Listening to Parents of Children with Autistic Spectrum Disorder:

Using Interpretative and Critical Research Approaches to consider 'how parent experience of bringing up a child with autism can inform professional practice and provision'.

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Note

The names of all children, parents, schools, professionals and the LA in the study have been changed to maintain anonymity.

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GLOSSARY AND ABBREVIATIONS

Please note that terms below are usually given in full on the first mention in the text and the intention is that abbreviations are then used, with this Glossary providing a reference point.

Autism Working Group	AWG
Autistic Spectrum Disorder	ASD
Child Development Clinic	CDC
Common Assessment Framework	CAF
Martom Autistic Society	MAS
Martom Autism Support Group	MASG
Educational Psychologist	EP
Educational Psychology Service	EPS
Every Child Matters	ECM
Individual Educational Programme	IEP
Interpretative Phenomenological Analysis	IPA
Local Authority	LA
Local Education Authority	LEA
National Autistic Society	NAS
Parent Partnership Service	PPS
Parent Professional Liaison Group	PPLG
Picture Exchange Communication System	PECS
Speech and Language Therapist	SALT
Special Educational Needs	SEN
Special Educational Needs Coordinator	SENCo
Treatment and Education of Autistic and Communication Handicapped Children	TEACCH

Note

(i)   The terms Autism, ASD and Asperger syndrome are often used interchangeably, though classic autism is seen as associated with severe learning difficulties, whilst a person with Asperger syndrome is usually seen to have cognitive skills, which are within the normal range. ASD is the more generic term.

(ii)   Shorter quotations from other writers and parent interviews are given in single speech marks within the text, whilst for longer quotations italics are used within a separate indented paragraph in accordance with the conventions of Doctorate work within the Department of Educational Studies.

ABSTRACT

The main aim of the study was to consider how parents' experiences of bringing up a child with autism might inform professional practice and provision. The enquiry investigated how mothers made sense of their experiences and the effects of bringing up their child, including their coping mechanisms and the arising key messages for practice.

The study was based in a LA context and was carried out by a practising Educational Psychologist (EP). This research practitioner orientation required critical or action research elements to merge with interpretative method. Thus, initial contact was made with autism parent groups to ground the study in a local context and to develop research and interview questions. Critical action planning resulted from concerns arising from these groups.

Semi-structured interviews were carried out with six mothers whose circumstances in bringing up their child had been particularly challenging. Their children attended both mainstream and special autism provision in the primary and secondary school sectors. The themes emerging from the powerful joint interpretative account of the mothers highlighted a deconstruction and reconstruction of self and expectations with unfulfilled wishes and control as key themes. Life impacts involved the child as central focus, an all-pervasive constant battle with self and others, including family, professionals and provision with associated child management issues being present. These key themes impacted on professional practice; and provision so that the importance of informed professional awareness, truly listening professionals, accepting school identity and service trust were highlighted.

Professionals and parents should develop an understanding and acceptance of the child and each other, which still enables challenge and change. The position of fathers in family support needs further research and careful professional consideration. Professionals, including EPs, need to address the way they listen to parents. Some recommendations for all agencies and parents are provided which should lead us to a deeper understanding of humanity.

CHAPTER 1: INTRODUCTION

'On another's sorrow'

Can I see another's woe
And not be in sorrow too?
Can I see another's grief,
And not seek for kind relief?

Can I see a falling tear,
And not feel my sorrow's share?
Can a father see his child
Weep, not be with sorrow filled?

Can a mother sit and hear
An infant groan, an infant fear?
No, no! never can it be!
Never, never can it be!

William Blake, *Songs of Innocence*

Blake here insists that we cannot watch someone else's feelings and fail to react with feelings ourselves. This study aims to describe the essence of mothers' experience of bringing up a child with autism and provision and considers the context for this experience, with regard to personal background and parent autism support groups. The researcher observes and interprets sorrow and loss, its meaning and developments in parent experience and coping.

Areas of Research Interest and Origins

The research combines the following areas of professional interest: autism; parent support, professional practice/provision evaluation and partnership working. These overlapping areas of interest are illustrated in the diagram below:
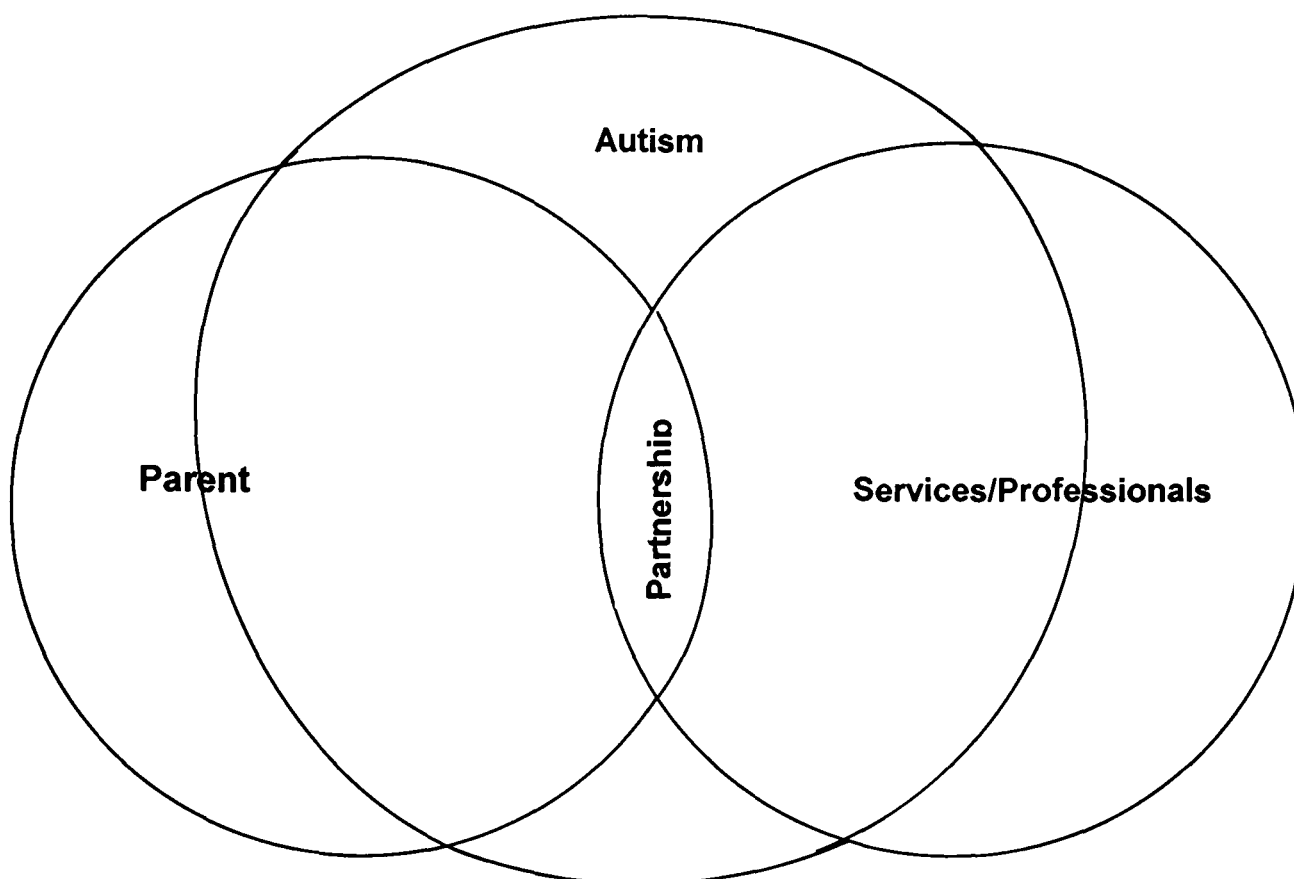
As a practising educational psychologist (EP) with lengthy experience and specialist interest in the field of autism, parent support and service or provision evaluation, this research area arose as a natural consequence of my own personal and professional experience and history, which are relevant to these research components and include my Part 1 studies at Sheffield University. Throughout my career as an EP I have worked in the area of autism, severe learning difficulties and parent support, going back to some workshops carried out with EP colleagues for parents of children with delayed development, including those with autism (Burton, Miller and Willis 1981). Indeed my Educational Psychology Masters Degree thesis of 1975 was concerned with implementing language developments programmes with parents of children with severe learning barriers. At First Degree level my dissertation looked at hypotheses around parent handling effects on the risk-taking behaviour and

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independence of pupils with complex difficulties. Doubtless, at some level, my personal experience of aspects of handling by my own parents and their effects on my own functioning will also have impacted on my desire to embark on this particular research journey.

More recently, since 2000, whilst undertaking Doctorate study, I have written Part 1 modules on service evaluation methods and parent feedback on Educational Psychology Services (Willis 2002). Within my own Local Authority (LA), such studies meshed with local and service needs and by bringing my specialist interest area of autism into the arena, the parameters of the research study were set. At the same time, as I describe in later chapters, I wished to move to a qualitative study of parent experience having utilised parent satisfaction surveys within my Part 1. The broad research was to explore how the experience of parents of children with ASD might inform professional practice – not just of EPs, but of all agencies.

In research, the position or standpoint of the author is a key component of the study, so that the distinct perspective of the writer is considered, to help the reader make sense of findings. It is recognised that people drive research and it is essential to have an in-depth understanding of the researcher's context and background. My positionality was that of being a Senior EP in Martom, who had worked there for around thirty years and gained extensive experience in the autism and parent support fields. My casework experience had also been wide-ranging and in-depth, especially in the special school autism provision area. I have also been involved in LA strategic and policy work and training, including membership and more recently chairing the Autism Working Group (AWG), which served coordination, development and support functions. I had written a published article on Martom's multi-agency approach to autism (Willis and Ward 2001) and presented on this theme at a multi-agency course at Great Ormond Street Hospital with a colleague. Hence, my position was one of some considerable investment in and familiarity with the local provision.

Other autism support professionals in Martom were also proud of their provision and hosted regional conferences, with their approach being viewed as a model for others, particularly because of perceptions about low levels of out of area placements and joined up multi-agency working. It will be of interest to reflect on this local position in the light of the parent experience to be described and interpreted.

Research Developments

The Methodology chapter of this thesis describes how I arrived at my chosen interpretative research method and the Research Process considers the nature of my research as a practising EP in a LA, thus embedding my study in a real local context through contact with parent autism support groups. This contact brought about developments in the study, which necessitated action at a political level within the LA in order to do justice to concerns and issues raised by parent groups. This critical and action research component of the study was not an initial research aim and indeed the parent group element was undertaken to clarify and develop research and interview questions.

The Interpretative Account of the experience of the mothers involved in the study, whilst based on Interpretative Phenomenological Analysis (IPA), which is described later, also used narrative approaches to attempt to produce an account, which flowed and conveyed the essence of the interpreted individual and combined experience of mothers. Interviews, whilst semi-structured, were interactive and worked towards the development of shared understandings, with the personal involvement of the writer. Understanding and meaning, rather than causes, were essentially sought.

The research process was non-linear and cyclical, with the aims emerging and the methods used constructed for particular purposes, which related to the emerging research questions. My research task, therefore, became to combine an interpretive method, which considered parent experience of bringing up a child with autism with approaches, which recognised the context and were at the same time critical, so that some change was incorporated.

CHAPTER 2: LITERATURE REVIEW

SECTION 1: BACKGROUND

As mentioned in the introductory chapter of this thesis, my main areas of professional interest, relating to the study include; autism, parent experience and service professional practice feedback. A further major focus, which has emerged almost as an over-arching theme, is that of stress and coping. Any literature review, which addresses these four broad fields, will need to be both selective and focused. Within my Part 1 modules, I looked at the evaluation of psychological services as a literature review and I also undertook a pilot study in the area of parent evaluation of such a service in my own authority. The field of study I have chosen and the qualitative methodology I have used are considerably distant from these beginnings. Indeed, the feelings of dissatisfaction, which I experienced with the rather superficial quantitative questionnaire rating scale approach to service evaluation led me toward this more in-depth research into parent experience and to ask the broad research question, 'how can parents' experience of bringing up a child with autism inform professional practice and provision?'

Whilst, the component interview research questions will be addressed later (see Appendix 2c), it is important to acknowledge at this stage that the research will also be asking questions of the research paradigms, which have been adopted. Furthermore, the reader should be aware that in the tradition of my chosen IPA methodology, the literature review has been written after the analysis of my research findings, so that new interpretations could be brought to the material.

The first section of this review will address the area of partnership with parents, including the responsibilities of researchers and the entitlement and responsibilities of participating parents. Discourses and dilemmas around pathologisation, autism labelling and social power relations in a partnership context will be considered. Finally, the nature of autism research mapping with families and the nature of autism will be discussed.

Secondly, the literature concerning professionals and families with SEN and autism will be considered with the effects of autism on parents being outlined. Further discussion will concern the experiences of mothers, stress in families and various theories of parent and family coping. Stress and coping models will be considered at both practical and cognitive levels. I will consider the ways in which meaning is sought through attributions, control is achieved and self-esteem is re-built. The nature of defences, illusions and their positive role in coping is emphasised.

In the final section, literature concerning professionals, provision organisation and multi-agency working will be outlined. The context of the Children Act (2004) gives rise to discussion around team working and dissent. The nature of management in schools to assist with effective autism provision is examined. Next, a consideration is provided of models of parent-professional relationships that emphasise accountable professional practice, thoughtfulness and responsiveness. Finally, further discussion of issues around good autism practice, inclusion and future ways of working provides the concluding part of the review.

SECTION 2: PARTNERSHIP WITH PARENTS; PATHOLOGISATION AND AUTISM RESEARCH MAPPING

There have been a number of recent influences, which have led towards an increased awareness of and sensitivity to the experiences and needs of parents. These have included the DfES Code of Practice (2001) proposals, Best Value service reviews and the DfEE Working Party Report on Educational Psychology Services (2000). The Children Act, of course, addresses parents' needs and themes such as multi-agency working. My pilot study made use of questionnaires to consider the views of parents about the work of the Educational Psychologist (EP) where their child had been through the statutory assessment process. One of the concluding paragraphs appeared to serve a directing function in relation to my subsequent thesis work, even though this

self-direction has operated at more of an unconscious level. Thus, my paper (Willis (2002), page 15) referred to:

> *Other research methods, such as in-depth interviews with a small sample of parents and the use of a parent focus group would usefully add to the information which has been collated by this questionnaire survey. Indeed, the triangulation of information sources from questionnaires, focus groups and interview methods, would provide a rich and varied bank of information which would assist service planning for work with parents. Where this information could be collected by different service groups, shared for planning purposes and supported through management systems, then the process should be in place to assist change and development.*

Whilst questionnaire approaches have not been used in this study, in-depth interviews and loose focus groups were utilised. Furthermore, an interpretative mode of enquiry has been adopted and attempts have been made to build findings into LA planning and development. Carr and Kemmis (1986) have described the interpretative researcher, who applies 'disciplined subjectivity', so that events are constructed and interpreted. Within this study, elements of emancipatory or action research have also been incorporated. Other methodological and procedural sections of the study will consider these matters in more depth, though key aspects of research orientation are relevant in this Literature Review.

Partnership with Parents

My pilot study also rather simplistically concluded (page 15):

> *By involving and listening to parents as service users and actively incorporating feedback into service operational systems, a genuine partnership with parents can be achieved, as envisaged by Wolfendale (1999) and the Code of Practice (2001a).*

The Wolfendale paper mentioned above warrants consideration in some depth in this section, as it provides useful guidelines or a code of conduct for research work involving parents. Whilst its major implications are perhaps procedural and methodological, the guidelines do provide a general context for considering parent partnership in general. The main elements or core values of the partnership model are rights and entitlement, equality, reciprocity and empowerment.

Researcher Responsibilities and Commitment Elements would include:

- open and honest descriptions of the aims and objectives of the proposed research;
- the provision to participants of verbal and written information about the proposed research, including a showing of the research instruments;
- clear statements about the nature of the involvement of the participants and the estimated time scale;
- sensitive, respectful handling of participants;
- guarantees (e.g. confidentiality, anonymity);
- provision of conducive surroundings in order to put participants at ease;
- a promise to provide information regarding the research outcomes and possible uses to which the findings could be put;
- building into the research design, opportunities for participants to contribute ideas at various stages.

Participants' Entitlement and Rights Elements

These include elements discussed above, such as research area and instrument information, sensitive handling in conducive surroundings and research contribution opportunities. Additional elements could include the right to:

- help to shape the research agenda (depending upon the nature of the proposed research);
- clarify how the participant might gain by contributing;
- withdraw from the research, without citing a reason.

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Participants' responsibilities and commitment elements could include demonstrating understanding the proposed research, providing the time commitment and co-operating along agreed lines. The above guidelines were seen to assist with the development of inclusive education and I have viewed them as a useful framework for my later procedural and methodological research approaches.

Partnership with parents is a key concept underlying my study and Wolfendale (1985, page 14) has usefully defined authentic partnership, so that:

> parents are active and central in decision-making generally and its implementation;
>
> parents are perceived as having equal strengths and equivalent expertise;
>
> parents are able to contribute to, as well as receive, services;
>
> parents share responsibility, thus they and professionals are mutually accountable.

Not all parents of course will be confident about engaging in partnership work with professionals, however this may be defined. Some may be resistant or antagonistic and reports recognise both the involved and the reluctant parents of children with special needs (Blamires, Robertson and Blamires, 1997). The real benefits of partnership may only be readily assessed by its absence in the form of families and children who are marginalized, frustrated, dissatisfied, feel unsupported and are not helped by services that are on offer. Efforts need to be made at early and indeed all stages to follow the principles described above by Wolfendale, so as to try to help all parents become active and involved. These background descriptions of partnership will be useful when considering parent experiences of provision later in the study.

Along similar lines, Gillian Pugh (1989) has consistently emphasised shared purpose, mutual respect and willingness to negotiate. Todd (2003) has

pointed out that, whilst the Code of Practice provides 'key principles for communicating and working in partnership with parents', policy documents do not emphasise the need for parties to discuss the meaning of partnership or the definition of roles. Services do not recognise the political nature of SEN assessment and any advocacy role that professionals adopt. She goes on to say (page 294):

A discussion of roles would provide an opportunity to recognise the differing power and position of the different parties and might help to redress the potentially disempowering effects of partnership.

Thus, the rather naïve positivist initial stance of professionals and services being openly receptive to feedback and parent views and working towards *'genuine partnership'* needs to be seen in this perspective of differing power relations. Todd has considered how the political nature of the discourse of partnership continues to be ignored. Her study considers how the existence of Parent Partnership Services can remove from schools the arena of parent partnership, when a child is undergoing a statutory assessment, so that partnership is moved into a space between schools and the LA.

Discourse and Pathologisation

Writers such as Derrick Armstrong (2003) have considered the broader political and historical context of special education in the UK, which he says 'illustrates the contested values and interests that have been struggled over.' A number of life histories of adults with learning disabilities were taken and their experiences were interpreted in this light. He says (page 116):

Historical analysis needs to take these voices seriously for they challenge both the homogeneity of experience and the social relations that have constructed difference as 'abnormal'.

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He describes the politicising forces of regulation in special education and the way in which resistance is the outcome of 'normal life', with the self always beginning. He goes on to discuss the need to break the 'culture of silence' through expression of experience and personal history as a step towards liberation from the constraints of subordination.

Along similar lines, Billington (1996) considers the issue of pathologising children, particularly with regard to educational psychology professionals. Dilemmas of regulation and resistance are discussed and psychology is seen to pathologise childen in order to regulate them, so that opportunities and resources can subsequently be regulated. Billington describes eight effects of psychological practices and discourses in education. These include: pathologisation and regulation; denying individuality; defining children and families within narrow value-laden limits; denying the effects of the practitioner on subjectivity; restricting resource allocation; employing superficial, simplistic and oppressive working practices; rejecting unconscious processes as legitimate concerns and regulating access to a psychologist according to class, gender and race.

Autism Labelling, Diagnosis and Parent Perceptions

Suzanne Oakley (2004), in an interesting Sheffield University Educational Psychology MSc. special study, has investigated the narratives of parents, whose children are diagnosed with ADHD. She draws parallels with the field of autistic spectrum disorder (ASD) and quotes Selfe (2002, page 9), who described concerns about the rise in the number of diagnoses from 7/10,000 in the 1960s (Lotter, 1966) to 58/10,000 in the 1990s (Wing, 1995). More recent figures given by Judith Gould (1998), Director of the National Autistic Society (NAS), Centre for Communication and Social Disorders in Kent, have suggested a total spectrum prevalence of around 91/10,000. Thus, when broader definitions are adopted, a total spectrum prevalence of almost one per cent is more currently suggested.

Selfe's concerns with the assessments related to them being conducted in an alien environment, yet relying on the reports and judgements of parents/carers. These two concerns however, to my mind, appear to balance each other out, as a broader evidence base is provided. Furthermore, they were seen as one-off with limited time available and relying on the subjective interpretation of behavioural checklists. No medical test is available for ASD, with cut-off points being constructed, whilst no attempt is made to weight the importance of diagnostic criteria. More recent and thorough approaches to diagnosis, of course, would utilise a range of evidence bases, which would include school and home contexts and incorporate the views of other professionals, as well as those of the parents. Information would be gathered over time and emphasise response to intervention.

Oakley (op cit) sees diagnosis as disempowering for the child and those who support them, including parents and teachers. She says (page 8):

> ... by labelling a child as having a psychiatric disorder, we are removing the very essence of ability to change and develop, to control oneself and one's environment; we are encouraging passivity in the child, the parents and their teachers and externalising the locus of control.

Such a view, which emphasises loss or reduced control, will be considered later in this literature review and in the discussion of the parent responses in my study.

Judith Gould (1998), however, would defend diagnosis and see it as 'a passport to resources', which gives parents access to information and services. Clarity is seen to be preferable to confusion for parents, who can then stop blaming themselves and develop understanding of their child's needs. This understanding should assist them to help their child and to work for more and better services, often in conjunction with other parents. The diagnosis in a way becomes a common bond.

The National Autism Plan for Children (NIASA 2003) provides guidelines on best practice in the identification, assessment and diagnosis of children with ASD. Key actions proposed include: a single diagnostic pathway; multi-agency assessment over different settings within a specified time–frame and discussion of the diagnosis and its implications, followed by advice on interventions.

Randall and Parker (1999) described their autism work in the multi-disciplinary Family Assessment Unit in Hull and the development of strategies for supporting and empowering families to better assist their children. They have surveyed parents of children with autism who attended the provision. They point out that complex stressors are created as the condition can be hidden behind normal appearance and enormous difficulties are created in acquiring a diagnosis. They say (page 1):

> *Not only do the parents have to tolerate increasingly obsessional behaviour, destructive acts, failure to communicate, emotional rejection, aggression and tantrums, but it also appears that they have to cope with fragmentary professional services that are difficult to obtain and sometimes downright destructive, from the time of seeking a diagnosis onward.*

In refusing to diagnose autism, the authors suggest that the label 'poor parent' may be applied or assumed by default. Professionals therefore need to question their conceptual framework, so that constructive help can be offered to parents.

Gray (1993) has described the 'emotionally difficult referral process', where professionals may talk of developmental delay, poor parenting and possibly a language difficulty. Experiences of waiting lists and being passed on are frustrating for all, though additional burdens, such as family rejection and perceived professional blame, would be present. At the same time defensiveness on the parents' part can add to the problems involved in the diagnostic process. Defended parents may cling to false explanations, like

'deafness', 'late development' and 'temperament', rather than face the prospect of life-long disability and dependence. The usefulness, or otherwise, of such defences will be an on-going theme of this literature review.

Tom Billington (2000a), now a tutor at Sheffield University, for both Suzanne Oakley and I, has described his earlier work in the Wirral as a specialist educational psychologist, which concerned the development of an autism service. He spoke with wide-ranging professionals and the parents of children with autism and saw parents as wanting the diagnosis of autism for the provision and resources it brought, but they did not want the stereotyped perceptions and constraints associated with the label. In talking of the representativeness of the parent groups involved, he said (page 9):

> ... many parents ... do not choose to engage with any of the voluntary organisations and the very nature of the consultation exercise, therefore (with parents so attached), perhaps increased the likelihood that the views expressed would be characterised by a degree of disenchantment. Seen positively, it might be said that parent organisations owe their very existence to an ability to prompt the enhancement of public services on offer.

He also noted that whilst the various participants often seemed to share similar views, however, this was not always the case and there were differences in terms of the required emphases of approach or preferred outcomes, as well as their desire for mainstream education, special placement or home tuition.

Billington (2000b) considered discourses in experience, expertise and learning, when writing with Mr and Mrs McNally (parents of a boy with autism), Professionals were seen to need to reflect more on their own theoretical first principles in their work with children, parents and teachers. Billington quotes Aristotle (1976 page 210), saying:

... the first principles of scientific truths cannot be grasped by science or art ... the state of mind that apprehends first principles is intuition ... wisdom must be intuition and scientific knowledge.

Professional accounts too often involve individual diagnoses, which may depend upon the language and power of the professional rather than the scientific rigour of their investigation. Deficit models of static abilities are rejected in favour of models of learning, which reflect thinking and feeling. For Donna Williams (1994, page 189), 'All thought begins with feeling' and she has described how her experiences are full of sensations and feelings, a hypersensitivity rather than a deficit.

Billington also refers to Bion (1962, 1970), who provides a scientific 'expert' model of psychological development that supports the complex links between thinking and feeling. Bion suggests that babies need to bring order to the physical sensations or incoming stimuli from touch, taste, smell, sound and sight. Professionals are implored to look more for abilities, than diagnoses or deficits and to try to believe what is being said to them. In the case of Tom, the McNally's son, pleas are made by the parents for others to view him as 'an individual human being with his own unique collection of thoughts and feelings.'

The diagnosis views of Billington and Randall and Parker (op cit), should not be seen as incompatible, there essentially needs to be a recognition of the uniqueness of difference, but within a framework which permits a parent to absolve themselves of blame, in terms of handling, for a child's condition. Nevertheless, in my view, it is hard to see how resourcing issues can be consistently and fairly addressed without the need for a diagnosis.

Social interaction and thought

Peter Hobson's (2002) excellent book 'The Cradle of Thought' considered how thought developed in the context of the social and emotional engagement between the child and caregiver. For children with autism, he said (page 44):

... what underlies autism is something lacking in just the kind of person-with-person engagement that is so characteristic of typically developing infants and their caregivers ... the abnormality ... could be described in terms of infant-like abilities that are missing or awry – especially things that have to do with emotional connectedness and communication before language ... there are signs that subtle but ominous pointers are already present by the second year of life.

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Whilst on occasions, development appears to have been derailed in children with autism, where there had not been early concerns; other such children may have seemed abnormal as babies. He described 'the patterned interplay between the typically developing infant and her mother or father, and how finely tuned and emotionally expressive are the transactions and mutual adjustments of action, gesture and vocalization.' It is against the backdrop of autism that we gain an appreciation of what infant social engagement usually entails and what the parent of a child with autism misses in interaction, feedback and engagement. Clearly, thinking patterns in the child with autism develop in different ways.

Hobson suggests that we have a basic human response to expressions of feelings in others and that forms of interpersonal engagement happen before thought and may provide its basis. Other theories, of course, may see the basis of thought more in terms of certain brain structures and such areas may be less well developed in children with autism. For these children, Hobson discusses difficulties arising through innate impairments in ways of relating to others. An interaction between social engagement and structural mechanisms is of course possible and indeed likely.

Partnership and Social Power Relations

Billington (2002) sees social power relations as operating on knowledge-making in professions and the way that professionals interact with parents, children and

others. He has discussed social exclusion and the way psychologists 'speak with, speak of and write about children'. He says (page 34):

> ... *it is through our activities (our modes of assessment, for example) and our language-making practices that we contribute to the creation of knowledges about individuals that too often bear little resemblance to that of real experience, whether child or adult. This is a matter of no little professional or analytical concern.*

Expert definitions, such as that provided in the DSM 1V (1994), can contrast greatly in terms of meaning with those provided by the pathologised themselves. Billington (2000b) contrasts such an expert view, with the words of Donna Williams (1992), saying (page 63):

Expert voice:
- *marked impairments ...*
- *failure to develop ...*
- *a lack of ...*

Donna Williams

> *The more I became aware of the world around me, the more I became afraid ... I was frightened ... My world was full of imaginary friends. They were far more magical, reliable, predictable and real than other children ... Other people did not understand the symbolism I used ... Trish cuddled me ... I was terrified. It seemed tears were welling up from a part of me long buried and forgotten ... I always paid for closeness with fear.*

Billington sees the accounts as neither exclusive nor necessarily incompatible, but views the professional account as being marked by language immersed in a deficit model of human development. Whether professionals should give so much time and emphasis to diagnostic issues, rather than helping parents deal with their distress is, of course, a crucial question. Billington has considered

how professionals construct ways of talking to parents, which create boundaries and can distance them from engagement with real issues of parent distress. With the movement away from the professional as a 'blank screen', he asks the question, 'Whose knowledge or evidence is it anyway?'

Autism Research Mapping and Families

An autism research mapping investigation carried out by Charman and Clare (2004) at the Institute of Child Health, London has gathered views from scientists and people with autism and their families about research needs and has compared autism research in the UK and the rest of the world. The report says (pages 5, 6 and 7):

> *Few people in either sector (researchers and non-academic community) gave high priority to (future) research on families and services. Attitudinal research is needed to identify the reasons for this, given the potentially beneficial impact of high quality research into the effectiveness and acceptability of services ... Little research is published on family issues and services for people with autism ... Research into effects on families and research into services are overlooked areas ... the reason for these being such low priorities deserves further investigation.*

Researchers and non-academics agreed that a greater emphasis should be placed on research into both environmental and genetic contributions to the causes of autism and into well-controlled intervention studies. More dialogue mechanisms were seen to be required to mesh the views of researchers, policy makers, people with autism and their families into future research and policy development.

The proposed need for attitudinal research is an interesting one, as it may link with discussions about defended subjects, so, for example, parents and families may not see the need for peering into their own world, just as

researchers may similarly defend against such investigations and be drawn to causation and intervention enquiry.

What is Autism?

Charman and Clare (page 4) also provided a definition of autism, which is perhaps more acceptable in its consideration of characteristics, which are shared with the general population, thus de-emphasising deficit. It draws on World Health Organisation; ICD10 (1993) criteria:

> *ASD is the term used to describe a range of behaviourally defined neurodevelopmental conditions ... characterised by impairments in social interaction, social communication and language development and a restricted repertoire of interests, behaviours and activities. Sensory abnormalities and unusual interests in some sensations are common. A lack of imaginative play indicates an underlying difficulty with generation of ideas that is highly relevant in the development of understanding of, and thinking about, other people and other situations. All of these characteristics can be seen in varying degrees of severity (World Health Organisation; ICD-10, 1993). As a developmental condition the manifestation of autism for any one individual will vary across the lifespan and also with maturation, the effects of different environments and due to specific interventions and treatments. One view held by many scientists and individuals with autism and their families is that these characteristics are shared in varying degrees of severity with the 'neurologically typical' population.*

Materials from the DfES and North West Regional SEN Partnership (2004) have drawn out the breadth of the term ASD, which refers to autism, infantile autism and pervasive developmental disorders as a description of individuals with a particular developmental disability. Some features of ASD are also seen in pupils described as having other related conditions, such as Pathological Demand Avoidance syndrome (PDA), Semantic Pragmatic syndrome and

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Oppositional Defiance Disorder (ODD). Collectively, these conditions are referred to as Autistic Spectrum Disorders. It is relevant to note that one of the parents interviewed in the individual case studies had a daughter, who was viewed as having PDA.

The current government guidance document *Autistic Spectrum Disorders: Good Practice Guidelines (DfES/DoH, 2002)* gives the description below for autistic spectrum disorders (section 2.1 page 6):

Severe autism ←--→ Asperger's syndrome

ASD is a relatively new term to denote the fact that there are a number of subgroups within the spectrum of autism. There are differences between the subgroups and further work is required on defining the criteria, but all children with an ASD share a triad of impairments in their ability to:

- *Understand and use non-verbal and verbal communication*
- *Understand social behaviour which affects their ability to interact with children and adults*
- *Think and behave flexibly – which may be shown in restricted, obsessional or repetitive activities.*

Such a definition, whilst still emphasising impairments or deficits, does bring out the breadth of the condition and hence an appreciation of a greater degree of difference between individuals, rather than encouraging stereotyped perceptions.

SECTION 3: PROFESSIONALS AND FAMILIES WITH SEN

Wall (2003) points out that the family has become increasingly diverse in its structure, but gives support and has the following key features (page 24):

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1. To provide a safe and secure environment in which children can develop their full potential.
2. To pass on culture, e.g. how we behave, aspects of history, languages.
3. To pass on norms and values.
4. To pass on family biology.

Dale (1996) has drawn out a helpful conceptual framework for working with families with SEN, which is highly relevant to discussions about autism. The framework considers differences of perspective and dissent between the professional and the parent, as well as issues of common interest and consensus. A model of negotiation is applied to the parent-professional relationship, which adopts a multi-level approach. Thus, Dale says (page 305) that the negotiation model:

> ... comes within the intellectual tradition known as social constructionism, which originated with Meade (1934) and Vygotsky (Wertsch, 1985) ... Instead of seeing human behaviour as located within the individual, social constructionism sees human behaviour as a product of the human community and seeks to understand the relationship between the individual and society. It argues for the necessity of multiple perspectives ... to understand the relationship between the individual and society.

When referring to 'partnership', Dale like Todd (op cit) makes the point (page 2) that:

> ... unless defined very specifically for the parent-professional relationship, the term can be used loosely to imply cooperation without telling us much about shared decision-making, the degree of consensus or disagreement, the power differences and gains and losses between the partners.

The Professional

Bennett and Hockenstad (1973) draw the distinction between traditional professionals, such as doctors, lawyers, architects and people workers, like teachers, social workers and nurses. Psychologists would presumably fall more in the latter group. Increasingly, in the childcare field, the term 'professional' is applied to all trained, qualified persons with a responsibility for the welfare of children and is used to distinguish qualified from unqualified lay persons, such as voluntary workers or parents. The professional in my study, holds a specialised body of knowledge and skills and has undertaken a period of often prolonged training to acquire them, so as to deliver this expertise through professional practice. There may be particular professional cultures and codes of ethics in relation to clients, as well as legal powers to carry out duties and make decisions. Professionals can also represent powerful interest bodies like an education or health authority and there will be dilemmas between such interests and those of the child or parent.

Parents and Carers

Parents and carers, on the other hand, according to the Children Act 1989, have 'parental responsibility' for the care and upbringing of children born to them, or adopted or where 'parental responsibility' is given to them. Parents tend to occupy a lower social status than professionals in their parental role, though not necessarily in their occupational role. Attwood and Thomson (1997, page 130), identify five key features that distinguish parents of children with special needs. Thus, such parents are long-term players and tend to become isolated, being more concerned with their own children than are others. Their emotional involvement is heightened and they know that the welfare of their children is much more dependent on the continued family effectiveness.

The perspective of each individual family member needs to be acknowledged and understood by the professional. The professional has chosen to come into a particular career after training and on a paid basis, with the opportunity to leave the work behind at the end of the day. Wall (2003) says (page 28):

Parents ... have little or no advance warning of having to bring up a child with special needs and...were expecting a healthy child for whom they had plans and expectations. Suddenly their dreams and expectations are eradicated and they are faced with a barrage of professionals, confusing systems, some lack of control of events, possible rejection by their friends, community and family, and an overwhelming feeling of failure and disappointment. The way parents are supported is crucial to their future, their child's... and ... other family members'.

The Effects of Autism on Parents

Professionals need good understanding of the effects of autism, the feelings aroused in parents by discovering they have a child with autism and the emotional and practical problems that ensue. Studies, such as that by Howlin and Rutter (1987) have acknowledged considerable difficulty for parents with long-lasting and daily problems with unresponsiveness, challenging behaviour and long-term special needs (also Konstantareas, 1991). First-time parents are often thought to be more at-risk of not recognising the early developmental signs of autism. Feelings similar to those involved in bereavement have been described (Frude, 1992) and the experiences described below in the *Stage Theory* section are relevant. Newson et al (1982) noted concerns about communication with the child at the pre-verbal stage. Relatives and family doctors may discount concerns and see parents as over-anxious, though reality may strike when a second child developmentally outstrips the first.

Obsessions, detachment and marked communication difficulties may become increasingly evident and parent confusion can become heightened with unsatisfactory contact with professionals (Frude, op cit). The term 'autistic tendencies' gave rise to further confusion for parents and a continuum disorder as described by Wing and Gould (1979) with a triad of impairments is generally accepted. Such descriptions, of course, do not reflect the experiential richness of the condition, as mentioned above.

Parents can experience tantrums and frustration-aggression, with associated social misunderstanding by others, as well as a possible tendency to keep away from social situations. Parent-child interactions are characterised by 'aloofness' and Sigman and others (1986) have noted that children with autism are less compliant than children with mental handicap or no handicaps at all.

Parents may also need to make use of medication for their children, which can be linked to challenging behaviour or the commonly associated condition of epilepsy or both. Where respite care has been of high quality, it has improved quality of the lives of parents, but also of siblings (for example, Wigham and Tovey, 1994). Experience suggests that users of such support would usually be expected to have more significant child difficulties and higher family stress levels.

Challenging behaviour is of concern for parents of a child with autism, even where they have had previous experiences of parenting. Schopler (1995) has pointed out that the core differences of autism prevent their affected child from learning in the same way. Emerson et al (1987) in Randall and Parker (op cit page 133) provide a within-child definition of challenging behaviour:

> *Behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit orderly access to the use of community facilities.*

Such a within-child definition, of course, would also need to consider the context and support arrangements that were in place. Challenging behaviour is a result of an interaction between within-child and external factors such as the physical and sensory environment, type and level of demands made and the adult(s) and other children present, if any.

Basically, a wide-range of approaches is required to assist with such difficulties and these can include parent support groups, counselling, behaviour and functional analysis and respite care (Bristol, 1984). Parents and professionals will have their own perspectives on the usefulness of such approaches, but the need for different services will vary with the age of the child and the particular stage at which the family finds itself. Jordan and Jones (1996) and Howlin and Moore (1997) have described the gap reported by parents between receiving the diagnosis and receiving useful advice on interventions. A useful review of the literature on research into autism interventions, commissioned by the DfEE, has been provided by Jordan, Jones and Murray (1998), where chosen interventions are based on a thorough assessment of the individual and family needs, together with appropriately trained and supported professionals. As will be argued later, there is a particular need for appropriately trained professionals to assist parents with non-compliance difficulties.

The Experiences and Stories of Mothers

Whilst the discussion so far has referred to parents and can include fathers, much of the literature, like my study, focuses on mothers, who are seen as the main carers for children, especially those with SEN. Barbara Cole, in a research presentation to my Doctorate group in November 2003 cast light on issues around mothers of children with SEN and parent professional interaction. Her research, expanded in her 2004 book, considered the professional and personal experiences of women who were both mothers and teachers of children viewed as having SEN. She listened, created the lived experiences of the mother-teachers and offered these as an alternative to the constructions of their lives made through the 'expert' discourses of powerful medical and educational professionals.

Following Oakley (1986), her methodological approach referred to mothers as the 'voice of experience' and she argued that to find out what someone thinks, then you should ask them. Professional knowledge issues were considered around the complex interaction and juxtaposition of personal and professional

experience. A qualitative, feminist ethnography and narrative methodology was used, which emphasised 'narrative analysis' rather than analysis of narrative. Life stories from the mother and collaboratively generated life histories were interwoven.

Some aspects of this approach were adopted; for example, establishing clear research expectations, trust and openness and encouraging parents to 'tell their story'. An interactive approach was also used, with mothers considering the interview and joint interpreted account, so that they had the opportunity to amend and develop the material.

Stress in Families

Early studies tended to look at large groups and used loosely defined concepts of stress. Mothers of children with disabilities were usually investigated and were shown to experience high levels of stress (Burden, 1980, for example) and depression was often found. However, stress is seen to be multi-faceted and linked to features of the coping environment, the individual and the experience itself.

Randall and Parker (op cit) discussed stress in families with a child with autism in relation to Maslow's (1954) hierarchy of needs, including self-actualisation and self-fulfilment. They report that it is a common finding that these mothers find it very difficult to pursue a career because of the excessive time and care demands of their child and the frequent lack of day-care services. Parenting their complex child becomes the primary means of meeting achievement needs. Feelings of rejection and social isolation are a further stress for these families (Intaglio and Doyle, 1984) and the need to belong tends to focus inwards towards the core family.

In the light of my own study, it was particularly interesting to note that uncertainty and ambiguity is viewed as a further family stressor for Randall and Parker, (page 17):

... not only with regard to the nature and degree of the disorder, but also in relation to the prognosis, educational needs, expectations regarding the child's capabilities and potential, and the quality of available services ... to cope with these uncertainties, many families ... place a strong emphasis on organisation and control within daily life ...

Wall (2004) suggested that parents of children with autism may feel that nothing is given back in interaction with the child and this will be difficult to deal with, especially where regression is experienced ... affection may be denied to the parent, supervision needs may be greater, contact with friends and family may be reduced and outings such as shopping can be traumatic. These effects will also impinge on others in the family.

Fathers

Fathers of children with special needs have received less research attention than mothers and whilst less stress may have been described, it is uncertain whether their greater stoicism and difficulty in expressing and acknowledging their painful emotions is involved, so they are not seen as weak (Seligman and Darling, 1989). These authors have also described an escape-avoidance approach for fathers, so that additional burdens fall on the mother and anger and resentment develops in family members.

Wall (2003), pointed out that fathers are often at work when the mother as primary carer attends professional appointments and so there may be a tendency towards marginalisation, which may deny them their own emotions, feelings and concerns. Carpenter (1997, page 137) has pointed out that:

They (fathers) need to be offered increased access to information and support, to be provided with opportunities to network with other fathers and to have their need for information and support within the family addressed. In order to achieve these aims, greater training and awareness among professionals is necessary.

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Considering the involvement of fathers, a study by Hastings et al (2006) looked at coping strategies of mothers and fathers of children with autism who completed an assessment to record the strategies they used to cope with raising their child. Factor analysis revealed four reliable coping dimensions: active avoidance, problem-focused, positive and religious/denial coping. Gender differences were suggested on the first two of these dimensions but there was no reliable evidence that parental coping varied with the age of the child. Associations were also found between coping and stress and mental health. Practical implications considered included reducing reliance on avoidance coping and increasing positive coping strategies.

Olsson and Hwang (2001) have investigated depression in mothers and fathers of children with autism and/or intellectual disability. A control group was also used and mothers of children with autism had higher depression scores than mothers of children with intellectual disability without autism. Fathers of children with intellectual disability and autism and control mothers and fathers had lower depression scores than mothers of children with intellectual disability without autism. Single mothers of children with disabilities were more vulnerable to severe depression than mothers living with a partner.

Siblings
The position of a child in a family can impact on their personality and development. Older children may take on a temporary carer role and acquire additional pressures and responsibilities, whilst a middle child could feel left out if the older child attempts to assume a caring role with regard to the child with autism. Some positive and negative effects of having a sibling with autism or special needs may include: jealousy; aggression; tantrums and lack of cooperation, as well as love, consideration and cooperation.

Adverse effects on the siblings of a child with disability have been predicted from many early studies. Seligman (1991), for example, describes anger,

resentment and guilt, as well as possible feelings of responsibility for the disability. However, Dale (page 105) states:

> *... that a variety of factors (including the nature of the child's disability, the behaviour of the child with special needs, the quality of relationship of the siblings, the openness of communication between the parents and child with special needs) ... mediate in complex ways to affect how a brother or sister develops.*

Lack of space limits the extent to which siblings can be discussed, though further consideration is given below in the *Support and Implications* section. Brenda Nally's (2001) NAS booklet is a useful resource for families and in addition to sibling issues, she also considers social networks, the family life-cycle and grandparents. She also described some of the benefits for siblings of a child with autism, which include: possible greater understanding of differences between people and increased tolerance, so that their experience might influence their future direction and career choice. Wider family issues are also considered in Howlin ((1998).

Marital Relationship

Following this assumed *pathological model*, strain on the marital relationship is expected, where there is a child with disability. For example, Sloper and Turner's (1993) study noted that eleven out of fourteen divorced or separated mothers attributed the marriage break-up, at least in part, to their husband's non-acceptance of a physically disabled child. Whether such stress factors would apply in the case of families with a child with autism, where the disability is often more hidden is open to question. Also the degree to which such perceptions are part of a defended outlook needs to be considered.

Grandparents

Grandparents can also present difficulties, as they have to grapple with their own reactions and feelings about the child. Blamires, Robertson and Blamires (1997, page 19) point out:

Further removed from the child than its parents, relatives may not see or may not wish to see the reality of the problems.

It is not easy to continually point out real difficulties to grandparents anxious to dote over 'perfect' grandchildren, and it is not easy to decide how open to be about difficulties that may only worry relatives who will often then feel powerless to help.

Support and Implications

The NAS publish some resources to assist siblings and families in coping with a child with autism. An example, mentioned above, is 'Experiences of the Whole Family', by Brenda Nally (2001) and she suggested that parents need to make time for themselves, stay positive in their attitudes, actively seek help and support and reach out to maintain contact with friends and other parents of children with autism.

She provided some insight into relationships with relatives, pointing out that relatives often have mixed feelings when they realise that autism is life-long and has no cure. If they stay in close touch, they probably feel that they should help with the child. If they do not help, they feel guilty and perhaps distance themselves and find some way to justify this.

Dale pointed out that 'there have been striking signs of variation between people in how stressed or adversely affected they were.' There are, of course, related methodological issues about the role of language in describing experience and the associated meaning and these will be discussed in later sections of this study. This *pathological or deficit model* is unlikely to reflect variation in individual experience, so that a wider view is required, not only of the family, but also of transactions with wider society and with professionals.

The view that families with a child with ASD present a 'needs deficit' and 'burden of care' on public services (Wilkin, 1979), tends to assume that they have homogeneous and similar needs and require a similar set of services.

However, what does appear to be pertinent is the notion of a support coordinating key worker for families and this will be discussed in later sections, as it is pertinent to Children Act discussion.

Parent Groups

Such groups can provide valuable support for families with children with special needs or autism (for example, Hatch and Hinton, 1986). A range of voluntary and support groups developed following the 1981 Education Act, as legislation did not extend far enough and problems around differing expectations and priorities for parents and practitioners still existed. Parent groups in autism and other areas of disability precede this legislation with the NAS, being founded by parents in the 1960s. Indeed, in the field of ASD, it is parent groups who have pioneered much of the specialist provision for children and adults with autism.

Nevertheless, parents will vary in the extent to which they wish to enter 'the world of disability' and the acceptability of the difference of these groups will vary. One teacher with whom I work, had spent time chairing an autism parent group, as she had a child with these needs. She had passed the stage where she needed such support and wanted to be involved in more 'normal' pursuits. She said that she had tired of hearing countless stories of the diagnosis process, often where parents were apparently competing to provide the worst story.

However, according to Dale (op cit), there is evidence that families, with low support in and outside the home, may appreciate such groups and that some professional support in their initial mixing in such groups can be beneficial.

Theories of Parental and Family Coping

Autism is often referred to as the 'invisible handicap', as children do not show the obvious physical signs of disability and this can lead others to have inappropriate expectations. Wall (2004) pointed out that for parents of children

with autism compared with parents of children with mental and physical difficulties (page 32):

> ... the same difficulties and feelings would be likely to arise ... but if diagnosis follows a period of apparent 'normal' development, then the difficulties and issues can be compounded.

She also notes further burdens for parents, which are made worse by 'the confusion arising from seeing a diverse range of professionals and having to fit in an array of appointments on a fairly consistent and regular basis.' The ongoing struggle may be compounded by the fact that many professionals may be reluctant to use the word 'autism'.

Dale's framework for viewing parent and family adaptation will be followed in this discussion. She described the KIDS Family Centre, in which she was involved and attempted to work towards partnership. The complex and changing context in which work was carried out meant that there was no easy prescription for partnership practice and no easy remedy for dissent or resistance.

Various theories of parental and family adaptation are considered and these include: stage theory, stress/coping and cognitive adaptation models. Some outline, at this stage, of the models described above should be helpful in creating a context for later discussion of the research findings in my study.

Stage Theory
Workers such as Drotar (1975) have likened the parent response to finding out that their child has a disability to the sequence of stages involved in bereavement. Thus, the stages of shock, denial, sadness, anger and anxiety are followed by adaptation and reorganisation. There is frequent oscillation between phases and Cunningham and Sloper (1977) have described the early traumatic period. Such models, which focus on emotional adjustment, help us to see these reactions as appropriate and the notion of stages helps the

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professional to intervene in a more timely way. However, reactions to disability are now seen to be more individual and there does not need to be one view of a generally accepted way of adjusting.

Where diagnosis is concerned, feelings of loss, grief, injustice and despair will impact significantly on parents' ability to take in information which will have major effects on their future life and that of their family. Dale (1996, page 51) comments that:

> *Parents complain about delays and evasion in the telling, being given false assurances, being told in an abrupt and uncaring way, having the negative consequences of the child's condition emphasised, each parent being told separately, being left to break the news to the other parent, being told in a public place and not being given access to a private place afterwards.*

Roll-Pettersson (2001) has investigated how parents talk and feel about having a child with cognitive disability. The study showed that parents' responses varied and that while some parents passed through phases as in *stage theory,* which the author termed *the adaptation-mourning model*, the majority reported that from time to time they experienced incidents and events, which they perceived as critical and difficult. The findings indicated that there was insufficient evidence to support professionals continuing to adhere to the *adaptation- mourning* model, together with its associated deficit or pathological-dysfunctional paradigm. Roll-Pettersson suggested that more encompassing models were required to better support families throughout their lifespan.

Blacher (1984) found differences in terminology and sequence, when reviewing the literature on the stages of the adjustment and mourning process; for example, what one researcher labelled 'guilt', another termed 'shock' or 'denial'. Theorists often intertwined stage theory or the adaptation-mourning process and associated defence mechanisms in response to the birth of a child with developmental disabilities. Professionals were concerned that if a parent did

not pass through the mourning process, they might 'freeze in their own sorrow' and thereby activate a variety of defence mechanisms, such as denial, isolation, reaction formation, projection and regression. Olshansky (1962), on the other hand, used the term 'chronic sorrow' for parents with a child with 'mental retardation', so that professionals needed to cease to encourage parents to think in terms of 'acceptance' of their child's disability, as their sorrow was a natural, but varying, response to a tragic fact (page 193).

A study by Sloper and Turner (1991) has compared the perceptions of paediatricians with those of parents, with regard to family needs. Professionals or paediatricians over-estimated parental needs in coming to terms with the child's handicap, as well as the parents' marital difficulties related to the handicap. Such professional perceptions encourage a dysfunctional or pathological view, which overemphasises 'acceptance'.

Stress/Coping Models

Multi-factorial or multi-measure studies, such as that by McConachie (1991), have noted the variability within and between individuals over time. Seligman and Darling (op cit) have stressed the need to move away from the *pathological model* and to see families as 'ordinary' families having at times to face specific crises around a disabled child. Such a conceptualisation stressing the essential ordinariness, though personally meaningful nature of experience, is in keeping with the approach used in the present study.

Dale outlines a number of risk factors, which include child, parent and family and service characteristics. Child level factors will include behaviour problems, degree of settledness at night, health and communication problems, appearance and general activity level. Parent and family characteristics include parent coping strategies, level of education and income, social isolation, leisure pursuits, family cohesion, marital satisfaction and moral or religious values. Service risk factors would relate to the degree to which family and child needs are met.

Resilience and coping are naturally associated with lower levels of the above risk factors. Other protective factors would include a supportive social network, friendship and support from other parents with special needs, a positive outlook, a practical coping style and positive problem-solving skills. McConachie (1994) has drawn up an exemplar stress/coping model, whereby outcomes in terms of adaptation are viewed as a function of the stressors, available resources and coping style.

Coping Strategies

Parents can deal with stress in a number of ways and I have broken down Dale's analysis (page 113) into the two broad areas of cognitive and practical strategies. Similar strategies feature strongly in the analysis of individual interviews. Thus:

- Cognitive strategies include: denial; positive thinking; changing one's view of the situation so as to worry less; giving over responsibility to others and withdrawing from stressful situations.

- Practical approaches include: use of respite; seeking help from others and actively seeking information.

This view emphasises diversity between families and an acceptance of their individuality, so that 'pathologisation' is avoided or minimised. Both risk and protective factors are identified, so that services can offer specific assistance. The danger, of course, is that there is an emphasis, or perhaps over-emphasis on coping and hence a removal of attention from the real vulnerabilities in families. This highlighting of the individuality of family responses, could absolve the State of responsibility for providing adequate care and provision for the disabled and their families.

If the family is viewed as a changing and dynamic unit over time, there is a need for continuous and flexible provision. Transition periods, for example from pre-school to school or from school to adulthood, are times at which services

are criticised for continuity issues. Different demands are presented at various times in the life-cycle, so that change over time is considered. Moreover, we can learn directly from the family over time, about resources, stresses and coping styles and more importantly, *what they mean to the family.* A flexible approach without the indiscriminate assumptions of the *pathological or deficit model* is required. Such an approach would assume an individualised support plan, using a 'holistic' view of the family and an individual professional, who operates within a co-ordinated multi-agency framework of service delivery.

The professional should respect the particular coping strategies used by a family, so that confrontation is avoided and coping methods are not undermined. Loss of income through attending frequent appointments should be considered. Also, denial regarding a diagnosis, can be useful in the early days, as it reduces stress, though later on, it may prevent positive problem-solving around the difficulties. Wall (2003) notes that practitioners should be prepared for parental resistance to acceptance for a number of reasons (page 31):

- Parents may be shocked and believe categorically that their child is just a little delayed or lazy and will 'catch up' in time.
- They may have friends who have undergone negative experiences of such situations and who relay their own 'horror' stories and warnings.
- Parents may not be able to fully comprehend the information or appreciate the importance of issues raised.
- Parents may be fully aware of the issues but be unable to come to terms with the reality of the situation.

As mentioned above, there have been few studies, which have investigated the feelings, experiences, needs and stresses of families, in which autism has been present. A broad, exploratory study by Liwag (1989) involved Filipino families of children with autism and has spoken of autism as 'one of childhood's most cruel diseases' and sees families and children as its 'victims' (page 3). There was considerable overlap between the findings of this study and those of

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Randall and Parker (op cit). Liwag looked at family stresses, coping patterns and differences in patterns between mothers and fathers. Depression and sadness were predominant and feeling stunned or disbelieving, feeling sorry for the child and for some, a sense of guilt and blame were mentioned.

Fathers appeared to experience less shock and more mothers than fathers kept questioning the reasons for their child developing autism. Mothers had developed their own theories or attributions for this and these included pregnancy, delivery and family interactions. Whilst a number of stressors were present, parents' biggest concern was about their child's ability to communicate and perceived long-term interpersonal relationship difficulties.

Coping strategies involved the family becoming focused on the child with autism in terms of time, attention, effort and expense. A second strategy concerned the emotional and behavioural adjustment of the family in terms of understanding, patience and acceptance. Whilst mothers sacrificed careers, fathers tended to work harder and sometimes worked away from home. Many parents preferred not to think too hard about the future, preferring to take matters one day at a time.

Provision of information about autism and social support systems was seen to be a protective factor. Information was needed to assist understanding of the meaning of how autism cannot be cured, but can be helped by education. Appropriate parental expectations about potential were therefore a key area and were linked to subtle denial. The 'gradually unfolding symptoms' of autism dictate that parents need to tread a delicate path when working with parents, so as to provide help, which is in keeping with their needs and conceptualisations at different stages. When parents become too adrift from reality in terms of their defences, then greater pain at a later date may ensue.

The extent to which parents, especially mothers, can retain their individuality

in the face of extensive and ever-present demands is open to question. Naturally, in order to cope, a certain degree of distance from the immediacy of the child's demands is required.

Cognitive Adaptation Theory

The search for meaning, mastery and self-esteem are the underlying themes involved in this theory suggested by Taylor (1983). It provides a useful conceptualisation that links to my chosen interpretative methodology. Such an approach seeks to elicit individual themes from the transcripts of intensive, semi-structured interviews and looks at how those involved make sense of personal experiences; for example, suffering from arthritis or having a child with autism. Personal events are made sense of by placing them within a coherent social and biographical context, so that a parent might link an illness to say treatment at work or the marriage of a daughter. Taylor (op cit) investigated patient's conceptions of chronic illness and suggested that interviews reveal three central themes: a search for meaning, an attempt to regain mastery of one's life and an attempt to enhance self-esteem. In order to regain mastery the condition can be attributed to a previously existing perceived causal event, which is no longer present, such as a previous partner. Downward social comparison can enhance self-esteem, with people comparing themselves with others who are less fortunate.

Control or mastery is a construct of considerable importance in psychology and many models of stress-control relationships emphasise the cognitive component. Thus, Abramson, Seligman and Teasdale (1978) suggest that the attributions an individual makes for a relevant stressor can lead to learned helplessness. Taylor, Lichtman and Wood (1984) report Thompson's (1981, page 491) review of the literature as suggesting that, of the strategies available, 'cognitive control may be most uniformly successful in reducing stress.' Cognitive control is seen as the ability of the individual to think of the situation in different terms. Rotter's (1966) locus of control construct is a measure of an individual's perceived level of control. Thus, the way an individual thinks about and labels a potentially stressful situation is an important factor in determining

their response to the stressor. Hence, in the autism field, the way a parent thinks about their child and situation will be crucial. Smith (1996) suggests that such interpretative research methods link feeling in control with affirming one's identity and that looking in detail at how individual parents talk about stressful situations and the meanings they attach to them can strengthen our understanding of the stress control relationship.

Attributions, the Defended Subject, Meaning and Control

Attributions

Suzanne Oakley (op cit) has drawn out the importance of attributions regarding the causation of behaviour. Jones et al (1971) saw attribution theory as examining the layman's analysis of behavioural causation for the purpose of understanding how this analysis affects his own behaviour (and) treats the actor as a constructive thinker searching for causes of the events confronting him and acting upon his imperfect knowledge of causal structure in ways that he considers appropriate.

Whilst Oakley applied attribution theory to the area of parents and children where there was a diagnosis of ADHD, it can also be considered in relation to autism. Thus, parental perceptions of control, achievement and social interactions will be influenced. Oakley also considered 'locus of control' and parental passivity following Law (1997, page 292):

> *In the discursive construction of ADD (attention deficit disorder) the child is not the problem. The problem is the dominant discourses of psychology, psychiatry and patriarchy, which subjectify parent and child – rendering them passive and separate from their abilities, competence and strengths, which would enable them to take action against the effects of violence, aggression and abuse in their lives – that is the problem.*

Oakley follows Selfe (2002), in developing this medical diagnosis related parental passivity argument in both the attention deficit and autism spheres.

Law's (1997) notion of children 'growing down' is seen as a consequence of external locus of control, following external attributions of control. For Oakley, the diagnosis of ADHD or autism appears to have absolved the parent of responsibility for the child's actions to some degree. This perceived parental passivity is seen as a consequence of external attribution and is perhaps an alternative to the 'mother blaming' that is described above by Randall and Parker (1997, op cit). In this latter case, the mother or parent is likely to have felt responsible through internal locus of control, for child misbehaviour, perhaps resulting from perceptions of other parents, relatives or professionals. It will be of interest to see how the parent descriptions of their experience in my study relate to these alternative internal and external attributions.

The Defended Subject

Hollway and Jefferson (2000) point out that the quality of analysis depends on the quality of data produced. They suggest that all research subjects are meaning-making and defended subjects may not hear questions through the same meaning frame as the interviewer or as other interviewees. These interviewees are likely to have invested in particular positions and may not know why they experience phenomena in the way they do. Furthermore, they may be unconsciously motivated to disguise the meanings of their feelings and actions. The open-ended questioning approach used by these authors recognises the importance of free association, so that incoherence will be present and is accorded significance. Personal meanings and the significance of particular events are built up over time through the use of further interviews where questions are devised to test out researcher hunches. Trust between the researcher and the interviewee is developed and data is co-produced through unconscious dynamics. For the purposes of the present discussion, however, it is most relevant to note that defensiveness within research participants is an acknowledged part of the research process. The degree to which the researcher adopts this more psychoanalytic approach will depend on their own methodological preferences as will be discussed in a later chapter.

Positive Illusions and Coping

Taylor (1983) in considering her theory of cognitive adaptation, has described how defences or attributions are helpful in establishing the meaning of a stressful or tragic event. Mastery centres on regaining control over the event and one's life and is exemplified by beliefs about personal control. Self-enhancement assists the process of recovery through a variety of cognitions, such as social comparison, as has been mentioned above. Successful recovery from a tragedy is seen to rest on illusion, so that defences are essential and functional in recovery. New attitudes to life, with changed priorities can develop, so that life is restructured.

Mastery is regained by seeing the cause of the tragic event in the past and is assisted by specific psychological techniques, such as positive thinking and meditation. The maintenance of the self-concept depends on the revision of one's personal history, so that the present is seen as better than the past. Taylor says (page 68):

> *The effective individual in the face of threat, then, seems to be one who permits the development of illusions, nurtures those illusions and is ultimately restored by those illusions.*

Disconfirmation can act as a threat to one's illusions, for example if cancer returns in a sufferer. However, Taylor sees the cognitive adaptation model operating through *cheerful ineptitude,* which characterises the disconfirmation of illusions in the adjustment to threat. Disconfirmation is conceptualised not as the violation of a single expectation, but as a temporary frustration. When parents' expectations for their children with autism are met with frustration, the model would suggest that some other goal or plan is substituted. People are viewed as adaptable, self-protective and functional in the face of setbacks. Whilst illusion is often seen as defensive and ineffective for learning and action, Taylor maintains that (1983, op cit, page 71):

... illusions can have a dynamic force. They can simultaneously protect and prompt constructive thought and action. As the literature on depression and on the self makes clear, normal cognitive processing and behaviour may depend on a substantial degree of illusion, whereas the ability to see things clearly can be associated with depression and inactivity. Thus, far from impeding adjustment, illusion may be essential for adequate coping.

Taylor and Armor (1996) continue the theme that the three positive illusions of self-aggrandisement, unrealistic optimism and exaggerated perceptions of control have been reliably associated with psychological adjustment. When traumatic events challenge these beliefs, active efforts are made to restore or enhance them. The authors addressed the concern that positive illusions fly in the face of reality and may be maladaptive and stated (page 893):

Specifically, we have questioned how individuals avoid setting themselves up for disappointment, faulty decision-making and pursuit of unrealistic goals, if they fail to acknowledge their personal weaknesses and limitations. Because positive illusions typically remain within modest bounds and because people show a high degree of relative accuracy regarding their strengths and weaknesses, the 'illusion' component may be less consequential than some critics have suggested. Moreover, there appear to be reliable time-outs, during which people are more honest with themselves and can recognise and incorporate negative information.

... preliminary evidence suggests that people ... adjust as well as or better than individuals sustaining the same setbacks who may not have held positive illusions.

The authors suggest that there are limits to the individual difference view of personality and that there are social as well as psychological factors involved. Some significant cultural beliefs also define the parameters within which

individual adjustment takes place. In Eastern societies, for example, where interdependence or the importance of the individual to the functioning of the overall group is prevalent, positive illusions may centre on group perceptions. Greater aggrandisement, control and unrealistic optimism about the group's ability to forestall subsequent negative events may exist.

Taylor et al (2001) consider how psychological beliefs such as optimism, personal control and sense of meaning may not only be protective of mental health in the context of traumatic or life-threatening events, but also can be protective of physical health as well. The work they carried out was concerned with males infected with HIV and Taylor's earlier work has considered areas such as cancer suffering. Later sections of my study will consider the applicability of positive illusions in the area of parent autism experience.

SECTION 4: PROFESSIONALS, PROVISION ORGANISATION AND MULTI-AGENCY WORKING

Randall and Parker (op cit) make the point that non-physical needs are notoriously difficult to pin down, including social and educational needs. Extensive debate about 'unmet need' and what is an acceptable level of social independence or quality of life has resulted. In determining need there should be at least a consideration of minimum standards laid down by professional expertise, as well as parent or family wishes for certain provision.

I have argued that professionals should accept the views and feelings of the parents they are working with and as Wall (2003, page 40) points out; 'While the child must always be the key focus of our work, family members must always be considered.' How then does the professional go about bringing progression to situations, when working from this standpoint?

Personal Construct Theory and Reframing

According to personal construct theory (Kelly, 1955), there are many ways of viewing the same situation and re-framing is a technique that can be used to

change a conceptual or emotional viewpoint. A situation is placed in another frame, which fits the facts of the original situation equally well or better (Watzlawick, 1974) and the personal significance of a situation can be changed. The professional can view the parent's position from their (the parent's) perspective; for example, the demanding parent can be seen as wanting the best for their child. A further re-frame can be developed by introducing a transactional perspective, so the professional might consider how they may be obstructing the parent getting what they need.

Multi-Agency Working

Where a child has a complex condition, such as autism, there will be a large number of professionals involved from different agencies. Autism is probably the area most in need of efficient multi-agency working. However, as Dale (op cit page 281) points out:

> *Although each (professional) will be committed to helping the child as best they can, the sheer scale of numbers and different disciplines and agencies involved sets the scene for conflicting advice, duplication in services, confusing input to the family, as well as rivalry between colleagues. Contact with suitable support services may be random and dependent upon the knowledge or goodwill of individual professionals to make appropriate referrals, (Brimblecombe and Russell, 1988).*

The Children Act (2004) requires services to work together in teams, with issues arising, such as co-location, different management systems, salaries, training and professional development systems. Both interpersonal and wider political or organisational differences can exist between agencies. Cunningham and Davis (1985) suggest that an inter-disciplinary team can have fewer problems in working together than a traditional multi-disciplinary team. Features of such a team include: sharing of specialist knowledge and core skills across disciplines, with every team member taking responsibility for coordinating information and intervention with other members of the team.

Interagency Team Dissent

Whilst the premise of shared understanding and consensus is present in the rhetoric of inter-professional cooperation, this may be illusory in some circumstances. Dissent or resistance in teams is often concealed and pushed beneath the surface at a cost to the team. Over the years, the difficulties have been great in establishing shared budgets between health, education and social services.

The professional may mirror the stress within families and this may show itself in a number of defence strategies or coping methods to minimise distress. According to Dale, these might include; 'detachment, avoidance, selective attention, inappropriate cheerfulness or false reassurance', (page 290). Open communication and the handling of dissent can be problematic and Bion (1961) in studying group behaviour, has shown how divisions and splitting between members and the projection of unresolved feelings and conflicts onto others could get in the way of mutual trust, honesty and openness. Competitiveness between staff can be generated in an organisational context and antagonistic relations may develop. In developing a negotiating climate within a team, Dale follows Bion in suggesting that each member of a working group has to have some authority of their own to be able to hold an opinion, while at the same time being prepared to change it. Hence, partnership between professionals seems to require the same type of negotiating model, described for parents.

Transdisciplinary and Transagency Working

Wall (2003) describes this approach, which recognises that areas of child development are inextricably linked and professionals need to work across disciplines. The model, like that of Dale, encompasses the needs of the family, as well as the child so that information and decision-making are crucial. The notion of keyworker underlies this model to coordinate and manage provision, as a single information contact source for the family. Action planning review meetings and case conferences are central to the process and research such as that of Mortimore (2001) and Carpenter (1997) sees transdisciplinary working as the most effective and supporting of current philosophies.

The SEN Code of Practice guidance (DfES, 2001, sections 10.1 and 10.4 page 135) highlights the need to work together:

Meeting the special educational needs of individual children requires flexible working on the part of the statutory agencies. They need to communicate and agree policies and protocols that ensure there is a 'seamless' service ... to provide integrated, high quality, holistic support focused on the needs of the child.

School Management

Whilst there is not time or space for an in-depth consideration of school provision and approaches, the most important starting point in helping a pupil with autism to function effectively in school is for all staff who come in contact with the child to understand their inherent developmental difference, which causes different behaviour and responses compared with other pupils. Such an understanding avoids the perception of the child as 'manipulative' or 'emotional' and helps to encourage an individualised approach to the child. Teachers' authority concerns need to be minimised, so that power struggles are avoided, as the child with autism may become stressed in such situations and become rigidly stubborn. Anxiety needs to be reduced, social skills assisted and peer relationships eased so that the child is protected from teasing or bullying.

There needs to be good links with families about plans and interventions, which should always include recognition of strengths.

Where Are We Now?

The benefits so far are difficult to pin down, but it is generally acknowledged that services have followed their own routes in reducing the negative consequences of disability. More damningly, they have worked competitively rather than cooperatively, often engaging in mutual blame to cover up

shortcomings (Brimblecombe and Russell (1988)). There is also a high degree of ignorance regarding each other's values, priorities and achievements.

Wall (2003) suggested that in progressing initiatives such as SureStart and Early Years partnerships, the following key issues need to be addressed for improved interagency working (page 68):

- Increased understanding and awareness of the roles and responsibilities of other professionals
- The expansion of the key worker scheme
- Joint funding
- Joint decision-making at all levels
- Joint training policies
- Rationalisation of professional differences
- Consideration of merging of roles and responsibilities, including shared or joint planning.

Models of Parent-Professional Relationships

As discussed above, power and authority differences affect the relationship between parents and professionals. Power conveys influence and sometimes authority to make changes or not and the person with greater power is likely to be in control of the relationship, though resistance opportunities will, of course, exist. Handy (1985) has distinguished various types of power, which are shown through different types of influence over the parent or other person. These include; physical, resource, position, expert and personal power. Overall the professional will occupy a higher position than the parent. Legislative changes, such as the 1994 and 2001a Codes of Practice have addressed this imbalance and greater authority is given to parental knowledge and decision-making, so as to change expert and position power to a degree. Greater use of litigious approaches by parents, may be giving rise to more defensive cultures within professional services. Certainly, there are requirements on services for detailed and accountable recording practices, which are being brought about by

legislation, such as the Freedom of Information Act 2000. At the same time, the child is beginning to be viewed as a person in his or her own right, rather than as 'property of their parents'.

Dale (op cit) also distinguishes various types of parent-professional relationships, which are viewed in a historical context. In the 1980s, *the professional as expert* was the dominant model, (Mittler and Mittler, 1983), with the parent providing information on request and needing to comply with professional advice and treatment. Children would be placed in special schools and meetings held without parental involvement or consultation. Whilst greater collaboration and parental involvement has developed, the tradition of the professional as expert still continues and is described later in the study.

Dale also discussed *the transplant relationship*, described by Dorothy Jeffree in the above Mittler and Mittler text. Parents were seen as an important resource for helping their children and professionals shared their expertise to help the parents become more competent and skilled as educators. Such thinking underlies approaches, such as the Portage home visiting programmes (National Portage Association www.portage.org.uk). My own work with parents in special school autism provision suggests that working with parents on one or two areas of concern is linked with optimism and strengthening of parent-child relationships.

Movement towards the vague concept of partnership has taken place, but issues about decision-making power are particularly pertinent. In *the consumer model*, developed by Cunningham and Davis (1985), the parent was seen as having the right to select appropriate services and intervention for their child. The parent is seen as having expertise in the form of knowledge about their child and family and this is viewed as separate to the professional's expertise. Whilst the professional would continue to adopt a number of roles, including 'expert', 'instructor' and 'consultant' in guiding parents, decision-making was becoming more of a negotiated two-way dialogue.

The empowerment model was a further partnership model and was put forward by Appleton and Minchom (1991), so that it combined the right of the parent as a consumer to choose to engage with a service at a personally suitable level, with professional recognition of the family as a system or social network. The interlocking family network needs to be considered by the professional, who will look at the type of help the parent will need to take up a position as *partner* and how they would need to be *empowered.* According to Dale (page 14):

> *The professional would ... promote the parent's sense of control over decisions affecting their child and be sensitive to parents' rights to get involved in professional services to an extent that they chose.*

Thus, Dale's *negotiating model* brings together diverse and discrepant viewpoints, reconciling them for joint decision-making, yet also recognising that dissent may be a major factor in the parent-professional relationship. Multiple perspectives are recognised and a multi-level analysis is used as described above. Negotiation can lead to either a shared understanding and consensus or a lack of shared understanding and dissent, but dissent is not necessarily incompatible with partnership working. It is important to say that all models of partnership have their limitations. Negotiation requires time and involves an authority and scope to experiment, explore and take risks and a balance of power that permits each partner to have a leading role in decision-making and in achieving ends.

Co-operation between parents and professionals is, therefore, not seen as easy to achieve, as (page 305),

> *... competition for scarce resources, higher demands and expectations of parents, coupled with their increased legal power, a shortfall between parental aspirations and professional delivery and greater divisions between and within professional agencies may increase the likelihood of conflict and mistrust. Unresolved distress in the parent, antagonism in the family, lack of empathy and poor communication skills in the*

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professional as well as a refusal to share power could also hinder co-operation.

Along similar lines, Wall (2003), in discussing the families of children with special needs, highlights the need for family support, so as to support the child. Such support can be from family, friends, professionals and other information sources and in line with current Children Act thinking, she says, (page 39):

Research assists professionals in understanding parental perspectives and supports the view that we may not know what families need or what is 'best' for them. We should support in the most appropriate manner and accept the views and feelings of the parents that we work with.

Parents, Professionals and Accountable Practice

Professor Jon Nixon at Sheffield University has considered the moral bases of professionalism in accountable practice. In a lecture delivered to Education Doctorate students in September 2003, he saw the need for theory to be shaped by professional practice and must be understood in terms of the relation between practice and human thoughtfulness. Theory is developed by devising collaborative models of thoughtful practice that challenge taken-for-granted assumptions and suggest new lines of enquiry. In his paper, which is extended in Nixon, Walker and Clough (2003), he says (page 1):

The process of theorising always involves thoughtful practice; thoughtful practice involves engaging with others; and engaging with others always involves the recognition of difference.

Public sector professionalism with its ethic of public service was replaced in the 1970s by a model of private sector managerial professionalism and its ethic of private entrepreneurialism. Nixon asks questions about the moral bases and theoretical links of such professionalism. He suggests that the professional

status of occupational groups is based upon its capacity to make informed and authoritative judgements regarding the adequacy of the available evidence, the provenance of that evidence and the options available in the light of that evidence. The key characteristics of professional practice involve judgement and how decisions are informed by this judgement. Professional judgement comes into play at the points where common sense guidelines are unclear and multiple interpretations are possible. Effective judgement is also always exercised in a social context, so that it must be dialogical.

The extent to which professionals manage this social aspect of judgement has been questioned, as listening and meaningfully consulting have not always been aspects of practice. Again, he suggests there has been an emphasis on considering symptoms, rather than the physical pain and social suffering that result from such symptoms. These issues and the way in which professionals, schools and authorities interact with parents have been key elements of my study. Nixon suggests that effective professionals must reach out to their public. 'Learning professions and listening institutions' are required. He says (page 5):

> *The moral content of professionalism focuses upon our learning to become accurate and sincere, attentive and honest, and courageous and compassionate. We fulfil the requirements of professionalism by initiating ourselves into these complicatedly inter-layered, virtuous dispositions.*

Thoughtfulness is seen as an ordinary resource and is not particularly different from general human contemplation, when people are considering their aspirations, dilemmas or pain, for example. Thoughtfulness is enacted through public dialogue, interaction, engagement and transaction. For Nixon, 'thoughtfulness is always striving for reflexivity', so that the other's concerns are taken into consideration. It would involve elements of Dale's *empowerment and negotiation models* of parent-professional relationship. Multiple perspectives

and multi-level analysis appear to be suggested in Nixon's work, which seems to provide a greater and more detailed sensitivity.

We are in dialogue with theory in our professional practice, so that presuppositions are tested against analytical frameworks, which are also questioned from the basis of practice. Reflection on professional practice assists us with relations with professional colleagues and clients. The extent to which the professionals with whom the parents in my study have engaged could be viewed as thoughtful and reflexive will be a matter for consideration in my Discussion chapter.

Good Support Practice for Children with Autism

The National Curriculum and its associated assessment frameworks, which would include Early Learning Goals (QCA, 1999) can provide restrictions for teacher and pupil and give rise to additional pressures for children with autism. The fundamental ingredient for successful provision is that of understanding of the child with autism and a willingness to adapt teaching approaches. Powell and Jordan (1997, page 17) suggest:

> *There are still numerous examples of where teachers, especially perhaps in mainstream, either do not fully appreciate the nature and extent of the child's difficulties or are unwilling (or perhaps unable) to alter their own approach to teaching to accommodate these difficulties.*

The recent DfES/DoH (2002, pages 15 to 18) good practice guidance documents suggest several key principles that should underpin all aspects of practice when providing for children with an ASD:

- knowledge and understanding of ASD;
- early identification and intervention;
- policy and planning
- family support and partnership

- involvement of children
- cooperation with other agencies
- clear goals
- monitoring, evaluation and research.

Whilst the guidelines do provide pointers and features or evidence to look for when considering effective provision, there are many implementation challenges facing those wanting to enhance practice and support effectiveness along these lines.

Inclusion and Future Issues

The 1981 Education Act (DfES, 1981), followed the principles of the Warnock Report (DfES1978), so that categories of disability were removed with a greater emphasis on individual needs, parental partnerships were introduced and integration was to be encouraged. The 1994 Code of Practice (DfEE, 1994) offered guidance on all aspects of special educational needs and this was subsequently revised in 2001 (DfES, 2001a). Further guidance, such as Inclusive Schooling: Children with Special Educational Needs (DfES, 2001b), was also issued, as well as range of documents, which related to early years settings.

A definition of inclusion

Wall (2004, page 132) has provided a definition of inclusion for children with autism, which related to early years settings and is adapted for school settings, Thus:

> *... a process which enables (young) children with autism to be active participants in local (early years settings) mainstream schools, which removes all potential barriers to full inclusion in the range of opportunities offered. Such a process will account for individual needs and enable children to develop their full potential.*

Finding the right setting for a child with autism can be problematic. Wall points out, that the quality of the provision and skills of the practitioners are perhaps the most important considerations. Provision options include autism specific schools, units attached to mainstream schools, special schools covering a range of disabilities and mainstream schools with additional support. The report by Evans et al (2001) analysed LA provision for ASD and concluded (page 80) that:

> ... *placement in a particular provision was related more to local circumstances and availability than to an exact match between children's needs and what was on offer. However, placement was less of an issue than expertise: children with similar levels of difficulty can thrive and make progress in a range of different provision, both integrated and segregated. One of the key issues for parents was the level of training and experience in autism of the people working with their children.*

The report indicated that a large number of children with autism may not be in the right placement, despite an increase in the number of placements. There may be an assumption that a specialist school or unit is the required provision, which may run counter to a supported mainstream placement. My own view is that a good proportion of the pupils with classic autism are likely to need a special small group placement and that pupils with Asperger syndrome in mainstream schools may well manage in some or all lessons, but there is a need for a quiet supported facility, with opportunities for social and life skills work.

Research findings by Jones (2002) highlighted the increase in provision by LEAs for children with ASD. A NAS parent member survey was carried out by Barnard, Prior and Potter (2000) with 1000 returns being analysed from 2,409 sent out. It indicated that most parents were satisfied with early years provision, but as children moved through the education system, satisfaction decreased markedly. No doubt contributory factors in these changes included: National Curriculum pressures; the widening gap between pupils and changes

in peer- and self-perception of difference. The report suggested that parents need more choice, as (page 7), 'very few schools have staff who are adequately trained and can provide the right level of support ... and autism-specific provision is very limited.'

The report also draws out the relatively frequent and high rate of exclusion amongst pupils with autism. It stated that twenty per cent of pupils with autism are excluded from their educational setting at some stage during their attendance. The suggestion was that a lack of staff with autism experience was responsible. A number of broader socio-political factors will underlie this suggestion.

Inclusion Issues

Nationally, there is wide variability in the availability and range of appropriate provision, which affects parents' choice and pupils with autism require both special and mainstream options. Furthermore, the inclusion of children with autism requires careful planning, monitoring and evaluation. The guidelines that are provided for schools and others require integration into a coherent national plan, which has at its core wider training and awareness for professionals. The plan would incorporate other areas of SEN.

There is a need for practitioners to understand the differing needs of parents with children with special needs and a number of groups have been established to campaign for the rights of such parents. The effects of having a child with special needs and/or autism have been discussed earlier and are well documented; for example; Dale (1996), Carpenter (1997) and Wall (2003). What is not so well documented is the variation in experience and the meaning of that experience for individual parents, so that it impacts on professional practice and provision. Practitioner reflection on the differing needs of parents and children should lead to more effective support for family members.

As specified in the National Autism Plan for Children (NIASA 2003), diagnosis is a time when a clear system is required, supported by trained and sensitive

professionals. Access to relevant and up-to-date information is needed, as well as thoughtful, supportive and sensitive professionals, particularly in the early years when emotions and feelings around the time of diagnosis are heightened. Practitioners also need an understanding of the world of the child with autism and sensory difficulties are one such focus. There are a number of useful intervention approaches and it is beyond the scope of this study to consider them in any depth. However, they do require early identification. An eclectic view of strategies is probably most helpful in view of the controversies around the relative efficacy of different methods.

Effective Provision

Wall (2004, page 155) has highlighted four recurring themes in her consideration of effective early years practice. It is not unreasonable to assume that these four themes also underlie effective provision at all ages:

- training – appropriate and accessible to all practitioners;
- funding – for training and resources
- resources – human and material;
- equity of access to provision for children.

The general policy elements contained in government legislation aim towards the realisation of potential for all children with SEN and disabilities, the raising of standards of teaching and learning and the strengthening of partnerships with children, parents and carers. Wall (2004, page 157) concludes that children with autism:

> *... are entitled to equal opportunities and equal access to high quality provision, so it is our responsibility to provide it.*

For Armstrong (op cit) resistance was formed behind the backs of dominant groups. The political system itself framed resistance, so that voices were constructed by the structures of power. Barton (1997) has suggested that inclusion involves 'listening to unfamiliar voices, being open, empowering all

members and [is] about celebrating 'difference' in dignified ways'. Armstrong suggests that this struggle is far from won and his book creates spaces for stories of resistance to be spoken and demands that the culture of silence be broken.

Let us turn to the research and reconsider its overarching aim of considering 'how parents' experiences of bringing up a child with autism can inform professional practice and provision' and its interpretation along these critical, political lines suggested by Armstrong. The following component questions emerged from the parent group meetings, and also link to the Interpretative Account master themes which are discussed in later chapters:

1. How did mothers make sense of their experiences of bringing up a child with autism?
2. What were the effects and life-world impacts of these experiences on mothers and their families?
3. How did mothers achieve control and coping?
4. How do parent experiences inform our quest for both quality and equality of professional practice and provision?
   - What is the value added from parent feedback?
   - Is an LA able to hear and respond adaptively to this feedback?
   - To what extent do parent experiences reflect thoughtful parent professional relationships?

CHAPTER 3: METHODOLOGY

INTRODUCTION

In writing the initial section of this chapter, my previous Part 1 doctorate study and planned area of thesis work have guided my search for useful and appropriate methodology, which will fit this purpose. My earlier pilot study work concerned parent evaluation of an Educational Psychology Service and used a questionnaire approach, which made me aware of the limitations of positivist approaches. Similarly, a feeling of disenchantment with such approaches resulted from my literature review, which also examined service evaluation methods. Many current service evaluation approaches lack depth in their analysis and do not consider factors such as feelings, thoughts and resistance operating in organisations.

SECTION 1: SELECTING APPROPRIATE METHODOLOGY FOR GOOD QUALITATIVE RESEARCH

With regard to planned thesis work, my interest in the area of autism and parent support led me to consider suitable methodology for making sense of and developing understanding of the experiences of parents in bringing up a child with autism and how this analysis can inform provision. There is a need to derive policy implications from research work and link theory with desired good practice. The main method used became semi-structured interview, with a sample of mothers. Other approaches were also utilised, such as initial parent group meetings, to attempt to enhance the quality of the research and this chapter represents an attempt to crystallise and explain my thinking and has helped with designing my thesis. This study has adopted an inclusive approach and is concerned with the mothers of both the 'classical' and Asperger groups of students.

Strauss and Corbin (1990, page 3), when considering qualitative research, provided a definition of methodology as 'a way of thinking about and studying

social reality', whereas methods are 'a set of procedures and techniques for gathering and analysing data'. Coding is seen as 'the analytical processes through which data are fractured, conceptualised and integrated to form theory'. Within this chapter, I will critically consider methodology, methods and coding approaches, which are relevant to this study. A further focus will be that of quality or criteria for effective research using qualitative methods. Qualitative research is simply 'the interpretative study of a specified issue or problem, in which the researcher is central to the sense that is made' (Banister et al (1994, page 2)). Whilst research would undoubtedly be much easier without the need for the researcher to interact with those studied, a meaningful understanding of research questions can only be gained by recognising the part researcher and participants play in a shared interaction.

LAs and Consulting with Consumers

As a practising LA psychologist, I am sensitive to the need to seek consumer views, which has been highlighted by initiatives such as Best Value and disability discrimination legislation. Autism provision and parents' views are areas, which my LA view as worthy of research and my study aims to draw some policy and service delivery implications from the understandings that are developed from listening to parents. Whilst a range of methodological approaches exist, a good proportion utilise large scale questionnaire studies, whilst methods such as focus groups are seen as helpful with hard to reach groups. Parents of pupils with autism, however, are a clearly identifiable group and so a qualitative or interpretative approach should provide helpful feedback for the LA. A crucial factor in designing a qualitative study is that of giving the parents a voice in planning key dimensions of the enquiry. With this in mind, local autism parent support groups have been consulted about research and key questions for subsequent individual interviews with mothers.

Principles of effective consultation include the need for actions to be competently carried out, with parents being encouraged to participate in an inclusive enquiry and with results being used in practice. Wolfendale's (1999) Code of Conduct for Co-operative Research with parents, has described the

main elements of the partnership model as rights and entitlement, equality, reciprocity and empowerment. Again, the responsibilities and commitment of the researcher should be clear, with sensitive handling, confidentiality and information regarding research outcomes being provided. The signing of a consent form, containing clear written information about proposals is required.

Recognising Good Research

With a qualitative approach it is important to recognise that general laws of human behaviour are not being sought through use of a large sample. The usual quantitative ways of judging reliability and validity to assess research quality are not applicable. Validity in terms of method is interpreted as being internally consistent, robust and providing findings that are generaliseable or useful. Coherence (Elliott, 1999) is a further dimension of quality and refers to the extent to which findings are consistent, comprehensive and integrated.

Stiles (1993) described criteria for qualitative research, with analysis or interpretations resonating with the reader and impact fitting simply with preconceptions or demonstrating change or growth. The writer discussed uncovering self-evidence and whether the question of the study was answered giving growth in understanding for the reader. If concepts are developed in a study that equips researchers or practitioners to think or act differently in future, then value has been added.

Salmon (2003), however, has pointed out that whilst checklist techniques are developing for qualitative approaches, 'it is a forlorn belief that quality can be guaranteed by following procedures' (page 24). Such procedures would include questions about whether a tape-recorder was used, a field diary kept, a transcript sample checked by someone, or if an audit trail was left. Approaches such as grounded theory or discourse analysis are seen as 'epistemological perspectives', rather than methods or techniques to be used. With remarkable honesty, he comments that researchers use the methods they have learned to use and that they can use.

Good research does not slavishly follow methodological rules, so that scientific progress results from imagination, creativity and common sense, rather from merely deduction and induction (Rennie, 2000; Robinson, 2000). Issues of qualitative versus quantitative methods are parochial in the debate about the ways in which psychological research should be evaluated. The approach used should be determined by 'fit' with the phenomenon being studied.

Research outcomes naturally reflect the researcher as much as the researched, so that the notion of participant in the field of study is acknowledged (Potter, 1996). Other evaluative dimensions relate to research being rigorous, though the methods used in their own right, may not necessarily enrich the research; for example, approaches such as triangulation, multiple coding or grounded theory can be utilised. Triangulation; for example, is often seen as adding information from multiple sources (Flick 1998). However, it is more appropriate that research is judged, by the extent to which it achieves its own aims, rather than by the number of methods used, or the slavish, detailed analysis of material.

SECTION 2: RELEVANT EPISTEMOLOGICAL PERSPECTIVES AND APPROACHES

The above discussion has provided a general evaluative background against which research approaches can be considered as they relate to gathering the views and experiences of a sample of mothers. Before considering methodological approaches more fully, broader epistemological perspectives will be discussed so as to help in the development of better quality research.

Social Context and Ideological Dilemmas

Billig et al (1988) highlighted the importance of society and social context as the basis for thinking. According to Moscovici (1984), cognitive psychology's individual orientation omits the processes of cultural and ideological history that flow through the minds of laboratory subjects. A consideration of ideological dilemmas and contrary themes in qualitative investigations bring counter

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meanings to the surface. Discourse analysis has similar benefits and is discussed more extensively later (Potter and Wetherell, 1987). Briefly, the approach seeks to elucidate psychological processes through the understanding of discourses. In the field of education and teaching, equality and authority dilemmas are prominent. With regard to the field of autism, issues and dilemmas around experts and non-egalitarian roles and categorisation are particularly pertinent and are likely to feature in discussions with parents.

According to Billig, ideology is seen as an incomplete set of contrary themes, which give rise to discussion, argument and dilemmas. Natural recording of interactions takes place, with observation not being intrusive and the observer's presence being an integral part of the interaction. In analysis, dilemmas are considered rather than solutions and thinking is viewed in a social context. When considering the nature of dilemmas, the theory of cognitive dissonance is relevant in that researchers may find what they are looking for, so that their original schemata are confirmed (Taylor and Crocker, 1981).

Psychological Discourse Practice

Balance theories suggest that people tend to avoid thinking in much depth about phenomena and yet there is an essential need to bring implicit meanings to the surface – the hermeneutic task. In discourse practice, dialectic and contrary themes are involved. Erica Burman (1996) described how psychology functions to determine knowledge in shaping and governing our lives and hence to maintain current institutional structures of inequality. The standards by which we evaluate normality and abnormality are used to legitimise actions and interventions. Psychology can thus function to create and preserve inequalities through gate-keeping, labelling and categorisation activities. The practice of psychology can be seen to form institutional power in creating forms of subjectivity, so that stigmatisation results from a failure to conform to normalized categories. At the same time in research, we need to recognise the possibility of dislocating institutional boundaries through resistance to categorisation and institutional definitions. There is a need to humanize

subjects and to adopt research methods, which recognise psychology's failure to theorise language appropriately.

More appropriate paradigms emphasise more authentic accounts of experience. Thus, the Foucauldian approach, described in Parker (1992), involves a system of statements that construct an object. The approach explores the consequences of psychological discourses and how they intersect with institutional practices. A theoretical resource described by Foucault is that of deconstructionism, which utilises social theory and the turn to language, so that categorisation is critically scrutinised. With my autism research, such methodological considerations are highly relevant to concerns about the usefulness and appropriateness of labels or categorisation for parents.

Furthermore, psychoanalytic approaches, which take into account the relationship between the researcher and the subject, need to be considered. Thus, what have been described as 'experimenter effects' in traditional positivist approaches are embraced as a crucial part of the research process. Hollway (1989), in her critique of positivist methodology, sees the desired objectivity of positive methods as a deluded form of subjectivity. Within post-modernist approaches, there is scope for dissonance. The forces of regulation and resistance are recognised, so that power is seen to produce effects, which include resistance. Whilst Hollway has described the policing and gate-keeping role of educational psychology, others have seen how psychological testing can valuably challenge negative perceptions of inabilities.

With discourse approaches, objectivity and subjectivity are important elements, so that categories of identities are wrought into very material and subjective reality. There is a need to describe subjectivities, so as to analyse positions and then move from general to specific issues in case histories. It is recognised that experience can inform analysis. Discourse perspectives can be applied to interventions and collective and singular voices may disrupt, unsettle and change oppressive practices.

Pathologising Children

Billington (1996), as discussed in the introductory chapter, has argued that psychology has adopted a medicalized, symptom definition approach, which relates to the allocation and distribution of resources and confirms pathology in individual children. Children's lives are regulated in accordance with the economic and political demands of government. Psychology's utilitarian value is founded on the usually unstated premise that it will define the normal human being and historical factors underlie this categorising role. The emphasis is on the regulatory work of psychologists, rather than their capacity for resistance. Discourse analysis techniques and psychodynamic methodologies hold the potential for political resistance at institutional and individual levels. Diagnosis or categorisation, exclusion and segregation issues are particularly relevant to the areas of autism, parent experience and professional support.

By adopting an extreme positivist or measurement approach, psychologists can deny subjects' identity, feelings and rights. Rose (1989) described 'the science of state' or governmentality, whereby economic pressures can dictate working methods and as a result of shortage of time, simplistic analyses are made and children can be viewed so as to confirm their own pathology.

Along similar lines, (Mitchell (1974 page11) stated that, 'the very nub of Freud's work was the elimination of an absolute difference between abnormality and normality'. Discourse analysis methods can provide the sites for the analysis of power relations and governmental control values and the subsequent resistance against them. Psychology drawing on discourse analysis and psychodynamic principles might yet hold the potential for resisting the pathologizing tendency.

Exclusion is an area of concern for pupils with autism as high proportions of the group with Asperger Syndrome are at risk of exclusion from mainstream school. Barnard and others (2000) in a National Autistic Society (NAS) publication have

suggested that this group are twenty times more likely to be excluded than their mainstream peers. Children with autism are also more likely to attend a special school, disproportionately more than any other child with a disability or special educational need. Marks (1996), has spoken with excluded young people who were not autistic, but offered a mirror for professionals to interrogate practices. She recognised that researching into experience is fraught with epistemological and ontological dilemmas. When encouraging others to give voice, we need to be aware of 'the fantasy of unmediated direct knowledge'. This immediate form of expression, as a guarantor of meaning is challenged by psychoanalysis and discourse practice. The subject is viewed as fragmented and constituted with language. Experience and memory are subject to construction and reconstruction over time, so that accounts are not final or fixed. Responses are ambivalent, contradictory and changing. Thus, the relationship between exclusion and the context in which it is expressed is considered. We cannot really say how exclusion or bringing up a child with autism is experienced, but asking about the experience can bring forth productive ways of seeing the event or process.

Transition, or change of school difficulties may involve separation, feelings of rejection, anger and loss for the child and parent and these may not be discussed. Discourses may put pain at a safe distance, so that severance of connections and loss of routines are not openly shared. The nature and context of research may be supportive, collaborative and empathetic, with some counselling element being involved in interview sessions.

Psychosocial Approaches

In 'Doing Qualitative Research Differently', Hollway and Jefferson (2000) acknowledge that making judgements about concepts can be complex, but there is a need to look at the meaning of experiences and concepts. They point out that 'research is only a more formalised and systematic way of knowing about people, but the process seems to have lost much of the subtlety and complexity that we use as a matter of course, in everyday knowing. We need to bring some of this everyday subtlety into the research process.' Riessman

(1993, page 8) claims 'we cannot give voice, since we do not have direct access to another's experiences. We deal with ambiguous representations of it – talk, text, interaction and interpretation'. Hence, there is a need to interpret accounts, whilst recognising that there is no end to the interpretative process or 'hermeneutical circle' (Denzin (1989)). 'Critical realism' is required to see the relationship between ambiguous representations and people's experiences. Research subjects' 'inner worlds cannot be understood without knowledge of the way in which their inner worlds allow them to experience the outer world'. Use of such a psychosocial methodology, would be helpful in considering parents' experiences of bringing up children with autism.

The biographical method in a structured interview is adapted towards free association narrative interviewing. The approach proceeds from the use of pilot questions and takes account of the defended subject, so as to assist with gaining access to their world. Thus, four interviewing principles are followed to facilitate the elicitation of interviewee meaning frames (or gestalts). These include: the use of open-ended questions; an elicitation of stories; an avoidance of 'why' questions and a following of respondents' ordering and phrasing. Free association is seen as important in adapting the biographical-interpretative method to accommodate the principle of defended subjects. Free association narrative interviewing can reveal significant personal meanings. The data are viewed as the co-production of the interview pair, where unconscious inter-subjective dynamics have been operating.

In terms of analysis, work is carried out with whole data and there is a movement away from coding. Links and contradictions are drawn out, and interpretation is theoretically informed. Some key issues for the approach revolve around ethics and the generalisability of knowledge. As such, principles rather than guidelines are used. The principles of honesty, sympathy and respect are seen as fundamental to the research approach.

Within the free association interview, data analysis utilises the narrative interview method and psychosocial theory. Subjects are encouraged to tell

their story and the role of memory in their constructions is highlighted. The process looks at how the person or subject is theorised, or how they understand or make sense of themselves. The authors critique the content and method of positivist research, whereby subjects are encouraged to tell it like it is. Such approaches may not draw out the meaning of events for subjects, so that processes are seen as events. As a result there is poor conceptualisation of experiences, an ignoring of context and a heavy reliance on recall.

More Structured Approaches to Interview Data Analysis

Grounded theory

Miller (1995) encourages practising EPs to generate data and hypotheses that stimulate theoretical developments. Moreover, as well as building theory, field research can guide social policy, but in order not to become detached from reality, consultative and applied research needs a body of theory which is grounded in and embraces the complexity of the consultative process. Qualitative methods, he suggests, need rigour to avoid privatising what should be open to scrutiny. We need research, which is concerned with more than individual private experience and grounded theory attempts to provide data that are real, deep and hard, as envisaged by Zelditch (1978).

Grounded theory has been developed from Glaser and Strauss (1967) and focuses on the generation of theory rather than verification of theory. Turner (1991) has discussed local variations in larger social or psychological theories and from local theories will emerge more all-embracing systems of understanding. Quality grounded theory will uncover a core variable, which recurs frequently in the data, links data together and explains much of the variation in data. Such core variables are termed Basic Social Psychological Processes (BSPP). In Miller's study, a commonly occurring phenomenon was the concept of 'boundary maintenance', which qualified as a BSPP. It involved the preservation of formally and informally agreed methods among school staff for construing and responding to difficult pupils and their parents. Turner (1992) described transcript analysis as initially chaos, with open coding

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gradually bringing order. Strauss and Corbin (1990) defined the process as breaking down, examining, comparing, conceptualising and categorising data.

The 'constant comparative method' is used in open coding, with each word or line being given a name and the aim is to move towards a higher or more abstract level name. New codes are generated and other examples of existing codes are found. Definitions of key codes are written in terms of the properties involved. Some codes may be reclassified and links or roots established. Strauss and Corbin describe three sources for codes, which include the researcher's own conceptual framework, technical literature and the informants' words. Turner (1992) has described the abductive process, or the interaction between conceptualising and fracturing the data. Glaser and Strauss see open coding and the 'constant comparative method' as the *sine qua non* of grounded theory.

Theoretical sensitivity involves theory that is conceptually dense and well integrated and derives from similar sources to open codes through interacting with the data to develop wider ways of looking at social phenomena. Level 2 codes derive from categories at Level1. Similarly, Level 3 codes develop through a process of weaving and fracturing. To develop patterns between open, categorical and theoretical codes in grounded theory, the process of memoing is used. During the generation of codes, questions are asked by the researcher and, as part of this analysis, connections are written as memos.

Data analysis can also feed back into the research design and the emerging theory can be presented to subjects. In Miller's case, teachers' thoughts and comments were noted after initial findings were presented to them. Once a BSPP has emerged, sorting takes place with this as a focus to establish code levels linked to the BSPP. A schematic drawing can aid the description of the theoretical process and product. Saturation point is achieved when no new codes emerge. According to Miller, the literature review is then used for support after the analysis has taken place. Whilst the approach is time consuming and support is needed, grounded theory has applicability where

there is a need to pull together into a more coherent form, a set of data that is complex and phenomenological in nature.

Template Analysis

Nigel King (1998) has described this technique, which is perhaps less open-ended than grounded theory and allows some loose initial structure. 'The essence of the approach is that the researcher produces a list of codes (a 'template'), which represents themes in their textual data. Some of these may be defined *a priori*, but they will be modified and added to as the researcher reads and interprets the text.' Miles and Huberman (1984) in considering the range of qualitative approaches, see these as ranging from 'soft-nosed positivism' to phenomenology. Template analysis is towards the phenomenological end of the spectrum.

We may ask why use template analysis rather than grounded theory, for which there is a wealth of instructional material available, for example, Strauss and Corbin (1990). Grounded theory is looking for real beliefs and is prescriptive, whereas template analysis is social constructionist and more flexible. As well as having semi-structured interview applicability with individuals, it can also be used with focus groups to give shared understanding or information about beliefs, but still allow some individual expression of views. King gives an example of using a ninety-minute, tape-recorded session with GPs to discuss mental health patients. Some cases were considered and then general issues were discussed. A template is developed in the analysis of the text and this is revised during the analysis. The template starts with a few predetermined codes, usually from the interview topic guide, which is assisted through initial exploratory research. The main questions may be the higher order codes with others developing as supplementary or lower order. It is possible to use collaborative discussion to decide on the template where two researchers are involved, or where tutor support is available. For example, there might be say four higher-level codes with three or four lower ones. The researcher would then go through all the text marking comments related to the initial template and then amending this.

The approach can be used qualitatively with computer analysis packages, such as Atlas.ti, Nud-ist or Ethnograph. Hand coding can also be used, for example, by using colour highlighting of text. It is likely that where there is a lot of data, a package may be required. Computer-based analysis packages claim that greater depth, precision and thoroughness are obtained than they are with hand coding approaches. When making a choice about an appropriate data analysis technique, the researcher will also have to bear in mind their own feelings of ease with technology, as well as issues concerning the amount of data and possible depth of analysis factors. My own preference would be to use an approach, which utilises more manual, rather than technological procedures. The main drawback of use of such computer-based approaches, from a personal viewpoint, revolves around feelings about the degree of interaction with and immersion in the data that may not be experienced. It is acknowledged that packages, such as Atlas.ti, do require the user to become very familiar with the data in order to produce the codes.

A thematic presentation approach can be adopted with separate case studies illustrating points for each theme. Template analysis can be relatively easy to use, where a phenomenological and experiential emphasis is required. However, it lacks the literature of grounded theory or discourse analysis. A further dilemma concerns the degree to which data openness can be maintained, when using an initial structure.

Use of Video

This approach can have some appeal in analysing interview data, as it can add to the richness of material available; for example, to enable the study of body language. In Dundee, the technique of Video Interactive Guidance (VIG) is used as a therapeutic technique in the area of parenting and family work. Analyses of the communication pattern between a parent or teacher and a child or children are developed and complex measures of the 'communicative musicality' between individuals are established. Trevarthen (1997) has used the term 'reciprocally attuned emotional narrative' to describe the interaction

analysis involved. The VIG approach requires a lengthy period of training and is a research approach in itself, having particular relevance to areas such as analysing the interaction between a parent and an autistic child. Whilst use of video alone, rather than a VIG approach, would have some advantages with regard to data analysis, it would also add an additional level of complexity to data recording. My use of video in the analysis of nurture group interaction did not significantly aid data analysis.

Interpretative Phenomenological Analysis (IPA)

Carla Willig (2001) described this approach, which was suggested to me in a discussion with Nigel King as a possible approach for my study. The method has guidelines for analysis and a more extensive literature than template analysis. IPA is a research method, which is informed by the philosophical branch of phenomenology. Phenomenology is concerned with the ways in which human beings gain knowledge about the world around them and the phenomena that appear in their consciousness in engagement with this world.

Willig suggested that 'it is not sensible to think of the world of subjects and objects as separate from our experience of it.' Thus, 'self and the world are inseparable components of meaning' (Moustakas 1994). Perception is always intentional and therefore constitutive of experience itself. In transcendental phenomenology there is a need to reflect on that which we bring to the act of perception through feeling, thinking, remembering and judging. Some similarities are present here with the psychosocial approaches described by Hollway and Jefferson (op cit.), where the subject's previous experience and view of the world helps the interviewer to make sense of their world, whilst recognising also the interviewer's position and background.

In terms of method, whilst IPA aims to explore the research participant's experience from his or her perspective, it also recognises that such an exploration must necessarily implicate the researcher's own view of the world as well as the nature of the interaction between the researcher and the participant. Phenomenological analysis is always an interpretation of the

participant's experience. Jonathan Smith (1997), IPA's founder, stated that interpretative engagement with texts and transcripts 'is facilitated by a series of steps that allows the researcher to identify themes and integrate them into meaningful clusters, first within and then across cases.'

Again open-ended questions are utilised aiming at participants sharing their experience of the phenomenon with the researcher. Focused or specific questions are used to elaborate, rather than to check agreement. Specific guidelines are available and after initial reading of accounts initial open thoughts are recorded and subsequently themes are noted separately. Later stages involve the linking of themes into clusters. The fourth stage of the analysis involves the production of a summary table of the structured themes, together with quotations that illustrate each theme.

Cases can be integrated by taking case summary themes and attempting to integrate these into an inclusive list of master themes that reflect the experience of the group of participants as a whole. Overall, IPA attempts to capture an experience and to unravel its meaning(s), using systematic guidelines.

Naturally, it also has some limitations, which concern the role of language, the suitability of accounts and explanation versus description. There is also the issue of the degree to which it differs from grounded theory. IPA relies on the representational validity of language, though it can be argued that language constructs rather than describes reality. Thus, the words we use to describe a particular experience always construct a particular version of that experience, so that language can prescribe what we think and feel.

With regard to suitability of accounts, there are questions about the degree to which participants are able to communicate the rich texture of their experience. The method may not be suitable for those who are not able to articulate their experiences in the sophisticated manner required. Also, IPA research focuses on perception or appearance of experiences and as such ignores their cause or

origin. Our understanding of phenomena may therefore be limited by a lack of awareness of the conditions, or past histories that gave rise to them.

IPA is usually seen to be concerned with cognition or what people think about a particular topic. Yet, phenomenological research aims to capture the way in which the world presents itself to an individual in an immediate (unmediated) sense, including 'vague feelings, pleasures, tastes, hunches, moods and ideas on the margin of consciousness' (O'Connor and Hallam 2000, page 245). It may be that genuinely phenomenological research should not study people's cognitions, but should aim to understand their lived experience.

IPA requires the interpretation of accounts, so as to gain understanding. It can be seen as a *realist* approach to knowledge production through engagement with thoughts, feelings and experiences, yet it is also *reflexive* in that it acknowledges the researcher's own perspective. IPA recognises that people attribute meaning to events, which then shape their experience of these events. Thus, a *relativist ontology* is adopted, so that the meanings people subscribe to events are the product of interactions between actors in a social world. Text analysis insights are gained through interpretation by a researcher's reflexive attitude. The description and presentation of findings involves a sense of discovery, rather than social construction. Themes are said to emerge and categories are identified, in a way, which is similar to grounded theory.

Selecting and Evaluating Approaches

Many research approaches are available to consider parents' experiences of bringing up a child with autism, including provision and support. Miller and Todd (2002) have considered the conceptual and methodological challenges involved in researching the area of difficult behaviour in schools. Many of these issues relate to the autism area and the key notion of boundaries between schools or professionals and parents is a central one. Difficult or challenging behaviour is likely to be involved and there is a need to try to understand both parent and professional cultures, as Miller has attempted. Multiple perspectives

need to be adopted in research and different methods are required for different research areas.

So far within this chapter, I have briefly outlined some quantitative approaches to LA consultation, but concentrated largely on qualitative methods as they appear to fit the purpose of understanding parents' experience. The relevant dilemmas facing professionals working in the area, in terms of identifying and supporting the inclusion of pupils with autism have been described and recognised. Discourse and psychosocial approaches have been considered and are concerned with the role of language in the construction of reality. Approaches, which aim to gain a better understanding of people's experiences, ways of thinking and acting (experiential), have included grounded theory, template analysis and IPA. Reicher (2000) has drawn the distinction between these two approaches – the discursive and the experiential and this suggests that in terms of methodological approach for my chosen area of study, that experiential methods hold sway. Experiential approaches also contrast with discursive methods in that they are essentially realist, rather than social constructionist. Language is seen as reflecting internal categories of understanding, rather than constructing versions of social reality.

How then do we adopt 'good practice' in qualitative research by providing systematic and clear presentation of analyses, which are grounded in the data and pay attention to reflexivity issues. Such good research should be aware of its contextual and theoretical specificity and the limitations that this imposes on its applicability and relevance. Henwood and Pidgeon (1992) have provided some criteria for judging qualitative research, so that rigour is ensured, while idiosyncrasy and creativity are also maintained. Below, I give evaluative dimensions, described by these authors in Willig (op cit), which I have adapted to incorporate some features mentioned by Elliott et al (1999). Thus:

➢ analytic categories need to fit the data well, so that clear labelling and categorisation is provided with good examples;

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- the process of integration of theory should be clear with links between units of analysis being explained, providing a coherent framework;

- the role of the researcher in the process needs to be acknowledged with disclosure of values and conscious assumptions, so that a reader can consider alternative interpretations;

- an inclusive and comprehensive account of what has been done throughout the research process should be provided;

- the researcher should continuously seek to extend and modify theory by exploring cases that do not fit as well as those that are likely to generate new insights

- the researcher should be aware of participants' reactions to the findings and attempt to explain differences in perceptions, so that credibility checks are provided and

- the contextual features of the study should be explained in full, so that readers can explore the extent of applicability beyond the research context.

Elliott et al (1999) have more recently provided guidelines for the evaluation of qualitative research reports and they are incorporated in many of the criteria listed above. However, they also emphasise that research should provide an appropriate range of instances, where general understanding of a phenomenon is sought. Where insight into a specific case is considered, the study needs to be systematic and comprehensive. Finally, they say that the research should *resonate with readers*, with the presentation clarifying or expanding subject matter understanding.

The key aim of essence description and understanding of parental experiences steered my research towards using a grounded theory or IPA approach. However, an awareness of the psychosocial approaches described by Hollway and Jefferson, the literature concerned with ideological dilemmas and the perspectives provided by Billington and others should assist with the broader interpretation of research data and hopefully provide material, which resonates with readers.

Grounded theory and IPA approaches share many features, with both methods aiming to produce something of a cognitive map representing a person or group's view of the world. Also both approaches work systematically through data, integrating individual views to obtain a composite picture, so that general understanding (grounded theory) or essence (IPA) characterising the phenomenon is drawn out. The perspectives are broadly similar, sharing many concepts, such as constant comparison of data and memo-writing.

In choosing between the approaches for my study, Willig (2001) usefully drew out the essential added value of IPA over grounded theory. She pointed out that 'while grounded theory was developed to allow researchers to study basic social processes, IPA was designed to gain insight into individual participant's psychological worlds'. IPA's interest in the nature or essence of individual phenomena and its emphasis on gaining a better understanding of individual experiences seem more in keeping with my study's aims. Furthermore, IPA may have some advantages over grounded theory, which has many types and a lengthy debate may be required before a researcher can choose an appropriate research topic version. IPA leaves the researcher with more room for individual creativity and freedom to explore. Bearing in mind my study aims and the degree of comfort I felt with both the IPA structure and freedom available, IPA provided my main research perspective.

SECTION 3: METHODOLOGY REVISITED: CRITICAL APPROACHES

A research defining eureka moment followed a tutorial discussion concerning my literature review and consideration of the work of Carr and Kemmis (1986) on becoming critical. I realised fully, that interpretive methods, for these authors are seen as observing passively, with possibly little interaction between researcher and participants. This reminded me of a comment from another doctorate student, which was made at the end of the session when I described my research proposals to the group. She was concerned about what could be done about research findings and the ethical aspects of adopting an apparently interpretive stance. Questions, therefore, arose about the purposive nature of

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research and making a difference. Can we detach ourselves as a passive observer or interpreter in enquiry, whilst also working in the field and being in active contact with parents and other professionals?

My study, however, was never planned to be passive. Whilst an interpretive methodology was used to make sense of parent experiences, critical and reflexive approaches were utilised, which recognised the research context and attempted to take forward issues and concerns arising at a provision, policy and political level. Thus, I interacted with parent groups, listened to their concerns and helped to set up a parent professional liaison group to address these. This more critical aspect of the research is described in the Research Process chapter and whilst it was not the major part of the enquiry, it emerged as an essential moral and ethical component of research in a real LA context for a practising professional.

Furthermore, individual mothers amended the interview transcript and agreed content, so that the research findings were shared and developed with the participants. Hence, whilst IPA was the dominant approach used to make sense of mothers' experience, a critical methodological approach was also adopted, with mixed methods being used.

In the introductory chapter, I have considered the context of my work, my background and positionality. Along these lines, Carr and Kemmis (1986) have stated (page 73), that:

> ... *knowledge is not, as positivism suggests, the objective, universal and value-neutral product of the 'disinterested' researcher. Rather, it is subjective, context bound, normative and, in an important sense, always political.*

The distinctive element of research in educational contexts is that it employs a methodology, enabling description of how individuals interpret their actions and the situations in which they act – it is descriptive and interpretive, rather than

explanatory and predictive. Social reality can be understood by understanding the subjective meanings of individuals and for Weber (1964), social science is concerned with 'interpretive understanding' of social action and the most significant feature about action is its 'subjective meaning'. From the interpretive researcher's point of view, actions have meaning in relation to the understandings, purposes and intentions of the actor, and the actor's interpretations of the significance of the context of the action. There is a two-way link between theory and practice and for interpretive social science the only aim is enlightenment and according to Carr and Kemmis (op cit), 'through enlightenment, rationality in a critical, moral and reflective sense.'

Carr and Kemmis (op cit, pages 98 and 99) when describing positivist and interpretive approaches, state:

> ... in both approaches, the researcher stands outside the researched situation adopting a disinterested stance in which any explicit concern with critically evaluating and changing educational realities being analysed is rejected. Thus, despite its insistence that educational realities are subjectively structured, rather than objectively given, the interpretive approach, like positivism, pursues the common methodological aim of describing social reality in a neutral, disinterested way.

Interpretive research has some difficulties dealing with practice and the dialogical relationship between theory and practice. A critical approach to theory and practice attempts to do this and Habermas (1974, page 44) asks:

> ... how can the promise of social philosophy to furnish an analysis of the interrelationships of social life, be redeemed without relinquishing the practical orientation of classical politics?

Habermas maintains that the methods of the interpretive approach cannot provide an adequate basis for the social sciences, as such approaches cannot

assess the extent to which forms of communication can be distorted by prevailing social, cultural or political conditions.

An emancipatory interest in making a difference, requires going beyond subjective meaning to acquire emancipatory knowledge, which concerns the objective framework within which communication and social action occur. Thus, Carr and Kemmis (op cit, page 136) have produced a diagrammatic model, which is developed below and considers science, medium, knowledge and interests:

Science	Medium	Knowledge	Interest
Empirical-analytic	Work	Causal explanation	Technical
Hermeneutic or interpretive	Language	Practical understanding	Practical
Critical	Power	Emancipatory reflection	Emancipatory

My research task moved to combining an interpretive method for considering mothers' experiences with a critical approach, which recognised the context and ways in which findings might be understood and used. A critical social science will provide the kind of self-reflective understanding that permits individuals to explain why the conditions under which they operate are frustrating and suggests alternative actions, which will eliminate these frustrations. External agencies can constrain the intentions of individuals and the source of subjective meaning lies outside the actions of individuals. Nevertheless, the constraints of time upon a lone researcher meant that the degree to which a critical approach was adopted was limited, with my main energies remaining with interpretative method. Thus, no attempt was made to undertake discourse analysis, as an additional approach, though there were

possibilities, particularly in the parent professional group meetings. Hepburn (2003) has pointed out that discourse analysis can be done badly.

The critical developments arising from my study came about as natural practical consequences of being a professional researching in a LA context. Habermas' work has provided useful insights into the link between theory and practice and our understanding of professionalism. The distinction between critical theory and critical social science is an interesting one, in that a critical theory can emerge from interpretive enquiry, but may not change practice. Critical social science, for Habermas, involves not only theory, but also a political determination to act to overcome contradictions in the rationality and justice of social action and social institutions. There is a dialectical reflection between theory and practice with an impact upon practical or professional judgement. There are three elements, which a critical social science needs to distinguish and these relate to theory, processes for the organisation of enlightenment or understanding and processes for the organisation of action. A critical social science involves relentless criticism of all social conditions and is not afraid of conflict with the powers that be. As a researcher with positionality fixed within a LA structure, the extent to which a pure critical social scientific research approach could be adopted is questionable in the organisation of action.

Psychoanalytic approaches appear to link to Habermas' methods, particularly with regard to self-reflection, though there is the assumption that change will result from bringing distortions in self-formative processes into consciousness. Critical social science is concerned with revealing to individuals how their beliefs and attitudes may be ideological illusions that help to preserve a social order, which is alien to their collective experience and needs. Such considerations concern previous discussions of defended subject, attribution and positive illusions.

Critical social science involves informed doing or strategic action and it is a form of social science to be carried out by self-reflective groups to organise their own practice in the light of their organised self-reflection. The extent to

which the LA AWG might be linked in this way to the research study is of interest. The group did not own the study, but engaged with it in ways described in the Research Process chapter. Certain individual professional group interests were present at times, rather than those of overall service or provision. A highly relevant criticism of Habermas, according to Bernstein (1976, page 225) is that:

> ... *the very idea of practical discourse – of individuals engaged in argumentation directed towards rational will formation - can easily degenerate into a 'mere' ideal, unless and until the material conditions required for such discourse are concretely and objectively realized. Habermas ... does not offer any real understanding of how this is to be accomplished ... in the final analysis the gap still exists ... between the idea of such a critical theory ... and its concrete practical realization.*

Action Research and Other Critical Perspectives

Action research is a critical approach, described by Carr and Kemmis (op cit page 162) as:

> ... *a form of self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own practices, their understanding of these practices and the situations in which the practices are carried out ... in terms of method, a self-reflective spiral of cycles of planning, acting, observing and reflecting is central.*

Elements of this approach emerged in the parent professional group work, which is described later. Hopefully, the work of a practising EP would more fully reflect this approach in their day-to-day work.

Hepburn (2003) provides a broad view of critical approaches in social psychology, so that aspects of society and psychology itself are criticised.

Critical social psychologists are concerned with change, which can be achieved in different ways; Hepburn (op cit, page 4) states:

Some social psychologists advocate action research, which directly intervenes in settings. For others the aim is to increase people's understanding, so they can change things, or generate resources for change and criticism.

Hepburn describes the relevance of perspectives like Marxism, psychoanalysis, discursive psychology and postmodernism. It is beyond the scope of this chapter to consider all these perspectives in any depth, though it is relevant to recognise their existence and the breadth of the critical field for the methodological context. We already have discussed psychoanalytic approaches, such as those of Hollway and Billig and the discourse analysis approach of Billington, for example. The Marxist perspective is concerned with power and ideology and ideological dilemmas and has been considered above. For Foucault, however, power is more about relations built into everyday life, than the Marxist version of power, as an authoritarian top-down imposition related to social class structures.

Feminist issues relate to motherhood considerations in my study and the position of the researcher as a male. The analysis and interpretation of the mothers' accounts of their experience are interwoven in a narrative form, reflecting characteristics of postmodernism. This approach emphasises the local nature of knowledge claims and according to Hepburn (op cit), doubts the modernist story (or metanarrative) that the self is an individual knowing entity, capable of rationally reflecting on reality in the pursuit of timeless truths capable of advancing human progress. Such a view emphasises language and communication and appears in keeping with the IPA approach adopted. However, in my study there is less of a focus on interactions and practices that characterise postmodern approaches, which have departed from an individual focus. Strikingly, approaches interact and methodology becomes mixed.

Essentially, critical psychology is a process rather than a product, with a range of approaches being used in order to achieve fitness for purpose.

Social cognition as an approach lies between the positivist and realist and is concerned with encoding and retrieval as key mediators in social judgement. Whilst both positivist and realist approaches emphasise empirical methods, realist methods produce underlying mechanisms that account for observable regularities. An example of such a social cognitive theory might emphasise the goal directed nature of individual information processing as a means of simplifying complex stimuli. Smith (1996) discussed how IPA provides some link between discourse analysis and social cognition and this theoretical discussion will be considered later in this chapter.

Justifying Enquiry

Moving away from this more philosophical background, Clough and Nutbrown (2002), in considering research as a more reflective practice suggested it should be persuasive, purposive, positional, and political. Thus, every writer would wish to persuade others of the value of their research or systematic investigation of a phenomenon. Research should also be purposive, so that it makes a difference, by bringing about change. This change, of course, could be in terms of self-development or enhanced understanding of the research phenomenon. We have already emphasised the political nature of critical research, whereby the context and change are considered. I have described my own positionality, as a practising EP within a particular LA context, in the introductory chapter.

For the above authors, methodology is seen to justify research methods, whilst philosophy justifies methodologies. In justifying research, a critical approach needs to be developed to confront one's own thinking and that of others with awkward questions. To provide persuasive methodology, a radical approach to looking, listening, reading and questioning should be adopted. Reporting of findings also needs to be seen as persuasive, purposive, positional and political.

Clough and Nutbrown (op cit) talk of the pervasive nature of methodology and see it as irradiating the whole of the research and being your research diary. Radical processing refers to being interpretive and critical and our own identity as a person, professional, mother or father drives our research, so that we are (as researchers) our own blueprints for methodology.

Use of Focus Groups

Both persuasive and political elements of my research were demonstrated through its links with existing support groups for the parents of children with autism. My aim had been to consult the two existing groups about the overall research questions and what I might ask the mothers involved in my main study about their experiences of bringing up a child with autism and provision. My intention had not been to analyse the discussion in detail using any particular qualitative or quantitative approach and so I did not follow standard focus group procedures. What did transpire, however, was that the parent group element of my research took on aspects of action research and became political. I describe in detail in the research process chapter how these group meetings developed along political and action research lines.

It seems appropriate to consider more formal focus group methods here to appreciate how my approach differed from focus group approaches described in the literature. Wilkinson (2003) provided useful background information about such groups, which have become popular within psychology, as qualitative research has burgeoned. Focus groups were used in market research before the late 1970s and this continues (Greenbaum 1998). In the 1980s and since, health researchers made use of focus groups in social action research and a substantial literature on the method was established across a wide range of disciplines, with Wilkinson (1998) providing reviews.

Focus group approaches involve collecting qualitative data from a small number of people in an informal discussion group, 'focused' on a particular topic. Focus groups are well suited to exploring 'sensitive' topics and the group context may

facilitate personal disclosures. Usually, the discussion is based around a series of questions and the researcher acts as a group moderator by posing the questions, encouraging and moving along discussion. In my study the groups were not asked particular questions, but were given the task of describing their experiences, so that particular questions might arise for the individual interview question schedule. In traditional focus groups interaction between participants is actively encouraged and discussion and debate progress in a 'naturalistic' way.

The discussion is usually audiotaped and transcribed, as was the case in my study and focus groups can be part of a multi-method project, as the approach is flexible and varied. According to Wilkinson (2003), numbers involved are usually between four and eight, though as many as twelve people can be involved.

Data transcription can range from a simple orthographic or word-by-word approach to conversation analysis (Drew 2003) and can involve computer-assisted approaches, like those mentioned above in the template analysis section of this chapter. According to Wilkinson (2003), the method can be used within an 'essentialist' or 'social constructionist' framework. An essentialist approach, like IPA, assumes that individuals have their own ideas, opinions and understandings and that the researcher will access these 'cognitions'. Co-participants are seen to be likely to stimulate debate and disclosure, so as to produce elaborated accounts. Social constructionist approaches assume that sense-making occurs collaboratively within the group social interaction, rather than seeing pre-existing cognitions as being located within the heads of participants. My work was more essentialist, as I was seeking to elicit views on the questions I might ask about how mothers' experiences of bringing up a child with autism might inform provision.

Interpretative Method in Perspective

We have seen that methods are not discrete, but should be fit for purpose. Having started in the first part of this Methodology chapter, with a commitment

to use IPA and then gone on to consider critical approaches, it seems necessary to return to a consideration of this interpretative method and phenomenology in the context of this broader critical discussion.

Phenomenological Approaches

Giorgi and Giorgi (in Smith 2003), describe phenomenology as a philosophy initiated by Edmund Husserl (1900-1970). A key aim was to build a secure basis for knowledge and according to Giorgi and Giorgi (op cit, page 25), Husserl started with:

> ... the problem of how objects and events appeared to consciousness, since nothing could be even spoken about or witnessed if it did not come through someone's consciousness ... consciousness is not to be understood as limited to awareness, but in a much broader sense which would also include pre-conscious and unconscious processes.

Whilst there is not time to go into detail about the interactions between psychology and phenomenology, it is important to recognise that both were concerned with the study of consciousness. The scientifically adapted phenomenological method can help psychology make discoveries about the experiential world in psychologically significant ways. IPA has been one such method. When considering general aspects of phenomenological method, the researcher should be mindful of contextual aspects, including non-verbal data as well as transcribed interviews. What mainly drives the analysis of descriptive data is the search for psychological meaning, as lived by the participant. For IPA, non-verbal data is addressed through the interpretative actions of the researcher, which can be assisted by note-taking during the interview process.

Intentionality is a key notion in phenomenology and it does not refer to 'goal oriented'. Giorgi and Giorgi (op cit page 31) say:

... intentionality is the essence of consciousness, rather than awareness, and it means that consciousness is always directed toward some world or other (... real ... imaginary ... dream) ... Strictly, intentionality means that all acts of consciousness are directed to objects that transcend the acts themselves (a perceptual act perceives a perceptual object; loving is directed towards a loved object, etc.) ... the object itself is grasped by consciousness, not some representation of it.

For Husserl, the difficult process of careful description communicated these objects of consciousness and a presentational rather than representational theory of consciousness was held. More precise data were obtained from descriptive practice by separating or bracketing other instances of the same experience or phenomenon, so that different nuances or dimensions could be noted. Scientific phenomenological reduction was a further methodological aid, which sees objects or states of affairs as presences, not realities. These objects are taken as they present themselves, though this does not suggest that they *are* as they present themselves.

With phenomenological approaches, interview data are analysed firstly through reading the entire script to acquire a holistic view. Parts of the description are then drawn out and these need to have psychological meaning, which are linked to the attitude of the researcher. Transformations of the data are made, though experiential variables are interdependent and descriptions begin from the perspective of the life-world of the participant, so that contextual and referential issues are built in. Transformations attempt to make psychological meaning explicit, descriptively articulate and more generalised. Whilst the world of the participant is subjective, the means of capturing that world by the scientist is inter-subjective or objective. Structure of the experience is gained by taking what is seen as essential or general from the last transformations of meaning units, to account for the concrete experiences reported. Structure refers to the key constituents and the relationship among them.

What is important is the way in which this discussion of phenomenological approaches provides an understanding of and links with the interpretative method used. The approach, like all qualitative research, does have vulnerabilities, yet whilst the memory and perception of the participant may not be accurate, these are subjective and the way events and experiences are recalled is psychologically meaningful. Knowledge is viewed as how phenomena present themselves to the experiencer, not how they actually were. Deceit can be problematic, but may be detected in longer interviews and is probably unlikely, as phenomenological research is trying to find out what happened, rather than advancing a particular theory.

A further vulnerability is the lack of total access, as the whole process is dependent on the researcher's subjectivity, especially with regard to transformations. Yet, there are often rigorous guidelines for such transformations and whilst the processes may not be easily checked, the outcomes can. Dialogue with other researchers can provide greater clarity and process information, which is also helped by leaving a complete track record. The researcher does assume an inter-subjective or psychological attitude, so that intuitions are *role* rather than *person* based. According to Giorgio and Giorgio (op cit), data richness through 'fidelity to the phenomenon', is of course a positive gain for such approaches.

Semi-structured Interviews

Smith (1995) describes this approach and the phenomenological perspective, whereby a relationship is assumed between what the person says and psychological beliefs or constructs that are held, following Giorgi (1995). Semi-structured interviews have advantages over more structured approaches in that they facilitate empathy and rapport, allow a greater flexibility of coverage and enable movement into novel areas, so as to produce richer data. There is at the same time, less control over the situation, additional time spent and a greater complexity in analysis. Interview schedules are constructed, though a co-determined interaction is used. Questions will relate to major themes of the topic under discussion and within my study, early experiences, child

management, family and relationships, services and provision were some key areas. At the same time there was a need to engage with mothers and parent groups from the outset, so as to provide a reflexive approach, which was persuasive, purposive and political and followed the principles proposed by Wolfendale (1999).

The interview schedule within a semi-structured interview can be seen as a co-determined interaction in its own right. An appropriate sequence is established, for example beginning with earlier experiences and more sensitive questions being introduced later. Again open-ended questions are used, with some prompts and the schedule being a guide rather than a crutch, so that the interviewee is able to talk freely and respond to questions in a more natural flowing manner. More specific questions should follow general ones, where necessary and questions can be redrafted. The interview is given plenty of time, with minimum probes being used, such as 'Can you tell me more about that?' Obviously, multiple questions should be avoided, so that one question is asked at a time. Tape-recording provides a fuller record of the interview than notes, though notes can add any significant non-verbal information or any key points.

Interviews can last for more than an hour; participants are put at their ease, with the interviewer as a facilitator and guide, giving time for full answering of questions.

The guidelines given above were generally followed in my study. The broad way in which analysis is carried out is discussed in the first section of this chapter. More details about the specific analysis approach used are provided in the Research Process chapter. It is worth reiterating that the respondent's story can represent a part of their identity and psychological world (Smith 1995), with meaning being primarily sought in analysis.

Devising a Study Using IPA

The aim of IPA is to explore in detail how participants make sense of their personal and social world and the main currency for an IPA study is the

meanings that particular experiences, events and states hold for participants. Life-world is investigated, but there is an active role for the researcher, who is making sense of the participant making sense of the world (double hermeneutic). As well as making sense of experiences, IPA asks critical questions of participants' text, to include: 'What is being achieved here?' The approach acknowledges a debt to symbolic interactionism (Denzin, 1995) regarding its concern with how meanings are constructed by individuals within both a social and personal world.

IPA has largely been used in health psychology and examples of areas of research work carried out include: experiences of chronic back pain (Osborn and Smith, 1998); anorexia nervosa (Jarman, Smith and Walsh, 1997); experiences of patients on kidney dialysis (Smith, 1996) and changes in identity of mothers during pregnancy (Smith, 1999a). In this latter study, the writer made use of interviews, diaries and repertory grids (Kelly, 1955) to gather data.

Examples of specific psychological research questions addressed by IPA studies are given in Smith (2003, page 53) and these include: how gay men think about sex and sexuality (Flowers et al, 1997); how people come to terms with the death of a partner (Coyle, 1999) and how do male partners respond to planned foetal termination (Robson, 2002). IPA research questions are in keeping with those in my study, in that they are framed broadly and openly.

More recently, I have come across one or two other EPs, who are using phenomenological methods, though the IPA approach is less widely used in educational fields, though autism transcends health, social and educational spheres. An IPA internet discussion group has widened my knowledge of the approach and has provided practical help, through raising issues and concerns and considering those of others.

Briefly, IPA aims to explore in detail the participant's view of the topic under investigation, so that the approach has a phenomenological concern with an individual personal perception or account of an object or event, rather than

trying to produce an objective statement about the object or event. The researcher's own conceptions are required to make sense of the personal world of another through a process of interpretative activity and the term IPA is used to signal these two facets of the approach. Smith (1999a, page 282) refers to 'the co-constructive aspect of the approach adopted, with participant and researcher both actively involved in the sense-making process, which is reflected in the title for the analytic method employed ...'

Smith (1994) also considered reflexive practice by engaging participants as co-analysts in psychological inquiry. In a study concerned with changing identity during the transition to motherhood, preliminary analysis of a woman's data was taken back to her for comments and reflections, so that this could be incorporated in the final case study. Reflexivity for orthodox psychological research might be seen as interfering with the researcher's neutral role in the project. Yet, as reflexivity cannot be avoided, it can be harnessed as a valuable part of the research exercise itself. There are, of course, differing degrees of co-operative inquiry, so that participants could be involved in all stages of the project. Within my own study, some reflexivity was provided in that participants were engaged in both the analysis of draft interviews and the combined interpretative account. One round of reflexive dialogue was used at each of these stages, as the process could be infinite.

IPA uses small sample sizes, with detailed case analyses, so that the detailed perceptions and understandings of this particular group are described, rather than making premature, more general claims. Thus, the mode of inquiry is idiographic, rather than probabilistic. Tentative theoretical statements can be made. The sample needs to be fairly homogeneous and is purposive rather than random, so that a group is defined for whom the research question is significant. Readers are able make links from findings with their own experience and the literature and around five or six is seen as a useful sample size, though no definite limits exist. Such a size enables similarities and differences to be examined without data quantity being overwhelming.

In a study concerned with the way in which personal therapy affects therapists' practice, Macran et al(1999), considered the multiple case study approach, which (page 420):

> ... uses a detailed understanding of each unique case to "triangulate" on the larger phenomenon, of which each case is an example. Each participant's experience is coloured by his or her own history and circumstances, and each may have experienced only part of personal therapy's potential effects (both positive and negative).

Thus, a more general understanding of the essence of the phenomenon is gained through multiple case studies.

Theoretical Aspects: Social Cognition, Discourse Analysis and IPA

Cognition is a central analytic concern and a chain of connection is assumed in interpretative phenomenological approaches between people's talk, their thinking and emotional state. IPA's concern with mental processes and commitment to exploring meaning and sense-making links it with cognitive psychology and social cognition approaches. Smith (1996) considered the social psychology debate between social cognition and discourse analysis. Social cognition helped psychology to move away from a narrow focus on external and directly observable behaviours to a concern with inner mental states. The cognitive approach is manifest in attribution theory, schema theory and attitude-behaviour research, so that mentalism and quantification are involved.

Discourse analysis offers a challenge to the social cognition paradigm; for example, Potter and Wetherell (1987) dispute the assumption that verbal reports reflect underlying cognitions. They suggest that what people say is largely contingent upon the situation they find themselves in and this kind of discourse analysis is involved with attempting to elucidate the interactive tasks being performed by verbal statements and how those tasks are accomplished. People will play the role of interview respondent and draw upon pre-existing

discourses, so that it is difficult to map responses onto underlying cognitions. Smith (1996, page 262) points out that:

> *Discourse analysis, as conceived by Potter and Wetherell, is critical of the social-cognitive paradigm for its privileging of cognitive attitudes, beliefs, intentions ... for discourse analysis it is not necessary to go beyond the verbal statement to seek relationships to other behaviours or to underlying cognitions and to attempt to do so proves problematical ... if verbal expressions ... are so heavily contextually driven ... then the researcher's concern shifts to close reading ... of texts.*

IPA emphasises a phenomenological concern with an individual's perception of an object or event and the symbolic interactionist view that the meanings individuals ascribe to events are only obtained through a process of interpretation. Meanings are also made sense of, through social interactions. According to Smith (1996, page 263), IPA and grounded theory researchers differ from discourse analysts 'in having a concern with cognitions, that is with understanding what the particular respondent thinks or believes about the topic in question.'

IPA aims to explore the participant's view of the world, adopting as near as possible, an insider's view of the studied phenomenon. Admittedly, access to this world is complicated by the researcher's conceptions, involved in the interpretative sense-making process. IPA recognises the importance of language and context in shaping participants' responses, so that according to Smith (1996, page 264) 'IPA can also engage in a fruitful dialogue with discourse analysis.' Discourse analysis, of course, is not a unitary phenomenon (see Pomerantz, 2004, for example) and it is not necessary to describe it further. The discussion purpose has been to compare and contrast IPA with this different qualitative approach.

Concluding Comments

Educational psychology, like health psychology, has debates about the appropriate unit of analysis, whether community, systems or individual focus, yet the individual experience of a shared condition and its boundaries will always need consideration. Clearly, this applies to the phenomenon of autism and mothers' experience of bringing up such a child. Furthermore, what mothers say about their experience relates to their thoughts about their child, family, support and provision. Mothers' autism experience, cognition and verbal response are linked. For discourse analysis, this talk and cognition chain is questioned, as is the thought and experience link. Discourse analysis has a different research agenda to IPA and as a critical approach would be more interested in how autism experience is constructed and the associated social and political elements.

The IPA researcher will attempt to tackle the gap between personal account and underlying cognitions. Through semi-structured interviews, rich accounts are obtained of how the person is thinking about and dealing with complex conditions. Such qualitative approaches are useful with topics, which are difficult to quantify and as Allport (1963, page 28) suggested, 'we should adapt our methods so far as we can to the object, and not define the objects in terms of our faulty methods'. IPA has a long tradition in medical sociology and other qualitative approaches have addressed areas, such as perception of illness, doctor patient communication and institutionalisation (Conrad 1987, for example). Smith (1996) argued that psychologists might qualitatively analyse the verbal reports of how individuals make sense of, or find meaning in their chronic illness. In educational fields, psychologists have used such methods to study many areas, which have been discussed in this thesis and have included, discourse and defended subject approaches to autism and ADHD (Billington, 2000b and Oakley, 2004), as well as studies of able under-achievers using computer- based methods linked to grounded theory approaches (Pomerantz and Pomerantz, 2002).

We have also already explored the useful contribution of Taylor (1983, for example) in looking at the coping strategies of cancer sufferers, including the central themes of searching for meaning in the experience, attempting to regain mastery of one's life and enhancing self-esteem.

In the final part of the first section of this chapter, the evaluative criteria for good qualitative research were considered (Henwood and Pigeon, 1992 and Elliott, 1999). IPA incorporates many of these markers of good practice in qualitative research. Reid, Flowers and Larkin (2005 page 23) point out that 'increasing confidence in IPA is reflected in the accelerated rise in published studies across a wide range of psychological inquiry.' Let us now turn to the Research Process before considering how IPA assisted our enquiry of mothers' autism experience and the interpretative account of this experience.

CHAPTER 4: THE RESEARCH PROCESS

INTRODUCTION

The Introductory chapter described how I came to study this particular area, so here I give an account of how the research developed and was carried out. The research guidelines provided by Wolfendale (1999) in the Literature Review were useful in determining my responsibilities and commitment as a researcher, as well as the entitlement, rights, responsibilities and commitment of participants. Thus, for example, I have provided participants with open and honest descriptions of the aims and objectives of the research, by giving both verbal and written information about the proposals. Names of all children, parents, professionals, schools and the LA have been changed, so as to maintain anonymity.

In reflecting on the degree of co-operation achieved with participants, I feel a quiet, but deep sense of satisfaction about the close relationships established with individual mothers interviewed. We have shared personal stories, feelings, hopes and fears and the mothers may also share these feelings regarding the research relationship. Other professionals have commented upon how I have been fortunate to work with such a pleasant group of people and I certainly share this view.

SECTION 1: SETTING OUT ON THE RESEARCH

An important step, marking the onset of the research journey, was the keeping of my handwritten research diary or journal. Following Clough and Nutbrown's (2002) guidelines, I have simply written down the date and the particular actions and events that took place, including discoveries, anxieties, thoughts and reflections and points to discuss with my supervisor. The sheets of paper have been kept in a plastic folder and have remained on my desk at work or in my

briefcase since the diary began in January 2003. At the time of writing this chapter, entries are still being made, though they are less frequent.

The main element of the research process has been the individual interviews, but these have been embedded in a wider context and process, which has hopefully helped to make the research purposive, persuasive and to a degree political. My positionality has been made clear in the introductory chapter, so that the reader can make his or her own interpretations about the research account. The other main elements have been discussions with parent support groups and the parent professional group meetings. My write-up of the research process will attempt to interweave these components in chronological order, as they are essentially interlinked. I give below a table, which provides a brief overview and summarises the main events over time:

Table 1: Chronological Research Events Summary

Date	Event	Date	Event
March 03	Parent group meetings and LA discussion	May 03	Research proposals presented and interview questions devised
June 03	Participant selection consultation with colleagues & parent concerns to LA	July 03	Parent & professional nominations for Parent Professional group
July 03 to January 04	Questions revised and individual parent interviews held	July 03 to January 04	Tapes transcribed and discussed/revised with parents
September & October 03	Parent group follow-up meetings	October 03 to March 04	Monthly Parent Professional group meetings
April to July 04	Interview coding and analysis	July 04 – to date	Joined IPA discussion forum
August 04	Interview Account write-up	September 04 to February 07	Thesis write-up and critical reflection
January 05	Parent participant meeting to discuss write-up	May 2007	Feedback to LA and AWG

Mother, Family and Pupil Profiles

I will describe the above profiles for the individual interviews, before considering the parent group meetings, as three of those ultimately participating in the individual interviews were also key figures in the parent group meetings. It should therefore help the reader to have this background information prior to discussing the parent group meetings. The individual profiles are given in the order, in which the interviews were carried out and the information provided relates to the date on which interviews were carried out. All information provided has been checked and agreed with the mothers concerned.

1   Mary was the mother of Terry, who attended a local Infants school and was five years of age. He was to start a dual placement in the autism provision at a special school, which catered for children with moderate learning difficulties. Subsequently, Terry moved to a different Infants school and continued with the dual placement, spending three days in mainstream and two in the special school. Mary worked full-time in an office, where financial advice was provided and her husband worked in adult autism provision. Both parents had changed their jobs to help with the management of their son. They also had an eleven year-old daughter, who attended the local secondary school. The parents had support from their own families, who lived nearby. At times, Terry was left with maternal grandmother or mother's sister. Mary was the chair of the Martom Autism Support Group for parents (MASG) and her husband Alex was also active within this group. Mary provided the interview material used, though Alex was actively involved in the care of their son Terry.

2   Donna had a seventeen year old daughter and a son, who was nineteen, as well as James her six year old son, who attended special provision for pupils with autism in a special school. James later moved to the autism provision in a school, which catered for pupils with more

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severe learning difficulties and autism. Her husband ran a number of food take-away establishments and was from Cyprus. The family had lived in Martom for about fifteen years and other members of her family did not live in the area. Donna was also the chair of the Martom Autistic Society (MAS) at the time, doing this work on a voluntary basis.

3   Louise had two boys with autism, who both attended the autism provision at a school for children with severe learning difficulties. Her husband worked in the library service and the family had always lived in Martom. Her two boys, Simon and Alan were twelve and ten respectively and both had attended a mainstream nursery initially. Simon then attended the LA's autism provision at a school for children with moderate learning difficulties, but after about two years, moved to the autism provision at the school for pupils with severe learning difficulties. He also suffered with epilepsy. Louise was an active member of the local church and had attended an autism parent support group in the past.

Alan attended an assessment unit after mainstream nursery and then moved to the severe learning difficulties autism provision.

4   Steph's daughter, Kelly was fourteen and attended a Catholic secondary school. She also had two older boys, who were seventeen and eighteen, as well as another daughter, who was fifteen. At the time, Steph worked as the Family Support Worker for the MAS and had previously worked as a support assistant in autism special school provision. Kelly had changed primary schools in the past. Steph had divorced from her husband and lived with her partner, as well as her four children. She had lived in Martom for seventeen years, so her immediate family lived elsewhere.

5   Sheila's ten year old boy, Adrian was an only child and attended a local mainstream primary school, where he had started at nursery stage. Her

husband worked in the police forensic department and Sheila did voluntary work in a local primary school. Her family lived nearby and she was from the Martom area. She had attended a behaviour management course for parents in the past, as well as a parent support group. Subsequently, Sheila and her husband separated.

6   Carol's daughter, Linda, who was fifteen, attended a secondary school several miles away, after being excluded from another secondary school. She also had a son, who was thirteen and attended the local secondary school. She was divorced and lived with her partner and his three children. Linda also had a diagnosis of Pathological Demand Avoidance (PDA), as well as autism and the conditions were viewed as overlapping. She had also originally had a diagnosis of ADHD, from the hospital in Leeds, though this condition was no longer seen as relevant. Carol worked full-time, managing a successful business practice. She had attended parent autism support group meetings in the past.

SECTION 2: PARENT GROUP MEETINGS

Here I describe meetings with parent groups and how this impacted upon the individual interviews. The meetings could only loosely be described as focus groups, as they had more than the six to twelve members that usually comprise such groups. Wilkinson (2003 op cit) has provided guidelines for focus groups. The parent groups I attended were established with their own procedures, histories and cultures. My meetings with them were set up to firmly ground the research and interviews in a real local context and assist with research and interview questions, which were relevant, purposeful and meaningful. I went along to the two Martom autism parent groups after explaining these aims both verbally and in writing, in the context of an overall research question of how parents' experience of bringing up a child with autism could inform provision. At this initial stage no decisions had been made about which or how many parents would be involved in the study.

Within the phenomenological approach followed, the main techniques used were transcriptions of meeting tape recordings, meeting notes and research diary, which contained my reflections on events. Within this section, I have not attempted to follow any distinct data analysis approach, but have simply tried to describe, illustrate and summarise the stages in the research process, before going on to the detailed analysis of the individual interviews with mothers. An interpretative perspective has been adopted, but no claim is made that the IPA method is used for this section. Because of time and space issues, I have not done full justice to the content of the discussion, but wish mainly to give the reader a flavour of the issues raised and events described.

In adopting this approach, there are some methodological dangers, as the way in which the account is constructed is selective and perhaps lacks process clarity. There is clearly value in reporting the direct experience of participants in that it has 'face validity' (Wilson, 1997) and this can prove very compelling in making points to a reader. However, here I have largely given a factual account of the research process and made some, but limited use of quotations, as it is difficult to demonstrate their representative nature and how they fit into a framework. The two parent groups differed considerably, so IPA use did not seem appropriate because of group size and homogeneity issues. Quotations are used to illustrate points raised to attempt to help the reader 'hear the voices and empathise with the 'stories', which emanate from the groups' (Wilson, 1997, page 211).

In terms of procedure, I contacted the Family Support Worker for the MAS and the Parent Partnership officer, who worked with the MASG about my wish to meet with the groups. Written information was sent about my research proposals and the purpose of my visit (see Appendix 1a) and this was sent to member parents, giving a visit date, corresponding with a planned group meeting. Both groups had established meeting procedures and were used to having guests giving or seeking information or providing presentations.

The chair and Family Support Worker from the MAS wished to see me in advance to discuss the meeting. They had concerns about how the MAS group might react in such a situation, as some parents were angry about system delays and lack of resourcing for their children. The meeting was arranged, a structure agreed, whereby after an introduction from the chair of the group, I would give my background, outline the aims of the meeting and research proposals and the discussion would proceed around the two broad areas of parent experience of bringing up a child with autism and their experience of provision. Use of a real local context would assist with making the research purposive, persuasive and political. The meeting was to be tape-recorded.

Ethical issues are relevant with parent groups, as with any psychological research and confidentiality was involved. It was necessary for me to check meeting transcriptions with the group, as well as my summary of issues and the concerns raised, which were later passed on to professionals.

MASG Parent Meeting

The first meeting was with the ASG, who met in a local hotel and saw their function as partly social, as well as providing support for parents. Eleven parents were present and a parent support community worker also came along. Those present included; the Family Support Worker (Steph) with her partner, Mary (chair) with her husband, a single father and other mothers. Two of the mothers present did not have an official diagnosis of autism for their child. Later the meeting also involved listening to the community worker and discussing on-going business, relating to planned outings and projects undertaken.

The meeting was tape-recorded, and detailed notes taken to help attribute statements to particular individuals. The discussion was held in a quiet, but public room in the hotel. I shared some personal information with the group about the date being my birthday, also saying that I was rather tired and emotional, as I had taken my daughter to Heathrow airport that day, as she was to spend six months in Japan on a student placement. Perhaps in response to

this information, the group were friendly, responsive and co-operative, but also open and honest in their comments. Some statements about their experience of bringing up a child were similar to those given subsequently in individual parent interviews, though were less detailed and personal. An introductory statement made by the Family Support Worker, no doubt in an attempt to initiate discussion, was as follows:

> *Every day is a struggle and this becomes normality. Little things are hard work, like putting shoes on. You try ultimatums, if you do this, you can have that. You repeat instructions four times, ask them to look at you, warn them. Things just get harder, a child doesn't have any inhibitions – they can take their clothes off in Tesco, they can wet themselves in public, the children are naïve - not crafty or street-wise – they are green and would go off with anyone ... You need to ask whether it will get any better.*

More specific interview questions were suggested about how parents identified something was wrong in the early years, how they got a diagnosis and how they felt at these times. Other possible questions included; life effects, where support was obtained, the effects on others and future care arrangements for the child. One parent reported that her ten year-old daughter had said she would take care of their child with autism, after the parents were deceased and others shared these future care concerns.

Provision-related questions suggested by the parents, were however, more directed at the local education and health authority systems. They asked why assessment and support took so long, how teachers' understanding of autism could be improved, why agencies didn't apparently talk to each other, why they weren't interlinked and how services could be improved. One parent (Mary) summed this up by saying:

> *It's always been a fight. It's all long-winded. You don't know the procedures and just stumble across the rules. There's a need for*

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information packs to give parents the knowledge they need at diagnosis
– where they can get help and self-help groups.

The support group was providing an information pack for parents and they made a plea that systems should be simplified and that plain language rather than jargon should be used. My diary notes after the meeting said that whilst some of the questions were related to what I might ask parents, others were more directed at professionals and support systems in general. The research dilemma, discussed in my literature review, about interpretative and critical approach balance had become apparent at this early stage, as I was quickly immersed in the critical, political domain, as some questions suggested for my interviews, needed to be addressed elsewhere by others.

MAS Parent Meeting

This meeting lasted one and a half hours, compared with one hour for the previous meeting. Fifteen members of the society attended the meeting, with four couples being involved. As anticipated by the chair (Donna) and Family Support Worker (Steph), it was largely political and provided a critique of professionals and support systems. All participants had a child with a diagnosis of autism and one couple, the husband in particular, was particularly critical of the educational psychology input to the assessment of their son and the LA's response, as additional resources were initially denied and then delayed. Another parent had taken the LA to a SEN Tribunal and subsequently to a Judicial Review, which she had won. Thus, two parents were particularly vociferous.

Again in the meeting, my role was largely that of a listener and recorder, so I did not respond directly to criticisms. After explaining that the aims of the meeting were to place my research in a real local context and draw out research and individual interview questions, I gave my professional background and pointed out the distinction between this role and my research position. I mentioned that contributions would be anonymous and confidential and then left the discussion to them. At the end, I did comment that professionals were also learning about the needs of children with autism and there was clearly a

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need to take some action by relaying their concerns to the professionals involved through the Autism Working Group (AWG). It was agreed that a transcription of the meeting would be sent back to the group through the chair, so that those present could consider it, to gain respondent validation. Contributors were anonymised and approval was gained regarding the accuracy and content of the transcription. It was also agreed that it would be more helpful for the LA to address a summary list of issues and concerns, which I compiled from the discussion transcription (see Appendix 1b). This list was also approved by the MAS group, passed on to the AWG and was considered at a meeting. Relevant service issues were also mentioned at Educational Psychology Service meetings.

The free-flowing discussion in the group was largely concerned with provision, assessment and diagnosis issues. Parents had to fight for support for their child and psychologists' reports and assessments were criticised for lacking consideration of social and communication skills specifically and not adequately reflecting parents' descriptions of their child's functioning. Statementing procedures were unclear and systems for establishing support levels were vague, so that parents took turns in almost competing about the number of hours support their child received. Parent partnership services were criticised for lack of impartiality as employees of the LA and diagnostic procedures lacked consistency. A general lack of awareness about autism was described, though one parent felt that this was improving, as she was a member of a Social Services consultation group. There was uncertainty about whether a diagnosis of autism was required to receive statutory support from the LA. Some parents mentioned lack of trust in services, whilst others felt that trust was established.

What was striking, despite preliminary information and initial discussion of the aims of establishing research and interview questions about experiences and feelings about bringing up a child with autism, there was little conversation about this more personal side. This was probably not surprising, given the public nature of the meeting, though one or two parents mentioned their

isolation, lack of contact with others, sibling effects and need for personal support. The discussion was predominantly about provision, professional practice, assessment and diagnosis. This is in keeping with the autism research mapping investigations, given in my literature review by Charman and Clare (2004), discussions about defended subjects (Hollway, 2000) and positive illusions (Taylor, 1997).

SECTION 3: PARTICIPANT SELECTION

Initially, I had envisaged interviewing a relatively large group of parents of around twelve to sixteen, though IPA literature guidelines (Smith, 1995), suggested a sample size of around five or six participants would be adequate. Six participants were interviewed. Participant selection involved consultation with AWG and EP colleagues, with my request for proposed participants being mentioned at AWG and service meetings and followed by a letter with reply slip. Colleagues were asked to nominate possible mothers for inclusion in the study, 'whose circumstances in bringing up a child with autism had been particularly difficult or challenging'. Mothers of pupils from both mainstream and special schools were to be included.

A list of twenty-eight nominations was collated and in order to establish 'homogeneity', certain criteria for selection were adopted. Participants needed to have autism as a primary need on their statement of special educational needs. About half of the nominations were from special schools and so I included both special and mainstream students and a mixed age range was also achieved of primary and secondary aged students. The age range of participants was between five and fifteen years. In fact seven pupils were discussed with six mothers, as one family had two boys with autism, who attended the same special school. Five of the participant children were boys and the two girls were the eldest in the group and attended mainstream schools. Gender was not a criterion for inclusion in the group. In selecting the participants the views of the specialist consultant paediatrician and the teacher in charge of the mainstream autism support service were important, as they had

an overview of relative need and mothers' experience. I worked in two special school autism settings and students proposed in these schools were known to me, as I had undertaken support work with two of the families, who became involved.

The main criteria for participant selection are given later, though crucially for the nominated group, in line with my aim to embed the research in the local political context and to link its findings to the parent support groups, the two nominated chairpersons from these groups were selected, as well as the Family Support Worker. In qualitative research and IPA, participant selection criteria are not as strictly controlled as in quantitative research where there are assumptions about an objective reality. Where researcher subjectivity is central, positivist objective reality requirements may lose their significance as sampling is purposive. The defining feature or homogeneity of the sample is the maternal experience of bringing up a child with autism. This topic is considered further in the Discussion chapter and further additional stages in participant selection from the original twenty-eight possible nominations are listed below:

1. The first three participants were chosen because of their political positions in local autism support groups.

2. Three pupils attending residential schools were omitted as this group is likely differ in terms of extremity of need, and the parents do not live with them full-time - although the stories emerging would doubtless have been of great interest and perhaps worthy of separate study.

3. As a pupil from one of the two LA special schools with autism provision was already selected, six others from that provision were excluded from the study.

4. Selecting one family with two boys with ASD from the other special school autism provision excluded a further five families.

5. One secondary pupil was selected from four after consultation with colleagues.

6. One older primary pupil was selected from five pupils after consultation with colleagues.

Table 2: Details of the children in the sample at the time their mother was interviewed

Children	Mother	Age & Gender	School	No. Children in Family & age(s)	Other Details
Terry	Mary	5 & m.	Mainstream Infants	2 Sister 11	Mother Chair of MASG
James	Donna	6 & m.	Special School	3 Brother 19 Sister 17	Mother Chair of MAS
Alan Simon	Louise	10 & m. 12 & m.	Special School	2	Epilepsy "
Kelly	Steph	14 & f.	Mainstream Secondary	4 Brothers 18 & 17 Sister 15	Family Support Worker for MAS
Adrian	Sheila	10 & m.	Mainstream Primary	1	
Linda	Carol	15 & f.	Mainstream Secondary	2 Brother 13	PDA diagnosis

In reality after selecting the first four participants, I waited before selecting the final ones, so as to achieve some balance and spread in the group, in terms of age and special/mainstream placement. I also consulted further with the Community Paediatrician and Head of the Autism Outreach Service to narrow down the field, particularly for the last two participants. Interviews were carried out over a period of six months and transcriptions were made and validated with parent respondents, in such a way as to spread them over time, as I

wished to avoid having a backlog of tapes to transcribe and needed to fit the time-consuming transcription work around my LA work demands.

Again for IPA, the precision in criteria for interview participant selection is not as crucial, as in more positivist studies, as variables are not controlled and broad generalisations about the data are not made (Smith 1995). Thus, the homogeneity amongst the participants required the following of parent participants:

- experience of bringing up a child whose primary need was autism, who was at school and had been in the education system in Martom for at least two years;
- their circumstances in bringing up the child, were judged as being particularly difficult or challenging by professionals working with the child or family;
- a balance of provision experience was built into the study, with regard to primary/secondary and mainstream/special school placement;
- participants would be likely to provide an articulate account of experience.

As mentioned above, I had selected three participants in key positions in autism parent support groups, as chair or Family Support Worker. This was helpful in terms of gaining liaison with and feedback from groups. I was aware that such parents were more likely to have been absorbed in general parent group discourse and that their accounts of their own experiences were likely to reflect this. In individual interviews, experiences described were certainly personal, though were undoubtedly influenced by group discussion or discourse.

I did not attempt to exclude parents I had worked with in a professional capacity, as I had worked in the LA for many years and it was hard to know, which parents had attended meetings or events, with which I had been involved. Again, two parents had had previous direct professional involvement with me and this was seen as an advantage in that rapport and trust were

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hopefully already established. Participant selection concerns were minimised, in that the aim of the study was for parents to describe their own experiences in a sense-making process with only tentative generalisations being made, so that hypothesis or theory-proving issues were not involved (see Smith, 1994 in Methodology chapter). Again, sample selection is seen as purposive rather than random.

Interviews with Mothers

Interviews took place over roughly a six-month period, with some participants knowing me professionally and my contact with parent groups and the AWG enmeshed the interviews and research in local practice. The reflexive approaches adopted meant that I re-engaged with participants about the accuracy of transcript analysis, so as to ensure that experiences were appropriately described and encourage participant involvement. I described the semi-structured interview approach in the Methodology chapter, attempting to gain professional knowledge through listening, rather than taking control along Foucauldian medical practitioner lines. Some interview participants knew each other and were aware of each other's mutual involvement.

In approaching participants about involvement, I first telephoned to give them some details about the study and if they wished to hear more, then I sent them the letter explaining the study with reply slip (see Appendix 2b). Three mothers had already heard about the research through the parent group meetings and little telephone explanation was necessary in these cases. All participants willingly and quickly agreed to become involved during the initial telephone discussion and saw themselves as doing something to help others and possibly to develop provision. Letters were sent and reply slips or consent forms were returned before the interview, the dates of which were usually provisionally agreed on the telephone. The letter explained elements of participants' rights and entitlements.

Participants were able to choose the location for the interview and usually this was in their home, though the chair and Family Support Worker for the MAS elected to have the interview at the organisation office base. Interviews lasted between one and a half and two hours and were leisurely. An interview schedule (see Appendix 2c) was followed, though participants were encouraged to 'tell their story' and these words were used and emphasised in the telephone or initial discussion, as well as on the interview day.

I felt comfortable in all the interviews and parents were friendly, relaxed and welcoming. I also felt emotionally close to all participants and was acutely aware that I was sharing sensitive and personal material. Recording was paused if some domestic interruption occurred, such as telephone ringing, child coming downstairs or a partner leaving for work. All interviews were carried out in good conditions, so that opportunities for attention and relaxation were maximised. I felt that rapport was excellent and that participants described their experiences fully.

I transcribed the interviews manually, though I used a technique whereby I transferred the recording to Dictaphone, whilst listening to the tape and then had this audiotape typed. Typing was meticulously checked and the original tape was available as a check when necessary. Transcriptions were then sent to mothers and changed or amended, if requested. As mentioned earlier, amendments on two occasions related to comments made about close relatives, which, might have been perceived as hurtful, if the person concerned read the material. I also met with two participants to extend and amend parts of the document and some requests to omit pause-like 'umms' were adhered to.

Analysis of transcriptions did not commence until I had transcribed all tapes, though I continued to read and think about the analysis method used. Naturally, some themes were emerging in my mind, though I was conscious of the IPA maxim of staying close to the data. Transcriptions were sent to and discussed with my tutor in an on-going way. The parent professional liaison

group meetings were also occurring simultaneously, so I also had other research activities to occupy my time.

SECTION 4: PARENT GROUP FOLLOW UP MEETINGS

I returned to both parent support groups after a period of about six months in order to follow up some of the concerns raised in the initial meeting and to consider any other matters. Meetings were tape-recorded and I also took full notes. The transcriptions of the meetings were again fed back to the groups later.

MASG Meeting

Seven parents were present at this meeting, including one couple and again the group met at a hotel. Most of the parents had attended the initial meeting. They also continued with their general business of arranging events after my part of the meeting. To initiate discussion, I passed around the list of concerns, which had been compiled following the earlier meeting and pointed out that these were to be addressed by the parent professional liaison group, which was to start its meetings the following month. I also asked if the concerns were a fair reflection of the experiences that people had when bringing up a child with autism. The list was used as a prompt at times during the meeting.

The discussion focused on school matters and issues, such as lengthy travelling time to special school placement, anxieties about break-time supervision and school requests for parents to supervise their child during a school training event. One parent mentioned lack of information and school contact: "So you get to see the teacher once in a blue moon and I sometimes feel that I am dropping him off and abandoning him. You don't know what's going off during the day. You get reports that he is doing well academically, but how is he at playtimes and when he is with others at dinnertime?"

Delays in LA contact regarding special school dual placement arrangements were a concern for one parent. The couple present mentioned their son's

reluctance to go to a mainstream school ('... you have to practically drag him in ...') and this was after they had changed schools. They had had concerns about their son not receiving statutory support and the mother later came along to the parent professional group, probably because of this concern. Other issues included: continuity of support from a teaching assistant; diagnosis delay; autism awareness raising; targeting of support and the constant need to push to get professionals to listen. Parents also mentioned variability between teachers in their use of a home-school diary, frustration in dealing with the system and how schools were focused on their overall achievement targets and league tables, rather than the needs of children with a learning disability. The variation between children with ASD, as a theme for teacher training and the way in which parents were the experts on their children were other highlighted topics.

It was clear that mothers in such groups were regularly exposed to shared dialogue or discourse about their experiences that would be influential in forming their own views or interpretation of experience in any individual interview. The chairperson (Mary) from this group was the only one who was involved in the individual interviews and she did make a significant contribution to the overall group discussion.

MAS Meeting

Ten parents attended this meeting, including one couple and again the majority had attended the previous meeting. The list of concerns raised from the first meeting (Appendix 1b), was again used as a way of starting the meeting and I summarised the main themes, as relating to diagnosis, lack of system clarity, statement and assessment ambiguities, training and support and general anger or frustration. This latter concern or feeling had certainly been a major feature of the initial meeting with this group. The couple that had been outspoken in the first meeting continued in this way, with father being particularly aggressive and negative, in such a way as to appear as though he wished to wind up the researcher/professional. One parent asked, jokingly, if he might represent her at her son's school review meetings

The group then focused on the questions they had raised earlier for provision (Appendix 1b), such as 'What would make diagnosis easier? The group then returned to the need for parents to be listened to more and for health visitors to receive more training. Discussion covered parent experiences of not receiving statutory support and the lack of knowledge about autism in some professionals (in this case an EP). Two sets of parents shared the same concerns about the same professional, who made warm and complimentary comments about their child, but transparently seemed to lack depth in understanding and knowledge of the child. Discussion generally was positive about the need for diagnosis; for example:

Parent D2 *Initially we got told it's not going to affect your son's life and so will diagnosis make any difference. Obviously with hindsight it's made a lot of difference. It can't be too early to have that diagnosis.*

Parent G *I mean since we've had a diagnosis on S it's changed the way we actually think and our whole approach to him has changed. But without that diagnosis, we'd have handled him wrongly.*

Parent C *You haven't got that naughty kid any more, have you?*

Parent G *No, he's gone.*

Parent C *You've got a child with a problem, not a problem child.*

Parent B *I used to cry my head off at night but as soon as I found out, I could cope. There's a reason behind it.*

Parents went on to mention their varied experiences of the diagnostic process and how they needed professionals to know them and their child in some depth, including having some familiarity with their home setting. Various inaccuracies and misunderstandings were evident about the school support system, such as the way in which EP time was funded in schools. Another parent mentioned how the EP had said there was nothing wrong with her child

because he had scored adequately on psychometric assessment, but a diagnosis from the paediatrician was seen to be more important. I found myself engaging in discussion or explanation at times in this meeting; for example:

I think diagnosis is a big area that we could spend lots of time on, but I think that's led us in a way to the methods of assessment, EP tests and ambiguities in reports, which are linked to that really. Some of the assessments are perhaps not looking at the right areas and not describing your child precisely enough.

Lack of responsibility clarity between the LA and schools was a further area mentioned: "I don't think it's clear between the school and the LA, who's doing what for autism. I think there is a lot of misunderstanding. The LA thinks school should be doing it and vice-versa ... You're fighting between both aren't you?"

The discussion was wide-ranging with all parents contributing. Further issues raised included: ambiguity in interpretation and lack of implementation of advice; waiting time; communication gaps with school; inappropriateness of SATs and league tables; the need for more teacher training; other parents pushing for the exclusion of their child; lack of understanding from other students; the need for parent support workers and a rapid response to problems; sibling support; distance of policy makers from parents; parents as the first professional; lack of independence of Parent Partnership Service and parent representation at SEN Tribunals; perceived lack of effectiveness of an autism support teacher; lunchtime supervision arrangements; transition and links between primary and secondary schools and the need for recognition of autism as a disability.

The meeting finished with the group making some proposals for outcomes for the PPLG, which was due to meet the following month. These proposals were given to the AWG and raised again at the PPLG, but met with some professional resistance and were never really adopted. They were as follows:

1   To develop action plans for key issues.

2   To act on these plans and on discussion.

3   To consider AWG minutes, so that action is transparent.

4   To develop positive working relationships.

5   To have mediation rather than Parent Partnership support.

6   To consider some feedback system for the effectiveness of different professional groups.

Again it is noteworthy that the group focused on provision issues and whilst this was largely determined by the use of the list of concerns from the first meeting, there was not really any discussion about personal feelings and experiences of bringing up the child in the home context. Again, this was in keeping with the previously mentioned findings of Charman and Clare (2004) and the discussions about defended subjects (Hollway, 2000) and positive illusions (Taylor, 1997). As with the ASG, the influence on individual mothers' views and experience descriptions from group dialogue was again evident and two of those present were involved as individual interviewees (chair and Family Support Worker).

Parent Professional Liaison Group

The list of issues and concerns, compiled for the LA and approved by the MAS and MASG groups, was submitted to the AWG, which had representatives from Education and Health. The AWG were told that the MAS group were also requesting parent representation on the AWG, though this was resisted by professionals at the meeting. Some comments made by professionals referred to a desire not to 'compromise professional integrity', by having parent representation on the AWG. The minutes of the June 2003 meeting, stated:

Colleagues discussed the involvement of parent representatives, but felt, as there was no democratic process for the determination of parent representation and the working group often discussed professional

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issues relating to schools and services, parent representation needed further consideration.

However, there was agreement about having a separate parent professional group, which addressed the list of issues and concerns compiled from parent group meetings. In July, I met with the chair of the AWG and agreed an approach and letter to colleagues requesting nominations for membership of the group. It was agreed, in informal discussion with the LA officer and the two parent group chairpersons that about three or four professional members and perhaps two representatives from each parent group would be appropriate. The groups decided on their own representation, though both chairs, participated.

Nominations were sought from the members of the AWG via a letter and reply slip. At the September meeting of the AWG, it was suggested that the chair of the AWG would also chair the PPLG meetings. In addition, those participating would include me as researcher, the senior Parent Partnership officer, the head of the mainstream autism support team and the specialist paediatrician, who was Dr Wilson described in interview accounts write-up. The Parent Partnership officer was invited as the parents had raised issues in connection with this service and they clearly played an important part in parent support. Despite expressing interest, staff from the special school provision did not in the end attend the group meetings as places were short and the parents' issues were seen to relate more to mainstream provision. The professionals concerned, despite reservations and anxieties, gave up their evenings, to support provision and also to help me with my research.

The AWG chairperson saw the meetings as one-off, rather than as on-going. Thus, the issues raised by the parent groups would be discussed, after a meeting structure was agreed, so that information and explanations would be given, to clarify systems. These explanations and clarifications would then hopefully be disseminated to members of the two support groups and the group would disband, presumably with the task completed. An alternative model,

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which was not adopted, saw the liaison group as meeting regularly, about three times each year and being on-going. The agreed outcome was that five evening meetings would be held on a monthly basis, with each meeting lasting at least one and a half hours.

The parent membership of the group was established with three from the ASG and initially two from the MAS. Provisional aims of the group were considered with the chairs of the two parent groups and their written proposals discussed at the AWG (see Appendix 1c). In an attempt to reassure some professionals, the overall, the aim was described as follows:

> ... To facilitate liaison between parents and professionals in order to provide effective support and provision. It would build on the excellent work done by a number of professionals in setting up parent support mechanisms in the Authority. Parents are aware that support and provision in Martom is high quality and wish to play their part in its continued development. Services need to reach out to parents in order to listen to their views and learn from them.

Some issues to be addressed at the first meeting were established, including the positions of chair and secretary of the group, objectives, key outcomes, possible support funding, liaison with AWG and meeting frequency. There were some anxieties amongst professionals about parent representation and my research diary negatively described the AWG discussion, when the proposals were considered. The parent representation anxieties were around confidentiality with individual pupil, school and teaching staff discussion. Another professional concern related to the possible presence of more extreme MAS member(s) on the AWG and the liaison group. However, it was agreed that the liaison meetings would go ahead and be held at the MAS. During this planning stage, my position had been that of asking questions about these fears and reassuring colleagues about the development.

Parent Professional Group Meeting 1

At this relatively polite and orderly event, it was decided, according to the minutes, that the meetings would be chaired on a rotational basis, with the professional chair alternating with the parent (MAS) chair. In actuality, the AWG or professional chair continued to chair all meetings and the meeting minutes were to be taken by a parent secretary. The plan was that these minutes would communicate the important elements of the discussion to other parents in the two groups. There was a request from the MAS to have the same numerical representation on the group as the MASG and it was agreed that the Family Support Worker would come along. The concerns listed from the initial parent group meetings were considered and discussion around diagnosis took place after the initial meeting format issues were resolved. The notion of attempting to obtain longer term funding for the group was seen as a possible future development. The above-mentioned group outcome proposals were also briefly considered, though they did not receive further attention.

My position in discussions was not simply that of a passive listener, as I made comments and provided relevant information that stemmed from the individual parent interviews and the group meetings. Some areas discussed included: lack of clarity around referral routes for diagnosis; gaps in health visitor understanding; delays and parent readiness for support. Some professional defensiveness was perhaps evident at times and an example taken from the minutes was as follows:

Parent: The whole process of the diagnosis and the Child Development Centre is very distressing. It's that feeling of being observed, combined with the apprehension about the possible outcomes ...

Professional   It has to be like this, because it has been proved to work.

There was professional reassurance that support systems on diagnosis had improved with the Early Bird parent support programme that was now in place

and additional support from the pre-school inclusion team. Aspects of language appeared confusing for parents and these included abbreviations such as CDC, VIP (Voluntary and Independent Providers) and PCT (Primary Care Trust). Professionals at times defensively mentioned staffing shortage and waiting list problems.

Discussion considered statements and one parent had come along because her child did not receive statutory support, despite having a diagnosis. There was discussion about the fact that schools had funding to help pupils, which was available without a child necessarily having a statement. Parents found it hard to understand why some ASD pupils received statutory support, whilst others did not and it was agreed that the next meeting would address the question of the statementing process.

Parent Professional Group Meeting 2

The same participants were present, though the parents had prepared for the meeting. They asked that the Family Support Worker be on the AWG, rather than the PPLG as agreed at the previous meeting, as she was a paid employee and a professional. This proposal was met with some resistance, as the AWG was considered to be too large. The parents pointed out that they had written to local MPs about this issue and the chair later agreed to look at the proposal, as the existing parent representative, who was employed in a family support capacity by an adult autism provision group, was currently seconded to another post.

The chairs of the parent groups had prepared a typed list of discussion issues for the meeting, after consultation with their members. These related to the following:

- the purpose of education, where social and personal independence goals were stressed;
- the involvement of parents with professionals in service development;
- the inappropriateness of the National Curriculum for these students;

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- awareness training for school staff;
- criteria for providing statutory support for ASD;
- the need to consider social skills and development;
- ways of dealing with support level disputes;
- mediation and the partiality of parent partnership officers as salaried officers;
- shortage of specialist autism support teachers;
- school funding devolvement and linked relationships between schools and parents.

These questions and issues were addressed during the meeting, though it is not possible here to do justice to the full discussion or the feelings and meanings involved. Again no pretence is made about the use of any particular research method to describe the meeting. I have drawn on my reading and personal interpretation of the meeting minutes, diary notes and the tape transcription (thirty pages), as well as my recollection and view of the dialogue and the feelings involved. The LA officer, who was chair of the AWG, fielded most of the questions, as well as the initial hostility. Discussion about the aims of education moved into talk of provision improvement at the local college, funding post-school, work placement opportunities for ASD pupils in mainstream and employment links. During the discussion services took the opportunity to clarify their work in the area.

When the Parent Partnership Service (PPS) was discussed, the officer concerned mentioned their steering group, which had parent representation and how the service aimed to involve, inform and empower parents. The service would challenge schools about provision for pupils. The close physical location of the service to SEN officers was recognised and LA professionals also described the cramped working conditions in which they operated. The need for clear evidence in describing pupils' social and interpersonal skills was stressed and parents with the help of the PPS were seen as a vital part of this evidence-providing system.

Training for schools and support staff, was clarified and the many demands and priorities facing schools were described. Professionals admitted that they were not in as strong a position as they would like to be, in order to be able to control or influence, who undertook autism training. Professional power and influence was acknowledged to be limited in changing practice in schools.

Power and challenge were clearly important dimensions of this meeting, in a situation where the discussion, at least initially, appeared to be parents against professionals. The LA members did assert their position, for example, by pointing out that education was led by the National Curriculum and there followed a lengthy discussion about the degree to which adherence to this prescribed curriculum could be changed and which subjects might be dropped, so that curricular demands could be reduced and social skills developed. Other issues discussed related to the effects of the Disability Discrimination Act (DDA) on schools taking up autism awareness training and how there were many demands on schools for teacher training time.

Other issues discussed included a description by the chair of the issuing of a note in lieu of a statement by the LA, where resources were not attached, but specified school actions and provision were described to help meet a student's needs. Parents were also reassured about how the vast majority of pupils with ASD were coping in secondary schools and about the useful progress that many went on to make. The meeting was rounded off with an up-date by the chair on the progress of the authority's Special School Review, which concerned many parents, as some school closures were planned. It was also agreed that Social Services representatives would be invited to a future meeting, as would someone from the LA team, which monitored how schools used their devolved SEN funding and assisted schools with development.

Parent Professional Group Meeting 3

Prior to this meeting there had been further discussion about parent representation at the AWG and no agreement had been reached about this. It was seen as appropriate to have individual pupil discussion at the end of a

meeting without the presence of a parent representative. There had also been some positive spin-offs from the previous meeting in that the Parent Partnership Officer (PPO) had attended a parent meeting at the MAS.

There was further discussion about some questions from the previous meeting, though the parents had prepared another list of questions. The main discussion concerned the nature and role of the mainstream autism support service; including training offered, telephone help-line and pyramid support assistant meetings provided. School rather than LA responsibility for annual review meetings was emphasised.

The written parent issues were concerned largely with inclusion and behaviour matters in secondary school and in reality had been brought by one parent, who had anxieties about her son's transfer to secondary school. Again parents were reassured that the vast majority of ASD pupils coped adequately in secondary schools and that recently exclusion had occurred for only two pupils with autism. Transition arrangements to secondary school were clarified and were described as LA policy. Parents were also seen to be able to support by asking schools about the training the school had put in place.

Parent Professional Group Meetings 4 and 5

In the fourth meeting in January 2004, a LEA Monitoring Review and Development officer gave a detailed presentation about the nature of her role and that of the other three members of her team. The monitoring of funding for SEN was described and inclusion data was collated. This data included school provision, numbers of pupils at different stages of the code of practice, IEPs, value added results and SEN expenditure. Clarification was provided on LA written SEN guidelines, training for schools and SENCo support systems.

No minutes were prepared for the meeting, as the handouts given by the monitoring and review officer were viewed as adequate. The meeting was largely based around the topic of funding and was quite complex. Other

professionals from the group subsequently arranged to attend MAS parent group meetings to explain support systems and provision developments.

In what was the final meeting of the group about six weeks later, two members of Social Services staff explained the nature of support provided by their agency. One of the professionals did not attend the meeting and two parents were unable to do so. The chair of the MAS arrived later and it transpired that she had resigned from this position. A number of difficulties were subsequently to emerge for this group, which will be discussed in the section below.

The manager for Children's Disability and Health provision gave most of the session input, with the other presenter describing her responsibility for mainstream child-care provision. The range of support provided included severe disabilities, such as physical, learning, sensory and complex health needs. Various initiatives were mentioned; such as summer play schemes, parent information packs, hospital social work support and the four special residential units, with one developing autism expertise. Care to share, sitting and befriending, special fostering and community initiatives were also described. Ways of accessing services, gaps in provision and delays were considered, as well as links with developments in Child and Adolescent Mental Health Services (CAMHS).

Finally, it was decided to leave any future meetings until specific issues arose and it was acknowledged that the parents felt confident about inviting specific professionals to meetings or coffee mornings, where there was always an open invitation to professionals to attend. Those involved agreed that the meeting time had been usefully spent, useful information had been provided, systems clarified and relationships had developed.

In reflecting on the meetings, it was apparent that parents remained seated on one side of the table, whilst professionals stayed on the other. I sat at one end of the table, though my position was partly determined by access to an electric

socket for tape-recording purposes. The two final sessions, where presenters were invited, may have calmed discussion.

Parents were always polite and hospitable and provided refreshments. The group had appeared useful and had gone some way towards achieving its aim, if not the proposed possible outcomes. Nevertheless, not establishing clearer and more definite follow-up arrangements meant that there has been a missed opportunity for maintaining and developing liaison with parents.

MAS Developments

At around the time of the last meeting of the PPLG, some difficulties were emerging within the MAS, as evidenced by the chair resigning, because of what she described as a conflict of personalities. This description of events is largely based on a conversation I had with Donna, the former chair, when I gathered feedback from the mothers about the joint interpretative account of the research findings from individual interviews. She still worked as a trustee of the organisation, but around the time of her resignation, two other staff had left the organisation because of a proposed restructuring, which left the voluntary chair carrying out duties such as organising activities and dealing with accounts and reports. A project manager was subsequently appointed, but did not take up the post.

The Children's Fund, who financed the project, later reviewed the situation. Reduced costs and improved organisation were seen to be required and some consultative support was provided to run the office on a part-time basis. Subsequently, the posts of Family Support Worker and activity manager were combined and one new person was appointed to undertake these activities. This part of the organisation was moved to a local adult autism support provision, which had supported the initial grant application for establishing the paid support workers. The MAS planned to continue on a charitable basis, as a parent support group, running coffee mornings in other premises and raising funds for outings and family days, where the emphasis is on parent-to-parent support.

SECTION 5: TUTORIAL AND RESEARCH DEVELOPMENT SUPPORT

It is obviously difficult to fully track and record the ways in which my thinking and approach developed during the period in which the work was carried out. Here, however, I describe some key influences in some loose chronological order, though no attempt will be made to give precise dates, as such detail would detract from the flow of the text. My regular sessions with my tutor, Mike Pomerantz, have been essential and invaluable, in terms of on-going support and the development of ideas; for example, with comparing grounded theory and IPA approaches and with regard to the place of personal constructs in data analysis. Tom Billington suggested contact with parent groups, which was related to the work he had carried out in the Wirral and is described in the literature review. The presentation of my research proposals to the doctorate group was formative and its significance in terms of considering critical, as opposed to interpretative approaches was to strike me later. Support meetings with Peter Clough at Sheffield, as suggested by my tutor, helped to broaden my conceptualisation of phenomenological approaches and more critical aspects of research methodology.

A talk by Jon Nixon was illuminative in considering the link between theory and practice and the nature of professionalism. At a residential weekend for the doctorate group in North Yorkshire, Derrick Armstrong emphasised the political context of professionalism and the way parents can receive inaccurate messages. His partner Ann-Cheryl, saw research as essentially your own journey involving your feelings and she also stressed the importance of a critical friend and a research diary.

A subsequent presentation to my doctorate group by Barbara Cole and a later meeting, helped me to consider narrative and life story approaches and gain a more creative view of research approaches. For example, the way in which trust developed between researcher and participants was described, as well as the reflexive process through which researcher and participants constructed

interview material, stories and narrative. Nevertheless, throughout this time, my interview analysis approach using IPA had been chosen and these influences helped to provide a more mixed, improved, purposive approach and perspective. Similarly, on-going discussion of discourse approaches at Sheffield provided a regular reminder of alternative techniques, which needed to be considered. A helpful warning from Tom Billington was to avoid any claim to use discourse approaches, without using the method thoroughly, as I had at times, felt tempted to apply the method in some limited way to the description of the parent group meetings.

SECTION 6: IPA AND INDIVIDUAL INTERVIEWS

Before embarking on a description of the lengthy process of data analysis, it is important to emphasise how account construction and interpretation developed during the analysis and write-up of the interview transcriptions. Analysis processes were not neatly linear and sequential and were in some ways 'multi-directional', whilst at the same time following the introductory description of IPA by Reid, Flowers and Larkin in the January 2005 section of the Psychologist (page 20), where it is portrayed as a 'a bottom up' approach. Essentially, the method had appealed to me, as I saw it as having rigour and providing a 'fit for purpose' approach, with which I felt comfortable. It has already been described as an inductive approach, so that hypotheses are not tested. The technique provides an analysis of people making sense of their world and their experiences for themselves and for the researcher, who reduces the complexity of the experiential data. There is a focus on and balance between what is individually distinct and the commonalities across groups of participants. Analysis is interpretative, transparent and plausible to all concerned, whilst also realist, reflexive and relativist.

My Methodology chapter described the broad steps involved in analysis and here I describe these steps in the context of my own research, using both my preferred guidelines (Smith, Jarman and Osborn, 1999b) and my research diary. These guidelines provided a detailed, yet flexible, description of the

steps involved and the process of IPA. Indeed, anyone wishing to use the approach can make use of this article 'Doing Interpretative Phenomenological Analysis'. Idiographic case-study material from individual parent interviews is interpreted and moves slowly towards theorising at group level regarding how parent experiences of bringing up a child with autism can inform provision. Underlying cognitions or thoughts about experiences are interpreted from verbal reports of the experiences. The aim is to capture the meaning of the experience for the mother and work towards more general categorisation or themes. The analysis took a total of around fourteen days, extending from April to August, and included a concentrated period of seven days at the end of this time. A further seven days was taken by the initial draft of the write-up and this followed on from the final analysis period in August.

Looking for themes in the first case (Mary)

In my study, I began by analysing the individual interviews in the order in which they were undertaken. Reading and re-reading of the first transcript was undertaken a number of times, whilst I noted interesting or significant statements made by participants, in the left hand margin. The whole transcription was read first for left hand margin comments, with some comments being attempts at summarising, or noting connections or making preliminary interpretations. After completing left margin comments, the other margin was used to document emerging themes, by using key words 'to capture the essential quality' of what was found in the text. Appendix 2d provides an example of initial coding and the left and right hand margin comments. Some connections with previous interview sections were noted and similarities and differences drawn out, with all sections of the transcript being viewed as important. No attempt was made at this stage to select particular passages for focused attention.

Seeking connections

The next step was to separately list and look for connections in the emerging themes, so as to see where some clusterings came together as super-ordinate themes. New super-ordinate themes can emerge at times, like a magnet, to

pull together or explain initial lower order themes. There was a gradual moving away from the initial question topics from the interview schedule as themes, as new more abstract themes developed. This re-ordering took place both for individual cases and for subsequent combining of cases, so that this is a constant feature of the analysis process. With newly emerging theme clusterings, it is important to check back to the original source material to ensure that they work for this data.

Some themes appeared to embrace, pull together or explain others and an example of a table of some initial themes for the first participant in the area of early difficulties is given below:

Table 3: Initial Themes Example

Early Difficulties

First Level	Second Level
Finding out	Child comparison
Developmental changes	Shock/anger/hope
Delay	
Professional denial	
Self-blame	
Other difficulties:	Behaviour stress
attention	Manageability
public comments	Constant battle
fatigue	
dependence	

Continuing analysis with other cases

I listed the themes afresh for each case analysis, though obviously analyses of previous cases were likely to influence decisions about the conceptualising and naming of themes. Whilst, individual interviews were analysed separately over a period of months, I later combined cases in an intense and creative way in a concentrated time-period, so that analytical continuity was retained. The same

continuity was required for the write-up of the account. In my study, the combination of cases and write-up was carried out over around three intensive weeks in the summer when I had time for continuous application in analysis and writing. Throughout this time, I remained cognisant of the personal advice from Jonathan Smith, obtained in a telephone discussion in July 2004 about staying close to the data and giving focused and continuous time to the creative analysis of combined case studies and the write-up.

For each participant, each theme is listed on the left of the page, under broader domain or master theme headings and then a table of themes is developed, with identifiers or key word components from extracts in the transcribed text. The table below illustrates identifiers for the first two themes from the first domain of Deconstructing Expectations. I have used the term domain to refer to the four master themes, which emerged in the analysis.

Table 4: Theme Identifier Examples

Deconstructing Expectations

Theme	Identifiers
Comparison with child's siblings and others	Other parents; child's siblings; lack of siblings; social difference; copying; lack of autism comparison group.
Reaction to uncertainty	isolation/despair; denial; upset/shock; anger; anxiety; guilt; process dislike.

Later page and line references for the identifiers from the extract are added for each participant to aid the writing-up process. Themes and domains are combined in a case-by-case fashion, with themes listed vertically on the left and line and page references on the right. There is an on-going cyclical revision of themes, super-ordinate themes and domains through clustering, so that new themes and domains might become subordinate or super-ordinate to previously listed ones. As the number of participants was relatively small, it was possible to retain an overall mental picture of each of the individual cases and the location of themes within them.

Master list for group

Moving ahead in the analysis, themes were later clustered, after much work and time by combining all six cases and revising the themes into conceptually higher order domains. Considerable progression emerged in material and the following table illustrates the way in which some of the above initial themes described as Early Difficulties, were included and developed into the first two of four domains:

Table 5: Theme Developments Example

Deconstructing Expectations	Life Restrictions and Impacts
Comparison with child's siblings and others	All pervasive/constant battle
	Missed opportunities
Reaction to uncertainty	Managing the child
Need for certainty	Family reactions
Shattered and deconstructed expectations	Peer group issues
	Perceptions of others
Future anxieties	

As new clusterings or themes emerged, these were again checked against the original transcript to ensure the meanings were in keeping with what was actually said in the material. Thus, for example with Mary, the initial themes of 'behaviour stress, manageability and other difficulties, including attention, public comments, fatigue and dependence' later combined at the group analysis stage to 'managing the child'. Similarly, in the final clustering, 'deconstructed expectations' seemed to comprise earlier themes, such as 'finding out, developmental changes, self-blame and shock/anger and hope.'

After themes and domains have been re-clustered in the group analysis, the page and line listings are re-grouped and moved into the final table, which was produced on separate pieces of flip chart paper for each domain. Some examples for the first 3 participants are given below for one of the themes in the domain of Deconstructing Expectations:

Table 6: Theme Page and Line Listings Example

Reactions to Uncertainty	Participant 1 Mary	Participant 2 Donna	Participant 3 etc Louise
Isolated/despair Denial Upset/shock Anger Anxiety Guilt Process dislike	 4(5,6) 3(1 – 4), (17 – 19) 2(23,30),3 (40,44) 5(47,48) 1(46,47) 1(18-21), (38 – 43)	2(2,3), 3(22,23) 1(50-53), 2(19,20) 1(38-43), 9(44-50) 2(24-28), (32, 33)	1(46-50) 1(18,19) 1(33)

The process of re-clustering domains and themes into a master list of themes is exciting and creative and involves working on the sheets of flip chart paper to interlink, connect and re-connect themes into more abstract higher order themes. This recombination is carried out initially on separate sheets using only domain and theme headings. The master list also contained the sub-themes for each super-ordinate theme. The following table illustrates how domain headings changed between the initial and final analyses:

Table 7: Domain Developments

Initial Domains (May 2004)	Final Domains (August 2006)
Identity/motherhood	Deconstructing Expectations
Boundaries	Life Impacts and Restrictions
Shattered Expectations	Reconstructing Self and Expectations
Comparison	Professional Practice and Provision
Support	Quality and Equality

Again, it is important to re-iterate that the transcriptions were re-read to check how they fitted into any new clusterings, so that what the person actually said was crucially linked to any interpretation. It seems helpful to hierarchically

summarise the main IPA terms that have been used, remembering that the process is creative with themes combining over time in new ways.

Table 8: Hierarchical IPA Terminology

Domains or Master themes Super-ordinate themes Themes Sub-themes (merge into themes)	Identifiers

Write-up

When the more developed data had been collated on the four separate domain flip chart paper, these sheets were used for writing up the interpretative account. It was necessary for some detail to be lost in the writing process, so some information and quotations were omitted, when particular themes had been adequately illustrated. Generally, however, the account provides information about the extent to which interpretations were general amongst participants and any perceived differences. Prevalence within transcriptions is not the only factor involved in the selective analysis, as the richness of particular passages in highlighting particular themes is crucial. Themes and domains were also revised during the writing process.

In writing the research findings account, I linked material, so that the account flowed and hopefully did justice to the interpreted meaning. Some short explanation about interpreted meaning was often given at the start of a paragraph or section, followed by some short quotations and then longer quoted illustrations, for which italics were used. I also used a further piece of flip chart paper, which listed the domains and themes and then added further identifier key words in a different colour for each participant, so as to provide an additional abbreviated interview content summary, which was helpful in the selection and organisation of material for the write-up in conjunction with the four domain sheets. Some items were starred, if they appeared to be of

particular significance and items on the sheets were marked, when they were included in the account.

The interpretative account was also narrative and provided a major opportunity for flexibility and creativity to produce a persuasive document, which would impact on the reader. Some theme excerpts were prioritised or fore-grounded and the breadth of other themes was highlighted through the verbatim reports. Whilst I have attempted to describe the IPA approach in a systematic way, it is important to emphasise that it is not a prescriptive methodology, with the crucial part of the analysis being the interpretative analysis that the investigator brings to the task.

Interpretative Account Follow-up Meeting

After the joint interpretative account of the individual interviews was written and sent to mothers, an evening meeting was arranged to discuss the combined account, so as to provide participant validity. Mothers considered the account for accuracy and comment on the validity of themes and the meaning interpreted. For those who were unable to attend the meeting, I arranged to discuss the write-up on the telephone or to receive comments by e-mail. I initially discussed these proposals with parents on the telephone and then sent them a letter (see Appendix 2e) or e-mail giving the date and venue of the meeting and enclosing the write-up. I also discussed the individual parent and pupil profiles, which are given at the beginning of this chapter to check on accuracy and acceptability.

All parents were happy with the write-up and amendments usually related to typing corrections, though there were some queries about whether information should be up-dated. All participants liked the themes and domains that had been interpreted from the interview data. One or two family details were amended and one participant had separated from her husband since the interviews were carried out. Several of the participants were interested in

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meeting at a later date to discuss further publication possibilities for the material.

CHAPTER 5: INTERPRETATIVE ACCOUNT OF RESEARCH FINDINGS

INTRODUCTION

This account conveys shared experiences across participants and through this process of combination the unique nature of each participant's experience can re-emerge. The analysis has revealed four main inter-linking domains or master themes:

- Deconstructing self and expectations;
- Life effects and impacts
- Reconstructing self and expectations and
- Professional practice and provision quality and equality.

Whilst, these domains and their related themes obviously interact and overlap, I will illustrate themes in turn, developing arguments and typologies and explaining or theorising from particular accounts. For each domain, a key or super-ordinate theme is given in italics heading the list at the beginning of each of the four domain sections. The aim is to give illustrative examples from original texts, which will be illuminative and hopefully provide essential, compelling and interesting material. Some closer contextual reading will be provided at times. To engage the reader, I have attempted to allow the account to flow and to become narrative, stemming from the analysis, as described by Barbara Cole (2004) and mentioned in the Literature Review.

Interpretation of the material is provided through the structure of the emerging domains and themes and my on-going meaning-making comments, which link and interweave shorter extracts from the accounts across subjects. Lengthier extracts from the accounts are usually provided with interpretative or interlinking comments and these extracts have been indented in the text, so that my own comments and those of the subjects can be distinguished more easily. Sometimes, extracts themselves provide a transparent link to the theme under discussion. In order to provide a concise account mothers' comments have

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been abbreviated, so that omitted parts are marked by three full stops. Linking words are often omitted and these included; 'I think', 'You see', 'I know', 'I mean'. Repetitions are also sometimes omitted where they do not appear to add to meaning.

Analysis has continued during the write-up process, with prioritising, revising and re-ordering of themes taking place. This chapter provides a discrete analysis and is followed by a later discussion chapter, which further interprets and relates the findings to the literature.

SECTION 1: DECONSTRUCTING SELF AND EXPECTATIONS

Unfulfilled wishes
Bewilderment and loss
Comparison with child's siblings and others
Reaction to uncertainty
Need for certainty
Shattered and deconstructed expectations
Future anxieties

This first domain is largely concerned with participants' attempts to make sense of their experiences and naturally, there is a considerable breadth of experience reflected across the account.

Bewilderment and loss, child comparison and uncertainty

Sheila commented on professional denial or lack of knowledge, "When I mentioned it to the health visitor, she said that I only had one child and didn't realise that it was just a phase." Sheila later became more aware of her son's difficulties at playgroup, "... some of the children played with playdoh and other toys. Adrian played in the toilets or on the chairs or anywhere, except where other children were."

Some parents were able to compare their child with older siblings, noting an initial difference, whilst for others the opportunity to notice difference did not come until the child was able to mix with other children. Mary described more of a change in her son at around sixteen months, rather than mentioning a comparison with an older sister, "... he changed from being happy, I wouldn't say obedient, but well behaved. He knew right from wrong, he was starting to do things like walking, playing nicely - even talking. He said 'go' at traffic lights, for example; he'd say 'bus'. We've got videos of him in the playgroup one week, with his grandma singing along, doing hand actions to 'wheels on the bus' and other nursery rhymes. Then he just changed. He started having screaming fits, had tantrums, mainly during the night; he'd throw toys, he wouldn't play, he was just completely destructive." After two health visitors did not have concerns, Mary began to compare Terry with his older sister, who did not behave in this way.

Steph, noticed early difference through child comparison, saying, "We suspected quite early on ... Kelly had quite delayed speech and we took her to speech therapy. Her behaviour at that point was quite different from the other two children that I had. She was very demanding and unpredictable; for example in the supermarket. But she sort of managed through infant school with the aid of a friend and they grew up together. Kelly relied on her, with her speech and she just copied her work."

Louise lacked a comparison group, having two sons with severe learning difficulties, epilepsy and autism. She mentioned her sons failing the eighteen months health visitor assessment, as they did not have the required six words. She described the valuable support she received from her husband and using downward comparison, said, "I think that to be somebody, who has to cope with these kids on their own, that would be my worst nightmare."

Uncertainty
During the process of finding out about a child's autism, mothers described varied feelings, including initial denial, anxiety, shock, upset, anger, feeling

guilty, hopeless or blaming themselves. Professional 'false trails' were described, delays experienced and some particular assessment processes were disliked. Parents generally felt unhappy and uncomfortable at the Child Development Clinic (CDC), where diagnoses were usually made.

Donna described isolation and depression, following several professional interviews and inaccurate diagnoses. Health visitors had recommended hearing tests and a community paediatrician had investigated autism at mother's request, but said this was not present. "Basically she made me feel that I was being a bit of a neurotic mother and the line of questioning that she was taking was like, I wasn't sure whether she was either trying to find out whether I had been shaking James, as she thought I'd given him brain damage or whether I was a bit of a Munchausen by proxy, sort of mum!" Her feelings of self-blame were exacerbated by the reactions of her husband and her older children: "I was still insisting that I felt there was something wrong with James. My husband and the other children were getting fed up with me by now and said the doctors had told me James was fine."

Donna approached the NAS for advice and attempted to see a well-known expert in Nottingham, though funding difficulties led her to be seen at the CDC. Her husband continued to be in denial and reproached her for pursuing referral. Donna felt increasingly isolated because of his reaction and that of their children. At the clinic, she felt under the microscope and judged as a parent.

It was very uncomfortable for parents, they're watching the child through the one-way mirror and I don't know whether they are watching the parents and how they interact with the children. But that's how it felt, as though we as parents were being watched ... Could that be improved by re-arranging the seating, because now you can't even talk to other parents. One group of parents sits here and another sits over there, you feel quite alone. I was just sitting there wishing that James would behave normally in some ways and feeling they were watching me made

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me feel guilty; perhaps I wasn't interacting with James and it was my fault.

Mary recalled:

There was no preparation for the diagnosis during the CDC assessment and that threw me completely. I wasn't aware of autism and at the feedback session the following week, our new health visitor came with us. There were probably about thirteen professionals in the room, with us at the edge; it was like a conveyor belt, one after the other. They described their findings and then they passed us a book, the blue book, with an autism title, and - that was the diagnosis. We were shell-shocked.

Even then I think there's been denial, because ... you come out, you've got the diagnosis and know what the problem is ... we start reading literature that we're given and your first reaction is he's not, you've got it wrong, he doesn't do this, he doesn't do that, he doesn't do the other.

Louise mentioned shock and upset following lack of understanding and unsympathetic handling by a paediatrician at the same CDC, saying "They could have been more sympathetic really. A reluctant acceptance was evident, with hope and ego-protection that if her second child had been a girl, difficulties might have been avoided.

At 30 months, Janet, the speech therapist - she was very good - said Simon should have an assessment at the hospital and we went somewhat reluctantly every Thursday morning for several weeks. We saw Dr Jones, who said she thought he was autistic. We had never even heard of it and we were completely devastated. But when Alan was diagnosed, we knew that it is common to boys and felt that if we'd had a girl she would have been without problems, or more likely to have been without problems. So it was less of a shock and the diagnosis of

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autism didn't really matter at that time, because he was already labelled as having severe learning difficulties. I mean it wasn't really a shock to us. We'd already been there.

The complexity of the area was illustrated by two of the parents, who had received earlier diagnoses of ADHD. For Carol, a later diagnosis of autism and PDA was made and the medication for ADHD was ceased, as apparently was that label. With Sheila, medical treatment for ADHD was continued. After a number of professional 'false trails' and denials, including several visits from a CDC support worker, she became exasperated and asked to see the paediatrician and her son was diagnosed as having ADHD, coming up to nursery age. "Adrian was very hyperactive, with uncontrollable behaviour and aggression. He used to bite and kick, was very disruptive, getting into everything and he was seen by the educational psychologist." Statutory support resulted for school entry and later in his Reception year, autism was diagnosed, following continuing problem behaviour in school and a CDC assessment.

With developing certainty and knowledge gained about their children, mothers sometimes described relief, especially where a child was diagnosed later. This was more the case with mothers, whose children attended mainstream school. Steph, whose daughter had learning difficulties identified, but not autism until around nine, commented, "I wasn't surprised that she had autism, but we felt her learning difficulties were more of a problem, the autism and all her routines were just Kelly! Obviously the autism was more noticeable as she got older and stood out more."

Sheila also commented on this sense of relief, which seemed to provide a liberating 'no blame' label and an opportunity to move forward. "To be honest I was quite relieved that Adrian had got diagnosed with something, so that I could probably help him. It wasn't me, it wasn't us as parents, it wasn't how we'd brought him up. Obviously once he'd got diagnosed we could move on and get some help. I still feel that having a diagnosis helps. I mean people say

you shouldn't label people, but if you don't use a label, then how are you going to get the assistance to deal with the problem?"

Carol extended the theme, saying:

> *When the psychologist told me it was autism, it was almost a relief ... It is very important, to have a diagnosis, you need to know. The only problem was that there was a lot of 'they will do this, they will do that,' 'these are the areas of difficulty' ... A lot of the literature was very negative and there weren't a lot of suggestions at the time about how to make every day life easier ... you need to know what it is, if your child is different and why, because a lot of the time, you get people just saying they are naughty.*

It seemed that for Carol, a lengthy period of searching for an explanation then helped with its acceptance. Positive strategies may not always result from labelling, though the confidence and control, which developed for Carol, may have helped her to deal with the judgemental, and inaccurate perceptions of others.

Shattered Expectations

Contact with professionals was usually the trigger for major changes in expectations on the part of mothers and relief was sometimes experienced when a diagnosis was made and this could be the starting point for new beginnings and hope. Professionals could also be encouraging, as Mary found at the CDC, when the mainstream support teacher, "Came up to me and said, you know, it's manageable, you can put things in place, its not the end of the world, but I wouldn't imagine you know that now." Searching for information helped Donna understand and begin to reconstruct their expectations: "It's helpful to have a diagnosis and know what James's condition is called, because then you can start to look for information about the condition and find out how best to help and understand your child more." Yet false hopes were also

created for or by Donna, "Once I got the diagnosis, I imagined all this help which never came, actually".

Expectations could be inaccurate and Donna described how professionals felt that her son would manage in mainstream school, whereas she felt guilty about wanting a special placement for him. "...Dr Jones suggested that with the right help ... they could prepare James for mainstream school. But having seen how he was around other children at playgroup, I just knew that he couldn't cope in a mainstream class." Indeed, it was necessary for James to move later from a moderate learning difficulties setting to a less developmentally challenging placement in a severe learning difficulties school.

Mothers generally commented that their expectations had been smashed and this was usually at around the time of diagnosis. Donna referred to her life, "Just completely being turned around" and said "I was depressed prior to the diagnosis, particularly in the mornings. My hopes and aspirations were smashed." Mary referred to "A massive shock. Your future is totally changed."

Louise brought out the wide-ranging and devastating family continuity implications for parents of having only children with autism and severe developmental delay:

> It's obviously not what we would have wanted for our children. We wanted better things for them. It's normal to us because it's all we've ever known with having both children with it. I suppose when you get married and you have children, you plan things for them and you think that they are going to leave home, get married, go to university, live a normal life and be independent. You know that they are not going to be able to achieve any of those things. They are always going to be dependent on you or somebody else ... Another angle, I mean ... there aren't going to be any more Hobsons (surname); we're not going to be grandparents.

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For Mary, professional expectations (and her own) were uncertain for Terry and she commented, "...the SENCo said it's because we don't know how to teach him and there are massive expectations in their job and they are just grasping it after four years. They were expected to teach Terry and integrate him as fully as possible into school and they've kept him twelve months behind his age group. The head teacher and SENCo now are planning for a tough time next year, because Terry is going into the year group that he dropped out of twelve months ago." A dual placement was being arranged for Terry, so that he spent time at his mainstream school and in special provision. During the course of the year, he in fact changed mainstream school at the parents' request, whilst his part-time special placement continued.

Sheila described positive expectations for her son Adrian, who was in year five, "Adrian is bright and they told me that he's got the potential for university. The mainstream support teacher suggested that he had this potential, if he carried on getting support and help. It's nice to know."

Two mothers of mainstream secondary school pupils, (Steph and Carol), described a lowering of expectations for their daughters in the later stages of their education. "She is slowly dropping down sets and is with people who don't want to achieve. I think now she has given up, sees and uses a lot of negative behaviour." Yet, Steph also recognised that the school were integrating Kelly into college courses that improved her IT skills. Carol felt that it was important not to expect too much, saying, "She is going to get some GCSEs, but what grades I am not sure. My expectations are low, she is year ten and she is aiming to get some GCSEs; she will achieve some with difficulty, but the school have been wonderful really."

Changing and Future Anxieties

Carol described the changing range of future concerns that confront parents, when the reality of the child's condition dawns: "After you find out, the reality hits you - how it's going to affect your child and you, how she affects other

people, what her future will be. At fifteen, is she going to be independent? What support will she need? It is a constant worry, which changes at different stages. When they are younger you worry about how they are going to be educated, what their learning skills are, are the teachers going to be understanding, are they going to be able to spend time in the classroom? ... I am now worrying about careers and the future for her as an adult."

For mothers of mainstream pupils, major areas of future concern were secondary school transfer, school leaving and the degree of independence that may be achieved. Even Sheila, to whom university had been mentioned as a possible future option for Adrian, said, "It seems that Adrian is never going to be independent, that I'm always going to be his shadow. Do you understand? He's always going to need prompting to do whatever he chooses in his life. Obviously, that would affect my husband's and my future. As I said, I don't want to dwell too much on that." She had previously commented:

> I try not to think about the future ... you can be overwhelmed by thoughts. Sometimes I find myself getting very upset about it, so I try not to go down that route. My biggest worry ... is secondary school. I'm going to visit three schools. It's a constant thing, it's not as though he could just go to his neighbourhood school ... I need to make sure that everything's in place for Adrian. There's no information that says this school does this and no-one says let me help you with this. Everything's such a battle, so it's all hard work. I'm not a negative person, so I just get on with it really.

The above illustrates how mothers are constantly trying to contain anxieties and take charge of situations, themes that will be expanded in later sections. Steph has other transition concerns about Kelly, "Post-sixteen is my big worry and we're trying to plan. We've got good links with the college and we're looking at adult classes. There are concerns about relationships, inappropriate behaviour and periods ... we haven't really planned as yet. We are never really sure whether she is happy or what she feels. It is hard to choose for her." Thus,

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Steph's problems are exacerbated by feelings of uncertainty about her daughter's feelings and anticipated response to situations. Students with autism may not express their own emotions well or easily recognise the emotions and efforts of others.

Anxieties about the future for mothers of special school students can be different, in that secondary school and college transition are less likely to be of concern. Dependency concerns are, of course, greater and there are also issues about physically managing a child, as they get older and bigger. For Louise, anxieties included: some local provision issues; care after the parents' death and managing the physical strength of her boys. Thus, "In the long-term, there's this shake up of special school provision and what will there be for Simon when he leaves? Will there be a College place? Also when we die what will be the long-term provision? Alan is getting stronger; can we cope in the future? Simon's got the strength of a man."

Mary's concerns were, "... leaving primary school for comprehensive school. Bullying, we know this can happen anywhere with new kids. In the long term when we pass away ... we think about this everyday, when we are gone but we don't want to think about it. The future - where will he live? Will he get better?" She thus described efforts to avoid intrusive thoughts about the care for their son after they had passed away.

SECTION 2: LIFE EFFECTS AND IMPACTS

Child as central focus

All pervasive constant battle

Missed opportunities

Managing the child and the child relationship

Family reactions and relationships:

Loss of friends

Peer group understanding and acceptance

Reactions to perceptions of others

Constant Battle

The 'constant battle' mentioned by several parents was described above, where Mary mentioned anxieties about the future and Louise's 'all pervasive' comments below: "If I'd have wanted to have gone to work, I wouldn't have been able to. You can't leave your kids with just anyone. I've got no parental support at all. Their behaviour over the years has been very difficult, very challenging and initially the challenges affect everything. They hit your marriage, your relationship, the friends you think you have, your whole life, you know. It affects where you go and what you do."

Steph pointed out: "The whole family know that we have to change, not Kelly and things are easier that way." Donna said "Your whole life revolves around James; everybody's life revolves around James in our house and keeping him happy. He has to come first because if he doesn't he lets you know about it". She has already mentioned bewilderment and isolation ("I didn't know where to turn") and how mental health difficulties develop and can easily lead to depression. "I found it frustrating and felt extremely isolated especially as James's dad was in denial, which is quite common in dads. So I felt totally isolated, desperate for help and I wanted somebody to say, 'ou're right, here's what we do and where we go from here ... They (professionals) should know that stress is placed on families with a child with autism.

Mary described the wearing lack of sleep resulting from Terry's active behaviour at night, "He was in a cot bed at 18 months; he defrosted freezers, emptied dry food out of the packets during the night, was up several times each night. It really got quite bad. I worked full time and it got us both down through lack of sleep."

Carol described the child as central focus, wide-ranging life restrictions and being the ever-present voice for the child:

It affects everyone around me, including my family. My dad still doesn't understand. I can only take her to certain functions, have certain people round... go to certain places with certain people ... everybody's different, especially with Linda, who looks perfectly normal, but isn't. I have to constantly get involved in every conversation, to put things right saying what they mean and what she means. I have been divorced once, so when I meet someone it is very difficult ... they have to understand Linda, because she is my first priority. I go into great depths explaining what Linda's about ... yet it is mothers that tolerate them more than anybody else.

She is on my mind twenty-four hours a day, at work I wait for phone calls ... work keeps me sane ... my employers know I need to go after I get a school phone call. I wonder if they understand and are coping with her ... She doesn't seem to feel it. When she has one of her outbursts ... she is big and very strong and I have back problems ... people don't understand, she looks very aggressive and they are shocked ... they misjudge the situation, make comments and get involved. I need them to leave it to me, because she has never hit me.

Linda is a constant focus for her mother and others hinder her. Like Louise, she finds the size of her child a burden. Also, like Steph, she saw her child as not feeling problems.

Louise illustrated the 'constant battle' with the school and the support systems for SEN:

... various difficulties along the way (with the school), but we sort them all out. I'm alarmed by increasing class sizes, as they need a quiet environment ... Alan gets distracted, overwhelmed ... Simon likes his own space.. I was horrified when I went into Alan's class ... he was in with some children with lots of other problems ... the class was full of paraphernalia they were using for these not very able children ... I felt

that he should be with children of his own ability. That teacher has left, but she was very short with me ... I sobbed my heart out and contacted the welfare officer that took us there initially and the head sorted it out."

Changing schools was difficult. There was a lot of hassle with them going to lower category schools. Every step has taken its toll and you have to fight for everything that you've got like the statements. The move from school Y to Z (moderate to severe learning difficulties) was supposed to be our choice, but they'd made their minds up. Also the move from mainstream to school Y, again they'd made their minds up and that's it. It's a foregone conclusion.

Sheila described battles about maintaining the same support staff for her son, which he had had since nursery, but school didn't like children to be reliant on one particular support assistant: "If it works it works why change it? We have that battle at every review ... they've realised she's really good and have kept her, because it provides structure for Adrian. He has another assistant ... having L (regular one) in the morning and someone else in the afternoon." Steph recalled review meetings, "where it's a constant battle about the hours of support."

Missed Opportunities

Donna, described how she kept the books for her husband's business, but gave this up and "James is at school full-time during the day and you get your jobs done to leave weekends free, as they are taken up with James." Family holidays were changed and flying abroad with James was just not possible. Mary also said "We don't go to places we know Terry won't like ... and will cause problems. We do go to different places and change the structure of the day, but we don't stay overnight anywhere really. Both Mary and her husband changed to jobs with less responsibility and shorter hours to suit Terry's care. Her husband worked in financial services but moved to adult care provision for people with autism on a lower income.

Sheila gave up full-time work, because of childminding difficulties, but received some support from her mother and worked part-time at that stage. After her mother died, she gave up work and tried several times to do a college course and was attempting an NVQ in childcare and education, because she wanted to work with children with autism.

Carol's husband stayed at home to look after Linda, whilst she went out to work. Yet, she still saw herself as 'in charge': "When I got home, I used to take over with the children."

Managing the Child and the Child Relationship

The themes of 'all pervasive constant battle' have provided conceptualisations of the extreme demands imposed by a child with autism. Donna provided examples of the complications and adaptations in everyday situations; for example, arranging appointments with the dentist or doctor.

> *James won't go into the doctor's surgery. I take a different route, when I go down to the shops so that we don't have to go near it. I've tried giving chocolate to the receptionist for him, but he just clings to the door. The doctor faxes a prescription to the chemist and I give James' symptoms over the phone ... we have to have strawberry or banana-flavoured medicine ... I'm on tenterhooks, whenever we go out in case he breaks a bone. I dread him getting toothache, because I can't get him to a dentist's or near people with white coats ... I get him to clean his teeth well and hope for the best ... putting him to sleep will be needed. I have to cut James' hair, as I can't get him to the hairdressers. You have to adapt your life around James.*

Inherent unpredictability, lack of response to danger or correction and extreme behaviour concerns were other difficulties. Mary explained: "He stood on windowsills, dived over the chairs - it was just outrageous. He was completely uncontrollable and discipline ... you couldn't discipline him ... he didn't feel it if

you smacked his hand. He's now just coming into our room once or twice depending on whether I make him go back to bed. Washing is difficult, if there's a speck of water on a sock or T-shirt, he has to have a dry one. "

Sheila emphasised how tiredness took its toll both on her and her relationship with her husband and opportunities to achieve a break from this stress were not available. "... When we first got the diagnosis, it was very difficult marital-wise, because it was a constant battle; I was constantly tired, I couldn't do what I wanted with my life. I couldn't go to playgroups, couldn't access anything; I was just at home. I stopped going out or to friends. Life was very difficult ... when my husband came home from working nights, he was sleeping during the day. It was very lonely ... I used to spend a lot of time with my mum, but dad didn't cope with that. So it was a big struggle for us."

Before starting school, Sheila experienced demanding and aggressive behaviour, "Adrian was very hyperactive, had very uncontrollable behaviour and was quite aggressive. He used to bite and kick, was very disruptive, getting into everything ... in nursery class, he continued to have uncontrollable behaviour and never played with other children or settled." Such difficulties continue for Sheila, even though Adrian was ten years old, "He's started to thump me again, which he's not done for a long time ... it's a lot to do with frustration at school."

Steph described her daughter's obsessional copying of peer behaviour: "As well as aggression and anger especially as a younger child, she picked up behaviours easily, including violence, bad language and she also has attention problems. At school, copying behaviours have led to some peer difficulties ... she latches onto someone, who she thinks will support her, but wears them out. She uses them to sort things out for her and seems actually to be that person ... she gets clothes like them, pencil cases, hairstyles and makes our lives hard until she gets these things ... we have to wander round town for things. She doesn't say 'I want a coat like Cheryl', she just stomps round and gets more and more angry if she can't find things.

Steph highlighted ways in which mental well-being is affected, as Donna and Sheila, have also described:

I would get the children settled and just sit and cry. Kelly was exhausting. She hurt me physically and mentally and still does ... physically things haven't changed, although it is harder punches now. I am a lot stronger now, mentally and can accept so much more ... you have to accept so much of the negative behaviour, which for other people is hard. I can ignore a lot of Kelly's behaviour and find the worst parts follow after other people try to sort it or her out! If it is just Kelly and I, life can be smooth. If she is allowed to do what she wants, things are fine. I can prepare and cajole her to accept changes, but if it goes too far, nobody can change her and we have routines to get her away from others.

Carol, highlighted difficulties dealing with their child's lack of embarrassment or capacity to take on board the feelings of others, "Up to being ten she went to the toilet and left the door open, would be dropping her pants before she got there ... she didn't feel the embarrassment." Yet, Carol understood Linda and saw her apparent aggression as fear, "Its people's perception of Linda that's difficult ... She fluffs her feathers up like a scared animal. But she is a gentle giant."

Carol also adapts her requests:

If the door was open and I said 'Linda, close the door,' she wouldn't. If I said that the door was open, she would close it, making sure it was in her time. When she comes in, I say 'Linda you have left your shoes in the hall', she wouldn't do it straight away. I have to be patient, later she will pick her shoes up and put them away. But if I said to her 'Put your shoes away', she would panic, 'I haven't left them there, I haven't done this or that. Why are you getting on to me?'

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Family Reactions and Relationships

Child care difficulties resulted from extreme child management problems and Donna described how family adaptations were made, "... you are reluctant to leave James with anybody, which means that I had to take a lot of responsibility and share it with my husband and the older children. Claire (daughter) can baby-sit, but I always make sure he's in bed because of his set routines."

Partners

Similarly, Steph emphasised the need for family adaptation and talked about her partner, who despite difficulties and using a different approach, has taken on some responsibility for Kelly:

> *The whole family know that we have to change not Kelly and that things are easier that way. He (partner) takes her out ... I have been with Noel for a few years. He's had a lot of ups and downs. Kelly's slept next to me for years. She's unhappy about this change and her behaviour gets worse ... things are getting better, she calls Noel dad, not Trevor (her natural father). Kelly was three when Noel came. He's learning about autism, but can be adamant about behaviour and won't let go. It ends up in an explosion.*

Partners' coping with the stresses and strains of bringing up a child with autism has varied, with Louise and Mary's husbands being very involved and also working with adults with autism. Four of the marriages did not last and all mothers spoke of relationship stresses. Donna's husband was in denial regarding the nature of her son's difficulties, "Dad was initially depressed, whereas I'd gone through that prior to the diagnosis. He was down and it took time to sink in, but he's been supportive since. But it affects your relationship, constantly thinking about James, especially if he's not happy. Your whole life revolves around James and helping him".

Louise commented on the support and strength of her husband: "I couldn't have managed without him, I really couldn't; he's very strong, very supportive. We've been through a lot together ... if he's not at work, he's helping coping with the kids."

Steph recalled the strains leading to her separation and her husband's initial lack of acceptance of Kelly:

Kelly's dad left when she was three. He couldn't bear her as she was. It was a very difficult time and I also needed support for her siblings. I needed time out but a child with autism takes your whole life... preparing for everything to keep life smooth, planning the week for Kelly with others fitting in ... Their dad recently came back into their lives after not seeing them for six years. He sees Kelly, but the others are not bothered. He sees her some Sunday afternoons and they go out together. She seems to want to go, I don't know whether she's happy or not. He rings up, they arrange it and she goes. Yesterday they put the Christmas decorations up. There are no major problems and he has a couple of hours with her. He'll ask her what she wants for tea and she's got a bit obsessive about Findus pancakes and this caused some difficulties. So there are little things like that.

Continuing from previous comments, Carol mentioned her divorce; "Not having time for oneself wasn't why we divorced, but Linda was a great strain on both of us. Now, when I meet someone ... they have to understand Linda, because she is my first priority. I go into great depths explaining, as I did with my current partner, what Linda's about ... My son doesn't go to his dad's quite as often as Linda. She goes every other weekend and on Monday and Friday night. At first the change was horrendous and she would ring me obsessively. The next morning I'd had about twenty missed phone calls ... it's a lot more settled now, she is accepting the change and we are moving on." Carol gained respite whilst Linda visited her father and both parties were committed to making the contact work, despite the difficulties.

Siblings

This section illustrates sibling experience as perceived by the mothers involved. Siblings were not present in all families interviewed with Adrian being an only child. Louise had two children with autism and severe learning difficulties, so she was unable to discuss sibling effects. Siblings are seen as supportive, though with variations.

Donna worried about how James affected his siblings and her handling of the situation. She valued their support and saw the stress on the whole family:

> *It has affected them and when they were young; Claire more than Colin. It's a mixture of embarrassment and protectiveness really. She didn't used to bring friends back to the house, because kids like to play pop music loud and James used to go to bed quite early ... I was thankful for that mostly, but she couldn't have many sleep-overs, because it was 'Keep it down, James is in bed now, don't wake him up'. She felt embarrassed about bringing her friends back. She's obviously changed since she's got older and she's great with James and very firm ... Colin isn't great with James, but he's great with me. He says, 'How are you mum, what sort of a day have you had? ... put your feet up, chill out, I'll make you a cup of tea.' Because of the hours his dad works, he's somebody I can offload to ... very supportive. He's not very good with James ... he always asks, when he comes in, 'What sort of day has James had?' If James has had a bad day, I've had a bad day. It has affected the children ... not too much I hope. I've tried to get it right and give them all time. Probably James has also been disadvantaged, without siblings around his age. Maybe if he'd had brothers and sisters his own age, he would socialise with other children; he's always found it easier mixing with adults.*

Mary brought out sibling related issues, including difference in attention received, protectiveness by siblings, reactions to peers and their perceptions of peers' siblings:

> He gets more attention than Melanie, not at the moment, but she feels it ... we talk in a different way to Terry. Hers is a different conversation, she participates, she's very intelligent, articulate and grown up. She doesn't always understand. If I ask her, say, can you just get Terry a drink, it's only something small but it's there.

> She's not particularly difficult; she's got a good understanding of how to handle him. She tries to boss him a bit. Mostly her friends are good ... and they accept Terry as he is. There are odd ones that make comments, but she sticks up for him. She tries to include him in whatever they're doing.

> She's got a few friends with brothers and sisters and she sees what they're doing and Terry's not doing. It brings it home again.

Steph brought out sibling issues relating to embarrassment, dislike of the autistic sibling, carrying the burden, lack of appropriate role model and the need for additional supervision of contact:

> David (18) detests Kelly, seeing her as a pain; he sometimes takes her to school if she refuses to go. He doesn't understand autism and just sees her as an embarrassment. There are difficulties in the holidays.

> Chloe's wonderful, she shares a room with Kelly and as a teenager, doesn't like it when her things are moved. Kelly can be nasty to Chloe, who takes over from me as mother. She has contact with other girls, whose siblings have similar difficulties. She'll go to university and she'll probably just stay away. She's had a hard life has Chloe.

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Chris, (Kelly's younger brother) has overtaken her in maturity. They do some things together and he tries, but they get angry. Their play doesn't last long - they play videos, but someone gets upset. They need an adult there. Kelly is a poor role model for Chris and at weekends, we split them up. The children feel it's better to let her be herself and giving in to her is easiest.

Carol described a very supportive relationship between Linda and her slightly younger brother, who showed dependence on her in primary school; so separate secondary schools were selected for them to develop their own identities.

She is very lucky; Mike is such a lovely character, laid back, calm, lets things wash over his head. He learnt from being little, not to respond if there was a problem. She has become more of an embarrassment to him, because she gets involved in things he does and he's embarrassed. Keeping their schools separate is important, so that he can have his own friends, without being attached to her. In primary school together, she did everything for him; remembered his bag, paid his dinner money, checked at break time that he had got things for the next lesson, completely mothered him and unbeknown to him. He didn't realise how much she did for him; at high school, he didn't pay his dinner money for two weeks, because he had never had to do it (chuckling). So she loves him to bits and would do anything for him.

Carol went on to describe the present complicated domestic situation, where she lived with her two children, her partner and his three children. As a result of friction between the two sets of children, they planned to separate so that the two groups of children were kept apart. Her partner's children would spend some of the week with their mother, which would enable them to be together for some of the time:

I am looking forward to being back on my own with my two children, because the other three children have been difficult with Linda. It's constant warfare at the moment. Linda often doesn't understand humour ... she takes it literally, gets angry and upsets them, then they want revenge ... they have cut hair off her doll, or drawn on her things. The young girl brings her friends round, and they make fun of her, because she acts younger than she is ... they get nasty verbally and get out of hand and it really upsets me.

I can't stand it and need to get Linda and Mike back together, because he has grown up with Linda and knows how to handle her ... she is so lucky to have a such a tolerant brother. She needs to be able to come in and have peace. If she wants to kick off, she can kick off and I will deal with it, without involving everyone else or without upsetting them and coming back at her.

His (partner's) humour is wasted, completely wasted, but he tries with her, but it is difficult when she is upsetting his children and for me, when his children are upsetting her. It puts a strain on the relationship. We are doing what we think is best for the children.

Grandparents and Wider Family

Reactions from grandparents were varied, though often understanding and acceptance were found difficult. Donna said, "Mum found it very hard and she kept saying things like, 'you know, he'll get better, there must be something they can do'. It's very hard to explain to her that, no actually he may improve but he'll never get better, he'll always be autistic. My mum, like me, worries about the long-term future for James and what will happen when I'm too old to look after him, it still upsets her".

Mary reported a lack of understanding from great grandparents, but positive support from grandparents. She said, "Grandparents (her own) don't understand, that generation, they're used to giving advice, but it's not always

practical because they don't understand Terry ... they haven't got the patience to deal with him. My husband's dad wants Terry to have money if anything happens to him. Nobody will need it as much as Terry ... Sometimes my mum and dad sympathise. They acknowledge the difficulties and try and give helpful ideas or advice. Not all of it's practical, because they've not tried it. Another parent with a child with autistic spectrum disorder, they don't look at you, as if you're from another planet. They know what you're talking about."

Louise obtained little support, acceptance and understanding from grandparents, which added to family isolation: "My dad is in his mid-70s and thinks that they are going to grow out of it. I've told him they're not going to be able to leave home; they're not going to be able to work. He's sort of said I don't know and I've said yes Popsy (which we call him), I do know. He tries to sweep it under the carpet; it's how it affects him. He doesn't accept that they need respite; he makes things very difficult for us. My mother is dead; she would have been more supportive. My father-in-law and mother-in-law are in the mid- to late-70s and can't help us either. They've accepted it, but only really latterly."

Steph described wider family acceptance problems regarding two cousins, who lived in Leeds and were on the autistic spectrum. She mentioned acceptance issues with her own parents, yet she received helpful support from her mother. Her own family had difficulties with acceptance: "My mother has her most holidays for a few days, but Kelly's opting not to go now and prefers to be at home. She likes the routine, doing what she wants. Our house is lovely when she's away and we prepare for her coming back after she's been having her own way. When we go out for meals, she has tantrums, if others get their food first, or the menu changes, or someone is at the table we used last time. Her grandparents accept her behaviours". Whilst Steph felt Kelly was best left without much correction, the right control balance seemed difficult to achieve, as there are family management consistency difficulties after visiting grandparents. Whilst this problem is common to many parents, the reaction of a child with autism to inconsistency is likely to be greater.

Sheila also received most valuable support from her mother, though the rest of her family were less accepting: "My mother was always a huge support when Adrian was little. She helped me tremendously, she was one of my support strengths, she was brilliant ... always there with advice, help and a very positive outlook on Adrian ... My dad suffered a little bit with his nerves, he's not as bad now, but found it extremely difficult to cope with Adrian. My brother still has absolutely no idea how to cope with him. He expects Adrian to go in his house, sit and behave. They have a cat and Adrian chases it. It's a very difficult (chuckling), as you can imagine, you've got to laugh haven't you. We have had a lot of difficulties at family gatherings, where we've gone along (chuckling). We've come in a last minute swoop and then gone off again." Sheila made light of the social difficulties facing the family and they adapted their visiting patterns and got Adrian to occupy himself with an absorbing electronic game.

Carol did not describe such support from her own mother, though talked of improved understanding over time. "For me it's been quite difficult, because in the early years I didn't have parents I could rely on, as they found Linda too difficult. My mum has similar traits to Linda and difficulties and I almost believe she suffers from similar difficulties. When they were together, things could be quite volatile. About five years ago, my mum started working with young adults with learning difficulties, which gave her greater understanding and now has a much better relationship with Linda, enjoying taking her out sometimes. She is someone that Linda and I can rely on."

Perceiving similar difficulties in family members was also mentioned by Carol: "My sister has got difficulties herself, although she won't admit it - socially she doesn't tend to get on with people. My brother has been a bit more understanding, but I don't see much of them. Family gatherings were too difficult and weren't worth the upset, so I tend to avoid them." This avoidance of family gatherings emerged as a general theme for mothers and encouraged use of other support networks and increased parent independence and control, as major themes to be developed later.

Peer Group Understanding and Acceptance

Sheila mentioned the helpfulness of familiarising her son's class group with his difficulties and needs. Steph also saw raising awareness as helpful and Kelly's sister had spoken to the class, "... making more people aware - teachers and peers. There are a lot of problems with peers. Chloe talked to Kelly's class when Kelly wasn't present and that was a major success. The pupils understood much more."

Peer group understanding and acceptance involved parent feelings about their child's integration or otherwise with peers and whether the child was feeling upset or left out. The dilemma facing mothers was that, they recognised their child's difference and need to be alone or quiet, but at the same time they regretted lack of acceptance and shared activities with peers. Mary commented: "Others not understanding him, though he wants to play. He likes to lead, but he doesn't understand the games. He's looking for interaction and approaches adults."

This question gave rise to more responses from mothers of mainstream pupils, as mothers of special school pupils seemed more accepting of separateness from peers, probably because of evident language and intellectual difficulties. Louise's concerns were around her children copying bad language from others at special school.

Sheila was aware of Adrian's social difference and was grateful that he had contact with her friend's son:

> *... a very quiet little boy and he seemed to have a friendship there. I think it's because he's so calm and quiet and Adrian tends to be the one who runs the show. He is very laid back and just lets Adrian get on with it. What he'll be like when he's 20, I don't know (chuckling). I'm just grateful he's there now ... Adrian came and it was like a whirlwind in the house and all the cupboards were emptied ... he decides to take over and it's his rules, his game ... we go and quiet settles again and I*

wonder why my friend rings me. I come away feeling really guilty, because even though she's my friend, it's unfair that Adrian has behaved how he has, you can't get away from that. You can deal with it when it's in your house, but when it's somewhere else it becomes difficult.

He's definitely different ... I notice them (the other boys) going like that (looking quizzically or lifting their eyebrows) or making some kind of comment about his behaviour ... They all think he's a bit ... I mean they deal with him but ... he's not invited for tea anywhere or to parties; he's never been invited back to a party. He used to have about fifteen people to his and we'd be lucky if we ever got an invitation back ... We used to find it funny, but now we don't find it funny.

Thus, despite humour and strategies like class discussions, peer group difficulties remained a source of anxiety, annoyance and guilt for Sheila. She was also concerned about secondary school transition and Adrian joining a new peer group in a non-catchment area, smaller secondary school.

Steph also raised peer group issues, particularly at secondary stage:

At school she's had problems and copied behaviours, giving rise to peer difficulties. The other children visit each other's houses, but Kelly doesn't. Her brothers and sisters go to other homes to get away from her and find her behaviour embarrassing. We try to explain and friends are beginning to understand, but they treat her as someone, who has more difficulties than autism and speak slowly to her.

... She has always had an obsession with twins, two of the same for everything. In the end we just get two of things to keep the peace. She loves identical twins and can often be found in town looking at some. She stares. She has all the twins' videos and watches them over and over again, saying the text with the video.

... She seems to actually be that person ... and makes our lives hard until she can get these things. Her behaviour is awful, but now we have started to understand and wander round and round town for things ... Her behaviour is always inappropriate ... her swearing is obviously learnt at school as we don't tend to swear at home and my other children don't swear in front of me. Kelly swears a lot, particularly in public places when she is angry.

... Kelly wants to try things like all girls, but can't understand a lot of the issues. She attempted to use make up. When she came down she looked like a clown, she had very blue eyelids and very red, large lips. It took a lot of calm talking to get her to wash some off and then we spent weeks going through how to apply it. Then she decided not to wear it! Her routines come and go, like at one time she wouldn't leave the house until her hair was in a ponytail and every strand of hair was neat. This could take hours and often we were late for school. Now she won't wear it up and hates people touching her hair.

... At one time Kelly managed the school bus in a morning, but now she will not travel by bus at all ... she was choosing one particular seat and only wanting that one. Peers soon found out and found it fun not to let her sit there. Chloe (her sister) would travel with her, but she soon got too hard to control. I now have to take Kelly to school every day.

Steph's support for her daughter extended to voluntarily running an adolescent support group, for Kelly and others with Asperger Syndrome.

Carol also talked about peer group embarrassment and how Linda mixed with and looked after children with difficulties, perhaps where she could be in control more easily. "Her own age group is very difficult, they don't really want to know and get embarrassed by her. Unsurprisingly, the few friends Linda has, all have difficulties, like D in the wheelchair and F, who has difficulties and has a taxi to school. The other friend that she has had from the primary school, still

goes to school N, she sees her maybe two or three times a month. She is also a bit of a zany character, not at all your typical fourteen or fifteen year old."

Loss of Friends

Mothers seemed to describe a movement away from their previous friendship groups after the child with autism was born. Sometimes a close friendship emerged. Donna commented: "You get a new set of friends. I have got a couple of good friends, the girl friends that I had, I used to go out and have lunch with and we still get together ... because James is at school and that's fine. But the friends you used to invite round for a barbecue or an evening meal, that had to stop ... They just couldn't understand ... when they were arranging a dinner party and I couldn't get a babysitter, they said 'oh, have mine'. But it wasn't that straightforward with James, I can't just leave him with anybody and ... they thought we were making excuses and invitations get fewer."

Mary saw relationships as being very different, but also noted contradictions with others trying to understand: "We have colleagues at work, we both work in offices, and obviously we go out occasionally through work. We have got a small cluster of friends, and they do try and understand - one came earlier today; but ... until they've got a child with autism and actually lived with it. They're alright. Terry will be looking in cupboards, but their children don't. They do try."

Louise mentioned a close friend, friends at church and her husband, but referring to her children's difficulties, said "We don't really talk about it. I've got one friend that I go to and you say that you've got respite or that they are going out with the sessional worker or that we've got some play scheme days ... but we don't really go into detail ... Take one day at a time, don't try to cope with too much at once. I've got my faith, support from Church and friends from there. There's my husband."

Sheila described changes in friendships:

I had had a friend for years and years and it was fine when I had Adrian, because I had him first and then she had her own daughter. Then, she didn't want him playing with her daughter and people disappeared out of my life, because they didn't want Adrian to come to their house and be involved with them. I used to find that really upsetting ... He managed to acquire a close friend, a very quiet little boy we met at Stepping Stones (pre-school group), years ago, when I was probably at my lowest. I'm very good friends with his mum. She's been absolutely fantastic support to me, because she's remained in my life and she's always invited Adrian and me. I thought she'd never invite me again, because he went next door and kidnapped the goldfish bowl.

Carol described a special close friend for herself and her daughter, "She is like a second mum and is absolutely wonderful with her ... when Linda has a difficult time, she will spend an hour on the phone with her and Linda goes there quite often. She is very strict, very straight-forward ... Linda trusts her as she would never hurt her or embarrass her and is there for her whenever needed."

Reactions to Perceptions of Others

Mothers of children with autism can be faced with unhelpful and undermining comments from others about the management of their children; a tendency linked to the normal appearance of and expectations for a child with autism. All the mothers, apart from Steph, commented on this and Sheila raised it as a particular concern: "Always having to apologise for the behaviour of my son. Going somewhere, it's hard to put into words; it's just been very, very difficult bringing up Adrian. He is a demanding little boy and he has no understanding of danger or sense of how he should act socially. We used to go to play areas or whatever and had to deal with a lot of comments from parents, who ... just thought he was a naughty little boy. That has been one of the greatest difficulties."

These comments had become more noticeable, as social difference has become more marked with increased age and Sheila in a contradictory way talked of not reacting in supermarkets, yet described a nightmare: "It's more noticeable as they get older, because as toddlers they blend in ... going to a supermarket is a nightmare because he has to sit in a trolley, I have to give him a magazine and he can read four in a twenty-minute trip. All this time he's sat in the trolley. The number of looks and comments I get is amazing, but it's the only way that I can go to a supermarket ... It doesn't bother me, I'm used to it."

Carol described dealing with her own feelings about the reactions of others to her daughter, even though rationally she recognised that her child would be less aware of the response of others and therefore less upset by them:

> On holiday, a little bus picked you up from the apartment and dropped you off. Linda ... wanted to run for it and ran across a snack bar with lots of people in it, leaving chaos behind and knocking chairs over ... the bus driver found it funny to drive off and leave her stranded ... most people in the snack bar burst into fits of laughter. I couldn't stand that, I couldn't stand that; they were laughing at her ... my partner said they were only human and I said 'Yes and so am I and that's my daughter they are laughing at'. The good thing for Linda was that she didn't feel it. I feel everything for her. Every time she is laughed at or ridiculed ... that's when I feel it, but she doesn't. She is lucky really that way.

SECTION 3: RECONSTRUCTING SELF AND EXPECTATIONS

Control and self-reliance
Being organised, in control, self-reliant
Mother issues
Coping strategies
Being the voice for the child

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Reconstructing Self and Acceptance

The notion of 'acceptance' appeared to result through the interaction of experiences in the previously discussed domains of 'deconstructing expectations' and 'life impacts'. The phases in dealing with life's major difficulties, which include anger and denial, have been described in the experiences above and the pattern and breadth of themes has been rich and detailed. With these mothers, the notion of acceptance seems to go alongside heightened control. By taking charge, meaning and acceptance are developed; 'shattered expectations' and burdensome and constant 'life restrictions' are managed, with coping being achieved. Through being organised, planning, being in charge, developing coping strategies and taking the initiative acceptance and identity develop.

Mothers varied in their acceptance of autism on diagnosis. Mary has described her initial denial reactions and difficulties in accepting the autism label.

Being Organised and in Control

Donna pointed out that, "You have to become slightly autistic yourself in order to understand how James is going to feel or react to certain situations and to understand him better. Everything needs to be organised, even down to the direction that you drive to the supermarket. If we don't go to school in the same direction, there are major tantrums and he's kicking inside the car. If we don't go to the same supermarket, he's panicking. You let him know from the night before what's happening the following day. If he can't understand it verbally, I have to show him pictures of where we're going ... if we want to go anywhere new, it's hard. If we go to a new park we have to say, it's like the park where we go to feed the ducks ... you need to break the whole day down."

Similarly, Steph said, "You need to prepare for everything to keep your life smooth, you plan the week for Kelly and the others fit in." Sheila illustrated how she needed to work with the school to aid preparation and organisation, "Simple

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things like how they give meals, they have changed to a canteen system and Adrian has to have a yellow tray, a yellow cup, a yellow bowl. If they're not there, there are problems ... I asked if they could send a weekly menu home. We'd discuss it in the evening and I would highlight what he wanted and the next day they already knew this, so that it was not an issue."

Donna saw the diagnosis as a starting point for being in control and this was helped by researching the literature, "You start to look for information about the condition, how best to help your child and understand more through that information ... You had to find your own, searching the internet, reading books." Her description above of being organised seems part of being in control. Steph also saw the importance of researching, "Well you get knowledge yourself and then find out what's available. But the mainstream support teachers have been good and very informative."

Along similar lines, Sheila commented, "... finding information out, reading information and trying different strategies ... you learn to cope with your child, how to deal with behaviour; you know your child so well, that you can foresee any problems that may arise. You see something that's likely to trigger your child. You cope because of that.... you've just got to get on with it yourself really, unfortunately."

Carol saw information from professionals as helping understanding and providing strategies: "Once he (clinical psychologist), had given me the information, which I researched ... and tried to understand, I made others aware, who were dealing with Linda. It became easier dealing with her, because I understood where she was coming from. That never stops, you keep ... trying to understand why she does a certain thing and there's always a reason ... it's just finding it that's the problem. Often for Linda, it's not her actions that cause her problems, it's her responses to situations ... All the support I've had has been off my own back, up to the support group in Martom being set up, which was late in Linda's life. I had to search, initially when it was ADHD, I had to get on the computer and researched the condition."

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Whilst her daughter spent time at her father's, she emphasised that she remained in charge and her role as information provider for others: "... as a mum, I keep checking that they are dealing with her in the right manner. At the end of the day she is mine and I need to make sure that they are coping with her and that she is coping with them. But they are really quite good with her. They have asked for all the literature, so that they can read and understand it, which is good." She acknowledged the support of others yet saw herself as supporting them, "Other parents of children with ASD ... I have found that I have been more the supportive person to others, because of Linda being the older child."

Mary emphasised the importance of working with her husband in promoting their son's development and helping him do his best. Whether their hopes are realisable remains to be seen. "It's being together as far as Terry is concerned. We want him to be as good, independent, bright and as self-sufficient, as we can make him. Initially, you realise nobody is going to come along and wave a magic wand and if we don't do it nobody will. The longer we leave it, the harder job it will be ... it needs doing now. We need to push him, he needs to be persuaded and the longer we wait the harder it is going to be. I'm always keen to do whatever we need to do now. He's having a computer. I like to be organised, to get on with it - don't leave it until tomorrow, get on with it today. We don't want him off our hands, we just want him to be his own person and as good as he can be."

Coping Strategies

Steph described her coping mechanisms or strengths as follows: "Being organised and planning for everything ... you don't have to rely on others, you need to sort things out yourself ... to arrange time out for yourself, ensure this happens and look after yourself ... you have to accept so much of the negative behaviour, which I know for other people is sometimes hard." She is aware of the importance of being in control, making time for herself and ignoring or

accepting a lot of the child's behaviour, whilst also understanding the difficulties others have regarding not correcting behaviour.

On the other hand, Mary stressed the importance of boundaries and appears to have a different view to Steph's regarding accepting misbehaviour: 'He needs to know what is acceptable, to have boundaries, firmness and discipline. When I say firmness, he needs to know you mean it.'

Louise had obtained strength and support from her faith, some friends and her husband and needed to "Take one day at a time; don't try to cope with too much at one time."

Carol described gaining support from her job, talking to others, being strong, but also becoming upset and seeing the positives in her daughter:

I cry a lot. To be honest when she has had a difficult day, when she has gone off to bed, a glass of red wine is good (chuckling). Talking to people definitely helps and the job has been so important. People say 'how do you cope with a full time job (managing an Optician's)? It keeps me focused ... they give me a lot of respect and time off for Linda.

People say you need to be a strong character to cope with these children and I do cope with her. But, at times I just sit and cry. You need to do that and that's how I cope, I shed my tears and then I look for ways forward ... that are going to make her better and I always, always look at the good that she does ... Linda has raised money for charity, for children in need. She raised more than the school put together for a little girl in a wheelchair, who she takes out ...since being nine, she has toileted her, helped with injections, taken her ice-skating. She has a heart of gold; she will do anything for anybody. The little boy next door, he's two, she baths him, puts him to bed, reads him stories, takes him for walks and shopping.

... I keep focusing on the good things and her talents. I truly believe that she will become an independent person. I will always be there and she will not be very far from me, but she will be independent. She will work with either disabled or older people, who need her. If she is in control ... with the disabled or elderly that need her to do things for them, that's her niche. It's about finding where she fits best.

Carol has developed positive beliefs and hopes for the future, which seem crucial coping strategies. When we later discuss how Linda coped in secondary school provision, from which she was excluded, this positive hope is seen in perspective.

Being the Voice for the Child

Mothers have often been the voice for the child, taking the initiative with schools, particularly in the mainstream sector. Mothers' experiences of special school liaison will be considered later. Steph said, "It's fine now, but pushing has always helped, if you just accepted the situation it wouldn't be as good, but the school want to support her. I've always been known in school."

She also described her experience of communicating with schools, "It's been one-sided really; they don't communicate well. I've been told on numerous occasions that Kelly is just one of the special needs children at school (secondary). We don't find out anything that goes on there, Kelly doesn't pass on information."

Sheila described how she dealt with and came to terms with her son's difficulties and then helped to make changes in school, again with taking charge being part of acceptance:

Coming to terms with the fact that your child's got autism first and then learning to deal with the behaviour and coping the best way you can. I

have tried at school and we have a diary now. I've always been quite consistent on how I want things to go at school.

Adrian has problems with crowds, so we access the building differently. If there's something in their curriculum that might cause a problem, I suggest that they might do it another way. We do have a good relationship, because I go in and talk to them about... Adrian's education and they adapt things for him. That's how things should be really, that's the only way he can access mainstream education.

Sheila provided an interesting account of how she, with the mainstream support teacher, helped the school to make adaptations for her son, who had difficulties in swimming lessons.

He's come on really well with swimming, but his support assistant is a lady and he has a male teacher ... he could go in the changing room with Adrian, but he was teaching the other children, so Adrian had to go out of the pool early. His support assistant ran round to the front of the building to block the front of the changing rooms, so he couldn't escape and the male teacher's on the other side with all the children.

But Adrian needs things like cards and a clock, to make him understand he's got a certain amount of time to change and computer-reward time for dressing ... before we had this in place, he'd be in his own little world, get the hosepipe down, flood the showers and changing rooms and spray the place. He escaped out of the building when they last went swimming, so they ran after him. I know that's likely to happen, as you know what your child's likely to do. They were filling the sweet and crisp machine at the time, so he decided to help himself. I said things could have been much worse, he could have run out of the building naked, but the school get very serious about things, where I wouldn't ... someone was running after him, so he wasn't likely to get away. It's the kind of thing that I hear when I go into school on a daily basis.

Sheila also helpfully recognised that support practice varies, "I go up a lot and we have meetings, every term or half-termly, depending on need. All the staff dealing with Adrian get together and we have a chat about strategies to help him, although they're not being provided particularly well at the moment. But there you go (sigh) ... it's one of those years."

Carol highlighted the importance of regular contact with secondary school, giving information on changes or significant events at home, so they understand Linda and why particular behaviours have occurred. She ensures she poses this question, when school report difficulties: "We talk constantly, school and I just about every day, or at least twice a week ... I know everything that goes on in school and they probably know everything that goes on at home, because Linda talks very openly. This morning when they rang about Linda not going to the dinner hall, I said that Tom (partner) was moving out within the next two weeks. She knows this and it will play on her mind, because the situation is going to change, for the better I think. I don't care or get embarrassed by talking about home situations. They need to be able to answer the question why, if difficulties occur."

Carol illustrated this further with an account of the incident, which she referred to above, where Linda was refusing to go into the dinner hall, "Sometimes you have to remind them why Linda has done things, or responded in this way ... her year tutor said that she really had got to go in the hall. So I asked. 'But why is she so worried about going in the hall?' ... something has happened. So she said, 'The day before she tripped and dropped her dinner in the hall and was probably laughed at' ... That's the reason why she doesn't want to go into the hall. But ... Linda could kick off today at dinner time, get in a state and say 'I'm not going in that hall', making a stand, quite simply because she fears going in ... its panic, she can't go in there. I said to them: 'You will have to work with her ... in a quiet area ... for a few minutes before so she knows she is not going to drop things and be ridiculed and feel embarrassed ... She can't stand that

constant pressure of people saying 'Oh have you dropped your dinner today?' It's all the teasing."

SECTION 4: PROFESSIONAL PRACTICE, PROVISION QUALITY AND EQUALITY

The Listening Professional

Early support bewilderment

Parent group identification

Professional variability and boundaries

School identity and expectations

Service trust and improvement

Early Support Bewilderment

Parents described bewildering early experiences including, lack of knowledge and support, feelings of isolation and anxiety and a lack of involvement in the support processes. Donna described her experience of not knowing about support and feelings of guilt about receiving a special placement:

I knew nothing, I didn't even know about the Disability Living Allowance until James was six, I learnt that from another parent. I wasn't given information, when James was diagnosed at three years and was told to have another appointment ... The next appointment, was six months and from then was twelve months ... no support other than that. I didn't get information about services available. I went through the statementing process ... mainstream school - I skipped that bit. It made us feel ... we had to justify James's place in a special school. The educational psychologist watched him in his playgroup and they wrote reports. I know the places are limited at the schools. We were given a named officer to help us with enquiries, but she never visited us at home. She didn't know James; she didn't know our family at all. It was a case of

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everybody having to give their evidence, to secure a place for James at the special school. We were on tenterhooks for a few months.

Steph also described general lack of support and involvement with educational support, "Didn't have any, not a lot, I was given a leaflet ... We were well on the way (with statutory assessment) and we had no connection with the school about the process. They just said she was a slow learner and I don't remember any support from the first school she attended: "It would have been helpful if that school had been more aware about autism. Some earlier support may have helped with her autism and social difficulties. The only support really was through Dr Wilson, we kept seeing her."

Mary referred to early support: "None. In a word ... we left the hospital with the book ... We read it and waited, not knowing what would happen." She had previously described the early developmental changes in their son and how a number of professionals had not heard their concerns. Mary spoke in a detached way about school arrangements, as though she was not actively involved in them: "But they held him back a full school year (after nursery). We didn't really know and we weren't trained." She felt disempowered, but later described how she and her husband were about to complete a PECS training course. Mary became chair of the Martom autism support group (MASG) and her husband is also active in the organisation. One of the achievements of the group has been to prepare an information pack for parents of children with ASD.

Parent Group Identification

All parents highlighted the usefulness of parent support groups, but in different ways. Donna and Mary chaired their respective groups and Steph was a family support worker for the MAS, with Donna being understandably glowing in her praise of the group:

I ... met lots of other parents and that's helped a lot. You get a sense of belonging; feel a lot less isolated; you are not on your own, as there are other parents with more gruesome horror stories than you. It's been wonderful meeting the other parents ... I really enjoy being involved and hopefully helping to improve future support for other parents, so they don't have to go through the same. There's a place where you can get information, have a visit from a family support worker... I wish I'd met other parents a lot earlier.

It is helpful - to get you out of the feeling of helplessness. It is empowering for parents and helping others, makes me feel better. Why, because I am involved on the social side, with Joan (another parent). They (children) are not shocked ... they're not bothered in public about difficulties. They're beautiful children with no physical or outward signs of difficulty. You can pass on tips to others ... You can do social things and new things.

Mary talked about the how the MASG was set up. "We went to a mainstream support teacher's meeting and Parent Partnership was there. That's how the group was started and parents drifted in and Barbara was there. She works for a disability group and there were a couple of parents and we just got chatting ... she said you know that the children can get free nappies. You can actually get a supply so we approached our health visitor ... we didn't apply for DLA until one of the other parents said you are applying for that aren't you? We didn't think we'd be eligible because we both work ... it doesn't matter, it doesn't go on your earnings, its not for you, it's for Terry. It was really through the parents' group getting together that we found information and passed it on to other parents, who said that we could have done with this information, when we first got diagnosed. So, that's how we got to pass things on."

Mary saw the support as most helpful: "The parents ... understand when you're talking about a particular issue or a problem. They've been there - they've had the same experience."

Louise gave a different perspective, as she had benefited from such a group, but no longer saw it as necessary: "I used to go to the parents' support group and found that helpful, because you felt that you weren't alone. I got to know quite a few of the people that were at the school (attended by her boys) and other schools ... But I wouldn't want it now, not unless we were continuing with that particular group. I wouldn't want to join another one now, because you hear a lot of everybody's depressing stories and it makes you feel even worse (laughing). Sometimes you get speakers ... and they rave on about how brilliant the services are and what's available. You turn round and say, well live in the real word ... It tends to rile you up ... like I said before, the trips that they arrange in the summer were great for the kids."

For Steph, the family support worker, the group provided a helpful perspective, as well as both emotional support and acceptance: "In a way the group took me away from concerns about Kelly, as I was working with lots of other parents of children in mainstream with autism. The best part for me has been meeting other parents. ... It is so good to have people you can be honest with. Before I ... kept all my upset to myself, but now I have parents I can phone and friends, who work within autism. Before, I felt people would be shocked if they found out how hard life was, particularly when I was on my own ...the parent group has been the most helpful thing and having friends working with autism. They accept Kelly for who she is and don't make problems worse. We have to leave meals sometimes, quite often actually, but they understand and we usually return! ... it is helpful to be able to call them and off load. It is good to have people who understand. I don't think it is the advice, but someone who will listen and understands autism."

Both Steph and Sheila benefited from courses on behaviour management provided by health service professionals. Steph said: "We went on lots of behaviour courses that were set up through the church and school. When she (Kelly) was quite young, she needed the same approach at home and at school - consistency. There was nothing available on autism."

Sheila recognised the benefits of the course for her marriage and realised that there were currently more resources available for parents: "I am sure they helped us survive in our marriage and it couldn't have come at a better time for us ... That kind of support group and behaviour management is absolutely brilliant. I can't express how much a difference it made to us, just knowing you're not on your own, that you are not the only person with a child with difficulties and that you can access information. I went to the MAS the other day and there is so much information there. You can just go in and take the information. I wished that had been available when we were having the difficulties."

Carol recognised the importance and practical problems: "Support groups are imperative ... It's about bouncing ideas off others. Something works for one parent; you then think I might try that." More importantly the group provided a reminder about difference to help understanding and support, "It provides a constant reminder that your child is not being difficult, just to be awkward or naughty. They are doing it because they have this condition, which makes them behave in a certain way. What I have had to do now I don't attend is to keep getting the literature out and reminding myself, because you forget. I forget and I am a mum. Teachers forget that they are dealing with a childhood condition."

Professional Variability and Boundaries

Professional helpfulness appeared to vary where their boundaries were drawn and sometimes, perceived competence related to degree of autism specialisation. Donna also saw herself as the ultimate 'expert':

> *James doesn't see his doctor, because they're too busy, but they should understand that autistic children don't like going to the doctors and even the ones who go don't like being kept waiting for long. But, the more specialised people like Dr Wilson, you and M (teacher in charge at*

school) are great; they've been really helpful, supportive and listened. That's the main thing, listened and taken on board what I've said. Not just nodded and made the right noises and let it go in one ear and out of the other. They've listened and that's important, because I know James better than anybody and what's right for him. Sometimes, somebody on the outside suggests things and you give it a try. But, I know what will work with James, what fits and what doesn't.

Mary described how N (mainstream support teacher) had probably provided the most consistent support: "... she'll ring at nine o'clock at night - she's really been very good, if there's problems at school, if she's unhappy with something, she lets me know ... We've had ups and downs with school, this year we've had an excellent year ... His class teacher's been very good, looked at his condition, what it actually means and she's got a good understanding. She's looked at unlocking Terry, ways of integrating him into the class and she has achieved a lot ... Terry's done very well and enjoyed attending. The year before was a shocker, a disaster. Basically, Terry was the first child with autism in that school and they didn't know how to handle or approach him. We had various meetings, where we said do you want him at this school. It was that bad. We asked the same question five times in the same meeting and they actually said no."

Sheila also described teacher variability:

This year's not been a particularly good year for us so far. Adrian had a brilliant teacher last year, she was absolutely fantastic, but she's left the school ... She adapted things, made her own worksheets and went into his SATs finding out about extra time for him. She was amazing; she'd bring him magazines, give him time-out and used a lot of reward systems. She's deputy head now at another school ... the teacher he's got now is male; he's never had a male teacher before. He's a very good teacher, but wants Adrian to sit and listen and stay in the classroom. He's learning the hard way (chuckle) ... this year, we've come tumbling

back, his social skills are also a lot worse ... because of lack of understanding in a different teacher.

Sheila had tried many approaches including dietary trials, counselling for Adrian and a range of ADHD and autism medications: "Professionals have been quite helpful and I had access to what was available at the time, as far as support went."

Louise earlier described her experiences with two different consultants, one of whom she found dismissive, whilst the other had a more suitable manner. Experiences with professionals were "...Very varied. When Alan was in for his epilepsy, a casualty department doctor asked, 'Why have you got two children with autism? I replied that I'd drawn the short straw". She felt hurt and blamed by this unfortunate remark.

"Carla (community nurse) has been round a few times and she is always a breath of fresh air, cheers you up, if now't else. The social worker, um, er, well, eh ... I suppose that says it all. She's about to retire, she's not too bad and has improved with keeping, but she's not really my sort of person. A different social worker would probably be better. She's not approachable, without you really, really hassling her, she won't do anything for you ... she has tried to get rid of us, saying we're going to be passed over. She's not been helpful, only latterly. But we are going to get another one in December and hopefully, she'll be of more help, but I'm not holding my breath ... the individuals working with you should be on your side, working for you and not against you ... be more straightforward, like Carla. People like that are more approachable and have got more people skills."

Carol's experience of professionals was:

Mixed really ... there have been good and bad teachers, those coping and those not ... we are all human. We have different levels of tolerance. Different personalities cope in different ways. Some people

are funnier than others; sense of humour makes a difference. Those that genuinely take an interest, that want to make it work, have the biggest impact. One or two teachers in primary school have dealt with her in a very positive manner. One teacher in particular ... in her last year at school, he'd start each day afresh. If he'd had a bad day, that was yesterday and he would start by being very well prepared, making sure that she had everything she needed at her table. He'd make sure her back was to the window, so she wasn't looking out but in the classroom. When she came in, he always said, 'Have you been to the toilet yet this morning?' Then that was one avoidance tactic she couldn't use. 'Have you got your pencil Linda?' Then he'd usually crack a joke ... to set the tone for the morning. He said he'd only shouted at her twice during the year and I don't know how he managed that. He was very calm, patient and saw Linda as a challenge. He said his aim was to get her to complete her work, without demanding this. He'd use different tactics to cajole her ... try something one day and a different tactic the next. He was an excellent teacher, but they are very few and far between, I am afraid.

Carol had strong views about a protective support assistant, including devotion to the child and physical contact:

She had the personality and qualities Linda required. I observed her to understand, what she had that others didn't, because they were all trained the same way. She had that loving, caring attitude for Linda and would say, 'I am here for you Linda, nobody else'. She'd make sure Linda knew that if people upset her, she was always on her side. Linda would hold her hand and stroke it almost as a necessity. I have been through the official guidelines with teachers about touching children. I said I'd put it in writing that she can touch my child and my child can stroke her. Linda will play with her hair or will want to touch her. Linda needs contact and would always kiss her goodbye when she went home.

Autism and School Identity

Mothers commented on varied teacher understanding and acceptance of the needs of children with autism, but this also varied between schools. Mothers often suggested a need for more professional training. The degree to which a school addressed the needs of this group of students, seeing it as their responsibility was crucial for pupil success and parent satisfaction. Several of the accounts highlight how expectations about the inclusion of pupils with autism were part of the ethos of the school, with teacher competence and confidence often being derived from this general school acceptance. Individual teachers do make a difference to pupil success, particularly at primary school level, but there is an over-arching factor of whole school tolerance and willingness to meet needs. Such school differences are emphasised below.

Following Mary's repeated question about whether the school wanted Terry to remain there, a dual mainstream and special placement was arranged. However during the next school year the parents moved Terry to another nearby primary school, whilst continuing with the dual placement. Difficulties had been present with establishing support arrangements for Terry with reorganisation and building work contributing: "The classrooms are being demolished and refurbished and a new staff room built. We've objected to this, because too much is going off for Terry. He likes a quiet stable environment ... and the head won't discuss it. We actually put it in writing, asking for a discussion regarding the arrangements and she said it's not up for discussion. We got it agreed on the last day of the summer term that he will return to his present class, with his previous class teacher and support assistant. He will stay for lunch and come home at one o'clock."

Steph had described a lack of awareness of Kelly's needs in the first primary school she attended and they later changed school. At secondary school, awareness also seemed to be lacking: "Just as you feel the teachers are beginning to understand she moves up a year and the whole process starts again. So many times we have attended parents' evenings to find teachers do

not know about her difficulties, but complain about her communication skills and her lack of understanding. They are always surprised to hear her diagnosis, but then things fall into place. How can this happen when she has support workers with her in every lesson?" Kelly also had difficulties with homework, reading out in class, doing things on her own and understanding work.

Exclusionary School Experiences

Donna raised concerns about lack of structure and inconsistency in practice within James' special school autism provision, whilst recognising the skills of the teacher in charge of the overall provision. Her son was about to move to another special school with autism provision:

James does need a lot of structure in his day – he gets bored if he's not occupied. As I was the only parent that dropped off and picked up her child, I saw and learned a lot more of what went on in school. The provision is headed by M ... she's a wonderful teacher, but I didn't feel that about James' teacher - I doubted her teaching ability and every time I went into the classroom there was no structure at all.

They didn't seem to stick to any one programme ... try something for a week and if it didn't work it was scrapped and they'd move onto something else. They didn't stick with anything long enough for a child to get used to it and if there's one thing an autistic child doesn't like is change. Constantly moving his desk ... changing programmes, this week we're doing PECS, this week we're not doing PECS. This week we're doing TEACCH and then we're not doing TEACCH. If they got one programme in place and really stuck to it, then things probably would have worked out better for James. He was in a win-win situation there. If he behaved he got his rewards, if he misbehaved he got taken for a walk, because he was disrupting the rest of the class, so again he won. Or better still they phoned mum to come and pick him up and take him

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home. James saw what behaviour was working for him and they gave more and more slack, until they couldn't rein him back in. They totally lost control of the whole situation and James knew it. He's very, very manipulative. It wouldn't necessarily be the teacher's fault; she's doing a special outreach programme and doesn't spend a lot of time there. So the support assistants look after the children and they're not qualified to teach, nor are they as knowledgeable ... all the school was doing was babysitting James and he was getting nowhere.

Some of Donna's concerns may be seen as relating to resentment about her son's need to change schools and she may also not have had a full understanding of the methods used in the school. However, her views were strongly held and probably not without validity.

Carol and her daughter Linda experienced strong, overwhelming and exclusionary interactions with her first secondary school. She said:

N school was horrendous ...a bad school for Linda ... far too big and the buses arrived at once, which was chaotic. The teachers seemed constantly under pressure and were more interested in academic results than Linda's needs, in a nutshell. They gave up on her and my biggest plea was 'Please don't give up on her'. She did nearly two years there. I was banging my head against a brick wall, the more I talked to them, the more it seemed nobody was listening. 'We cannot have her in this school, we cannot meet her needs.' I asked why ... it wasn't her fault they were not meeting her needs.

There was no thinking about what could be done, just 'Well we can't meet them'. That was it. The academic results were more important than Linda's needs. That's sad, very sad ... She was excluded three times there.

Carol summed up the debate about ethos and the continuum of inclusive and exclusionary schools:

It depends on the (whole) school, the teachers and the LSAs. People make the difference. A school is a building, but it's the people that make the difference ... Support comes from the people, working with her or against her. You need to establish whether they are with her or not. If they are not, it's just a losing battle and you may as well give in.

Secondary school is a big, big move for kids, moving from one class in a small school with one teacher and one set of children. Then, when Linda moved there, she had, eleven different lessons with eleven different teachers, eleven sets of kids and nine different support assistants, because they were subject based. So she went from one class to another with no consistency ... horrendous. Nobody knew why she was kicking off in the next classroom, because there was no one person to know. She'd lock herself in the toilets, ring me screaming and crying, run away and avoid corridors with all those children moving about ... a bad move.

My advice to parents is that the area that you are in should not determine your child's high school; you should visit several and take things on board. N school was far too big, too many children and too much activity going on. You need a smaller school for these kids. School B (where Linda now attends), is a village school, so there are not lots of buses turning up. She went on a bus to school, in her first secondary school. She had her tie and hair cut and had her blazer slashed. It was an awful time ... as a parent you go through the guilt trip about not having paid enough attention to school choice. That needs to be looked at for these kids; advice does need to be given to parents about schools.

Whilst Carol may not have all the details correct about support levels and methods, there are vast differences in how schools cater for pupils with autism and probably SEN more broadly. That Carol, like any mother, can experience

guilt and self-blame about choice of school highlights the need for parents to be supported, when selecting the appropriate school. School identity is a choice major factor, so that mothers need to be asking themselves whether the school sees itself as dealing with a child like theirs.

Inclusive School Experiences

Many positive school experiences have been mentioned, including statutory support received and playground supervision. Statutory support from the LA functions separately from how a school itself views its commitment to autism and parent support. Sheila described how her son Adrian received statutory support at an early stage and was available when he entered nursery. Nevertheless, he was sent home on the first day because of difficulties encountered.

Sheila also described how the school made adaptations, often after a good deal of discussion and work on her part. Examples included: special swimming arrangements; menus taken home in advance to make food choices and the use of reward systems, such as computer time. Regular planning meetings were held and future release of Adrian's support assistant was planned to ease transition into secondary school.

Nurturing positive pupil attitudes towards her son were crucial: "He's managed to get on better and stay in mainstream school. The school have always been honest with the children in Adrian's class. His mainstream support teacher decided they would discuss with the children the fact that Adrian had Asperger Syndrome and that he would react in odd ways. They might think things were not right, but Adrian couldn't help it and this is how he was. So he's grown up with children, who know that he's going to act inappropriately and they just accept that Adrian is Adrian. That's been one of the most helpful things ... He's quite popular in school, although he doesn't have any friends coming home or playing out with him. He doesn't have any social interaction at all outside school, so it's all purely in school." Sheila displayed some acceptance that

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Adrian may not deal with and perhaps didn't need social contact outside school, as much as other pupils.

Carol contrasted the differences between two secondary schools, which her daughter had attended and their identification with Kelly. Her present school adopted inclusive and positive approaches:

> ... her school see her as a challenge and they want to succeed with her, whereas at school N didn't really want her there in the first place. She was a hindrance, a difficulty they could do without. Sad but true I think.

> At this school, they are doing everything. There are certain times when I have to go in, talk to people and remind them why she has done things ... the school have moved heaven and earth to keep Linda there. For example, one of Linda's strengths is drama where they have to use group situations for exams and the other children are worried that she might let them down or get them downgraded, because her abilities might not be up to theirs. The deputy rang the examining board to ask if she could do a set piece with the support assistant and be examined in that way, rather than with other children and they have accepted that. I thought that was absolutely brilliant; they were thinking of ways that Linda can pass her exams, without affecting other children. That's a school that cares. They've put together a timetable for her where she starts off in the Learning Support Unit first thing in the morning, spends a bit of time there and finishes the day there. So she has a start and finish base and she has an area for her. When she is not coping in class, she goes there. It's not like you're not coping, so we are going to isolate you ... for punishment.

> ... she is difficult. There is no getting away from it, managing Linda is probably the most difficult thing that those working with her face. If they succeed in managing her, then they can really pat themselves on the back. They have achieved great things if they... can deal with Linda,

they will be able to deal with anybody, as far as I am concerned ... So your expectations can't be that Linda will go to school all week without any problems, because that is just not going to happen. I always expect that there will be problems, on a day-to-day basis.

Other Special School Experiences

Special school provision experiences have been considered, such as absence of placement preference and consultation for Louise, who felt that a placement was a 'foregone conclusion'. She dealt with school issues in a resigned on-going way and staffing levels for her boys were a constant source of tension. After her younger son had not been able to enter reception class, he was offered an assessment placement and the parents hoped he might stay at that special school (moderate learning difficulties). Her initial feelings, on a visit to a special school, were of horror and protectiveness towards her child:

They said that he had got learning difficulties and should go to a special school - severe learning difficulties. I lived quite close to that school, so had heard some horror stories and I sort of said, over my dead body. We were understandably horrified again, because we thought that he might be able to stay in the special school with the assessment unit or go back into mainstream. Then we went to have a look at school Y (severe learning difficulties) and I was horrified. There were nursery children; it was a very hot day. They weren't particularly prepared for our visit and we went in the afternoon. Somebody showed us round and there were children with nappies hanging off. They were saturated and there was a child at the desk, foaming at the mouth. I came away and said no way, you're not taking my baby into that place, because he was four, I said 'you're not having him, you're not taking him there', and then we went to school Z. We got to see the head teacher at the school and although things weren't wonderful, they were better. They weren't putting him in the nursery class; they were putting him in the second class. Things weren't wonderful initially ... Mr Davies was an excellent headmaster.

It's gone down a bit since he left, because he really put his whole body and soul into it. It wasn't just a job; it was his life. He was very sincere.

Donna emphasised the separateness of special school and how contact is limited:

... parents don't pick up children and meet outside, like you would at a mainstream school. You usually stand outside the gate, chat and compare notes on children. You don't get that with a special school at all, you don't get to see the other parents; you don't have parents' evenings, so there is never an opportunity to meet other parents ... in special school there is no contact with other parents. The home-school communication at James' school is appalling. There is a home-school book, but in three years there have been twelve entries. When James is dropped off I get to know staff, but they don't let us know about the bad days - the serious incidents - injured staff - we should have been told. I have friends among the support assistants - they would be threatened for telling. Why this secrecy? In mainstream school you would hear about these things. We've got a right to know.

There's been no parents' evening ... His teacher came to my home once and called me into school to discuss strategies, but these weren't in place for long. The programme stopped after a particular support assistant left. Someone else took over, a new assistant, but James manipulated her - he sat on her knee. She couldn't do anything with him. The Head has been helpful and approachable and the teacher-in-charge of the unit, but they don't know about these things ... in autistic provision there should be more understanding of children's hearing sensitivities. So why scream at him? With his work he just needs structure. There have been difficulties with peers - one particular pupil - they were happy the first six months in the nursery and would play, now there's fights and these work as James gets to walk round (with staff) and enjoys this. He didn't like the screaming and she (pupil) did this to

upset him. It's not her fault. James needs to tolerate others. He hadn't siblings of his own age. He finds other children so unpredictable. He understands adults and remembers everything, for example, if he's been hurt. At school he does love praise, if he gets things right.

Donna expressed despairing disappointment about appropriateness and lack of interventions; she felt let down and hopeless about the James' prospects:

I haven't had any (interventions). I still insist that James needs a structured day and people to be consistent and firm ... if he's naughty, leave him until he calms down on his own. Don't take him away from that situation, because he's won again, he's laughing. This is what I've been trying to say all along where he was. That's what's annoyed me, it's not a case of James not coping, it's the school that's not coping - they need to make allowances and have the right expectations. I know there are financial restraints, but it makes me feel hopeless. Children with autism - they shouldn't be babysat. If they are not meeting National Curriculum targets, they may be overlooked even if they are bright. Instead of working on their strengths, they are left behind and seen as a lost cause - it gets to me it really does. They've got a lot to offer. It shouldn't be Day Centres after school; they are capable of more.

Inclusive Professionals

With professionals not employed directly by schools, many received positive comments. In the early years, SALTs have been helpful, around diagnosis. Louise, in particular found this and the approachable community nurse cheered her up ('if nowt else'), whilst the specialist consultant was described as compassionate and down to earth. Steph was also positive about this consultant; "Dr Wilson has always been in contact and at the end of the phone for parents. She'll always ring you back about things that you contact her about. She always tries to attend reviews to get the right support, which is not always easy. She seems to understand every type of the spectrum and has

always made me feel as though she is the only other person except me, who understands Kelly's needs and autism."

The mainstream support teachers were highly valued by parents and were seen as the main support for their children. Sometimes they challenged schools and would work as change agents with parents. Mary described this and Sheila was also supported at meetings: "She's really been very good if there's problems at school, if she's unhappy with something she lets me know." Carol glowingly appreciated the head of this service, "... R has been an absolute tower of strength ... like opening a door ... I've moved on to other support and meetings."

Support assistants were valued, though dilemmas exist about when staff changes should be made and continuity has been a source of conflict with some schools. The degree to which emotional closeness, single pupil support and physical contact is allowed is also open to debate because of fears about possible staff abuse allegations. Educational psychologists were mentioned for early assessment contributions, though Steph mentioned how the educational psychologist acted as a change agent for her daughter by encouraging school change. Several parents positively mentioned one member of the Parent Partnership service, particularly where conflict had occurred. This officer also assisted with setting up the autism support group.

Other supportive professionals or interventions included counselling for a pupil or parent, help from the family support worker and respite. Louise valued recent increases in respite, sessional worker help and increased school holiday support. Several mothers commented on the need for more respite. Sheila had tried several medical and psychological interventions and wanted to try new approaches: "I love to be challenged, someone to give me direction. We're going to do this or achieve that. Perhaps try something other than drugs and diet, maybe some psychological approach ..." Whilst a professional challenge was apparent, support was not offered.

Service Trust and Improvement

Mothers had commented on provision issues, such as lack of early support, system clarity and provision awareness. Some mentioned changes made since their diagnosis experience and new support like the Early Bird programme and MAS information and support. There were concerns about the diagnosis process, lack of professional awareness and how parents were treated at the CDC.

Donna felt services generally:

> ... they *need to mesh better. Health, LEA and Social Services; numbers and data need to be common and shared ... At the CDC - you feel intimidated and it's a circuitous route. You need to be able to ask questions later, after you've had the time for things to sink in. You need something (provision) half way between special and mainstream. They are closing the remaining boarding provision, there should be other options, but they might be out of the authority. Sometimes children benefit from boarding, where both behaviour and learning difficulties put strains on families ... Situations can fall apart where people aren't coping. There's more diagnosis of children with ASD, but instead of opening more schools they are closing schools. There should be more schools with better facilities and speech therapy on site. Resourced provision in mainstream school is good. There should be more resourcing and more training opportunities for support assistants and teachers.*

Like professional variability and meshing with parents' own style, trust in services also related to particular individuals, though school ethos was also a factor. Louise said: "Transfer between schools could be handled differently. Maybe it's different for everyone ... Some people aren't suitable for us. They might not be suitable for some of the jobs that they are doing. When Simon

moved from School Y ... it was underhand. They need to be more sympathetic, think what parents are going through - how they feel. Some people are sympathetic and helpful but it's the same with special schools - they vary."

Mary also mentioned diagnosis preparation, availability of speech therapy in mainstream school, links between Child Health and the LEA and the need for a shared autism database.

Sheila was more positive about the diagnostic process, perhaps because her experience was more recent without the complication of special school placement and Adrian received support from starting school. She saw interagency links as "Quite good, especially after the three day assessment at the CDC ... quite a lot of support was put in place, such as mainstream support team and clinical psychologist referral. Lots of the things happened - really good - lots of support went into place ... Now there's a lot of links, the support teacher and the school are in contact and the psychotherapist sent in a useful report for the review. Its useful to have all the help and advice you can at review time." This latter comment reflected the 'constant battle' to maintain support levels.

Sheila felt services "... are being improved ... lots of things are in place now for children with ASD. I'd like to see more improvements for older pupils. They've improved things for younger children. There has been growth in autism numbers for those like Adrian, who are ten and upwards, more support and help could be there for transition periods, such as accessing groups for older children." She felt let down by discontinuation of therapeutic counselling for her son when the worker left.

Steph mentioned the need for awareness-raising and the helpful class session that Kelly's older sister gave. She described alternative types of mainstream provision: "Yes if there had been a unit in a mainstream school, Kelly would have achieved a lot more. She recently worked with staff at the provision in Sheffield. It was really good to see what she could do with the right support."

Steph saw a need for more befriending support, increased liaison between services and felt her family support worker role might encourage service liaison:

We have had no home support, no befriending service, but this would be good for her ... Nobody links, I wish they would. You have to repeat things over and over. Reviews are important and people discuss your daughter, but they don't know her.

My current role helps me gain trust through contact. Other parents have had bad times with professionals and services and find it hard to regain trust ... this job has given me a wider perspective, Kelly's not the only person with autism, I am working with lots of others. It's important not to talk generally about a child with autism, as they're all different. I hope in my new role and as part of MAS, we can encourage all agencies to work together to improve services in Martom.

Carol also mentioned greater diagnosis preparation, staff training and saw a need for befriending services to give parents a break: "There needs to be more finances available to improve services, more training is required to deal with children with these difficulties. With selecting people like support assistants, more care needs to be taken to find the right person. Teachers won't change, but the support assistant works more closely with the child. They need more training and need to be the right person ... more funding is needed ... Some (trust in services) yes, again it's individual people not services generally. There are some you trust to do a good job or get things done. There are others that you don't, but that's life in general really."

CHAPTER 6: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

INTRODUCTION

This chapter is concerned with the validity, implications and limitations of the research. To address these issues the chapter is subdivided into five sections as follows:

- Section 1. The extents to which the Interpretative Account and parent group process provide answers to the Research Questions. This section explores the extent to which the research questions were answered that the research sought to address, with reference to key points in the Literature Review chapter.

- Section 2. A schematic representation is provided, which links the main domains and themes described in the results or Interpretative Account section.

- Section 3. Methodological issues. This section reflects on the relative strengths and weaknesses of the chosen methodology. Specifically, it considers the suitability and limitations of the approaches described in the Methodology chapter.

- Section 4. Implications of the research for practice. This section considers how practice in the field of autism and parent support might develop in the context of current government policies.

- Section 5. Limitations of the study and directions for future research. This section identifies areas related to the topic of study that this research has not covered. It highlights new questions that arose during the course of the study. Directions for future research are proposed on the basis of these limitations.

SECTION 1: THE EXTENT TO WHICH THE RESULTS PROVIDE ANSWERS TO THE RESEARCH QUESTIONS

Whilst this chapter will be primarily concerned with the mothers' interviews carried out using IPA, I will also refer to the parent group process, incorporating critical and political elements. There is a need to make sense of the individual and joint experience of mothers, whilst also bearing in mind personal contextual, as well as broader social and political influences. I have considered myself to be in a most privileged position in this research with parents and hope that my work reflects the richness of personal and political data given to me, so that the reader is persuaded by both its interpretation and its critical implications. Implications for action are expected to arise from the interpretative study of experience, as well as the parent group process. The main research question posed in this study was 'how can parent experience of bringing up a child with autism inform professional practice and provision?' The main components of this question, which were described at the end of the Literature Review, and developed through the study are as follows:

1. How did mothers make sense of their experiences of bringing up a child with autism?
2. What were the effects and life-world impacts of these experiences on mothers and their families?
3. How did mothers achieve control and coping?
4. How do mothers' experiences inform professional practice and provision quality and equality?
   - What is the value added from parent feedback?
   - Is a LA able to hear and respond adaptively to this feedback?
   - To what extent do parent experiences reflect thoughtful parent professional relationships?

These questions correspond with the four master themes or domains emerging from the interpretative analysis of the individual interviews and will be discussed in the order established in the Interpretative Account, whilst acknowledging the

essential interaction between domains. This interaction is illuminated in the schematic model described in Section 2.

1 Making Sense of Experience - Deconstructing Self and Expectations

There was a major contrast between discussions carried out with the parent groups, particularly the MAS and the individual interviews; in the former there was little mention of personal feelings and experiences of bringing up the child in the home context. The parent group meetings' discourse was largely concerned with provision or what others were or were not doing, rather than with conversation around personal feelings about bringing up a child with autism. Again, this was in keeping with the previously mentioned findings of Charman and Clare (2004), the discussions about defended subjects (Hollway and Jefferson, 2000) and positive illusions (Taylor, 1997).

Yet individual mothers in a semi-structured interview situation, graphically described the intensity of personal feelings, so that they were bewildered, when their dreams and expectations were eradicated and were faced with a barrage of professionals, confusing systems, some lack of control of events, possible rejection by their friends, community and family, and an overwhelming feeling of failure and disappointment. Wall (2003) has described similar experiences and argued that the way parents are supported is crucial to their future, their child's future and the future of other family members. Positive reconstruction of experience or new meaning needs to emerge and appropriately informed professional understanding, support and beliefs are required.

A model of self is required to help us understand the way in which a mother reconstructs herself and her expectations, when faced with something she does not like or finds unacceptable. Whilst we may feel that there is an 'I' inside us that thinks, feels and acts, Buddhist philosophy helps us to see that the self is simply a collection of thoughts, feelings, perceptions and actions. Paul Broks (2003), a neuropsychologist, has explained how the brain's systems for social

cognition and action have assembled a 'self', which can be thought of as a device we employ to negotiate the social environment. Within this assembly of self there are ideas about who we are and who we want to be, which are linked to our survival desires. Our self contains many ideas about our three main aims, which are to be acceptable to ourselves and to others and to feel secure in the world in which we live. When a phenomenon like having a child with autism is present, then our notion of self is strongly challenged and there is a need to reconstruct our aims for self, which include our expectations. Such a concept of self is linked with identity and for Paul Broks (op cit.), cohesion is given to experience, by imbuing perceptions, thoughts and actions with an emotional hue. Thus, "feelings are generated which form the basis of our sense of identity creating the conditions for the ownership of thoughts and for agency in the control of actions. These perceptions, thoughts, wishes, beliefs, utterances and actions are *mine*. ... I feel, I think therefore I am." (page 100).

The component themes for this domain are listed below and highlight the need for parents to move towards certainty, though at the same time defences and illusions are maintained, so that timely, dovetailed and sensitive professional input needs to be planned.

    Bewilderment and loss
    Comparison with child's siblings and others
    Reaction to uncertainty
    Future anxieties
    Need for certainty
    Shattered and deconstructed expectations

Moving on from bewilderment to discuss comparison, mothers mostly had older siblings to consider their child's development against, though Adrian was an only child. Sheila, his mother, recalled how she became vividly faced with the extremes of his behaviour at playgroup. Louise, in some ways found it easier to cope with the issues associated with autism and development delay for her second child, as she had already gone through the experience. Yet, at the

same time, immense burdens were placed on the family and she greatly valued the support of her husband. Positive illusions were evident in terms of downward comparison (Taylor 1983), as she saw that others would be worse off where such support was not present ("that would be my worst nightmare").

Through early bewilderment, mothers were faced with uncertainty and ambiguity, such as the nature and degree of the disorder, the prognosis, educational needs, child capability expectations and potential, and the quality and availability of services. Both Donna and Mary described professional denial or uncertainty in paediatrician, family doctor and health visitor contacts, which they viewed as related to perceived professional anxiety. Also, the professional can reflect the stress within families, which can show itself in a number of stress-minimising defence strategies or coping methods. Dale (op cit.), described mechanisms such as detachment, avoidance, selective attention, inappropriate cheerfulness and false reassurance. Mothers described such strategies in the Interpretative Account.

Donna also described denial on her husband's part, which she saw as continuing and Mary mentioned family denial or illusion and saw school expectations for Alex as being negative – they didn't really want him.

For Donna, mental health issues arose through shattered expectations, self-blame and depression. She referred to her life, "Just completely being turned around" and said "I was depressed prior to the diagnosis, particularly in the mornings. My hopes and aspirations were smashed." She also described helpful aspects of diagnosis in providing certainty, but false hopes emerged regarding subsequent support. Louise brought out broader aspects of shattered expectations, when she described how there would be no family continuity for her and her husband. The implications of such realizations for self and identity are dramatic.

Concerns for the future were part of uncertainty and also represented ideas that gave rise to insecurity and were not acceptable to notions of self. Thus, Carol

talked of her anxieties about the future independence and care of her daughter, as well as coping with her considerable physical strength and size. Both Sheila and Mary had concerns about transition to secondary school for their sons, whilst leaving school gave rise to anxiety for both Carol and Steph. The time of transition has been well highlighted and Steph talked about how her daughter's achievements in secondary school were increasingly falling behind those of others, as she approached school leaving age.

Sheila had justifiable fears about the future of her relationship with her husband, because of the demands and restrictions brought about by her son. Mary and Louise expressed anxieties, no doubt also felt by others, about the care of their children after their death.

Certainty, Diagnosis and Locus of Control

Dilemmas exist around the implications and usefulness of a diagnosis. Mothers seemed to see diagnosis as useful in that it brought them closer to certainty and helped with self-perception, so that self-blame was reduced and difficulties were more easily externally attributed. The mother is helped to be more self-accepting and her view of herself in the eyes of others is enhanced, giving rise to a more secure self-perception. Donna improved in her emotional well-being and Sheila also described how resources for the support of Adrian were made available from school entry as a result of the diagnosis, which was required by the LA as one criterion for providing additional support. Carol also seemed to gain esteem and pride from the diagnosis after a lengthy search and also attributed caring, dedicated and skilled support to this improvement.

Billington (1996), in considering parent professional discourse concerning labelling, categorisation and resourcing, has noted the circularity of knowledge, in that professionals and parents see something helpful (provision) coming from diagnosis, as this provision is made dependent upon the categorisation. Dilemmas of regulation and resistance are present as psychology is seen to pathologise children by categorising them, so that opportunities and resources can subsequently be regulated.

Along similar lines, Oakley (op cit) saw labelling and diagnosis as disempowering for child, parents and teachers through external attribution of control, which removes the need for change. The diagnosis of autism was wanted for the provision it brought, but not for the stereotyped perceptions and constraints associated with the label.

Generally, mothers in my study (Carol, Steph, Donna, Mary and Sheila), however, described the need for a new beginning, which they perceived as stemming from the diagnosis, so that they were able to seek information about the condition and progress emotionally from this position of increased certainty. The belief in an external attribution can also be seen as a cognitively helpful positive illusion (Taylor 1983), especially in a local context where professionals and fellow parents appear to share the same illusions or beliefs.

2   Life Effects and Impacts – Child as Central Focus

In the autism field, authors such as Konstantareas (1991) have described long-lasting daily problems with unresponsiveness, challenging behaviour and long-term special needs.   Parents can experience tantrums and frustration-aggression, with associated social misunderstanding by others, as well as a possible tendency to keep away from social situations. Similarly, the themes for this domain emerged as follows:

All pervasive constant battle

Missed opportunities

Managing the child and the child relationship

Family reactions and relationships:

Loss of friends

Peer group understanding and acceptance

Reactions to perceptions of others

Louise graphically described the 'all-pervasive constant battle', where grandparent or baby-sitting support and employment were not possible, but extreme challenging behaviour and reduced social and family contacts were present. Sheila's concerns about following educational courses and gaining employment are also illustrative of this ever-present struggle, where opportunities are missed. Donna has talked of the way her mental health was affected and Carol mentioned whole family and social life restrictions arising from primary responsibility for twenty four hour supervision and care. Sheila emphasised how tiredness took its toll both on her and her relationship with her husband.

Mothers' state of 'constant battle' was also illustrated by how they interact with the school and the support systems for SEN. Louise, for example talked of her negative feelings about the stressful transfers between schools, for her boys and the way in which there had been little meaningful consultation with them as parents. Sheila described battles about maintaining constancy of support staff for her son and Steph recalled review meetings where a secondary school unhelpfully wished her daughter to have a different support assistant for every lesson.

Such views and battles can, of course, be seen as contrasting with the LA view, where a need to establish independence and increased child flexibility is emphasised. Oakley and Billington (op cit.s) may view such parental perceptions as linked to labelling and locus of control issues, though in reality a balance needs to be achieved between acceptance with understanding and developing change.

Further dilemmas existed with the extreme management demands imposed by a child with autism. Donna provided some interesting examples of the complications and necessary adaptations, which arise in everyday situations; for example, when arranging appointments with the dentist or the doctor and said "... you have to adapt your life around James." Similarly, Mary said, "You can't discipline him". At playgroup, Sheila experienced demanding and

aggressive behaviour, where all involved required both understanding and strategies for change.

The control dilemma, or the degree to which a parent accepts or ignores particular unwanted behaviour, as opposed to trying to change it, was illustrated by Steph, who saw Kelly as being fine if allowed to do what she wanted, though interference by well-intentioned, but perhaps more controlling partners or others could lead to difficulties. A difference in views about handling strategies between schools and mothers was evident; for example with Donna, who after James had moved to his second special school placement, was perceived by experienced staff, as over-protecting or spoiling her son and allowing him to rule the home and her. Such consequences could be a likely outcome of categorisation, labelling and external locus of control described by Billington and Oakley above. Indeed, Donna's strong critique of the management approaches used by the previous school, were perhaps defensive or positive illusions for her.

Further emotional difficulties can arise for the parent, resulting from the child's lack of embarrassment and awareness of the feelings of others, with Carol, for example, describing how Linda, up to the age of ten, did not close the toilet door and tended to take her pants down before she got there. Steph had also talked about how Kelly, at fifteen, still slept in her bed and became obsessed with particular peers, so that she "wore them out".

Broader family reactions also involved extensive adaptations and the partner may have seen family life as revolving around the child. The involvement of fathers seemed to vary, with the partners of Mary and Louise appearing to be actively and supportively involved in management. Four of the marital relationships did break down and Carol felt that the child was the "first priority" and also commented on the increased complexity of stepfamily relationships. More will be said about this matter, when we consider control as our next domain.

Sibling issues have been mentioned in the literature and the Interpretative Account described variability between siblings within families, so that strong caring and protective feelings could be present, alongside embarrassment about having friends round, in addition to relationship difficulties with the child with autism and negative sibling comparison with those of peers. For Linda there was strong dependence on her brother, whilst Kelly displayed dislike towards her sibling. Others, such as Dale (op cit.), have described sibling relationship issues and there is now more awareness of the support needs of siblings and families.

Just as with siblings, the focus on the child with autism, was also present for the wider family, with grandparents often showing a defensive lack of understanding, which sometimes could change over time. Understanding by peers was crucial for the child as isolation, rejection or bullying could occur, as illustrated by Kelly's experience on the school bus. Linda mixed with or looked after children with difficulties, perhaps so that she could establish control and esteem. Peer group understanding could be helped by talks from professionals or siblings, though issues about categorisation, labelling and possible over-protection can again be debated as the downside of understanding and acceptance. Adolescent autism group support was seen to be helpful by Steph.

Mothers also experienced loss of their own friends, though this could be perceived as linked to control and mastery (Taylor 1983), so that Carol talked positively of getting on with her life. Both Louise and Sheila referred to one close friend, whilst Donna, Steph and Mary were very involved with autism parent support groups. Donna and Sheila talked of people disappearing from their lives. Whilst perceptions of this loss was not always seen as negative, Intaglio and Doyle (1984) described stressful feelings of rejection and social isolation for families with a child with autism and the need to belong can lead to an inward focus on the core family, as illustrated by Louise. Where these inwardly focused aims are not shared, then partner relationship difficulties may result, as appears to have been the case for some of the mothers.

The public reactions of other adults to the management of their children highlighted the categorisation dilemma, perhaps requiring understanding, as opposed to the usual expectations arising from the normal appearance of the child with autism. All the parents, apart from Steph, commented on this public reaction difficulty, with Sheila being particularly concerned about having to apologise for the behaviour of her son, who had limited understanding of danger and how he should act socially. A redeeming feature for Carol was that Linda was not aware of negative social reaction, though she felt everything for her, no doubt reflecting Linda's perceived central focus for her mother.

3 Reconstructing Self – Self-reliance and Control

Being organised, in control, self-reliant

Mother issues

Coping strategies

Being the voice for the child

Dorothy Rowe (1991), a clinical psychologist, following Buddhist principles, has seen the notion of pride or an exaggerated sense of self-importance as underlying the negative feelings we experience when faced with life experiences, which are not acceptable to how we see ourselves, how we think others see us and how secure we feel in the world. Taylor (1983) described how we seek new meaning, control and self-esteem and the experiences of the mothers in the study have shown how these three elements of reconstructing self are interlinked. Essentially, through fighting a strongly controlled 'constant battle' with the child as central focus, a fierce independence can emerge, as the mothers' accounts have shown. Such reconstructions may be part of motherhood generally, but seem to provide an exaggerated or more extreme change in self or identity, so that there is a new or different interpretation of reality

The concept of 'acceptance', a term often used by professionals, seems in keeping with a deficit, loss or disability model, yet can be viewed as part of the

reconstruction process, which emphasises varied patterns of normally occurring defences or positive illusions, resulting from an attachment to a previous self or identity and lack of knowledge about a new way of being or self. Anger, blame and denial have all been described in the Interpretative Account, though the pattern and breadth of experience has been varied, rich and detailed. Clearly, this discussion develops Wall's (2003) position that practitioners should be prepared for parental resistance to acceptance, because of shock or not being ready. Mothers may have developed their own theories or attributions for the unacceptable phenomenon and these can include pregnancy, delivery and family relationship difficulties.

For mothers in the study, reconstructing self and acceptance go alongside heightened control; thus, by taking charge a new happier and more accepting self is developed, with 'shattered expectations', burdensome and constant 'life restrictions' being managed, so that self-reliance and coping is achieved. The reconstruction process involves being organised, planning, being in charge, developing coping strategies and taking the initiative. Donna pointed out that "You have to become slightly autistic yourself in order to ... understand him better". Reading the literature was often seen as a starting point for getting in charge. Following diagnosis, all the mothers spoke of a strong emphasis on organisation and control within daily life, often with a set of rules and procedures that governed the way the household was run. The 'cognitive adaptation' theory, described by Taylor (1983) does mesh with much of what has been described here, and forms part of the 'self reconstruction' model, so that phenomena and our experience of them depend on how we construct or look at them.

Carol emphasised her role as a mother, saying that she checked that others were dealing with Linda in the right manner ... "At the end of the day she is mine and I need to make sure that they are coping with her and that she is coping with them." On returning from work, she would "... take over with the children".

A contented and happy parent might, on the other hand, fight and struggle less and be more of a team player. Carol also emphasised that she saw herself as a strong character, seeing this as necessary for coping with Linda. Mothers also seemed to provide the 'ever-present voice of the child', in some ways explaining the child's uniqueness to others, so that following Donna Williams (op cit.), the child's thinking and feeling were better understood in school and appropriate learning could be achieved. Mothers appeared in many ways to be the expert for their child and tried to achieve some control in school, as Sheila illustrated: "I've always been quite consistent about how I want things to go at school". This desired control, of course, was not always achieved and less positive exclusionary provision examples will be considered later. What is important is how an empowered, acceptable and secure self developed for the mothers through acquiring new meaning, control and self-esteem. In line with Randall and Parker (op cit), parenting a child with complex needs becomes the primary means of meeting achievement needs for a reconstructed self. Taylor and Armor's (1996) notions of self-aggrandisement, unrealistic optimism and exaggerated sense of control seem to fit well with these newly acquired cognitive beliefs.

4   Professional practice and provision quality and equality

      Early support bewilderment

      Parent group identification

      Professional variability and boundaries

      School identity and expectations

      Service trust and improvement- the listening professional

Previous discussion of parental bewilderment in Deconstructing Self and Expectations, has highlighted parental uncertainty and lack of knowledge about support and provision. Provision dilemmas and uncertainties have been illustrated; for example, Donna had feelings of guilt about receiving a special placement, whilst for Mary the mainstream school did not feel competent to meet her son's needs, though she has resisted categorisation and has

maintained a dual placement. Professionals appeared to vary in the extent to which they were able to help and this related to feelings about personal and professional boundaries and levels of expertise, so that egalitarian provision was not always present. The mothers felt there needed to be recognition of them as 'expert', though the extent that this linked with the child being their central focus and the possible difficulties involved with detached child management approaches, should also be considered.

In some ways using IPA to provide the essence of experience and its meaning has appeared less directly relevant in this provision part of the analysis. Nevertheless, the method provides a structured approach to analysing the material provided by the mothers, but appears more like a template analysis, in that the themes described relate more to the interview questions. Naturally, in discussing these themes they will be linked to existing and new psychological dimensions or constructs.

Mary, Carol and Sheila described how mainstream support teachers had provided most useful support, sometimes with personal telephone contact regarding concerns and a willingness to challenge schools. Life in school seemed to be viewed as being up and down with teacher and support assistant variability and for Carol, perceived effectiveness meshed with her view of child caring, or indeed the child as central focus.

Experience with health professionals also varied. Louise experienced consultants positively and negatively, yet she liked her contact with a community nurse, who cheered her up and a helpful speech and language therapist, whilst a social worker was seen as hard to reach. Some key elements of mothers' experience with health professionals were discussed in Section 1 above, where certainty, diagnosis and locus of control were considered.

School identity and expectations
The extent to which a school identified with meeting the needs of a pupil with autism as an acceptable part of its aims, practice and feelings of security was a

crucial factor in pupil success and parent satisfaction. An over-arching factor of whole school tolerance and willingness to meet needs has been considered as highly significant for inclusion. Perhaps emphasising deficit, categorisation, labelling and locus of control, for Wall (2003), it was necessary, "for all staff who come in contact with the child to understand that he has an inherent developmental difference, which causes him to behave and respond in different ways to other pupils."

Mothers' experiences of teacher quality were varied and primary schools could display rejection, as Mary described for Terry. At secondary school, Carol and Steph experienced an absence of understanding accompanied by strong, overwhelming and exclusionary experiences. Steph described lack of teacher knowledge about Kelly and regular complaints about her communication skills and understanding difficulties. Referring to Linda, Carol said, "You need to establish whether they are with her or not. If they are not, it's just a losing battle and you may as well give in." Fortunately, her experiences were very different in her next school, where Linda was seen "... as a challenge and they want to succeed with her". Sheila's experiences were positive and inclusionary, comprising general adaptations, regular meetings and a willingness to generate peer support.

Special school experience also varied, with Donna describing a lack of structure, inconsistency in practice, poor parent liaison and low expectations. Louise was critical of the lack of sensitivity and consultation about moving her child to another special school placement and the rejecting and exclusionary feelings that arose.

Service Trust and Improvement
There was recognition of progress and developments, such as the Early Bird programme and the MAS information and support. Yet there were general concerns about the diagnosis process and parent preparation, lack of professional awareness and parent treatment at the CDC. Whilst, such a formal setting provides an experience that parents may defend against, for

professionals it is seen as removing illusions, so that the parents acquire certainty, adopt the label and hopefully begin the reconstruction process. Professionals as the messengers become the bearers of bad news (Dale op cit.) and can experience parental negativity. Nevertheless, there is a need to listen to parent views, which can run counter to conventional parent-professional power relations. Donna highlighted her feelings of intimidation at the CDC, the circuitous route and the need for questioning opportunities after a period of time, when information has been absorbed. On the other hand, Sheila saw interagency links as adequate, especially after receiving support following the CDC assessment.

Further general themes mentioned by parents, which were part of national and local parent group discourse included: the need for agencies to mesh themselves better through shared data systems and raising professional autism awareness. Other provision issues related to planned closure of a special school with autism provision, befriending, growth in number of pupils, focused help at transition stages, group support for older pupils and the need for resourced secondary school autism provision. Essentially, trust in services was seen to concern individual professionals rather than services generally.

Parent Support Groups: Power and Parent Professional Relationships

The parent group element of the study assisted with gathering multiple perspectives, through a broader local and critical context and helped to provide research and interview questions. Billington (2000a) has argued that such groups are provision improvement oriented and this was certainly found, though the two groups differed in their emphasis, in terms of support and action demands, with both groups taking a good deal of self-help initiative The capacity for control and change was evident and the service improvement summary described above from the individual interviews, obviously also contained this critical, action-planning element. In line with Habermas (op cit.) participants explained why their conditions were frustrating and suggested alternative actions. Indeed, much of the multi-agency working together agenda

from Every Child Matters (ECM) is foretold in these parent interviews and group meetings.

Having considered the main emphasis of parent groups as provision improvement, we can now focus on some additional questions, which centre on power and parent-professional relationships. Thus:

- What is the value added from parent feedback?
- Is a LA able to hear and respond adaptively to this feedback?
- To what extent do parent experiences reflect thoughtful parent professional relationships?

I will discuss the first two questions jointly in relation to the parent groups and later consider parent professional relationships. The general purpose of parent feedback is to provide professionals with improved understanding of child and family needs, as part of a process of gaining multiple perspectives through consumer feedback. For critical approaches, action planning is required, which arises from this understanding and to achieve this planning, the concerns raised from the initial group meetings were given to the AWG and the PPLG. From the two initial parent group meetings the main themes were: diagnosis; lack of system clarity; funding; statement and assessment ambiguities; training and support and general anger or frustration. The groups also emphasised the need for parents to be listened to more, variability in professional awareness and the need for more health visitor training (see Appendix 1b Parent Group Concerns).

The political nature of the MAS group was such that the group made specific proposals for the aims and outcomes for the planned PPLG, which were given to the AWG and raised again at the first PPLG meeting. However, these proposals met with some professional resistance and were not adopted. Further parent professional power skirmishing examples related to numbers of parents on the group and chairing of the group. During the first meeting when the proposed aims and outcomes were not adopted, parent voices insisted on

changing practice by having a parent MAS worker on the AWG. Reluctant agreement was achieved.

Following the initial parent suggested aims and the boundary and power issues discussion from the first meeting, the parents had prepared a typed list of questions for the second meeting, after consultation with their members in an attempt to gain more control for change and provision improvement.

Armstrong (op cit) had described resistance, forming behind the backs of dominant groups and such parent resistance was demonstrated through their meetings prior to group meetings. The political system or LA practice, framed resistance, so that voices were constructed by the existing local structures of power. Following discussion of these issues, the professional chair established a series of themes and invited speakers for future meetings, so as to provide structure and no doubt control through professional resistance. During the meeting concerned with funding and support monitoring, parent impotence, wasted energy, uncertainty and underdeveloped teamwork were illustrated by the following words: "I think there is a lot of misunderstanding. The LA thinks school should be doing it and vice-versa ... you're fighting between both aren't you?"

Health, mainstream autism support teachers, Parent Partnership and Social Services made inputs to the meetings to provide information for the parents to be fed back to their support groups. There was a negotiation of roles about input between parents and professionals, in line with Dale's negotiation model. At the same time, professionals were keen to sell the merits of their own service, so that rivalry issues remained. The professional aim for the meetings was to inform and help parent understanding of systems used and services available. Nevertheless, the language of power maintained a distance between parents and professionals, who continued to sit on separate sides of the table. Whilst the meetings met the manageable purposes envisaged by professionals, the ambitious longer-term and specific outcomes initially outlined by parents were not achieved. However, given the subsequent resignation of the MAS

chair and restructuring of that organisation, the group had made useful and realistic achievements at that stage.

Partnership and parent professional relationships

Dale (1996) saw the limitations of partnership as needing to be openly acknowledged, so that dissent is part of a negotiating approach bringing together diverse and discrepant viewpoints and reconciling them for joint decision-making. The background to dissent can lie in illusions and defences as they relate to beliefs about self and identity. The background of parent dissent, frustration and bewilderment relates to different disciplines and agencies, conflicting advice, duplication in services, confusing input to the family, as well as rivalry between colleagues. Again, competitive working, mutual blame and lack of knowledge about the values and priorities of other services can lie beneath the rhetoric of professional partnership with major negative impacts on parent professional partnership.

For Barton (1997) an inclusive professional would listen to unfamiliar voices, be open, empower all members and celebrate 'difference' in dignified ways.

Similarly, the moral values to which partnership aspires would include; truth, respect, care, compassion and love and these values would be expected to apply equally between professionals, as well as between parents and professionals. Such professional values would involve negotiation (Dale) and human thoughtfulness (Nixon). These values were not totally reflected in some aspects of practice in the PPLG and in some of the less positive examples of professional practice described in the interviews with mothers and parent groups.

Thoughtfulness examples included occasions where parents were kept informed of important issues through evening telephone calls, or a mother being taken aside at the busy CDC and given comforting, reassuring and honest words after a diagnosis shock. There were many instances of what Nixon saw as effective professionals reaching out to their public.

Nixon also highlighted professional judgement, where common sense guidelines were unclear and multiple interpretations possible. Such judgement was exemplified where professionals supported parents in challenging schools regarding good inclusive practice and helping parents, such as Donna, to see that circumstances require a change of placement, or helping Carol, to identify a situation, which she subsequently describes as one "where you may as well give in". Again thoughtful professional practice varied.

SECTION 2: A SCHEMATIC REPRESENTATION

The schematic representation attempts to combine interpretative and critical approaches, with both impacting on provision. Understanding and essence (interpretative) are seen to underlie action planning (critical) and all components of the representation interact. It is not possible to provide a theoretical model with interpretative small sample approaches and a visual summary of findings and approaches used is provided. Part 3 of the model acknowledges background considerations, such as individual personal history, illusions, defences and attributions, as being formative for interpretation and hence any subsequent action planning (Hollway and Jefferson and Taylor). Whilst the research did not primarily adopt the psychoanalytic and defended subject approach of Hollway, or the discourse methods of Burman and Billington, all contributed to a broader, mixed method analysis. Personal histories came out, albeit indirectly, through open-ended semi-structured interviewing and elements of discourse and action research approaches were developed through the parent group meetings. IPA was the primary approach, though by drawing on mixed and interacting approaches, a dialogue has been created between IPA and critical, discourse and action research methods.

Part 1 illustrates the main domains with their key themes and then provides linkage between domains and visual clarity about how experience was interpreted. Whilst all components interact in Part 1, this interaction is not seen to be necessarily totally symmetrical, neatly sequential or fully specified. All four domains interact with deconstruction developing ahead of reconstruction.

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What is important is that experience of life impacts and provision will influence deconstruction and reconstruction of self and the interaction is reciprocal and ongoing. Within this framework, there is no set or pre-determined pattern of interaction between components, with individual experience of mothers converging and diverging, rather than being general. In many ways experience was ordinary in that it resembled our reactions to more stressful events, such as bereavement and yet it was also individual and varied. Deconstruction and reconstruction are seen to be similar to analysis and synthesis in psychodynamic models, so that there is a breaking down and reconstitution of experience.

Part 2 of the schematic representation provides a critical dimension, considering provision conceptualisations and action planning. Part 3 illustrates the interaction of the interpretative domains, their key and component themes with critical background and provision elements. Part 4 visually summarises the overall representation of critical and interpretative approaches.

The discussion in Section 1 of this chapter has considered the study's interpretative findings in relation to the research questions, as well as issues arising from the parent groups. Here, the discussion is extended to cover some Background and Critical considerations, which bring an essential context, greater depth of understanding and complexity to the schematic representation.

Defensiveness

The concepts of defensiveness, illusions and locus of control, like all background factors described are key or over-arching for all themes described in the analysis. Mothers' expectations about their child's potential were initially linked to denial, an everyday mechanism for helping us deal with threats to our view of self, wishes and desires and feelings of security. Coping is enhanced by establishing a degree of cognitive distance from the immediacy of the child's demands, through Taylor's 'positive illusions'. The categorisation or labelling process assists mothers to achieve this distance, though writers such as Oakley following Selfe (2002) have described parental passivity with children

'growing down' (Law 1997), as a result of external locus of control, following external attributions of control. The sample of mothers was strongly focused on their child's autism and hence an external location of control was apparent with possible child management sequelae.

Hollway's defended subject analysis saw interviewees as investing in particular positions, so that they might not know why they experience events the way they do. Furthermore, they could be unconsciously motivated to disguise the meanings of their feelings and actions. Blaming professionals or provision, was particularly evident in the parent groups and Donna's provision perceptions could be understood in these terms.

In considering Taylor's (1983) analysis, recovery from a tragedy or loss does seem to rest on illusion, with defences being essential and functional in this recovery. New attitudes to life develop, with the changed priority of the child as the focus, so that life is reorganised. For Taylor, mastery is regained by seeing the cause of the tragic event in the past and is assisted by specific psychological techniques, such as positive thinking and meditation. In my study, mothers' cognitive control is gained by adopting understanding and beliefs about autism, influenced by local and national discourse through literature, parent groups or Internet searches. This control is manifested through highly planned organisation of life with the child as central focus. The maintenance of mothers' self-concept does seem to depend on the revision of their personal history, so that the present is seen as better than the past. New and fewer friends are acquired, though parent group support assists with maintaining a secure self.

This newly acquired cognitive functioning and behaviour can depend on illusion and provide a positive, detached view, whilst seeing phenomena clearly can be associated with depression and inactivity. Illusion, rather than being maladaptive, may be essential for adequate coping. For Taylor and others (2000), psychological beliefs such as optimism, personal control and sense of meaning can protect both mental and physical health from the negative effects

of traumatic events. Also, we are helped to understand self-aggrandisement, perhaps shown by Carol and unrealistic optimism (Mary). Similarly, exaggerated perceptions of control seemed present within the parent groups, which also seemed to see professionals as having exaggerated control, so that professionals spent time explaining their limitations or boundaries within the liaison group. All these processes seem to be associated with psychological adjustment and when beliefs are challenged, active efforts are made to restore or enhance them, which can result in professional discomfort. Parent political resistance can be understood in these terms.

Defences and cognitive control: stress, coping and resilience

The schematic representation described and the use of IPA has illuminated and extended the tentative stages model described in Dale (op cit.), where the stages of shock, denial, sadness, anger and anxiety are followed by adaptation and reorganisation. Again deconstruction, life impacts and reconstruction are essentially variable individual experiences, which change over time and have no fixed or certain consequences. Meaning was established through control, with an ever-present central focus on the child and a constant battle emerging.

The development of deconstruction and reconstruction of experience, expectations and self, emphasises cognitive control approaches, similar to the 'cognitive adaptation' of Taylor (1983). For the mothers involved, cognitive control does seem to be the most generally successful component of stress reduction, so that essentially the individual became able to think of the situation in different ways. Cognitive, practical and social elements are involved in the process of coping or developing resilience and these have been described, so as to include interlinking aspects of thinking, management strategy development and parent and professional support. Indeed, cognitive control and child focus are key themes, which enable a movement away from unfulfilled wishes towards new hopes and dreams. The Interpretative Account and the PPLG description are in line with Taylor and Armor's (1996) findings, whereby the three positive illusions of self-aggrandisement, unrealistic optimism

and exaggerated perceptions of control were reliably associated with psychological adjustment.

Critical approaches: discourse analysis and action research

Like the Background Considerations we have discussed, these Critical Approaches are also key or over-arching for all themes described in the analysis. The provision orientation of parent groups has enmeshed interpretative and discourse approaches and brought about some dialogue between the two, which Jonathan Smith (1996) has sought. Through its emphasis on essence, IPA can provide enhanced understanding of mothers' experience and assist professional understanding, so as to nurture the thoughtful and inclusive professional described by Barton and Nixon (op cit.s)

SCHEMATIC REPRESENTATION

1) Background Considerations

Individual personal history

Illusions, defences and attributions

Local and national autism discourse

2) Interpretative Themes and Interactions

The domains emerging from the analysis, with their super-ordinate themes were as follows:

Table 9: Domains and Super-ordinate themes

Domains	Super-ordinate Themes
Deconstructing Self and Expectations	Unfulfilled wishes and desires
Life Impacts and Restrictions	Child as central focus
Reconstructing Self and Expectations	Control and self-reliance
Professional Practice and Provision Quality and Equality	The listening professional

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The way in which the main domains interact is displayed below:

Figure 1: Thematic Interactions

Deconstructing ⟷ Self ⟷ Life Impacts

Reconstructing ⟷ ⟷ Professional Practice/
Provision
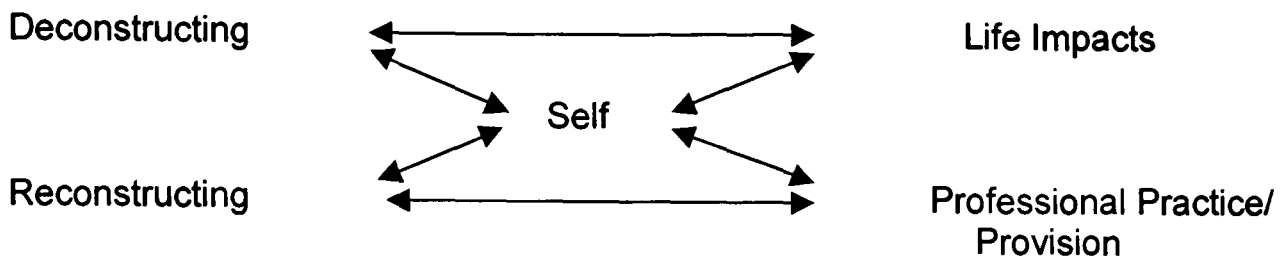
Figure 2: Schematic Representation of Interpretative Interactions

Deconstructing Self and Expectations
Unfulfilled Wishes
Bewilderment and loss
Comparison with child's siblings and others
Reaction to uncertainty
Future anxieties
Need for certainty
Shattered and deconstructed expectations

Life Impacts
Child as Central Focus
All pervasive constant battle
Missed opportunities
Managing the child and the child relationship
Family reactions and relationships:
Loss of friends
Peer group understanding and acceptance

Professional Practice/Provision
The Listening Professional
Early support bewilderment
Parent group identification
Professional variability and boundaries
School identity and expectations
Service trust and improvement

Reconstructing Self and Expectations
Control and Self-Reliance
Being organised, in control, self-reliant
Mother issues
Coping strategies
Being the voice for the child

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3) Critical Elements – Provision Conceptualisations and Action Planning

Discourse and Dilemmas

Categorisation

Locus of control

Child management- control and child focus

Power and Parent Groups

Provision Orientation

Self and Other provision orientation

Parent Professional Relationships

Action research and planning

Power skirmishing

Parent and professional resistance and dissent

Human thoughtfulness

Professional boundary variation and locus of control

4) Schematic Summary

Figure 3: Overall Interaction of Themes and Approaches

Critical, Discourse, Action Research and Planning
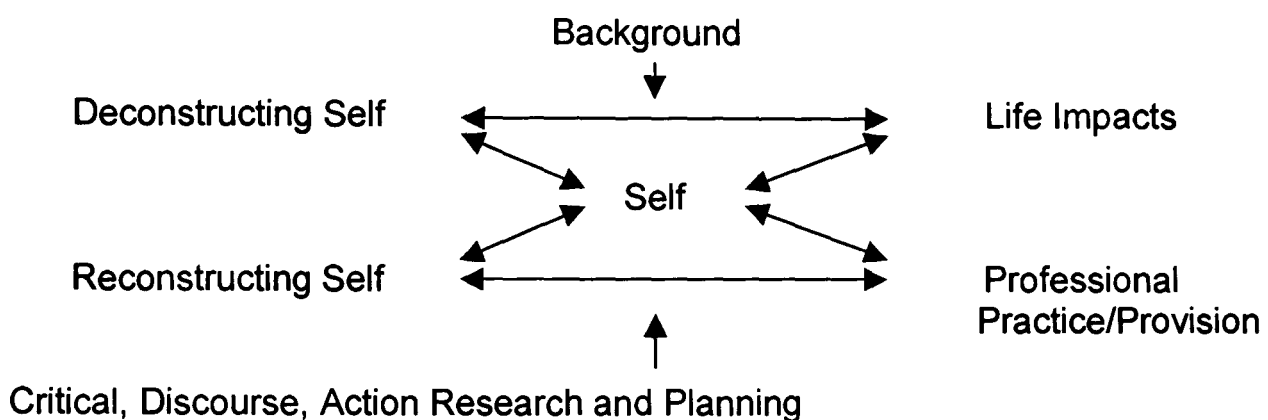
Thus, through making interpretative sense of self and experience the four master themes emerge and relate to both background and critical approaches. Whilst IPA does not seek explanatory causes from background, interpreted meaning is assisted by knowledge of the participant's context and background, which develops in the interview. Professional practice and provision issues

appear to link Interpretative and Critical approaches, so that action research can arise from interpretative method, particularly where the researcher is working in a LA context.

SECTION 3: METHODOLOGICAL ISSUES

Within this Section, I will firstly consider the position of IPA in the broader context of qualitative research including that of the 'defended subject' (Hollway and Jefferson op cit.). Further areas discussed include: motherhood; self and identity; researcher and sample issues; focus groups and the use of multi-methods; IPA's use in a broader ECM and multi-agency context and finally research quality issues.

Justifying Interpretative Enquiry: IPA in Context

Marks (op cit.) described 'the fantasy of unmediated direct knowledge', with experience and memory being constructed and reconstructed over time. Goodson and Sikes (2001) have talked of the lies and social positioning of participants, brought about through group discourse. With individuals, Hollway's approach, however, provides a context for research through understanding the life-world of participants. The schematic representation provided has built in background considerations to the interpretative process.

Discourse analysis also challenges IPA's social cognition paradigm; for example, Potter and Wetherell (1987) dispute the assumption that verbal reports reflect or can easily be related to underlying cognitions. What people say largely depends on their situation, with discourse analysis attempting to elucidate the interactive tasks being performed by verbal statements and how those tasks are accomplished. Participants role-play the interview respondent through drawing upon pre-existing discourses, so it is difficult to link responses to underlying cognitions.

Yet IPA emphasises a phenomenological concern with an individual's perception of an object or event and the symbolic interactionist view that the

meanings individuals ascribe to events are only obtained through a process of interpretation and social interaction. IPA is essentially concerned with understanding or making sense of what the particular respondent thinks or believes about the topic in question. Grounded theory, which is also interpretative, shares many features with IPA and these have been discussed in the Methodology section. The schematic representation provided describes how shared and essential understanding can take into account broader contextual factors from the interview as a whole and in my study from previous parent group discourse. The list of concerns from the parent groups, given to the LA provided common discourse exemplars, which influenced individual participants' interpretation of experience, though at the same time the researcher was aware of this influence in jointly making sense of that experience.

Defended Subjects and Psychoanalytic Approaches

Having discussed Taylor's positive illusions and Oakley's locus of control issues in the previous part of this Chapter, I now focus on the views of Hollway and Jefferson. Elements of their approach have been incorporated in the study and included encouraging participants to tell their story and following the principles of honesty, sympathy and respect with participants. Aspects of their interviewing principles were also adopted, with questions being open-ended, stories elicited and subjects' ordering and phrasing partly followed and interview questions being revisited when required. More life history details could have been taken initially, though much emerged naturally throughout the interview. Dale (op cit.) has acknowledged defensive strategies, such as detachment, avoidance, selective attention, and, inappropriate cheerfulness or humour. Defences, of course, apply equally to professionals, as to parents and no doubt also to researchers. Whilst Oakley (2004) has suggested that defences are not challenged and the functions of attributions are considered as leading to external locus of control, Taylor has seen the positive purpose of these illusions in enabling reframing of events. Control does appear to be a strong feature of mothers' experience in this study, probably stemming from categorisation.

IPA research focuses on perception or appearance of experiences and as such may not fully appreciate their cause or origin. Thus, understanding of phenomena may therefore be limited by a lack of awareness of the conditions, or past histories that gave rise to them, though meaning is interpreted. The schematic representation attempts to consider the broader context of enquiry and to see researcher interpretation through reflexivity, as being able to take into account such factors. IPA recognises that people attribute meaning to events, which then shape their experience of these events. Thus, a *relativist ontology* is adopted, so that the meanings people subscribe to events is the product of interactions between actors in a social world, with the reflexive researcher being part of this process of discovery, rather than being social constructionist. Along these lines, O'Connor and Hallam (op cit.) suggest that genuinely phenomenological research should not study people's cognitions, but should aim to understand their lived experience and feelings. Hopefully, the proposed schematic representation assists with this and provides added subtlety and complexity.

Validation of interpretation is also achieved through the co-construction process (Smith 1999a), where participant and researcher are both actively involved in the sense-making process. Thus, participants were engaged in the analysis of both draft interviews and the combined interpretative account. Summaries of the parent group meetings and the concerns arising were also checked out with the groups. The mothers on the PPLG produced the notes for these meetings.

Motherhood and Identity

The participant's story represents a part of their identity and psychological world and Smith (1999a), for example, has looked at changes in identity of mothers during pregnancy. The central theme for mothers has been their interpretation of reality, where control and focus on the child has affirmed their identity, which the Interpretative Account fully illustrates. Mothers sought to become the 'ever-present voice for the child', helping others to understand and working hard to obtain the best resources possible. They also saw themselves as the expert on the child, by providing this voice.

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Researcher and Sample Issues

The issue concerning parent perceptions of the researcher as a practising EP within the LA, warrants some discussion as it could be seen as a source of bias in more positivist studies. Whilst I knew three of the mothers through casework (Donna, Steph and Louise), I did not feel that this affected homogeneity of sample, as contact with other participants had been made through the parent group meetings. Again the advantage of being able to set the research in a real local context was a positive feature, enabled the PPLG to be established and subsequent parent professional liaison opportunities to be developed. Longer-term development possibilities were facilitated, with improved knowledge and relationships being shared by parents and professionals.

As a mature, experienced professional and having worked in the LA and ASD field for many years, there was probably a perception of me as being knowledgeable and perhaps also as having power. Such perceptions are likely to have encouraged mothers to relate their story at length and indeed all took the task very seriously. They expressed the desire to help others through their experience and were also no doubt pleased that their input was linked to a credible local university. All these characteristics and features are likely to have contributed positively towards the quality of the interview process and content.

Another related issue involved the researcher being male, with writers such as Anne Oakley (1986) discussing possible male dominance effects. Also Smith (1999a) in describing mothers' identity development during pregnancy had considered this factor and felt that such issues were a positive part of IPA, in that readers are aware of the gender of the researcher and make their interpretations on the basis of this knowledge. Gender effects are an acknowledged feature of interviewing and Hollway and Jefferson (op cit.) have described psychoanalytic experimenter effects and the unconscious dynamics of the research process, which were present in my study.

Same-sex interviewing, however, would not seem to be a sensible or equitable option. The semi-structured nature of the process, with open-ended questions does provide opportunities for the interviewee to remain in control of what is said and the co-construction of material also reduces any possible dominance effects. Given the varying but high degrees of cognitive control and mastery described in the participants, interviewer dominance, certainly did not appear to be an issue to the researcher. The adopted principles of doing research with parents, following Wolfendale (op cit.) also built in ethical safeguards.

Furthermore, through my dual role as researcher and LA employee, the research process was probably seen as having additional credibility as there was a perceived longer-term link between the research demands and desired outcomes, so that a wish to make a difference through improved practice was built in to the research process.

There are, of course, possible limitations of the researcher being employed by the LA involved, as they may be disposed positively or negatively towards their employer and perhaps consciously or unconsciously react defensively or encouragingly towards particular comments made by the interviewee. Participants may also feel guarded about the views they express if they perceive the interviewer as representing their employer. However, once more in qualitative psychology the positionality described by the researcher assists the reader to make their own judgements about the findings described.

Readers should be reminded that being able to provide an articulate account of experience was a selection criterion for the sample of mothers as described in the Research Process chapter. Again in IPA, precise interviewee selection criteria is not as crucial, as in more positivist studies, as variables are not controlled and broad generalisations about the data are not made (Smith 1995).

It is also possible that mothers of either mainstream or special school students could have been interviewed, though this would not have been inclusive. Also criticisms of IPA have been made because of suitability of accounts and so this

difficulty was avoided from the outset. Where sampling is concerned we are also not looking for homogeneity of experience, as in analysis we look for ways experience diverges and converges.

Focus Groups and Mixed Methods

Focus groups can be suited to exploring 'sensitive' topics, as the group context may facilitate personal disclosures, yet the provision rather than experience orientation of such groups has already been highlighted. The individual interviews did provide more personal and perhaps honest accounts, though group discourse effects have been acknowledged. The schematic representation described the need for individual, group, interpretative and critical perspectives.

Quality Issues

Attempts have been made to follow the qualitative research guidelines and principles mentioned in the Literature Review and Methodology chapters. These have included: criteria provided by Salmon (2003); Henwood and Pigeon (1992); guidelines from Jonathan Smith (1999b, 2003) and the research principles of Wolfendale (1999), Burman (1996), Billington (1996, 2002), Hollway and Jefferson (2002) and Clough and Nutbrown (2002). Positional, purposive, persuasive and political aims have been sought, with reader resonance being a further aspiration.

Validation of interpretation has been provided through a number of approaches and these included: the initial parent group meetings; feeding back individual interviews and the interpretative account to mothers; on-going tutor discussion and sharing the interpretative account with an EP colleague, who is undertaking Doctoral research, using IPA. It is, of course, for others to judge the extent to which such validation approaches and methodological quality criteria have been successfully applied. My main hope is that the experiences of the parents have been meaningfully and usefully interpreted.

A most useful article by Brocki and Wearden (2006) has provided a critical evaluation of IPA in health psychology, whereby 52 articles using this approach were reviewed. A key area was that of evaluating the analysis and the need to ensure that themes are actually represented in the transcripts. Notions of 'objective reality' are not relevant for such approaches because the centrality of researcher subjectivity means that traditional research evaluation criteria such as representative sample and appropriate statistical analyses are irrelevant (Touroni and Coyle, 2001 and Yardley 2000). Sampling in IPA is purposive not random and involves a degree of homogeneity. It is through 'grounding in examples' (Elliott et al, 1999 page 222) that criteria are provided for the reader to make his or her assessment of the interpretations made.

Brocki and Wearden (page 98) point out that 'as a qualitative research method, IPA is inevitably subjective as no two analysts working with the same data are likely to come up with an exact replication of the other's analysis.' Yardley (2000) argued that reliability may be an inappropriate criterion against which to measure qualitative research if the purpose of the research is to offer just one of many possible interpretations. For those who question the objectivity of knowledge, the use of 'inter-rater reliability' (Yardley 2000, page 218) measures merely produce an interpretation, agreed by two people rather than functioning as a check of objectivity. Validity checks in this context aim not to prescribe to 'the singular true account' (Osborn and Smith 1998, page 69), but to ensure the credibility of the final account. It is therefore from the viewpoint of validity and credibility that such checks are helpful.

Salmon (2003, page 26) has noted that 'results of psychological research reflect the researcher as much as the researched'. A statement of the researcher's positionality has been provided and is of assistance here. Thus, 'the very detail of the individual brings us closer to significant aspects of shared humanity' (Smith 2004, pages 42 – 43).

SECTION 4: IMPLICATIONS OF THE RESEARCH FOR PRACTICE

Research into the effects of autism on families and into services are relatively overlooked areas (Charman and Clare 2004) and the current study has shown the breadth and complexities involved in these overlapping fields. Clearly, further and more detailed work is required and again that research should be persuasive (meaningful), purposive (make a difference), positional, and political (provide context and change).

IPA: context and agency

Given that it is impossible to separate the individual and society, an interpretative emphasis can add to our understanding of the essence of experience and phenomena. Individual and joint accounts of experience provide agency for action and change for parents and professionals. IPA has a Heideggerian (1927) emphasis on lived and situated experience, rather than the discourse analytical cultural and social representation.

In gaining meaning, experience is mediated or filtered through layers of context, from which it cannot be separated, with a representational notion of being in a social cognition paradigm. Thus, the respondent's story can represent a part of their identity and psychological world (Smith 1995 op cit.) with homogeneity of experience being challenged.

Making a difference

The study has attempted to provide a balance between interpretative and critical approaches, so that it is descriptive and interpretative, yet, there has been a degree of critical interest, with some desire to make a difference. Thus the study has gone beyond subjective meaning to acquire political knowledge, which concerns the objective or local framework within which communication and social action have occurred. The extent to which the research was set up to make a difference must be questioned, as agreed longer term, national and local initiatives are required to develop action plans. An example might include CDC assessment and diagnostic procedures, which did not appear to be

parent-friendly, where an initial high-level Health Authority commitment to consider change would have been required from the outset. Gaining such a commitment would have added complications to the research process, yet this is a crucial element of an action research approach.

Furthermore, IPA does not lend itself to generalisation of findings because of the small numbers involved, though themes can be identified and considered with other groups. Whilst some vocal groups of parents may raise issues, issues such as labelling can have implications for services to be generally sensitive to the pros and cons of categorisation in areas such as ADHD, dyslexia, dyspraxia, cognitive or physical disability.

A further related issue concerns the researcher with fixed positionality within a LA structure and the extent to which change can follow. There are times when change can be more easily implemented following an external study, so that ownership of action plans can be adopted by an agreed management group. At the same time, researchers in LA settings do need to address real needs and give initial planning attention to the organisation of subsequent action. Cycles of planning, acting, observing and reflecting are central to any action research approach. The AWG in the present study needs to give further consideration to findings from the interpretative account and related discussion. The continued benefit or missed opportunity provided by the PPLG should be re-considered so that a periodic focus on parental concerns can be maintained. A presentation of the research findings has been provided in May 2007 for parents involved and professionals from the AWG with implications and professional practice recommendations being drawn out.

Developing awareness

Critical social science reveals to individuals how their beliefs and attitudes may be ideological illusions that help to preserve a social order, which is alien to their collective experience and needs. Such illusions could concern issues around categorisation and diagnosis, where the professional and parent cultures and resource allocation procedures can encourage an over-focus on

the child within the family, with possible child management implications. These factors impact on the position of fathers and the achievement of consistent approaches and harmonious marital relationships. Such considerations relate to the defended subject, attribution, locus of control and positive illusion discussions. Essentially, ways need to be found to consider the findings with professionals, parents and children.

Professional and EP Practice

The study has major implications for the way in which professionals and parents interact and whilst the parents' experiences investigated related to a range of professionals, as a practising EP, the findings may gravitate naturally towards EPs. The very nature of an open-ended interview, whereby a mother or parent tells their story is more likely to inform professionals and provision about real needs than many one-off or indeed extended assessments using observation, psychometric or developmental measures. It is through listening to the powerful words of parents and their honest descriptions of experiences and feelings that significant knowledge about humanity will develop and professionals are seen as reachable. A more valid, holistic and meaningful appreciation of child and family needs should be achieved and the more clearly these are expressed and understood, then the more easily they should be met in the context of a trusting and open parent-professional relationship.

So what should EPs make of this when asked to provide advice and support for the child? There will need to be a movement away from the set agenda of gathering developmental information towards an intention to listen more to experience and to understand the positive if illusory functions of interpretations. Through shared reflection on meaning, real support can be provided. The assessment will merge into a therapeutic intervention for both the pupil and the mother. Parents can be empowered to assist schools and others to understand and hence manage their child, but also to meet their own needs so that a growing up on the part of the child is encouraged.

The EP's knowledge of and concern for the emotional well being, feelings and happiness of the child and their parents and their skills with interpreting psychological meaning should form the basis of a trusting and effective parent-professional relationship. Support for EPs from more autism-experienced colleagues will be necessary, so that whole-service supporting specialism mechanisms are required, rather than experts narrowly wedded to a role. The focus should be on those children and families where circumstances are particularly challenging in a broad sense and usually this will involve issues around compliance.

Specific examples of what an EP might do following information gathered through an open-ended interview might involve the bringing together of school and home around issues such as the confusion experienced by Donna about the teaching methods used for her son and the way in which these appeared to change. The EP would in general help with giving voice to parental concern and provide support. Specific questions from the interview schedule might be built into an EP's information gathering and communicated to schools and providers with the agreement of the parent. Indeed the approach used in the study whereby professional interpretation is checked out with parents should in some cases be used before reports are sent to other agencies. Particular questions which might be generally useful for EPs would include information around the helpfulness of interventions, support and family reactions (Questions 5 to 15, for example, in Appendix 2c). The area of child management described in the next two sections will remain a key area for EP intervention and as Sheila described parent behaviour management support through a psychologist was highly valued by her and her husband.

Whilst ASD Outreach and Support services can manage to support the majority of such children and families, EPs need to continue to develop skills, which allow them to mesh with these services at consultative, intervention and support levels. Indeed, as Billington (2006) has argued, the EP can function in multi-disciplinary teams to bring together the emotional, social and learning

perspectives to provide support approaches which recognise the human and psychoanalytic aspects of coping and bringing up a child with extreme needs.

Parent Support, Training and Child Management

IPA enables tentative theoretical statements to be made with simple rather than generalised models being developed. An understanding of the essence of experience is required by professionals and indeed parents and this should be developed from research studies, such as the present one. The key super-ordinate themes from the interpretative research were unfulfilled wishes, the child as the central focus, control and self -reliance and the listening professional. There is a particular need for appropriately trained listening professionals to support and assist parents to deal with difficulties, particularly non-compliance and such training can draw on these research findings. A balance of understanding and change strategies are required and these need to be shared by the family and all agencies through a key worker or lead professional.

We need to be mindful of the gradually unfolding symptoms of autism, which dictate that professionals need to tread a delicate path when working with parents, so as to provide help, which is in keeping with their needs and conceptualisations at different stages. Furthermore, in line with Taylor (1983), professional awareness requires recognition that newly acquired cognitive functioning and behaviour can depend on illusion and provide a positive, detached view. Seeing issues clearly can be depressing. Practitioners should be prepared for parental resistance to acceptance for a number of reasons, which have been discussed here.

A detailed professional understanding of the parent readjustment process following unfulfilled wishes is needed so as to develop the listening professional. A graded, flexible, joined-up and patient support programme is implied, so that parents can adopt a more relaxed approach, where control is shared. Parent support groups should be encouraged, as well as parent representation on LA working groups. Knowledge and understanding can be

disseminated about parent experience and needs, as well as professional support procedures, limitations and priorities.

Child as central focus

A major theme of the study concerned how mothers reconstructed themselves and their expectations and appeared to have gained confidence and mastery. A role as expert was assumed, with a central focus on the child developing and this was possibly linked to labelling and external locus of control. Consistency in child management appeared hard to establish and was a 'constant battle', with mothers sometimes seeing others as lacking understanding and being harsh. Fathers, on occasions, were absent or lacked involvement and schools and other professionals were not always viewed as supportive.

A recent joint suicide in April 2006, of a mother and her autistic (Fragile X Syndrome), twelve year-old son, who leaped from the Humber Bridge, has illustrated the central child focus of the parent. Family members (Sunday Times May 21) have suggested that Alison Davies, the mother involved, was a troubled individual, who herself needed her son Ryan to survive so long. Ryan's father had left after about one year and Alison had been isolated from professional, family and social support. She had not been able to envisage how Ryan might be cared for later in life. Such a tragic story underlines the need for co-ordinated support, including parent group help and a need to address the high degree of child focus in such families. Parents need support to make time for themselves and all members of the family.

EPs, ECM and multi-agency working

The approach described above would assume an individualised support plan, using a 'holistic' view of the family and individual professionals, who operate within a co-ordinated multi-agency framework of service delivery. Multi-professional teams are being developed to overcome professional rivalry and the random service contact, which was dependent upon the knowledge or goodwill of individual professionals in making appropriate referrals, (Brimblecombe and Russell, 1988). The ways of meshing smaller, more

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specialised, perhaps centrally based autism services into a local or neighbourhood delivery model need to be established locally. Disability, SEN, common assessment framework (CAF) and lead professional procedures need to be brought together for the benefit of all children, including those with autism. Hopefully, professional understanding of parent experience will underlie such developments.

Such teams need to develop a negotiating climate and Bion (1961) suggested that working group members need to have some authority of their own, to hold an opinion and perhaps change it. Thus, as for Dale (1996) partnership between professionals seems to require the same type of negotiating model, as does partnership with parents.

Educational Psychology Services need to re-align themselves within such developing contexts and teams, with changing priorities, so that they work to create the future, involve and help others to learn and provide an emphasis on continuous improvement for the benefit of children. Work in local Children's or Community Centres is required, with regular referral and panel discussion and consultation opportunities, which emphasise outcomes for the child. EPs need to bring an awareness of the dangers of categorisation, pathologising and the deficit model, particularly where mental health and social emotional needs are concerned, including autism, in the context of developing CAF procedures. The EP needs to function from an interpretative base, as a scientific practitioner, assisting with action research in a reflexive and collaborative fashion.

Service improvement and parent feedback

In considering parent views and service improvement, with many government initiatives, there are dangers of an over-emphasis on centrally determined targets and control, which can cause us to miss important parts of the jig-saw puzzle. This tendency has been evidenced in recent Home Office difficulties concerning immigration policy, where an over-emphasis on failed asylum seeker targets has led to a de-emphasis on immigration related public safety risks. We need to listen to and understand parent voice and the interpreted

meaning, so that a balance between harder indicators or targets and more qualitative interpretative and critical approaches is achieved. We need to remember that marginalized and 'hard to reach' parents will always exist as a challenge for engagement in partnership work with professionals.

SECTION 5: LIMITATIONS OF THE STUDY AND DIRECTIONS FOR FUTURE RESEARCH

Use of IPA

Like all qualitative research, IPA has vulnerabilities, which have already been discussed and include participant memory and perception accuracy, which are subjective, so that events and experiences are recalled in a psychologically meaningful way. Knowledge is the presentation of events themselves to the experiencer, not how they actually were. Deceit can be problematic, but may be detected in longer interviews and is probably unlikely as phenomenological research is trying to find out what happened, rather than advancing a particular theory. The study made use of participants who were viewed as articulate and also met the selection criteria, so that other professionals anticipated helpful accounts.

A further drawback is the lack of total access, as the whole process is dependent on the researcher's subjectivity, especially with regard to transformations. Helpful and rigorous guidelines exist for such transformations and whilst the processes may not be easily checked, the outcomes can. Further positive features of the study included a complete research diary and dialogue with tutor colleagues and other researchers, which provided greater clarity and process information.

Whilst IPA was not used in the initial parent or focus groups, it is possible to use the method in a more structured way with such groups. The study did make use of joint accounts within an 'essentialist' or 'social cognition' framework. An essentialist approach, like IPA, assumes that individuals have their own ideas, opinions and understandings and that the researcher will

access these 'cognitions'. Co-participants in groups are seen to be likely to stimulate debate and disclosure, so as to produce elaborated accounts. Further research could usefully access such groups to provide an interpretative account, which would no doubt give greater recognition to political or provision dimensions.

Further use of IPA with other groups of parents or mothers with children with barriers other than autism might be considered, as the nature of the experiences described here would be likely to converge and diverge in ways to be discovered.

Limitations of critical, contextual, discourse and psychoanalytic approaches
The study made use of parent groups in order to ground the research in a local context and establish initial research and interview questions. An action research element developed in the study through the AWG and a PPLG was established after the elicitation of parent concerns from the initial groups together with professional consideration of these concerns. The nature of the discourse in the parent groups and PPLG strongly reflected power, categorisation and resistance issues and dilemmas and so elements of discourse approaches were involved in this part of the study. Also in making sense of experience contributions from the psychoanalytic concepts of defended subject, positive illusions and locus of control were considered. Whilst IPA does not seek causative influences, through focussing on lived experience, the combination of critical and interpretative methods has ensured dialogue and meshing between the approaches, as reflected in the theoretical schematic representation, where background or context is considered.

The limitations of the critical approaches are not something that as a lone researcher, I have time or space to discuss. However, what is important is that interpreting individual experience has added an essentialist dimension, which hopefully has made the research more persuasive, purposive and real; and helped the study to achieve its aims. The use of critical and psychoanalytic

approaches has been limited and future research could build these elements into the initial research plan more explicitly.

Inclusion of critical or action research elements from the outset, may have helped establish an initial agreement to implement findings, though some professional resistance would no doubt have accompanied such agreements. A critical social science involves criticism of all social conditions and is not afraid to conflict with the powers that be. As a researcher with positionality fixed within a LA structure, the extent to which a top-down critical social scientific research approach can be adopted is questionable from the viewpoint of organising action. LAs like parents and researchers are defended. However, critical research aims to increase understanding, so those involved can develop change, or generate resources for change and criticism. The LA EP researcher should be in a position to develop more meaningful bottom-up change.

The schematic representation has breadth and complexity, though there is a downside of inevitable theoretical and conceptual gaps where combination of approaches is involved. Hopefully, the advantages of breadth are that research makes a difference in context, is persuasive and this is aided by an essentialist basis in lived experience.

Families and fathers

Families and fathers have received less research attention than mothers and Seligman and Darling (1989) suggested that fathers might be less stressed, though it was uncertain whether their greater stoicism and difficulty in expressing and acknowledging painful emotions was involved. These authors described an escape-avoidance approach for fathers, similar to the findings of the previously mentioned study by Hastings et al (2006).

Diamond (2005) has explored the positive and negative impacts of raising a child with autism as well as the coping resources that make a difference for mothers (114) and fathers (76). The coping resources of interest were

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empowerment beliefs, self-efficacy beliefs, advocacy involvement, formal and informal social support systems and emotion and task-oriented coping styles. Such findings mesh with the reconstruction themes discussed in the present study. It was important that connecting families with formal support services required great thought and exploration so that mothers' support did not result in greater paternal distress or greater family stress (disruption, time or financial demands). The greater parenting self-efficacy beliefs were then the better parent and family outcomes became. Clinicians were to provide knowledge skills and strategies, but also maintain the belief that parents have the ability to deal with their child effectively and were the true experts.

The themes and understanding arising from my study provide additional backing for these findings and add to the implications for EPs and supporting professionals. Support arrangements for fathers need to be more equitable and professionals need to be mindful that the increased mastery achieved by mothers can come at a cost to themselves and the family.

Thus additional burdens fall on the mother and anger and resentment can develop in family members. Such an interpretation can follow from what the present study has described as mothers' central focus on the child. What is certain is that support is required to assist families address these issues and related consistent child management approaches. Such support should be based on an understanding of essential lived experience. IPA could well be used to gain a view of fathers' experience and indeed family groups could be interviewed together.

It would be of particular interest to consider the experiences of say five or six fathers using a similar approach to the present study. The ways in which experience converged and diverged within the group would be the main interpretative focus, though in terms of action research and making a difference, support needs in relation to life impacts and 'child as central focus' would be highly pertinent.

The present study did, of course, describe the mothers' experience of family reactions to bringing up a child with autism, though a more direct focus on fathers separately and indeed additionally with all immediate family members would be of value. The central control issue of some mothers might be more usefully considered without their presence, as dominance or being in charge or in control might impact on joint interviews.

Parent Support Groups

Parents need a clear and flexible range of support options, including a coordinating key worker for families. A range of parent support groups is required and the study's contact with local groups showed variation in their provision emphasis. Parents will also vary in the extent to which they wish to enter 'the world of disability' and in their preference for particular types of group. Wider national studies of parent experience of such groups would be of value.

Promoting Inclusion

Reports such as Barnard et al (2000) have drawn out the extent of exclusion for pupils with autism, so that twenty per cent are excluded from their educational setting at some stage during their attendance. The mothers in my study described how this occurred at special as well as mainstream school, with positive and negative practice being displayed. However, the study did not gain a school perspective and present and retrospective school experience would be of interest, though admittedly difficult to obtain, as experience of personnel will vary and may lack depth.

The above report had suggested that a lack of staff with autism experience and training was responsible and in my study Carol emphasised that "If they are not with you, you may as well give in ...". Central training initiatives are required, so that both mainstream and special school skill and awareness are raised. Exclusion and out of authority placements are usually higher in the secondary sector and this should be a priority for research and development. It would be useful to have good practice case study research with parent, professional and pupil views and experiences being considered. Critical, political and

interpretative study is required. The essence of an inclusive ethos should be explored at many levels and the interpretative case study accounts of schools, parents and pupils would be excellent starting points.

Multi-agency support

Bernstein (1976) has described the illusory nature of inter-professional cooperation and Cole (2004) has emphasised interagency power struggles. The nature of successful ASD and multi-agency support teams requires highlighting, particularly within the current ECM climate and the need for a central rather than locality base for such teams. Within my study the existence of an AWG has assisted wider ownership of the research process and findings, though this could have been greater, as has been discussed above under critical and action research approach limitations. Extended use of the PPLG could have been built in to a more thorough action research process involving local decision-making. We have already considered how avoidance of a deficit model needs to be part of multi-agency team panel practice and future research could consider ways of monitoring and developing this.

EPs would have an important role in assisting with an outcomes-oriented approach to children and families and where this is based on a shared interpretation of experience then parent-professional relationships and mutual trust should be enhanced.

Partnership and the listening professional

The study has adopted Wolfendale's (1999) principles and core values of the partnership model, which are rights and entitlement, equality, reciprocity and empowerment. Attempts have also been made in the critical and action research part of the study to avoid Todd's (2003) concern of a failure to include parents. However, power struggles have been illustrated; for example, in achieving parent membership on the AWG and the missed opportunity of continuing the PPLG. Nevertheless, the LA has made valuable efforts in including and listening to parents, though this needs continued development. Good practice LA parental involvement case studies would be of value.

The study has described parent experience of professional and service helpfulness, though more focused studies will consider ways in which parents' perceptions of professionals change in a multi-agency and trans-disciplinary context. The extent to which becoming a thoughtful and listening professional is facilitated in these new settings will be of interest. In Nixon's terms, will the acquisition of complicated, inter-layered, virtuous dispositions be aided, so that we are accurate, sincere, attentive and honest, and courageous and compassionate?

CONCLUSIONS AND RECOMMENDATIONS

The study has balanced interpretative and critical approaches, so that background factors such as personal history, defences, illusions and local and national discourse has provided a context for interpretative phenomenological analysis. Whilst this probably departs from the traditional IPA approach, in drawing out the essence of mothers' experience in bringing up a child with autism and considering how it informs provision, the nature of the study of a practising EP carrying out research in a LA context required critical, discourse and action research elements to be incorporated. Whilst mothers' experience has been varied, with convergence and divergence, some key points relating to the research questions were as follows:

- Parents made sense of their experiences in different ways, though there was a deconstruction of self and expectations, so that unfulfilled wishes and desires were prominent.
- Life impacts and restrictions were significant, varied and wide-ranging, with cognitive adaptations being made and the child becoming a central focus, so that the mother engaged in an all-pervasive, constant battle. Child management implications, family cohesion, consistency of approach and support reachability were noteworthy issues.

- Mothers achieved control and coping through a process of reconstruction of self and expectations, where meaning and self-esteem were re-established through strong control and often being the ever-present voice for the child.

- Mothers' experiences of professional practice and provision quality and equality were varied and listening and reachable professionals were not easily found. From early support bewilderment, parent group support was often helpful, with professional variability and boundaries being experienced. School inclusivity identification appeared to be part of varying professional boundaries and reachability.

Essentially, trust in services was seen to concern individual professionals rather than services generally. In many ways this was similar to the response described to the London bombings of July 7 2005, where there was system frailty and individual humane triumph.

The other professional practice and provision component questions related also to the critical and action research parent group part of the study, thus:

- The value added from parent feedback is evident in that research assists professionals in understanding parental perspectives and supports the view that we may not know what families need or what is 'best' for them. We should support in the most appropriate manner and accept the views and feelings of the parents with whom we work. Parent understanding of support systems with improved professional practice and parent professional relationships can be achieved through regular parent professional contact.

- The extent to which a LA is able to hear and respond adaptively to parent feedback is dependent upon professional boundaries and defences, as was indicated in the mothers' Interpretative Account. Resistance to parent control and power was evident in the PPLG, though positive steps were taken to improve mutual understanding and relationships. There is a need for longer-term development and maintenance.

- Parent experiences reflected thoughtful parent professional relationships to a greater extent, when individual interviews were carried out, as compared with the more political and provision orientation of parent groups. However, parent support groups, like professionals and mothers varied in the extent to which they saw locus of control as internal or external. More effective parent professional practice can be achieved through continued attempts to encourage mutual reaching out, with parents being involved in joint funding, development and training cultures.

- In many ways an essential ordinariness of mothers' experience was reflected in bringing up a child with autism in that the experience concerned loss of a desired attachment to a person, including hopes and aspirations for self and others. A reconstruction of experience and expectations was linked to on-going deconstruction, which interacted with life impacts and experience of professional practice, provision and support. Each mother experienced the trauma of loss in a different, but converging way, though the intensity of the experience involved an on-going constant battle and strong central focus on the child. In acquiring new meaning and identity, strong control and self-reliance was often achieved, with experience of the listening professional, support and provision being linked to professional practice boundaries and defences.

- Professionals and parents should aim to work together over time to develop practice through an open and inclusive acceptance of the child and each other, which still enables challenge and change. For me, this was summed up admirably in Jack Kornfield's book 'A Path with Heart' (1994 page 23), where his Buddhist teacher Achaan Cha described our on-going battle, denial and defences as follows:

> We human beings are constantly in combat, at war to escape the fact of being so limited, limited by so many circumstances we cannot control. But instead of escaping, we continue to create suffering, waging war with good, waging war with evil ... with what is too small ... with what is too

big ... with what is too short or too long, or right or wrong, courageously carrying on the battle.

By recognising and understanding our shared constant battle and underlying defences and limitations, parents and professionals alike can adopt a more detached, accepting and inclusive position for the benefit of themselves and the child.

Recommendations

Whilst the study was based on a small sample, some key points in keeping with the National Autism Plan (2003) are as follows:

All agencies should:

1. Recognise the improvement in services, but increase the sharing of data and plans between agencies.
2. Encourage on-going feedback and liaison between professionals and parent groups.
3. Listen to and understand the lived experience of parents, so as to develop plans and support which mesh with real child and family needs.
4. Recognise that support needs of the family are great and ensure that respite and befriending schemes receive appropriate funding.
5. Encourage further research to investigate and support the position of fathers, so that more equitable and consistent support strategies can be implemented.

Health should:

6. Maintain referral pathway clarity as a high priority and regularly check parental experience of this.
7. Encourage Child Development Clinics to sensitively prepare parents for assessments and provide follow—up within a short time-scale.
8. Provide feedback mechanisms that sensitively reflect parental choice, so that parental overload by professionals is avoided.

LAs should:

9. Provide placement clarity so as to maximise local inclusion with trained outreach support. Special school placements should meaningfully involve parents in planning.

10. Recognise the complexity of dual placements and minimise their use.

11. Provide timely advice and support for parents about transition options.

12. Build an awareness of the 'constant battle' described by parents and encourage longer term funding packages to increase planning and support certainty.

Schools should:

13. Maximise peer group understanding and support for pupils with ASD.

14. Provide an inclusive ethos emphasising that 'people make the difference' through ensuring caring relationships in pupil and parent support.

15. Maintain a consistent and clear parent communication system, which supports the development of understanding and support.

16. Maximise opportunities to develop special school parent contact and home-school communication.

EPs and Support Services should:

17. Develop Service specialisms and CPD systems, which support service-wide awareness and training.

18. Maintain a support role in challenging behaviour and parent support, including helping parents to move on where school circumstances require this.

19. Use more open-ended interview techniques, eliciting parent experience and story to enable meaningful family and therapeutic support to develop.

20. Use a wider assessment framework to highlight a holistic view of the child with family, emotional, social and personal independence skills being drawn out to complement cognitive and educational perspectives.

21. Actively set up and maintain on-going parent feedback mechanisms, which mesh inherently with quality professional practice and provision through a sincere desire for improvement.

Parents should:

22. Seek appropriate life balance support through awareness of the demands on mothers to become organised, in control and provide voice for the child.

23. Note the dangers of an over-focus on the child for consistency in shared child management and seek wider support.

24. Be provided with on-going encouragement and help to seek out listening professionals and provision.

25. Seek support through parent groups with professional support and liaison.

Final Remarks

The quality of this research is for others to judge, with the main criterion being the extent to which it achieves its own aims and addresses the research questions, which have been considered above. The guidelines offered by Henwood and Pigeon (1992), Salmon (2003), Wolfendale (1999) and Clough and Nutbrown (2002), amongst others have been followed. Similarly the methodological guidelines provided by IPA and Jonathan Smith in particular have been adopted, whilst considering the local research context, discourse, psychoanalytic and action research approaches. It is through these mixed methods that the research has hopefully been positional, persuasive, purposive and political.

Returning to the IPA theme, Reid, Flowers and Larkin (2005) have stressed that the 'increasing confidence in IPA is reflected in the accelerated rise in published studies across a wide range of psychological inquiry' (page 23). Indeed this study, when published, may well be one of the first to use the method in a largely educational context. It is used in other departments at

Sheffield University and its wider use in more integrated settings resulting from ECM developments is to be welcomed. Hopefully, professional and parent understanding of the essence of experience will be enhanced by such studies.

Within the sphere of Educational Psychology, the research has illustrated how interpretative method can be used alongside more critical approaches to provide the essential links between LA and University settings in practice development. Such studies may also provide helpful curriculum for the new three-year doctoral training of EPs.

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APPENDIX 1a)

PRELIMINARY INFORMATION FOR PARENT GROUPS AND RESEARCH PROPOSALS

LISTENING TO PARENTS OF PUPILS WITH AUTISM

As the major study for my Doctorate at Sheffield University, I plan to carry out a number of interviews with parents of pupils with autism in Martom. With the assistance of parents, I wish to consider the nature of parents' experiences in order to improve understanding of this area by developing my thinking and that of other workers. A secondary aim will be to obtain feedback from parents about their experience of support through involvement with professional agencies and provision. Such information would hopefully be considered by the local authority and other services in planning for future needs.

At this stage I am seeking to consult with parent groups in Martom about my research questions and what I might ask when I am undertaking the research at a later date.

I would wish to tape record the session and would hope that those attending would identify themselves when speaking. Of course, should anyone wish me to remove any comments from the transcript I would be happy to do this. Up to about 16 people (or sets of parents) would be a manageable group from the viewpoint of recording the proceedings. The time required might be around an hour. Further meetings could be arranged if required, if more parents wish to attend than can be managed.

So what questions should I be asking about your experiences, including the area of support?

BRIAN WILLIS
SENIOR EDUCATIONAL PSYCHOLOGIST

January 2003

APPENDIX 1b)

PARENT GROUP ISSUES AND CONCERNS JULY 2003

Preliminary information was given regarding the research aims and my role in the LEA and as researcher. Parent rights and method to be used were described - confidentiality and withdrawal option available.

Group A

15 - 4 couples present.

Main themes

Diagnosis/system clarity/statement/assessment ambiguities/training and support needed. Lack of trust and faith in the system/general anger.

Questions and Issues

1   *What would make diagnosis easier?*

     Delay and variety of professionals and approaches.

     Not a proper diagnosis.

2   *What are appropriate methods for assessing pupils with autism?*

     EP tests insensitive to needs.

     Ambiguity in reports.

3   *Provision*

     Why do they have to fight for everything?

4   *Training needs of schools and varied SENCo experience*

     - We proved them wrong.

5   *Views of other parents and difficulties*

6   *Effects on siblings*

7   *Lack of support for parent - stress and medication*

8   *Relationships with others in community - friends and adults*

9   *LEA response to specialist views - just listen to EP - tests too short and lack rigour - lose confidence and trust. Child variation in behaviour between home and school.*
     Need to be literate and articulate to get resources.

10   *Need for parents on LEA.*

11   *Effectiveness of support staff and training for teachers, LSAs and HVs*

12   *Comparability with regard to hours received - start with maximum and reduce over time.*

13   *Social and play skills deterioration and playtime supervision.*

14   *Practical strategies needed to help parents.*

15   *Is diagnosis required for statement?*

16   *Need to see consultant for diagnosis - helps with benefits and others understanding, but not necessarily with LEA support.*

17   *SALT not able to give diagnosis - need to be passed on to Consultant. Can HVs or GPs refer you to the Consultant?*

     Do you need a psychological assessment before you see the Consultant?

18   *Awareness of services and their roles.*

19   *Lack of system and you are blindfolded*

     Different routes to diagnosis eg H Visitor or not.

20   *Lack of consistent approach between paediatricians.*

21   *On occasions at diagnosis advised to apply for benefits and get a statement*

22   *Need for support worker on diagnosis.*

23   *LEA confidentiality issues around Parent Partnership support - files open to other LEA officers when dealing with a complaint about LSA support in SATs. Need for someone can talk to.*

24   *Loss of faith and trust in the system - mechanisms should be in place.*

25   *Expectations of professionals and need for signposting.*

26   Lack of trained professionals and Specialists.

27   *New Support Workers.*

28   *Difference between Special School and mainstream support - more satisfaction for special school parents, but variation in support received in special school.*

29   *Lack of awareness of home difficulties and containing children.*

30   *Hope present when working with agencies.*

31   *Use of information from transport staff.*

32   *MMR.*

33   *Professionals need to ask what can be done to help you and your child now?*

Parent Group B

11 parents - 2 couples and 1 Community support worker

<u>Main themes</u>

Difficulties faced by parents as well as provision and systems.

1   *Experiences*

> Every day a struggle eg wetting
> Relationships problems
> A nightmare you just have to live with
> Can't make plans
> You change, they don't
> Communicating needs of child eg illness for child
> Dealing with siblings - their understanding and time required for autistic child
> Day to day everyday life effects eg shopping rituals
> Concerns for the future - when you are gone.

2   *Getting diagnosis*
     How you get this and how you feel - the next steps.

3   *Provision and time to get a statement.*
     Always having to fight.

4   *Teacher understanding*
     Difficulties with parent liaison in secondary schools.

5   *Interlinking of agencies*
     Health and repeating of information - rules and system unclear - stumble across the system.

6   *Preparation of resources*
     Group providing leaflets and lists of useful books and internet information.

7   *How can services be improved?*

APPENDIX 1c)

POSSIBLE OUTCOMES FOR PPLG

1) **MASG**

- They can implement what arises from the meetings, topics covered.

- That matters are taken to Education - Education is the big one.

- Improved relationships between parents and teachers.

- Happier children.

- Better feeling of satisfaction that systems are working.

- That there are fewer issues raised (recognising that there will always be some difficulties).

- Some measure of parent satisfaction be used, so that there was less grumbling.

2) **MAS**

- To develop action plans relating to key issues.

- To act on these plans and on discussion.

- To consider Autism Working Group minutes, so if action transparent.

- To develop positive working relationships.

- To have mediation rather than Parent Partnership support.

- To consider some feedback system for effectiveness of different professional groups.

APPENDIX 1d)

NOMINATIONS LETTER TO PARENTS AND PROFESSIONALS FOR PPLG

Brian Willis

17 July 2003

Dear Colleague

As part of my Doctorate Research, I have recently met with the two Martom Autism Parent Support Groups and attach a summary of the main issues and questions arising from the discussions.

I have spoken with the Autism Working Group Chair and it has been proposed that a small sub-group from this Group meets with a sub-group from the parents group(s) to discuss the issues/questions. Parents have raised some concerns about liaison, provision, assessment and various other issues. It would be helpful if these issues and concerns could be addressed. Around three from each of the parent and professional groups would probably be adequate. My position would be that of researcher. It would be helpful if one LEA, one special provision and one Health person could act as representatives for professionals.

Please let me know if you would like to be on such a group by returning the attached reply slip. If any one would like a copy of the full transcription of the meeting (20+ pages) please let me know.

It is anticipated that the group will meet in September.

Yours sincerely

Brian Willis
Senior Educational Psychologist

REPLY SLIP

NB Please reply by 5 September 2003 if you wish to be considered for the group.

I would like to be on the Parent/Professional Group

Name _____ Date _____

Please return to Brian Willis, Senior Educational Psychologist, Educational Psychology Service, The Mansion House, University Road, Martom, MN1 3AD
by 5 September 2003

APPENDIX 2a)

PROFESSIONAL NOMINATIONS FOR INDIVIDUAL INTERVIEWS

INTERNAL MEMORANDUM

To: EPS and Autism Working Group Colleagues	From: Brian Willis
Date: 2/06/03	Tel:
Copies:	

AUTISM: PARENT SUPPORT RESEARCH

As you may know, I am listening to some parents of pupils with autism about their experiences of bringing up a child with autism, as well as their experience of support and provision. I have attended meetings of the two main Parent Support groups in Martom, so as to consult with parents about the questions I might ask, when I interview parents on an individual basis. I will be talking with parents of both mainstream and special school pupils and will interview up to 12 parents (or couples) in this part of my study.

Please could you assist me by nominating 1 or 2 parents, from your experience whose circumstances have been particularly difficult or challenging with regard to bringing up a child (or children) with autism. You do not need to be concerned about obtaining their permission, as I will write to them to ask if they are happy to participate and will provide further details.

For special school staff I will not limit the number of nominations you make. A limit of say 6 from any one professional group would probably be adequate.

A reply by **Monday 8 June 2003** would be helpful.

Nominations

....
Thank you for your assistance.

Name of nominee ....

APPENDIX 2b)

INTERVIEW LETTER TO INDIVIDUAL MOTHERS

Brian Willis

19 December 2003

Dear Parents

LISTENING TO PARENTS OF PUPILS WITH AUTISM

Please could I ask for your help in carrying out my Doctorate study at Sheffield University. I wish to interview a number of parents of pupils with autism, who attend or have recently attended Martom schools.

I am writing to a number of parents who professionals working in the area have proposed because their experiences have been difficult or challenging.

I wish to consider the nature of parents' experiences in order to improve understanding of this area by developing my thinking and that of other workers. A secondary aim will be to obtain feedback from parents about their experience of support resulting from their involvement with professional agencies. Such information would hopefully be considered by the local authority and other services in planning for future needs.

The interview will be carried out at your home, or another venue if you prefer, and should take around an hour or so. Occasionally, a second or follow-up interview might be required.

If you wish to withdraw from the research at any time, that will be acceptable. All information will be treated as confidential and anonymous.

Please could you complete the attached reply slip and return in the SAE to me at the address indicated.

Yours sincerely

BRIAN WILLIS
Senior Educational Psychologist

REPLY SLIP

LISTENING TO PARENTS OF PUPILS WITH AUTISM

I am*/am not* willing/able to join in the research interview with you.

Signed: _____ **Date:** _____

_____

If willing:

1   Please give any dates (holidays etc) when you are not available.

_____   _____   _____

2   Preferred time (morning*/afternoon*/evening*)

3   Any days not available   _____   _____

4   Telephone number _____ day _____
      evening

    5   Any other relevant information: _____

_____

_____

Signed: _____ **Date:** _____

*(*please delete as appropriate)*

Please return to Brian Willis, Senior Educational Psychologist, Educational Psychology Service, The Mansion House, University Road, Martom MN1 3AD
Thank you for returning this slip

APPENDIX 2c)

INTERVIEW SCHEDULE AND QUESTIONS

1   **Basic background data**

Name   School
Family
Child name
DoB
Other family members
Are you/have you been a member of a parents autism support group?
Other information
How long have you lived in Martom?

2   **Tell me about how you found out about your child and autism**

Your feelings - then and now
Could it have been made easier?

3   **How helpful has it been to have a diagnosis?**

4   **Tell me about early support**

Support at the time of diagnosis?

Support in the early years?

Knowledge of services?

5   **Tell me about the helpfulness of support**

6   **Tell me about the main difficulties/effects on your life of bringing up a child with autism.**

Worst difficulty?

7   **Tell me about the views/reactions of others.**

Family
Siblings
Your partner
Friends
Professionals

8. **Tell me about the most helpful support or intervention.**

9.   **Tell me about the helpfulness of parent group support.**

OR

Tell me why you preferred not to use a parent group.

10   **Tell me about your own coping mechanisms/strengths.**

11   **Tell me about school/home support.**

What outcomes?

What has been your experience of school support?

What have been the main difficulties at school?

Work?

Peers?

12   **Tell me about home support.**

Respite?

School links?

13   **Tell me about assessment and support from other agencies. (Health/Social Services)**

What outcomes?

Interagency links - experience.

14   **Tell me about your experience of transition stages between schools.**

15   **Tell me about your concerns for the future.**

16   **How could services be improved?**

Do you have trust in services?

17   **Any other issues or concerns?**

INITIAL INTERVIEW CODING EXAMPLE

INTERVIEW WITH MARY(CHAIR MARTOM AUTISM SUPPORT GROUP)
AT HOME 28 JULY 2003 (2 hours)

BW   First of all I want you tell me about finding out about your child and autism?

M   Hmm ...it started - he was one on August 10th 1998 and he started to change about Christmas of that year so he was approximately 16 months old and he changed from being happy and I wouldn't say obedient, but well behaved. He knew right from wrong, he was starting to do things obviously, walking, playing nicely - even talking. He said 'go' at traffic lights, for example, he'd say 'bus'. We've got videos of him in the playgroup in one of the weeks with his Grandma singing along in their own way doing hand actions to 'wheels on the bus' and various other nursery rhymes. Then Christmas came and went and he just changed. He started having screaming fits which we'd never had before. We had tantrums, mainly during the night, tantrums, he'd throw toys, he wouldn't play, he was just completely destructive, he just changed. He climbed out of the cot and nearly had the chest of drawers over. He'd throw things across the room and it went on for quite a few weeks and I arranged it to go for an assessment and he passed all the 18 month tests. He scribbled and did all the things he should have done and passed it.

early change
screaming / tantrums / throwing up at night
passed assessment

early change
– behaviour
– language
– other factor
– diet

extreme behaviour

early assessment is accurate

Then they asked me if I'd got any complaints and I said yes, he's changed. I couldn't put my finger on what it was. I've been investigating and all the different juices, whether it was because we were putting more things into his diet. We started to take things out again; we noticed blackcurrant affects him, so we took him off blackcurrant juice. They just said "Oh, we just need to calm things down". Christmas upset his routine so it went on a bit longer and then it got worse. We ended up taking the bars off the cot because he was bending them. So he was in a cot bed at 18 months; he defrosted freezers, he emptied dry food out of the packets during the night. He was up four, five times a night. It really got quite bad. I worked full time at the time and it got us both down.

dietary changes
disturbed sleep pattern

mother's role

BW   It sounds worrying.

M   It just got, I don't know, it just got, well - it got really hard and I raised it again with another Health Visitor. He wasn't doing things that he should be doing. He wasn't toilet trained; he wasn't talking. This other health visitor, she basically accused me of being a neurotic mother and was saying there was nothing wrong with him. He was having terrible 2 tantrums.

Further professional denial

professional not hearing

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BW   That was the second health visitor?

M   That was the second health visitor and then she just - I began to think that it was me - I wasn't doing something right but I think deep down we still knew there was something not right because we had Chloe and she didn't do any of these things.

Well, you know, I don't - I never move ornaments. We like things nice and they will climb on furniture. But it got where he was standing on my windowsills, diving over the chairs - it was just outrageous. He was completely uncontrollable and discipline - you couldn't discipline him. I mean he'd... although we've never smacked. I don't believe that smacking's right, but even occasionally, if you patted his hand or his leg, he never felt it, he completely ignored it. He would not even know if you smacked his hand.

Then, the third visit ... he was still having these screaming fits in the night, he was going bright red, really hot to touch. We initially put it down to teething. He had a really high temperature. We gave him Calpol, and he just used to roll around in the middle of the bed. We used to put him in our bed for safety and with the one or other of us on each side of him and he'd just be groaning around inconsolable. You couldn't touch him 'cos he just screamed louder. He didn't want touching and after a couple of hours it just went back to normal, quiet, and it was over and done with. His temperature went down, his colour receded and we just put that down to teething. I mentioned it to the doctor and got no answers really.

Then it came to March, so he was now 2½ and he wasn't talking, he wasn't toilet trained. I was getting in a bit of a panic because school was approaching, because obviously he was going to be 3 in the August and he had started pre-school nursery. He was going to a school nursery that linked him to infant school. I rang them and I said could I see somebody - we were very, very worried and felt he needed some sort of speech therapy or something. There's something not right, and it sounds awful but, an older health visitor came out, a lady probably 55-ish a lot older than the other two I'd seen. She told me I had to - and this time I left him. I didn't settle him with sweeties I didn't - I just let him do what he always did. I offered her a cup of tea and she came in, and within 5 minutes of sitting in the room she asked me if this was what he was like and I said "yes". She said "If he was mine I'd be very worried too" and she asked if she could use the phone. She rang and she had him with speech therapy within a fortnight and she had an appointment made for us with the Community Doctor which then was Dr Munro at the Community Centre.

Now she wasn't our health visitor, she was only covering temporary.

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We went down and saw Dr M... it was a bad day and Terry didn't want assessment cooperation problems
to go in. He lay for the whole session with his legs up the wall at the
door. He wouldn't do anything that the doctor wanted him to do,
wouldn't acknowledge his presence, and the doctor referred us to the
hospital. At the time it was Dr C, the Consultant. We went in, and this
clinic assessment was June/July then within 2 months of visiting Dr M we were in the Full assessment
Development Clinic. We went for 3 sessions in the Development Clinic
with everybody up there then us and Terry.

Diagnosis shock
There was no preparation for the diagnosis. That was one thing that Diagnosis disbelief shock
threw me completely. I wasn't aware of autism, didn't even know what
it was. There was no preparation for the diagnosis in all the sessions
Professionals numbers we went to and when we went to the feedback session on the following preparation professional numbers
week our new health visitor came with us. I think there was probably
about 13 professionals in the room with us sat round the edge. We
were sat there and they just said ...yes, there was something and they change in management hopes
went on to describe what their findings were and then they just passed
us a book, the blue book, with autism on top of it, and - that was the
diagnosis. And we were shell shocked.

BW   A massive shock............

M   Hmm.. The book was Autism ... I think it was the National Autistic
Disbelief Society's book ... and I think it was blue. Yes. And I just looked at it
and I just said well what, what is it? Y'know, what is autism? And then
we were stunned and I think it was disbelief really.

We knew there was something but not what ..... perhaps you could
give him a pill and he'd be better. We thought it would have been
Hoped for cure solvable. We thought it was even something that he was eating that
was causing it. One of the health visitors even fetched us a book from
America on bedtime routines... in the early stages ... I think we
seriously thought it was something that was ...
Change hopes

BW   Changeable?

M   Yes. That would change, you know, we just hadn't quite grasped ...
Feelings Devastation

(Brief pause to check tape is working)

BW   Tell me about your feelings then, and now, about your child having
           autism?
Devastation
           I was upset. We were absolutely devastated.

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M It's a question of where do you go from there? We didn't know where *Lack of direction/certainty* to go.

Lack of sensitivity They could have handled it more sensitively than they did and yeah, a *Future changed* massive shock, your future its totally changed.

But even then I think there's been denial because when he was first ... you come out, you've got the diagnosis, you've got the labels and know what the problem is. Then we start reading the literature the *initial denial* book that we're given, straight away your first reaction is he's not, he's ? *negative acceptance* *initial denial – difference* not, you've got it wrong, he doesn't do this, he doesn't do that, he doesn't do the other.

Well, I mean - just watching a TV programme could trigger it off. It's like a bombshell - we do look to the future. Loads ahead. You've got to really. I mean, consider what is going to happen in 20 years' time, I *continued coping difficulties, Future concerns* think like that.

BW Do you think it could have been made easier?

M *Improvement need shared information, sub preparation, simple, expected answer* I think so. I personally think that the assessment could be improved. *Diagnosis improvement* The professionals must have had some idea as to what they were looking for from the first. They see children every day with various difficulties in that room and we'd been there 3 mornings. We'd been in and out of the room for various tests and whatever, so they'd observed his behaviour and the way I'd handled that behaviour, the way he'd responded to the changes and the requests that were made of him, the lack of language, his lack of movement and the way he was playing with those other children. They must have known they came to the conclusion over those 3 days and I just think that, you know, some sort of preparation, it was like a bombshell really. I think we were very naïve going in there as we did. We were looking for an answer really.

BW What might have been done?

M *Informal discussion – seeds – avoid bombshell* Maybe by full discussion with us either during the assessment or even, you know, while telling him to eat his biscuit or whatever when he went for a drink. Do you know what I mean, where maybe all the possibilities of what they were looking for could have been discussed with us just to sort of put the idea in there, sow the seed, so that when the actual diagnosis came it's not such a bombshell, - you're sort of preparing for the worst.

[handwritten margin: Lack sympathy]

They could have been more sympathetic really. It was like a conveyor belt one after the other. *[handwritten: sympathy sensitivity conveyor belt]*

When we got the diagnosis and they told me and I don't know whether that was when he was there or what but I know the Communication Difficulties teacher came up to me and said, you know, it's manageable, you can put things in place, its not the end of the world and I wouldn't imagine you know now.

BW   That was positive. How helpful had it been to have a diagnosis?

M   Lucky, I think - having been in contact with parents who haven't got a diagnosis, they're still looking for the reasons why their children are like they are and I think its not an excuse for Terry's behaviour but at least I know, and it's like, when other people observe him you know, when I'm out and about, I know he's not— just being naughty, we know he can't help most of the things he does.

[handwritten margin: Now understand]

[handwritten right: Diagnosis helpful where; understand; acceptance; beyond excuses; Not naughty; Cloud control]

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APPENDIX 2e)

JOINT ACCOUNT FOLLOW UP MEETING LETTER

Mrs Newton
Parking Road
Outtake
MARTOM
DN2 5HB

Brian Willis

10 December 2004

Dear Mrs Newton

First of all, thank you for your interest in seeing the joint write-up and agreeing to meet together to discuss the document. Secondly, Christmas and seasonal greetings to you.

I wrote up the findings over the summer (about four weeks solid work) and would like you to see them and hopefully approve them. I hope to finish my thesis in the near future and then later, it might be possible for us to use the information and project for some publication if you wish to do that. I will be very interested in what you make of the findings.

I realise that you are all sharing your personal experiences and I hope I have done justice to them, whilst following the particular research method I used - interpretative phenomenological analysis - takes some saying and spelling. The interpretations are mine and this is part of the method.

I hope you will be able to work out your new names and those of your children, as I changed these.

I have booked a room at the **Grantley Hotel at 6.00 pm on Tuesday 18 January 2005** and promise to buy you at least one drink. Please let me know as soon as possible if this is not convenient.

Kind regards

Brian Willis
Senior Educational Psychologist