse a subject that will help establish a rapport between the researcher and the person with a label of 'autism'.

A communication profile can also work as a way of helping to translate particular aspects, patterns and meaning of communication. Within this chapter it will be argued that by developing research methods that closely resemble how people with a label of 'autism' think (a visual research methodology), then such a development can enable individuals to become engaged in the research at a level of their own choosing. It is perhaps at this point that it could be argued that this research study strived to develop along the lines of emancipatory research. The emphasis was on developing my own skills, as an emancipatory researcher, rather than achieving objectives of an emancipatory research study.

Understanding how people with a label of 'autism' think and feel and relate to the world was important to establish before I could begin to develop and design a research proposal along emancipatory research frameworks. It was essential to explore a way of communicating with people to motivate them to become involved in the research process to begin with. A review of the literature had emphasised that people with a label of 'autism' tend to be 'visual thinkers' and Temple Grandin's book (1995) was pivotal in influencing the research design at this stage. Photographs had been used with some success in the past, but more as a visual aid to show the stages in a schedule of teaching a person a skill (e.g. the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH programme), Mesibov et al, 1983).

Guided by the vision to pursue emancipatory research, I started to explore the idea of young people taking photographs of what was important to them in their life. The idea of giving young people a disposable camera (to identify with as *their* property) was a mechanism to enable the young person to lead the research. Traditional ways of engaging disabled people in emancipatory research were going to be difficult to use when working with children with a label of 'autism'. Such approaches had caused barriers that served to exclude this group, who it was reported tended to be concrete thinkers and who had difficulty using the skills of reflection (Jordan and Powell, 1995:116). The use of photographs as the basis for an interview would enable me to facilitate the person (with the use of their photographs) to tell a story, within a process of structured reflection.

Chapters 3, 4 and 5 are data chapters with chapter 3 introducing the 11 research participants. Chapter 4 presents the findings from the 1350 photographs taken by the young people and chapter 5 explores the complex issues involved in social relationships and friendships. The data presented in these chapters will challenge the assertions made by professionals advocating different 'theories of autism'. It will be argued that much of what is seen as a 'professionalised (medicalised) view of autism' can be challenged, when young people become directly engaged in the research process.

More specifically, chapter 3 presents an alternative perspective of 'autism' arguing that those with the label are not necessarily 'disordered', 'impaired' or 'deficient'. This chapter explores the experiences of people through their senses and the way they process information and re-positions the defining of 'impairments' of autism from the collective experiences of those with the label of 'autism'. This Chapter provides evidence that the support provided within different environments can either be disabling

or enabling. This chapter examines the concept of barriers: barriers present in the physical environment; barriers in the support provided and barriers in the way information is given. Evidence that barriers exist in this way is explained by two writers with the label of 'autism' (Grandin, 1995; Williams, 1998) who propose that those with a label of 'autism' experience the world through a 'sensory continuum'. Proponents of the social model might argue that such a positioning by writers with the label of 'autism' justifies the maintenance of the 'impairment' model in their lives. Another way of looking at this would be to understand that the writers are 're-claiming' and 're-defining' impairment. This is in line with Goodley's (2001) proposal that 'impairment is social not the product of isolated individual pathologies' and that he argues that the collective activism of people with 'learning difficulties' are incorporated into social theorising.

Within chapter 3, the discussion of the 'sensory continuum' serves to illustrate how *differently* the barriers exist across different environments and from different support structures. The research participants understood that they experienced difficulties, but they explained these difficulties as 'external' to themselves (barriers) rather than as 'internal' (impairments). Ultimately, the continued use of words such as 'impaired', 'deficit' and disorder, by the researchers, professionals and academics will have some direct effect upon their self-esteem.

Chapter 3 challenges the current definition of autism based on the 'triad of impairments' and proposes that 'autism' is experienced as a disability and that this disability may be evident across a range of environments or may not be apparent at all. This chapter proposes the theory that people with a label of 'autism' can move through the 'sensory continuum'(Grandin, 1995; Williams, 1998), yet this move is not based on advances or

'treatment' of 'impairments', but on the breaking down of disabling barriers in the physical and support environment. Equally it could be argued from a 'social model' perspective, that as the barriers in the environment are challenged and dismantled, the person develops an increase in self-confidence within particular environments. What may look to the observer as the 'impairment' becoming 'cured' or the person responding to 'treatment', is really the enablement of a person to have more control over their environment, the support provided and their access to information.

Chapter 4 considers 'the lived experiences of 11 young people with autism' and presents an analysis of 1350 photographs taken by them. The use of photography in social sciences research has been termed 'autophotography' (Emmison and Smith, 2000:36). Autophotography is a term, which describes the process of the research subject taking the photograph, with the analytical task of interpreting the photograph remaining with the researcher. In this research, the task of analysis was a combined process with the young people, as the interview was used as a basis to discuss the image and to clarify what meaning the photograph had to the person. The literature on the use of autophotography reveals that photographs can reveal personality types, gender/sex role differences and concepts of self. For example, women are more likely than men to provide photographs of themselves, men are likely to include photographs on leisure activities as well as pictures of prized possessions such as cars or motorcycles (Clancy and Dollinger, 1993). Shy people are less likely to include other people in their depictions of self (Ziller and Rorer, 1985).

This research sample was made up entirely of young men and this reflects the prevalence rate of 2:1 boys to girls at the lower ability end and 15:1 at the highest ability end of the autistic spectrum (Wing and Gould, 1979). Although girls with a label

of 'autism' were identified in the initial stages, none responded to the invitation to partake in the research process. To overcome any difficulties of broad over-generalisations in relation to gender and 'autism', the analysis of gender issues will be limited to an analysis of gender in respect of the inter-relationship and rapport issues between the research subjects and the researcher (Chapter 6).

The photographs were established for *credibility* in so much as the researcher checked with the person if they were the instigators of the image and if they had 'technical control' (which the photographer can exert over the final production of the photograph). The photographs were not analysed in isolation from the young person's narrative and, in fact, where no narrative accompanied the photograph (where the tape recorder failed to record), the photographs were not included for analysis. This was an attempt to safeguard the analysis from researcher bias.

Parents and carers play a crucial role in introducing children to the shared meanings of objects, by drawing the child's attention to the object and then demonstrating how it is used. Many people with a label of 'autism' continue to relate to objects through their proximal senses, of touch, taste, and smell and may fail to see the relevance or function of a particular object. Rather they may see the colour, feel the texture or taste the item. The use of an object e.g. the camera enables individuals to relate to it in a sensory way as well as from a functional perspective. One young man who had a special interest in Japanese culture, was so motivated and excited by the camera, which was not only made in Japan, but was finished in a shimmery silver colour, that he continued to comment on. So many of the symbols, the routines and the rituals, which make up our society may not be immediately evident to people with a label of 'autism' and instead other priorities, for example landmarks in the environment, take precedence. Williams et al,

(1999) argue that our world has already been shaped by human activity and is full of things designed by people, who share a common body shape, needs and a cultural history to be used in specific human activities. People with a label of 'autism' may not necessarily see the relevance of this 'cultural history' and what emerges from their perspectives are alternative ways of viewing the world.

Chapter 5 examines the disabling barriers that are present in human relationships. The Special Educational Needs Code of Practice, indirectly refers to 'barriers' in their recognition that staff need skills to communicate with children with special needs. They argue this specifically in relation to Learning Support Assistants:

> *'Learning support staff have a critical role in supporting*
> *Many children and their training should include an element on*
> *Pupil participation and the development of communication skills'* (p.31)

The ability to relate and communicate with people with a label of 'autism' extends outwards in relation to peers and friendships. This particular chapter examines friendship and how some of the barriers exist within particular environments, which create difficulties for the young person in forming friendships and relationships.

Research by Curcio and Paccia (1987) illustrated that support staff can breakdown barriers of communication between themselves and people with a label of 'autism'. There was a direct correlation between the increase in facilitating features of adult utterances and the increase in adequate replies from the children. Facilitating features included yes/no questions, questions that were conceptually simple and questions that were semantically contingent on the child's topic. One of the negative findings from this research was that 64% of adults did not simplify their subsequent utterance following an inadequate reply from the child. The researchers found that there were many missed opportunities for adults to simplify their questions when children incurred

a lapse in their turn. A focus on how barriers exist in the communicative/support relationship with people with a label of 'autism' can enable professional development that can enhance the teaching and learning of individuals with those so labelled. This chapter argues for the breaking down of barriers in social relationships as opposed to using behavioural management strategies to focus on 'impairments', 'deficits' and 'disorders', particularly when things start to go wrong. This chapter also argues for proactive support in the area of social relationships and friendships, so as to enable not only people with a label of 'autism' to learn from experiences, but to help others build tolerance and understanding of the way such individuals may view relationships and friendships.

Chapter 6 is a 'reflexive chapter'; it analyses my role as researcher in the research process. As this research study was guided by the principles of emancipatory research, this chapter sets out to examine how (if at all) these objectives were met. It also critically examines the experience of the research participants, to identify through evidence what the research participants got out of their involvement in the research. This chapter also explores how, as a researcher, I would do things differently next time and identifies the lessons that have been learnt.

Finally, chapter 7 concludes this research with further analysis of the social model. This chapter recommends that we should no longer be following an 'impairment model' unless the use of the term 'impairments' have been reclaimed by those with the label of 'autism'. More importantly however is to explore ways to break down the barriers between access to the social model and the wider disabled people's movement and those with a label of 'autism'.

CHAPTER 1

THEORIES AND UNDERSTANDINGS OF AUTISM

Before outlining the aims of this chapter, I will reflect on my own theoretical and practical position in relation to my understanding of 'autism'. I came to this research study with an open mind. My previous work with people labelled with a 'learning difficulty' had been predominantly based within a multidisciplinary team perspective and much of my practice as a nurse in the 1980s was guided by the philosophy of 'normalisation' (Wolfensberger, 1972). It wasn't until much later and early in the last decade that I started to feel uncomfortable with the philosophy and principles of normalisation. There appeared to be contradictions in a theory that imposed a set of principles on the service design and delivery for people with a label of 'learning difficulties', by able-bodied people. I did believe at the time that it was the ideas of normalisation that drove an attitude change and fostered the belief that people with a label of 'learning difficulties' were able to 'self-advocate' and speak up for themselves. This then guided the practice of individuals (and influenced service design) when working with this group of people.

It was difficult at the time to understand any other perspective. I remember listening to Dr Michael Oliver (a disabled activist) at a conference and I struggled to come to terms with the fact that many disabled people were critical of professionals (like myself) in the learning disability field. I really did believe that my colleagues and I were empowering people with a label of 'learning difficulties' through the principles of 'normalisation'. I was one of those individuals who would argue that we had to advocate on behalf of people with a label of 'severe learning difficulties', when they do not have the language (or communication ability) to advocate for themselves. It was only much later that I could begin to understand that in order for people to really have a voice and to have

power in their expression, then this needs to be on their terms and to be defined by them. I have moved on in my theoretical position and this has been shaped predominantly by the influence of people with a label of 'learning difficulties' with whom I have had contact and also through my reading and understanding of the social model of disability. My experience of working in partnership with people so labelled, has been the motivator and the driving force to develop a theoretical perspective that enables their voice, but perhaps equally of importance, challenges the oppressive and often patronising assumption that 'we' need to speak on behalf of others.

It is within this framework of openness and self-reflection that I review the theories and understandings of autism.

It is the aim of this chapter to review the theories of 'autism', to examine how the theories relate to the lives, experiences and realities of people with a label of 'autism'. The theories will be examined from the perspective of their method of inquiry and it will be argued that the current day knowledge or the 'truth' we have of 'autism', has emerged from a particular perspective of inquiry. A more contemporary understanding of 'autism' has more recently been dominated from an exploration of 'autism' from a 'cognitive' or 'affective' psychological perspective as opposed to a 'social model' approach. It will be argued that by explaining 'autism' primarily from a psychological perspective, the power remains with professionals and the research agenda is dominated by positivist research methodologies. I propose that past and current theories of 'autism' still appear unrelated to the lived experiences of people with a label of 'autism'. Instead, often the theories of 'autism' become a rationale by which decision, power and control are denied to individuals. The theories emerge from an 'impairment' model, which perpetuates the view that 'fault', lies with the individual, rather than exploring

ways in which society disables individuals through a range of social, cultural and political barriers.

An alternative understanding of 'autism' will be outlined using the 'social model' approach. It will become apparent within this thesis that to enable the voice of people with a label of 'autism' to be heard through the research process, that an examination of disabling barriers is required. The social model approach also has its critics, but it will be argued that this approach comes closest to explaining the experiences described by this group of people. This is apparent not only in a review of the literature but also in the data chapters presented in chapters 3, 4 and 5.

In many areas the services for people with a label of 'learning difficulties' have moved on, emerging from the experience of 'normalisation' and are now working towards the social model of disability. This cannot be said for services designed for those with a label of 'autism'. Normalisation did not have the same impact on services for this group of people and in some respects a review of the literature suggests that the theory conflicted with the psychological theories of autism. Where normalisation did not take hold, the theories of autism and the 'Triad of Impairments' did. Whereas services for people with a label of 'learning difficulties' advanced from the theory of normalisation (where choice, advocacy and decision making were major themes), 'autism' specific services struggled to, as they directly conflicted with the dominant theories of 'autism', for example 'theory of mind'.

The theory/practice gap within 'autism' research continues. Researchers use language and position research questions within the medical/deficit model, support services for children and adults with a label of 'autism' are developing from within the 'social

model' of understanding disability. Much of the practice development has been influenced by government policy changes, not least the development of Person-Centred Planning, which emerged as a recommendation from the white paper "Valuing People" and involved individuals becoming active in the control and decision-making processes in their lives (DoH, 2001). The medical/deficit model does not relate philosophically or ideologically to practice as people with a label of 'autism' start to advocate for themselves and to become involved in decisions that affect their life. Current and past theories of 'autism' serve to deny and to perpetuate a powerlessness and material deprivation in the lives of people with a label of 'autism'.

The current theories of 'autism' fail to explain the increased over-representation of children excluded from mainstream school and the reason why more children with a label of 'autism' are increasingly found in 'special schools'. Adults with a label of 'autism' continue to be excluded from the labour market and experience discrimination. The theories, in my view, serve to mystify 'autism' as 'impairment' and to justify the maintenance of segregated and 'special' provision. Many of the difficulties experienced relate to the 'social' aspect of life yet the theories of 'autism' dominate in the psychological examination of individuals.

I argue here that more research needs to be undertaken to understand the 'social' aspect of those living with a label of 'autism' and for this to happen, researchers will need to make a 'paradigm shift'. This chapter concludes with a proposal to enable people with a label of 'autism' to have opportunities to inform the research agenda, so that the body of knowledge on a theory of 'autism' emerges from the collective voice of people so labelled. This research project goes someway to starting this process and suggests ways in which a research methodology can be developed to advance this objective (see

chapter 2). Firstly however we will examine the different theories/understandings of autism.

Understanding autism from a behavioural perspective

It was not until Leo Kanner (1943) published his observations of eleven children, that 'autism' was first discussed and recognised as a particular condition, marked by a particular pathology. Hans Asperger wrote of his observations of four children in 1944, although this work was not translated into English until the 1970s, when Wing and Gould (1979) drew upon Asperger's (1944) work to support their study of the prevalence of children with a label of 'autism' in Camberwell, London. Wing and Gould concluded that there were those children who had a label of 'severe autism' (identified and supported by the case studies illustrated by Leo Kanner, 1943) and there were those with a label of 'mild autism' (supported by the observations of Hans Asperger). Wing and Gould believed that children could present with Kanner's autism and then develop into adulthood presenting with Asperger syndrome. They concluded that there was an 'autistic spectrum' and that 'autism' should be recognised as an autistic spectrum disorder (ASD) with those labelled with Asperger syndrome, included within this spectrum. Most of the theories or frameworks for understanding 'autism' have emerged from a study of the behaviours of 'autism', which are essentially:

- An impairment in the ability to interact socially

- A 'communication disorder'

- Certain 'bizarre' behaviours

- Bizarre responses to sensory stimuli

- Impairment in the use of imaginary play.

The influence of Kanner, Asperger, Wing and Gould in the development of an understanding of the behaviours of autism, were influential, in so much as they developed a set of behavioural criteria for the assessment and diagnosis of autism as 'impairment'. This work had important national and international influence as autism became a diagnostic category in the Diagnostic and Statistical Manual of Mental Disorders (4th Edition) (DSM-IV) (American Psychiatric Association, APA, 1994) and the World Health Organisation International Classification of Diseases and Health Related Problems (ICD 10). The work of Wing and Gould, (1979), developed and framed what we understand as Wing's 'Triad of impairments' (1988): impairments in social interaction, communication and imagination, and it is the triad that influenced the categories of the DSM-IV and WHO ICD-10 diagnostic criteria.

The official diagnostic criteria have not been without their critics who have argued that current diagnostic criteria do not sufficiently address the 'sensory' and 'physical' aspects of the condition labelled 'autism'. The critics primarily come from within the 'impairment'/'medical model'. It has been argued that some people with the label of 'autism' experience difficulties in movement disturbance (Kohen-Raz, et al, 1992; Leary and Hill, 1996) while others have motor difficulties (Miyahara et al, 1995). Assessing behavioural criteria as a main area of focus in the diagnosis of autism results in other aspects or 'dimensions' of autism being missed. There is also the difficulty in that by focusing on the observation of behaviours, there is insufficient focus on the 'cause' of behaviour. People with a label of 'autism' have written in their autobiographical accounts about the suggested causes/reasons for their behaviour. Some have reported that autism can be defined as an information processing difficulty 'feeling over-loaded with information' (Cesaroni and Garber, 1991:310), when this happens it may result in behaviours which appear to the onlooker as strange. One of the reasons

for presenting 'behaviour' could be the way the person is responding to stimuli via their senses. Williams (1994) illustrates the experiences of acute hypersensitivity through one of the senses:

> *"I discovered I could use cotton wool in my ears in order to*
> *tolerate the pitch and intonation of her voice, but it still set my*
> *nerves on end"* Williams: (1994:41)

For others, more specifically there is a need to convert or translate concepts into visual images:

> *"I thought of peace as a dove, an Indian peace pipe or TV*
> *newsreel footage of the signing of a peace agreement.*
> *Honesty was represented by an image of placing one's hand*
> *on the bible in court"* (Grandin, 1995:33)

Such processing of mental events of people with a label of 'autism' appears to be carried out mainly by visual thinking (Hurlburt et al, 1994). 'Visual thinking' can take a longer time to process information and can be misinterpreted as 'non-compliance' or 'demand-avoidance' behaviour. Lawson (2001:33) argues that she and others with a label of 'autism' experience 'monotropism' in relation to information processing. It is argued that this is demonstrated by difficulties with change in routine, expectation, instruction, daily schedule, and movement of attention and even incorporating another channel into the present scenario. Lawson is unable to partake in listening and participation in decision- making (without due time to process information) thus moving from one channel to another. Again differences in information processing can clearly slow down an individual's responses, which may initially be observed (from the medical model) as difficult behaviour.

Although we have evidence of the different cognitive or learning style of people with a label of 'autism' and their information processing differences, there is evidence that

barriers remain in place that prevent access to information for people with autism. This was illustrated by the work of Curcio and Paccia (1987) who found that where adults recognised a child with autism has processing problems, the adult did not necessarily simplify their subsequent utterance following an inappropriate reply from the child. Such a finding was supported by Potter and Whittaker (2000) who found that as adults reduced the complexity of their speech and language, this increased the levels of children's engagement in interactions. Such research findings support the argument for analysing barriers that exist for people with a label of 'autism', rather than for professionals and researchers to continue the analysis of 'impairment'.

Instead of adaptations in approaches to aid information processing (breaking down barriers in the presentation of information), the behavioural approach which advanced in the sixties and seventies still has a major influence in support services today. The Lovaas approach or applied behavioural analysis (ABA) aims to provide an intensive behavioural programme (usually of 40 hours a week) to teach a range of functional tasks with the goal to ensure the child can become integrated into mainstream education (Lovaas, 1977). The early behavioural approaches used 'time-out' extinction procedures to eliminate behaviours and punishment was used. The focus was on reducing self-injurious behaviours such as head banging and self-mutilation, hyperactivity and tantrums (Lovaas et al, 1965). Many claim they feel the approach has been well researched and 'tried and tested' (Watkins, 2001:303) while others argue that there is too much rigidity in the programme that can ultimately cause an individual child distress (Lubbock, 2001).

The original focus of behaviourism and its origins emerged as a direct response to the theory of 'autism' that people with the label of 'autism' had retreated into their own

world as a consequence of a failure to bond with their mother. There is a legacy of this psychoanalytical approach and remnants of it still prevail today. Some observers believe that people with a label of 'autism' are responsible for their condition and believe they *choose* to live a life that involves them *voluntarily* withdrawing from others or from the *world*:

> *"they don't harm the parents nearly as much as they harm the victim when they say a child chooses to be autistic. The results of these assumptions are often subtle, but they're pervasive and pernicious: I am not taken seriously. My credibility is suspect. My understanding of myself is not considered to be valid and my perceptions of events are not considered to be based in reality* (Sinclair, 1992).

People with a label of 'autism' may develop survival strategies as a way of coping with the onslaught of intensity of interaction from the behavioural approach. Bogdashina (2001:36) argues that sometimes people with a label of 'autism', give up fighting in an incomprehensible world, and rescue themselves from overload to an entertaining, secure and hypnotic level of hyper-watching the reflection of every element of light and colour, tracing patterns and shapes. Williams (1994, 1996b, 1998) talks about the survival strategy of 'Resonance' which is losing oneself in certain stimuli. Williams calls this resonance to 'disappear', (to be discussed later in chapter 3).

Autism as a disorder of emotional contact

Leo Kanner (1943; 1979) believed that 'autism' was a disorder of 'affective contact'. He believed that essentially the parents (particularly the mother) had failed to develop an emotional bond with their child and that these parents were likely to be from middle-class families. Kanner claimed the parents were highly intellectual with a 'great deal of obsessiveness'. They were preoccupied with abstract aspects of science, art and

literature and their interest in people was limited. Such a proposition, at the time, prepared the way for other theorists to develop this theory of 'autism' based on the assumption that there was a dysfunctional relationship between the child and parents, particularly the mother.

Bettleheim in the book 'The Empty Fortress' (1967) argued that the cause of autism was based on poor bonding between mother and child and proposed an 'emotional theory' of autism (Bettleheim, 1967). Such a theory was later discredited, and mothers were often left to workout for themselves ways to connect with their children. Information and advice on supporting a child with a label of autism was virtually non-existent. One mother documenting her experiences at the time wrote of her daughter:

> *'Yet we could not leave her there, we must intrude, attack, invade …. there in Nirvana, why should she ever come out? …. We had no choice. We would use every stratagem we could invent to assail her fortress, to beguile, entice, seduce her into the human condition'* (Claiborne Park, 1967:17).

Parents struggled to support their children, and Bettleheim advocated for the initial isolation of the child in the clinic, where staff would help to rebuild the emotional security the child lacked, because of an unresponsive mother. Such a theory has been dismissed and unsubstantiated by research and there is no evidence that autism is linked to social class (Gillberg, 1990).

Autism as a sensory impairment

An alternative to the behavioural and 'lack of emotional contact' theory/approach was to understand autism from a physical/sensory perspective (Creak, 1961; Rimland, 1964; Delacato, 1974). These authors noted that individuals with a label of 'autism' related to their senses in a different way to those without such a label. They also started to see

that such behaviours varied according to different environments and the different levels and types of stimuli in these environments. Some individual's behaviour may be the result of stress, pain or discomfort to stimuli in the environment, yet the person may not have an awareness of this or is aware that such experiences can also be shared with others who share also share a label of 'autism':

> *'Until I actually had met someone else like me, I hadn't, realised that my 'quirks' and 'difficulties' were anything other than my mad, bad or sad personality'*
> (Williams, 1994:71)

Sensory experiences and the way the senses relate differently to environments and stimuli are most likely to occur as a feature/experience of people with a label of 'autism', yet this was not included as an essential component in the 'Triad of Impairments'. Sensory experiences (although confirmed by people with autism) are listed as an associated but not essential feature of autism within DSM-IV.

> *'There may be odd responses to sensory stimuli, (e.g a high threshold for pain, oversensitivity to sounds or being touched, exaggerated reactions to light or odours, fascination with certain stimuli)* (APA, 1994:67-68).

This has led some writers to express their surprise by such an omission (Gillingham, 1995; Bogdashina, 2001) others have chosen to include 'abnormal sensory responses' as a fourth defining feature of autism (Richard, 1997:15).

Gillingham (1995:5) believes that many of the problems in the lives of people with a label of 'autism' are caused by their reactions to sensory stimulation. Richard (1997:84) argues that much of the behaviour observed of individuals is due to poor attention problems that can be attributable to the sensory system. The environment can be extremely distressing but what may be distressing to one person may not be to another, as each person responds to environmental stimuli differently. This is referred to as

either a hyper (over) or hypo (under) response to stimuli. All six major sensory systems can be affected. They are taste, smell, movement, sight, hearing and touch.

Psychological theories/understanding of autism

Psychological theories started to emerge in the 1970s, to present an alternative understanding of 'autism' to that of the behavioural/emotional/physical/sensory theories presented. The psychological theories are divided into two main approaches: the *cognitive*, involving the lack, partial or total ability to perform a particular cognitive operation; the *affective*, which is defined as the complete lack of normal emotional responses (developed from Kanner's original theory).

The Theory of Mind approach emerged as a cognitive theory to explain 'autism' (Baron-Cohen, 1988, 1993; Frith, 1989; Leslie, 1991, 1993). It was argued that the earliest detector of autism can be found in the lack of understanding attention in others. Baron-Cohen (1991, 1993) argued that people with a label of 'autism' will fail to appreciate that others look at objects selectively, because of their own interest, rather than to look at an object and see it for its physical characteristics. A lack of 'Theory of Mind' explains that autistic children do not make use of eye gaze or share the attention of an adult. Baron-Cohen argues that the lack of theory of mind can explain the Triad of Impairments that form the basis of diagnostic criteria used when diagnosing a person with a label of 'autism'.

Despite various experiments, a lack of theory of mind has only been evident in 80% of the children tested and the theory fails to explain why 20% of children with autism do have 'Theory of Mind' yet still experience difficulties with social interaction. Although cognitive theories have now moved on, to explore a more comprehensive theory of

'autism', the 'Theory of Mind' approaches did contribute to the diagnostic category of 'autism' to be seen more as a developmental disability rather than just as a set of behavioural problems needing modification or as a mental health problem.. The theory also started to inform teaching and learning approaches based on the particular cognitive style of people with a label of 'autism'.

Happé (1994a, 1994b) however, argues that the theory of mind does not explain the 'non-Triad' aspects of autism. It doesn't explain for example a restricted repertoire of interests, obsessive desire for sameness, islets of ability, excellent rote memory and pre-occupation with parts of objects. Happé argues for a cognitive theory of autism that will encompass these 'non-Triad' aspects of autism and suggests that 'weak central coherence theory' can explain this (Frith, 1989). Frith (1989) argues that children with autism are 'mind blind', and suggests that people with a label of 'autism' do have mental states, such as perceptions, desires, wishes, beliefs and knowledge, but they are not conscious of them.

The theory of 'weak central coherence' proposes that autism can be explained as a result of a disturbance in the information processing ability for formulating meaning in context out of diverse information (Frith, 1989). Happé explains that a characteristic of 'normal' information processing appears to be the tendency to draw together diverse information to construct higher-level meaning in context – 'central coherence'. The theory proposes that those without the label of 'autism' tend to get the gist of a story and have a general impression of the whole, there is not such a focus on detail. Central coherence also helps to recognise a contextually-appropriate sense of many ambiguous words in everyday speech (son-sun, meet-meat, sew – so). Frith (1989) suggested that this universal feature of information processing is disturbed in those people with a

diagnosis of 'autism' and that a lack of central coherence could explain the assets and deficits of 'autism' more so than the theory of mind or the Triad of Impairments. Happé goes on to suggest that having a weak central coherence can give the person strengths in recognising the detail rather than the whole and suggests that this would explain savant skills (p.121).

Happé (1994b:125) concludes that we can best understand 'autism' as a 'different cognitive style' and that the central coherence hypothesis 'differs radically not only from the theory of mind account, but also from other recent theories of autism'. It is argued that 'every other current psychological theory claims that there is some significant and objectively harmful deficit primary in autism'. The central coherence explanation helps to move from a 'deficit' perspective to understanding the strengths and the talents of people with a label of 'autism'. This approach, however, still remains within the 'medical model' of disability and the research methodology is still within the positivist paradigm.

The 'deficit'/'medical' model still prevails within the psychological approaches to understanding 'autism' with the theory of 'impairment' of underlying *affective or emotional processes* (Kanner, 1943; Hobson, 1989, 1993; Baron-Cohen 1991). Another cognitive theory is the '*Executive Functioning Deficit Theory*' (Ozonoff et al, 1991a, 1991b; Ozonoff, 1995). The theory of underlying affective or emotional processes argues that 'autism' is a biological disorder of affective engagement and relatedness with others (Kanner, 1943; Hobson, 1993) and argues that children with a label of 'autism' lack the basic ability to experience relationship based emotions. The theory was first proposed by Kanner (1943) whose description of the eleven young people was 'a pure culture example of inborn autistic disturbance of affective contact'.

Only limited research exists to explore the inter-relationship of the person with a label of 'autism', with peers, family and others. It may be that what impacts on the ability of children to form relationships is that the emotional expressions and language may be too over-stimulating in the interaction, causing the child to withdraw from the situation (Dawson et al, 1990). Dawson et al, (1990) found that mothers were less likely to display smiles and respond to their children's smiles than mothers of children without a label of 'autism' and Kasari et al, (1988) highlight the critical role of others in shaping children's behaviour. Such findings indicate an argument for exploring the barriers that exist in the environment that continue to disable a child in relation to social interactions with others. Barnes, (2003) argues that a social model approach may be used to highlight the interpersonal barriers within the context of personal and family relationships.

Sigman and Mundy (1989) argue that children with a label of 'autism' do show positive affect and they do form positive attachments with carers. However, these research findings suggest an 'impairment' in cognitive/affective underpinnings to make sense of the emotional cues from others.

Executive Function Deficit Theory proposes that autism is the outcome of a biological fault in the frontal lobe and the limbic system of the brain, which is the area that enables an individual to maintain appropriate problem-solving for attainment of a future goal (Bishop, 1993: 284). This theory suggests primarily that autism is caused by deficits in systems underlying the control of actions and thought central to autism. Boucher (1998) believes that this particular theory will not be with us for very long in its present form

and that within 5 years executive function impairments, like mentalising impairments, will have become part of what has to be explained rather than part of the explanation.

One of the major criticisms of the cognitive theories and Executive Function Theory is that they are unable to provide a satisfactory explanation for some of the central traits of 'autism', especially those involving social development. Bushwick (2001) argues that since the main definition of autism is in terms of abnormal social relationships and these are by definition, always involved, it seems likely that the cause of autism itself is likely to be social. Bushwick argues that the social learning process breaks down for people with a label of 'autism', and it is this that causes the observed behaviours presented by people so labelled.

It could also be argued that insufficient attention is paid to the information processing styles of people with a label of 'autism', which will significantly impact upon their performance in any experiment or 'Theory of Mind' tests. Kochmeister, (1995), Grandin (1995), Williams (1994) and Lawson (2001) argue that 'information processing' is one of the core areas of difficulties for people with a label of 'autism':

> *'I would like to say at this point that I disagree with much of what professionals think they know about autism and people with autism...... the real difficulties occur in speed and style of processing, digesting and responding to what has been presented'* (Kochmeister 1995).

The second major criticism is that the cognitive theories and the theory of disorder of affective contact have all been explored in an individual way without reference to a social context, which in turn determines the methodological choice of researchers and the interpretation of results. There is very little research on the exploration of how a

child with a label of autism's, 'deficits' may affect and be affected by other's responses to them (Mavropoulou, 1995).

The third major criticism is that the cognitive and affective approaches of understanding autism, start their research from the assumption that there will be a deficit in the cognitive or affective processes of the brain. The emphasis on 'deficit' influences research design and the selection of research subjects, which ultimately relies on the researcher to make decisions as to who is included and who is not, on their pre-determined inclusion in research criteria.

People with a label of 'autism' still experience being the subjects of research as opposed to being empowered to take some leadership in the research agenda. Such theories of 'autism' do not allow or make provision for the voices of those so labelled, but heavily rely on the 'deficit' model to influence research design.

Dyson (1998:3) argues that the research process actually constitutes the object of its inquiry, both through the categories through which it seeks to understand that object and through the relationships it institutes between researcher and research subjects. The researcher concentrates on 'impairment' issues through the use of the 'deficit' model, this is likely to reduce the complexity and richness of human lives to a few selected characteristics. Discussing this in relation to the lives of disabled people, Dyson argues:

> *'moreover, since these categories are determined by researchers, they effectively exclude the subjects of research from any participation in the construction of knowledge about themselves; they are instead constrained to be known simply in terms of the reductionist categories to which researchers allocate them'* (Dyson, 1998:3)

Oliver (1992a) argues that he is in favour of academic debates about the nature of disability, however he argues:

> '...*what concerns me about this one is that it is yet one more example of people with abilities attempting to speak authoritatively about us*' (Oliver, 1992a)

The dominance of scientific/positivist research and an absence of qualitative research with people with autism, lead to a perpetuation of stereotypes and misconceptions about people themselves. One of these misconceptions is that people with a label of 'autism' are 'asocial'. Volkmar (1987) argues that people can no longer be viewed in this way, he argues : 'their capacity to form attachments and to develop differential social responsiveness, even though limited has become clear' (Volkmar (1987).

It is the perpetuation of the stereotypes of people with a label of 'autism' that have somehow continued the myth that they cannot be engaged in the research process. Oliver (1992) calls for an attention to the 'social relations of research production' if research is to become more helpful and relevant in the future than it has been in the past.

The early cognitive theories have, however, made significant inroads to contributing to an understanding of the barriers in place for people with a label of 'autism'. Understanding 'autism' as impairments, the cognitive theories and theorists have challenged previous labels ascribed to this group of people such as, spiteful, manipulative or sadistic. The cognitive approaches were helpful to inform the structure of teaching and learning to enable access to learning, but did not particularly help to explore and analyse the barriers in place. The environment can be seen to have barriers in place that serves to exclude the person from participating fully within it.

The writings by people with a label of 'autism' make reference to the concept of feeling on the margins of life and feeling excluded. Donna Williams explains this:

> *'They [The Millers] were coming from a foreign place and speaking a foreign language, just like I was. I began to see that given how totally different our underlying systems were, it was a miracle that we bothered at all'* (Williams, 1994: 98)

Cognitive theories of 'autism' have major influence today and it is argued that such approaches prevail because the research paradigms in cognitive and perceptual psychology and psycholinguistics were and are still readily available (Mundy and Sigman, 1989:4).

Physical theories of autism

The 'sensory' experiences of people with a label of 'autism' have been explained as the disruption of neurological pathways to the brain. Leary and Hill (1996) argue that one of the failings of the DSM-IV criteria is that it does not describe physical symptoms, for example abnormal posture, abnormal tone, but rather particular behaviours in a socially interpreted context. They write that for the purpose of diagnosis, behaviours are often described with phrases, such as 'prefers to' 'failure to' or 'unusual interest in' without specifying what particular symptoms may lead to that impression. The authors argue that applying a social context to the behaviour observed distracts from an appreciation of the possible neurological explanations for behaviour.

Others have argued that 'autism' can be explained as more of a physical rather than a neurological disability, namely as a 'metabolic disorder' (Shattock and Savery, 1997; Johnston, 2000). Shattock and Savery argue that autism could be the consequence of the action of peptides of exogenous origin affecting neurotransmission within the central nervous system (CNS), resulting in the normal processes within the CNS being severely

disrupted. Increased levels of peptides in the gut may result in 'leaky gut syndrome'. It is this connection to 'leaky gut syndrome' that has been at the heart of the MMR controversy where Wakefield et al, (1998) argues that the combination of the measles, mumps and rubella vaccine will produce gross abnormalities in the gut wall. It is argued that the attenuated strain of the measles virus, such as is used in vaccine manufacture, promotes an immune response which is insufficient to control the virus.

Whiteley et al, (1998) found that children with a label of 'autism' were more likely to suffer from eczema and asthma (both exceeding the general population incidence figures) and that this would imply the involvement of the immune system in some fashion. The authors argue that the cause could be due to some environmental factors or it could be due to an increased susceptibility to these health problems. While researchers continue to explore the physiological nature of autism and its causes, the people who have a label of 'autism' call for more of an understanding of the way the environment impacts upon their lives. Thereupon moving away from a medical examination of the condition of autism to looking at how individuals are disabled from the barriers that are presented in the wider environment.

Although research into the physiological aspects of 'autism' has helped to identify that some people may benefit from a gluten and/or casein free diet (Whitely and Shattock, 1997) these dietary interventions do not benefit all people with a label of 'autism'. While an Allergy-Induced Autism support network exists to provide people and their families with information about allergies related to eczema and asthma and other conditions, more significant support and help can be provided to *all* people with a label of 'autism' in relation to barriers that exist in the physical and support environment.

Proponents of a neurological theory of 'autism' argue that people with a label of 'autism' are sufficiently connected by the similar way the central nervous system processes a range of information Dawson and Lewy (1989:144). A neurological theory of 'autism' argues that disturbances at the sensory level are the primary symptoms of 'autism' and that disturbances of social relating, communication, language and the bizarre responses to the environment are consequences at a secondary level (Ornitz, 1983, 1985, 1989; Dawson and Lewy, 1989).

Ornitz (1989:174) argues that such a model of understanding assumes that distorted sensory input, when transmitted to higher centres, becomes distorted information and that this in turn becomes the basis of the deviant language and social communication. Lower level sensory processing can occur without involving the cortex. For example background noise, such as a fan blowing or papers rustling, do not require interpretation from the cortex. However, a teacher's voice presenting information needs to be sent to the cortex for language decoding and interpretation. The proponents of the neurological theory argue that it is this that causes information-processing difficulties for people with a label of 'autism'. It is the vestibular system that appears to be hypoactive, requiring a great deal of stimuli to work appropriately.

Those who support a neurological theory of 'autism' claim that there is a direct neurological connection between a child's rocking and the ability to pay attention and learn. A teacher who tells a child to stop flapping his hands may be telling him indirectly to turn off his brain and stop processing information. Insisting on 'quiet hands' may result in a switched off brain (Richard, 1997:86-87). The physical/neurological theory of autism makes the link between stereotypical behaviours and information processing. Information-processing difficulties were also part of the

explanation of the weak central coherence theory and they have been identified as being a central feature of the impairments of 'autism as described by people with a label of 'autism'.

Anxiety

The neurological theory also explains 'anxiety', which has been identified by people with a label of 'autism' as a significant barrier in the physical and support environment. Williams (1996) refers to this anxiety as 'exposure anxiety' and has published a book on the subject *Exposure Anxiety – The Invisible Cage* (Williams, 2003); Lawson (2001:97) argues that anxiety for people with a label of 'autism' may be experienced in a number of different ways. Crowded environments may overwhelm the neurological system is and make the person feel threatened or over-loaded. This can result in a trigger of a hormonal response of high anxiety. The high-anxiety chemicals start pumping, resulting in the person exhibiting behavioural outbursts when a tolerance level has been exceeded. The neurological system starts to shut down to protect itself from the aversive stimulation. A flooded neurological system results in a release of endorphins that are 'anxiety-reducing' chemicals. The implications of such an environment for a person with a label of 'autism' is that there may be a loss of skill and inability that would ordinarily be apparent when a high anxiety state is not evident. Jollife explains how the impact of barriers in the environment can produce fear:

> *'I was frightened of the toilets and you had to ask to use them which I was not able to do, also I was never sure when I wanted to go to the toilet anyway and the teachers got fed up with having to take me to the nurse to change me'.* (Jolliffe et al, 1992)

Research shows that endorphins may be released by certain foods as well, such as chocolate and caffeine, which may explain why some people go on binges when they

are stressed. The more strenuous or sustained our physical activity, the more endorphins we trigger.

People with a label of 'autism' learn that when they engage in repetitive motor movements, such as self-stimulatory behaviours they can calm down and feel better. Richard (1997:87) argues that self-stimulatory behaviours play a double-positive role within autism. The sustained, rhythmic, repetitive movement triggers release of calming endorphins. It also provides vestibular stimulation to innervate the reticular formation to arouse the cortex to make sense of the world.

Understanding autism through the 'social model'

The 'social model' is a way of understanding disability that directly challenges the traditional assumptions of the 'medical model', which focuses on the 'impairment' of the person and can be set apart from much of what we have discussed in the earlier sections of this chapter. The social model of disability is first and foremost a focus on the environmental and social barriers, which exclude people with perceived impairments from mainstream society. The following extract written by a woman with a label of 'autism' explains how barriers in the environment can have a disabling effect:

> 'The lights were damned bright. Adrenaline was running through my veins and noise was already climbing up through the roof, despite the cotton wool in my ears. It would have been so easy to 'disappear'. It would have been too easy. Being numb and unaffected, being someone other than yourself is simply too addictive when being affected is so difficult and so sensorially overwhelming'. (Williams, 1994:151)

Jim, cited in Cesaroni and Garber (1991) talks about the way he processes information:

> "*sometimes the channels get confused, as when sounds come through as colour. Sometimes I know that something is coming in somewhere, but I cant tell right away what sense its coming through*"

Proponents of the social model do not deny the importance of 'impairment' and the appropriate medical interventions required and they understand and respect the differing experiences of disabled people. Although not making any reference to the 'social model' Wendy Lawson, a woman with a label of 'autism' (2001:12) supports the sentiment of the social model in her writings as she argues:

> *'I do not experience my being autistic as being "Disordered" or "impaired" so much as I experience it as being "dis-abled" in a world that doesn't understand Autism".*

Barnes (1998:78) argues that the social model is a concerted attempt to provide a clear and unambiguous framework within which policies can be developed which focus on these aspects of disabled people's lives that can and should be changed. The philosophical underpinnings of the social model are echoed in many of the writings of people with a label of 'autism'. However, this chapter concludes by arguing that people with a label of 'autism' have not as yet been included in the wider disability movement, or embraced within the social model:

> *'Because of the many difficulties associated with autism, this [participation in society as a whole] has been twice as hard to accomplish, I am still trying to break through the barriers that have been set for me'* (Carpenter, 1992: 289)

The social model of disability emerged from the dissatisfied views of those with a physical disability when in 1975 the Union of the Physically Impaired Against Segregation (UPIAS) was developed. There was at the time a backlash against

academics and researchers who researched 'disability' issues, within positivist methodologies, rather than working alongside people with disabilities to define their own research agenda. New definitions of understanding 'disability' and the proposing of social theories themselves have emerged from within the organisation of disabled people (Campbell and Oliver, 1996). The social model must not be confused with a 'social theory of disability', although Barnes et al (1999:2) argue that 'the necessary steps in that journey are being made'.

More recently academics and professionals in their writings on 'autism' have also started to appear dissatisfied with the medical/deficit model and it could be argued that their contributions are becoming more directed towards the values and philosophy of the 'social model'.

In the second edition of Howlin's book (1999) 'much greater emphasis on environmental factors was also considered necessary (in the new revision) is argued. Peeters, (1997) argues:

> *'It is still the case that the quality of an autistic person's life depends less on the extent of his handicap and more on the place where he was born and whether it is a place where autism is properly understood'* (Peeters, 1997:7)

Jordan and Jones (1999) argue that so-called challenging behaviour must be considered against the environment:

> *'Difficult or challenging behaviour is not part of an autistic spectrum disorder, but it is a common reaction of pupils with those disorders, faced with a confusing world with very limited abilities to communicate their frustrations or control other people'.* (Jordan and Jones, 1999:35)

Some people with a label of 'autism' recognise 'autism' as a 'disability'; others tend to speak of autism as an 'impairment', to see it as an impairment or a medical condition that is internally driven. It is perhaps this difference in perspective on the 'impairment' or 'disability' debate that has halted a larger scale partnership between people with a label of 'autism' and the wider disability movement. However, a closer analysis of the autobiographical accounts, provides evidence that 'autism' is beginning to be more recognised as a 'disability', with examples and illustrations of the way barriers exist to exclude people from society. Richard Attfield (2001) argues:

> *'society failed to give me the means with which to communicate as a child. I was actually roughly fifteen years of age before I acquired a communication aid in the form of a canon communicator'*
> (Attfield, 2001)

Jolliffe et al, (1992) makes suggestions as to how the environment can be adapted to break down barriers to enable access to a child or adult with a label of 'autism':

> *"Because to an autistic person things are so complicated and frightening, it is far better to take things in stages. First getting used to the room, then your voice and appearance while not actually being directed at him and then finally talking to him and looking at him. The child should be able to see the consulting room first without the professional actually being there. The longer the time given to this the more beneficial this will be".*

Pamela Hirsch (2001) explains the consequences of 'labelling': *'I was labelled disruptive and accused of attention seeking'.* Hirsch argues that it was the barriers in the environment that were causing the problems and she identified ways in which these barriers could be overcome: *'as a young person it would have helped me if the teachers had some knowledge of ASD and had been more sensitive'.*

Whilst other disabled people have used the 'social model' as the central process to interpret their experiences and organise their own political movement (Oliver, 1992), people with a label of 'autism' have not had the opportunity to be part of this process.

People face not only barriers in the wider mainstream society, they also face barriers within services for people with a label of 'learning difficulties'. Approximately two-thirds of people with a label of 'autism' have been assimilated into services designed for people designated with 'learning difficulties'. In the past, support services themselves have not always recognised or differentiated between the barriers that face people with a label of 'autism' and those designated as having 'learning difficulties'. Where the barriers have not been considered to be different for people with a label of 'autism' this has resulted in people leading isolated lives and not being facilitated to relate to others who experience the same barriers. There is evidence that people use symbols and language to communicate to each other:

> 'The autistic children would not (perhaps could not) use any of our symbols, whether those symbols are alphabetical, numerical or graphical. I tried getting them to use a set of Compix pre made, drawings of cats, dogs etc. but no, they couldn't use them. When they drew their own versions, however they had no problem. Indeed, they were even able to interpret the meanings of one another's symbols'
> (Coldwell, personal communication cited by Fulcher 1996)

Within this research it was evident that the young people had particular ways of communicating with each other and this will be discussed in the data chapters 3, 4 and 5. Where people have been able to access computers, many have started to forge connections with each other through the World Wide Web and an international advocacy site for people with a label of 'autism' has been set up, Autism Network International (ANI). One of the consequences of not recognising that barriers in the

environment will affect disabled people in different ways is that assumptions can be made about people. One of these assumptions could be that 'self-advocacy groups' are a way forward to enable the voice and empowerment of people designated as having 'learning difficulties'. 'Self-advocacy groups' have been the forum for service-user involvement but not all people with a label of 'autism' participate in the self-advocacy process, even when they may be physically present in a self-advocacy forum as the following example highlights:

> "Rachel arrives at the meeting by minibus from the local 'Autistic Community'. She does not speak often. She spends her time quietly and apparently contentedly smelling her fingers and looking around the room. She doesn't appear to interact with any of her friends. At break time Bill asked her if she would like a cup of coffee or tea. Erica, who lives with Rachel, replied, 'she likes coffee don't you Rachel? Bill looked at Rachel, 'coffee then?' (Goodley, 2000)

This example illustrates how Rachel is 'superficially' involved in the self-advocacy process, (as she is physically present), but there are barriers in place that inhibit communication and interaction. This sufficiently impacts on the two-way process of communication between herself and Erica and a barrier is evident that excludes Rachel's active participation. The two people with designated 'learning difficulties' fail to utilise ways to communicate with Rachel and they are not aware of any barriers in the communication process. In some respects the people labelled with a 'learning difficulty' are left with no other alternative but to answer for Rachel. This example highlights how the lead and the power in the relationship is being led by the people with a label of 'learning difficulties' in the interaction, and the person with a label of 'autism' is passive.

Chappell et al (2001) argues that the self-advocacy movement can provide participants with a collective voice and a framework for resistance and her research showed evidence of how this was effective with people designated with 'learning difficulties'. A collective voice can still be achieved for people with a label of 'autism', if we enable opportunities for individuals to make connections with each other. They will need to do so where they 'operate at a cultural level by generating "collective action frames"' (Dowse, 2001) as shared interpretations of the world. Dowse (2001) argues that this can create the impetus for mobilisation (2001). Before any 'mobilisation' can take place it will be crucial to examine the barriers that exist to exclude people, not only from mainstream society by from processes within services for people designated with 'learning difficulties'.

For the social model to relate to the lives of people with a label of 'autism', 'support barriers' must be given as much attention as 'physical barriers' and there needs to be a recognition of the role of particular cultural and social perspectives that shape people's world views. It is important to examine a materialist dimension to understanding the history of oppression, but also to understand that conceptually people with a label of 'autism' may understand culture and cultural and social rules from different frames of reference. This approach supports the stance taken by Oliver (1983, 1992, 1992a, 1996, 1999) Barnes (1992, 1998) Barton (1996,1997) in developing the social model and rejects the notion that there is a need to understand an 'impairment' perspective (proposed by French, 1993; Crow, 1996; Corker, 1999). It is perhaps the impairment approach (based on individual narrative) that has prevented the recognition of people with a label of 'autism' as a collective and to receive inclusion into the BCODP.

There has been an absence of a 'structural' and 'materialist' analysis of the oppression of people with a label of 'autism' and this chapter aims to set the scene for a framework for an emancipatory research methodology, proposed in chapter 2. Such an approach supports Oliver's suggestion that we need to stop 'parasiting the experience of disabled people by focusing on the actions of the oppressors' (Oliver, 1999:190) and the need to produce 'useful knowledge for disabled people in their struggles against oppression'. To address this issue I have presented an analysis of my own role in the research process in chapter 6.

Critique of the social model

Much of the criticism regarding the social model has been advanced on behalf of those who work with people with a label of 'learning difficuties'. Chappell (1998) argues:

> *'People with learning difficulties are neglected by the social model of disability which ought to promise them so much in terms of its analysis of their experiences and its strategies for change'* (1998:211).

While Chappell (1992), Goodley (2001), Walmsley (2001) have critiqued the social model on behalf of people with a label of 'learning difficulties', no such critique has been made by or on behalf of people with a label of 'autism'. The experiences of the latter, suggest that they are *as* disabled by the barriers in society in much the same way as disabled groups with a wide range of impairments are. The autobiographical writings of people with a label of 'autism' suggest that they experience exclusion from mainstream schooling (they make up the largest group of children to be excluded); they are also excluded from the employment market and excluded from a wide range of housing, recreational, vocational and leisure facilities.

Watson (1998:160) argues that being around other disabled people, enables people to see they lived valued and creative lives and they can 'throw off' definitions imposed by non-disabled people'. We perhaps are conditioned into believing that we need to be in the physical presence of others to form a collective. Chappel et al (2001) argues 'self advocates themselves can create a group setting that facilitates the development of self-advocacy'. Such a group or 'collective' could just as well be formed through the use of the computer as some people with a label of 'autism' may not necessarily need to 'be physically around other disabled people' to form a collective. This could equally enable people to connect to each other, to share experiences and to seek to explore ways to break down the barriers that prevent them from accessing mainstream society.

The social model has been criticised by different authors for failing to address the individual experiences of the 'personal aspect' of 'impairment' (Morris, 1991, 1996; French 1993; Crow, 1996), for 'adding on' Black people, (Vernon, 1996) gay people' and for not analysing the issues of people with a label of 'learning difficulties'. (Chappell, 1998, Chappell et al, 2001). But the social model proponents argue that by getting caught up in this debate, dilutes the effective argument that barriers at a socio-political level exclude disabled people. Barnes et al (1999:2) argue that the social model does not deny the significant impairment, but rather it concentrates on 'society's blatant failure to accommodate their [disabled people's] needs'.

Those advocating for the social model are themselves only too aware that there is still a long way to go to understand how barriers exist differently for those other than those who are physically disabled. Barnes argues that more needs to be done:

'particularly with reference to the way in which disability interacts with other oppressions and, as a consequence, how it is experienced differently by different sections of the disabled population' (Barnes, 1998:76).

Shakespeare and Watson (1997) argue that the main priority is to advocate a social model analysis of disability, not to nit-pick or navel gaze among ourselves. As a non-disabled researcher I need to be reflective that I do not critique the social model at the cost of being divisive amongst the disability movement. Shakespeare and Watson (1997) argue that:

> *"the views that have to be debunked are not those of other disabled people, but those of the non-disabled academics and commentators who continue to view disability as a personal medical tragedy".*

Within the social model there has been a general debate about the role of *impairment* and some have called for and argued for a 'sociology' of impairment. Others have explored and discussed the role of the body within the disability movement. Chappell argues that for people with a label of 'learning difficulties' the body is not the site of the impairment (1998:214). The impairment may not be immediately apparent and nor may it be associated with any physical imperfection.

The social model proponents have been criticised by those in the field of 'learning difficulties' for not including people designated with 'learning difficulties' within the wider social model debate (Chappell, 1998 ;Corbett, 1998;). Chappell, (1998:213) argues that very little use of literature by writers with a label of 'learning difficulties' is used within the social model debate. They are also often excluded from participating in wider disability research. Thomas (1999:6) regrets not making a greater effort to reach women with a label of 'learning difficulties' in research and 'to find ways of enabling them to share their experiences with me'.

McCarthy (1999) argues that the social model of disability has not been so rigorously explored in relation to people with designated learning difficulties as opposed to physical impairments. McCarthy (1999) argues that few people are likely to discuss the issue of whether individuals with an intellectual impairment can engage in this debate as this would be seen as politically incorrect (p.85). Such a comment suggests that there is a tendency to want to accommodate some more 'impaired' people with a label of 'learning difficulties' into a different framework other than the social model. Goodley (2001) writes:

> *'are we finally prepared, in this post-modern theoretical climate,*
> *to accept a personal tragedy perspective over a social model of*
> *disability, in the case of certain impairments?'*

It is obviously not, as disabled activists remind us of their daily experiences of oppression and resistance. It is a failure of our own limitations as researchers that we have not yet done enough to explore ways to break down the barriers of communication that exist between ourselves and some people with a label of 'learning difficulties'.

Chappel et al, (2001) argue:

> *'The majority of research has not attempted to explicitly use the*
> *social model as a tool for analysing the views and experiences of*
> *people with a learning disability, nor invite people so labelled to*
> *inform a social model'.*

Perhaps the most obvious omission from the analysis of the social model when applied to people with a label of 'learning difficulties' is that *support barriers* are not sufficiently examined.

Walmsley (2001) argues that the issue of 'support' is one that perhaps differentiates the experiences of people with physical impairments and those designated as having

'learning difficulties'. Proponents of the social model emphasise the *physical environment* with more emphasis than the *support environment:*

> *'We are disabled by buildings that are not designed to admit us, and this in turn leads to a whole range of further disablements regarding education, our chances of gaining employment, our social lives etc.,'* (Brisenden, 1986)

And:

> *'.. Hostile built environments, ones where access to buildings, streets and places is often impossible'* (Imrie, 1998:129).

Even where barriers are explored in relation to inclusion into mainstream education, the emphasis is on physical barriers as opposed to support barriers. Priestly refers to disabled children with physical impairments, in mainstream high schools and his analysis is centred on physical support, even though the title of the chapter is 'Discourse and identity: disabled children in mainstream high schools' (Priestly, 1999:95). Oliver (1996) while reflecting upon his own experiences does not refer to support as a 'material factor':

> *'The experiences of spinal cord injury, therefore cannot be understood in terms of purely internal psychological or interpersonal processes, but requires a whole range of other material factors such as housing, finance, employment, the built environment and family circumstances to be taken into account'* (p.35).

Critics of the 'medical model' recognised the failure of professionals working within this model to:

> *'Explore whether the support given [to people with a disability] was adequate, effective or what disabled people really wanted'* (Barnes et al., 1999:10).

However, there is still little evidence that the social model has adequately addressed the issue of support and the barriers in the support environment.

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The social model proponents argue that it was not that the social model excluded people with a label of learning difficulty, it was more that 'normalisation' as a theory, took hold from within services, because of the power of professionals to direct the process of change. Barnes et al (1999) argue:

> 'Normalisation did not challenge the legitimacy of the professional role in the lives of disabled people, but guaranteed its continued authority' (p74).

In a similar way it could be argued that the theories of 'autism' (particularly the 'theory of mind') has also legitimised the professional's position of power in the lives of people with a label of 'autism'. Mesibov (1990) argues against the use of 'normalisation' with people with a label of 'autism', but he does so from a 'medical model' perspective. He argues:

> 'The normalisation principle often causes professionals to overlook the deficits of handicapped people when planning educational and treatment programmes'.

To support this argument Mesibov claims a special case for people with a label of 'autism', staking that leisure is the most difficult time for people to cope with and a lack of structure often results in severe behavioural difficulties. But the emphasis by Mesibov on a 'lack of structure' suggests that the problem lies external to the person and it is not the *deficit* of autism that is the handicap – rather it is the environment and the support that disables the person. Mesibov's critique of normalisation would be as prolific of the social model, as his fundamental starting point is with a defence of the medical model or 'deficit' model in working with people with autism.

Walmsley (2001) argues that it was through the process of normalisation that led to the development of self-advocacy. There appears to be some evidence that self-advocacy has advanced sufficiently in services for people with a label of 'learning difficulties',

but such a development has not been equalled in services for people with a label of 'autism'. The concepts of 'self-advocacy', choice, empowerment and decision-making are still largely absent in the latter. Professionals have used the deficit model of 'impairment' to argue that the person with a label of 'autism' may not have the 'capacity' to make choices.

Morgan (1996) argues that, for the adult with a label of 'autism', there is a need to impose regularity on what for them, is an especially irregular and unpredictable world. Without the opportunity to gain some control and, therefore, to elicit predictability within their living environment, life for the person may become confusing and ultimately terrifying (Morgan, 1996:38). Interestingly, Lorimer, et al, (1995) asked questions of 31 adults with a label of 'autism' living in residential accommodation as to what they considered to be important issues in the establishments they lived in. They reported the following:

1. Access to amenities within the locality, e.g. being near to a post box, shops, etc

2. Staff, e.g. more choice in new staff

3. Compatibility and involvement with peers, e.g. choosing who to go on holiday with

4. Environmental factors within the home, e.g. to be able to go to one's room and not be disturbed

5. Food, e.g. choosing food and drinks

6. Social life, e.g. being able to go out and to stay in

7. Leisure activities, e.g. having the opportunity to develop new interests

8. Communication factors, e.g. needing help to communicate better

9. Views expressed on behalf of non-verbal peers who did not convey their views included the perspective that there should be a lack of surprises.

The findings reveal that 'service users' want more choice in their lives and they also expressed a desire to partake in many socially interacting situations. The above is not only evidence of people with a label of 'autism', self-advocating, but point nine reveals how willing the people are to advocate for their peers. However, Morgan (1996) is unconvinced that people with a label of 'autism' are able to express choice: 'One can only respect an individual's free choice if that individual is capable of making a meaningful choice'. Such assertions about 'choice' can mislead others within the wider 'disability rights' movement, as is highlighted in the following extract from Deborah Marks (1999) in *Disability: controversial debates and psychosocial perspectives*:

> *'The concern within the disabled people's movement to ensure that disabled people have greater choices and control over their lives is a central part of campaigning. Yet presenting choices to autistic people who have been placed within the category of having a learning disability may be experienced as bewildering and even threatening. A person who is autistic often needs the security of routines to feel safe (Williams, 1994; Tustin, 1992). Being 'empowered' with choices may, for an autistic person be experienced as a shattering of security"* (p.133).

To argue that people with a label of 'autism' do not have the capacity to make choices because of their 'impairment' is to argue for the maintenance of professionals (and parents) to continue to control the lives of others. To understand 'autism' in relation to the way barriers may inhibit information processing offers a different perspective. To offer choices that result in anxiety, confusion and information overload is irresponsible, but to offer choice in a way that enables the person to have some control over their life is an important principle to uphold and to maintain. From a human rights perspective choice includes:

> *'Demands for greater choice in the nature and amount of services provided, more control over allocations of resources, especially in relation to independent living'* (Barton, 1996:13).

Support Barriers

The *attitudes* of support staff and the *prejudice* prevalent in people's lives have been explored in relation to the social model (Morris, 1991; Oliver 1996). It is important to explore power relations when examining support barriers. Barton (1998:54-55) argues that it is important to explore how the particular vested interests of professionals serve to encourage a culture of expertise in which disabled people experience relationships of dependency. Corbett (1998:54) argues that the expressions and opinions of powerful professionals talking about disability are listened to with more serious attention than those of disabled people themselves. Brisenden's experiences also reflect the power differential in whose voice is listened to the loudest:

> *'Our opinions, as disabled people, on the subject of disability are not generally rewarded with the same validity as the opinions of 'experts' particularly medical experts'* (Brisenden, 1986:20).

So in light of Barton, Corbett and Brisenden's concerns, the failure of a person with a label of 'learning difficulties' or 'autism' to respond to support, will often be seen as the fault of the person with the perceived impairment. It is only when the support is analysed to explore and examine the extent to which barriers disabled the person, will the right levels of support be identified. Shakespeare and Watson (1997) argue:

> *'Disabled people's functional capacities have to be placed in a broader social and environmental context, which can incorporate issues such as disabling barriers, availability of aids and personal assistance and financial and material factors'.*

It is to the issue of 'personal assistance' 'support workers' or 'professionals' that we will now explore in relation to 'support barriers'. Support barriers have been identified by disabled mothers with a physical impairment, in their interaction with service providers (Thomas, 1997). Thomas identified that the lay-practitioner relationship was one-sided. Professionals feel obliged to 'take-over'. The support provided by the service providers was often perceived as inadequate or inappropriate. There was also

evidence in the views of the women that in many instances the professionals seemed less than fully informed about the woman's impairment or about her particular needs. Although the literature on 'disabling barriers' makes reference to the barriers in social support, a greater level of analysis is given to the more physical and structural barriers that exist to disable individuals with a disability, for example education, employment, built environment, physical access. Most people with a label of 'learning difficulties' or 'autism' will face barriers in relation to accessing appropriate support with individuals who can communicate with them effectively.

An inability for support staff to communicate effectively must be seen as one of the disabling barriers within the social model when the model is applied to people with a label of 'learning difficulties' or 'autism' (*a support barrier*). It is not sufficient to transfer the 'social model' as a political and social framework from disabled people with physical impairments to understand those with a label of 'learning difficulties' or 'autism', without giving particular analysis to 'support barriers'. The absence of such analysis fails to address the 'inequalities' and power imbalances within the care relationship. Coles (2001) reflects on his observations of two people with a label of 'learning difficulties' and the relationship they have with their support worker:

> *'We walk towards the playground. (Gary to me) 'If he wants to he'll get on a swing'. Danny walks up to a swing and turns to Gary. Gary helps him to get on and gives him a push from behind. Danny turns his head – Gary pushes again. Danny sings, 'Bee bi bee bi bee, Gary copies. They take turns'* (Coles, 2001)

Coles argues that Danny is being supported within a 'social model'. Such an assertion could be challenged when no analysis is made to the 'support' barriers (access to children's swings as opposed to education, employment or adult leisure activities) and

'communication' barriers (the insufficient analysis of the communication exchange between Gary and Danny).

Coles expresses Danny's communication by using the words Bee bi bee bi bee. It is limiting and reductionist to express the communication of another in a way that is limited to sounds. The enormity of literature on the need to enable support staff to develop skills in communicating with people with a label of 'learning difficulties', is evidence that barriers exist that prevent support staff effectively communicating with people effectively. Bogdon and Taylor (1982) in their work with Ed and Pat (two people with a label of 'learning difficulties') wrote:

> *'If he said things that we did not understand, we assumed that it*
> *was the result of a deficiency in our capacity to understand,*
> *rather than of a deficiency in him'* (p22).

They were clear that Ed and Pat were capable of communicating a message. Coles indicates that Danny was communicating, but the content of the message was not apparent and there was no obvious effort to explore ways in which the barriers preventing effective communication exchange could be challenged.

Without support staff having the skill to communicate effectively with people with a label of 'learning difficulties' or 'autism', this will effectively exclude the person from taking part meaningfully in community life. This will also cause barriers to the person to be unable to relate to peers to form 'collective action' which is so necessary for minority/oppressed groups to enable social and political action. Walmsley (2001) argues that most people with a label of 'learning difficulties' will need some support and thereby suggests that the support role (or co-researcher) is an important one, in relating the social model of disability to people with a label of 'learning difficulties'.

Goodley (2001) develops this idea and reflects upon the support role of advisors to self-advocates and writes:

> *"I played with the idea that interventions of support could be viewed as reflecting different discursive positions in relation to disability, namely the social model and the individual 'impairment' model of disability. One continuum of support specifically exemplifies this analysis: 'Deficit' – v – 'Capacity' interventions. At one end of this continuum, deficit, advisors lean towards presuming incompetence on the part of self advocates".*

With barriers of communication, individuals are effectively excluded in partaking in discourse about themselves, their oppression and their experiences.

Conclusion

'Autism' has a history of being 'medicalised' and from being subjected to an analysis of 'impairment'. This is just one perspective and it has been argued within this chapter that this can sometimes result in a 'reductionist' approach with a focus on 'treatment'. To date there has not been an appraisal of the 'social model' and its relevance to the lives of people with a label of 'autism'. Oliver argues that a materialist social theory (explained through the social model) offers disabled people the opportunity to transform their lives. The aim of such an approach is for disabled people to form a collective with each other and within the disability movement to challenge their oppression and to reclaim a voice in the social policy agenda. Fulcher (1996:170) asks if this can really be possible without consideration of culture. This study asks if this is really possible without an understanding of support and communication barriers that will affect people with a label of 'autism' in different ways.

One way of understanding more about the extent of these barriers is to enable people to identify themselves in relation to how barriers in the environment affect information and

sensory processing. One method of enabling this to happen is to develop a 'communication profile' with the person that will 'de-code' and 'translate' the personal and unique style of communication of the individual. For some people this may be the only way to enable consistent access to two-way communication and thus serve as a way of including the person in the research agenda and about decisions that will affect their life. The communication profile could be the start of the process towards developing a 'collective voice' of people with others. The main aim, whichever the method, is to explore ways that people with a 'label' of autism can express themselves as a 'collective'. What is apparent is that the writings and the experiences of those with a label of autism echo the experiences of disabled people of exclusion, discrimination and prejudice. Yet there is an absence of their voice from the BCODP and from the wider disability movement.

The 'self-advocacy' movement, may not be the most appropriate forum for some people, as barriers may be present that inhibit the process of participation and inclusion to occur. For some people the internet may be a better communication medium, while for others it will be evident that limited expressive language to engage in political discourse at this stage will act as a barrier. When this is the case, other ways to enable people to form a 'collective' could be facilitated.

Fulcher (1996:175) proposes that disabled people do not need to engage in political discourse to form a collective. It can be argued that, if as a society, we are able to overcome the stereotypes of what is seen as economically productive activity, we may be able to accept the cultural contribution of disabled people. Fulcher illustrates this with the example of 'art' and argues it can be a medium for the development of identity and capacity of disabled people. The aim is to move beyond individualistic forms of

practice with disabled people towards cultural forms of practice, such as collectively produced paintings (Fulcher, 1996:175). While barriers in individual 'communication' will still be evident, such an approach could assert the legitimacy of disabled people to 'communicate' or express themselves amongst others, but in a different way.

This chapter has critically reviewed the theories and understandings of 'autism' in relation to the impact that they have on the lives of people who are so labelled. It has been argued that the theories reflect the professional body of knowledge of the particular theorist, rather than the experiences or assertions of people with a label of autism. The theories of autism continue to be developed within a 'deficit', 'disordered' or 'impairment' perspective and such a positioning of 'autism' theory continues to remain alienated from the experiences and realities of the lives of those so labelled. While theories of 'autism' serve as a rationale to deny a rights-based perspective of 'advocacy' and 'choice', researchers continue to exclude the voice of people in the research agenda. As people with a label of 'learning difficulties', start to become involved in social policy changes (a group acted as consultants on the white paper "valuing people" (DoH, 2001)) , people with a label of 'autism' are *still* heavily defined by theories of 'autism' that continue to focus on their impairment as opposed to social issues.

What is required is for people with a label of 'autism' to be part of the 'social model' of disability debate and the wider disability movement. Currently writers, with a label of 'autism' are remaining within the 'impairment' framework when defining 'autism', but are re-framing 'impairment' from their own perspective. The numerous examples of how barriers disable people with a label of 'autism' in the literature, requires steps to be taken to engage this group of disabled people in the wider debate on the social model.

CHAPTER 2

RESEARCH METHODOLOGY

The aim of this chapter is to outline some key principles in the development of a research methodology to include people with a label of 'autism' in the research process. Most research in the field of 'autism' has a history of identifying research participants to take part in tests or experiments to help develop particular theories of 'autism' (for example 'Theory of Mind'). Participants are often selected by researchers (rather than self-selected) if they fit certain criteria, for example performance on an Intelligent Quotient (IQ) test. Fombonne et al, (1994) required research participants to be assessed on standardised psychological tests of at least a mental age of 4 years. This excluded 47 young people and adults with a label of 'autism' from the research process as only three people met these criteria.

In addition, the dominant psychological research 'paradigm' often requires researchers to involve people with a label of 'learning difficulties' as a 'control group'. It is relatively rare for people with a label of 'autism' to be involved in 'participatory' research although a person called 'Larry B' was involved in the first recorded 'participatory' research with people with a label of 'learning difficulties' (Edgerton, 1967; Langness and Turner, 1986:66). A critical appraisal of Larry's experience of participation in Edgerton's research will be presented in this chapter. In addition, it will become apparent how Larry's experience and the work of researchers in participatory research, since Edgerton have informed the development of my own research methodology.

Oliver (1999:191) argues that as disabled people continue the political process of collectively empowering themselves, research based upon the investigatory discourse

and utilising the 'tourist' approaches by 'tarmac' professors and researchers will find it increasingly difficult to find sites and experiences ripe for colonisation. 'Disabled people and other oppressed groups will no longer be prepared to tolerate exploitative investigatory research based upon exclusionary social relations of research production" (p.191).

Edgerton's work (1967) was the beginning of participatory research that was underpinned by an understanding that the concept 'learning difficulties' or 'mental retardation' as it was then known was, 'socially constructed'. Such labels, including the label of 'autism' were not used with the research participants throughout Edgerton's six year study. The consequences of this for one research participant 'Larry', was to try to explain his 'difference' and also to explain discrimination and prejudice based on this difference. Ultimately he explained his difficulties as a particular 'disability' in relation to barriers that excluded him from the wider environment.

The work of Edgerton (1967), was the first attempt to develop a socio-political interpretation of disability, for people with a label of 'learning difficulties'. Such an interpretation of disability provides the conceptual clarity and language that are the foundations upon which the social model and emancipatory research rests (Barnes, 2003).

The Introduction and chapter 1 of this thesis set out the tenets of the social model. This chapter will explore how dominance of positivist research methodology led to a call for another paradigm for social research – the name for this approach has been called: critical enquiry, praxis or emancipatory research (Oliver, 1992).

This new paradigm research must:

- illuminate the lived experiences of progressive social groups

- change the social relations of research 'so that both researcher and researched become changers and changed' (Lather, 1986)

- the methodology of research must also change and be built upon trust and respect and build in participation and reciprocity

(Oliver, 1992; Barnes,2003)

Oliver (1992) argues that the emancipatory research paradigm is about the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs. While Oliver refers to emancipatory research as 'new paradigm' research, Walmsley (2001) refers to the term 'inclusive research' which it is argued:

> *"Refers to a range of research approaches that have traditionally been termed 'participatory' or 'emancipatory'".*

Walmsley summarises inclusive research as 'research which people with a label of 'learning difficulties' are involved, as more than just research subjects or respondents'. Walmsley clarifies a differentiation between 'participatory' and 'emancipatory' research:

> *'participatory' research is based on a model of seeking the views of consumers, but the term 'emancipatory' research is almost exclusively associated with the disability movement'*

Emancipatory research is seen as a part of disabled people's struggle for civil rights and disabled people should control, rather than merely participate in the research process. The researcher moves from being the 'expert' interpreter of the world to being the servant of disabled people, putting his or her skills at their disposal.

Barnes (1992) defined emancipatory research as:

> *'the systematic demystification of the structures and processes which create disability and the establishment of a workable 'dialogue' between the research community and disabled people in order to facilitate the latters empowerment. To do this researchers must learn how to put their knowledge and skills at the disposal of disabled people'* (Barnes, 1992:122)

In 2003, Barnes goes further than advocating a 'demystification of structures' and the creation of a 'workable dialogue' in the defining of emancipatory research:

> *'Emancipatory research is the empowerment of disabled people through the transformation of the material and social processes of research production'* (Barnes, 2003)

It has been recognised that 'participatory research' can be a pre-requisite to 'emancipatory' research (Oliver, 1992; Zarb, 1992; Barnes, 2003), but participatory research is not seen as being as powerful in its 'transformative' role in disabled people's lives. Barnes (2003) argues:

> *'The integrating theme running through social model thinking and emancipatory research is its transformative aim: namely barrier removal and the promotion of disabled people's individual and collective empowerment'* (Barnes, 2003)

My own research methodology was guided by the principles of 'emancipatory research', yet ultimately only achieved the goal of 'participatory' research. One way in forwarding the emancipatory research agenda with people with a label of 'autism' is for researchers to reflect upon their own communication style/method as a possible barrier to inclusion in the research process. The account of 'Larry', who was involved in Edgerton's study, illustrates how barriers are maintained by the researcher. Several attempts are made by Larry to communicate his perspective but such a view was not validated. Instead his view was seen as problematic, deviant and challenging. It is this perspective of being accountable to the research participants that led to my own research becoming

'reflexive'. Chapter 6 is dedicated to an analysis of my role as a researcher and my influences over the research process.

The case of Larry B

The case of Larry B is documented by Langness and Turner (1986) and documents 6 years in the life of an individual who is struggling to explain his differences from others. Larry has a label of 'autism' but the use of the term 'autism' was absent in reference to Larry's life by the researcher. Langness and Turner (1986:66) write that Larry's life can be described:

> 'As centring around five rather obsessive and related concerns: stardom, sex, companionship, loneliness and retardation'.

Such an observation fits with a medical model approach, where the difficulties lie with Larry. Larry saw the situation differently. He described difficulties in getting a job and being able to relate and communicate with people. Larry recognised that he was different, but nobody seemed to be able to help him find out why he was different and in what way. He knew that he was not like his sister, nor like others who are mentally retarded or mentally ill. The authors propose no other suggestion to explain Larry's 'difference', even though they write:

> 'First it must be acknowledged that it is quite likely that Larry is not really retarded at all' (p.66).

They suggest that Larry has some type of 'mental problem'. The authors write that Larry speaks:

> 'In an inappropriately loud and monotonous nasal voice and is conversationally aggressive, often broaching quite personal subjects in most inappropriate situations' (p.66).

Whereas to the reader (familiar with autism as 'impairment') Larry's constant questioning is about 'checking out' and working out a social understanding of the

relationships between people. However, the authors argue that Larry is being 'provocative' (p.69).

Larry communicates his uncertainty about homosexual (sexual) experiences. He is unsure about the social rules and says:

> *'It turns my stomach to kiss them, I would rather do that with*
> *girls, I find it more relaxing'* (p.70).

Yet he has had difficulties finding a girlfriend and is unsure what he should do and how he should approach them. The authors conclude their analysis of the questions Larry has asked the researcher as:

> *'There is little doubt that Larry was challenging Laura to set*
> *limits and that his aggressive sexual talk was deliberately*
> *provocative'* (p.70).

The researchers had disregarded the label of 'autism' and the distinction between 'impairment' and 'disability' did not emerge until a decade later. If Larry's label of 'autism' had been recognised at the time as 'impairment' his behaviour would not have been subjected to an analysis and conclusion of 'sexual deviancy and sexual provocation'.

Larry struggles to explain his difference. He has awareness that he experiences things differently, but he is unsure about how to explain this. The authors fall into a 'deficit' perspective and write: *"his lack of maturity and sophistication is a continuing theme"* (p.71). Larry exclaims: *'I am not retarded!'*, when he learns that the research project is to do with those with a 'mild retardation'. He says: *"I think everyone has learning disabilities in one area or another, do you agree?"* (p71). The researcher asks Larry if being retarded bothered him and he replied *"No, I am used to my handicap. I have learned to enjoy it and be happy with it"* (p.71). Larry preferred to use the term

learning disability rather than retarded and when the researcher asked Larry what this meant to him he replied:

> '*It means that to me no one will hire me in a job unless they hear from a rehab counsellor or social worker. Get what I mean when I say it is hard for handicapped people to find a job*' (p.71).

Larry himself is aware of the discrimination he is experiencing and he understands that the problem is outside of himself (the social model approach). He explained how he quit his job at the workshop because he didn't think it was fair to pay on a piece work basis.

The concern about his difference and what it is called was a theme throughout the 6 years that the researchers were involved with Larry. The authors say that Larry fastened on to the label 'developmentally disabled' which he defines as a person who "lacks the right brain chemistry". As autism is defined as a 'developmental disorder', Larry has perhaps come closest to explaining what has happened to him. Jordan and Jones (1999:3) sum this up: "*the difficulties in learning that are a direct result of the autistic spectrum disorder are better characterised as 'differences', since they only become difficulties if they are not accommodated .... they might be better characterised as developmental difference than impairments*".

The story of Larry B illustrates that, even though the authors are clearly not supportive of labelling people with a label of 'mild mental retardation', this does not stop the person with a label of 'autism' trying to seek out an explanation for their difference. The authors argue that:

> '*Larry disavows his handicap as he searches for an acceptable social identity and a meaningful way of accounting for his apparent differences from others*' (p.79).

It could be argued that for Larry it is not about seeking an 'acceptable' social identity, it is about seeking out 'an identity', being able to explore if there are others who feel or experience life the way he does, seeking a 'collective' opinion. The authors argue that Larry rejects any peer affiliation, but he does not see other learning disabled people as his peers. The researchers do not feel it would have been impossible for him to find a companion of some kind, but they ask the question 'where would he look?' They go on to say he doesn't understand the cultural rules about tipping and conversation and tries inappropriately to engage the waitresses (p.80). The authors are not optimistic for Larry and argue:

> *'His obsession with stardom, his loud monotonous conversations and his inappropriate behaviour all combine to maintain his appearance of being retarded or otherwise mentally handicapped'.*

Larry appears to be in 'no man's land' he is isolated and is desperately seeking some understanding about who he is and why things happen the way they do. Without any reference to 'autism' or any reference to 'difference' the researchers respond to Larry as a person devoid of any 'impairment' or 'disability'. For myself as a researcher it will be important not to deny the experiences of the research participants and also not to deny any reference the person makes to 'impairment', 'disability' or 'difference'.

Emancipatory research and research methods

There is a debate within the disability movement as to whether to pursue *individual* or *collective* research methodologies in order to be truly emancipatory within the research paradigm. Narratives have been developed with people with a label of 'learning difficulties' as a method of emancipatory research, but such a method does not necessarily result in generating a social or political collective amongst people with a label of 'learning difficulties'. Instead, a dependency relationship can occur with the

participants involved in the research. The 'collective' in relation to 'learning difficulties' appears to centre within self-advocacy groups (as discussed in chapter 1), and such a development has been powerful in the way people with a label of 'learning difficulties' have challenged and influenced power imbalances.

Oliver (1999) believes that we do not have the methodological techniques to undertake collective research, "nor do we have the language to produce ourselves collectively" (p.189). A new epistemology for research praxis must be generated which should be sufficient to go beyond investigatory research. The challenge in the creation of a discourse which sees research as an act of production, will be to develop a new language which enables us to talk about it (p.189).

Since Edgerton's research, there have been some creative and innovative research undertaken with people with a label of 'learning difficulties', through appropriately designed interview and questionnaire formats (Sigelman et al, 1980; Lovett and Harris, 1987). Autobiographical and biographical methods have been popular since the work of Bogdon and Taylor (1982). There is now substantial evidence of working partnerships between people with a label of 'learning difficulties' and researchers (Atkinson, 1993; Aspis, 1997; March et al, 1997; Walmsley, 1997) to pursue changes in the social relations of research as recommended by Oliver (1992).

Riddell et al (1998:85) argue that although people with learning difficulties have been involved in research, this tends to be around issues to do with service delivery. Even where people have been involved in research design, they are rarely involved in data analysis. There is no debate on the issues involved between researcher and the person with a label of 'learning difficulties', although power relations have been explored in

the research relationship (Goodly 1998; Stalker, 1998). Riddell et al (1998:86) argue that certain types of theorising may be difficult to engage people with a label of 'learning difficulties', but this should not be an argument for ditching the theory. Developing an emancipatory research agenda led by people with a label of 'learning difficulties' is recognised by researchers as being fraught with difficulties.

One of the failings in much of the research and research methodologies for people designated as having 'learning difficulties' is that the main research participants tend to be those with mild learning difficulties and those who have verbal communication. The researcher somehow takes as given that there will be those who can articulate and those who cannot. Researchers start at the point of arguing for emancipatory researchers to enter into a 'dialogue', but such a process of dialogue requires a shared understanding of meaning and a means or method of communication. Researchers do not necessarily consider themselves or the research process as one of 'enabling communication', or exploring the social model from the perspective that their own communication style may tend to advantage some research subjects and disadvantage others.

Riddell et al, (1998:87) after considering the methodological difficulties of engaging people with a label of learning difficulties, decided to involve people in the following way:

> 'Another possibility, the one we finally pursued, was to bring together a group of people with learning difficulties who had already participated in the case studies and involve them in discussion of the initial research findings and of key themes within the research".

McCarthy (1999) defined the criteria for including women with a learning disability in research to explore the 'sexual lives of women with learning disabilities' in that 'they had to be verbally articulate enough to be able to talk about these [sexual] experiences (p.120). There has been less time, effort and creativity spent by researchers to explore ways to engage people with either complex communication difficulties, 'challenging behaviours' or people with a profound multiple disability.

One of the exceptions has been research funded by the Department of Health (DoH) which enabled researchers to undertake a 2.5-year programme to consult with children with severe and complex learning difficulties, about their views on residential and respite services (Minkes et al., 1994). Qualitative researchers working with people with a learning disability have at least attempted to explore ways of involving people and debating the complexities of involving people (Booth and Booth, 1996; Walmsley, 1997, 2001; Riddell et al, 1998). It may be difficult to engage people with communication difficulties, but this is not reason enough to exclude them from the research process.

I was aware of the difficulties of involving people with a label of 'autism' in the research process, but I was still inspired by the potential of 'emancipatory' research to include any person with a label of 'autism' who would like to be involved. At the outset of the research and at the design stages of the research methodology, I perhaps naively felt that I did not want to exclude any person with autism who expressed an interest to partake in the study. I was prepared to develop a means and method of communication with young people, even where a person did not have the words or language to express themselves.

Guided by the values of 'inclusive research' (Walmsley, 2001) to be available to *all* people with autism who wanted to be involved in the research process, I decided to make initial contact with schools who had some experience of teaching children with a label of 'autism'. I was not aware at the time that not all people would share my sentiment of enabling inclusiveness for all young people regardless of their perceived level of 'impairment'. This ultimately did have some baring on who eventually became research participants and this is discussed below in relation to 'gate-keepers'.

In relation to 'getting to know' the young people, my main concern from reading the literature was that I might cause the young people 'exposure anxiety' (discussed in chapter 1) by entering their private space in their own homes to interview them. A decision was made to have a second arm of the research process. This would involve shadowing the young people at school for 1 day a month for the duration of 1 year, collecting ethnographic data on a small lap-top computer. This would be done only with the consent of the young person, their family and the school. This ultimately did help to build a relationship between the researcher and the research participants and this is discussed further in an exploration of the research process in chapter 6. In relation to my preparedness to develop a research methodology in involving young people who did not have language, was not ultimately an issue. This was primarily because others pre-determined the ability and relevance of these individuals to partake in the research. This is discussed below.

Although the research methodology was designed to be inclusive of all people with a label of 'autism' (across the autistic spectrum), like most other qualitative research with children, the researcher was faced with 'gate-keepers'. The schools and parents were essentially the gate-keepers and dependent on how both parties viewed the research

design, usefulness of the research objectives or value to the potential research participants, impacted on their decision to support the inclusion or exclusion of young people in the research.

Initially schools were identified within a city in the north of England, Newton, where they were supporting a significant number of young people with autism. Three schools were identified in this way and were telephoned in the first instance and asked if they would like to receive a letter outlining the research proposal. All three schools were happy to proceed with this and they were all sent an outline proposal of the research. One school, (South Down's Secondary Modern) a mainstream secondary school, with an autism learning support unit, responded straight away and invited the researcher to the school to discuss the proposal further. The second school (St Francis Secondary), a special school for young people with severe/moderate learning difficulties, did not respond so favourably and, in fact, suggested that there was currently 'a lot of research going on at the school at the same time'. The third school (Oxford Stanley) a special school for those with severe/profound learning difficulties did not respond at all.

After engaging South Down's Secondary Modern a letter was designed for parents and a pictorial flier for the young people, (Appendix 1). The Head of the autism learning support unit sent a covering letter and flier to families, endorsing the research. In response to the letter, five young people and their families made contact with the me expressing an interest in partaking in the research. The five young people were Charlie Hill, Anthony Garrett, David Kent, Philip Court and Jason Smart.

Eager to engage young people with autism from special schools, St Francis Secondary and Oxford Stanley Schools were contacted again, but it was apparent that there wasn't

the support and enthusiasm from a key individual, in the same way as there had been at South Down's Secondary. To try to enlist further support and engagement in the research from other young people, I placed an advert in the local autistic society newsletter. The parents involved at the society invited me to speak at one of their meetings. After attendance at this meeting, one set of parents expressed an interest on behalf of their son and invited me to meet him at their home, to explore his involvement further. The family was unsure as to how useful their son's involvement in the research would be. After meeting the family and their son, James Frazer,[1] all consented to become involved in the research, although James exhibited extreme exposure anxiety from my presence and would not tolerate being in the same room (issues of consent and exposure anxiety are discussed in chapter 6). James Frazer attended St Francis Secondary and the involvement with James and his family gave me a way into that school. The head teacher then identified a teacher with a special interest in 'autism' (Marcia) with whom the researcher could meet with, to identify others who might wish to become involved in the research. Letters to the families and a pictorial flier were sent out and from this mail out, four further families and young people expressed an interest in partaking in the research. These were Kevin Scarborough, Wills Martin, Simon Sands and Andrew Jones.

Only one family responded to the advertisement in the local autistic society newsletter and this young person (Jonathon Frost) attended the Breckon Charter School (a mainstream school). At this point three schools were involved in the research, two mainstream schools and one special school and a total of 11 young people with a label of 'autism'. I was still keen to engage those with designated severe/profound learning

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[1] All children have been given pseudonyms and schools have been given different names to protect the identity of those who participated in the research process. The young people and their families have given permission to the researcher to use selected photographs for this thesis, they are not for wider

difficulties and a label of 'autism' and the Oxford Stanley School was contacted again. This time it was agreed to send out letters to families and fliers to the young people. The families or young people expressed no interest from this mail-shot. This left me with the dilemma of including only those young people with autism who either attended a special school for children with severe/moderate learning difficulties or those who attended an 'autism' specific learning support unit in a mainstream school. Those with severe/profound learning difficulties were not included in the research. I felt that the gatekeepers had the power to include or exclude young people based on their perception of the usefulness of the engagement in the research process for these young people.

Unfortunately as professionals and researchers we somehow collude with the assumption that there will be those people who cannot be engaged in research due to complex communication difficulties. Such a positioning by professionals/researchers may reinforce ideas (with parents and teachers) that this group are unable to partake and be meaningfully engaged in the research process. The work of Minkes et al (1994) showed how researchers can engage disabled children with the use of photographs. Pictures can decrease the verbal-loading of questions; reduce the need for the interviewee to make a verbal response (she or he needs only point to a picture). Pictures might reduce the systematic response bias often associated with the responses to verbal questions (March, 1992).

The experience of this research illustrates that a research methodology can be designed to work with each participant's current skills in communication and to provide the opportunity and the environment of research, for the participant and the researcher to co-develop their skills and abilities of communication throughout the research process.

publication or dissemination. Copyright of the photographic images remains the property of the young people.

New paradigm research is about reciprocity, it is about giving something back to the people who are engaging in the research. Lather (1986) argues:

> 'Emancipatory knowledge increases awareness of the contradictions hidden or distorted by everyday understandings, and in doing so it directs attention to the possibilities for social transformation inherent in the present configuration of social processes'

We need to find the courage and the determination to engage the people themselves, not seek substitutes.

Emancipatory or participatory research

It is questionable if any research with people with autism can ever be emancipatory (including this study) Zarb (1992) and Oliver (1999). Zarb argues that the difference between participatory and emancipatory research is that the former is an issue of inclusion and the latter is *"conceptualising and creating a different game where no one is excluded in the first place"*. Zarb argues that only when the material and the social relations of research production are over-thrown will emancipatory research be possible, until then participatory research is all we have got. In light of an absence of emancipatory research with people with a label of 'autism', people who have the ability to do so, have published narratives and biographies of their lives (Williams, 1992, 1994, 1996b; Grandin, 1995; Willey, 1999; Schneider, 2000).

Narrative, first person accounts and autobiography

Narratives have been the subject of much debate within the disability movement, with some claiming that *individual* stories detract from the *collective economic, political and cultural* experiences of disabled people (Oliver, 1992a; Barton1996; 1998; Barnes1998; Watson, 1998). Whilst those calling for an emphasis on narrative claim: *"If it [the narrative] is left out of the social model, then a crucial aspect of disabled people's*

voice is also left out" (Marks, 1999). Narratives do need further exploration in relation to their use as a research methodology and the reasons why they are selected either by people themselves or by researchers. They also need to be analysed in relation to their claim that they enable research to be emancipatory with those who are telling the stories. Narratives by people with a label of 'learning difficulties' have not resulted in people necessarily relating to each other as a *collective*.

The collective has been discussed in relation to the growth of the 'self-advocacy' movement. But the self-advocacy movement does not explain the experiences of those who have been absent from this movement (people with a label of 'autism' and most people without verbal communication). This has resulted in a fragmentation of the voices and the stories presented by people with a label of 'learning difficulties' and a bias towards those whose communication style suits that favoured by the format and structure of self-advocacy groups. It is perhaps the partnership with a non-disabled researcher in the story-telling that has fostered a form a dependency, a wish for participants to become like the researcher, to want to be part of their life (Booth, 1998).

The autobiographical accounts written by people with a label of 'autism' have a different history. They have not (predominantly) emerged in partnership with non-disabled researchers and by making their accounts available to others through the world wide web, this have resulted in connecting some people with each other and generating some connection in a *collective* voice. It is difficult to ascertain how and in what ways these published accounts have formed a 'collective', yet there is evidence that reference is made to each others work which indicates some linkage and connection. There is evidence of a positive development not of 'self advocacy' but of 'peer advocacy' which

has resulted in the development of a partial *collective* movement of people with a label of 'autism' (The development of ANI, outlined in chapter 1).

Narratives have been defined by Greenhalgh and Hurwitz (1998:3) as: *"concerned with how individuals feel and how people feel about them, rather than simply what they do or what is done to them"*. One of the difficulties of working with people with a label of 'learning difficulties' is that they may depend on the researcher to present their narrative and the researcher may become involved in influencing this reporting. Booth has argued that such a process is a valid one, and considers the challenging question "how do you give a voice to people who lack words?" (1996a:240). Yet Oliver argues that the disability movement does not support such an approach. Tim Booth was faced by anger and outrage at a seminar in Leeds in 1996, when he suggested that many of his research subjects (people with a label of 'learning difficulties) were unable to produce coherent accounts of themselves, so it was the researchers responsibility to do it with them, though not for them. Oliver's reaction was anger and he had not as then understood that emancipatory research can only be an act of collective production (Oliver, 1999:188). This is where Oliver and others in the disability movement may depart from those working with people with a label of 'learning difficulties', as narrative and story telling tends to be an *individual* activity.

The impact of autobiographical accounts by people with a label of 'autism', has had an influence on the *personal* rather than the *political* processes that operate around and affect the lives of people labelled. Individual accounts have promoted a wide array of reading material that has changed and influenced the way people work with people with a label of 'autism'. Plummer (1995) argues that it is through the sharing of stories that communities grow and a political sense of citizenship evolves. This citizenship can

help people challenge the prevailing orthodoxy surrounding disabled people and by reflecting on their own experiences and incorporating those of others they can begin to define their own identity.

Some people assume that because people have difficulty articulating, that they need help to tell their stories (Booth, 1996; Booth and Booth, 1996). Work from the disability arts movement has shown that this may not always be the case. People without words are enabled to express themselves through different mediums and on their terms, (Fulcher, 1996), providing the environment is right. The collective for people with a label of 'autism', may be through the written word, not necessarily a collective with people together in the same room as this may indeed be anxiety provoking. The important issue is that the research methodology challenges the materialist structures and that people with autism are not restricted to the methodologies available to the researcher.

The *collective* versus the *individual*

This is an important methodological issue. The researcher is often struggling to explore ways to engage people with a label of 'learning difficulties'. The researcher may be exploring ways to enter into a dialogue or to develop a shared means of communication. I will argue that it is important to do both. That the researchers need to be equipped themselves with alternative frameworks to break down barriers that prevent them from communicating with individuals. It is only by starting at the *individual* (through the development of a means and method of communication) that the *collective* can ever be achieved. Some people with a label of 'autism' may find idiosyncratic means and methods of communicating with each other; however achieving change at a political and

social level will not only require a wider means of communicating with each other but with non-disabled researchers.

Watson argues that the *collective* results in a political, social and cultural identity. He writes: *"being around other disabled people, they saw, they lived valued and creative lives, they could throw off definitions by non-disabled people"* (Watson 1998:160).

People with a label of 'autism' may use a language that has its own cultural and social origins that may need effort by the researcher to translate and interpret (this will be discussed further in chapters 3, 4 and 5). This is a different issue to the one raised by Booth. He makes the point that: *'There is a danger of researchers misappropriating (by oversight or design) the lives of the people whose stories are being told'* (Booth, 1996:245). Booth warns that researchers are at risk of imposing their own preconceptions on the raw data: of finding what they are looking for or casting it into a ready-made mould (p.246).

Booth does, however, make some reference to 'translation' or 'interpretation' and argues that there may be times when the researcher needs to use his/her discretion to preserve the message that the words convey. It is argued: *'If this entails redrafting the material using different words in the same idiom they should not spurn the task'* (p.251). Booth discusses asserting the researcher to use power in the relationship with the subject, if he or she wishes to convey the meaning of words used. This contrasts with Bogdon and Taylor (1982:20), who recommend that people's stories should be unfiltered through the analysis and the understandings of professionals. It is perhaps in the development of a means of interpretation and translation that will lead researchers to

develop the courage to explore ways and improve a research methodology for people with a label of 'autism'.

Some people with a label of 'autism' may have developed 'metaphorical' language (Kanner, 1946) and have learnt certain phrases in relation to a particular social context (this is discussed in chapter 3). One cannot assume that there is a basis of shared meaning of words. It could be argued that such well meaning by the researcher sufficiently distorts the interpretation of words by a young person with a label of 'autism'.

Bogdon and Taylor (1984) advise that when listening to the stories told by people with a label of 'learning difficulties', researchers and professionals need to understand that people, who are labelled 'retarded', have their own understandings about themselves, their situation and their experiences. These understandings are often different from those of the professionals (p.168). They write that in their experience the vocabulary of the therapist often contradicts that of the patient. They argue that the so-called 'retarded' respond to therapy and services according to how they perceive it, not according to how the staff sees it.

> *'Devaluing an individual's perspective by viewing it as naïve,*
> *unsophisticated, immature or a symptom of some underlying*
> *pathology can make research one-sided and service*
> *organisations places where rituals are performed in the name*
> *of science'* (Bogdon and Taylor, (1982:168)

Bogdon and Taylor also point out that there is a lack of alternative ways that those who are different have to conceptualise their situation.

Corbett (1998:55) argues that disabled people tend to be dislocated from their social contexts and viewed as inadequate because of personal deficits. This is the danger of

narrative. The researcher can use and deploy narratives in ways that reflect their personal, social and political stance. It is clear that a focus on the appeal to the personal, the need to listen to voices, on their own will not change the structural, economic and political oppression of people with a label of 'autism'. We must explore how the social model in its purist sense can be utilised to advance and change the oppressive research culture that exists in the field of 'autism'. Corbett (1998:55) warns that it is important to explore *'how to listen and what to hear'*, and argues that vulnerable people's ideas are open to interpretative distortion and abuse.

Developing an emancipatory research methodology

Emancipatory research requires research subjects to participate in the construction of knowledge about themselves and ultimately to lead the research agenda. If researchers are failing to communicate effectively with people with a label of 'autism', such individuals will, inadvertently be excluded from the research process. Barnes (1992) argues that emancipatory research requires the utilisation of emancipatory methodologies that breaks down the barriers of communication and results in true discourse. Barnes argues that the usefulness and validity of emancipatory research methodologies are determined by the integrity of the researcher and their willingness to challenge the research establishment.

The emancipatory researcher

One young person, James Frazer, experienced such high levels of 'exposure anxiety' (chapter 3) that it was essential to understand how this occurred and how being a research participant may cause him to experience this. A format for a 'communication profile' was developed from a review of a range of communication assessment tools and a review of the 'autism' literature. It then became used as the basis to plan and prepare

a specific strategy of engagement for the young person and to translate and de-code a significant amount of metaphorical language.

People with a label of 'autism' will need support in the research process by non-disabled people as allies, supporters and facilitators. This has been argued to be the case for people with a label of 'learning difficulties' (Chappell, 1998; Walmsley, 2001). For the young people engaged in this research study, these allies, supporters and facilitators will need to include parents/carers who will often have knowledge of how to 'de-code' or 'translate' some of the metaphorical language that is used; and, therefore, break down the barriers that exist in the development of a means of communication. Some people develop language before they have developed the ability to fully communicate. Such language may emerge in direct association to an experience. Both Chappell and Walmsley outline the dangers of the researcher playing a dominant role. The researcher needs to reflect upon their role. After all, it is the absence of a communicative, philosophical and methodological framework of reference for researchers that reinforces and maintains the exclusion of people with a label of 'autism' from the research process. The need to enable people to have not only a 'voice' but also sometimes establish a means of communication and to engage and participate in wider collective action is an important role of the emancipatory researcher.

Dyson (1998:5) argues that emancipatory research calls for:

> *'a shift in the former 'subjects' of research from the background to the foreground by enabling their voices to be heard and by handing over to them increasing control of the research process itself'*

Such an aim within the emancipatory research paradigm is only achieved when the researcher:

- Understand how the person communicates (and is able to translate and interpret significant aspects of language to determine if this has a communicative function)

- Adapts their own communication style and their position in the environment to enable effective communication to occur.

The design of an emancipatory research methodology – The use of the disposable camera

The use of the visual image within sociological studies has not been particularly encouraged and there is an 'underutilisation of visual information within the social sciences' (Emmison and Smith, 2000:11). The authors go on to argue that not only have social scientists been indifferent to the use of the visual to disseminate research findings but also to the ways technologies of visualisation are used in the topics they study. However, the advantages of using photography and photographic images with people with a label of 'autism' are:

1. The young people can lead the research (in terms of what they wish the researcher to see, through the use of the photographic image, ultimately following the rules of emancipatory research)

2. The young people are likely to think in a 'visual' way, hence visual images may help in the development of the communication process between the research participant and researcher

3. Visual images will help prompt recall of past experiences, when recall of past events (with the use of words) can sometimes be difficult

4. The photographic image can act as a medium to direct eye contact so as to avoid exposure anxiety and direct eye contact, between the person and the researcher

5. Photography does not require a particular level of intellectual ability to engage with

6. Photography does not require clear, direct and functional language

7. Photographs can be flexible in their use by the researcher, depending on how best to engage the young person in the research process, for example grouping the photographs together, asking the person which is their best one, or placing photographs of friends in a position of closeness to the young person.

The interviews

Each young person's parents were given dates of 6-7 interviews scheduled for a year (all interviews took place between September 1999 and June 2001). James and Charlie had a total of eight interviews including a pre-research interview to develop a 'communication profile'. All the young people were scheduled to have seven interviews, but the occurrence of a residential school holiday at the end of term resulted in four young people having six interviews instead of seven. Andrew moved home and he and his family moved 20 miles west of Newton, which resulted in him only being involved in four as opposed to seven interviews. All interviews were tape-recorded and each tape transcribed. Two sets of photographs were developed: one set was left with the young person to insert into a photograph album, the other set was used to scan in to the taped transcript. The total amount of photographs taken (1525) were not all analysed as part of this research study. Photographs that were not included for analysis included:

- photographs with no accompanying transcript (tape failure)

- no taped interview (due to the person's 'exposure anxiety)

- photographs where the content was not discernible and the young person was unable to explain it

The total amount of photographs for analysis were 1350.

Amount of interviews, duration and number of photographs

Name of child	No. of interviews	No. of photographs	Total time of interviews
Jonathon Frost	7	70	1 hour 57 min
Jason Smart	7	134	1 hour 31 min
Charlie Hill	8	171	3 hour 40 min
Anthony Garrett	7	180	1 hour 37 min
David Kent	6	144	1 hour 26 min
Phil Court	6	156	1 hour 49 min
Wills Martin	7	181	1 hour 41 min
Kevin Scarborough	6	132	3 hour 7 min
Simon Sands	6	98	1 hour 23 min
Andrew Jones	4	100	23 min
James Frazer	8	159	54 min
Total	**72 interviews**	**1525 photographs**	**19 hours 28 minutes**

Adapting the interview process

Interviews can help the researcher to find out more about the social world of the individual. Denzin and Lincoln, (1994) argue that through interviews:

> *'We can describe truthfully, delimited segments of real-live person's lives. Indeed, in so delimiting, we may get closer to people's lived experience'.*

In order to achieve such an aim, it is important to establish a 'dialogue' a means of communication exchange. For the purpose of illustrating this point, some aspects of the research data will be drawn upon although the data will be thoroughly discussed and analysed in chapters 3, 4 and 5.

For each young person, there will need to be consideration of the meaningful and effective ways in which communication between the young person and the researcher can be established and how 'communication' barriers in the communication process can be broken down. Barriers were sometimes still evident in the interview process and the following example highlights 'language' barriers. In one interview I asked James the

question: 'Whose this?' pointing to a person in the photograph and he would answer me in response as if I had asked the question 'what is this?'

Jill: Horses ..... so you go horse-riding James .... Whose this James?
James: Blaze
Jill: Blaze ...and whose on Blaze James
James: (chatting away to himself) we are always being big boy .. you've been framed ..
I'm a big boy now .. and perfect from time to time
(James Frazer – Interview 4, lines 83-88)

James had difficulty with the words 'on' 'at' and 'in'. Even though I had established this in the communication profile, the nature of the interview process required me to 'think on my feet' and much of what I had learnt about the person's communication style became lost when I was actually carrying out the interview. James's mother played the role of facilitator and 'translator'. In addition to James answering 'what' to 'who' questions, he had difficulty identifying himself in the picture. If I asked *where* James was in the picture, he would respond by pointing to himself and saying: 'here I am'.

Jill: So James whose this?
James: Wearing a jacket
Jill: And who is it .. whose wearing the jacket?
James: (no response)
Jill: Is that James?
James: Yes .. yes
Jill: And where is it James?
James: That's me
Jill: That's you .. where are you?
James: Here
(James Frazer – Interview 4 lines 47-58)

McCarthy (1999:84) argues that when interviewing people with learning difficulties, there is a need to contextualise the interview within a disability rights perspective: *'Which identifies that it is the non-disabled world which denies opportunities to and oppresses disabled people'*. Such a disability rights perspective becomes more complex, when the basics of language and communication and communication intent are evident

as 'barriers' in the relationship between the researcher and the research subject. This was not possible to explore with James, but the role of the emancipatory researcher should be to reflect upon the 'disability rights agenda' so as to facilitate research participants to explore these issues when the opportunity arises. A disability rights perspective did become a focus for one of the research participants:

Jill: Do you not think its as good a school as South Down's Secondary?
Jason: I would have probably preferred being there [referring to the special school]
Jill: Would you?
Jason: Yeah ..but if Sam [his brother] *doesn't like it .. then I suggest he stop upsetting him*
Jill: Yes that's right..... why do you think you would have liked it at St Francis Special School?
Jason: Because it might .... It might ..have reminded me ... I might have known from ..my old school .... there isn't anyone I know from my old school
Jill: And do you sometimes feel lonely when you are at school?
Jason: I just feel like ....I have been transferred to another planet
Jill: Yes? When you moved from your old school to this school?
Jason: No ... its just that I feel on my own
(Jason Smart – Interview 6, lines 118-128)

Jason was advocating for his brother and appeared protective of him against his father's teasing. He was also communicating his concerns about the transition from one environment to another.

This was also evident with Jonathon Frost. Jonathon explores how he understands the label of 'autism' and is suggesting that the difficulties lie outside himself:

Jonathon: No .... I know autism when you don't understand what people are saying... like saying .. if they said someat to you like ...erm .... Look.... if a teacher at school said to you "look you haven't .... you haven't corrected this, do it again" I just feel like I am getting told off, I am being treated like I am naughty.
Jill: Why do you think that is?
Jonathon: I'm not sure, that's why ... I get wound up ..every so often .. it comes and goes

He then goes on to talk about his school:

Jonathon: That's why .. that's why I don't feel happy that much about Brecken Charter School, ...
Jill: No?
Jonathon: I just feel like ..... nearly all of them are against me..... and also I don't like about the school is ...I've got a lot to remember
Jill: Why do you think that they are all against you?
Jonathon: Well .... pushing and shoving
(Jonathon Frost – Interview 2, lines 71-83)

A disability rights perspective may not immediately appear apparent, when the young people do not have the language to express their experiences socially or politically. Some of the young people will experience teasing or bullying as they go through their life (this is explored further in chapter 5) and thereby the importance of applying a disability rights perspective becomes even more apparent. Although some experienced teasing and bullying, only three of the young people actually had the words to explain what this was or communicate to another person that it had been experienced by them. If photography and taped interviews were the only aspects of the research methodology, then 'observations' of bullying would not have emerged. I witnessed incidents of bullying at the school through the use of non-participant observation. This was helpful to understand what was happening to those who didn't have the words to explain it themselves. Three of the young people had the language to communicate about bullying or teasing, indicating this was part of their life experience:

Jill: No... have there ever been times when people have taken the Mickey out of you.. or called you names at all?
Jonathon: Only when I was a first year
Jill: Yes and did you... how did you... feel when that happened?
Jonathon: Wound up really..
Jill: mmm
Jonathon: But.. as I ... like er... as the years went by I lost me temper with them.. ..not these (referring to the picture) but the others
(Jonathon Frost – Interview 7, lines 147-152)

A level of sensitivity came through from the research subjects and they gave examples of what had upset them. Some of the people directing the words, may think they are

being light hearted and joking, without really understanding how this will be received by the young person. This was illustrated when Jason talked about his father:

Jason: Yeah its better when my mums' here when you come
Jill: Why is that Jason?
Jason: 'cos my mums different to my dad ... my dad teases me
Jill: What does he say?
Jason: Oh just things like .. like... like like ....oh just things ...
Jill: Yes?
Jason: Oh I don't really want to talk about it
Jill: No? oh okay
(Jason Smart – Interview 6, lines 102 – 110)

The three young people who chose to talk about their experiences of bullying, found it difficult and raised a level of emotions that they obviously found painful. The three were also only able to reveal these insights after they had developed a level of trust with myself as the interviewer. Such discussions took place in the last or second-to-last interviews. With Jason Smart, I tried to encouraged him to talk about the teasing by his father by using my own experiences. This acted as a probe or a prompt for him to be encouraged to talk further on the issue. Jason then revealed how he felt empathy for his brother who he felt was soon to be diagnosed with 'autism':

Jill: My dad used to tease me a lot you know and it was very painful at the time ... it used to hurt me
Jason: He hurts Sam by saying that he's going to... because he calls him autistic and saying he is going to ... he might go to St Francis Special School

A disability rights perspective for one young person resulted in him becoming interested in the research process itself and offered some thoughts on how he might like to be engaged in carrying out research in the future. Wills had been through bullying of such an extreme that it had caused him some physiological and psychological trauma. This experience had been while at a mainstream school and before a diagnosis of Asperger syndrome had been made:

Wills: Have you put all my pictures in an album?
Jill: No all your pictures erm ... will actually just accompany the tape and you get all
the pictures back at the end of the research
Wills: I've already got the pictures ...
Jill: You get a second copy
Wills: So are these used in classes?
Jill: What these are used for is presenting findings to say to people look this is what
young people with Asperger syndrome and those with autism are saying that's
important in their life......... and to be supported at school. And all those findings will
go to the teachers to let them know
Wills: I've got to get into a project like this
Jill: Yes?
Wills: Although I might be in the project .. I want to take on the role which you are
taking .. now .. and help out
Jill: hmmm ... absolutely
Wills: But in my own way I guess I am
(Wills Martin – Interview 6 lines 196-206)

Glassner and Loughlin (1987) found that interviewees told them, if given the chance, what assertions from the researcher make sense or nonsense to them. The authors discuss instances in their study in which the interviewer brought up a topic that was seen by the subject as irrelevant or misinterpretation and they offered correction. This was evidenced in the research. For one young person, who was a keen Sheffield Wednesday supporter, my lack of knowledge of football, prompted Charlie, to correct me:

Jill: Oh of course .. and is Sanderson one of your favourite players?
Charlie: this is the sponsors,
Jill: Oh of course.. sorry .. its one of the sponsors (laughs)
Charlie: but they've actually changed it .. to chubba chucks
Jill: Arh ... Like those lollies?
Charlie: hmmm
(Charlie Hill – Interview 5, lines 131-141)

But for others if they did not understand the question they might become frustrated or they may use avoidance techniques:

Jill: And where's this?
James: De da de da de da
Jill: Where's this?
James: When you finish ... the car
Mum: No this one darling [mum helps prompt James to re-engage in the interview]
(James Frazer – interview 4 lines 102-104)

The young people were also able to tell me when they did not recognise the photographs or if someone else had taken the picture:

Andrew: Yeah .. and there's the fridge .... and Ed on a potty
Jill: (laughs) Did you take that picture
Andrew: No
(Andrew Jones – Interview 2, lines 26-29)

It was the fact that Andrew Jones commented on the fridge as the main focus of the photograph and not his brother that prompted me to ask if he took the picture. He then went on to tell me exactly which ones he had taken and which ones he hadn't taken:

Jill: Who took them?
Andrew: I think Ant did
Jill: Do you think Ant took this one?
Andrew: I did
Jill: What about this one?
Andrew: Ant took that
Jill: This one?
Andrew: I took it
Jill: That's a nice picture isn't it
Andrew: Ant took that
Jill: Yes .... So you took the one of Ant, the one of Elizabeth and ....
Andrew: Mum did
(Andrew Jones – Interview 2, lines 44-54)

Reference has already been made about the experience of exposure anxiety, as a particular issue for people with a label of 'autism'. Within this research it soon became apparent that overtime the young person could cope better with a greater level of exposure to myself as the researcher. Such a finding strongly supports the use of longitudinal research as part of the research methodology requirements with this group of children. In addition to exposure anxiety, social distance and disconnectedness from the neurotypical world can result in suspicion and a lack of trust. This was apparent particularly with Jason, who would often ask me what I was doing and why.

Rapport building is a key to developing trust between the research participants and researcher. Glassner and Laughlin (1987:35) argue that: *'Establishing trust and familiarity, showing genuine interest, assuring confidentiality and not being judgmental'* are some important elements to rapport building. Success of the rapport building is demonstrated by the continued length of time the young person wanted to be engaged in the interview process and if they wanted to continue talking at the end of the interview, even when all the photographs had been discussed:

Jill: Okay ..... right well what we will do Phil ..... are you happy to end the interview here .... Or is there anything else you want to talk about?
Phil: I was thinking I could put my photos in the album .. lets put them in now
Jill: okay ......
(Philip Court – Interview 2, lines 217-219)

In the following extract, Jason said he didn't want to talk about anything else, then he initiated a conversation about one of his favourite television programmes:

Jill: Was there anything else that you wanted to talk about?
Jason: No
Jill: Okay shall I show you what I've got you?
Jason: mmm
Jill: This is the very last interview I have bought you, an instant camera you could get your mum to help you put the film in and when you take the picture the picture comes out of here .. so um.........
Jason: Do you watch the thin blue line?
Jill: Yes I have seen that
Jason: I think that's funny, because Rowan Atkinson like .... Like sees more to being a policeman .... he thinks that (I think you have to) but he thinks.. he thinks there's more to being a policeman .... cos his wife Patricia works in the reception and he thinks that .... he has to be strict with his wife ...... and erm ... and then .... I don't think he cares how .... I don't think he cares how erm .. about his wife's feelings, because what his wife .. she was about to hit him, he said if you hit that you will be assaulting a police officer
(Jason Smart – Interview 7 lines 179-186)

It was apparent that Jason had wondered about 'Patricia's feelings'. This suggests that he has reflected upon the impact of a set of 'behaviours' on the feelings of another. Although he was smiling while recounting the story, the programme had served not only served as humour but had also helped him to reflect upon the social interaction he

had observed. He had then initiated the conversation with me at a time (at the end of the last interview) when he felt comfortable to do so.

In the same interview Jason illustrates another way in which he wanted to lengthen the interview process:

Jason: .... It's like probably like ..... it being number one... its like 2nd .. however people like it .... its like a tribute .... like like theres people been a CD....... Like Kareoke Abba ..... and this has been Abba mainly and where other people have done some songs
Jill: Right ..... (pauses 5 seconds)
Jason: I was going to ask you .... As you asked me .... what do you listen to?
Jill: Well I tend to listen to erm music when I am working, because sometimes it helps me to concentrate
Jason: Music helps you to concentrate?
(Jason Smart – Interview 7 lines 143-145)

By pausing and creating the opportunity for Jason to speak if he wished too, he was able to initiate asking me a question in a similar style to the way I had asked him. He was interested in my response and was curious to find out how music could help me to concentrate.

As it was important for me to build rapport and a relationship with the young person, I enabled the person to lead the length of time of the interview. I tried to create a structure by going through the same procedure each time. For all the young people this procedure was as follows:

- Each young person had the dates of the interview in advance and parents often reminded the young person when the time was due for me to come to the house

- I would ring the young person's family at home 1 week before the interview was due and ask if he could bring the camera into school for me to collect or I could pick up the camera from home

- I would take two sets of photographs to the young person's home and I would usually go into the lounge or the young person's bedroom (whichever one was preferred by the young person); and on most occasions the interview was carried out in private. Only the interviews of James were consistently carried out in front of the mother and father, as there was a need for continual interpretation and translation of his communication style and method

- I would set up the tape recorder and then ask the young person to take me through the photographs. I would then go through my set and place the pictures in the same order that the younf person had done. This would help in the accuracy of transcribing with reference to the right photograph

- Usually at the end of the interview I would ask the person if there was anything else they wished to talk about. Sometimes I did not ask this question if I felt the young person was anxious to close the interview. This happened on some occasions as the following example highlights:

Jill: That's lovely ...... which one is your favourite ... is there a favourite one that you took of you ....
Andrew: (Packs the photos away)
Jill: Do you think we've finished now?
Andrew: Yes
(Andrew Jones – Interview 3, lines 128-131)

- I would always then leave the person with a 'new' disposable camera and check that they were still consenting to continue to participate in the research process.

One young person talked about how he 'looked forward' to seeing the photographs:

Jill: It is the 18th November and the time is nearly a quarter past nine
So here are your photographs do you want to put them on here ...... (the table) or on there (the arm of the chair) do you want to...
Simon: Looking forward
Jill: Yes? You've been looking forward to this?
Simon: Looking forward to it
Jill: Yes that's good ....what's this a picture of?
(Simon Sands – Interview 2, lines 7-12)

The young people did not need to feel pressurised in the process and I was to ensure that they were only prompted to remember that they had a camera and not told to take photographs of any set images. I originally had intended not to give feedback on individual photographs, so that the person would not take photographs just to please me. It soon became apparent, however, that I needed to give the young people feedback and praise on their work, to encourage them and to help them build their confidence in photography. I would then ask them to pick out their 'favourite' or 'best' picture and then ask them why. I found that I needed to be enthusiastic and positive to encourage the young person to feel good about their achievements.

Non-participant observation in schools

Non-participant observation was used as part of the research methodology to enable the goal of 'participatory research' to be achieved. As has been discussed earlier in this chapter, some of the more pertinent (social and political) issues emerged from the last or second to last interviews. At the beginning of the research process, it soon became evident that my contact with the young people, through the interviews, would not be sufficient time to build trust and rapport. The non-participant observation was intended for me to have a 'low-profile', in the presence of the young person to ensure that 'exposure anxiety' caused by my contact at the interviews would lessen over time.

Young people asked for their consent for me to shadow them for 1 day a month for a school day over the period of a year. Consent was sought on each occasion and for each lesson the young person had to attend. There were some occasions when the person asked me not to attend but these occasions were few and usually involved one young person. Jason experienced high levels of anxiety in my presence for some time and the following illustrates how I was keen to regularly obtain consent and to maintain

accountability to the young people. I was keen from the start to ensure that the young people could request me to be absent from any sessions. It was important for me to ask for consent to be with the young person on each occasion. On one occasion, Jason was able to request to speak to the teacher and to ask that I not be there:

> Document JS 21 March 2000, Section 0, Paragraph 22, 233 characters
> *In the learning support unit, the teacher says we have done some algebra and some percentages and we now know that we need to do some more work on percentages. Jason, you wanted to talk to me? Jason says "yes, do you mind if we do it with Jill out of the room?" I immediately exited at this point*

For about 4 months Jason experienced difficulties with my presence in the same classroom. There was a point when I considered the value of Jason continuing in the research process:

> Document JS 19 June 2000, Section 0, Paragraph 1, 320 characters
> *I am aware that my presence may be affecting Jason's ability to do his work, I must ask the support assistant if there is a difference when I am around. Jason is probably the most disinterested person involved in the research and I am really concerned about my presence causing him anxiety*

Later that morning I spoke to the support assistant and she responded: *'Yes, he has been different, he normally sits closer to me and at one time I had to ask him to sit closer. He didn't answer the questions as he normally does, but this could also be because it was a new subject today'.* He did ask the classroom assistant why I was in the classroom and he had said to her: *'She comes to see me at home, so why does she need to see me at school?'* I told the support assistant, I will write down why I am in the classroom so that she could pass this on to Jason. Later that day, as we walked across to the main school building, I spent some time explaining to Jason why I was in the classroom and gave him the chance to talk about any of his concerns. I also asked him if he wanted me to

write down what I was doing and he said no. I wrote in my notes: *'It is more important to accept and understand that Jason has apprehension about being involved in the research, so I can appreciate when and if he wants to exit from the project'.*

It was only 10 months later that I noted that Jason appeared to be feeling positive about my involvement with him. In January 2001 I wrote:

> Document JS January 2001 Section 0, Paragraph 1, 433 characters
> *I asked Jason if it was okay to be with him in lessons today and he said okay. I try to be sensitive to the needs of the children and I do check with them all the time if it is okay to be around them. I am checking their consent and also watching their behaviour to see if they are communicating any distress at all by my involvement with them. I really think Jason is enjoying the process now although at first it did cause him some anxiety*

If the research had not been carried out over a period of a year, it may have been that the barriers in place that caused Jason's 'exposure anxiety' would have been of such intensity that he would have got very little out of the research process. The period of 1 year was sufficient for him to relax in my company and to feel comfortable to ask me a series of questions at opportune times.

In the same way that I asked the young people for their consent for me to shadow them at school, I also asked the support assistants and teachers if they were happy for me to be in the classroom. I found that over the period of engagement across the schools that the most teachers and support assistants were happy for me to be in the class. The mainstream schools often made positive comments about the children labelled with 'autism', as the following example highlights:

> Document DK 31 March 2001 Section 0, Paragraph 16,
> 149 characters
> *Sam (another child with autism) is sitting next to DK
> and he has nearly completed his work, and the teacher
> says he could do with a lot more Sams in the classroom*

There were occasions when the teacher would brief me and spend time explaining to me

what was happening and the aims of the lessons. At more relaxed times I was asked by

one teacher if I would participate in a quiz:

> Document DK December 2001 Section 0, Paragraph 5,
> 92 characters
> *10.52 the teacher asked me if I would tally the results of
> the three groups*

There were occasional times when there was resistance to my presence. When this

occurred in the mainstream school it was usually when the teacher had not been

informed of my involvement in the research project. In the two mainstream schools the

teachers in the learning resource unit had briefed most mainstream teachers and this had

proved to be sufficient to enlist the support of the teachers to my participation in their

class. Most resistance to my presence in class was from those who had not been briefed

about my involvement or if I had not met them before (outside of the classroom) to

introduce myself.

> Document JS September 2000 Section 0, Paragraph 1,
> 155 characters
> *The teacher was not really responsive to me, I haven't
> met him before and he said one support person is
> enough. (He was implying I was another support
> assistant).*

Where there was resistance to my presence at St Francis Special school it was usually

where the teacher or the support assistant had a lack of confidence in their own practice

in working with the young people. I made a note on the computer as I was sitting in the class:

> Document AJ 3 July 2000 Section, 0, Paragraph 10, 372 characters
> *I don't know where the support assistant is, she did tell me earlier that she couldn't concentrate when I was in the room 11.14*

At St Francis Special School there was one particular male teacher who became quite critical of my presence in the classroom and my method of data collection with the use of the lap-top computer. He was quite suspicious about my presence and became quite demanding on one occasion to see what I had written on the lap-top:

> Document KS 15 November 2000 Section 0, Paragraph 4, 452 characters
> *The teacher shouts at Wills Martin and says to Wills: 'you are not supposed to be going out there'. I turn the computer off as the teacher demands to see what I have just written and he says he is not happy about me writing things down.*

I spent time with this teacher and explained about the method and focus of the research. It did appear that ethnographic research appeared threatening, as he himself became defensive about his own practice. I did negotiate re-entry into this class with the teacher concerned; however, 3 months later the teacher was still not happy with me inputting data on the computer in his class and I recorded the following:

> Document AJ 6 February 2001 Section 0, paragraph 11, 226 characters
> *The teacher asks me again if he can see my research and I start to feel upset and become defensive of the research. He then accuses me of being defensive, and I agree that I will let him see the bits that affect him at the end of the research project. I feel quite upset with him questioning me again.*

At the end of the research study, I did a presentation at two of the schools and presented my findings. This teacher was not at the presentation as he had left his post at the school before this research project had finished.

One support assistant, who ran a literacy group at St Francis Special School, did not want me to attend any of her sessions and whenever I was scheduled to be in her class I agreed with her, to spend time in the staff room instead.

> Document KS April 2001 Section 0, paragraph 3, 81 characters
> *Period 2, the support assistant doesn't want me in her literacy class so I go into the staff room instead.*

At St Francis Special School, there was very little support for the teachers and support assistants in supporting children labelled with 'autism', although two teachers had obtained a post-graduate teaching qualification at the local University in 'autism'. Within the two mainstream schools the specialist resource units were able to provide positive advice and recommend practical strategies to the mainstream teachers, to enable more effective teaching by the breaking down of 'barriers' that cause confusion in communication. Such a support infrastructure was not as evident in the special school and such advice and support appeared more 'ad hoc'. It appeared evident that demand for more practical advice and support from the teachers in the special school was clear, as they would sometimes ask me for advice (when this was not apparent in the mainstream schools).

> Document KS March 2001, Section 0, Paragraph 3, 375 characters
> *The teacher asked me if I am in again this week and I say no and she said she wants to pick my brains about the child I was with yesterday and another child*

In the above example I was able to provide the teacher with some reading material on 'Social Stories' (Grey, 1995) and this was reported to have been a successful approach to a particular problem.

Another teacher at the special school illustrated a lack of understanding of the 'impairments' of autism :

> Document WM January 2001 Section 0, Paragraph 1,
> 347 characters
> *The teacher asks do you have any insight into his*
> *language .. the pedantic language and I said that this is*
> *a theme with children across the spectrum*

In some respects the mainstream schools were more equipped to break down 'barriers' to include the education of children with a label of 'autism', than did those in the special school. Where the mainstream teachers had been given training on 'breaking down barriers in communication' and practical support by the learning resource unit, this did appear to result in increased confidence of the mainstream teachers in their ability to teach pupils with a label of 'autism' in the classroom. What is of concern from this research is that there may be an assumption by the local education authority that special schools are more equipped to teach children with a label of 'autism' than the mainstream schools. The research argues that this is not necessarily the case.

On the whole, the pupils, their peers, the schools, the teachers and the support assistants were supportive of my presence in the classroom setting or on the games field. Because of the nature of specific events, such as school trips, charity fund-raising days, sickness of pupil, sickness of researcher some of these days were not full days of observation, but partial days or half days.

Name of child	Days of observation	Total Hours of observation
1. Jonathon Frost	5	22
2. Jason Smart	10	40
3. Charlie Hill	11	33.5
4. Anthony Garrett	10	42
5. David Kent	10	46
6. Phil Court	10	41
7. Wills Martin	9	32.5
8. Kevin Scarborough	9	36
9. Simon Sands	10	32
10.Andrew Jones	11	38.5
11. James Frazer	8	25
	103 days	**388.5 hours**

Ethnographic data were collated in classrooms and observations were made between classroom changes and at break times. Most non-participant observations were, however, made in the formal part of the school day.

All observations were documented on a small Sony via laptop computer in word files. They were then transported into a software package Nvivo and 274 nodes and codes were formulated from the data. The codes were developed from working 'up' from the data. Themes generated from this data and that of the interviews and the photographs will be presented in chapters 3, 4 and 5.

To conclude this chapter on research methodology, there are a number of themes that emerged that generated knowledge in the development of an 'innovative' research methodology to engage young people with a label of 'autism' in the research process:

- A longitudinal qualitative research methodology is required to advance participatory and emancipatory research for people with a label of 'autism'

- A number of contacts with the research participants will result in a greater level of trust being established and the person using more communication to describe their experiences

- Non-participant observation may be required as a precursor to engaging research participants in 'participatory' and eventually 'emancipatory' research. It is also a useful method to understand social processes that are difficult for the person to articulate

- The style of communication of the researcher may act as a 'barrier' to some people becoming engaged in the research process

- The development of a 'communication profile' can help to identify ways to 'dismantle barriers' in communication and social interaction

- Some people may not have the words to describe particular experiences, e.g. bullying. More than one research method ensures capturing issues of import and prevalence

- Involvement in the research process needs to be fun for the person and they need to feel motivated to be involved. One way that this can be achieved is from the person taking photographs of their special interest and discussing this with the researcher

- Non-participant observation can be difficult in schools and will require more consideration regarding the ethics of other adults and children being involved in the research process.

INTRODUCING THE DATA

The three chapters that follow are data chapters and form the basis of the research findings of the thesis. Within these chapters, 'autism' is understood from the perspective of the 'social model of disability'. There is a focus on the 'barriers' that disable people with a label of 'autism' rather than a focus on 'impairment'. Initially the data was presented to illustrate the different ways in which young people experienced their life in relation to a 'sensory continuum'. It soon became evident, however, that the young people were experiencing 'disabling barriers' within their environment that caused them to incur 'disabling experiences'. The data chapters do not aim to illustrate 'experiences' in isolation of these barriers. Barnes (2003) warns of the dangers of doing this:

> *'Social scientists have been documenting the experiences of*
> *powerless peoples, including those who could be defined as*
> *disabled, for most of the last century'*

There is the difficulty, however, of representing the *collective* experience of young people and justifying the selection and representativeness of what is outlined within this thesis. The principles of emancipatory research set out by Barnes (2003) will guide the data presented:

> *'It is important therefore that within an emancipatory disability*
> *research framework, any discussions of disabled people's*
> *experiences, narratives and stories are couched firmly within*
> *an environmental and cultural setting that highlights the*
> *disabling consequences of a society organised around the needs*
> *of a mythical, affluent non-disabled majority'*

Their lived experiences will be examined in relation to how the person experiences 'barriers' in relation to:

- the physical environment and its impact upon the senses

- information processing

- social understanding and social relationships.

Chapter 3 will present 'cameos' of the 11 research participants and illustrate how each one of the young people experience 'disabling barriers' in their day to day life. This is in line with the emphasis from the young people, that the problems they incurred were usually found external to them and not experienced as 'impairments'.

Chapter 4 will present an overview of the themes and issues that emerged from an analysis of the photographic data of the young people. It will be argued that the dominant theme to emerge from the photographs was of 'social interaction'. This supports the argument for 'autism' to be understood from a social perspective and the 'social model' is advocated as a framework for advancing this analysis. It will be argued in this chapter that the themes generated from the data often contradict and challenge the position of some of the theories of 'autism' discussed in chapter 1. This chapter argues for further research that is led by people with a label of 'autism' as a way of continuing the development of a body of knowledge which represents an alternative understanding of autism, rather than a focus on 'impairment'.

Chapter 5 takes a closer look at the way people are disabled by 'barriers' present in 'social interaction' and in the formation of social relationships. This chapter looks at friendships and argues that the barriers that people experience in society will be particularly evident in the formation and maintenance of friendships. Examples from the data of Simon, Wills, Kevin, Jonathon, David and Anthony will be drawn upon to form the basis of chapter 5. I would draw the readers attention to the finding that the research participants were trying to work though and understand how to develop meaningful social interactions with others, but this was often an area which was viewed as problematic in terms of management within schools. Schools have started to build up experience and expertise in breaking down the barriers in the teaching of children with a

label of 'autism'. However, there is little evidence of ways in which social relationships with and between children are the focus of teaching and support. This chapter concludes with the suggestion of a need to advance the development of support and develop 'enabling environments' in schools, with an aim to facilitating individuals to learn about the development and maintenance of social relationships. Chapter 5 contrasts with chapter 4 in that while social relationships were one of the most important themes evident throughout the photographic data (chapter 4), it was the one major area that caused the most problems in the lives of the young people (chapter 5).

Chapter 5 will examine the experiences of the young people in relation to their experiences of 'being bullied'. It will also propose that a move away from the more traditional approach to managing bullying is required, and a worker is essential to support this group of learners in this area.

CHAPTER 3

PHYSICAL BARRIERS IN THE ENVIRONMENT – DISABLING THE SENSES

The theories of 'autism' were outlined and reviewed in chapter 1 and it was argued that people with a label of 'autism' will process information through their senses in different ways and in different environments. Some environments can have a 'disabling' or 'enabling' effect on the senses.

Using the 'social model' it can be argued that by understanding and listening to people with a label of 'autism', practitioners will be able to make the right adaptations to the environment and to amend and tailor the support provided. It is the need to develop such strategies 'outside' of the person for example in supporting and adapting the environment that then takes priority, rather than looking to change the behaviour of the person.

Without a theoretical framework to understand the 'sensory continuum' (Grandin, 1995; Williams, 1998), practitioners are often left to respond to the behaviours presented by individuals, using more traditional behavioural interventions (as outlined in chapter 1). Such approaches may interpret behaviour as 'difficult' or 'challenging'. The theoretical framework of the 'sensory continuum' helps to interpret and understand behaviour that has a sensory origin in relation to stimuli in the environment. The introduction to this thesis (and further expansion in chapter1), outlined that the writings by people with a label of 'autism' are often contexualised within the current body of knowledge and positivist underpinnings of this knowledge. This body of knowledge is predominantly presented from within the 'medical model' or 'impairment' perspective. It is important to recognise that in the absence of these writers engaged in the wider debate on the

'social model of disability', their work can often be critically interpreted and understood from an 'impairment' perspective.

The sensory continuum - Sensory to the Significant

Autism as an experience describes a very complex interplay between identity, personality, environment, experience and the equipment with which to integrate and make sense of that experience (Williams, 1998:9). Describing 'autism' as an experience, Williams argues that it is the degree to which these 'experiences' affect how one expresses oneself and relates to one's inner and outer world.

Both Williams (1998) and Grandin (1995) make reference to a 'sensory continuum'. Williams discusses this continuum in relation to three component parts:

Sensory   Literal   Significant

Williams argues that all people on the 'autistic spectrum' will start within the 'sensory' and will move to a greater or lesser extent towards the 'significant'. Some will stay within the 'sensory' and may fail to make the transition because 'barriers' in support or 'barriers' may be present within an inappropriate or frightening environment. Others will make the transition and may ask lots of questions as they make this transition, but may revert completely to the sensory if a situation, event or an environment leads them to experience a high level of 'exposure anxiety'.

It is this sensory continuum that exists (to a greater or lesser extent) in the lives of people with a label of 'autism', regardless of their ability, and it is the extent to which they experience exposure anxiety that will determine the extent to which they revert to the 'sensory'. It is the interplay between a person's senses and the environment that can

cause that person to become disabled in one environment and not in another. It is the barriers in place that create a 'disability' and it is this that should enable their access to support services. Such access should not depend on an IQ measurement that assesses if the person with a label of 'autism' also has 'learning difficulties', as this is usually the way people with a label of 'autism' may access support services.

Grandin (1995:52) argues that people with autism are on a 'sensory processing continuum'. This continuum is presented in three parts:

Low-functioning person who receives jumbled inaccurate information both visually and orally	Children who are echolalic are at midpoint (p54)	Asperger or Kanner's autism who have mild sensory oversensitivity

Williams and Grandin differ in their description of the sensory continuum. Williams argues that there is a differentiation between 'sensory' and 'information' processing. Grandin argues that at one end of the spectrum, autism is primarily a cognitive disorder, and at the other end it is primarily a sensory processing disorder (1995:58). Williams (1998) elaborates more on the 'process' of development of people with a label of 'autism' as they progress or not through the 'sensory continuum'.

The 'sensory' element of the sensory continuum

In the sixties it was argued that people with a label of 'autism' relate to the world through their senses (Schopler, (1965). An infant uses his receptor processes to obtain meaningful sensory information about his surroundings. It is through the use of the senses such as vision, audition, touch, taste and smell that the child develops an adaptive interaction with his or her environment. Children with a label of 'autism' are

likely to avoid distance receptors as audition and vision in preference for near receptors, such as touch, smell and taste. It is this argument for 'near' and 'distant' receptors which relates to Williams' theory of the 'sensory' to the 'significant'. Distance receptors of vision and audition enable the person to survey the environmental space around them, to enter or avoid, depending on the information supplied by these receptors.

Williams' uses some specific terms to explain the 'experience' of living with a label of 'autism'. People who relate to the world at a 'sensory' level, will be relating to **The Systems of Sensing**. For those individuals who move through the continuum and who make the *transition* they will move to relating to the world through **The System of Interpretation.** In the systems of sensing the person is to *'be'*, and are at one with themselves relating to objects through their senses. They are 'the whole world' a time without boundaries or restriction and every experience of that world is an indistinguishable and *resonant* part of one's self, with no need to explore it as a separate entity (Williams, 1998:12). They will not see the function of the objects, but be intrigued by them by touch (texture), taste, sound. They may not hear words in terms of their content, but instead hear the sounds and the vibrations. They may like to say particular words over and over again for how they 'sound' in their throat, or how they can form the words through their voices. They may even elect not to speak as the sound of their own words disconcerts them.

The Literal

Moving into the 'literal' occurs when the person passes beyond seeing contours, sound, texture and pattern of objects. At this stage, Williams could, at first understand the 'concept' of objects, but would not question the function. For example one could tell the

age of a cardboard tube from the number of rings it has. This judgement refers to trees and was thought to a logical explanation (1998:16).

The System of Interpretation is about a *learned system of interpretation.* The person *'appears'* in the system of interpretation. It is a world of the *mind* where words are expressed to communicate a function, not because they have a nice sound. The *'be'* is the home we come into the world with, the *'appear'* is the home we learn to construct in its absence (Williams, 1998: 12).

Williams argues that all *sensing* existed before *mind,* but that most of us, as babies are socialised immediately into *'mind'.* Those who relate to **The Systems of Sensing** start to see the individual pieces, not the whole picture. The person will see and *experience* the patterns, yet those who start to see with mind first will see the idea or the *meaning* before they see the pattern.

Williams developed a framework to understand the extent to which people with a label of 'autism' are relating to others and the world around them. It is argued that we probably take for granted that we can experience ourselves: the room we are in, the object we are holding or the person we are with – all at the same time (1998:13). Non-disabled people can simultaneously experience 'self' and 'other'. Yet there are times when we can also become oblivious of others: when we look up, embarrassed to realise we had started to pick our nose, when we were not alone. It is at these times that we have 'slipped out of gear' and slipped into a mode of 'all self and no other'.

All self and no other – where one is in the company of others but momentarily slips into a state of pre-occupation with one's own behaviour

All other, no self – one is caught up in the awareness of another person or object, that it is not evident why one is in this environment

No self, no other – lost in limbo, unaware of self or anything beyond self.

Williams (1998:13) argues that there are those with a label of 'autism' who are constantly jumping between one or the other and who never reach a state of simultaneous 'self and other'. It is in the area of support and in the way people with a label of 'autism' are 'connected with' that can enable them to make a difficult journey through the often confusing and frightening environment.

There are times when the environment becomes too overwhelming and the information is not provided to the person in a way that they understand. This can result in people being disabled by their 'environment' and the 'support network'. The combination of *sensory and information processing difficulties* combines in a way that can completely disable a person with autism if they are not adequately supported (the presence of support barriers).

It is the aim of this chapter to explore ways in which such barriers can be challenged, and to move away from seeing the person with a label of 'autism' as having the problem. Chapter 1 highlighted how the theories and understandings of 'autism' have depicted people in negative 'medical'/'deficit' and 'impairment' terms'. Billington (2000:95) argues that such negative representations of people are about 'pathologising' difference. It is with respect to people with a label of 'autism' that the presentation of data (within these data chapters) is presented in a way that doesn't perpetuate this oppression. Jasmine Lee O'Neill (1999) argues:

> *'Autistic people are often victims of oppression, they are often discriminated against in the same manner as people of various colours or religions are discriminated against'* (p.13)

People with a label of 'autism' are asking professionals to understand them within the contexts of their environments and identify what changes are required to be made to the physical environment and what appropriate support should be in place. Many adults are living in psychiatric institutions with a label of 'mental illness' or 'mental disorder' (Peeters, 1997:6). People have appealed against being 'misdiagnosed' as being mentally ill and for professionals to increase their knowledge of 'autism' and hence break down the support barriers that exist to deny their full participation in society.

> *'I had been assigned many labels: mentally retarded, emotionally disturbed, borderline personality disorder, aggressive personality disorder. But these labels were only a shot in the dark'* (Carpenter, 1992: 293)

The aim of the next section of this chapter is to present 11 individual biographies. Sacks (1995) argues:

> *'If we are to understand the autistic individual, nothing less than a total biography will do'* (Sacks (1995:238)

With the word limit of a doctoral thesis, I have presented small cameo biographies in a way that portrays the 'disabling barriers' experienced by each young person. It is the aim of this section to make some attempt to present the 'collective' experience of the young people.

Child 1 James Frazer

James is a 14-year-old young man who lives at home with his mother and step-father and his older sister. He has regular contact with his birth father and stays with him on alternate weekends. James attends St Francis special school and has attended special schools since his primary school education. He has very little language from **The System of Interpretation** and his language has been developed through the use of 'borrowed phrases' from his favourite videos **The Systems of Sensing.**

He often uses stock phrases from his favourite videos as 'social openers' with people. Certain phrases are used to enable him to socially interact with those around him. He enjoys the social interaction with others but often lacks the words to engage and socialise. He makes several attempts throughout the research to communicate with others', however, if others are unaware of how to extend the social interaction, the opportunity will be lost. James has a limited vocabulary (language) to enable him to communicate.

James will sometimes ask the question 'Do you want a tickle?' This serves as an important way that he initiates social contact with another person, when he lacks the words or phrases to socially interact. Other ways that he initiates contact is through the direct contact of touching and stroking hair or lifting hair to smell it. The usual response to the question 'Do you want a tickle?' for most people is to say 'No thank you' or 'I don't want a tickle'. James's peers will often ask the question of James as a way of having 'banter' or 'dialogue' with him. Not all of James's attempts to socially interact will result in a communication exchange. This is illustrated by the following example:

9.49 James says 'I am going to daddy's this evening, I am going to daddy's this evening, what do you think Audrey? (a question to his form teacher)' (James lives with his mother and step-father and sees his birth father at alternate weekends). Audrey says 'you are going to daddy's'. James says 'James Frazer has a sad and miserable face' 9.51 others are working and are busy and James is wanting to interact. He walks around the classroom and is talking to himself and as Audrey comes near he says 'are you alright Audrey?' and she says 'yes' and he says 'such a silly boy, not at willow at daddy's ' as he addresses Lesley (the support assistant) 'nowhere to be seen' says James and Chloe (the support assistant) repeats this back to James. James says 'is that you Audrey' and she says 'it is me James Frazer'. Max (another pupil with autism) says 'James Frazer do you want a tickle? (others use the same question back to James). If some of James's phrases are used by others he can get upset and looks offended. Kevin is quietly getting on with putting the certificates in the file, James Frazer says 'no thank you, not being silly again' 9.56.

As can be seen by the above extract, James's primary aim is to engage either the teacher (Audrey) or the support assistants (Lesley or Chloe) in social interaction. He starts with the teacher, he is also communicating that he is unhappy about something he says: *'James Frazer has a sad and miserable face'*. Because James, like others who use metaphorical language, has a difficulty with pronouns and present, past and future tense, he is unable to say 'I' feel or 'I' was. The others in the class (all children with a label of 'autism') are engaged in writing, filing and storing certificates. They are relating to their work as they have made some transition from the 'sensory' to the 'significant' (Williams, 1998). James is unable to engage in the work, he is excluded. He repeats the same statement to Lesley; the same question he had seconds earlier asked Audrey, although this time he includes the words: 'such a silly boy'. When he says 'nowhere to be seen', Chloe repeats this and then Max uses one of James phrases back to him. James is maintaining a level of 'participation' with the adults and his peers, even though he is excluded from currently understanding the *literal* or *significance* of the task in hand.

The adults and the young people in this interaction are not only failing to interpret the 'metaphorical communication', they are perhaps inadvertently teaching James to

maintain his use of echolalic speech, as they repeat to him what he has spoken to them. It could be argued that James is at the 'midpoint' of the sensory continuum (Grandin, 1995:58) and that a communication strategy is needed to support him to advance through the sensory continuum. The social exchanges between James and others do not result in a continuous social exchange or a conversation. He is unable to maintain a dialogue, although he makes several attempts to do so.

The children in James's class are aware of his interest in cartoon network and it is often used as a basis for communicating with him:

> Document 'KS March 2001' Section 0, Paragraph 5, 233 characters
> 'Okay Kevin sit down please' the teacher asks. Mr Hunt (teacher) brings some boxes and Kevin spots' his, he says 'aha, cartoon network' and it is his and he gets this handed back to him by the teacher (Kevin likes cartoon network and this interest is shared with James Frazer.) James Frazer says 'boomerang' and Kevin says 'never mind boomerang' Kevin pauses a couple of seconds and then he calls out to James Frazer, 'James' he calls and James looks to Kevin and Kevin says 'Fred Flintstone'.

James was reminded of boomerang by seeing the box portraying the black and white 'cartoon network' logo. It was an 'association' between cartoon network and boomerang that inspired him to speak the word. Kevin then interacted with James, still on the theme of cartoon network and made reference to Fred Flintstone. Kevin makes an attempt to initiate communication with James and he has connected to James through the sharing of a 'special interest'. It is interesting to compare this exchange with the one above where the initiation of communication was being attempted by James with Audrey, Chloe and Lesley. In this exchange there is a connection between the two young people and it is in relation to the 'shared interest' that the basis of a dialogue can occur. In this instance it is the exchanges between the young people, which can inform and guide non-disabled people (particularly researchers) on how best to develop a dialogue with a person with a label of 'autism'.

James uses particular phrases with particular people, as unique repertoires of social interactions. He greets his art teacher (former form teacher) with a statement: 'Marcia, you are a cat,' she is expected to make a meow sound. With the support assistant Lesley, he says: 'Lesley, Barney Rubble'. For others he may use a general question prefixed with the person's name and ask: 'Do you want a tickle?'.

> Document 'JF' 1 Feb 2001 Section 0, Paragraph 3, 374 characters
> 10.01 literacy, James says: 'Hello Marcia, are you a cat?' she says 'No, I wasn't the last time you asked and I am not today' and he says: 'say I am not' and she says 'I am not' 10.02 James says 'Poor James Frazer and poor Penelope Pitstop' and Marcia says 'I remember Penelope Pitstop, she was in wacky races'. Marcia goes on and says she used to watch that when she was 8. James turns to Jane (the support assistant) and says 'Jane you are not Penelope Pitstop you are Jane' 10.04

In this instance the repertoire of social interaction with James's use of language from cartoon network extended the social contact for 3 minutes. James's enjoyment of social interaction is shown when he tries to develop a social interaction when it is his turn in a game which includes five other pupils, a teacher and a support assistant:

> Document 'JF' 1 Feb 2001 Section 0, Paragraph 3, 374 characters
> Choose a colour James (Marcia says), 'I will choose a yellow one' James says and then he says to Marcia 'Do you like dastardly and mutterly?' He looks at the clock and adjusts his watch accordingly. James laughs and he is more relaxed, James looks to Marcia and he smiles 10.07 James calls out 'sacreblur'.

It had been 3 minutes earlier that Marcia had mentioned wacky races. It is likely that James did not pick up the whole content of her exchange with him, but picked up on two words he was familiar with. He then asks Marcia a question when she has initiated communication with him.

The wacky races theme continues for James. As he waits for his turn he sings a line from the theme tune of wacky races:

> <u>Document 'JF' 1 Feb 2001 Section 0, Paragraph 3, 92</u>
> <u>characters</u>
> 10.10 Katrina has a turn, 'catch the pigeon' James says. He waits patiently for his turn 10.11

The wacky races theme had been the basis of a dialogue that lasted 9 minutes. It was Marcia's ability to socially interact on the theme of wacky races that resulted in James being engaged, relaxed and able to participate in the game being played. What was also evident was that there was no 'exposure anxiety' from James. It appeared that the 'special interest' of discussing wacky races (being shown on Cartoon Network) served not only to maintain his interest and involvement but also to prevent exposure anxiety.

Although James struggles with the use of pronouns and the use of past, present and future tenses, it is important for him to have some reassurance on what is going on in his life. His parents use a calendar with him and at the weekend they plan with him what will be happening in the week. This gives James some security in knowing what he will be doing and the calendar is a visual reminder of those activities. The calendar appears to be helping him to acquire some understanding of concepts such as 'now' and 'later'.

> *Mum: He is quite good at days of the week ... yes I think he does know the days of the week doesn't he? (refers to dad)*
> *Dad: Again he had no idea until he was 7 or 8 ... we work with him on his calendar .. he is very keen to fill in his calendar each week or month .. He knows what's on it and he knows where he is on it ... and if it is a holiday away from school .. We can explain that there is no school Monday, Tuesday, Wednesday, Thursday and Friday, then school .. he is fine about that*
> (James Frazer – Interview 0, lines 73)

James has difficulty coping with the transition from one environment to another. As he relates to the world predominantly through his senses, his needs will predominantly be 'sensory'. For example, he was trying to cope with the pending transition that he would

need to make to go with a school group to Bewley Camp. He needed to take something from his 'safe' and 'secure' environment to help him make the adjustment and the transition from one environment to another:

9.30 James says 'I will take four videos'. Foster (the teacher) says: 'no, I have said no videos to Bewley Camp' and James says: 'Just one video please, just one video please, just leave one video to a bag and take it, okay Mr Allen? Foster Allen says: 'yes, now Jack Downs ... you will be a prison officer, Simon James a pig farmer and Sam Clarke is going to be a photographer' and James Frazer says 'Foster Allen is being silly'.

James is still unconvinced that Foster will let him take a video with him to Bewley Camp (a school residential break for a few days). Almost 10 minutes later, James initiates communication with Foster:

9.39 James calls: 'Mr Allen', Foster looks to James and James raises his shirt and Foster says: 'put it away' and James says 'Just one video for Bewley Camp'. Foster doesn't respond and James continues: 'Just one video, just one more, just one more, just one video, just one video' 9.43 and Lesley (support assistant) comes in and hears James and she says: 'Yes you can keep it in your bag' and she prompts James to continue his work by putting the words underneath.

The above example illustrates how James went to great efforts to initiate communication with Foster Allen. It was only when Lesley, the support assistant came into the class (13 minutes later) that James was sufficiently reassured, that he no longer needed to discuss the videos.

James experiences hypersensory sensitivities in relation to hearing. He found the noise level so intolerable that he called out to people to be quiet, whilst he had covered his ears:

> ### Document 'James Frazer' 17 November 2000' Section 0, paragraph 19, 62 characters
> When everyone shouts out: 'Yes!' in unison, James Frazer covers his ears. 'James do you want to sit here instead?' Jane says: 'it is a bit noisy in here', James says to all in the room 'Be quiet'. Chloe says: 'Do you want to come over here to sit James?' and Mr Stanley says to Chloe: 'Do you want to take him into my room?' and Mr Stanley says to James: 'Do you want to go on the computer?' and James says: 'Yes'

James's strategies for coping with his hypersensitivity to noise is to put his fingers in his ears, to try to escape from the noise and on other occasions he was observed trying to bury his ears in his clothing:

> ### Document 'James Frazer' 17 November 2000' Section 0, Paragraph 15, 254 characters
> We are in the dining room, James is hiding half his face in his jumper 11.54 James has put his face entirely in his jumper, James' head is in his jumper, his face is submerged, they give big cheers and James says: 'Shut up everybody! shut up every body' 11.58

In fact noise becomes a constant nightmare for James and he spends much of his time trying to quieten people around him from making noise that is distressing to him:

> ### Document 'James Frazer' January 2001' Section 0, paragraph 10, 197 characters
> As people are shouting out James holds his ears and says: 'Shut up everybody' 2.24

There is a lack of consistency around James as to the control of noise around him. The placing of his fingers in his ears appears to be seen by some of the people around him as part of his stereotypical behaviour and part of the 'impairment' of autism. There appears to be a lack of awareness by others that certain noise and sound in the environment could be painful to James.

Child 2 Andrew Jones

Andrew Jones a 13-year-old young person who lives at home with his mother, step-father, brother and sister and half-brother. His birth father lives nearby and he has regular contact with him. Andrew attends St Francis special school and his 'special interest' is Jackie Chan films, the Simpsons, the Blues Brothers and other films. He enjoys talking about the films and television programmes and asking questions of other people's opinions of these films.

Andrew: I took a photograph of myself
Andrew 3.16

Jill: Did you? That worked out really well
(Andrew Jones - Interview 3, lines 76-77)

In a similar way to James, Andrew uses his special interest as a way of initiating communication and social interaction with another person:

> Document 'Andrew Jones' 31 January 2001' Section 0.
> paragraph 3. 954 characters
> **10.09 Andrew says to me: 'Have you seen Beavis and Butthead?' and I nod my head and smile, he says: 'Did you think it funny?' and I nod and he asks: "What did you find funny about it?" and I said: 'I had better not disturb you while you are working' 10.09**

Andrew likes to watch the films over and over again and he learns the script and the actions. He likes to re-enact the script and he enjoys being watched doing this.

He can become absorbed in the sensory feel and touch of objects. He will do this when he is not engaged in a task or he will just 'switch' into relating to the 'sensory' of the objects around him:

> <u>Document 'Andrew Jones' May 2001' Section 0, Paragraph 5, 256 characters</u>
> Andrew chinks his pot and listens to the sounds and Zoe (child with learning difficulties) corrects him and the support assistant prompts him to continue his work
>
> <u>Document 'Andrew Jones October 2000' Section 0, paragraph 13, 229 characters</u>
> 2.29 Andrew changes the tracks he is listening to. He then finds a track and starts flapping his hands and tapping his feet, he is nodding his head with the music

Andrew uses touch as a way of initiating communication with others. He is comfortable with the use of touch but he needs to use it on his terms and when he is not feeling anxious:

> <u>Document 'Andrew Jones' 13 June 2000' Section 0, paragraph 1, 107 characters</u>
> Andrew is talking to the boy and leaned towards him and touched the fringe of his hair for about 4 seconds
>
> <u>Document 'Andrew Jones' 13 June 2000' Section 0, paragraph 1, 423 characters</u>
> Andrew touches Simone's (the teacher's) hand for a second

Moving from one environment to another is likely to be a time that causes Andrew some exposure anxiety, particularly in the first 10 minutes of moving into different environments at lesson change time at school. If someone should touch him when he was feeling anxious, this would have a negative effect upon him and would cause him distress.

There is a high level of stimuli in the environment in the transition from lesson to lesson. Andrew is quite sensitive and alert to the sensory stimuli and it makes him anxious at these times. He finds he can cope with the transition by re-enacting his

favourite videos. It is a comfort and a survival strategy against an environment that continues to bombard his senses:

> <u>Document 'Andrew Jones' 6 February 2001, Section 0, Paragraph 3, 294 characters</u>
> Jade comes to stand next to Andrew as they queue up outside the class for the RE lesson, she says: 'Sshhh!' to Andrew as he is enacting the video scripts and Mags (support assistant) says: 'Andrew! You are Andrew now, not a character in a video, you are Andrew'. He says: 'I know' and he chats again and she says: 'Andrew you need to concentrate' and he says 'I am concentrating'. Mags repeats again: 'You are Andrew today' and he says (impatiently): 'I know'.

Mags (the support assistant) interprets Andrew's behaviour as being deviant or 'difficult'. Yet to Andrew it is a survival strategy, in a place of unpredictability and confusion. Andrew reverts to this behaviour at the end of lessons or when there is a break in the lesson. It relates to what Williams argues is the state of *all self, no other* (Williams, 1998:11) and that under various degrees of stress or overload (from barriers within the environment) people can slip out of gear – from the significant back to the literal or further back to the sensory (p.21).

When there is a break in the teaching, Andrew is likely to re-enact the scenes from some of his favourite videos or films.

> <u>Document 'Andrew Jones' 13 June 2000' Section 1.1.1.1.1.1.1.1 Paragraph 2, 490 characters</u>
> 2.28 Andrew has finished his work and he is putting his arms in the air, miming a character from one of his videos. 2.29 Andrew is waiting by his work where he has finished.

Andrew shares a similar experience to James in that he believes that some of the characters in the videos he watches are real. He wanted to email Jackie Chan. He tends to immerse himself even deeper into the world of **The Systems of Sensing** when **The System of Interpretation** is a difficult place for him to be in. Evidence that Andrew moves between the sensory to the literal is presented in the following example:

<u>Andrew Jones July 2000</u>
'What do you wish for Andrew?' The teacher asks. He copies what the
last child has said in his reply and she says: 'No – it is what you wished
for, we are talking about wishes and the magic lolly'. She asks: "Where
would you find your magic lolly?" He says: "Around the world". She says
"Where?" and he says: "I don't know".. She explains: "We are
pretending". He says: "I went to Fat Jacks". She says: "Oh yes there is a
special jar with lollies there, is that what you mean?" She continues: "Do
you choose a lolly from there and does it turn out to be magic?" Andrew is
making hand movements, pointing (it looks like the blues brothers scene).
"Have you thought of a third wish?" she asks:, 11.42 he replies "let me
think, I wish I was grown up already". She says: "What would be so good
about that, what would you do if you were grown up?" He says: 'I would
do anything I want, drive a motorbike and my voice would be deeper'.

Andrew uses an enormous amount of energy to maintain his connection to the literal.

He is able to move from the 'sensory' to the 'literal', but as the above example

illustrates there is very little to motivate him to maintain and advance his transition to

The System of Interpretation. And so he reverts back to the world of the 'sensory'.

Child 3 Philip Court

Philip 'a self portrait'
   3.27

Philip is a 13-year-old young man with a diagnosis of Asperger syndrome. He lives at home with his mother and father and is an only child. Philip has a special interest in cars and has extensive knowledge on makes and models as well as having a large collection of matchbox cars. Philip has an extensive vocabulary (sometimes using words outside of their social context). He attends South Down's Secondary Modern School. Although Phil has expressive language, he does have difficulty managing the way his senses relate to the environment:

> Document 'Philip Court' 14 April 2000' Section 0. paragraph 6, 246 characters
> **Philip is sitting at the table, Simon (the support assistant) has left the room, 1.41 and Philip is rubbing something against the edge of the table and rubbing his boots against the leg of the table. He picks up his book as the teacher walks towards him and she asks: "all right Philip?" and he says: "okay"**

> **1.42** Document 'Philip Court' 28 March 2000' Section 0. Paragraph 2,219 characters
> **He is swinging on his chair and is not doing his work, although he has his pen in his mouth. He is off task now and has been for a while, it is now 9.51 and he has his hand on his head and is swinging back on his chair.**

Phil has difficulty concentrating when there is a lot of stimuli in his environment. He also needs prompts by those around him to 're-engage' with the task when the

environment sufficiently distracts him. In the following example it helped having his 'mainstream' school friend Drew, (sitting next to him), who prompted Phil to get back on task:

> <u>Document 'Phil Court' 23 June 2000' Section 0, paragraph 24, 558 characters</u>
> 1.31 Phil is flicking his pen on the table and the others in the class look over to him. Steve, the classroom assistant, is speaking to the teacher clarifying the task in hand and Phil has written one sentence and the other children have on average written one third of a page. 1.36. I can't help thinking that the instruction has been quite abstract and that he needs some guidance to translate the task into practical steps. When he was clicking his pen, Drew (a mainstream pupil and Phil's friend), corrected him. He is using a tippex pen to scrub out where he went wrong, he is not writing, he is tippexing out a sentence. The other children have by now done about half a page.

Drew is aware of the attention that Phil is drawing to himself by others in the class and he corrects Phil. It is not enough to get Phil back on task but Drew's contact serves as a prompt. Phil attended sessions at the learning resource base (at the school) to help him develop some 'self-awareness' of how the environment and others were impacting on his concentration levels. He was able to have 'reflection time' in the learning resource to be able to think about his behaviour and how others may see him:

> <u>Document 'Philip Court' 28 March 2000 Section 0, paragraph 5, 344 characters</u>
> Phil says: "Maybe a bit too aware of people around me. When I do my work I get distracted and hear what people are saying". Mr Mason asks: "Are you getting distracted by people talking? We talked about you not being able to screen out noise, like a dripping pipe?" Phil says: 'I sit in a place in maths where I don't have to get up. When I am in art, I don't like to be told what to do'.

Phil is able to pinpoint the aspects in his environment that causes him distraction. For example, he mentions his awareness of people around him and he also refers to a place in the maths class that he likes. It wasn't just the environment that Phil appears to have difficulties with, he makes reference to the approach of others (support barriers) when he says: "I don't like to be told what to do". It would have been interesting to probe with Phil as to what he would like to happen instead. He may be making reference to the

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attitude, the tone or how he understood the communication rather than commenting on what at first may appear unhappiness about the content and what was said.

The reflective session with Phil continues and the teacher points out how others see Phil in the classroom:

> <u>Document 'Philip Court' 28 March' Section 0, Paragraph 5,</u>
> <u>900 characters</u>
> Mr Mason went through all the good things that Philip did when things were going well. He then pointed out some observations to Philip he said: "Writing and concentration, you seem to be having difficulties with, yet domination of conversations has gone down, which is good". Mr Mason pointed out to Philip that he has been hitting difficulties again, maybe not entirely down to his own doing. Mr Mason asks Philip: "can you think of things at the moment that are not going well?" Philip replies: "Writing and concentration". Mr Mason says: "There are some behaviours started that haven't been seen before. Not seen the rolling of the head, excessive head movements are you aware or unaware of these behaviours?" Philip replies: "Unaware".

When questioned, Phil confirms that it is writing and concentration he is having difficulties with. He also says he is not aware of the behaviour of the rolling of the head and excessive head movements. It appears that Phil's senses are relating to the stimuli in the environment, causing him some involuntary movements. Phil is asked to raise his awareness of these behaviours and after 1 month of this counselling session, he was observed trying to use self-restraint:

> <u>Document 'Philip Court' 24 May 2000, Section 0, Paragraph</u>
> <u>2, 115 characters</u>
> 9.28 Philip was slightly rolling his head, I can see he is trying to use self restraint, 9.29

> <u>Document 'Philip Court' 24 May 2000, Section 0, Paragraph</u>
> <u>16, 171 characters</u>
> 2.28 "It has taken this long for the class to settle", the teacher says and Philip has had about 5 seconds of rotating his head in circular movements from side to side and swinging back and forth on his chair before he corrects himself.

In a similar way to Andrew, Phil is using self-restraint, but it is possible that such sensory responses will emerge in other ways. Philip continues to use self-restraint 6 months later:

9.16 Pupils coming in from the library, Philip is squeaking his boots and the teacher says: "who is making that noise?" 9.17 "is it you Philip?" He says "yes" – (and immediately says) "I will stop it".

Philip's book is 'Harry the Winkle 9.27 there is complete silence in the class. 9.28 Philip is getting fidgety and the teacher looks over to Phil, he settles after a couple of seconds. I wrote: "What is interesting is the changes in Phil's behaviour. Could it be that helping Phil develop some self-awareness and using problem solving with him has had this positive effect? Or could it be that he is just using self restraint, because the environment hasn't changed, but he is expected to"

At South Down's Secondary Modern School, where counselling and support is provided from the 'autism' support unit, there is still an underlying behaviourist approach in practice. The above examples highlight the effort Phil is making to use self-restraint to curb his behaviour. The following example highlights how Phil feels when over-corrected by the support assistant:

'Stop swinging on your chair' she says and he says: " I wish you wasn't so critical" and she says: 'I'm not , I just want you to get on with your work'.

Exploring this data in relation to the 'sensory continuum', it is evident that whilst Phil relates to **The System of Interpretation,** he continues to slip out of gear and move to **The Systems of Sensing**. He never appears to stay there for very long, as he is either self-checking himself or he receives a prompt by the support assistant, teacher or mainstream friend.

(Jason Smart - Interview 4, line 30)

Jason is a 15-year-old young man with autism who attends South Down's Secondary

Modern School. He lives at home with his mum and dad and two brothers. Jason relates

to the world at a 'hypersensory' level and much of his schooling is affected by the way

his senses interact with his environment. He can sometimes find environments 'over-

stimulating' and a 'sensory flooding' may occur:

> Document 'Jason Smart' 5 October 2000' Section 0.
> paragraph 8. 361 characters
> **There were about 9 children who had not partaken in the game so far and
> then Jason was given a netball shirt and asked to join the team. The games
> were in the large hall and there was a lot of whistle blowing and running
> around, a lot of movement and excitement and Jason started to jump up
> and down, clapped his hands, flapped his hands. He just became
> immersed in his environment and almost oblivious to those around him.
> The environment was causing a 'flooding' and there was too much
> stimulation and too much arousal. Just because he had the shirt on, he was
> never going to be included within the game when he was experiencing this
> amount of sensory arousal and stimuli from the environment.**

There were other times where Jason had been able to prepare himself for the large

amount of sensory onslaught in the school environment at lesson change-over times. He

had developed a coping strategy to help him in the busy mainstream environment and

ensured that the environment had a minimal effect on his senses:

> Document 'Jason Smart' September 2000 Section 0,
> Paragraphs 5-6, 468 characters
> **Driving over to the Langton Site in the rain, Steve and I spot Jason waiting
> by the railings of the Langton site. I said to Steve: 'There is Jason' and I
> ask Steve: 'is he waiting for you?' Steve gets out of the car and asks Jason
> if he was waiting for him and Jason says: "I am just waiting for some
> quiet". He did not feel comfortable to say excuse me or to push against the**

crowds he wanted to wait until he was ready to go when it was quiet and less anxiety provoking for him. Was this one of Jason's survival strategies?

When the environment is quiet and Jason has the opportunity to focus on an activity that he feels confident in, he is then content to do his work. The following activity was carried out through the use of the computer and appeared a positive way to engage him to learn:

Jason Smart January 2001
Jason needs thinking time for each sum but he seems confident to take his time and work through them. He has earphones on whilst the other children do not have theirs on. 10.32 He seems relaxed and comfortable with the activity and continues this. I have not seen him rock or flap his hands or use any stereotypical behaviour as yet. 10.33 He seems focused and comfortable with learning. 10.33 He types in his answer and then folds his arms while the computer computes a result and a score. I wonder if the earphones worked as a way to keep out any unnecessary noise level from the environment that would impede his concentration?

I was curious to find out which school building Jason preferred, as the environment seemed to play a major role in either enabling or disabling learning. When asked which building Jason preferred, he did not hesitate when he named the building. He was also able to say why he preferred this building. It had the resource, which he found comfortable and because it was quiet.

Jill: Yes of course........ Which building do you prefer?
Jason: Ashton
Jill: Why do you prefer Ashton
Jason: I just do ... its got the resource
Jill: What do you like about the resource?
Jason: (pauses) hmmm I just er ... I like the quiet there
(Jason Smart – Interview 7 line30 – 36)

In a different environment, with a different level of support and without the use of the computer Jason appears to experience exposure anxiety and his learning is disrupted.

10.55 She then turns to Jason and asks: 'What else can be done to this poster?' Jason picks up his pencil case and starts to shake it and hold it near to his face, after about 6 seconds he puts this back on the table. 10.58 He picks up the pencil case for 18 seconds and holds it by his face, he puts it down and then picks it up again for about 6 seconds. He now talks to Ms Hughes about his ideas 10.59

The above extract shows how the environment and support are affecting information processing. Without due consideration to these factors Jason could be the focus of the problem. For Jason the environment has played a significant part in his life. He reflects upon the move he made from primary to secondary school and expresses his thoughts that he should have gone to St Francis Special School, rather than attend South Downs Secondary Modern:

Jill: Why do you think you would have liked it at the special school?
Jason: because it might ... I .. It might... have reminded me ... I might have known from ... my old school .... There isn't anyone I know from my old school
Jill: And do you sometimes feel lonely when you are at school?
Jason: I just feel like ... I have been transferred to another planet
Jill: Yes? ... when you moved from your old school to this school?
Jason: No ..... its just that I feel on my own
Jill: There have been people with autism who have written about feeling like an alien, not feeling ....
Jason: (shouts and interrupts) NO! I don't ... it's just................
Jill: Yes?
(Jason Smart – Interview 6, Line122-130)

At the start of this exchange, I thought Jason was making reference to the difficulties he was experiencing because he stated 'there isn't anyone I know from my old school'. I immediately made an error of assuming that as no one had come with him from the old school, that he must be missing *their* company. He may not have understood when I asked him if he felt 'lonely', but he emphasised that what he was referring to was the 'environment' as opposed to the people at school. He was making the comparison as to how different the two school environments were 'I have been transferred to another planet'. I tried to clarify what he was saying but I was unable to use words that explained that I knew what he was communicating. He stated: 'It's just that I feel on

my own'. He was explaining how he was feeling socially excluded. I again made an error when I associated his use of the word 'planet' and my use of the word 'alien'. He shouted at me for getting it wrong. He was emphasising that it was not he that had the problem and his emphasis appeared to be external, to lie somewhere within the environment. He broke away at this point and turned his attention to the photographs.

Whereas I was focused on 'impairment' issues, Jason was reminding me of the 'disabling barriers'. It is my own failing to constantly revert to an impairment focus when I am being reminded by the young people that this is not the focus of their difficulties. This was emphasised again in the following example:

Jason reveals what he first understood by the term 'Disneyland, Paris': "*I thought that Disneyland was like er... their version of Paris, that's why it is called Disneyland Paris.. and I thought they were trying to like .. copy the Eiffel tower*" (Jason Smart – Interview 5, line 101).

Jason is informing me that language is confusing and that there are barriers in place for him, where words have more than one meaning. I compounded these difficulties by creating further barriers in the interview with Jason:

Jill: Was that the ferry to get to Disneyland, Paris?
Jason: No, the one what goes to Dover
(Jason Smart – Interview 5, line 30-31).

I found that it was important to change my interviewing style to ensure that I did not perpetuate barriers in communication with Jason.

Child 5 David Kent

David is a 15-year-old young man with a diagnosis of high functioning autism, who

lives at home with his mother and his older brother. David has a dry sense of humour

and is quite comfortable to laugh at himself:

David: now here's a human knot (laughs)
David 4.8

Jill: (laughs) Yes?
David: It looks a lot like a knot (laughs)   I look very serious there
Jill: Yes you do
David: Dm like 'get me the hell out of here '........ and the next few pictures are of me
and Katy which Rose took but   she took me at all the worse times   I didn't have
time to pose or anything
(David Kent - Interview 4 lines 42- 48)

David attends the South Down's Secondary Modern School. David has a special interest

in Pokemon and one of his favourite characters is Pikachu:

Jill: And if you were then to think of Pikachu in relation to your friends,   where
would Pikachu come?
David: Pikachu would be close   cos he's cute isn't he?
(David Kent - Interview 2, lines 173-174)

Although David has a high degree of expressive language, he still experiences a degree

of sensory hypersensitivity especially in relation to noise in his environment:

Two years ago, David underwent some counselling at the school to help him understand and accept his diagnosis and label of 'autism' and to help him to develop a positive sense of self. David reflects on his understanding of autism after the counselling sessions:

> *'Before I knew about the disability of autism, I wasn't really aware of much at all. I did wonder why I acted a bit stupid sometimes, but I wasn't really thinking much about it. Perhaps people didn't tell me because they thought I wouldn't understand. I also have diabetes so life can be a bummer sometimes.*
>
> *I thought why is autism a communication disorder, if it affects how I behave, not how I speak? Before I knew about autism, teachers were like enemies to me. They threw hard work at me like it was hell or something.*
>
> *When I was first told the name of my disability, I thought what the hell is that. I was confused and angry, as usual. I thought, this would have to happen to me, wouldn't it. I began to realise why people in The Resource behaved a bit differently. Before I knew, I didn't really understand other people and they didn't understand me. Very often, because of this misunderstanding, I got into arguments and fights.*
>
> *There are some good bits about my autism. I get to skip some lessons, especially history, which is really boring. I get to come to this school because it has a special place for people like me. At The Resource, there are people who like me and understand me, or at least they try. I finally have people I can rely on. I guess I may have given up on life because nobody understood me.*

In relation to the 'sensory continuum', David appears to have developed a simultaneous sense of self and other. It is apparent that **The System of Interpretation** requires the retaining of one's separateness from others whilst having a simultaneous sense of self and other. Williams (1998:118) argues that having a simultaneous sense of self and

other is necessary to being able to compare and contrast ourselves with others, whether these are objects, creatures or people. Williams argues that for those who live primarily by **The System of Interpretation** identity is an important concept, but it also leads to a feeling of alienation from others. It could be argued that the effect of counselling about identity and 'autism' has resulted in David developing a positive 'disability rights' perspective in his understanding of autism. He had also developed an awareness of the use of negative and positive words used to explain 'autism'. Yet the counselling and support had been done primarily within an 'impairment' perspective. In the following extract David becomes upset when the teacher continues to use the word 'normal':

> <u>Document 'David Kent', December 2001, section 0,</u>
> <u>paragraph 3, 578 characters</u>
> In a science lesson with David Kent it is 10.04. The teacher is explaining that there are standard cards to test colour blindness and he asks the children in the class if there is anyone present with colour blindness. One child puts up his hand. The teacher goes over to the child and then proceeds to test the child on the colour blindness cards. (The child was not asked if he wanted to do this in front of others, and the whole process starts to feel uncomfortable.) Another child in the class asks the teacher a question and says if Richard had children would they also be colour blind? The teacher explains that colour blindness is carried on the X chromosome, he says if you marry someone normal ..... some girls in the class speak out at the teacher and say: "don't say that, don't say normal, can't you say someone with the dominant or recessive gene?" and David Kent says at the same time "that is so unfair" and looks over at me, as he is obviously offended by the teacher's reference to the word 'normal'. The teacher continues ...... "if you marry someone normal then the children are likely to be normal". The use of the word 'normal' again, is getting David angry, and the girls in the class protest again. David says to me "see if I come to another biology lesson again" 10.07.

David was aware that the use of the word 'normal' was excluding him. He understood that people without a 'label' define themselves as 'normal'. It left him having to consider himself in relation to the opposite of this. He identified himself in relation to 'other', and was offended that this 'other' implicitly meant a category that was *not* 'normal'. The girls in the class were sensitive that some pupils were different and who also related to 'other'. (The whole class had received disability awareness sessions that incorporated an understanding of the 'impairments' of autism, some 2 years previously.)

They appealed to the teacher to use language that would include the pupils who were different. The experience to David was an oppressive one that continued to play on his mind in the following two lessons that day:

At midday we are back in a science lesson with the same teacher
<u>Document David Kent, December 2001, section 0, paragraph 9, 400 characters</u>
12.01 The teacher talks to the class and uses the term 'normal' and this time David shouts out "stop using the word normal". He looks at me and says: 'I hate him using that term'. He looks upset. I bring my chair closer to him and suggest that he may want to talk to Mr Mason about this when he goes back to the learning resource unit.
The teacher continues to teach and continues to use the word 'normal'.
12.06 The teacher says the parents are 'normal'. So they have a gene for the normal gene because they are normal. One of the girls shouts out and says "can't you use the word carrier or dominant gene rather than normal?". The teacher either doesn't hear the girl or ignores her and he continues with his explanation and David continues with his work. The teacher says: 'Part c, what is the chance of the fourth child of also having the disease?' He writes on the board to illustrate, it is either a 3:1 against being normal and David asks me: "Why does he keep using that word?" The teacher continues: 'Part d'. He says: 'When you are ready. Inherited?' The teacher asks the question. David puts up his hand and gives the correct answer and there is too much noise in the class preventing David finishing. The teacher says to the class: 'You need to have respect to listen to David as he gives the answer, I have never known a Year 11 class to be so juvenile'

What was evident from observing the above was that the teacher needed to correct the class for not listening to David as a way of showing the class that he valued David's contribution. The teacher was trying to show that he did not mean anything personal to David by the use of the word 'normal', yet he had not changed his use of this term. David was offended each time that the word was used. I felt helpless as an observer to watch him becoming visibly upset.

In the English lesson, which was sandwiched between the two science lessons, David was still affected by the use of the word 'normal'. There was a quiz in the English lesson as it was the last week before the close of term. David's team finally won the

competition and he turned to me and said: "and who said autism is a disorder?" The boy sitting next to him overheard David say this and added, "and who said ADD was a disorder". David asks: "What's that?" and the boy says attention deficit disorder. David questions the concept of 'otherness' in this statement. From the previous lesson, the use of the word 'normal' had made him feel excluded but all he could relate to was how autism had been defined as a 'disorder'.

David is left with an unsatisfactory situation. He shows that he is competent in the work he does; he also shows how he can contribute to a winning team. He has to ask the question "and who said autism was a disorder?" as the term cannot be explained in relation to his experience. What he had experienced that morning was the continued use of oppressive language. David felt excluded from being a member of a group who identifies as 'normal' and he also felt excluded from an official definition of 'autism' which is defined as a 'disorder'. He himself had began to build a positive sense of self when he received counselling to understand autism. He had come to the conclusion that to understand autism was to understand difference. Yet his experiences showed that the world around him would continue to exclude him not on the basis of difference but on the basis of being seen as of less value than non-disabled people.

The 'sensory continuum' a framework to understanding how the senses relate to the environment, is inadequate to explain the oppression experienced by David. 'Barriers' are not only in place at a physical level in the environment but at an attitudinal level also. It is clear that his experiences show how prejudice and discriminatory practices continue to exist in schools at almost a subconscious level. There were barriers evident in the attitude of the teacher, that served to continue and maintain a lowered sense of 'self-worth' for David. It is clear that to continue to describe David's experiences and

those of others with autism solely against a 'sensory continuum' does not deal with the pervasive and corrosive element of disempowerment that is perpetuated by barriers in attitudes within particular environments. The sensory continuum as a concept has been advanced by two people with a label of 'autism', but this does not necessarily explain the wider social, cultural and political experiences of those so labelled. What it does highlight is the division within the writings of people with a label of 'autism' that a significant contribution of autobiographical accounts promotes and maintains an 'impairment' perspective to understanding 'autism'.

Child 6 Wills Martin

Wills is a 14-year-old young man diagnosed with Asperger syndrome. He lives at home

with his mother and father, two sisters and younger brother. Wills has a pet dog called

Max, who was seen as an important part of the family:

Wills: And there is one of me and Max .. you can keep the actual photo for that one ..
keep one of max and keep one of me
Wills 7.4

Jill: That's lovely
Wills: Max (he calls Max and when Max comes in he shows him the photograph)
Come and take a look.. come and take a look.. its you .. its you .. its you max .. this is
you!
(Wills Martin - Interview 7, lines 70-76)

Wills had received a diagnosis of the label 'Asperger syndrome' just a few weeks before

he had became engaged in the research process.   Wills (unlike David or Phil) had not

received any counselling to help him understand his difference and how Asperger

syndrome can be understood. 'Autism' had not been explained as 'impairment' or as

'disability'. Whereas David had been offended with the use of the word 'normal', Wills

uses it to explain the difference between him and his cousin:

Wills: Oh yes it is ..It's my er Wendy's er oldest son .. er second oldest son
Jill: Oh right
Wills .. Thus that means me and him have a lot in common in looks and in a whole load
of things.. but he's normal and I'm not
Jill: What do you mean that he's normal and you 're not?
Wills: As in he has nothing wrong with him and he can fit in ... he's got social skills and
I don't
 (Wills Martin - Interview 1, lines 150-157)

This lack of confidence and his understanding of himself became apparent in a later interview as being of "less value" than others. Wills was explaining why he would be the best person to help his teacher with a particular school project:

Wills: Ah ah ..... she's seen a lot ...... and I'm the only one with a clear enough head to stay focused for just an hour ... people are a lot more focused than me .. but it is the time period they are ...... I just know how to stay focused a bit longer ... not really focused but I can expand it
Jill: Right
Wills: I'm very self-centred aren't I?
Jill: No .. you just know yourself and you tell people the way it is ....
(Wills Martin – Interview 6, lines 212-215)

He reflected on his own language and he posed a question to me about his self-centredness. This illustrates some awareness and some insight into how others see him. It demonstrates his position of simultaneous 'self and other', in relation to the 'sensory continuum'. Wills had many questions about his diagnosis and he often asked me questions about 'Asperger syndrome'. It was apparent that Wills was searching for information. He was asking questions to aid the development of his understanding of the label he had been given of 'Asperger syndrome'. If Wills had received counselling these questions could be asked and he could be given time for a meaningful discussion on the issues. Wills had been bullied at a mainstream school before for a period of 2 years and this had caused him considerable trauma. He had now been placed at St Francis special school and he had no answers for many of the questions that he had about the 'label', the 'impairment' and the 'barriers' that had led to this point in his life. Such a situation appears to echo the story of 'Larry B' illustrated in chapter 2.

Wills has a high degree of expressive language and uses sophisticated and complex language. This often disguised some of the difficulties that he had in the transition from one environment to another:

> Wills Martin May 2001
> I meet Wills and his support assistant and we drive to Upton Grange High and when we get there we walk down the corridor towards the classroom. As we are walking down the corridor, Wills has a stern look on his face and I ask him if he is okay. He said to me: "there is a lot of pushing and shoving and so I have to put this face on. When I first came here the corridors made me nervous, but now it is okay".

Although it was not immediately apparent that Wills was affected by his environment, when asked if he was okay he referred to the environment and the 'pushing and shoving'. He tells how the environment first made him nervous but that he was okay now. Yet what I observed from watching him was a level of anxiety that was a direct response to the transition from moving from one school environment to another. Although Wills was affected minimally by the impact of his senses in his environment, he used 'touch' with his peers and the adults in his environment. The use of touch for Wills, appears to be a compensatory means of seeking out social interaction with others. It was, however, one of the topics of feedback in his weekly 1:1 feedback session with his teacher:

> Document 'Wills Martin' September 2000' Section 0, Paragraph 7, 212 characters
> I am really pleased that you have been able to put your differences aside and Lesley (support assistant) has said that your inappropriate touching has stopped generally.

The teacher classifies Will's touch as 'inappropriate', yet to Wills it serves a function, serves a purpose in that he has often failed in the past in the use of language as a basis for social interaction. He has a wide vocabulary, but the use of this vocabulary has been the focus of bullying in his previous school. His use of vocabulary at St Francis special school sometimes results in others accusing Wills of being 'arrogant'. For Wills then,

his touch serves a purpose to pursue social interaction as his previous experience with the use of words has often failed.

The difficulties Wills has with his environment gives him some sense of certainty about what sort of home and environment he would like to have in the future:

Wills: Now this is a dream home
Photo 1.12

Jill: Now where is this dream home?
Wills: Right next to my school
Jill: Oh wow
Wills: It has been for sale for quite some time and now its been sold .. I wish I could have been the buyer
Jill: Really and what did you like about this house?
Wills: Look at it! .. It's got a brilliant garden!! I bet the back is beautiful.. it's fully furnished so I wouldn't have to decorate
Jill: hmmm
Wills: Off course I would have to borrow a quarter million .. but it's a 6 bedroom house .. a lounge.. ALL THAT! And plus it is in a very nice area
Jill: Hmmmm
Wills: Where there are very few hoodlums around
(Wills Martin - Interview 1, lines 80-91)

It was apparent that the experiences of bullying had impacted on him sufficiently to express his wish to live in an area *"where there are very few hoodlums around".*

Child 7 Jonathon Frost

Jonathon is a 15-year-old young man with a label of 'autism', (although recently after the completion of the fieldwork, he has had a diagnosis of the label 'Asperger syndrome' confirmed). He lives at home with his mother and father and his younger brother (who also has a label of 'autism'). Jonathon appears to be minimally affected by his senses and the following photograph shows him enjoying social contact with his teacher on his last day at school:

Jonathon: y e s   this is me with Mrs Plant ... hugging each other
Photo 7.23

Jonathon: it looks as if she has been crying.... It was after I had finished the both shows
(Jonathon Frost - Interview 7 lines 253-255)

Jonathon relates to the world through The System of Interpretation and he appears to have acquired a simultaneous sense of 'self and other'. Jonathon's brother, however, experiences the world predominantly through The System of Sensing although he moves between the *sensory* and the *literal*. He appears to be more comfortable in the mode of '*all self no other*' and this is evident in his enjoyment of special interest in light bulbs and travelling on buses. The following photograph portrays his discomfort of touch:

Jonathon: And this next ones Sarah … Sarah ..holding onto Andrew
Photo 7.25

Jill: Arhh
Jonathon: And Andrew looks a bit fed up there
Jill: He does look a bit fed up...because everyone is hugging him?
Jonathon: Yeah .. he must get fed up with people fussing around him
Jill: Do you think he does get fed up with people touching him?
*Jonathon: Yes**...........***
(Jonathon Frost - Interview 7 lines 267-274)

Jonathon attends the Breckon Charter School and although the environment has minimal impact on his senses, he refers to the 'busyness' of the school environment:

Jill: Why do you think that they are all against you?
Jonathon: Well.... pushing and shoving
(Jonathon Frost - Interview 2, lines 79-80)

Jonathon has difficulty in processing information at school. It could be argued that while Andrew (Jonathon's brother) is influenced by the 'sensory continuum', Jonathon is on the 'cognitive' or information processing part of the sensory continuum, as was outlined by Grandin (1995:54). Jonathon reveals that he has a "lot to remember".

"I just feel like ..... nearly all of them are against me..... and also I don't like about the school is ...I've got a lot to remember" (Jonathon Frost Interview 2, line 81)

Certain subjects at school are presented in subjective ways that do not suit Jonathon's information processing (cognitive style). In the Breckon Charter School religious education was a mandatory lesson for all pupils and Jonathon expressed his concerns about his result in this subject:

Jonathon: Well the internal one I did in May .. the RE one was out of 136 and I only got 16 and it was .... I got .. I got unclassified
Jill: But RE is quite hard isn't it?
Jonathan: I know
(Jonathon Frost – Interview 2, line 93)

Although Jonathon has expressive language and could ask questions, he was still unable to gather sufficient understanding to clarify the meaning of 'concepts' conveyed within the Bible and a wider religious education framework. Religious education was compulsory in the Breckon Charter School, but even with support Jonathon failed to gain any level of understanding, and the barriers to learning remained in place. Jonathon needed support for information to be translated for him at a level that he could understand. For this understanding to be developed, the subject matter needs to be introduced at a point where new concepts and meanings can be attached or built upon his current frameworks of reference. For religious education such frameworks were virtually non-existent.

Jonathon explained how he had misunderstood what was required of him in an examination. He had understood the question at a *'literal'* level and struggled to have access to the more subtle cultural knowledge and expectations. The way information is translated or communicated to the young person will greatly impact on the outcome of learning for them:

Jonathon: And the worstest (sic) one was DT, because I thought I could do it .. I thought yes!..I might know em all. I thought they were going to ask us questions like "what is a design proposal?"
Jill: Right..
Jonathon: .. Of three designs ....
Jill: What questions did they ask?
Jonathon: We had to draw three .. a writing ...we had to draw a writing set and put cartoon characters in, one on corner and one above it, for example South Park or the Simpsons.
Jill: Yes .. and did you manage that then?
Jonathon: Not very well
Jill: Mmm
Jonathon: And it was out of a 100 and I only got 9
(Jonathon Frost – Interview 2, lines 97-105)

Jonathon is good at the subject data transmission (DT) but he tells me what he had expected the questions to be in his exam. He had understood exam preparation in a *'literal'* way in relation to the 'sensory continuum'. Because Jonathon had expressive language it would appear to the onlooker that he had processed the information required and is as prepared as his non-disabled peers. How well an individual with a label of 'autism' does in an examination, is more likely to reflect the level of preparation, the amount of translation and the checking of social understanding of a particular individual. A lack of such support systems, will only illustrate that the information was not processed sufficiently. A poor examination result, when there has been no support, will not reflect an accurate measure of competence of the individual.

Whereas young dyslexic people are compensated for their information processing styles, this is a not an expected standard of practice for people with a label of 'autism'. Jonathon often had a support assistant around him who provided 'support' yet nowhere was this support specifically focused to explore ways in which to translate information provided (expectations) and to communicate this to the person (in their particular communication style). A failure to attend to the detail of the 'quality' of support may

result in the young person becoming anxious and stressed and the support assistant failing to understand why this is occurring.

Being able to achieve is important for those who experience the world from **The Systems of Interpretation** and from **The Systems of Sensing**. Jonathon Frost, however, is similar to David Kent in this instance where being able to compete and to win is important to him:

Jonathon: It's like when I go bowling I want to get the highest score of the game
Jill: Oh yeah yes you go bowling, you go canoeing don't you, so there's lots of pictures you could take
Jonathon: The highest score I ever got was a 141
Jill: That's a great score
Jonathon: I remember once I actually got three double strikes
(Jonathon Frost – Interview 5, lines 55-59)

Williams (1998) argues that people with a label of 'autism' do not experience loneliness until they step into **The System of Interpretation**. For Jonathon this was an experience he reported and this will be discussed further in Chapter 6. Williams argues:

> *'It is perhaps equally little wonder that the greatest emotional plague faced by those who live primarily by interpretation is a loneliness that cant be shaken off'* (Williams, 1998:112).

Jonathon does not appear to have a 'special interest' as such, and this is a disadvantage for him in that he does not appear to have a focus for his time. He is preoccupied with the need to develop friendships and often expresses his frustrations as regards his few friends.

Child 8 Charlie Hill

Charlie Hill is a 16-year-old young man who lives at home with his mother and father and his younger sister. He attended South Down's Secondary Modem School for half the duration of the research and then went on to study retail at college. Charlie enjoys walking and he describes the type of environment he likes to walk in:

Charlie4.18

Charlie: (pauses) And that's a bit of the paths .. where I like my quiet .. I like walking on the paths

It soon became evident that Charlie has more information-processing difficulties than he has sensory difficulties on the 'sensory continuum'. Charlie is resourceful in that he creates compensatory ways to process information to overcome 'barriers' around him. For example, while walking, Charlie tends to have 'visual' landmarks to help him identify where he is in relation to one of his regular walks near his home:

Charlie: Yes .. my mum likes me to walk along the right side
Jill: Yes .. that is a very small road
Charlie: And that's looking at a house ... where there's a dog .. I like looking at dogs .. I tend to ... as I walk across the road going up towards Sprout Lane .. look at that house

Charlie: I usually have that house to look at to remember where I am
Jill: oh really? Excellent
(Charlie Hill - Interview 4, lines 82-87)

Charlie experiences similar barriers to James, when he has difficulties remembering certain types of information and so he also uses aids to help him in this:

Jill: Yeah .. you have something called 'remembering'
Charlie: Hmmm .... That's remembering things to do ....
Jill: And do you find you stick to it every day .. in terms of ticking it?
Charlie: Hmmm I have only tried it for this week., so
Jill: Right.. so what did you have before you had that Charlie?
Charlie: Erm .... I just didn't have that before that .... I still have the notes to remember what I had before..
Jill: Oh I see so this is like a development on the notes you had to remember?
Charlie: Hmmm
(Charlie Hill - Interview 5 line 347-357)

As well as a 'tick chart' for 'remembering', Charlie also uses a calendar. There are times when Charlie refers to the difficulties he has in information processing and appears to be suggesting he experiences 'information overload':

Jill: So when you are at school relaxing.. what are you thinking about then?
Charlie: Usually about school and about sort of occasionally when things get too much for me and I get stressed and it's usually often when I'm thinking of lots of things at once so ... I try and relax from that
Jill: And are things stressful at the moment at school?
Charlie: Eer.. not at school ... now.... it used to do
Jill: And at College?
Charlie: It's not so much stressful.. but when I've got to concentrate on lots of things at once
(Charlie Hill - Interview 8 line 148-157)

Reference to thinking time emerged when Charlie revealed he thinks about the days

events whilst lying on his bed:

Charlie: And that's a picture of the bed ..saying I like to sit and think on the bed
Charlie 8.18

Jill: Cos those times are really important aren't they?
Charlie: Hmmm
Jill: What time of the day do you like to think most?
Charlie: It's usually night times ... usually when I'm in bed
Jill: Yes
Charlie: I have a long think
Jill: Yes   and what sort of things d'you think about?
Charlie: Probably football   things that people have said to me and ...what I like ... I
tend to think about what people have said to me and think ... my opinion and then
compare it.. what they said to me and my opinion
Jill: And do you ever think about what you would have liked to have said in the day
time?
Charlie: Yes
Jill: And does it help you to think about how you will be the next day?
Charlie: Think about the future .,. yes

Charlie experienced barriers in understanding social rules and social roles and he

devised a system to help him overcome this. He developed a system called "Pleasure

Life" that not only helped him to understand social and cultural rules, but this intricate

system was developed to enable him to enjoy his 'special interest' in football.

Charlie Hill explains in his own words how he managed to make the transition from the

'literal' to **The System of Interpretation.** He explained: *"Got a bit confused and so*

thought I would make something up". Over the period of the research year, Charlie

explained how the creation of his "Pleasure Life" was a way in which he could

understand what was going on in the world around him. This appears to document the process of Charlie developing his sense of *'simultaneous self and other'* in relation to the 'sensory continuum':

Jill: So Charlie where did the idea come from for the Pleasure Life?
Charlie: I kinda got a bit confused with life, so I thought I might make something up so I came up with a pleasure life .... erm .... Not on that one (Charlie picks up a sheet of paper) I've got one like that, I've got lots of copies because I really like it ...... erm ...... er .. oh here we are ... there ..... (he hands me a piece of paper which is two A4 type written sheets) ...... you might not understand ....
Jill: Hmmm .. do you want to talk me through it?
(Charlie Hill – Interview one – page 2)

Charlie explained that he had developed a system by which he could understand the different roles/jobs that people had:

Charlie: Well I kind of have a Pleasure Life that I have like my own little world and I have like the 'Pool People' and the 'Main Job People' and they sort of like ... if you think there's a lot of people in life ... erm ... there is the Pool people, but there's 22 Main Job People .... And I've got a list of the main job people ... erm .. shall I show you?
Jill: Yes please
Charlie: Yeah .. (small laugh) .. and this is where I keep my pleasure life things and stuff (Charlie produces a basket onto the bed that is filled with lots of typed up paper and notes).
(Charlie Hill – Interview one – page 1)

What Charlie had done was to devise a system within his Pleasure Life to group people of different occupational status and this was done as follows:

Charlie: Well ..... erm .. I've got a bus driver, which is any vehicle driver, that I sort of like .... just like ... and then want to do .... Erm .... Any minibus driver ..... I have put that twice because they mean different things .... The first one means to take anybody to school
Jill: Okay
Charlie: And erm .. the other one means to take anybody anywhere
Jill: Right ... yes
(Charlie Hill- Interview 1, page 2)

Charlie appeared to use the "Pleasure Life" system to help him cope and adapt with change. For example as he came across new experiences and new people, he had incorporated and classified them within "Pleasure Life". This he had done with the workers at the local SPAR supermarket where he was attending for work experience.

Charlie's "Pleasure Life" also served as a leisure activity, as a 'special interest'. This leisure activity enabled him to develop his interest in football and to play and re-enact football matches that were either real matches he had watched or part of his pretend football rallying. Charlie is a Sheffield Wednesday fan and he often goes to football matches. He likes to listen to the football scores and likes to watch the matches on TV. The "Pleasure Life" then extends the whole concept of job roles within the football profession. Charlie used the opportunity of having a camera (throughout the research project) as a way of creating scenes of his football matches and photographing them. He categorises them as Main Job People:

Charlie: Yeah .. erm .. then there's the other Main Job People ... erm in teams .. the England Team have Sebastion the Crab, David Seaman, Big Dog, Tim Flowers, Bobby Charlton, Rupert Bear, Terry Venebles and Glen Hoddle
Jill: Right so you have given Glen Hoddle a place there?
Charlie: Yeah hmmm .. and then there is Newcastle United which is Kevin Keegan and then I've got the commentators, Barry Davies, Peter Joy, Ron Atkinson, Brian More and Rob Palmer
(Charlie Hill- Interview 1, page 5)

For Charlie it is important for his "Pleasure Life" to stay the same. He can create his own rules for the Pleasure Life and feel safe that these will not need to change:

Jill: Do you think it [Pleasure Life] might change when you leave school or when you do other things?
Charlie: As I have made it up ... no
(Charlie Hill- Interview 1, page 6)

Charlie can be in control of everything that happens in "Pleasure Life", even to the extent of either awarding pool people for their achievement or paying them a wage.

The control Charlie has over "Pleasure Life" obviously gives him pleasure and satisfaction. It was important for me to find out exactly what Charlie got out of taking part in developing and maintaining this interest:

Jill: What do you get out of doing this when you are giving them their money?
Charlie: Er it gives me pleasure, it makes me feel happy yeah
(Charlie Hill - Interview 1, page 12)

Charlie is under no illusions about the role that such a system has in his life. He provides evidence to show how he has moved to from the *'literal* to **The System of Interpretation.** He does this by explaining how he differentiates between the concepts of 'pretend' and 'real' in relation to Pleasure Life:

Charlie: (pauses for 6 seconds looks at next photo) And that's ....sort of saying about two things.... That I enjoy that ...big globe and the little globe and it's also to say that there's things in pleasure life that exist and don't exist and I'm sort of aware that things don't exist but I don't picture that in my mind and the things that do exist are what I am actually doing ... like this (the interview).... Like reality

Charlie 8.13

(Charlie Hill - Interview 8, lines 192-201)

Charlie was clear that he had started his Pleasure Life (with the aim of understanding job roles) in 1996, and that in his words he had been 'a bit confused', the development of his football league had different origins:

Jill: This is amazing Charlie, it is wonderful, so what do you think it was about 1996 that made it all start?

Charlie: Erm ... I don't know ..... I just sort of like ... that was the year that I just did it really, not sure that anything really came up for me to do it, it was just when I wanted to do it

Jill: Nothing prompted you at school?

Charlie: No .. that was when I did have Year 8 an in PE. I was finding that difficult and I was wanting to find the results of every game and I didn't get them so I think that's what got me into getting this pleasure life, to sort of like ... solve the problems of that .. to get better

(Charlie Hill- Interview 1, page 8)

It became apparent that when Charlie doesn't use the figures, his interest in pretend football rallying comes out in other ways. He explains the difference between actional games, finger games and games in his head:

Charlie: The things like the TV matches have just been here but the whole point of actional matches was to do it outside..... I do do actional matches in here .. but very rarely

Jill: Hmmm and that's when you use your fingers and thumbs?

Charlie: They weren't really called actional matches they were finger matches cos .... the fingers weren't actually the players .. they were my fingers but I used them as like.. often like the players ... so I imagined them as the players

Jill: So actional means doing it .. being out there and playing

Charlie: Yes and games in me head ... would be imagining them in my head

Jill: Hmmm

Charlie: Thinking about them .. yeah

(Charlie Hill – Interview 7 lines 224-236)

The actional games featured more for the first time in interview 7, then in the last interview and coincided with a drop in portraying the figures in pretend football rallying:

Charlie: Yeah ....so that's saying ..... I call it actional if I am doing it as normal
(Charlie Hill – Interview 8 lines 124)

He explains playing football with his fingers:

Charlie: It's become a habit now
Jill: Yes ..... what's become a habit?
Charlie: Playing football with my fingers
Jill: Oh has it? so erm .....is it a problem or is it what you do and you enjoy?
Charlie: Yeah its just :... I enjoy it
(Charlie Hill – Interview 7 line 83-97)

Even though Charlie invested a lot of time in football rallying, he was still up to date and informed on the progress of the team he supported. He was clearly following his football team in much the same way as his peers would be and the following picture and account illustrates how much he identifies with his football team:

Charlie (looking at the next picture) That is a picture of me.. as I am myself
Charlie 5.6

Jill: And this is your Sheffield Wednesday shirt ...
Charlie: Hmmm that I've got on now.. cos I like Sheffield Wednesday yeah
Jill: And how are they doing at the moment Charlie?
Charlie: Not very well.. they haven't won yet
Jill: Oh no ... oh no!
Charlie: (laughs) They are in division one.. they've drawn one and lost one..
Jill: So it's very shaky at the moment.. about their future
Charlie: Hmmm I have a fixture list of who they are playing ...and they are playing Grimsby away today
Jill: And how do you think they will do?
Charlie: I think they will win against an easy team like that
Jill: Yes
Charlie: Hmm
Jill: And when will you hear the results? Its tonight about 5 o'clock isn't it?
Charlie: Yeah ... yeah
Jill: So what do you think they need to do to get themselves better?
Charlie: Erm .. they need better players but they haven't got the money
(Charlie Hill - Interview 5 lines 112 - 130)

The above dialogue demonstrates how closely Charlie follows his team and illustrates the knowledge he has of the football league. He is able to give a guess at predicting an outcome in relation to his team and he justifies his prediction by saying 'I think they will win against an easy team like that'. He is also able to give some evaluation on what the team needs to do to better themselves. He identifies that they need better players but also suggests that they have not got the money for this solution. An observer, listening to Charlie, would not have any inclination that another side of Charlie is just as important to him. This is his pretend football rallying which stems from his "Pleasure Life".

Pretend football rallying is more than just a leisure activity for Charlie. It is also linked to the way Charlie sees the social and cultural world around him. Pretend football rallying reflects Charlie's deeper worries about social issues like 'change':

*Charlie (small laugh) Er that's saying about organisations   and organisations were that things had to be in that way   and if they changed I'd worry a lot about that...
so   pretend football rallying is an organisation*

Charlie 7.6

Where Charlie has control over pretend football rallying he is able to resist change:

Jill: That's quite a score isn't it 27 goals to 13 wow
Charlie: Yeah... the balls went in very quickly ... in the goal
Jill: Yes .. yes I think they are probably going to sack their goalies aren't they?
Charlie: (Laughs) Hmmmm ... they don't sack goalies in the jobs they keep the same jobs .. They don't change the jobs .....
Jill: It's not then like the real Premiership then because they would sack them wouldn't they?
Charlie: But with this one no .....keep the same jobs...... we don't change them
(Charlie Hill – Interview 7– lines 370-375)

It appears that "Pleasure Life" acts as an anchor or perhaps more of a vehicle or a tool to help Charlie interpret social and cultural concepts and thereby enable and enact his maintenance in **The System of Interpretation**. Equally it could be argued that "Pleasure Life" is a strategy devised to overcome the 'barriers' that Charlie faces in understanding social roles. Such barriers caused him to, *'get a bit confused with life'* and he found that in year 8 *'in PE I was finding that difficult'*. "Pleasure Life" and football rallying had made a difference to Charlie's life. Both were created by him not for him and served a purpose in breaking down the confusion caused by barriers within the environment.

Child 9 Kevin Scarborough

Kevin is a 15-year-old young man with a diagnosis (and label) of 'Asperger syndrome' (More recently this diagnosis has been changed to high functioning autism).   Kevin lives at home with his mum and dad and older brother (who also has a label of 'autism'). The following picture shows Kevin (on the left) interacting with his older brother at a family celebration in the local pub:

Kevin 6.18

Jill: Do you get on with him?
Kevin: Sometimes but when he comes in my bedroom **...**
 (Kevin Scarbrough - Interview 6, lines 72-73)

Kevin is developing a simultaneous sense of 'self and other'. He relates predominantly to The System of Interpretation while his brother relates to the world predominantly through The System of Sensing. His special interest is inventing slot machine games and he enjoys playing on them to generate ideas for these inventions.   He reverts to the sensory numerous times throughout the day and it appears that it acts as a way of relaxing and unwinding from the stresses of demands placed on him in The System of Interpretation.

Kevin attends both St Francis Secondary School and the local mainstream secondary school. The latter is for one afternoon a week to undertake a GCSE in art. Kevin likes

drawing and designing arcade games, so he enjoys visiting places to look at arcade machines and this generates ideas for his designs. He drew a picture for me and this was discussed at one of the interviews:

Kevin: Yes ..do you remember that picture I gave you?
Jill: Yes I have still got it and will treasure that picture it is lovely
Kevin 3.8
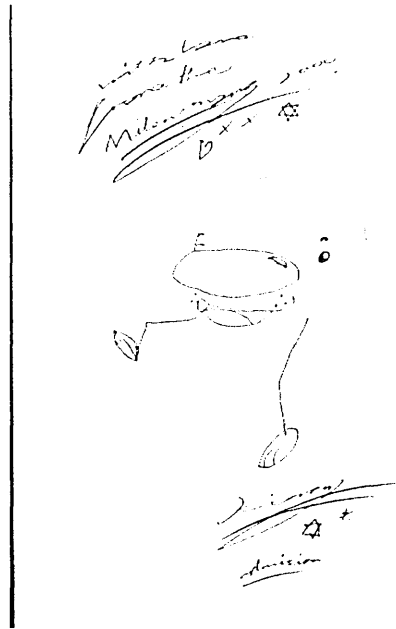
Kevin: I have a game I have invented with that
(Kevin Scarborough – Interview 3, lines 113-117)

Kevin has difficulties in his transition from one environment to another and this is a particular challenge for him when he has to leave St Francis Secondary to attend the mainstream school for his GCSE art class. He talks about the 'panic attacks' he sometimes has when trying to undertake journeys to various places:

Jill: Yes ……how do you manage to cope with those panic attacks?
Kevin: Erm hold on to my mum
Jill: You hold on to her ….are there any other ideas that may help at those times
Kevin: I don't know ….. when it happened the other week ….I had to sit on the chair
Jill: ………Do you ever feel panicky at school
Kevin: Erm ..when I'm going to Upton Grange High.. I would like to have my own business actually .. but I don't know what to do … know what I mean?
Jill: Hmmmm
Kevin: And I'm like such a mess ….
Jill: So have you talked to your teacher about this?
Kevin: No
(Kevin Scarborough – Interview 2, lines 196-224

Kevin was worried that such panic attacks could have an impact on what he wants to do for the future. He describes the need for physical support in this environment but is unable to communicate his need for support to those around him.

What Kevin revealed was a sense of fear. In a later interview he talks about the headaches and the stress that can result from these experiences:

Jill: You said that you had a headache was there anything in particular that gives you a headache?
Kevin: Stress
*(*Kevin Scarborough – Interview 5, lines 66-70)

Another contributory factor that may add to Kevin's stress is that he is particularly hypersensitive to noise:

<u>Document 'Kevin Scarborough' December 2000' Section 0, Paragraph 1, 224 characters</u>
When Max shouts, Kevin covers his ears, we are in the hall for the Christmas play rehearsal and I wonder if it is the acoustics that is making the sound painful for Kevin

Friendship is important to Kevin and in his last week of school, he took a range of photographs of his friends. He talked about one of the girls 'fancying' him:

Jill: What do you think of Ann?
Kevin 6.41

Kevin: Ann fancies me
Jill: Does she?
Kevin: That's why she's always there
Jill: And what do you think.. do you fancy Ann?
Kevin: I like her as a friend

Kevin is ambitious and he is always inventing new games. He plans to have his own business. It is the barriers within the environment that appear to cause Kevin his stress and fear. Yet it was evident that he would not automatically initiate a discussion about these concerns with those at school. Kevin was being disabled by his environment yet it was the same environment, that disabled him from communicating about these concerns.

Child 10 Anthony Garrett

Anthony Garrett is a 14-year-old young man who attends South Down's Secondary Modem School. He is a sociable young person who enjoys being around others. He particularly likes to have friends and may check out with others if named individuals like him. Anthony likes to have fun and enjoys playing a joke on people around him when he is feeling relaxed and happy. He took the following photograph of himself when he was asleep:

Anthony 5.11

Anthony: (laughs)
Jill: Are you laughing at the picture? Is that you?
Anthony: (laughs) Yes
Jill: What are you doing?   what are you doing there?
Anthony: Asleep
Jill: Who took the picture?
Anthony: I did
Jill: How could you take a picture of yourself while you are asleep?
Anthony: Laughs
(Anthony Garrett - Interview 5, lines 100-112)

Anthony lives at home with his two younger sisters and his father. His mother left the family home 6 months into the research project. Anthony experienced high levels of exposure anxiety throughout the duration of the research and this anxiety was directly correlated to the level of stress and change in the environment. When his anxiety levels

were particularly high, he would sometimes be physically sick on the journey from home to school.

Particular voices and intonation affect Anthony and it appears that he is hypersensitive to noise:

> Document 'Anthony Garrett' 26 March 2000 Section 0,
> paragraph 16, 120 characters
> The issue of noise is something for Anthony, as we came into the main
> building a girl screamed and Anthony said quietly: "don't scream"

Anthony enjoys spending time on the computer: he is able to communicate more freely and fluently through the computer:

> *Jill: Ah yes that's great .. now do you like to spend time on that computer? [Referring to one of Anthony's photographs]*
> *Anthony: Yes*
> *Jill: Yes? .. what sort of things do you do on the computer?*
> *Anthony: I like to write German*
> (Anthony Garrett – Interview 2 lines 6-9)

It was through the use of the computer that Anthony gave me some feedback on how he had felt about being engaged in the research process. He was not asked to provide this information, but he was in a room with a computer available whilst I was busy writing up some notes. It was only after he wrote the piece and printed it off that I was aware of what he had written:

> *The very first time I met Gill was in February 2000.*
> *I knew Gill as a camera lady who used to send me cameras to take photographs and once I have finished with the camera, Gill used to come and collect the camera. And then in a few days time, Gill used to come round to my house and this was before my mum left.*
> *Gill used to come round to my house and she used to show me the photographs I've taken and she had a tape recorder so that I card [sic] explain on the tape recorder to Gill what those photos are.*
> *So after Gill had finished with the tape recorder, she used to give me another camera to use. This is how I started to know Gill.*

For Anthony it was important to ascribe me a tangible social role. I became the 'camera lady' and I became known as associatied with the blue disposable cameras. Anthony processed information in relation to landmarks. He was likely to connect visual landmarks to people:

Jill: Why do you like Simon so much what is it about him?
Anthony: He looks nice with his hair
Jill: And what sort of things does he like to do?
Anthony: Er .. on the computer
(Anthony Garrett – Interview 6, lines 35-38)

Anthony's special interest was 'friendship' and he spent much time and effort trying to secure friendships with named individuals, but it was often overwhelming for the individuals who became the focus person. (This is discussed more fully in chapter 5.) Anthony got a lot of satisfaction from chatting about the people in the photographs. Many of them were people he had chosen to be photographed with and many of them were described by him as 'friends':

Anthony: This is just me and my friend Simon on the computer
Jill: Oh lovely
Anthony: That's Dave, Tim and there's Kevin
Jill: What are you doing on the computer .. are you playing a game?
Anthony: Watching
Jill: Who or what are you watching?
Anthony: Simon
Jill: Right
(Anthony Garrett – Interview 7, lines 201-208)

In relation to the 'sensory continuum' it can be argued that Anthony is at the stage of simultaneous 'self and other' and he lives his life predominantly in **The System of Interpretation**. Although Anthony has not ascribed the concept 'lonely' to himself, he was often observed to experience social exclusion from peers at school, who were the ones he recognised as his 'friends'. This situation is discussed further in chapter 5.

(Simon third from the left)
(Simon Sands - Interview 6, line 52)

Simon is a 14-year-old young man who lives at home with his mum and his younger brother. Simon is very quietly spoken and likes to take time to respond to questions asked of him. He has a delayed information-processing style that sometimes makes it appear that he doesn't know the answer to questions asked of him. Hebecomes frustrated by delayed information-processing and can often be seen watching others to mimic their answers and responses to situations:

> Simon Sands September 2000
> **'Where is your skull she asks?' Simon copies the other children as they all point to their heads and she says: 'This is what it looks like when you take your skin ofiP She makes the jaw go up and down and Simon mimics this movement with his own jaw.**

It is easier to copy peers than to process the information for himself. For Simon, it can take an average of 3 extra seconds to process information compared with his peers. Because of this extra time he seems to have adapted a strategy of copying his peers, so he gives the impression that he is always slightly behind and is passive in the way he presents himself.

After Jack hits his drum, Simon copies, it's as if he needs a prompt. They play the drum, Simon is able to copy the beat from Steve and he is happy to do this. He is smiling. He almost needs someone to be able to copy the beat from (almost a need to mimic). He likes to play the drum and he can follow Steve's lead and he looks over and follows him. Its like Simon gets stuck without having a person he can copy from to move on

Simon's delayed information-processing style becomes more apparent when Simon is required to take part in a group session or work with a partner, his information processing-difficulties become more apparent. In the following extract Jake (a child with 'learning difficulties') takes the lead in the partnered activity and interprets Simon's delayed information-processing style as incompetence:

Simon Sands April 2001
Sam (the teacher) comes over and says: 'You have missed a letter out'. She asks Simon: 'Points to which one it is'. He says a 'y' and Jake is surprised, but Simon knows. Sam says to Jake: 'You need to believe Simon when he is telling you what the next letter is'. Simon is quick on the computer and manages to type the letters in quickly and he says: 'go on' to Jake in a quiet voice

There are occasions when the teacher prompts the children to let Simon think:

Simon Sands November 2000
Marcia says what could it do to you, "why would you need matches Simon?" Another child is keen to answer the question and Marcia says "Let Simon think" …….. er …. Er……. Er he then says "to light a fire".

Marcia is a teacher who studied 'autism' at a post-graduate level and her understanding of barriers to learning, enables her to ensure that barriers do not prevail to exclude Simon. She adapts her teaching to a level that is suited to his information processing style. On another occasion, however, a different teacher (new to the school with no previous experience of teaching children with a label of 'autism'), is unable to pick up that Simon is trying to initiate communication with him:

Simon Sands November 2000
He tells me on the way to the Spanish lesson that he will tell the Spanish
teacher, that Russell will not be able to come to class. When we are in the
class, Simon makes an attempt to tell the Spanish teacher, but he can't find
the words. While taking the register the teacher calls: 'Russell?' (looking
around the class). After a second Simon says in a quiet voice: '... Russell'.
.... He is just about to say that he is not here when the teacher continues
with the register ...... When the support assistant comes in the teacher
asks her where is Russell and she says he has gone to the dentist. Simon
had so much wanted to communicate this to the teacher.

During the period of the research Simon, however, was observed to be quite astute in

some situations and he demonstrated a level of competence and ability in his work that

would not always be apparent to the observer watching him in a shared group activity.

When Simon worked against himself he appeared more relaxed and more confident

particularly when working on the computer. The computer appeared to suit his

information processing-style as he worked at his own pace:

Simon Sands February 2001
Simon is on the computer. 2.19 He is clicking on different types of music.
The music changes and he starts to clap his hands with the beat just ever so
slightly and then he mimics playing the drums to the drumbeat and looks
at me and smiles. So he is able to identify a drum from a drum beat! he
changes the colour and the music 2.24 And again he changes the music,
he likes to change the music and he tries to turn the volume to hear it, he
changes the music and puts his head close to the speaker. 2.26 He clicks on
to change the music every 2 – 3 seconds. He likes the strong beat, bass
beat, a reggae rhythm. He leaves that on for at least 10 seconds, then he
hears a drumbeat and mimics the sound of the drum by pretending to beat
on an imaginary drum

Simon's information-processing delay may be hampered by a hypersensory sensitivity

to hearing. In one of the interviews, Simon gave a clue that he may be able to hear

more acutely when he referred to the ticking of a clock in the town centre:

Simon: That's the clock
Simon 4.11

Jill: Oh yes .. the clock again   it's beautiful ... what is it about the clock that you like?
Simon: Er ..I like it when it goes click clock, click clock (as he mimics the sound of a clock ticking with his mouth)
(Simon Sands - Interview 4, lines 92-95)

In relation to the 'sensory continuum', Simon appears to experience more 'cognitive' and processing difficulties as opposed to more 'sensory' difficulties. His hypersensitivity to noise may simply be that he has processing difficulties in relation to white noise which has been identified by Delacato (1974) and defined as 'internal interference'. Simon also appears to have developed a sense of simultaneous 'self and other'.

Difficulties with information-processing were more evident with some of the young people than others. These included Simon, Jonathon and Charlie. Those more affected by **The Systems of Sensing** were James, Andrew, Phil and Jason. Those who appeared to be able to switch from **The Systems of Sensing** to **The Systems of Interpretation** were Kevin David and Wills. Anthony and Jonathon appeared to be in **The System of Interpretation** and would sometimes struggle with the feelings of exclusion and alienation from their peers.

Information-processing difficulties were directly related to the environment that the person was in. Many of the young people had developed a trust in their home environment; they had 'landmarks' around them to alleviate any anxiety and they often had memory aids, e.g. in the form of a calendar. They also had translators in the form of parents and siblings. When they moved from this secure environment without support from someone they knew and trusted, the person could become disabled by barriers in a new or different environment.

James and Andrew tried to understand the social world through the subject of their special interest. They often had difficulties understanding what was 'real' and what was 'pretend', as there was often a lack of information and support in their environment to help them to see the significance of the social world. They often lacked the words to initiate communication with others, although they both enjoyed social interaction. They would sometimes use stock phrases from videos as social openers to communicate with others. This was not always received as a social opener, as a way to initiate social

interaction. Sometimes the words were repeated back to them, thereby closing the opportunity for a dialogue to develop and presented a barrier to social interaction. Although there were differences in the way the young people processed information, they were all enabled or disabled by responses in their environment. Marcia was able to continue a dialogue with James on the subject of his special interest, which resulted in the continued engagement of the young person in the group task. Others, such as Jason, David, Phil and Andrew were significantly distracted by the bombardment of information on their senses from the immediate environment.

Phil, David and Wills all had quite high levels of expressive language, yet they all used words that they were sometimes unsure of the meaning of. Adults sometimes used expressive language with the young people yet there were times when the person did not understand the social relevance of the task. When the young person's special interest was used as a way to teach a new skill or task, this often resulted in an increase in motivation.

Philip, Jason and Andrew found that their senses were often bombarded when they changed locations and environments. Both Phil and Jason sometimes experienced 'sensory overload' and this impacted upon their ability to learn. Charlie gave clues to how the experience of 'information overload' affected him and how he needed to think about what had happened while he lay on his bed at night.

Charlie and Anthony tended to use 'landmarks' to help them connect to their environments and this aided their ability to process information. Jonathon needed further guidance to help him develop 'landmarks' in a revision strategy for his GCSE

examinations. He felt he had a reasonable grasp of what was required of him, yet he was unable to 'translate' the questions asked of him in the exam.

Jason and Jonathon found it difficult to process a large amount of information at one time. Philip, Wills and Kevin found that the environment can impact on their senses to a degree where learning is impaired. Simon experienced information-processing delays. All the young people are disabled in relation to the way the environment and the support is often *not* adapted to suit their individual information-processing style. If the barriers that exist to cause the information-processing difficulties were to be challenged, then access to learning opportunities would increase. This became evident throughout the research.

The young people were able to overcome some of the barriers in relation to their differences in information-processing. This was particularly evident with Charlie and the creation of his ingenious "Pleasure Life", that helped him to develop an understanding of social roles. Memory aids in the form of calendars were popular with Charlie and James and the computer became a useful tool for Anthony, Jason and Simon to enable them to learn at a suitable pace.

An 'overstimulating' or 'understimulating' environment

For the young people and others with the label of 'autism', it is important for the environment to be balanced sufficiently to stimulate and enable concentration. Some environments can be "understimulating" whilst others can be "overstimulating". An environment that is understimulating can cause the person to disengage from the task in hand and revert to relating to the world at a sensory level. There is the risk that the person can become 'dis-engaged'. This became evident when David, Kevin and James

would immerse themselves in drawing their subject of 'special interest' at times when there was no structure to their learning. They may revert to the 'sensory world' and resort to using comforting self-stimulatory behaviours. Andrew used his arms and became animated in the re-enactment of his favourite video scripts.

Jason, Phil, James, and Andrew can, however, just as easily become 'lost' in their environment if their senses are 'flooded' or 'bombarded'. Williams (1998:21) argues that "slipping out of gear", under various degrees of stress or overload, means that people slip from the *significant* back to the *literal* or further back to the *sensory*. Williams (1998:21) describes this experience: "When we slip back we may find ourselves helpless in a system we left behind before we'd mastered it as a usable and cohesive system". This process of 'slipping out of gear' is clearly identified:

> 'I seemed to be heading towards shutdown .... I blew a fuse ....
> yet I looked at my publisher and named her, I felt I could trust her. She
> hadn't freaked out. She hadn't run about like a mad hen. She hadn't gone
> into verbal blah-blah-blah, making overload worse or forcing
> disassociation. She hadn't slapped me trying to make me "come back".
> She just stood there waiting for me' *(Williams, 1994:152)*

Sensory Hypersensitivity

This research found that the young people were more likely to be hypersensitive to sound than hyper or hypo in relation to any other of their senses. David found some sounds distracting and this affected his ability to concentrate. Also, Phil found some noises distracted him from doing his work. James was sufficiently hypersensitive to noise which led him to putting his fingers in his ears several times during a school day and at other times he would shout for people to be quiet, bury his head in his jumper or want to leave the room. Kevin found some noise painful. Noise was not an issue for Charlie, although he made reference to 'liking his quiet' and Anthony asked others to be quiet. Although hypersensitivity to sound was evident for the above throughout the research process, it was not raised as a specific issue in the provision of support to the

young people. There was no assessment for sensory hyper or hyposensitivity. Bogdashina (2001) describes the assessment tool to identify an individual's sensory sensitivity. Every person with a label of 'autism' will be different in relation to how his or her senses relate to the environment and thereby how barriers in the environment will affect some people and not others.

Some people find touch painful or aversive. Others will seek out touch irrespective of who this might be or the relationship they have with that person. In relation to touch, all the young people involved in the research felt differently about this, but for all of them, what was important was that touch had to be on their terms.

The challenge with accepting touch on the terms of the young person is that they themselves set the boundaries of what they feel comfortable with, not in relation to what is safe, what is appropriate or what is acceptable. I felt uncomfortable with high levels of touch at St Francis special school particularly with attempts by Andrew to kiss me:

> Document 'Andrew Jones' 13 June 2000' Section 0, paragraph 3, 574 characters
> 10.00 He did surprise me as he kissed me at the end of the last lesson
> 10.03 He read a book to me and I said: "you read well". He wanted to read another book to me and I said: "you can read that one by yourself". But he kissed me on the cheek after reading the first book and he had kissed me when I came into school............ He held my hand and said: "let me kiss you". I said "it was not so good to do this". But he replied: "just one" and told him that he had given me two kisses already. The bell went for lunch time.

My own discomfort was perhaps more of a reflection as to what messages it gave Andrew about the closeness and intimacy of such contact between a teenage boy and an adult. If I were seen by him to comply and to be pleased with his interaction with me, I would be sending him a message that such behaviour is acceptable. My own analysis of the social contact was to understand this behaviour from within a wider social world and

the potential for abuse. The teachers within the special school appeared to have accepted the levels of touching in the school and it was apparent that not only were levels of touch acceptable where they would *not be* in mainstream school environments, but touch was actively encouraged on some occasions:

> <u>Document 'James Frazer' May 2001' Section 0, paragraph 1, 1825 characters</u>
> Sam Clarke (a child with a label of autism) says to James Frazer: "your mum will smack your bottom" and James Frazer goes to Foster Allen (teacher) and says "James Frazer will get angry", James goes up and puts his arms around Foster and Foster says: "James Frazer is giving me a big hug".
>
> <u>Document 'Kevin Scarborough' 15 November 2000' Section 0, Paragraph 3, 197 characters</u>
> Period 2, RE we came over to residence for RE and on route we meet Pam (residential social worker) from residence and she says to Kevin: "It's Kevin's birthday and he is sweet 16 and never been kissed!" and she kisses him on the cheek
>
> <u>Document 'Kevin Scarborough' 15 November 2000, Section 0, Paragraph 11, 69 characters</u>
> And James is stroking Chloe's face and hair (support assistant). She doesn't correct him.

Within the special school there is much more of a 'touching' culture compared with the mainstream schools. During the course of a year collecting the data for the research within the schools, touch was discussed once in a session with one of the young people at the special school. But as the culture in this school was one of an acceptance of different types and levels of touch, this issue did not appear to have made much impact on this child, when it was discussed

Touch was evident in the mainstream school, but it was not accepted as part of the school culture. There were three young people at South Down's Secondary Modern who did used to touch others, yet this was often talked about between the person and the support staff. The support staff felt that if they did not give advice and guidance about appropriate and inappropriate touch this might disable the young people further and also

mark them as being a subject of ridicule. At South Down's Secondary School touch was

addressed in the counselling sessions and the children developed an awareness of

'appropriate' and 'inappropriate touch':

> <u>Document 'Philip Court' 28 March 2000' Section 0, paragraph 5, 284 characters</u>
> Mr Mason said to Phil: "some adults are concerned that your touch or pressure is too great. The touching of the arm is slightly turning into a pinch, I think you are getting more touchy anyway". He continues: "but it is okay, but maybe we need to say hugs and touch are okay at home and not at school, is that okay?". "Yes" said Phil.
>
> <u>Document 'Anthony Garrett' 23 May 2000' Section 0, paragraph 15, 123 characters</u>
> Before coming into the class, Anthony was touching Marilyn (support assistant) and she said that it was not right to touch people's bottoms

I would argue that a higher level of touch, in the special school versus that tolerated in

the mainstream school, creates a barrier for the young people as they are increasing their

vulnerability and dependence on adults around them.   This culture perhaps reinforces

(inappropriately) a dependency on 'touch' without teaching the appropriateness of touch

in social situations and with whom this is acceptable. For young people with a label of

'autism' such a culture may contribute to a level of confusion as regards the social

norms and what is acceptable in environments outside of the 'special school' setting.

How do people with a label of 'autism' view themselves?

Let us return to an incident we discussed earlier involving David:

In a science lesson with David Kent it is 10.04. The teacher is explaining that there are standard cards to test colour blindness and he asks the children in the class if there is anyone present with colour blindness. One child puts up his hand. The teacher goes over to the child and then proceeds to test the child on the colour blindness cards. (The child was not asked if he wanted to do this in front of others, and the whole process starts to feel uncomfortable.) Another child in the class asks the teacher a question and says: "if Richard had children would they also be colour blind?". The teacher explains that colour blindness is carried on the X chromosome, he says if you marry someone normal ..... some girls in the class speak out at the teacher and say: "don't say that, don't say normal, can't you say someone with the dominant or recessive gene?" and David Kent says at the same time "that is so unfair" and looks over at me, as he is obviously offended by the teacher's reference to the word 'normal'. The teacher continues ...... "if you marry someone normal then the children are likely to be normal". The use of the word 'normal' again, is getting David angry, and the girls in the class protest again. David says to me "see if I come to another biology lesson again" 10.07.

David had received counselling to help him understand autism and he had reflected upon this. Yet this did not sufficiently empower him to cope or deal with the situation. He has developed a knowledge of his difference yet he becomes frustrated with the covert way that he was being viewed as being the opposite to 'normal'. This had an effect on the way he felt about learning when he said: 'See if I come to another biology lesson again'. The responsibility in this instance is the failure of the teacher to understand how the oppressive use of words, are powerful enough to impact upon a person's sense of self-worth and their motivation to learn. There is a need for young people to not only understand 'autism' as impairment, but to understand it in relation to barriers, including attitudinal ones.

Information on autism needs to move beyond the psychological description of autism as a set of 'impairments', to the discussion of autism from a social, cultural and political dimension. This may enable the development of a more positive sense of self for people like Wills Martin, who described his cousin as 'normal' and himself as not.

For young people with a label of 'autism' who face exclusion from mainstream culture, their concept of 'self' in relation to 'other' has often been at odds with what they see as mainstream cultural images. They identify their difference, yet are unsure as to who to connect with. In the literature (written by people with a label of 'autism') there are often references to what is 'normal' and descriptions of their experiences as being different, but with a loath to acknowledge and identity with what is 'abnormal'. They see themselves in relation to 'other'. Non-disabled people define themselves as 'normal' in opposition to disabled people who are not (Shakespeare, 1997:228).

I have been arguing in this chapter that the 11 young people in this study understand autism not as an 'impairment' but as a 'disability'. They face discrimination and disadvantage as their information-processing style requires particular support and the provision of information *in a way* to help them learn best. The environment can sometimes disable the young person's ability to learn, as their senses may be over-whelmed with information.

To the observer the young person may simply be viewed from a behavioural standpoint as being difficult. An 'impairment' approach may lead to the provision of support that is predominantly within the medical/behavioural model. A completely alternative approach is required to best support the young people. All people should receive information on 'autism' (and counselling) at the point of diagnosis of the label of 'autism'. This should include a differentiation of information on 'impairment' and 'disability' to help connect people to the wider body of theory and practice in the disability movement.

In the following chapter I will illustrate how the photographs which the young people in the study took, seek to challenge some of the main assumptions that underpin the 'impairment'/'medical model'. Whereas this chapter has focused on understanding autism from the 'collective' experience of barriers faced in society, chapter 4 examines the issues presented through the 'collective' photography of the young people.

CHAPTER 4

THE 'COLLECTIVE' EXPERIENCE THROUGH PHOTOGRAPHY

Leo Kanner (1943) made use of 11 case studies of children in his article: 'autistic disturbances of affective contact'. Some of Kanner's theory/understanding of 'autism' has now been discredited, including his claim that all the children he observed came from 'highly intelligent families' and that 'there are very few warm-hearted fathers and mothers. . . . . . even some of the happiest marriages are rather cold and formal affairs'. Kanner's theory of autism rests on some basic assumptions and one of these is that people with autism desire aloneness and sameness:

> '*extreme aloneness from the very beginning of*
> *life, not responding to anything that comes to*
> *them from the outside world*' (Kanner, 1943)

Kanner argued that all of the child's activities are governed rigidly and consistently by the powerful desire for aloneness and sameness.

By contrast, my own research study found that the 11 young people I worked with, more than half a century later, do have a desire for social interaction and social contact. Certainly they are often presented with 'barriers' from others or from the environment that prevent them from achieving social interaction, but still, desire it. This study asserts that the young people did not necessarily desire to be alone, but that, sometimes, the bombardment of information on their senses could be so overwhelming that they needed time to process this information adequately (as discussed in chapter 3), and, therefore, require time alone for this purpose. 'Exposure anxiety' was discussed in chapter 1 in relation to theories and understandings of 'autism', but has been explored in more depth by writers with a label of 'autism', Williams (2003). It has been described as a 'survival strategy' to cope with the 'barriers' present in the environment:

> *'Exposure anxiety is a self-parenting survival mechanism, an intense often ticlike involuntary self-protection mechanism that jumps in to defend against sensed "invasion"* (Williams, 2003:10)

It is the experience of 'exposure anxiety' that is caused by confusion (barriers) in environments. As a way to minimise the experience of 'exposure anxiety', people with a label of 'autism' often seek to preserve the sameness in environments. This sameness served the purpose of creating some stability in their life as they managed to process additional information from confusing and demanding social situations. This chapter will argue that when people are understood in relation to their environment, a greater understanding can be ascertained of the disabling effects of some environments in relation to others.

The biggest single photographed category of the study was 'people', and this was accompanied by accounts of how important people were in the young people's lives. This chapter will challenge some of the assumptions made about people with a label of 'autism'. It will be asserted that the main difficulty for people is that the environment (and people supporting them in this environment), often maintain barriers that deny them the ability to access and understand information that could aid their development of and participation in social understanding. We will also explore what is important to these young people by analysing the content and meaning of 1350 photographs taken by them. An overview of the content of the photographs are illustrated in Diagram 1 on page 229.

One-third of the photographs (34%) were of people; family and family friends (20.5%); friends (5.5%); paid workers (3%); peers (children with a label of 'learning

difficulties') (2.5%); peers (children with a label of 'autism') (1.5%); peers (mainstream children) (1%). The pictures of people were taken in a range of settings with family and family friends being taken either at home doing day-to-day tasks; celebrating a birthday either at home or in a restaurant or friends and peers which were mostly taken in the school setting.

As stated in the methods chapter (chapter 2), all the young people over saw when to take photographs and what to take photographs of. Parents were asked to remind the young people that they had a camera and that they might like to take the camera on an outing or to a place, but ultimately the young people took charge of what they took photographs of. This was emphasised throughout the research process and guided by the principles of emancipatory research.

I have arranged the findings in this chapter in relation to a series of subheadings: *Family networks and siblings; 'Special Interests' versus 'Obsessions'; The physical environment and landmarks; Holidays and days out; Self Portraits; Pets and animals and Creativity.* Each subsection will explore the findings presented by the young people with reference to the theories/understanding of autism outlined in chapter 1.

Family networks

By far the biggest category of family members photographed were brothers and sisters and the narrative of the young people revealed that there were sometimes difficulties in the relationship they had with siblings. These difficulties were often compounded when the person had a brother who also had a label of 'autism' this was the case for Jonathon and Kevin. Statistics, identify a 25-30% chance of a sibling also being labelled with 'autism', Gillberg, 1990). Jason, David, Simon, Andrew and Wills all have brothers,

(who do not have a label of 'autism'). Charlie and James each have a sister and Anthony has two sisters. The girls were not identified with the label and Phil is an only child.

Kanner (1943) had originally suggested that children in his study did not differentiate strangers from family members in the formation of a relationship. He argued: 'The relation to the members of the household or to other children did not differ to the people at the office'. When Kanner was assessing the young person 'at the office', the environment obviously had an impact upon the young person and an absence of landmarks may have caused a level of 'exposure anxiety' for the person. This study interviewed young people in their own home environment where they had landmarks and a level of stability. This would ensure that the only variable that could cause exposure anxiety would be myself, as the researcher. Kanner (1943) also suggested that: 'there is a far better relationship with pictures of people than people themselves'. In this study the young people were often observed interacting with siblings and they were also found to have established important friendships (chapter 5).

It was important for these young people to have time to think and time by themselves. Some of the difficulties they experienced with their siblings was near frustration and that they were being 'closed in' upon:

Jonathon's brother Andrew has a label of 'autism':

Jonathon: And he [Andrew] asks me lots of questions the same thing every ... ev .. again and again and again..
Jill: Right and how does that make……?
Jonathon: ..Then why don't I like this? And I don't know …….. cos I don't .. cos I don't know what he is thinking when he asks me that
Jill: So what is the best thing to say in those situations?
Jonathon: Well tell him to leave me alone
Jonathon: Now, I am thinking of making a new rule, he can only ask me one question a day and that's it.
Jill: Oh dear that's a hard rule though isn't it? Do you think it's a bit hard?
Jonathon: only one a day and no more
(Jonathon Frost – Interview 3)

At the next interview, however, Jonathon's frustrations appeaed to have subsided and there was evidence of a level of tolerance between him and his brother when he shared his camera with him:

Jill: Did he? Oh great it's lovely of you to share your camera with Andrew
(second photo taken by brother)
Jonathon: Yes, he wanted to take this ... Take this one he usually does ... when I take photos he says 'can I have a go?'
Jill: Ah ... that's nice ... I think it's nice that you share ... how do you feel about it?
Jonathon: Oh okay... oh fine
Jill: Oh good
(Jonathon Frost - Interview 4 line 64-67)

The young people appeared to appreciate time on their own in their bedroom:

(Jason Smart - Interview 6 line 35 -42)

Jill: Yes right... so how do you get on with John?
Jason: Not really too well, he keeps coming in my room all the time
Jill: Yes ... what does he do when he comes into your room
Jason: I've got a video player in my room

Having their own space and having their own belongings is important to the young people and this was discussed in chapter 5 in relation to the person having 'landmarks' in their environment. Kevin feels similar to Jason about his brother:

Jill: Do you get on with him (referring to a picture of Kevin's brother)
Kevin: Sometimes but when he comes in my bedroom (Kevin frowns and pulls a frustrated facial expression)
(Kevin Scarborough - Interview 6, line 71)

Charlie revealed how important his sister was to him:

Charlie that's a picture of er . . . Jane . . . she thought she would put some shorts on her head
Charlie 8.21

Jill (laughs) Did she?!   Are they your shorts?
Charlie: Yeah .. she just wanted to do it I don't know why I didn't mind but   thought I'd take a picture of her   she is important to me
(Charlie Hill - Interview 8 line 310-322)

He, however, also expressed the importance of having time on his own:

Jill: No? .. so she [Jane] likes to play with your things?
Charlie: Hmm
Jill: How do you feel about her coming in and doing that?
Charlie: I enjoy it
Jill: Yes?
Charlie: Gets too much to a certain extent and then I want time on me own .. but ...hmmm
(Charlie Hill - Interview 5 line 192)

On another occasion (approximately a year previously, in the first interview), Charlie

had not felt so positive about the relationship with his sister:

Jill: So how do you get on with Jane?
Charlie: Not very well really
Jill: No?
Charlie: We do get on very well a lot but then we don't get on very well a lot
Jill: When are the times that you do get on well?
Charlie: Usually when we are playing games together and she is doing things for Pleasure Life and she has done a lot of posters for me for my pleasure life, she's done that (he points to a picture on his bedroom wall) *and that* (he points to another picture) *and she has done a lot of things really which has made me feel very happy*
(Charlie Hill – Interview 1, page 15)

Wills found it more difficult to get on with his brother:

Wills: Well that's our David alright
Jill: Yes? And how are you getting on with him?
Wills: (makes a sound of pretending to be sick)
Jill: Ss that how you feel about him or how he feels about you?
Wills: Vice versa
Jill: Alright .. why do you think it is difficult to get on with him at the moment?
Wills: Because he's a brat, he's annoying and he is just plain David
Jill: (laughs) Do you think you are very different .. you and David .. have you got different interests?
Wills: Hmmm .. we have nothing in common whatsoever
(Wills Martin – Interview 3 lines 62-71)

Wills had a more positive relationship with his two older sisters:

Jill: So how do you get on with Jess then?
Wills: well as you can see we are pretty close .. right
(Wills Martin – Interview 7, lines 94-95)

By Interview 7, I asked Wills again how he was getting on with his brother David, he

said:

Wills: we are like two peas in a pod .. right but we quickly dissolve and that's it
(Wills Martin – Interview 7, line 181)

James, Andrew and Anthony did not necessarily have the language to communicate to

me the type of relationship that they had with their siblings, but the photographs

included siblings and indicated a sharing of time and activities with each other:

Jill: So who was there at the party?
Anthony: My sisters and me dad
(Anthony Garrett – Interview 7 lines 213-214)

Andrew: That's mom taking a photograph we were waiting for the train to go to York
(Andrew refers to a picture of himself and his two brothers and sister)
(Andrew Jones – Interview 1, line 40)

Simon took a considerable number of photographs of his little brother and commented

on his brother's expressions:

Simon: Yes it is ... looks like he is .... A monster
(Simon Sands – Interview 4, line 23)

Siblings were seen in a different relationship category to 'friends'. I encouraged David

to group friends in terms of closeness to him (placing the photographs on the floor), and

I asked him where his brother would feature:

Jill: and Marcus there ... and then you've got your brother
David: Jack is not my friend
(David Kent – Interview 2, lines 145-146)

One of the keys to a successful relationship between the young person and their

siblings, parents, and friends was the ability to 'share' time on the person's special area

of interest. The family member did not require great expertise in this area, but a

commitment to spend time with the person was important and was a focus in which

positive relationships developed:

Anthony: This is a picture of er ..... Callam Island .. where the machinery is
Jill: Oh right .. what sort of machinery?
Anthony: Like .. when it was like this (points to the photograph)
Jill: What was you doing there?
Anthony: Listening to a lady .. talking about what Sheffield used to have .. like steel
Jill: Did you go there with the school or did you go with your family?
Anthony: One Sunday with me Dad
(Anthony Garrett – Interview 7 lines 25-32)

When the person did not spend time with their family on an activity it would sometimes

cause frustration:

"Sometimes I think about . . . why don't ...why doesn't me dad take me to a football match cos this is a bit . . . and I go . . .urrhhhhhhhhh . . . cos er the things that wind me up just come come [sic] into me head when I start revising".
(Jonathon Frost – Interview 6, line 175)

Another child had a more positive experience of spending time with his dad:

Charlie: That's a walk that I did (referring to the photograph)
Jill: Where was that Charlie?
Charlie: Erm . . . I have forgotten . . . but . . . I know. . . but I have forgotten
Jill: Was that when you went walking with your Dad?
Charlie: Erm.. yeah
Jill: Was your mum with you as well on that day?
Jill: No .. just me and my dad
(Charlie Hill – Interview 1)

Jill: Oh it's a beautiful picture .. it looks like you had a nice time when you went away
Charlie: Hmmm
Jill: So what was ...... did your mum and Helen stay behind?
Charlie: Erm just went with dad yeah
Jill: Hmm .. that's nice
Charlie: We both like walking so ......
Jill: yes that's nice spending some time together
Charlie: hmmm . . . yeah
(Charlie Hill – Interview 5, line 333-337)

Charlie not only went walking with his dad, he also played computer games with him:

Jill: So do you tend to play it on your own?
Charlie: Yeah on me own .....or with dad ..
Jill: Great
(Charlie Hill – Interview 8, line 35-36)

Some of the frustration that the young people experienced with the relationship with their father could possibly be on an emotional level. People with a label of 'autism' need to be around people who are calm and are able to hold themselves together in a crisis. Jason expressed his frustrations with his dad and made comparisons between his father's temperament and that of one of the teacher's at school:

Jason: Yeah .... It's ..... sometimes he's nice to me, sometimes he might ... has a go at
me
Jill: Why does he have a go at you?
Jason: It's just .. its just what I don't really like about him ..... cos he panics about
things that he cant fix. . . . . . . like someone's dying
Jill: Do you think it is his way of coping with the situation?
Jason: I don't ... Mr Mason doesn't do that
Jill: Right, so what do you think it is that makes Mr Mason different from your dad?
Jason: Because he's a teacher
Jill: Yes .....is that what makes him calmer do you think?
Jason: Hmmm not sure
Jill: Is it that Mr Mason doesn't loose his temper?
Jason: He has before
Jill: What with you?
Jason: No
(Jason Smart – Interview 6 lines 82-84)

On the whole, most of the young people had a more positive relationship with their

mother than with their father. Jason explains why this was the case for him:

Jason: Cos my mums different to my dad ... my dad teases me
(Jason Smart – Interview 6 line 104)

Mothers played an important role in the lives of the young people and Phil revealed a

level of sensitivity when talking about his mum:

Philip: these are what I like (pointing to the car pictures). . . . . . these are ones that I
thought I had better take ... ... at least one ....(pointing at pictures of mum)
(Philip Court – Interview 2, lines 168-169)

The largest number of photographs Phil took were those of his special interest (cars) and

his second largest category was pictures of his mum and dad. His special interest gave

him a lot of pleasure, but it did not replace or emphasise a greater level of importance in

his life than his family.

Jason gave an insight into the support role that his mother played in his life:

Jill: Does it make your ears pop when you are on the plane?
Jason: I get used to it when I am in the middle of it.... it's just that when I am on my
heart starts to make me feel ... ... I get scared when I am, on it.. and then I get settled ..
and when we are up in the air I like to hold on to my mums hand and then my mum says
we are okay now.. and that's when ... ... (pauses)

Jill: That's when you feel comfortable?
Jason: Yes
(Jason Smart – Interview 6, lines 174-177)

This support role was also extended to help the young person access things that were

important to them:

Kevin: I don't know .. (referring to a slot machine) it wasn't anything special it was
made in 1980 .. I asked mum if I could have it
(Kevin Scarborough – Interview 1, line 108)

Kevin's mother was seen as someone who was enabling him to be creative in his design
of slot machines, he explained why he wanted it:

Kevin: And also it would give me ideas
(Kevin Scarborough – Interview 1, line 111)

Kevin's mother continued her enabling role
Kevin: Mum says it will be good for me and I don't know what the best thing is to
choose
(Kevin Scarborough – Interview 2, line 214)

Looking and reflecting on the photographs sometimes brought back (or recalled) an

emotion for the young person. Anthony remembered when there was a difficulty

between him and his mum:

Anthony: And here in this photo ... before I took this photo I was naughty to my mum
Jill: You was what?
Anthony: Naughty to my mum
Jill: Oh was you .. what happened?
Anthony: Shouted at me. . . . . . And said get in
(Anthony Garrett – Interview 3 lines 113-117)

On another occasion David humorously commented on his mum embarrassing him in

one of the photographs:

David: There's a picture that Rosie took of mum
Jill: Oh yeah .. that's quite good isn't it? (laughs)
David: Embarrassing
Jill: Why is it embarrassing?
David: BECAUSE SHE'S MY MUM (shouts) and she's doing stupid stuff!
Jill: What would you like her to be doing?
David: I don't know ... but just imagine if there was a giant wave here ....

(David Kent - Interview 5, lines 95-100)

In a later interview David approves of a photograph of his mother:

David: Did I take this picture? .... At least she doesn 7 look embarrassing
Jill: (laughs)
Jill: Does she ever look embarrassing?
David: When does she ever not?
Jill: (laughs)
Jill: When does she look embarrassing?
David: Mostly on holiday
(David Kent - Interview 6, lines 15-22)

On another occasion Wills, demonstrated his sensitivity about missing his mum's wedding anniversary:

Wills: Oh mama .. she was not really happy ... I forgot her wedding anniversary
(Wills Martin – Interview 6, line 111)

Jonathon, Jason, Anthony and Kevin experienced frustrations in their relationship with their fathers. It appeared that whereas the mothers were able to adapt and change their role in response to the needs of their children, the fathers may have found their traditional 'male-parenting' role being compromised. The more positive relationships between the young people and their fathers were based on sharing activities/experiences or the person's 'special interest'. The relationship was difficult when the fathers exerted discipline or did not appear to understand (in the eyes of the young person):

Kevin: And sometimes I pop into see my uncle .. who I don't even know .. on my dad's family ... oh it's weird though 'cos I don't even know much of my dad's family ... I only know uncle Simon and uncle Mark .. my dad's got three brothers and two sisters. James on my dad's side he went to [inaudible]*... and I wanted to go and my dad wouldn't let me*
(Kevin Scarborough – Interview 2, line 267)

Wills, Charlie and Phil had positive relationships with their fathers. Andrew, James and David did not live with their birth father, although all three had regular contact. James and Andrew lived with their mothers and step-fathers. Simon lived with his mother and younger brother and there was no evidence of contact with Simon's birth father.

Where mothers featured in the research they appeared to take the principle caring/parenting role, and there appeared to be a positive relationship between the mother and the young person. Kanner (1943) observed that the children in his study had an excellent relationship with objects and apparently non-existent relations with people. This was not apparent in this research study. Kanner's findings are likely to have been influenced by his research methodology (the interviewing and observing of young

people outside of their environment). Rogers (2000) calls for further research in naturalistic contexts and public settings, to explore further the social issues for people with a label of 'autism'.

Grandparents played an important role in the young person's life and the relationship between the young person and their grandparents was not defined by a 'shared interest'; but one of extended family support and was, however, an important relationship to the person. Grandparents were not well represented within the photographs, although this did not detract from the young people talking about the importance of grandparents in their lives. Wills described the relationship he has with his nan:

Wills: And I said I'm not doing the plates mama. See you later mama and nan was currently visiting at that time
Wills 6.15

Wills: So I got a snap of her
Jill: That's nice and how do you get on with your nan?
Wills: Oh me and her are like solid
Jill: Oh really
Wills: She's like a rock and so am I
(Wills Martin - Interview 6, lines 115 - 122)

Jason's grandmother was in the background of this picture:
Jill: And is your grandma in the picture there?

Jason 6.12

Jason: Yeah
Jill: So how do you get on with your grandma?
Jason: Okay
Jill: Yeah .. what sort of things do you do when you are with your grandma?
Jason: Er ..I just go up to her house **..............** *Sometimes.. sometimes I help her with her shopping*
Jill: Oh right.. I bet she likes that
Jason: Yes
(Jason Smart - Interview 6, line 61-70)

There was usually frequent involvement on occasions, such as birthdays and Christmas:

Jill: Yyes that's excellent.   so what are you going to do over Christmas?
Jonathon: Erm .. I am going to me grandmas at er .... on Christmas day for Christmas dinner
Jill: Oh that sounds good
(Jonathon Frost - Interview 4, line 171-173)

Simon took a photograph of his grandad at their house at Christmas:

Jill: and who else is in the photograph?
Simon: er **..............** *er* **............** *Peter and grandad Tim .. got sunglasses on*
(Simon Sands - Interview 3, line 48)

Charlie had frequent contact with his grandparents whilst others had more infrequent

contact:

Jill: So how often do you get to see your nan and grandad?
Charlie: Er. once a week., usually go on Sunday
Jill: Because now you have Fridays free
Charlie: I go on a Friday now
Jill: Instead of a Sunday

Charlie: Instead of a Sunday
Jill: Do you walk there?
Charlie: Hmmmm I usually go with my mum 'cos she's at home yeah
(Charlie Hill – Interview 4, line 24)

There was generally a support network from within the extended family. Tunali and Power (2002) found that mothers of children with a label of 'autism', socialise more with the extended family than other mothers do. The authors argue that the extended family may become an important source in fulfilling some of their social/affiliative needs. This research found that six (James, Jason, Wills, Jonathon, Charlie and Simon) out of the 11 young people, featured grandparents either in the photographs or in the commentary on the photographs. Kevin and Anthony talked about cousins and aunties and uncles. Andrew and Phil did not make reference to any extended family member throughout the research, although David discussed his 'sister' (not a birth sister) a family friend, who had been 'adopted' by him as his 'sister'. The extended family featured as not only an important support role for the parents but played a part in the growth and social development of the young people:

Jill: Does anyone else that you know like classical music?
Charlie: My nanna
Jill: Oh
Charlie: Me grandad
Jill: Do you listen to music when you go there?
Charlie: Yeah
Jill: Did they help you to get into liking that music?
Charlie: Yeah 'cos I listen to it ...... erm to their tapes
(Charlie Hill – Interview 8, line 300-307)

Relationships are important to the young people and it is the relationships with brothers, sisters, mother, father (or step-father) that maintain an important level of stability in their lives. It is when difficulties occur in these relationships, that the young person may develop increased anxiety and stress. An example of this is the experience of Anthony

Garrett (chapter 5). Stability in the family environment is important to the young person as they form major 'landmarks' within their immediate environment.

'Special Interests' versus 'obsessions'

An analysis of the photographs found that 'special interests' were the second highest category of photographs taken. There were 234 photographs, constituting (17%) of the 1350. Amongst the 11 young people however, only three took photographs of a particular theme or special interest that rated as the highest category of pictures. Kevin took 101 photographs of slot machines out of a total of 131 photos (77%); Phil took 60 photographs of model/toy cars or real cars from a potential of 155 (39%) and Charlie took photographs of paths 'where he liked to walk' and his Pleasure life.

For Charlie, the paths and walks were his biggest category and he took 49 photographs out of a potential 143 (34%) and his second largest category was "Pleasure Life" and football rallying of which he took 37 pictures (26%). Only one person had a 'special interest' as a second highest category and that was David with his interest in Pikachu and Pokemon. David took 21(17%) photographs on this theme out of a potential 123.

A discussion on 'obsessions' or 'obsessional interests', is one of the characteristics that define 'autism' from an 'impairment' perspective. Jordan and Powell (1995:100) argue that although a particular intense interest in one precise aspect of a subject has been termed an 'obsession' in the autism literature, the authors argue that they are really only a natural product of a style of thinking that is highly attention-specific. The term 'obsession' presents difficulties in terms of its negative connotations. The term 'special interest' will be used, as it is often when observing the person with the 'special interest' that this is interpreted as a negative issue. Within this research the young people did not

view their 'special interest' as a negative activity. Anthony had been told he had an obsession as opposed to him understanding his 'special interest' in this way:

Jill: So why are there so many pictures of Simon?
Anthony: Because ... it has been an obsession with him
Jill: How do you know?
Anthony: Because Mr Mason told me
Jill: Right okay ... do you still have that obsession?
Anthony: I think it's gone
(Anthony Garrett – Interview 7, lines 170-174)

Anthony's special interest was people, particularly 'friends' at school and those also with a label of 'autism' or mainstream peers. Yet those whom he defined as 'friends' only made up 8.5% (11) of the total amount of photos taken and those that were of his peers made up 9% (12). His biggest category was made up of family and family friends 13% (17). For Anthony social interaction and acceptance by others was important and it was often his anxiety (experienced from barriers in social interaction), about being accepted and being liked that presented itself as a problem to the people he wanted to be his friends. It was his anxiety over friendships that made it appear to the observer that he had an 'obsession' with people.

Anthony talked about his 'obsession with a white bus' yet only 7 photographs out of 128 were of white buses (5.5%):

Anthony: There's number 17. . . it's a white bus

Anthony 5.1

Anthony: This is ..er a picture of.   er . . . when I got obsessed with a white bus
Jill: Oh right why do you say that you got obsessed with the white bus?
Anthony: It changed colour

Further analysis of the interaction between Anthony and named children at school suggests that this was a way in which Anthony's anxiety was portrayed. As Anthony's home situation became more and more insecure (when his mother left), his relationship with his father became tense and often resulted in aggression and conflict. This then resulted in an increase in his exposure anxiety and thereby an increase in a need for landmarks in his life and those around him to stay the same. What may have developed as an interest in people or an interest in buses now reached a crisis, as he was desperately seeking some stability in his life.

Others involved in the research made reference to their special interests in the interviews, but this was not always recorded through the photographs. For example, Jason, Kevin and James had a particular interest in cartoon network. The category of cartoons was not coded as a 'special interest' as the theme was not generated in a visual form through the photographs. Simon did not appear to have a special interest, but further analysis of his photographs revealed that 44 (44%) of his photos were taken of

family and family friends and 30 (30%) of these were of his brother. Jonathon's largest category was also of family, and mainstream peers became his second largest category (13.5%).

David portrayed Pikachu in different guises (17%); of his photographs (his second highest category) were of Pikachu and Pokemon. Not once was he concerned with his pre-occupation with this theme or did he see it as a problem:

David: There's Pikachu with his shades on (laughs)
David 2.22

David: There's Pikachu wearing my Macdonald's cap (laughs)
Jill: Oh that is lovely.. a lovely picture
David: He's sitting on my chair and I've only just realised
(David Kent-Interview 3 lines 106-110)

Jill: Yes (laughs) I remember
David: And also the one of Pikachu in my hat?   there's Pikachu in both
(David Kent-Interview 4, lines 4-7)

David: There \s Pikachu looking at how to do dice and card tricks
David 6.12

(David Kent-Interview 6, lines54)

Those who took photographs of their 'special interest' saw it as a positive activity. Kevin talked about how the photographs of slot machines, helped him with his ideas in inventing new games. His ambition was to have his own company and he revealed through the research process that was constantly developing ideas for new games. David talked about his artwork as a way of developing his creative side. Phil had ambitions for continuing his hobby of collecting cars for the future.

Local area - the use of landmarks

This was the third highest category of pictures taken by the young people 134 photographs out of 1350 (10%). There was a sense that the young people had a need for 'landmarks' in their life in a whole range of ways. Charlie enjoyed walking and the paths and walks in the local area were the largest category of photographs taken by him. He took 49 (34%) of photographs which followed a similar theme

Charlie 3.14

Charlie: Hmmm. . . that's just sort of like describing the paths where I walk
(Charlie Hill-Interview 3, line 170)

Charlie: that's the one I took out of the window.............looking at the paths of where I walk at dinner times
Charlie 3.16

(Charlie Hill-Interview 3, line 180)

Paths were important to Charlie in a whole range of different locations and environments. He observed them whilst walking with his family, when at school and when walking alone. The latter is illustrated in the following photographs:

Charlie: (pauses) . . . and that's a bit of the paths . . . where I like my quiet. . . I like walking on the paths
(Charlie Hill-Interview 4, line 188)

Charlie: This is a path going to a valley
Charlie 5.24

(Charlie Hill-Interview 5, line 405)

Charlie: A path
5.26

It was important to the young people that I knew of the area they were talking about. There were examples where Charlie, Jason and Anthony would check my understanding of a particular location:

Jill: Is that in Eden Road?
Charlie: I think so. . . like a garden . . . big gardens. . . Have you been there?
Jill: Yes . . . I've been there
Charlie: So you know where it is yeah?
Jill: Yes .. but I didn't see the pond there Charlie
Charlie: Right. . . hmmmm. . . That's where the fish is hmmmm
(Charlie Hill – Interview 3 lines 152-154)

Jason: And that's the road ... I don't know if you recognise it?
Jill: Yes I do
(Jason Smart – Interview 4 – lines 49-50)

Anthony: Have you ever been up this road?
Jill: I have never been up there
Anthony: This road leads to Dore
(Anthony Garrett Interview 2, lines 25-30)

In chapter 1, the 'Theory of Mind' was outlined (Baron-Cohen et al, 1985, 1993) and this theory argued that most people with a label of 'autism' are unable to 'mind read' to understand the beliefs of others. In the above examples Charlie, Jason and Anthony were keen to work out my belief and my position as regards the location they were discussing in their photographs. They asked me a question that indicated that they understood my experience might be different from theirs.

James took photographs of actual places he went to in the local area, for example the coffee shop, the library, the shops, the chip shop, Meadowhall, the garden centre and bowling. This was also a similar experience for Andrew and Simon. Andrew, Simon and James walked to places in their local area accompanied by a parent. It was Jason, Charlie and Anthony who took photographs of places where they walked to (independently) in the local area. Phil's special interest (cars) served as a continuous positive landmark in many different environments. For example, he went on holiday to France and most of his photographs were of French cars. This was also the case for Kevin who took photographs of his special interest 'slot machines' on a holiday to

Spain. The special interest for Phil and Kevin served as a way of embodying them into a new environment.

So landmarks are not only portable (the taking of something from a stable environment to a new environment). The same effect can be obtained from seeking out the special interest in new environments. David and James had 'portable' special interests that they took with them to new environments. They both loved to draw: David drew Japanese comic strip animation and James drew pictures of cartoon characters from cartoon networks. Kevin also drew. He would draw the designs of his slot machines for arcades. Wills and Jonathon did not have any obvious special interests.

Holidays and days out

Kanner (1943) had originally suggested that: 'the child's behaviour is governed by an anxiously obsessive desire for the maintenance of sameness'. Kanner also argued: 'the dread of change and incompleteness results in the limitation in the variety of spontaneous activity'. It could then have been hypothesised that the young people were most unlikely to go on holiday, especially holidays abroad in different cultures. This was, however, the fourth highest category of photographs taken 104 (8%). Nine out of the 11 children had been away on holidays. The 10th child, Anthony Garrett had been away on day trips and the 11th child, Simon Sands did not refer to any holidays or day trips.

Jonathon had a holiday in Amsterdam with his brother:

Jonathon: The third ..and this one   Is a picture. . . of er... of a boat. . .
it's not much really
Photo 7.6

(Jonathon Frost - Interview 7 line 75)

Jason and Wills both had holidays to Disneyland, Paris:

Jason: This was the magic kingdom. , . that was the sleeping beauty castle. . . it was
like through there was fantasy land
Jason 5.15

Jill: You've captured the magic of it, because it is right in the foreground isn 7 it?
Jason: It's the .. it's the main thing you look for in Disneyland
Jill: Right
Jason: I thought that Disneyland was like er... their version of Paris, that's why it is
called Disneyland Paris. And I thought they were trying to like .. copy the Eiffel tower

Wills: Now this is one of my favourite shots
Wills 3.9

(Wills Martin - Interview 3, line 80)

Charlie went on walking holidays to Wales and the Lake District. Even on holiday he

was able to take photographs in a similar style as to the one he would take in his local

area. He discussed what he thought makes a good picture:

Charlie: That's a reservoir..................it might be the same reservoir or. . .   a different reservoir
Charlie 6.14

Jill: And do you now look out for what would be a good picture
Charlie: Hmmm
Jill: What sort of things do you look for that would make a good picture?
Charlie: Erm well er. .. I often look at paths 'cos that's where I often like to walk on paths so. . . I like to take that

David and Kevin both had holidays in Spain:

Jill: Is that when you just arrived in Spain?
David: I think so   Here's kind a like a window thing in the apartment
David 5.9

(David Kent Interview 5 lines 50-52)

Both Kevin and Phil took photographs of their 'special interests' abroad:

Kevin: This is PK soccer
Kevin 6.25

Jill: And this is in Spain?
Kevin: Hmmm .. this is a Sega machine   instead it has one of those display LCD
screens and not to mention such a good cabinet
(Kevin Scarborough - Interview 6 lines 96-99)

Philip and James had holidays in France:

Jill: So did you find there were very many different cars when you were in France
Philip: Yeah   there's a Citroen LN ...as well
Philip S. 10

(Philip Court - Interview 3 lines 104-106)

James 4.20

Mum: The fire and where were you .. what house .. in
James: France
Mum: Yes
Jill: And what are you doing here James
James: It's colouring and drawing some pictures
Jill: Your drawing pictures.. what pictures are you drawing.. can you remember?
James: Cartoon network
Jill: Cartoon network

Philip, James and Kevin had continued their pursuit of their 'special interest' in new

environments on holiday. It appeared to be a level of continuity for them in being able

to adapt to a changing environment and culture. It appeared that the young people were

able to discover 'landmarks' in their environment that were familiar to them and they

were able to tap into their 'special interest'. These aspects appeared to make the holiday a success for the person.

Andrew took photographs of animals whilst on holiday with his father. Animals constituted his second highest category of photographs taken, 13 pictures out of 62 (21%).

(Andrew Jones - Interview 4 line 4.4)

It was interesting to note that whilst at a summer playgroup, James had taken a photograph of Andrew with an animal:

Jill: Do you know who this is James in the picture? Who's this boy in the picture?
James 4.22

w '

James: Rabbit

Anthony and Phil both went on a school trip to Eyam at the same time:

Anthony: That \s a picture of Burbridge..............   it was when I went to Eyam
Anthony 5.2

Jill: What was it about that picture that you like?
Anthony: The outside
Jill: What was you doing on that day.   Did you go for a walk?
Anthony: Rockclimbing
(Anthony Garrett - Interview 5 - line 26)

Philip: Yes   now that's in Eyam
Philip 3.16
(Philip Court - Interview 3 - line 124)

There were no day trips or holidays documented through Simons's photographs.

Anthony did attend other school trips and did have days out, but he did not go on an

annual holiday.

Pictures of self

The young people enjoyed taking pictures of themselves (by turning the camera directly on to themselves) or by asking others to take a picture of them. The turning of a camera on to oneself requires not only some imagination, but to ask someone to take a picture requires social interaction. It requires one young person to communicate with another. This challenges some of the traditional assumptions made of people with autism outlined in chapter 1. The young people enjoyed creating a pose and either taking the picture themselves or asking another person to take it of them. There were 88 photographs of self (6.5%).

Jonathon said of the following picture, *"as if I am celebrating a victory";* this was taken on his last day at school:

Jonathon: As if I   as if I am celebrating a victory

Photo 7.8

Jill: Yeah .... *Do you think it* [school] *was a victory?*
Jonathon: Yes
(Jonathon Frost - Interview 7, lines 97-100)

Pictures of self while partaking in an activity (taken by a relative or other person):

Simon: That's me
Simon 5.1

Jill: What are you doing there?
Simon: Holding the ball
Jill: Can you remember where you are?
Simon: Bowling
(Simon Sands - Interview 5 lines 4-9)

Pets/animals

It was not only Andrew who appeared to have a particular affinity with pets/animals. Wills referred to, Max, his dog as 'one of the family' and David described his dog, Cookie as his 'friend'. Kevin found that walking a dog at school helped him to calm down and not to feel so stressful. Jason took pictures of his dog and was intrigued by the 'red-eye' effect in the dog's eyes:

Jason 2.8
Jason : (Jason laughs as he looks al the next picture)

Jill: (laughs too) What do you think has happened there to his eyes?
Jason: How come they have come out like that in the photo?
Jill: Well um It's just something that happens with the reflection of the eyes. . . more expensive cameras um actually have a little button that you can press, so that it doesn't come out. . . Your eyes don't come out red

Anthony, Jonathon and Phil took photographs of their cat and spoke of the cats in an

affectionate way. Jonathon took photographs of his cat in particular poses.

Jonathon: Er blackie again on er the table . . . with a .. . with a toy, he's holding a toy
Photo 5.3

Jill: (laughs) That's lovely and what made you want to take that picture?
Jonathon: I wanted to see what he looked like with it, with a toy, holding a toy
Jill: That's a good picture isn't it with his eyes?
Jonathon: His eyes are like glowing
(Jonathon Frost, Interview 5, lines 20-23)

Only three of the children did not have pets and this appeared to influence the lack of

photographs taken of animals, with two of them taking no photographs at all of animals.

James did not have a pet, but he enjoyed horse riding and took photographs of his horse Blaze.

Peers and Friends

Peers were distinguished from friends (5.5%) and photographs were taken of individuals that the person might not necessarily even like. Peers were categorised as children with a label of 'autism' 21 pictures (1.5%); young people with a label of "learning difficulties" 33 (2.5%); and peers from the mainstream school 13 (1%). Peers and friendships are discussed chapter 5.

Technical and non-technical interests

This category consisted of all hobbies or interests of a technical nature, e.g. television, computers, computer games, stereo/hi-fi equipment. There were a total of 57 pictures (4%) of this nature and this compared with 45 pictures (3.5%) of a non-technical nature. Non-technical interests comprised of pictures of books, calendars, music videos, tapes, chess set and any other interest not of a technical nature and not an interest which appeared as a 'special interest'.

Miscellaneous pictures

This category coded pictures that the young people commented on in relation to the poor photographic quality. So they were pictures which were not recognisable, had a finger over the lens or were of a reflection on glass. Photographs were categorised in this area if the image was not recognisable underneath the fault. Only 36 pictures (2.5%) fitted this category. On the whole the young people developed their photographic ability favourably over the research period:

David: Oh I think I took that one . . . Yeah I took that one on the way to Spain . . . I saw a lot of stars out so I'm like 'can I get a photo of that?' and now I am looking at it . . . and like . . . Oh dam!
David 5.8

(David Kent. Interview 5, line 46)

Creativity

An impairment of imagination is the third part of the 'Triad of Impairments' that is used

to frame diagnostic criteria for labelling people with 'autism'. Wing (1996:99) argues

that:

> *The value of true imagination and creativity is in associating past and present experiences and making plans for the future, ranging from the mundane what to do tomorrow to the grand plans for the whole of life'.*

It was evident not only from the photographs that the young people were able to express

the ability to be creative, but they were also able to express ideas about their future:

Jonathon: And er the day the day I leave I will be doing a comedy show on an NRA night which stands for National Record of Achievement
Jill: Wow
Jonathon:. . . Shall be doing impressions of people
Jill: Yes?
Jonathon: And they've got ... the audience have got to guess what . . . what it is I'm doing
Jill: Oh right… So is your mum going to be there that night?
Jonathon: Yes. . . and I am gonna try and act like a comedy person
(Jonathon Frost - Interview 6, lines 137-144)

The National Record of Achievement (NRA) night was so successful that in the next interview Jonathon reflected on how he felt about it and he remarked that he would like to do this in the future:

Jill: And what ambitions do you have.. what do you want to do in the future?
Jonathon: Comedy
Jill: Yeah .....so is that what you want to do?
Jonathon: Yes
(Jonathon Frost – Interview 7, lines 285-292)

This study found that it is not the 'impairments' that inhibit individuals making plans for the future, but their worries and anxieties about the environment and the support they will get in realising their future plans. Some of the young people in this study had plans and ambitions for the future. For Kevin, although he was clear about what he wanted to do for his work experience, he was not quite sure what he could do to enable it to happen:

Jill: . . So have you talked to anyone at school about what you would like to do with your work experience?
Kevin: I would like to be a computer programmer
Jill: Have you talked to anyone about that yet?
Kevin: Hmm I don't know . . . I think it was with John Miller but he's left
Jill: Hmmm . . . what about the careers guidance lessons that you have . . . do you manage to talk about it there?
Kevin: I'd like to
(Kevin Scarborough – Interview 2, Lines 116-123)

Such worries can lead to levels of stress in the young people and for Jonathon it resulted in him dreaming about his exams:

Jill: You were talking about your exams earlier on that you had a dream.........
Jonathon: Yes . . . me exams . . . last week I dreamt that I got disqualified . . . cos I dreamt that I had er a sensitive nerve in me mouth.. and the examiner thought I was like chewing . . . Which I wasn't supposed to be so that was when I got disqualified.. so he took me out of the room and said 'are you chewing?' . . . . . . and I said no
Jill: So how did that dream make you feel when you woke up?
Jonathon: oh as if it was realistic
Jill: Yeah and how did you feel about that ... did you feel anything about that experience?
Jonathon: Er no after I woke. .. . . . After I woke I felt a bit nervous when I felt, oh dear this could really happen if . . . if I did something like that
(Jonathon Frost – Interview 6, lines 122-127)

Kevin explained he felt stressed about the prospect of college:

Kevin: I am really stressed about college
Jill: At college you will get support from people like Lesley and Chloe
Kevin: I went on the Internet . . . and I wrote to this video game company and ask them
what I need to do to become a video game programmer and they told me I need to go to
high school
(Kevin Scarborough – Interview 3, lines 110-111)

Kevin could make use of the Internet for research on how he could realise his aspirations. He felt more able to do this than to seek the advice of a teacher or key person at school. In chapter 3 it was argued that due to the experience of barriers in the learning environment, the use of the computer could be more effective for some individuals. Kevin attended the special school and so did Wills who also explored his own ideas in realising his ambition to obtain qualifications:

Wills: Basically I've seen this advert where when I begin to study I can get A levels,
study in your own time and its for all ages .. GCSEs and A levels ..... and I am very very
. . . . do I have to put this in (referring to one of the pictures) this is the worst
picture(a picture of his sister) and she can go out back!
(Wills Martin – Interview 2, line 72)

He was determined to acquire the qualifications he needed and could not see how his current special school environment would help him to do this:

Wills: I'm 18 months ahead of my age ...... and they are holding me back ...... that's
why I know if I take this course for the GCSE level .... in the specific time ....
Maybe ... just maybe .. I might just get GCSE A levels
(Wills Martin – Interview 2, lines 234)

By the last interview Wills was still determined to take GCSEs and he later enrolled onto specific GCSEs at the mainstream school:

Jill: As you are doing more and more classes now at Upton Grange High .. do you have any plans for your future and what you hope to do in the future?
Wills: It is very simple .. live life one er.. one day at a time and see where life takes me
Jill: Are you thinking of going to college?
Wills: Yes .. right .. a full educated mind ... fully experienced in a lot of things .. would er really really make an impression in the world ... because the only way you get by in this world is money .. right? .. and you need an education to get a good job and a good job or good pay .. equals a lot of money .. and more money the better you get by in life
(Wills Martin – Interview 7, lines 186-189)

David wanted to please his mother in his selection of a career choice. His own aspirations were 'maybe I could be an artist or something'. His own preference was to be creative and to develop his interest in Japanese animation, yet he felt he should do an IT course and computing:

Jill: When you leave school what do you hope to be doing?
David: Well . . . maybe I could be an artist or something
Jill: Yes . . . So do you want to go to college?
David: Maybe . . . . . . well definitely go to college but ...
Jill: But you don't know what you will be studying yet?
David: Erm . . . . . . mum wants me to do all this like IT course and computing and everything . . . but you know I am into all Japanese animation aren't I so . . . I don't know whether if the IT thing will help . . . you know if I can create er . . . If I can create a . . . a game or something
(David Kent – Interview 6, lines 108-115)

Some young people are already compromising their aspirations, as they fear future environments will not sufficiently support them to do what they aspire to do. Rioux (1997) warns that if, researchers focus on the 'individual' or 'functional' approach to disability research, there is a risk of losing sight of the environmental and situational factors that may limit individuals from achieving their ambitions. It is clear from the following that Jason does not have aspirations to 'stack shelves'. It is a job that he feels he will have the *knowledge* to do:

Jill: So what do you think you are going to do when you leave school?
Jason: Well . . . Retail I would quite like ....
Jill: Any particular retail?
Jason: Hmm stacking shelves
Jill: Yes . . . do you feel quite comfortable and relaxed doing that?
Jason: Well it's the only easy job I know
Jill: When you say easy ...
Jason: I am not sure what other jobs there are that I would be good at
Jill: Is it because some jobs could cause you more anxiety or make you feel more nervous than other jobs?
Jason: Well . . . . . . erm . no its just hard
Jill: Hard in terms of . . . feeling tired?
Jason: its not feeling tired its just that . . . I might not know how to do. . . Say if I became a hairdresser . . . I might not be sure about doing hair
(Jason Smart – Interview 7 line 102-118)

Jason was insistent that it was not tiredness or anxiety that would be the limiting factors, but assimilating the amount of information required to do the job. Others had a general idea that they would like to go on and study at college when they leave school. They had given it some thought:

Jill: Right great excellent. so now it is your last year of school have you thought about what you are going to be doing when you leave school?
Jonathon: Yes, I would like to go to college
Jill: Yes .. what do you want to study when you get to college
Jonathon: I want to study software application, which is that text processing and er motor mechanics
Jill: Wow
Jonathon: . . . Fixing cars
(Jonathon Frost – Interview 2, line 223)

Even though James was aged between 14 and 15 throughout the duration of the research, the issues about the future were still of concern to him. He also had difficulty expressing his concerns and anxieties about the future. One particular day he was found to be asking the same question to his support assistant 'different St Francis?', 'Different St Francis?' He had heard that there were plans to develop a post 16 provision at the special school and he was communicating his concerns about the future and how this was going to change from what he now did in terms of attending the school.

The future and post 16 issues did not concern Andrew, Anthony, Simon and Philip, but were forthcoming concerns from the other remaining young people. It appeared that the issues of the future and of post 16 concerns were well defined and expressed by young people 15 years of age and the issues started to be raised with some of them at age 14.

There were 29 (2%) photographs where the young people had either photographed their artwork or used photography to be creative. Two examples of this creativity is presented by Philip and David. Philip sequenced photographs to get a close-up picture of a yew tree and David used the photographs to develop what he called a 'photo-board':

Philip: Oh I know why! I know why
Jill: Why?
Philip: I tried to make it so that they'd all join up…… so that ..so that you can see the tree
Jill: Oh I see ………
Philip: (Tries to piece together the photos on his lap)
Jill: Do you want to try putting them together on the floor?
Philip: I am not sure if they have all come out
1. Phil 6.10 (All the tree photos connected together)

(Philip Court - Interview 6 line 43)

David started to develop the idea o f a photo story in interview one. He was not very

confident with the idea at first and appeared to be unsure as to how I would react:

David: And that's Charmander and Evie again
David: Don't ask me why I take pictures of Charmander and Evie ...   it doesn't really
matter
Jill: (laughs) Why do you take pictures of Charmander and Evie?
David: (laughs) I told you not to ask
Jill: What is it about them that make you want to take pictures of them?
David: I was trying to do a photo story with them ... Charmander visits Evies pokemon
centre and says that he's ill, so Evie asks Charmander to lie down on the bed, but

Charmander uses special powers to make the bed fly, so he'll nick out. . . don't ask me why he does that. . . and don't this time
(David Kent, Interview 3, lines 113-118)

On David's instruction the question was not pursued again and later in the same

interview David continues the story, as another photograph prompts him:

David: I thought I took a picture of Charmander lying down on the bed
Jill: Right
David: I probably missed it.. . anyway they say Charmander laying away . . . even though its not very clear ... . think it was too close. . . and then they see Charmander fly all the way up there with the big Charmander and Jigglypuff
Jill: Oh I see … so here is a sequence . . . this one comes over here
David: That one goes at the start . . . anyway since I got the choo choo rocket that came in the post. . . you see they are flying away in a rocket and they are going 'help!' so Charmander has a secret plan to fly away to save them .. he pretends he's ill., goes to Evie's Pokemon centre and flies away on the bed
Jill: Right
David: You see there's a big Pikachu where Charmander flown away   he spots the hat and puts it on
Jill: Arh excellent.. that's very good!
(David Kent - Interview 3, lines 141-146)

David continues his 'photo story' theme in interview 5.

David: okay here's Blastoise and Charizard starting a Pokemon battle

David 5.2

Jill: right
David: the next one Charizard knocks Blastoise down ...

David 5.3

Jill: Yes
David: It doesn 7 look as though Blastoise is going to give up as he is going to do a gunning power bum on Charizard ...

David 5.4

Jill: Right
David: And he knocks him to the floor

David 5.5

David: You can see that little baby Togepi comes along

David 5.6

Jill: Right
David: While Charizard and Blastoise are still fighting
Jill: Hmmm
David: And Togepi knocks both of them out
Jill: Right. . . they look quite sad there on their backs there (laughs)
David: I think they were just embarrassed because they were beaten by a baby Pokemon
(David Kent, Interview 5, lines 22-40)

In interview six (the last interview with David), he continued the photo story theme, but by this interview he talked about putting the photographs in a sequence like a 'comic strip'. It was evident that as he had used the camera over time, he had developed his ideas of sequencing the photographs to illustrate a story, and to communicate this story to me in the interview. There is a change in his confidence from interview three to interview six, where he was initially 'cagey' and cautious about telling his story. In interview three he is almost uncertain as to how he will be received, as he says, 'don't ask me why I have taken photographs of Charmander and Evie'. I encouraged him, and by interview six he is confident and clear in his storytelling. David was able to lead the research process in a way that he wanted to. There were no expectations of him to take photographs in a particular way and, only through encouragement, did he discover his interest in developing 'photo stories' illustrated through a comic strip.

Other examples of the young people's creativity were of them setting up a scene for a photograph: Jonathon with his cat blackie above; Charlie, with his football rallying and "Pleasure Life" (chapter 3); Andrew Jones being photographed acting out a scene from a Jackie Chan movie. Although only a small percentage (2%), it contrasted with only 15 photographs (1%) that were taken by the young people looking out of their bedroom window. These pictures indicated perhaps the opposite of creativity, as they appeared to be taken without thought of the image.

House and garden

There were 30 pictures (2%) of the house and furnishings where the young person lived. There were also 14 pictures (1%) of the young people's gardens and garden furnishings. Jason, Wills, Peter and Andrew took photographs of the house where they lived. Wills also took a picture of a house that was for sale and said it was his dream house (chapter 3) and Andrew commented that the house where he was living was the best place he had lived. The other young people in the research concentrated on the interior house furnishings, with Charlie taking a picture of the bath and his bed; Anthony taking a picture of the mirror and a picture on the wall. Philip took a picture of his parents' bed as he 'liked the design' and Kevin took a picture of a cabinet in his bedroom where he stored his model car collection. Simon took photographs of different perspectives in the lounge, including the ceiling, the photographs on the wall, the door, the window, the settee.

School

One percent of the photographs were of the school environment. Only 12 pictures were taken of the environment only. Many more photographs were taken in the school, but the subject matter of the photographs tended to be made up with friends or peers or

marginally teachers or classroom assistants. Only four children took photographs of the environment only. Charlie took a photograph of the learning resource unit and said 'this is where I like to study', he also took a photograph of a path in the school commenting on how he likes his 'quiet'. Anthony also took a photograph of the learning resource and the computer room as well as the car park. Wills and Simon each took a photograph of the playground and the wider school environment.

Conclusion

This chapter has presented a content analysis of 1350 photographs taken by 11 young people involved in this study during the period from June 2000 to June 2001 (Please see Diagram 1).

	Family and family friend	Special Interests	Local area	Holidays/ Days out	Self	Pets/ animals	Friends	Tech interests	Non-Tech interests	Paid workers	Misc	Peers LD	Creativity	House or furnishings	Food or drink	Auty Peers	Main Peers	Look out of window	Garden and furnishings	School env		Total amount of photos per child
JF	15 23%			1 1.5%	5 7.5%	7 10.5%	3 4.5%	4 6%		9 13.5%	2 3%	5 7.5%	2 3%		4 6%		9 13.5%					66 (99.5%)
JS	40 36%	6 5%	21 19%	15 13.5%	4 3.5%	5 4.5%	3 3%	6 5%	1 0.9%		3 3%				2 2%			3 3%	2 2%			111 (100.4)
CH	7 5%	37 26%	49 34%	19 13%	4 2.5%		1 0.7%	9 6%	5 3.5%	1 0.7%	6 4%				2 1%			1 0.7%		2 1%		143 (98.1%)
AG	17 13%	7 5.5%	16 12.5%	16 12.5%	7 5.5%	3 2%	11 8.5%	7 5.5%		4 3%	3 2%		2 1.5%	5 4%	4 3%	12 9%		7 5.5%		7 5.5%		128 (98.5%)
DK	8 6..5%	21 17%		19 15.5%	4 3%	6 5%	25 20.5%	7 5.5%	5 4%	3 2.5%	9 7%		13 10.5%		1 0.8%	1 0.8%	1 0.8%					123 (99.4%)
PC	15 9..5%	60 39%	5 3%	5 3%	18 12%	5 3%	5 3%	5 3%	5 3%	13 8.5%			7 4.5%	2 1%	2 1%				8 5%			155 (98.5%)
SS	44 44%		23 23%		2 2%		1 1%	4 4%	7 7%		2 2%	3 3%		10 10%	1 1%			1 1%		1 1%		99 (99%)
AJ	21 34%		7 11%	7 11%	8 13%	13 21%	1 1.5%			1 1.5%				4 6.5%								62 (99.5%)
JaF	43 28%	2 1.5%	13 8.5%	2 1.5%	25 16.5%	7 4.5%	1 0.6%	8 5%	21 14%	1 0.6%	6 4%	9 6%	1 0.6%	1 0.6%	6 4%			3 2%	3 2%			152 (99.9%)
KS	5 4%	101 77%				12 9%	6 4.5%	4 3%		2 1.5%				1 0.7%								131 (99.7%)
WM	62 34.5%			20 11%	11 6%	16 9%	15 9%	3 1.5%	1 0.5%	9 5%	5 3%	16 9%	4 2%	3 1.5%	1 0.5%	8 4.5%	3 1.5%		1 0.5%	2 1%		180 (100%)
Total	277	234	134	104	88	74	72	57	45	43	36	33	29	30	19	21	13	15	14	12		1350
%age	20.5%	17%	10%	8%	6.5%	5.5%	5.5%	4%	3.5%	3%	2.5%	2.5%	2%	2%	1.5%	1.5%	1%	1%	1%	1%		(99.5%)

Diagram 1. A content analysis of 1350 photographs

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Although this was a study with 11 young people, it was important to highlight some of the issues that challenged the current mainstream literature on autism.

Firstly, an important issue was that relationships with people were fundamental in the lives of the young people. They had important relationships with siblings and often had to work through difficulties to maintain these relationships.

Secondly, the young people in this study did not have an affinity with objects, rather the objects may or may not be the focus of their 'special interest' that served a purpose to them to create some stability and lessen anxiety in their lives. Some of the young people had a 'special interest', which gave them satisfaction and enjoyment, but was sometimes referred to by others as an 'obsession'.

The environment was important to young people particularly their home environment. Most of the pictures of family and family friends were taken in the context of 'the home'. Transitions from one environment to another was evident as a 'barrier' to many of the young people and illustrated in chapter 3. There was evidence to show that the young person could become resourceful in managing these transitions and this was also evident when the environment changed, for example going on holiday. The young person explored ways to integrate their 'special interest' into this new environment. Such accommodation of the person's 'special interest' appeared to enable the person to enjoy their holiday.

This chapter challenged some of the assumptions made about people with a label of 'autism' in the theories outlined in chapter 1. The social model of disability offered an alternative research paradigm to explore ways to listen to people, in a way that recognised and attempted to break down 'disabling barriers' for inclusion in the research process. The findings in this chapter proposed that what we had originally assumed about people may have been limited by the choice of research methodology available to the research community. By changing the research method are better enabled in our understanding of 'autism' to view it as a 'disability' as opposed to the 'Triad of Impairments'.

Chapter 5 will conclude with an analysis of the important role that social interaction plays in the life of people with autism. Chapter 5 will develop the theme of 'social interaction' and draw upon findings from the research to argue that it is barriers that deny the social interaction between people with autism and others. The 11 young people in this study did not have an impairment in social interaction rather they experienced barriers that excluded them in the social interaction with others.

CHAPTER 5

'DISABLING BARRIERS' IN THE SOCIAL INTERACTION WITH OTHERS

> *"the biggest obstacle to disabled people's meaningful*
> *inclusion into mainstream community life is negative*
> *public attitudes. These range from overt prejudice and*
> *hostility, condescension and pity to ignorance and*
> *indifference and in these diverse ways they influence*
> *how we think about ourselves and other people"*
> (Barnes, 1998:4)

In the previous two chapters, I have argued that people with a label of 'autism' are

sociable in their interests and that the formation of interpersonal relationships with

brothers, sisters, parents and others are important to them. This chapter will focus in

more detail on the area of 'social interaction' and will examine the importance of

friendship in the lives of the 11 young people.

It will, however, be argued here that friendships are difficult to forge and to maintain

because of barriers within the environment, in communication and in terms of support

to access and invest in friendships. Some children with autism experienced bullying

and others experienced exclusion from social contact. Sinclair (1992) has identified that

it is not always the person with a label of 'autism' that causes difficulties in social

interaction:

> *"not all the gaps are caused by my failure to share*
> *other people's unthinking assumptions. Other people's*
> *failure to question their assumptions creates at least as*
> *many barriers to understanding"* (Sinclair, 1992:279)

Shakespeare (1994) argues that people with perceived impairments are not only

disabled by material discrimination (in relation to poverty) but also by prejudice.

Shakespeare argues that this prejudice is not just interpersonal but that the prejudice is

implicit in cultural representations in language and in socialisation. In chapters 3 and 4

this was illustrated with the experiences of David Kent. The use of the word 'normal'

in the continuous explanation of the process of genetics, was used in a way that resulted in David feeling alienated. Mainstream peers recognised this and when they asked the teacher to address the issue in his use of language, he failed to do so. This supports Abberley's argument (1997:42) who suggests that disabled people have inhabited a cultural, political and intellectual world from whose making they have been excluded. Scientific knowledge has been used to reinforce and justify this exclusion and this was discussed in chapter 1 with the all-consuming 'impairment' research that prevails in the lives of people with a label of 'autism'. Abberley (1997:42) argues that:

> *'New sociology of disablement needs to challenge this*
> *'objectivity' and 'truth' and replace it with knowledge*
> *which arises from the position of the oppressed and*
> *seeks to understand that oppression'*

This chapter aims to meet these challenges in some small way. Building on from the words and the pictures of young people in chapters 3 and 4, the chapter will explore the barriers to social interaction in the lives of the young people.

The young people did not use the words and language familiar to those of the disability movement, for example 'oppression, exclusion and inclusion'. (Even those within the disability movement question what is understood by the concept 'oppression' Abberley 1997a:161). Abberley, (1997a:161) argues that, although the term 'oppression' is used in the analysis of disability, it is not defined but rather seen as an 'obvious' but difficult to substantiate characteristic of 'social relations under capitalism'.

I was conscious not to use such words and tried to use expressions that the young people were familiar with and in a context that they would understand. Despite these efforts there were times when the words I used, were not familiar to the young people at all (further discussion and analysis of this is developed in chapter 6).

Walmsley (1997:72) warns of the danger of misinterpreting the views of people with learning difficulties when they may not be using similar means and methods to communicate. In 'Equal People' the dilemmas of co-authoring and co-editing with people with a learning difficulty are explained: "yet I do not know how to support them in translating these experiences from the personal to the political without taking over" (Walmsley, 1997:72). It is hoped that the research methodology developed within this research study (chapter 2) has gone some way to minimise the need for translating the personal to the political. The young people themselves (through discussion of the photographs) were insightful and reflective of the difficulties that they faced from the barriers external to them.

This chapter will argue then that the 'social' experiences of the young people mirror the experiences of others with a disability, yet it is often the 'barriers of communication' that prevent children with a label of 'autism' from being given the opportunity to be involved in the research process. A study carried out by Morris (2001) on the experiences of young disabled people, found that the individuals were able to clearly communicate what 'social exclusion' meant to them:

- Not being listened to

- Having no friends

- Finding it difficult to do the kind of things that non-disabled young people their age do, such as shopping, going to the cinema, clubbing, etc

- Being made to feel they have no contribution to make, that they are a burden

- Feeling unsafe, being harassed and bullied

- Not having control over spending money, not having enough money.

This chapter will assert that, in spite of lacking the words to describe their feelings of social exclusion, there is a considerable overlap between the way that young people in this study *feel* socially excluded and the ways highlighted in the research carried out by Morris (2001). In addition, the young people of this study found that information and the way it was imparted to them could be a barrier to their social interaction, as well as feeling disorientation/anxiety in new or different environments.

Finally this chapter seeks to understand ways in which young people express their need for 'social inclusion'. The myth that people with a label of 'autism' 'live in a world of their own' or 'prefer objects to people' has, I would assert, been challenged by the data generated in chapters 3 and 4. People *do* want social inclusion yet they may not be particularly clear as to what or how this should or could happen. Such a finding is in line with the research of Morris (2001) who found that in discussions with young disabled people that: 'It was easier for the young people to identify their experiences of exclusion and the causes than it was to identify what inclusion might be like'.

Corbett (1997:94) suggests that the 'social' is an important element of inclusion. The bleak isolation faced by individuals isolated in their own flats is explained:

> 'For it to become a much richer form of social inclusion, this kind of bleak independence has to be supported by wider social networks and friendships'

Morris (2001) argues that there is no current policy initiative that tackles friendship as a dimension of social inclusion. Yet friends can be the most important part of any child or young person's life. In support of this assertion by Morris, it will be important to re-define social inclusion from the perspective of young people with autism. It was evident in this study, that friendship was important to the young people. Friends could be those

who have been known to the person over many years or they could be those who are of a similar age and who share the partaking of activities with the person whilst on holiday. There is perhaps less emphasis on the need to stay in touch for the purpose of social exchange. However, barriers were evident in the development and maintenance of these friendships and, more particularly, barriers were experienced by two of the young people in forming a relationship with a girlfriend. Barriers were also evident in accessing 'age-appropriate' social activities and restrictions were often compounded with an inability to access these events independently. Jonathon's mother and younger brother would escort him to a youth club, but he often expressed frustrations about being around young children and would have preferred to be with those of his own age:

Jonathon: As I say I don't like ... I don't like being with mixed children ....
Jill: No?
Jonathon: eight, five year olds and sixteen year old, I just want .. to be somewhere where they are .. my age or a bit older
Jill: Yes off course .. yes .. mmmm
(Jonathon Frost – Interview 2, lines 57-60)

Jonathon was striving to develop his own identity. Whereas mixing with others was important for Jonathon, this was not a priority for Charlie and he was clearly happy to spend time on his own:

Charlie: Yes .. there is a field over there
Jill: Yes and do you ever get walking in that field?
Charlie: I am walking in the field .. yeah
Jill: And that's what you like to do at lunch time?
Charlie: Hmmm
Jill: Do you spend time walking there on your own or do you spend time with others?
Charlie: On me own yeah ... ... I enjoy it
(Charlie Hill - Interview 3, lines 195-100)

It is, however, when the young people 'feel' excluded from involvement with their peers in 'social events' or 'activities' that the feelings of exclusion are most felt. Jonathon and others often referred to friendship in relation to 'doing things together'. It

was the act of being absent from the social event itself that caused Jonathon the greatest concern:

Jill:... So is there anything else you want to talk about?
Jonathon: Well about birthday parties .... Er ... I don't get invited to anybody's .. but I did once but I think once isn't enough....
Jill: Who invited you to their party
Jonathon: It was a girl called Katy
Jill: Was that in your primary school?
Jonathon: l it.. secondary school three years ago
Jill: So why do you think that you are not invited to parties?
Jonathon: Oh.... I don't know... but I feel a bit lonely
(Jonathon Frost - Interview 3)

Jonathon had a close friendship with another young person (involved in this study) and he spoke highly of this friendship. The feelings of inclusion in the life of his friend and in shared activities with this friend were not sufficient to safeguard against the feelings of exclusion from not being invited to birthday parties. Although Jonathan experienced a feeling of 'exclusion' from the mainstream at a social (events) level, he explained how supportive his mainstream peers had been to him:

Jonathon:... and er... This one ... er all... are all the other pupils in my class

Photo 7.11

Jill: And what are their names?
Jonathon: Sally Scully, Jane Hayworth, Sam Fisher, Jo Althert.... Alberton , Katy Staples and Megan Riley
Jill: Oh right. And how do you get on with them?
Jonathon: I get on with them well
Jill: Yes ... that's good... So what would you say... thinking about the girls ...

Jonathon: Well . . . they've been good to me and everything
Jill: Have they?
Jonathon: especially Katy
Jill: In what way have they been good to you?
Jonathon: Well . . . helping me . . . er . . . talking to me . . . when . . . when I am alone
. . . when I am sat on me own with no one to talk to
(Jonathon Frost- Interview 7, lines 129-140)

Jonathon was astute enough to know and to be able to differentiate between those who have 'been good to him' and what constitutes friendship.

Defining Friendship

There was a difference between how the young person perceived friendship and how other non-disabled people defined friendship. The young people in this study defined friendship in relation to:

- Longevity of knowing

- Doing things together

- Sharing a special interest

The mythology of people with a label of 'autism' seeking to be 'alone' is still a theme in the literature on autism. Gillberg (1991:129) in outlining a case study about a young girl with Asperger syndrome writes: 'The fact that she has several "friends" may at first seem to detract from the possibility of this (Asperger Syndrome) diagnosis'. Gillberg then goes on to question the true validity of these friendships and writes: 'this girl at the age of fourteen in the middle of her pubertal period, has interactions with other people that are either obsessive or passive'. It is not the aim of this research study to judge the quality of friendships but to examine the barriers that are in place that sometimes cause emotional distress to people with a label of 'autism'. Jordan and Powell (1995:24) recognise the importance of friendship to people and explore ways in which barriers can be broken down, by teaching social interaction skills to form friendships.

The young people in this study had already established friendships and had developed the social skills to form friendships. The challenge for parents and others was to explore ways to help the young people maintain these friendships:

Wills: Simon Peters., one of my best friends . . . erm . . . me and him are continuously in competition on er who can do the best work
Jill: Arh right
Wills: We respect each other . . . and er . . . well er . . . he does excellent practical work better than I .. .
(Wills Martin - Interview 1, lines 104-104)

Friendships were apparent and evident in the lives of all the young people, but it was evident in different ways. Andrew Jones socially interacted with people around him using many of the stock phrases from some of his videos. He interacted minimally with other young people at school and an observer would not necessarily name individuals who would be seen as a friend by Andrew. When looking through the photographs with Andrew at the third interview, he volunteered information about his friend, who was in his home/social network:

Andrew: There's Charlotte and Bob

Andrew 3.23

Jill: Whose Charlotte?
Andrew: That's my friend   and that's his mum
(Andrew Jones - Interview 3, lines 105 - 110)

This may suggest that the environment can have an impact on either enabling or disabling the development of a friendship. Andrew (discussed later in this chapter) experienced bullying at school and he found many situations difficult and stressful. At home the environment could be sufficiently relaxing for friendships to be formed and maintained.

Longevity of knowing

For the young people, it was important to keep connections with friendships formed from primary school. This concerned continuing stability and connection with people even when the environment changes (such as a move from primary to secondary school)

Doing things together

A friend could be someone who the person had only just met on a social activity holiday, but it was the shared experience of 'doing things together' that classified this person as a friend. It did not matter if the person's name had been forgotten (after the event) and they probably would not keep in touch for 'social' reasons, but if the holiday was to reoccur then the friendship would pick up where it left off. This was evidence that the young person had a more practical than emotional expectation of a 'friend'.

Sharing a similar interest

For other young people, sharing a similar interest was a factor that connected them with another person and, therefore, reinforced their friendship. It was interesting to note that Philip Court was encouraging his friend to develop a special interest in cars:

Philip: That's me and my friend Drew, who you have seen in class before
Jill: Yes ..... how are you getting on with Drew?
Philip 6.2

Philip: Very well... And that's some of my cars
(Philip Court - Interview 6, line 17)

Philip's friendship with Drew was important. He enjoyed Drew's company and he was encouraging Drew to share his 'special interest' with him. Phil defined the quality of his friendship with Drew in relation to the extent to which Drew shared this special interest:

Jill: So why do you think you get on with Drew so well?
Phil: We share the same interests... we both like cars
Jill: Does he collect them?
Phil: Well he doesn't collect them but... He likes them
(Philip Court - Interview 3, lines 206-209)

Phil identified reciprocity in the friendship, but this reciprocity was based on the value of a skill, a tangible level of competence, that he admired in Drew:

Jill: I was wondering if... you know Drew's interest in cars ... is there anything else you both have in common or that you like doing together?
Phil: er... we both like taking things to bits
Jill: what does he...
Phil: Which I suppose is not one of my strongest points as I can't always put it back together
Jill: Right
Phil: He usually manages to put his back together again
(Philip Court - Interview 3, lines 216-220)

Phil reveals his humour when discussing Drew's interest in cars:

Philip: I have a gold Cabriolet here . . . oh the DS 21 that's nice
Jill: Hmmm that's nice
Jill: So does Drew share your love of cars . . . Is he into cars?
Philip (pauses for 4 seconds) He doesn't particularly like them . . . But he is growing into it
Jill: Is he (laughs)
Phil: I am working on him . . . look that little Ford escort GL that's nice
(Philip Court – Interview 4, lines 71-74

Drew was an established friend and featured throughout the period of research and from observations, the friendship was supportive and reciprocal. Analysis from others may assess Drew as being passive in the relationship and, therefore the supposition of whether this is a real friendship could then be called into question. From observations in the class and documented in chapter 3, Drew played an active role in class when he would give Phil prompts to get on with the task. The friendship appeared to be mutually supportive and beneficial to both parties.

Jonathon defined friendship by: 'longevity of knowing':

Jill: Is there anybody else up there who is a friend of yours?
Jonathon: Er . . . no
Jill: No, so its Kevin you get on well with?
Jonathon: yeah
Jill: Because he is taking pictures as well for this project
Jonathon: I have known him seven years
(Jonathon Frost- Interview 3 -19th October 2000)

Jonathon did not have an obvious 'special interest', so for him, friendship was about 'doing things together', friendship is about sharing experiences in 'doing', such as going bowling, playing football, and sharing in other activities.

One of the barriers that exists to prevent the formation of friendships between young people and others, is that the young people in this study did not have a great need to

'keep in touch'. The social banter and conversation that often defines friendship is not referred to as being an essential element of friendship to the people in this study. They do not necessarily need to talk to each other to maintain a friendship. When a young person states that an individual is their friend, they may not be using the same terms of reference that others define 'friendship' as, for example for emotional needs in conversation. The following example highlights how David refers to the importance of friendship to him:

Jill: Which do you think in terms of your favourite pictures   which ones would they be?
David: I like the pictures of all my friends
(David Kent-Interview 3, line 135)

Yet in the next interview he referred to friends in the pictures (taken on a social activity holiday), but could not remember their names:

David: It's kind a weird. . . There's some more of our friends . . . had quite a good time up there

 3avid 4.16

Jill: what are their names David?
David: oh I can't remember actually
(David Kent-Interview 4, lines 75-81)

David had a really good time and enjoyed the activities and company he was in:

David: We did a lot of that over there ... but Joe and me we became friends really fast
Jill: Yes and this is Joe... It would be nice if he keeps in touch
David: Should have got some photos of when we went bowling and to Camelot
Jill: Right
David: Bowling was wicked
Jill: Yes... what did you do indoor bowling or outdoors... did you do it in teams?
David: It was indoor... we did work in teams and the thing is in my team I came fourth on the first game, 2nd on the 2nd game and 1st on the third game
Jill: Wow
David: Mind you that was because the third game only lasted about a few seconds, only two of us got to bowl and suddenly it stopped (laughs) ... my shortest and first victory ever in bowling
(David Kent-interview 4, lines 197-203)

It was interesting to note that it was my emphasis to make the point: "it would be nice to keep in touch". There was no motivation for David to 'keep in touch' as he had his interests; his friendship might more than likely resume again with Joe, should he find himself in a similar social/activity situation with him.

Bowling was popular with Simon who took the following picture:

Jill: Who else was there that night... who are these people?

Simon 5.2

Simon: They are people that stay in school
Jill: Can you remember their names?
Simon: Neil, Sam and Shirley, and Martha, Dave
Jill: Is there anyone there who is your friend?
Simon: Yes, Sam

Jill: And what do you like about Sam?
Simon: He's a good lad
Jill: He's a good lad. Hmmm and what does he do, what does he like?
Simon : er... we bowl

For much of the time, throughout the research, I had to guard against my own values, understandings and interpretations of social relationships and 'friendship'. I was surprised when Charlie expressed to me that Alex Green was his best friend, as I had not seen them communicate with each other whilst at school:

Charlie3.18

Charlie: Hmmm . . . now that's one of Alex Green
Jill: That's good... so how would you class Alex is he somebody in the resource or would you see him as a friend?
Charlie: He is in the resource . . . but he is my best friend
Jill: He is your best friend?
Charlie: Hmmm
Jill: Brilliant and do you do things together when you are at school?
Charlie: I see him a lot.. . but I don't have time to talk to him . . . like I could do
(Charlie Hill-Interview 3, lines 201-208)

Charlie's friendship with Alex Green was based on 'longevity of knowing' and he felt this would present opportunities of 'doing things' together. While Charlie felt that Alex Green was his best friend, Alex did not invite Charlie to a birthday party (that Charlie expected an invitation to). Charlie took this very hard and found it quite difficult to

understand. Charlie had been around Alex for all the years of his attendance at South Down's Secondary school and had often been supported in classes by the same support assistant. They even sat closely together while the support assistant facilitated both their learning. It was also the experience of 'doing' things together in relation to learning that Charlie felt had connected them both.

David and Jason also reported on their friendship with Alex. Alex appeared to be a popular person as a friend, yet he related to the world at a sensory level and used lots of metaphorical language:

David: Nah … And there's Alex
David 2.9

Jill: Yes
David: Off course we all know Alex
Jill: So would you say that Alex is a friend?
David: Yes
(David Kent-interview 2, 50-55)

David was, however, able to explain that Alex was a close friend but not as close as others, such as Marcus, Steven and Debbie. At the end of the interview, I asked David if

he wanted to spread the photographs out on the floor. This was made easier for me as David preferred to be interviewed sitting on the lounge floor:

Jill: [separating out the photographs] *We will put Marcus and Steven right next to you there . . . very close . . . where would you put Alex . . . where would Alex come?*
David: So I have to put these in a place?
Jill: Well would Alex be very close to you or is he a little bit over there . . . not quite as close as Steven and not quite as close as Marcus
David: Not as close as them . . . no
Jill: So would he come about here?
David: Marcus, Steven and Debbie are all as close as each other aren't they?
Jill: Right . . . What about Roger where does Roger come?
David: About the same distance as Alex
Jill: Right . . . and Nicholas?
David: Basically the same
Jill: So these are the close friends and these are friends, but not as close as these friends?
David: Hmmm
(David Kent-Interview 2, line 155-75)

It appeared that 'longevity of knowing' a person was a factor that indicated closeness for David:

Jill: Does he . . . so would you say there are any special friends . . . some are closer than others?
David: Well Marcus and Steven are my best friends . . . I have known Steven for a long time
(David Kent-Interview 2, line 153-54)

David had known Steven since they attended primary school together and David had only met Alex when he started secondary school. Jonathon indicated that the length of time knowing Sarah was important in the status of their friendship:

Jonathon: Ah... right... this one is a picture of Sarah
Jill: Yes?
Jonathon: So I wouldn't forget what she looks like in her uniform
Photo 7.10

Jill: Ah. Did she ask you to take that?
Jonathon: No it was.... actually it was my idea
Jill: Oh was it? So how much do you like Sarah is she like a special friend or is she a friend?
Jonathon: A special friend... We've known each other for near... almost five years
(Jonathon Frost - Interview 7, lines 117-128)

Anthony had a desire to form friendships (like most young people do), but he faced a

barrier of others excluding him on the basis of his tendency to form too 'intense'

friendships. He himself recognised that he is likely to 'get in his face too much'

(Anthony Garrett-Interview 6, line 75-80). It was important for Anthony that he had

friends, but what he himself understood to be friendship was not understood by others in

the same way:

> Document 'Anthony Garrett' December 2000. 2 passages. 894 characters
> **We arrived at the art room and waited outside for the teacher to arrive, Anthony had said hello to all the boys from the learning unit as we had walked across sites and he had passed them, he told me he had lots of friends including Wayne and Jake. As we were standing outside waiting for the teacher to open the door, Anthony spotted Wayne coming over in the distance. He ran towards Wayne to catch his eye and waved to him. (Anthony has been instructed not to talk to Wayne, because of the intensity of his relationship with him.) Wayne ignored Anthony and Anthony was**

determined to wave at him and to say hello. Wayne ignored him again and carried on his way, Anthony persevered and waved again and I noticed that Wayne was having none of this, as he increased his pace, his head was down and he was determined to get to lesson without any interaction with Anthony. Anthony came back to wait outside the art room, he looked anxious.

Anthony's behaviour becomes manifest to others as a management problem. An emphasis is placed on minimising the occurrence of the behaviour and protecting those who are identified by Anthony as 'friends'. As the behaviour increases in intensity it becomes observed as an 'obsessional behaviour' with individual-named children identified as 'friendship' targets. The situation is not observed or understood by others as Anthony's desire to seek out 'friendships', for his need to satisfy emotional responses, such as feeling a sense of belonging, seeking to be liked, and to feel included.

He would often feel doubtful about how people felt about him and would seek reassurance that others liked him:

> <u>Document 'Anthony Garrett' January 2001, 1 passage, 273 characters</u>
> And while we were waiting he had asked me if Jake and Wayne were his friends and I replied 'what do you think?' and he replied to me 'what do you think?' and I said I don't know the people you mentioned. He said 'okay I will go and ask Mrs Marilyn then'. I went with him to ask Mrs Marilyn. He asked her the question and she said 'yes' and he seemed happy with this answer.

Feedback and reassurance are important to Anthony and this is illustrated in his need to obtain feedback from the young people themselves. This need for reassurance has a social origin.

For Anthony, a pattern developed where his desperate need for reassurance resulted in his overpowering relationships towards his peers. They in turn rejected him and he moved on to another individual who became the target for his advances of friendship.

The following picture shows Anthony (on the right) and Simon (a friend) and what he had to say about his friendship emphasised his need to feel included and to be accepted by others.

Anthony 7.8
Jill: that's a good picture . . . who took that picture?
Anthony: Mr Mason
Jill: you look very happy there . . . What is making you happy there?
Anthony: friendship

Jill: what makes a good friend?
Anthony: talking
(Anthony Garrett-Interview 7, line 119-123)

Relationships between people with a label of 'autism'

The young people in the research study demonstrated the skills of listening to others and showing an interest in each others pastimes. Jonathon defines his friendship with 'another boy' is defined by a shared interest:

Jonathon: And there is another boy who is a bit of me friend as well . . . his name's Peter
Jill: Oh right how do you know peter
Jonathon: Well oh we . . . when we er ... do impressions of er a famous boxer Chris Eubank ... he doesn't stop keeping on about him . . . (mimicks Chris Eubank) and he laughs when I start
Jill: Oh I see so that's what you have in common, does he do any other impressions?
Jonathon: Er... no
Jill: Just Chris Eubank. . . Hmmmm
(Jonathon Frost-Interview 6, lines 85-90)

Charlie talked about how he was able to share his special interest with another young person. He played a 'fantasy football game' and explained how Ben participated with him in this game. When I asked Charlie who this was, he replied saying: 'he's my friend'. It is clear in this example that sharing a common interest connected the two in friendship.

Charlie: Hmmmm that was another match the gold cup match,, that I did at Millhouses Park and I played that match when I went to Ben's house and it was the first round and Sheffield united drew 17 all with Sheffield Wednesday. . . and it was a battling game . . . and Ben actually. . . was the only person to ... to . . . make the gold cup ... to make a competition up other than me of pretend football rallying... and he made the gold cup u up… we both decided it together and we both made the gold cup up ......
Jill: Yes . . . that was Ben Stilworth?
Charlie: Yeah … he's my friend
Jill: Yes . . . its good you can do this with someone else isn't it?

Jason revealed the following about his friendship with Alex Green:

(Interview 1, when the tape was switched off)

Jill: Who is your friend at school?
Jason: Alex Green

Jason 3.5
Jill: I have noticed that you seem to get on well. Who else is your friend at school?
Jason: Trevor Sandhurst
Jill: What is it about Trevor that makes him a friend?
Jason: He has similar interests to me
Jill: and what are they?
Jason: Cartoons
Jill: What type of cartoons?
Jason: (pauses)
Jill: Like Pokemon?
Jason: I don't really like Pokemon

Wills Martin talked about the exchange of Pokemon cards as a 'shared interest' with his friend:

Wills: His name is Simon
Jill: Right . . . is he a friend of yours or . . . is there something else about him that made you want to take the picture
Wills: He's got loads of Pokemon cards and he's a mate
Jill: Oh right
Wills: A specifically very good mate . . . because he will love to trade for special cards . . . he likes the little kind but he don't like big ones . . . and I love the big ones as they're worth a lot
Jill: Yes
(Wills Martin - Interview 2 lines 309-316)

Even though the young people mentioned the qualities of individual friends, it was usually the shared interest that established and maintained a connection of friendship. Wills talked of his friendship with one of the pupils at the mainstream school he attended for some GCSE classes. He used particular words to describe his friend. He said: 'He doesn't patronise; and he is always ready to listen'. This would suggest that his previous experiences had brought him into contact with others who are not so willing or able to listen and whose communication and interaction could be interpreted as 'patronising'.

Wills: Unfortunately I didn't have a flash on when I took this on. . . this is one of my mate's Tom
Wills 6.2

Wills: Right... he doesn't patronise ... he doesn't do anything. . . right he is always cheerful and always friendly. . . and always willing to listen
Jill: Which lesson is that... Do you actually talk to him about your experiences and what has happened to you?
Wills: No not really. . . I just talk to him about wrestling
Jill: Right. . . that's good
Wills: That's what he listens about
(Wills Martin - Interview 6, lines 16-23)

I had assumed that Wills was referring to his personal experiences of bullying in the

mainstream school, but he was referring to his 'special interest'.

Differentiating between friendships, siblings and girlfriends

Young people were clear as to who 'is not' a friend, in the same way as they were clear

as to who 'is' a friend. Jason made reference to a 'friend' and then acknowledged that

this person 'is more his brother's friend' than his:

Jason: And that's Jake Fisher's house
Jill: Oh right and who is Jake Fisher?
Jason: He's a friend... he's my brother's friend
Jason: I just walked around taking these photos and he didn't know I took it
Jill: So do you spend time with Jake Fisher or is he more your brothers friend?
Jason: He is more my brothers friend.. I mean I go places with them sometimes
Jill: Yes
(Jason Smart-Interview 4, lines 106-111)

Friends were also differentiated from girlfriends:

Jill: Yes . . . are these friends or girlfriends
David: I don't have a girlfriend
(David Kent – Interview 3, lines 136-137)

Relationships

Throughout the duration of the research five out of the 11 young people expressed an

interest in developing a 'relationship' with another young person. The young people did

not always feel comfortable in discussing these issues with me:

Jill: So do you have a girlfriend?
Wills: I will keep that one to myself if you don't mind
Jill: Okay
(Wills Martin – Interview 7 lines 172-175)

The way relationships were referred to was not purely at a sexual level, it was at a level

of desiring closeness or 'intimacy'. There was evidence of the person feeling attracted

to another person and attraction was discussed:

Jonathon: Andrew [Jonathon's brother] *went to visit, er . . . went to . . . went to wirl . . .*
went to a playscheme at wirlow farm and these people (pointing to people in the
photograph) . . . who I was attracted to . . . I wanted to take pictures of
Jill: Right. And who was you attracted to?
Jonathon: Well . . . the one who took me . . . my picture . . . they called her Stacey and
erm . . . and her daughter Kylie
(Jonathon Frost – Interview 2, lines 13-17)

David expressed how he felt about Molly's appearance:

David: Yeah . . . there's a picture of Molly and me that was took
Jill: Oh that's a nice picture
David: She looks cute even with red eyes
Jill: Have you seen her since?
David: I am going to see her . . . when I do the play at the Crucible . . . 'cos you know
the youth dance are in the play that were doing. I suppose I am the only one stupid
enough to wear one of those Macdonald's hats
(David Kent – Interview 3, lines 65-70)

David identified that it would be through a shared activity that he would be able to see Molly again. Even though he felt attracted to her he was not sure what he should do about this.

Sometimes it was not clear why the person found the individual attractive:

Jill: Oh right. What was it about her that made you feel attracted to her?
Jonathon: Mmm . . . couldn't stop thinking about her.
Jill: Yes?
Jonathon: I wanted to . . . took me a year to get around her
Jill: Oh so you have known her before?
Jonathon: Yeah last year
Jill: Oh, so you have been thinking about her in the year?
Jonathon: Hmmm
(Jonathon Frost – Interview 2, lines 26-28)

Jonathon had wanted to get in touch with Kylie but he was unsure as to how he should make contact:

Jill: *Did you have any way of getting in contact with her afterwards?*
Jonathon: no . . . I was a bit shy
Jill: Oh right. What would you have liked to have done . . . if you wasn't so shy?
Jonathon: got talking to her, but she is . . . she's actually quiet herself
(Jonathon Frost – Interview 2, lines 22-25)

Even though Jonathon expressed an interest in seeing Kylie again, he found it easier to say that he would obtain her mobile phone number:

Jill: Would you like to see her again?
Jonathon: Yes
Jill: Is there any way that you think it's possible to see her again?
Jonathon: By getting her mobile number
Jill: She has a mobile?
Jonathon: Yes

David had been out with Ella and, emotionally, he appeared to be quite neutral in his observations of this past relationship:

Jill: So the picture of you and Ella . . . is Ella a good friend of yours?
David: We used to go out
Jill: Oh yeah as girlfriend and boyfriend?
David: Yeah
David: And the good thing is the only person I look like I am strangling is Andy because of the expression on his face
(David Kent – Interview 4, 144-147)

David had now changed the subject, but he allowed me to probe further:

Jill: Are you still okay about being friends with Ella even though you went out at one time?
David: Yeah we are still okay about being friends yeah
Jill: And why did you stop being girlfriend and boyfriend
David: I don't know actually . . . I mean it wasn't my decision
Jill: It was her decision?
David: Hmmm
Jill: Right . . . but your still friends . . . that's nice
(David Kent – Interview 4, lines 151-157)

From this discussion, David could not explain why the relationship finished. He was also none the wiser in understanding what had happened between Katy and himself:

Jill: Yeah . . . so this is Katy?
David: Yeah
Jill: Now you are holding hands with Katy here . . . was that in terms of friendship or was it more than friendship?
David: it's kind a weird really . . . 'cos I went out with her for a day . . . then the next day she whacked me over the head with a clip board . . . and I'm like what the hell is going on . . . and at the disco she asked me to dance with her
Jill: oh right
David: of course I accepted but . . . it's kind a weird isn't it?
Jill: Yeah because she's giving you mixed messages?
David: Hmmm
Jill: How did you leave things with her then . . . did you find out what she felt about you?
David: I think . . . I think we have managed to stay good friends actually
(David Kent – Interview 4 – lines, 168-175)

David experienced a lack of closure from his relationships with girls. He was unable to learn from and understand what happened in both the relationship with Ella and Katy. Ericson (1974) argues that it is important to go through a stage of developing awareness and learning as we go through adolescence. It was evident that David had not learned from past relationships to inform him of future ones. There is no support for David to reflect upon these experiences and to ensure adequate learning takes place.

Maintaining friendships and relationships

This study supports the suggestions made by Nunkoosing and John (1996) that there are practical difficulties in maintaining contact with friends. Even though Charlie had made it quite clear that he and Jack were good friends, he was not sure how he was going to see him again or how he would stay in contact. He was dependent on others around him, caring enough about the importance of friendship to support Charlie to maintain his friendship with Jack:

Jill: Do you still see Jack?
Charlie: No . . . he is at another college . . . at Carlton college
Jill: Oh that's a shame . . . shame if you got on with him
Charlie: I am wondering about me going there or coming here . . . mum's saying about him coming here
Jill: Have you talked to your mum about that?
Charlie: Yeah
Jill: That's good . . . its good to keep in touch with friends isn't it?
Charlie: Hmmm
(Charlie Hill-Interview 7, lines 396-407)

It appears that staying in contact with Jack is not happening as much as Charlie would like. In interview 5 (26 August 2000), Charlie was asked if he had been in contact with any of the young people from school through the summer holidays:

Jill: Yes . . . have you been in contact with any of the other children at the resource . . . in the holiday time?
Charlie: I have yeah but . . . I haven't seen them in the holidays . . . I have seen about . . . I've got the phone numbers but . . . but I think we are both busy . . . we are all busy too busy to call
Jill: So who would you like to call if you . . . you had the time?
Charlie: Jack Hunting he's a good friend

Although Charlie had said that he was 'too busy to call', he still expressed a desire to have contact with Jack. It was on 16 December 2000 in interview seven where Charlie continued to discuss his friendship with Jack and at the same time talk about the difficulties of staying in contact. There was a barrier in place that prevented Charlie from accessing the telephone to arrange contact. This was left for his mother to arrange on his behalf.

Relationships between people with a label of 'autism' and adults

Relationships between young people with a label of 'autism' and adults are not only necessary to enable people to challenge the barriers that exist, but are vital for the establishment of effective communication. This study found that parents acted primarily as a 'bridge' for people, to help promote their understanding and to break down barriers in understanding the social rules within wider society.

Parents enabled the engagement of their sons in the research process and there were times when the development of the relationship between the young person and me was assisted by the parents:

Jill: Do you want to speak on there to test it . . . do you want to say something?
Simon: Er . . . er . . . er . . . er . . .
Mum: Tell her what your name is Simon?
Simon: My name is Simon . . . And I live at number 73 Angel Park Road
(Simon Sands – Interview 2, lines 1-4)

Simon's mother could hear that Simon was struggling when he was asked to do something 'obscure', when urged to: 'say something'. She took on the role of telling me that Simon needed to be asked more specific questions in order for him to answer.

Parents took on a role of 'interpreter' or 'translator':

Jill: What about strangers? Can they communicate with James?
Mum: Sometimes again . . . it depends . . . less so than we can I think . . . we have to interpret . . . usually . . . people look at us as if to say what is he saying
Jill: Right
Dad: It usually works if people use fairly simple sentences . . . when they are no longer strangers they soon get used to him . . . but while they are strangers they will be more unclear won't they (looks to mum)?
(James Frazer – Communication Profile)

Barriers in communication can exist if the non-disabled person does not take measures to go 'half way' towards the 'world-view' of the young person with a label of 'autism'. Watching the person's favourite videos and reading the person's books are just two ways to help to develop a good rapport and a relationship with the person.

My own failure to recognise barriers in my communication was evident with James Frazer. He had a limited understanding of the rules of **The Systems of Interpretation** and I had an almost non-existent view of his world. Although I had taken gone to great depths to develop a communication profile by interviewing James' parents, I failed to find out what his 'special interests were' and what his favourite books and videos were. I had not equipped myself with any language that James could relate to, from his frame of reference. He was not able to be in my company for more than 2.8 minutes for the first interview, although he had taken a range of photographs. I was causing him considerable exposure anxiety.

My lack of preparation and success with the first interview disabled me for the second interview with James. He did not want me to tape record the interview and he could still not be in the same room as me. His exposure anxiety was still high, yet I still did not have anything to share with him or say about his subject of special interest to help develop the relationship. He had taken a picture of Mr Bean:

Mum: It's Mr
James: Bean
James 2.1

Mum: Yes you know Mr Bean don't you? Do you want to show Jill . . . your Mr Bean
you made at school?
James: (shows me what he had made at school)
Jill: Oh did you make that?
James: Der der da der der (humming a song)
Jill: That's very good James
James: Is it . . . liar liar liar . . . say that's much better
(James Frazer -Interview 2)

James had a wide array of interests that were portrayed in a range of photographs that included books and videos. On reflection, I should have asked questions about James special interests while researching and developing the communication profile. My knowledge of the subject, e.g. Mr Bean could have been used as 'openers' in the communication whilst trying to establish a rapport with James.

A sense of humour is important to foster a relationship between young people and adults. Jonathon Frost, defined 'laughter' as one of the important factors that helped

him to relate to one of the care workers. Jonathon Frost discussed the relationship he had with Dave:

Jonathon Frost Photo 6.2

Jill: And how d'you get on with Dave
Jonathon: I get on with him o ... alright... good
Jill: What are the things you like about him?
Jonathon: Well he's funny
Jill: Yeah ... why does he tell you jokes?
Jonathon: Erm ... not lately no
Jill: What sort of things does he say to you then?
Jonathon: Well er ... when we watch the television programme, a comedy man who was on this roundabout and he had like been sick and he had a beard on
Jill: Oh err... no
Jonathon: And then Dave says "oh no"
Jill: So is it his expressions that make you laugh?
Jonathon: (laughs) yes.
(Jonathon Frost-Interview 6, lines 12-28)

Jonathon gave an explanation as to why he felt his relationship with Dave was positive. He explained that it was through 'social interaction' that connected him with Dave. It was not the content of what he said i.e. telling jokes, it was the sharing of an experience with him (watching television) and the sharing of laughter about a social mishap.

Kevin explained how important the role of a 'support assistant' was to him at St.Francis special school. He identified Lesley as being of even greater importance than any peer. The importance of the role of support assistants can not be underestimated and Lesley

and other support assistants often took over the role of 'interpreter' and 'translator' from the parents for the duration of a school day:

> Jill: Are you looking forward to going back to school?
> Kevin: no
> Jill: Is there anything good about school that you like?
> Kevin: (pauses)
> Jill: Is there any person you like being with at school?
> Kevin: Lesley (the support assistant)
> Jill: Lesley? why do you like being with Lesley?
> Kevin: She's nice and she supports me
> (Kevin Scarborough – Interview 3 lines 95-100)

It is the qualities in the relationships between people with a label of 'autism' and adults that require further analysis and research. It is likely to be the success in the social interaction of the relationship that may well be a key factor in motivating the person to challenge the disabling barriers that are around them. It will be argued that where the person experiences barriers in social interaction (negative relationships with an adult), this is likely to lead to the to 'slipping out of gear' and reverting to the world of the sensory or *all self, no other* (chapter 3).

Bullying

Andrew reverted to the world of the 'sensory' as a means of escape from either the confusing demands of the school environment or the ridicule and teasing he was subjected to from his peers. Andrew's form teacher however took a behavioural management approach with him and Andrew had a list of behavioural targets to follow. The behavioural targets were successful in modifying Andrew's behaviour, but it soon became apparent that new behaviours began to emerge in their place. He also started to show signs of his unhappiness and sadness as he continued to endure the teasing from his peers.

When I first started the research with Andrew Jones, (June 2000) I was able to watch how Andrew reverted to the safety of the sensory world. I could hear him acting out the scripts from his favourite videos and I witnessed the pleasure this gave him. He would often smile at me as I became his audience and he injected enthusiasm into his portrayal of the characters. The words were clear, as he confidently articulated. But one year on (July 2001) he was miming the scripts and the words were barely audible. He no longer smiled or appeared to have much enthusiasm. It was as if he had learnt that he had to do this covertly. What to him was a coping strategy to help him through a confusing world, was observed by the school to be 'inappropriate behaviour' and was not acceptable behaviour at the school.

The new behaviours appeared to be more sensory related such as licking and picking his fingers. Another new behaviour was his apparent need to 'hide' behind physical props as a way of managing his anxiety, whereas previously I had not observed this. Previously, the acting out of the video scripts was sufficient as a 'self management' strategy to help Andrew cope with the demands of his environment, or even to cope with bullies. He used to act out the scripts with relish and show his pleasure and enjoyment. In June 2000, he would periodically revert to the 'sensory' world of the video scripts and video characters as they were safe and predictable and gave him some relief from the intense demands of the school day.

> Andrew Jones June 2000
> I wrote: 'uses sensory stimulation to make sounds of a
> machine gun when he has finished doing the work he was
> doing. He is re-enacting scripts from a video, he is talking
> about inspector gadget, I think he is Inspector gadget'.

In July 2000 I observed that Andrew used the characters and the scripts from videos as a way of socially interacting:

> Andrew Jones July 2000
> Using his characters to interact with me. Andrew is pointing
> to me and says 'you are ready to get done' he then says that is
> in Mr Bean, he explains that is funny, he says the funny bit is
> when he rubs his face off

There was evidence that Andrew was being bullied at school. Andrew handled his

distress from being hit, by reverting to his sensory world:

> Andrew Jones February 2001
> He walks around the room, comes back to get his disk and
> then re-enacts Beavis and Butthead, he is standing by me and
> says "for my first day here at Highland High I want to see as
> many students as possible, why don't you tell me your earliest
> memory" (a line from Beavis and Butthead video)

In March 2001, there was conflict between Andrew and Jade and this led him to be sent

out of the classroom and asked to sit in another classroom on his own. As I was

shadowing him that day I asked the teacher if it was okay for me to follow Andrew to

the other class and she said yes. What then happened gave me a deeper insight into the

importance of acting out the video scripts as almost a 'haven' from the stress and

distress caused by the barriers of confusion and misunderstandings:

> Andrew Jones March 2001
> I go to find Andrew and he is sitting alone in the classroom
> and he has his head lowered towards his desk, he is looking at
> his behavioural targets as he was reminded to look at them
> while in this class on his own. I enter the room and he asks
> me why I am here with him and I tell him I want to be with
> him and he says shouldn't I be with the others and I say I
> want to be with him. His face lights up and he then gets out
> of his seat and starts to perform. He re-enacts a scene from
> Beavis and Butthead and alternates between the characters. It
> is a magnificent performance, he knows the script word for
> word and it is quite funny. He does this for almost five
> minutes and then he asks me what I thought. I said it was
> good and then I asked him how it made him feel and he said
> happy and he smiled at me. He then says right, what shall I
> do now and he then starts to re-enact another script. He keeps
> looking over to me to check that I am watching. Kate the
> teacher comes in and says to Andrew are you ready to come in

yet and he says impatiently 'no, I need some more peace and quiet'. She reminds him that he didn't follow his targets, that what Jade did was wrong but that what he did was also wrong. I become aware that it is perhaps not good to continue to be an audience for Andrew and I say to Andrew I need to leave now.

In June 2001, I observed significant changes in Andrew. He still needed to re-enact his video scripts, yet this appeared to be toned down. I could barely work out the words and they were almost like a mime. Andrew's behaviour had changed, but his understanding of what was going on did not appear to have done so. Andrew's behaviour looked more socially acceptable now. But for Andrew fear was still apparent in his life as he failed to understand some of the things that were required of him. The need for Andrew to use more severe strategies to 'hide' within his environment and to serve as some protection from the exposure anxiety was seen to have increased some months later:

Andrew Jones June 2001
He has a polo neck jumper on and it is going to be in the 80's today, as Clara (support assistant) was talking he pulled up the neck of the jumper and covered half his face.

Andrew endured teasing as quite an extensive feature of his schooling experience, yet I was not aware of any recognition by the school to deal with this as a major social problem. The negative social interaction between children with learning difficulties and Andrew put a significant amount of pressure on him and started to cause him some 'anxiety'. The bullying can be done covertly and in a way that misses the attention of the teacher:

Liam turns around and he and another boy start to stare intently at Andrew, the other boy is whispering words under his breath at Andrew, at a level that the teacher cant hear. Andrew says shut up and he repeats it. Andrew says shut up and he says it again, Andrew is trying to concentrate 10.11 the teacher does not see what is happening and the other boy starts looking at Andrew and smiling and Andrew ignores him. Andrew tries working and Liam and the other boy look at each other and then both look at Andrew and then laugh, Andrew says shut up.

When Andrew reported the bullying he was told to get on with his work. Andrew had not had any response to his attempts to report the bullying. It was when he was given the opportunity to role play someone being interviewed (which builds on his special interest of videos and films) he was able to say what it was he liked and what he didn't like. It was at this point that it emerged the bullying was a problem for him.

Andrew Jones Document 6 February 2001

He practices his script and then the support assistant comes in and Andrew asks her some questions. She then says can I ask you some now Andrew and he says yes and she says what do you like and he says 'I don't like bullies and my favourite food is pizza'. Andrew is then supported to interview a teacher that he has chosen to interview. She says she likes music and teaching maths, got two children, do the garden, likes it when people cant do something but can do it the next day.

The existence of bullying can go unrecognised when for many children they have not got the words to explain what is happening to them. Even when the child has the words they may not be able to communicate the extent of the problem, due to the barriers that exist in listening to young people with a label of 'autism'. As the above example illustrates it is only when Andrew is given the opportunity to communicate through his 'special interest' that it emerges that bullying is a problem for him.

To conclude it can be argued that barriers exist in the development and maintenance of relationships between people with a label of 'autism' and others. It does, however, appear that friendships may be defined differently and may present with an entirely different set of barriers in the development and maintenance of friendships. There may be less of a need for emotional fulfilment from friendship, but more of a need to feel wanted and to feel included in shared activities. Wayne and Jake felt threatened by Anthony's advances in him seeking out a friendship with them, yet their fear of his advances may have been interpreted at an 'emotional level' as opposed to a 'social' or 'practical' level of him wanting inclusion.

Barriers were experienced by Charlie in maintaining contact with his friends. Although he expressed an interest in keeping this contact he experienced a barrier in making contact through either the use of the telephone or from being able to use independent travel.

The emotion in social interaction was more likely to be experienced when the social interaction was negative as opposed to positive. Anthony, Wills and Andrew experienced some 'anxiety' when things went wrong in the social interaction. Sometimes they also experienced fear, which could be compounded by the barriers that existed to prevent their social understanding.

Greater awareness and knowledge appeared to be developed of different learning styles and the appropriateness of different teaching methods to enable the successful learning of the young people. This was apparent in chapter 3, where Jason, Jonathon, Charlie and Simon were all witnessed to have very different information processing styles and

to face barriers in the learning environment. In relation to social interaction and the development of social understanding such advancement had not yet been made. It was evident in chapters 3, 4 and 5 that social relationships and social interaction were important to the 11 young people. This chapter illustrated that many of the social issues were not being addressed by the support environment for many of the young people. David and Jonathon each expressed difficulties in understanding the relationships they had (or had not) with girls. There were unresolved issues that were demonstrated by the challenges being broached almost accidentally in the research process. Anthony and Andrew were struggling in their social relationships with people around them, yet the overwhelming approach appeared to be a behavioural management one, to control the 'problem' behaviour rather than to explore ways to enable social understanding. Such approaches appeared to exacerbate the problems for the individuals concerned and the observed behaviour of these individuals was seen to have escalated.

Bullying appeared to be equally problematic in mainstream and special schools. The impact of bullying was likely to be felt as equally traumatic by those who were at different points of the 'sensory continuum'. Wills who related to the world through **The System of Interpretation** was able to communicate and express his emotions in relation to his experiences. Andrew, who experienced the world through **The System of Sensing,** was not able to report his experience of bullying, but opportunities to help him and others to express themselves could be developed through the avenue of the person's 'special interest'. This facility became the route for him to communicate, yet it was not interpreted as a designated way to report incidents of bullying.

CHAPTER 6

REFLECTION ON THE RESEARCH PROCESS, ETHICAL ISSUES AND CONSENT

> *'We need to remind ourselves as sociologists of the importance of humility . . . there is no room for complacency and every reason for identifying the limitations of our work, including its partial incomplete status'* (Barton, 1996:3)

This chapter will critically explore the extent to which this research achieved 'emancipatory' disability research outcomes with its research participants. The nature of qualitative research is such that the socio-cultural values and experiences of the researcher can easily influence the research process. Thereby any analysis of the research process needs to be sufficiently 'reflexive' to explore these issues. Traditional ethnographic research methods have not only been criticised for being ethnocentric, but it could be argued that the research has been influenced by an 'able-bodied' researcher bias.

This research set out to work in partnership with people with a label of 'autism', to enable research participants to have a voice. It was not the role of the researcher to categorise individuals or to reinforce myths and stereotypes. Bogdon and Taylor (1984:168) argue that the categories available to place individuals can not help but affect how we feel about them and how they feel about themselves. The authors argue that when we present 'subjects' or 'clients' as numbers or as diagnostic categories, we do not engender in others a feeling of respect for or closeness to the people being discussed. This research aimed to prevent this from happening and presented data in chapters 3, 4 and 5 with an aim to foster 'a feeling of respect for or closeness' to the people being discussed.

Dyson (1998:9) explores the notion of 'voice' and argues that many voices tell many often conflicting tales and that it is up to the researcher to determine which 'voice' is to be taken note of and whose 'tale' is to be told. This research departs from Dyson's position in that to prevent this research from being not only ethnocentric but from being subjected to 'researcher' bias, 'the 'voices' of the participants need to speak for themselves. Dyson's critique raises two major issues:

- the power of the role of the researcher to determine/filter the 'voice of service users
- the issue of representation of the 'voice' of service users.

A key issue for this research study was the volume of data collected: photographic, interview and observations. It was through the adherence of the principles of 'emancipatory disability research' and from discussion and reflection in supervision with my two supervisors that gradually the balance was struck between editing the multiple examples of 'voice' and maintaining the issues portrayed as significant by the research participants.

Representation of 'voice' of service users

Representation is a controversial issue. More 'able' people with a label of 'autism' are sometimes challenged and questioned if they can really represent those people who are more severely disabled. This is an example of where the critics hold the 'moral high ground' and question the validity of 'collective' action by disabled people. Dyson (1998:9) argues that individuals, however oppressed, may not see themselves as belonging to a particular group. Groups, even where they exist, may give rise to many contradictory voices. It is not necessarily up to the researcher to speak on such issues, but to provide the opportunity for a forum for this type of discussion and debate to

ensue between people with a label of 'autism', amongst other marginalised groups. An example pertinent to this research is how there is a split view amongst people with a label of 'autism' as to how they view 'autism' as either an 'impairment' or as a 'disability'. Some individuals argue that it is not the 'impairment' of autism that causes them problems, but people in the wider environment who disable people with autism by their attitudes and prejudices (Sinclair, 1992; Grandin, 1995; Lawson, 2001;). But this is not necessarily the majority, or representative view amongst people with a label of 'autism'.

Regardless of these opposing positions, there are themes in the writings of people, that show people with a label of 'autism' connecting to each other. These positions could, ultimately, enable individuals to form a *'collective'* voice. The words used do not necessarily reflect the words used by others in the wider disability movement, yet their experiences overlap with others who are marginalised through the experience of being disabled by the barriers in the environment.

The learning from this research study has been about the challenges presented in the development of a methodology that will enable young people to 'tell it as it is'. This research study did not only suffer from the risks of researcher bias from a values perspective, but it was also fraught with difficulties (and barriers) of a novice researcher trying to break down barriers in communication and social interaction. Establishing a dialogue is essential in order to break down barriers in communication and to channel the 'voice' of people within the wider social model of disability debate.

I entered the professional field of 'autism' after working for most of my life supporting people with a label of 'learning difficulties' within a range of different residential and

supported living arrangements. This was an important move that required me to reappraise my own values and perspectives. I discovered that some people with a label of 'autism' are submerged within specialist residential establishments, special schools and are defined by a largely medical and impairment perspective. I started to be assimilated within the 'impairment model' thought processes of the field of 'autism', and doubted my own values (predominantly led by the service user involvement movement in 'Learning Difficulties'). I was influenced by research findings that emanate from a behavioural and medical perspective and began to believe that 'autism' was a 'special' case where specific treatment and interventions were required. This led me to initially write critically of the social model and I could not see the relevance or the application to the lives of people with a label of 'autism'.

It was only when some months into the research that I started to develop the confidence to listen to people that I discovered what they had to say was at odds with the psychological frameworks and previous definitions of 'autism' with which I was familiar.

I had reflected seriously upon my research methodology and was still being influenced by positivist terms of reference. I was concerned about objectivity and worried about influencing the young people. I had not sufficiently considered the power of the interactive nature of the research and had not considered my own role in the research process, with as much thought as I should have done. Barnes (1996) writes:

> *'Researchers should be espousing commitment, not value freedom, engagement not objectivity and solidarity not independence'*

Participatory or emancipatory research?

Barnes et al (1999:217) suggests that researchers should consider the following when reflecting upon the emancipatory nature of their research:

- Is there a break with the primacy attached to the researcher-as expert?

- Did the researcher place their skills and knowledge at the disposal of those being researched and did they become active participants in the process?

- Is the elimination of power differences always necessary or feasible?

- Is the relationship reversed or equalised?

- How is accountability to research subjects guaranteed?

- Is there a break with the primacy attached to the researcher-as expert?

- Is there a break with the primacy attached to the researcher-as expert?

I tried to place the expertise (and the power) of engagement in the research process with the young people. This meant ensuring that I created an environment of trust so that they would feel comfortable to exit from the research process at any time should they find the whole process too 'anxiety-provoking'. Throughout the research process I considered 'exposure anxiety' as a factor that could impact sufficiently upon the young person to prevent their involvement and active participation throughout the research process. It was through the reading of the autobiographies that alerted me to the importance of 'exposure anxiety,' as a barrier to involvement in social interaction with others.

I had not anticipated that with at least one young person their 'exposure anxiety' would be significant enough to affect the content and the exchange within the interview. It was only in retrospect that I could analyse the extent to which my interview techniques

with Jason appeared to cause or exacerbate his exposure anxiety. I had not given him sufficient time to respond to questions, I had rushed my questions and had spoken too quickly. This compared with subsequent interviews, where I paced myself slowly in asking questions. This resulted in a reduction of his exposure anxiety and enabled him to ask questions (Interview 7). Evidence of his exposure anxiety became apparent when he was waiting for me to arrive for the second interview. His mum informed me that, as he was waiting for me, he had said to her (about me): 'that woman is so obsessed with cameras' (17 June 2000).

I was surprised about the level of honesty and openness of the young people. Jason at the second interview was clear about the boundaries he wished to maintain between himself and me: (Interview 2)

Jill: So this time you didn't take the camera into school.
Jason: I would like to take it into school
Jill: Yes?
Jill: Cos I would love to see some pictures of your um ...place where you work
Jason: Work? Who told you
Jill: Well ... Mr Mason
Jason: I don't like to tell many people
Jill: Oh why's that?
Jason: Because I just do as people might fuss over me
Jill: Do you think I fuss over you?
Jason: Well ... a little
Jill: Would you like me to change in any way?
Jason: No ...your alright
Jill; Yes, okay
Jill: Well I won't fuss over you
Jason: Thank you

I started to wonder if Jason's 'people fussing' caused him what Donna Williams calls 'exposure anxiety'. If this was the case, then he was clearly using management strategies to reposition boundaries around him as a way of managing this. It was, however, interesting to note that in the same interview, I was keen to find out what exactly caused Jason 'exposure anxiety', but Jason was not familiar with the word

'anxiety'. He used a range of sensory behaviours to cope in different environments and was often observed to experience a form of 'anxiety' but he may have been focusing on the cause of the 'anxiety' (people fussing over him) rather than the outcome and the term exposure anxiety.

Jill: What sort of things makes you anxious?
Jason: Anxious?
Jill: Okay . . . um unhappy
Jason: Just . . . I don't know . . . Nothing really
Jill: So what sort of things don't you like?
Jason: Um . . . I don't like . . . I don't really like . . . (pauses)

Exposure anxiety was also apparent at school as well as at home:

On 19th June 2000 I wrote:

> *It is more important to accept and understand that Jason has apprehension about his involvement in the project. If I raise my awareness of this then it helps me to look for non-verbal 'cues' in communication that could indicate his need to exit from me at any stage of the process.*

I tried to foster a confidence with the young people that they could trust in the relationship between researcher and research subject. This required me to create opportunities in the environment for them to initiate their exit. This appeared to have happened with Jason because on 21 March 2000 he asked me not to be present for one of his lessons. In May 2000, I asked Jason if I could be with him in all his lessons for the day and he said I could (except for the resource lesson). With all the young people, I did not rely solely on the words communicated to me. I understood that there may be incongruence between the words spoken and the communication intent. It was then important to ascertain and to analyse how I could cause exposure anxiety with the young people and how this exposure anxiety is presented (as behaviour) with each young person.

- Did the researcher place his/her skills and knowledge at the disposal of those being researched and did he/she become an active participant in the process?

It was important for me to be able to differentiate behaviour that is a response to the stimuli in the environment and that, which is linked to the stimuli of support. I would be able to withdraw or retreat if I knew I was the person causing 'exposure anxiety'. It was not always possible as an observer to be clear as to why certain behaviours occurred, but it was clear that I should not become judgmental of the young people and make assumptions about the meaning and function of their behaviour.

At St Francis special school there were some examples of where the staff found it difficult to understand the communication intent behind behaviour. It was sometimes a lack of knowledge of 'autism' as a 'disability' that led to assumptions being made about the person's behaviour being attributed to their 'impairment'. One young person was labelled as 'attention-seeking', when they were often trying to find out what sort of impact their behaviour had on others. Wills Martin spoke loudly and deliberately and sometimes even spoke above others, if he was not aware that others were speaking. He sometimes presented a challenge to teachers and on one occasion the teacher asked me if I could provide any insight into Will's pedantic language:

> Wills Martin January 2001, Section 0, Paragraph 6, 555 characters
> He asks: 'Do you have any insight into his language and the pedantic language?' and I reply: 'this is a theme with children across the spectrum'. He says it is almost as if he is trying hard to be understood. 11.57 Wills turns to another child with a label of autism and asks: 'Why do I always make you uncomfortable when I come close to you?' The child didn't respond and I say: 'some people find it a bit frightening when someone comes too close to them too quickly'

While Wills was curious to find out the effect of his behaviour on another child, the teacher struggled to understand Wills and found Will's behaviour frustrating. My own

role was to try to ensure my involvement had a positive outcome for the young person. It was not my place to advise the teacher, but now I could feel the frustrations of the teacher and wanted to enable some rational understanding of what was happening. I felt that the teacher needed support (perhaps in the form of training) to help him to recognise barriers that may be inadvertently in place and that is hindering learning and development.

I found that that the young people could become more active participants if the interview process allowed sufficient time for 'reflection'. In this way, the participants could take the interview in a direction of their choosing (or a direction they felt comfortable with). I provided opportunities for active participation and enabled the young person to lead the interview, but this was not always taken up.

If the interview was a short one (with very few photographs and very few responses from the young person), I would ask the young person at the end of the interview if there was anything else they wanted to talk about. After the first interview with Jonathon Frost, he responded immediately with a 'no'; I then asked him if we should end the interview and immediately he said 'yes'. This first interview lasted 9 minutes and 13 seconds and he had confided in me that he had difficulty thinking about what to take pictures of. At the end of the interview I asked him for some ideas about where and what he could take pictures of. In later interviews, he took the opportunity to discuss other issues of concern. I understood that his interest in talking to me about pictures and other subjects indicated his continued interest in the project:

Jill: Yes that's right, any places that you may go you can take your camera, I have bought you another camera (gets it out of bag) in case you are interested in taking more pictures, it is exactly the same as the last one ... and we can have another chat about them. Is there anything you want to ask me?
Jonathon: (immediately says) er, No.

Jill: Shall we stop the tape then?
Jonathon: Yes
Jonathon Frost - Interview 1, 20.06.00

This research study enabled reflection by offering a visual image of an experience. But not only the experience, the viewpoint or the vantagepoint of the photographic image would have been taken by the young person and thereby there is a greater chance of their recall of the experience. I enabled the young people to reflect upon their photographs (and hence experiences) by asking the person questions, not only of who, what and where, but how they got on with particular people, what they liked or disliked about a place and also what they thought of their particular photographs. I also used these opportunities to probe further on a wide range of social issues.

The process of reflection soon broadened into other areas of their life and the research revealed areas, which had a major impact on the young person's life:

Jill: Oh thanks a lot David . . . as it is the last interview today . . . how have you found taking the pictures over the last year? Has it been difficult or have you enjoyed it?
David: Yeah I loved it
Jill: Yes . . . what bits did you like best
David: Well . . . I like you know . . . letting the pictures bring out my imagination . . . you know like making up the stories and that
(David Kent – Interview 6, lines 131-135)

An absence of supported reflection (in day-to-day life for people with a label of 'autism') can lead to a failure to support the person appropriately and can result in the person failing to learn and subsequently confusion and misunderstandings. Confusing situations may lead the person to resort to 'coping strategies' which, to the onlooker, may be interpreted from a medical or behavioural perspective and treated as the person presenting with 'challenging behaviour'. Hirsch explains how her behaviour was observed as being 'difficult' instead of being understood as her need for support in the kitchen:

'I would repeatedly put on the gas without lighting it, or overflow the kitchen sink. Having seen my written work, the teachers assumed that this behaviour was deliberately meant to cause trouble. I was labelled disruptive and accused of attention seeking' (Hirsch, 2001).

- Is the elimination of power differences always necessary or feasible?

As an adult carrying out research with children, there will always be a 'power difference'. The young people established a relationship with me along the clear demarcation lines of a 'child/adult' relationship. I was referred to by Anthony as 'the camera lady' and the fact that I was always in the classroom with a small laptop computer observing the lesson, created an identity that was different to one of the authoritative role of the teacher. The mainstream children were often surprised to see an adult in the class who did not correct their behaviour. The mainstream teachers were often surprised to come into a noisy class with the children misbehaving and being noisy without my having corrected them. This confusion sometimes led to teachers misunderstanding my role, where the they did not have knowledge of the research project

<u>Anthony Garrett, October 2000, Section 0, Paragraph 5, 450 characters</u>
The teacher comes to me and says: 'I thought you were supporting Anthony'. I explained my role as an observer and the nature of my research. The student teacher goes to Anthony and helps him move on to the next task

- Is the relationship reversed or equalised?

I tried to let the research process be led by the young people. They guided me in terms of the time scale for developing the photographs and carrying out the interview. Sometimes there were technical problems where only some of the photographs had been developed. At times like this I tried to seek decisions about what to do from the young

people themselves. The following example illustrates how David takes the lead in the decision-making over what to do when only three photographs are available:

> <u>David Kent 12 February 2001, Section 0, Paragraph 5, 450 characters</u>
> While walking over to the other site, I said to David: 'only 3 pictures have come out from the last camera'. I asked if I should come round the house with three pictures or wait until we have the next film developed. David said it would be better to wait until the next film was developed.

On another occasion, however, I discovered by accident that if the disposable camera had features that overlapped with the young person's special interest, then this was likely to have had a motivating effect and may result in the person taking photographs with a higher frequency. David had a special interest in Japan and all issues associated with Japanese art and animation. When I gave him a disposable camera that was made in Japan, it increased his motivation and interest considerably:

> <u>David Kent 6 June 2000, Section 0, Paragraph 1, 604 characters</u>
> David said to me 'Jill I have something for you'. He then gave me the camera and said that he had finished taking the pictures in the half term. I said great and the teacher said he had shown her the camera yesterday and had asked her where I had bought the camera from. She said that David had wondered if I had Japanese connections. It made me realise that David's motivation had increased since I gave him the Japanese disposable camera. My dilemma was that he should have hung on to it for another seven weeks. I will need to ring his mother to arrange for an earlier interview.

Anthony's home situation had an impact on deterring his motivation to take photographs at one stage of the research process. He had been experiencing stress at home and this had coincided with a time when his mother had left the family home, I wrote the following:

9.17 Anthony is in the computer room. I think it has been 2 weeks now
since his mother left home and school has helped him to make a timetable
to help him cope with increased levels of stress. 9.19 He has also
announced to me this morning that he has not taken any photographs yet. I
said this was okay.

Almost half an hour after this exchange Anthony asks me if he can have more time to

take photographs as he will not be ready by 16 December, I say that is fine.

- How is accountability to research subjects guaranteed?

Firstly accountability to the research subjects takes place at different levels. In the first

instance it is about being accountable and respectful to their status as young people. I

also wanted to ensure that I did not correct them when they talked about 'autism' as

'impairment'. Learning from 'Larry B' in chapter 2, I wanted to ensure that I did not use

my role in a way of projecting superiority of knowledge over something that was

affecting them on a day-to-day basis. I did however converse with the young people to

help them to gain knowledge of 'autism' from a 'disability' perspective. Secondly,

accountability it is about recognising the gender and race of the young person and being

respectful about difference in relation to these. On two occasions, I have been asked to

talk about the research findings and I have spoken to some of the research participants

to ask if they would like to co-present at a workshop with me. One event was

particularly successful, where one person agreed to co-present and brought his

photographs along to talk through to the audience. He talked about how he had got

involved in the research and what he had taken photographs of.

My own accountability to the research subjects is that I will not use any material

generated by the young people without their permission. The consent forms signed by

the young people and their parents assured their copyright of the photographs and the

material generated throughout the research. I will also make sure that I give the young people an opportunity to speak about the process of their involvement in the research whenever there is the opportunity to do so.

At the outset I had said I wanted to engage young people with autism. I was aware that all the participants were acquainted with the use of the word 'autism'. I needed to ensure my accountability to the young people, in that my language must be anti-oppressive and my involvement must add to the quality of their lives and not detract from it. Many people with autism, are denied information on how people define them. As 'autism' is defined as 'impairment' it is a word that projects negative value and causes embarrassment to some people. I was embarrassed when I was introduced by one of the children to his mainstream peers, as a researcher working with people with autism. I reflected upon my reaction. I had not realised that I was carrying around the baggage of defining and valuing people by their impairments, so much so that I did not want the young people given the label to use it. Riddell et al (1998) highlights this as a major issue. The authors argued that people with a label of 'learning difficulties' were grouped together on the implicit understanding that they had certain common characteristics and required particular types of provision. They however point out that:

> *'The basis of their social grouping and the attributed social*
> *identity which flowed from it appeared not to have been*
> *discussed by parents and professionals with those whose lives*
> *it concerned'* (Riddell et al 1998:90).

Young people are diagnosed as having the label of 'autism' but it will vary as to how much information in the form of counselling and advice is given to the young people. It is crucial that the young people know about autism and how others define and thereby exclude people on the basis of this label. Children in the mainstream schools tended to

be more aware of the label of autism and had been given advice as to some of the barriers that young people may come across in society..

How is accountability to research subjects maintained?

Not acknowledging 'autism' and how it is experienced as 'barriers', ensures that adults who use labels and definitions of 'impairment' extort the control in the lives of young people. This inevitably results in people being denied access to discourse that will enable them to become socially and politically aware of the implications of the label of 'autism'. The following example highlights how one young person who attended a mainstream school, was becoming aware of the social and political issues related to the label that had been attributed to him:

Jonathon: "Mr Mason (Teacher in the resource at the mainstream school) told me that 98% of people with autism don't have a job, they are discriminated against"
JA: "Yes – that's right"
Jonathon: "But that is wrong and if I found out I didn't get a job because I am autistic I would get angry and shout 'you can't do that, it is wrong' and then I might get into trouble"
JA: "No – you are right to challenge them and there are now laws in place to try to stop this discrimination. People like Mr Mason are working hard to change things and are helping people with autism to get jobs"

The above dialogue is important as it establishes my position with the young person. It was important to communicate to him that I also believe discrimination is wrong and so does society, which is why there are laws in place. I also advised that Mr Mason is working to try to change things and has helped young people to get jobs. This indicates that things will not always be this bad and that things are changing positively. Jonathon is 16 and his thoughts about future employment were on his mind as he had left school for about 4 weeks.

Race and Culture

The philosophical starting point to engage young people with autism in the research process starts from a belief that people create and maintain meaningful worlds. In this research study, the notion of an identity in relation to the person's label of 'autism', shaped the young people's realities more than their culture and gender. David, who is mixed parentage, does not make reference to his 'Black' identity and demonstrates he is not familiar with words associated with a 'Black' culture:

> David Kent December, 2001, Section 0, paragraph 3, 203 characters
> The teacher asks them to put their pens down. He says the following characteristics are known to be dominant and he rubs the board, negroid hair. David asks: 'What's that? (in an accentuated tone suggesting that's a strange word) and the support assistant says its hair like yours.

Gender Analysis

All the 11 participants were boys. The proportion of boys to girls with autism can be as high as 14:1 and even though girls were invited to participate the rate of return would have been small. One of the surprising findings of this research study was that the issue of sexuality and gender played a minor role in the research process. I was confronted with more issues regarding sexuality and gender issues from the mainstream peers than by the research participants. In both mainstream schools and the special school, there were some couples who engaged in holding hands, kissing and general social chit-chat about relationships. In one of the mainstream schools (South Downs Secondary) and the special school (St. Francis special school), I witnessed an example of a male/female partnership engaging in inappropriate sexual activity in the class (the use of touch with the outcome of male sexual arousal). I witnessed no such examples of sexualised behaviour amongst the research participants.

In chapter 5, reference to girlfriends by the research participants alluded to more than a relationship based on sexuality. The young people also made no reference to gender or sexuality either directly or through innuendo to me during the research process. I came to the research study from exploring policy and practice in the area of sex and sexuality, as this was an area of professional interest to me. The fact that sexual behavioural matters did not emerge throughout the research, did not mean they were not an issue to the young people. The young people may not have the words to describe their sexual awareness, but it was not the remit of this research to present categories or 'subjects' for discussion.

Innovative Methodology

The design of appropriate research methodologies for people with a label of 'learning difficulties' appears to still be in its infancy. Riddell et al (1998:82) argues that researchers (from the social model) can not simply transfer their expertise to people with cognitive impairments (people with learning difficulties). In fact the authors are quite dismissive of research methodology used by researchers with this group. They argue:

> *'Current models of the consultation and involvement of people with learning difficulties in issues affecting their lives suggest that the pulls either to the trivial or to the professionally staged managed are hard to resist'.*

One of the most significant and powerful findings of this research was the design of a research methodology that would sufficiently engage people who are at different stages of relating to the world (see chapter 3, the 'sensory continuum'). The research methodology successfully engaged children who were at a mainstream school and equally those who attended a special school. It was interesting to note that initial discussions with two teachers at the special school had identified that some of the

children were unable to use the camera. However, after contact with the young people and their families all of them wanted to use the camera, and the 11 children were engaged successfully with the use of a camera.

At the mainstream school, the competence of the young people's ability to use a camera was not questioned, although the findings from this research showed that at least three young people attending the mainstream school had not used a camera before. These were Jason , Charlie and Jonathon.

The first photographs taken by Jason tended to be of either heads or feet and he had

failed to use a flash on two occasions.

Jason Smart (interview 1)

The photographic competence of all the young people improved over time, with their ability to increase the consistency of their positioning of the subject in the photograph. It was, however, the initial expectations of the teachers supporting the young people at the mainstream school which were higher than those at the special school. Chapter 4

illustrated the creativity of David and Philip, who acquired creative photographic skills over the period of the research process. It could be suggested that high expectations of these individuals enabled them to develop creativity through photography.

Empowerment through research

Should researchers hold the power in decision-making to choose what they will allow participants to achieve as outcomes from the research? Corbett (1998:55) argues that when professionals speak of 'empowerment' they mean on their terms and using their own perceptions of what is appropriate. Swain and French (1998:28) argue:

> *'In emancipatory research the research processes themselves and the outcomes of research are part of the liberation of disabled people – that is part of the process of changing society to ensure their full participation and citizenship'.*

Swain and French (1998:51) explore their own research and evaluate the extent that it is either participatory or emancipatory research. The three questions they ask are as follows:

- Does the research promote disabled people's control over the decision-making processes which shape their lives?

- Does the research address the concerns of disabled people themselves?

- Does the research support disabled people in their struggle against oppression and the removal of barriers to equal opportunities and a full participatory democracy for all?

An analysis of this research study has been explored in relation to these three questions:

- Does the research address the concerns of disabled people themselves?

The young people were able to use their camera to take pictures of whatever was important to them in their lives. There was no direction as to what, who, and when pictures should be taken. The parents were asked to prompt the child to remember that they had the camera. They were given a notional period of 8 weeks but most of the young people asked for extra time. When it came to the 7th week I asked the young person at school or via their parent at home if they had finished taking all of the pictures. Sometimes the child would ask for them to keep the camera to cover a holiday that they were going on, or to use it to take photographs over the half term period. I worked with the young people and waited until they were ready to hand the camera over to me.

The young people were also in control of which pictures they wanted to talk about at the interview. Sometimes they would first look through the pictures on their own to see them before talking through the issues with me. It was the emancipatory disability research methodology used within a longitudinal study that helped enable the participants to learn to take control over the research process.

- Does the research address the concerns of disabled people themselves?

The research addressed only the concerns that the young people raised themselves. I never introduced a topic or subject that they had not encroached. I would probe the young people by asking further questions on an issue they had raised, for example racism, getting on with a parent or friendship. At the beginning of the research I started to formulate research questions such as "how is sexuality defined from the perspective of those with autism?" I knew that had I even broached the subject that this would not have been in line with emancipatory or participatory research and, in some senses, could

have been seen as voyeuristic. All issues and concerns presented in this research have come from the young people themselves.

- Does the research support disabled people in their struggle against oppression and the removal of barriers to equal opportunities and a full participatory democracy for all?

When particular issues were raised that identified barriers I would ask the person what they could do about a particular issue. I helped to give information if they needed it and this might support their initial thoughts on inequalities and barriers.

They knew that I was researching into what young people with a label of 'autism' had to say about their experiences through adolescence, so it was perhaps this that made them feel comfortable about raising such issues with me. Kevin had also commented to me on the tone and the sound of my voice, saying that it reminded him of a psychologist in a cartoon (Dexter's Laboratory). He told me that when this character finished a session she would say 'thank you very much for coming' and when I said: "thank you very much", he would laugh and remember the cartoon. One day I was explaining why we were laughing to another child and I said to Jonathon: "so that is why Kevin laughs at me". Kevin touched my arm and said: 'but it is not a bad thing, you give children confidence by the way you speak.' I thanked him and told him it was really good to get that feedback.

Riddell et al (1998:86) argue that:

> 'If people with learning difficulties are to be involved in the research, then it should be in ways which draw on their expertise and specialist knowledge, with accountability remaining a guiding principle'

It is the issue of accountability of myself that is important to highlight. The issue for me was that all the young people engaged in the research process had something to say about their lives. It was not my remit to get involved in highlighting any 'intellectual impairment', for that had been done by researchers previously. It was important that the young people were recognised as having the potential for 'abstract theorising'.

Riddell et al (1998:76) argue that less attention has been paid to the conditions under which emancipatory research is possible and, crucially, whether research which falls short of this is, therefore oppressive. But others argue that there can be a middle ground that professionals do not necessarily have to engage in emancipatory research (Dyson, 1998:5). Dyson sees the process of emancipatory research disadvantaging the 'professional intellectual', and writes:

> *'The further such moves go in handing over research to the researched, the more problematic and marginal the role of the 'authoritative researcher 'voice' becomes'*

The challenge to Dyson should be to see the changing role of the researcher. It is a role of enabling research participants to access appropriate research methodologies where many face significant communication barriers. There is a need to design and develop more appropriate research methodologies along the principles of emancipatory research.

What would I do differently next time?

It is important for me to reflect upon how I would do things differently if I were to do the research again. I would most definitely secure the involvement of young people much earlier in the research process. In my efforts to ensure that each child was shadowed for one year, I fell seriously behind my time schedule. I feel that I should have had more confidence in my belief that the social model was a suitable model, not simply appropriate but ethically and morally right to work within. The disability

movement has not embraced people with a label of 'autism' in its struggles and the professional world of 'autism' strives to maintain the exclusiveness of 'special' resources and professional services to people so labelled. This then results in the isolation of people who are marginalised and excluded from mainstream society and denied the opportunity to engage in a collective discourse.

I also ultimately only achieved 'participatory' research with the young people. I would like to develop and refine a research methodology that enables 'transformation' of research participants' control of the social and material means of production of research.

Ethical issues

Rodgers (1999) found that the ethical committee was: 'in part at odds with an emancipatory research paradigm'. In my own research I found that in order to gain access to the young people and their families in an National Autistic Society (NAS) school, I would have had to submit an application to the NAS ethical committee in London. I was doubtful if such a process would enable me to gain access, as my research (from within the social model) was directly opposed to the positivist tradition research that the NAS had approved to date. Rodgers had to compromise with a research proposal and was being questioned as to why there was not a control group. The consent of the young person's family and his or her GP was also required. Rodgers writes: 'in order to do the research within the timescale available, I agreed to what I believed to be an unsatisfactory condition. I contacted GPs and families by letter'.

In this research the continual consent of the young person was established as an on-going feature of the research. I also gained consent from the young person's family and the school. If I were to undertake similar research again I would need to consider the

ethical issues as they related to other adults involved in the research, e.g. teachers and classroom assistants. I would also need to consider the ethical issues of including other children in the research process.

The interview process

<u>Using words in the interview without knowing the child has knowledge of these words:</u>

An analysis of the transcripts identified that I on some occasions used words which the child was not aware of. This did not become apparent at the time of the interview and only in retrospect could this error be detected. The child would not be able to tell me at the time but an analysis of pause time, is an indicator of this. I introduced the word 'drama' into the interview with Jonathon Frost; I had not used this word with Jonathon before and had not checked out if he had 'drama' scheduled as a subject at school. I did not check that he understood what I meant when I used the word, even though his response to me indicated that he was unsure:

Jill: Sometimes drama is good at school isn't it to help you get into dancing and that sort of thing?
Jonathon: Hmm. Hmmmm
(Jonathon pauses for 10 seconds)
Interview 1 with Jonathon Frost 20.06.00

When I used the term computer studies in the interview, on analysis of the transcript, I wrote: 'how would he know what computer studies is? If it was not a term to describe a subject to him then it would not make sense would it?" I later found out that the word he used to describe what I would understand as 'computer studies' is 'text processing'.

<u>Using abstract (subjective or intangible) concepts in the interview process:</u>

The analysis of the transcripts indicated to me that on occasions, I used abstract concepts and this then generated a strange response. I was asking the wrong question and using the wrong words that generated the wrong answer.

<u>The use of the concept 'time' in the interview:</u>

It was neither useful nor helpful to use the concept of 'time' in the interview process.

There could be other ways to determine how important something is to the person. The

reference to 'time' only creates confusion and uncertainty for the interviewee.. If I was

to interview again I would avoid all 'time' concepts in the questions in future:

Jonathon: So how much time do you spend on your Nintendo?
Jonathon: About .. about .. every two days, and every day or once a week
Jill: Yes
Jonathon: I play it now and again
Interview 1 – Jonathon Frost 20.06.00

Getting feedback from the young people on the research process

A few of the young people gave specific feedback on what they got out of being

involved in the research. Two of them had photographs of others (friends and family)

looking through the photograph album, which suggested that they used the album as a

means of communicating with others. This, as an outcome, is a positive one if it

enables the individuals to initiate communication with others and to talk about their

lives.

David Kent told me directly what he thought of being involved in the research:

Jill: Oh thanks a lot David . . . as it is the last interview today . . . how have you found
taking the pictures over the last year? Has it been difficult or have you enjoyed it?
David: Yeah I loved it
Jill: Yes . . . what bits did you like best
David: Well . . . I like you know . . . letting the pictures bring out my imagination . . .
you know like making up the stories and that

It is interesting that David summed up his involvement in the research as 'letting the pictures bring out my imagination' when he is specifically labelled as having an "impairment" in this area, within the official diagnostic criteria o f 'autism'.

Wills Martin wanted to give me a gift, a photograph of him and me, taken from the camera I had given him as a thank you for being involved in the research. Wills was also philosophical about his future and he was able to have a vision about what he wanted to achieve:

Jill:.. . Do you have any plans for your future and what you hope to do in the future?
Wills: It is very simple . . . live life one er one day at a time and see where life takes me
Jill: Are you thinking of going to college?
Wills: Yes . . . right. . . a full educated mind. . .fully experienced in a lot of things . . . would er really really make an impression in the world. . . because the only way you get by in this world is money . . . right. . . and you need an education to get a good job and a good job or good pay . . . equals a lot of money . . . and more money the better you get by in life
Jill: Hmmm well thank you Wills
Wills: There's one last little thing,,,,, he gets his camera out and takes a picture of the two of us together with his new Polaroid instamatic camera and we will keep on chatting until it develops ... you can have this one.. keep this one
Wills 7.25

Jill: I hope you have a lovely birthday ... thank you
Wills: Thank you ladies and gentlemen and goodbye

To conclude this section it is argued that although the principles of emancipatory research guided the researcher in the design and implementation of this research study, emancipatory disability was not ultimately achieved. Earlier in this thesis it was argued that emancipatory research can only be achieved if a 'collective' action rather than an 'individual' action is the outcome the research. By pursuing an individual participatory research process, with the principles of an emancipatory researcher, it is hoped that I

have at least contributed towards the development of a research methodology to enable participatory research to occur, with people with a label of 'autism'. Achieving emancipatory research will require a wider debate within the disability research community and people with a label of autism will need to access the continuing discourse and debate on the 'social model of disability'.

CHAPTER 7

CONCLUSIONS AND RECOMMENDATIONS

The starting point in this research study was to examine ways in which people with a label of 'autism' could have a voice in the research process. It was sometime later, in the development of an appropriate research methodology, that the work from the wider disability movement started to have an influence on shaping this research study. One of the major factors in disability research is the recognition that the environment, prejudice and discrimination disable individuals more than any perceived 'impairment'. Through the reading of autobiographical accounts it became clear that this is what had been experienced by many from their child and adulthood. However, it was significant that, unlike disabled people with a range of physical and sensory impairments, people with a label of 'autism' were rarely involved as research participants or as researchers from which knowledge could be gleaned as to their perspective on these issues.

The challenge to me in this study was to find a way of communicating with young people, that would enable a dialogue to be established, so that individuals could fully participate in the research process. It is perhaps this point that is the most critical, when aiming to enable 'voice' through the research process, that is taken so much for granted by researchers. There is almost a given expectation that a communication channel will be open between the researcher and the research participant for the research process to proceed. To enable the voice of people with a label of 'autism' to be heard through the research process, the researcher needs to be prepared to invest a significant amount of time in the establishment of a shared understanding of communication. Once a means of communication has been established, it is possible to start to explore the impact of the development of a body of knowledge on 'autism' that emerges from a collective of those who have experience of living with a label of 'autism'.

During this study, I found that even when a person uses words and language that do not appear to have immediate communication intent (for example, James Frazer, chapters 3 and 4) there are ways and means of translating the communication to 'decode' the communication intent of language. There may be times when people with a label of 'autism' will use words because they like to hear the way they sound (a sensory function). There are those however who may use particular words to ask questions about life, but this may not be immediately apparent, if they are using language from **The Systems of Sensing.**

Take the example of Alex Green who features throughout this research as a friend to Charlie, Jason and David. Alex would ask questions:

> *What happens if you fall off a cliff?*
>
> *How many letters have you got from the postman?*

Instead of dismissing the questions as bizarre and meaningless (Breakey, C. Personal Communication, 2001) made efforts to 'break the barrier' of communication and found out (through a translator) Alex's parents, that these questions were coming from television programmes or from videos that he watched. Breakey states that the starting point in developing a means of communication with Alex was to watch his favourite videos in order to gain some understanding of the social context of the 'stock phrases' that were being used by him. There were certain discoveries made by doing this, for example Alex used to call the maths teacher 'the jailer's daughter' as she had a large bosom. The character had come from the *Wind in the Willows* and he was using an 'association' to help him remember or relate to new people or concepts in relation to

what he already knew. Another example was in a French lesson and the students were being asked about pets. Alex said 'I have a penguin' as he was thinking of the penguin in *Wallis and Grommet*. Alex had been unable to differentiate between what was 'real' and what was 'pretend' which indicated that he related to **The Systems of Sensing** rather than **The System of Interpretation**. When new staff were assigned to working with Alex they would need to watch two of Alex's favourite videos as so much of his communication was rooted in the language of these. Breakey started to explore how else Alex interpreted the world, in terms of what he thought was 'real' and what he thought was 'pretend'. By doing this it would be possible to help Alex see the 'function' and relevance of what was 'real' and thereby help him to move from **The Systems of Sensing** to **The Systems of Interpretation** (chapter 3). The goal was to work through the barriers that were in place to enable communication between the teacher and the young person.

The importance of partnerships with the family

Breakey explained that to enable the transition through the sensory continuum (chapter 3), work had to be carried out to understand the 'metaphorical communication' expressed by Alex. Establishing a working partnership between the person and their family and the support staff was the only way to achieve this objective. Family members remain a crucial link to the person with a label of 'autism' as they enter adulthood. This was one of the significant findings of this research, in that parents played a critical role in 'translating' and helping others to 'de-code' language that originated from a particular unique point in their life experience. This was a way of enabling access and to challenging the communication barriers which may be immediately evident with some young people.

By moving from an impairment approach to understanding how barriers in the environment and support and information disable the person it is easier to explain how important it is to invest time, effort and energy to 'decode', 'translate' or even build knowledge of patterns and meaning in communication. If we continue to understand autism as an 'impairment', any improvement in support, or breaking down the barriers that disable the person will not be recognised. Instead any improved quality of life will be seen as the 'autistic condition responding well to treatment'.

A move from 'impairment' to 'disability'

What emerged from this research was that people with a label of 'autism' do not identify with Wing's (1988) 'Triad of Impairments'. In fact this study found that the research participants were sensitive to the use of words generally and how they were applied, in some cases using the terminology within the professional literature did have a negative effect on particular individuals. By engaging young people in the research process it became evident that the perspectives of the young people were defined from a different perspective than that explained in the 'professional' literature on 'autism'. The young people did not feel at ease with the use of the terms expressed in the literature and were seeking their own explanations.

What this research did not achieve nor did it get anywhere near, was to listen to how the research participants define 'their experience' of autism in alternative ways other than 'impairment. It can not be argued that the term 'disability' replaces 'impairment' as people in this study did not debate this. Instead this research has started the process of moving away from defining 'autism' from the professional arena of 'impairment' to exploring explanations that can relate to understanding the worldview of people with a label of 'autism'.

It has been argued that, because the primary diagnostic criteria are based on the observed behaviour of individuals and assessed as 'deficits' or 'impairments', this then serves to continue and reinforce the 'impairment' approach. The way the person relates differently through their senses to the environment is often not assessed or taken into account in the overall plan of support.

For the young people in this research it was important for 'autism' to be explained in a different way, that does not rely on oppressive language such as the use of the words, 'impairment', 'deficits' or 'disorder'. This has major implications for autism specific services who will need to engage in a dialogue with people to revisit and rewrite the information they provide, to ensure that it is written in a non-judgemental and non-oppressive way.

This research concluded that the young people experienced many barriers in their life. These barriers were often found to be in relation to:

- Information
- The physical environment
- Social relationships

The above emerged from an overview of the 'collective' data presented by the research participants in chapters 3,4 and 5. The above were recognised as 'barriers' that would inhibit their ability to take part in activities or to achieve their goals.

- Information Processing

It will be the responsibility of the carer, support staff, teacher, college lecturer, parent to find out how the person processes information. This can be done by developing a comprehensive 'communication profile' which should detail how the person takes in information, learns new skills, how they recall information, and how they remember social facts. The support person would then need to modify information to make it accessible to the information-processing style of the person. It could be that the information we need to provide to the person is 'translated' into a visual-sequencing format. Also, more obscure concepts may need to be translated into tangible concepts, for example time could be illustrated on a calendar or a wallpaper strip indicating the extent of time over distance.

This study found that, although enabling access to information was a crucial role of the learning support assistant, sometimes the priority in the school environments was to support the child through a behavioural approach. A child's behaviour may be a response to 'information overload' or 'sensory flooding', so an analysis of the barriers to information processing may help to understand the role and function of behaviour. Even though there was an underlying reference to the support environment, and the need to change or adapt the environment, the onus was more likely to be on the young person to make changes in their behaviour. This inevitably resulted in barriers remaining in place that would inhibit information and sensory processing.

What did appear to work well with the young people involved in this study was changing the teaching method to suit the person's learning style. Simon Sands had a delayed information processing style which often disadvantaged him in contributing to group discussion or working in pairs. His peers observed his silence to

indicate a lack of knowledge or ability in a certain areas. However, when given the right method to learn (for example a computer) he was able to achieve.

One of the ways in which a person's information processing can be assisted is to help the person engage in a task in a way that relates to their subject of 'special interest'. There are numerous examples in this research study that shows the connection to the person through their subject of 'special interest'. This will encourage not only motivation but could also help the person develop social understanding. Lawson suggests ways in which people in a support role can help in this area:

> *"our concentration span is very limited and we soon tire. Using subject material that we are interested in is very helpful and will facilitate longer interest . . . Maybe I lacked the connections to build appropriate pictures if the material to be learned didn't have a familiar component to it. Maybe, if I didn't have a picture for it I couldn't think of it?"* (Wendy Lawson, 2001)

The young people are likely to have developed and trained their memory in relation to their special interest. By using their special interest as a structure to build new learning upon, will help not only with their motivation to engage in the learning process, but may also help them to remember information in a way that they have become accustomed to.

The young people in the study described their frustrations with how they coped with the information provided at school and some of them had come up with creative ways to overcome these barriers. Some of the teachers were beginning to provide information and adapt their teaching style to enable the young people with autism to access learning. The young people did not relate to the way they 'thought' as being a 'problem' it was part of the way they were. They had to cope with the way information was being imparted that suited a majority cognitive learning style.

The young people recognised that there were lots of things to 'remember' but some were quite resourceful in devising ways to overcome this for example the use of remembering charts.

Much has been written about people with a label of 'autism' being visual thinkers and needing to have visual prompts to enable their learning. Such difficulties in exams and 'remembering' could well be a result of the young person needing to store 'non-visual' information in a way that does not come natural to them.

Much of what is currently in place to support young people in mainstream and special schools may not be sufficient to enable the person to maximise their learning potential. Pupils may not necessarily need 'extra time' for the completion of tests or exams, but may need additional explanation in interpreting what is required for the task in hand. Such support is currently not recognised with the rules and regulations of school exam boards.

- Sensory hyper or hyposensitivities

All people with a label of 'autism' are likely to be identified in relation to the 'sensory continuum' (Chapter 3). They may experience a level of relating to the environment via their senses that is different and no two people will experience the same effect through their senses. A sensory assessment can help to workout the extent to which a person is disabled by their senses and can explain why some environments may enable the person whilst others disable them (Bogdashina, 2001). This may also explain a range of behaviours that have a sensory function and may require more pro-active sensory activities for the person who craves sensory satisfaction. Such findings can be helpful to provide practical and useful information to enable insight into the way environments

can either disable or enable learning or participation. If information on 'autism' as a disability is reviewed in light of 'barriers' as opposed to 'impairments' then this could provide interesting discussion amongst those who share a label of 'autism' to argue for better access and support to certain environments.

- Environments and exposure anxiety

The young people in this study had ideas about the future and they indicated that they were anxious about being able to realise these plans. Their anxiety was about the support that might be in place to enable them to accomplish their goals. Even the research participants, whose language was expressive and articulate, demonstrated that different environments affected them. Being in transition from one environment to another will take its toll on individuals. It will not be immediately evident to the onlooker that the environment is causing anxiety, but awareness that transition can be stressful could enable support and reassurance to be given at these times.

The writings by people with a label of 'autism' will argue that the behaviours they present with are due to the responses to their senses within different environments. Such accounts by people have been disregarded throughout history. Much of the literature proposes that their stereotypic behaviour is often meaningless (Nijhof et al, 1998), but the authors argue that stereotypic behaviours may be considered adaptive responses to an over or understimulation in the environment. They argue that the view by some authors that 'stereotypic behaviour is non-functional, harmful to the individual and, therefore, in need of suppression' is of questionable validity. Even when individuals have been exposed to behavioural modification approaches and have learnt new behaviours, this has not necessarily resulted in the suppression of stereotyped behaviours. In this study, the example of Andrew illustrates

how a behavioural modification approach can suppress a sensory behaviour, but it never really deals with the reason why the person finds the need to retreat to the sensory world in the first place.

It was only later I appreciated that what may appear as a positive outcome for observers of Philip's behaviour, may not be positive for him. How much of a price is there to pay for the use of self-restraint of such behaviours? Has anyone appreciated the origin of this behaviour and how much the environment plays a part in exacerbating the situation? Could the environment be over or understimulating, could it be causing the person 'sensory overload' or 'sensory flooding'? In what other ways could the individual possibly be helped? Is 'pain' an experience for these young people and should we not be exploring a wider function of such behaviours to cope with the extreme demands of the environment?

The emphasis on 'impairment' instead of a social model of disability perspective somehow justifies the need to focus on the individual to change their behaviour, rather than for adaptations to be made in the environment or the support provided.

- Social relationships and friendship

Chapters 3, 4 and 5 presented data that sometimes challenged previous knowledge and understandings of autism. This was particularly evident in chapter 4, when the photographs taken by the young people predominantly featured people in a social situation. The young people involved in this study were clearly sociable in their interactions with others and indicated that friendships were important to them. What became apparent, however, was that the environment and support barriers disabled the young people in a range of ways that served to exclude them from maintaining and

developing friendships and relationships. Parents played a role in facilitating the young people to keep in contact and to meet up with each other and thereby challenging some of the barriers that existed.

The social difficulties incurred by the research participants (discussed in chapter 5) were not particularly addressed as a 'support issue' by the staff supporting them across the three schools. Social issues that did not present as problems (for example the ending of a relationship with a girlfriend), were not seen as issues that needed support. Yet the evidence in this research identified that there were unresolved issues on such occasions when the person was left not knowing why a particular relationship had ended.

There was also very little support provided to enable individuals to connect socially with each other through holiday periods or to stay in touch when an individual left school. The barriers soon became firmly fixed in place, and individuals were at risk of becoming socially isolated and dependent on their parents and parents' friends for social support. Support in the form of behavioural management interventions was likely to be implemented to deal with social relationships that were going wrong. Social interaction and social relationships were not a priority area of focused learning for the young people, yet they were the important issues that emerged for the young people within their photographs and accompanying narrative. It also appeared to cause some of the greatest difficulties for some people (chapters 3, 4 and 5). This then resulted in barriers remaining in place that hindered the person to forge successful relationships with others.

This concluding chapter has attempted to summarise the particular ways in which the young people involved in this study experienced difficulties in the physical and social environment. I conclude here that more should be done to ensure the environment helps

enable people with a label of 'autism' to maximise their concentration and learning span. Time needs to be built in for support staff to immerse themselves in the person's 'special interest' so as to help 'de-code' any metaphorical language. The barriers that exist in society will maintain their existence and continue to exclude people if this fails to occur. There is a need to enable people to reflect upon how they cope within different environments, to raise their self awareness so that they can have more control over influencing the development of an enabling as opposed to a disabling environment. In addition to a lack of support, if a person has increased stress in their life then the difficulties in the transition from one environment to another can be exacerbated.

Difficulties in transition can also be evident if the person is living predominantly in the world of the sensory. Such an individual will depend on 'landmarks' to connect to different environments. For some people, for example James Frazer, he will need to take something of his own (a favourite video, even though he there is no video recorder in the new environment) to help him in the transition from a safe and secure environment (his home) to a school residential holiday.

It is not the place of the doctoral student to make recommendations for practitioners, but it is part of the researcher's duties to signal what needs to change to enable others to access the voices of people with a label of 'autism' in the research process. This thesis argues for advancing the following agenda:

- The social model of disability needs to explore ways to become accessible to people with a label of 'autism

- People with a label of 'autism' need opportunities to generate a 'collective' discourse on the debate between 'impairment' and 'disability'

- 'autism' needs to move away from being understood as a set of impairments and to move towards an analysis of the barriers in the environment. These barriers being *physical barriers, information barriers or support barriers*

- The environment, support and information needs to be assessed to the extent that it causes 'exposure anxiety' and supporters need to know how exposure anxiety is communicated by individuals

- A need to develop a system of communication with the person, that will enable individuals to have a dialogue with others. A starting point will need to be the development of a 'communication profile' developed in partnership with the person and their family

- People need to be supported to form a 'collective' with others with a label of 'autism', and to take some leadership in the social policy and research agenda

- A need to challenge positivist research proposals and to advocate for a more emancipatory research agenda

Would you like to be given a camera every three months
to take pictures of all the things you like to do,
the places that you go to and the people in your life..........?

and then to talk to me, Jill

every 2 months about your poctures?

I will give you a photograph album, for you to keep your photographs in
so that you can remember what you were doing in
the Year 2G00

To find out more, please ring Jill Aylott on
0114 276 3280

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