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Parent-Professional Partnerships in the Autistic Spectrum Disorders (ASD) monitoring and support process

How do parents and professionals perceive the working relationships that they form within the context of a service providing monitoring and support for children with ASD and their families?

Anna Read

A dissertation submitted to the University of Bristol in accordance
with the requirements for award of degree of Doctor of Educational
Psychology in the Faculty of Social Sciences

Norah Fry Research Centre

September 2009

Word count: 47,539

ABSTRACT

Research identifies that Parent-Professional Partnerships (PPP) benefit a child's development and a parent's sense of wellbeing. However, parents can be critical of PPPs as being professionally top heavy, marginalising rather than optimising the parental role. However, their evidence is limited to Positivist and mainly self-reported data and there is little qualitative research that identifies both parents' and professionals' views on PPPs or assesses the underlying processes at work in the PPP.

This study addresses the gap in the research by considering both the outcomes and the processes of a PPP supporting Autistic Spectrum Disorders (ASD), from both parents' and professionals' viewpoints. It uses a mixed methods approach, drawing on the experiences of six parents and six professionals who care for and work with children with ASD.

Findings identify that parents lack confidence in schools' and professionals' ability to support children with ASD. Parents do not feel that their needs are heard or addressed and they are sensitive to the ASD diagnosis process. Professionals feel little confidence in their own knowledge and ability to support families of and children with ASD. Professionals recognise that they need to broaden their involvement in the support process but feel that the Multi-Agency element of the PPP can assist their work with families. Both parents and professionals identify that the use of a professional "key contact" benefits the effectiveness of the PPP.

Recommendations focus on the provision of more direct support in the home, school and community contexts, extended professional training in ASD and improved networking between schools and professionals.

For June Mary Read

my nanny

ACKNOWLEDGEMENTS

I would first like to acknowledge, Mr Andrew Price, my fiancé. I am still in awe of his brilliance and indebted to him for his love, kindness and understanding.

Mr David and Mrs Joanna Read, my parents and Mr Stanley and Mrs June Read, my grandparents, have been hugely influential and supportive throughout my life. In particular, I would like to thank my grandmother, June. You remain my inspiration. I miss you everyday.

Dr Anne Knight-Elliott has been a fantastically supportive supervisor. Her knowledge, guidance and generosity have been beyond the call of duty and I am very grateful to her.

Similarly, I am grateful to all of the fantastic people at the Norah Fry Research Centre who have assisted me throughout the last three years: Dr John Franey, Mrs Carmel Hand, Mr Rob Green, Dr Val Williams and Mrs Maggi Walton.

I would also like to thank Mr Chris Baldwin, Mrs Denise Ford, Mrs Heather Sharp, Mrs Jenny Humphreys, Mrs Helga Oakdon and Miss Alison Stewart for enabling me to fulfil the tasks of this thesis in a way that did not sacrifice my soul!

Finally, thank you to all of those parents and professionals who took part in my study. I am very grateful for your time, understanding and commitment to my research.

AUTHOR'S DECLARATION

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED:.................................... DATE: 2nd March 2010

TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

1.1 Introductory comments

For the purposes of this thesis, Parent-Professional Partnerships (PPPs) are considered to be the working relationships between parents and professionals to support the special needs of children (Department for Education and Skills/DfES, 2001a). PPPs are intended to empower, involve, facilitate valued contact with and bring confidence to parents (ibid). For these purposes, empowerment refers to the opportunities provided by professionals to parents to *"recognise and fulfil their roles as parents,"* (ibid, paragraph 2.2) as well as be in a position to access support, information and voice their views around issues related to their child (ibid). Involvement describes how collaboration between parents and professionals takes account of parents' wishes, feelings and perspectives with regards to the child (ibid). Contact refers to the ways in which parents are enabled to contribute their knowledge and understanding of the child to professionals as well as be able to receive support such as intervention strategies (Ryan, 2003). Finally, it is important that parents have confidence in order to feel that they can achieve their goals (DfES, op. cit). As well as these benefits to parents, PPPs can lead to improved academic achievement for children (Deslandes, Potvin and Leclerc, 1999); better language development (Chavkin and Williams, 1993; Bermudez and Rakow, 1993); positive attitudes and behaviour (Deslandes et al, op. cit); increased attendance and less "drop out" (Chavkin and Williams, op. cit).

The key benefit of a PPP is that it should enable parents and professionals to share expertise (O'Connor, 2008). This should mean combining the professional insight of agents such as teachers and Educational Psychologists (EPs) with the familiar knowledge brought by parents, other relatives and associates, such as extended family and friends (Jelly, Fuller and Byers, 2000). In ideal form, a PPP enables co-operation and accountability amongst all those involved (O'Connor, op. cit). However, the literature has also identified a number of practical limitations to a PPP. Tensions can arise between parents and professionals – for example, some parents feel that professionals fail to include their perspectives in meetings (Frederickson, Dunsmuir, Lang and Monsen, 2004) and that professionals can adopt a *"gatekeeper"* role, working in isolation rather than with reference to other agencies (Erchul and Martens, 2001, p12). This can reinforce professionals' traditional dominance in their relationships with parents (O'Connor, op. cit). Equivalently, there are professionals who identify some parents as irresponsible, litigious, selfish, unreasonable and even violent (Lumby, 2008) whilst some professionals note the high number of parental absences from parent-professional meetings (Maddern, Franey, McLaughlin and Cox, 2004). Collectively, these failings can restrict the quality of combined parental and professional input and inhibit the realisation of the goals of a PPP.

The focus of this study is on PPPs in the context of providing support for families of children with Autistic Spectrum Disorders (ASD). In this regard, whilst there is a significant amount of literature on theoretical aspects of ASD – causality, characteristics and diagnosis – there is relatively little research on the practicalities of addressing children's needs through a PPP. The research that has been published has highlighted many of the same issues as illustrated above. Specifically, there is evidence that such families are dissatisfied with the PPP process and often feel undermined by it (DeMyer, 1979; Billington, McNally and McNally, 2000; Hodge, 2006; O'Connor, op. cit). This lack of extensive research is perhaps striking given the diverse continuum of needs presented by children with ASD, its increasing prevalence(1) and the legislative drives to include children with difficulties, such as ASD, in mainstream schools (DfES, 2001a, 2001b).

Using one Local Authority's (LA) ASD "Monitoring and Support Group" as its base, this study considers in greater depth the processes through which a PPP for families of children with ASD operates in order to support families of children with ASD, as well as the outcomes that result. I also hope to address the professionals' perspective on the processes and outcomes of the PPP, an

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(1) For example, 1 child in 100 (National Autistic Society, 2009); 107,000 children in Britain, with ASD (www.channel4.com, 2007).

area which has appeared to have been neglected in the literature to date. Indeed, most research on PPPs seems to focus on parents' views (for example, Hodge and Runswick-Cole, 2008; Webster, Feiler, Webster and Lovell, 2004; Abbott, Watson and Townsley, 2005). Whilst this can usefully inform the provision made for a child (DfES, 2004b), it should not override the importance of gaining an equal and balanced perspective on a system that is jointly made up of both parents and professionals (Department of Education and Science/DES, 1978). As such this study includes both parents' and professionals' view points on PPPs.

1.2 Support for children and young people with ASD

Existing support strategies for ASD are very much geared towards addressing the needs of the individual child with relatively little emphasis typically placed on support from a PPP.

1.2.1 UK government-funded support

Existing government funded initiatives attempt to improve the child's cognitive and social skills through the provision of funding for additional teaching support, either through mainstream provision (including statementing, School Action or School Action Plus) or sometimes the use of specialist provision. These can give children access to more wide-ranging and specialist support, such as input from EPs and outreach support. Whilst government recommended strategies such as statementing and specialist provision can lead to developmental improvements (for example, Whitaker, Barratt, Joy, Potter and Thomas, 1998), nonetheless, they have limitations. The Lamb Inquiry (Department of Children, Schools and Families/DCSF, 2009a) identified that, at a general level, parents with children with Special Educational Needs (SEN) can lack confidence in professionals' abilities to support their and their child's needs. Similarly, the Bercow Report (DCSF, 2008) identifies that some parents can feel that professionals lack understanding of their child's needs.

1.2.2 Intense interventions

Some families prefer alternative ways to support their child and can opt for either privately funded or government funded initiatives, such as Early Intensive Behavioural Interventions (EIBI); Applied Behaviour Analysis (ABA) and the Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH). These are highly structured and intense interventions. However, there are criticisms that they are mainly geared towards reframing autistic behaviours rather than accommodating wider family needs (www.researchautism.net, 2009).

1.2.3 Medical interventions

Another alternative approach is the use of bio-medical interventions. These recommend changes of diet and the use of vaccines (Charman and Clare, 2004). However, their focus on supporting ASD is aligned to the medical model which some believe pathologises ASD (Hodge and Runswick-Cole, 2008). There is, moreover, inadequate evidence, as yet, to prove that there is a biological cause for ASD which therefore negates the rationale for bio-medical intervention (DfES, 2006a).

1.2.4 EarlyBird and EarlyBird Plus

The National Autistic Society's (NAS) EarlyBird and EarlyBird Plus programmes (National Initiative for Autism, 2003) address the child's needs in both home and school settings through the training of parents by professionals (such as a teacher or EP) who work regularly with that child. The programme teaches parents about ASD before considering how to develop communication or manage behaviour (the key areas of difficulty for children with ASD). The key objective of the programme is to build confidence in both parents and professionals. It does this partly by encouraging joint working to increase the knowledge, skills and understanding of the participating parents which in turn lead to improved social and communication behaviours in their children (NAS, 2007).

Reviews of the EarlyBird and EarlyBird Plus programmes highlight their value. Shields (2001) found that this programme was popular with parents and delivers positive results for them and their children. Hardy (1999) found improved child behaviours, particularly increased communication and social engagement, and lowered parental stress levels following eight weeks participation in the programme. Engwall and MacPherson (2003), Morris (2002) and Shields and Simpson (2004) reported similar results. Although small scale and limited by the focus on parent-reported data, these results highlight the positive ways in which parents can impact on children and professional practice through PPPs.

Not all LAs provide access to EarlyBird and EarlyBird Plus Programmes although most offer alternatives that equally posit the use of PPPs and run on similar lines to EarlyBird and EarlyBird Plus. For example, Bexley LA runs Parents of Autistic Children Training and Support (PACTS), a home and nursery based programme that offers professional support for families to help support children's daily life skills, such as communication and social skills.

1.2.5 The ASD Monitoring and Support Group

This study focuses on a PPP run by an LA in south east England that provides professional support for families and teachers of children with ASD. Known as the ASD "Monitoring and Support Group", the service aims to support families as well as professionals who have contact with children with ASD, such as teachers and teaching assistants, in a programme that bears some resemblance to EarlyBird and EarlyBird Plus. In particular, training is offered in order for participants to learn and use strategies to help a child's development. These can include: anxiety-reducing strategies and visual communication strategies. The group also provides specialist resources and equipment; regular forums to discuss and address parents' and professionals' challenges; advice and for parents, a professional contact who will telephone every three months. As far as I am aware no other LA runs the same programme.

1.3 Omissions in existing PPP and ASD research

There are three significant gaps in the existing literature. First, parents of children with ASD are found to experience significantly greater stress than parents of children with other SEN (Baker-Ericzén, Brookman-Frazee and Stahmer, 2005), prompting a need for further research into this discrepancy. Second, much of the existing research into ASD support for parents adopts a Positivist paradigm (Davis and Oland, 2007), whereby researchers have aimed to assess objectively the extent to which a service has achieved its intended goals, for example improved language scores (Baxendale and Hesketh, 2003; Diggle, McConachie and Randle, 2004) and behavioural improvements (Birkin, Anderson, Moore and Seymour, 2004). Accordingly, this work can be considered evaluative. While this may be useful for target-setting, such as establishing baseline language assessment scores for children with ASD, it does not enable insight into the effectiveness of the processes taking place at the level of service delivery – an oversight that has become increasingly recognised as in need of redress (Carpenter, 2005; DfES, 2004a). Third, existing research has focused on the parental perspective of PPPs, ignoring the added insight possible from also examining the perspectives of the professionals (Choo, 2004). This study aims to enhance the research base in respect of each of these omissions.

1.4 The focus and structure of the study

This study examines both parents' and professionals' perspectives with respect to a PPP established by an LA in the south east of England. Specifically, it seeks to explore and analyse their perspectives on the key characteristics that the DfES (2001a) has highlighted encapsulate a PPP, namely, parental and professional confidence, involvement, empowerment and contact to support children with ASD and their families.

Accordingly, the research questions are as follows:

1. How confident are parents and professionals, respectively, when supporting the needs of children with ASD and to what extent is their respective confidence influenced by the PPP?

2. How involved are parents in the PPP?

3. How empowered are parents in the PPP?

4. Is contact between parents and professionals in the PPP valued by both parties?

The research methodology adopted in this study is that of Pragmatism (Johnson and Onwuegbuzie, 2004). Pragmatism is an approach that enables the researcher to select the method and procedures that best answer the research questions. This is a flexible approach as it means that research can adopt any combination or mixture of procedures and methods without failing the criteria of the approach. This is important given that other approaches such as Interpretivism direct a solely qualitative approach and Positivism directs a solely quantitative approach. However, the disadvantage is that its "anything goes" philosophy means that it lacks the same rigour that these other approaches have and as a result forces the researcher to be more aware of and insistent on accountability throughout the research process, to ensure transparency. In this study, to achieve this, I kept a reflexive log which discussed my thoughts and feelings towards the research process (Appendix V). This offered both me and the reader an opportunity to check for any influences that I may have had on the research process and to account for these, where necessary.

Within this paradigm and in order to consider both the processes and outcomes of a PPP, this study incorporates a mixed methods design, considering both qualitative and quantitative data. Qualitative data drew on the Interpretivist tradition. This directs the researcher to gain information based on parents and professionals talking through actual experiences that they have lived through. These descriptions can develop the analysis. Data was gathered using semi-structured interviews and interpreted through Thematic Analysis (TA) (Hayes, 2000) to address the four research questions highlighted above. TA is an efficient way to reveal participants' insights without overloading the reader as could be the case with more extended versions such as Interpretative Phenomenological Analysis and grounded theory. Quantitative data drew on the Positivist tradition and analysed data derived from Likert Scale responses to four evaluative questions using simple statistical techniques. The data attempts to highlight significant differences or similarities in the perceptions of parents and professionals as to their confidence in the outcomes of the PPP.

1.5 Position of researcher

As a trainee EP and former teacher, who is not a parent, I am aware that my own experiences will have influenced to some extent my thoughts and feelings towards the processes through which a PPP operates. For example, I have experienced both the conflicts and collaborations that can take place in parent-professional interactions, from the perspective of a professional and which have been thus far alluded (Lumby, 2008; Maddern et al, 2004) and which are discussed in detail in Chapters 2 and 3. I am aware that these experiences have, at times, made me more sympathetic to the professional as opposed to the parental cause and I am conscious that these biases need to be avoided, where possible. It was my aim to be as balanced as I could in my interpretations around PPPs through the use of continuous reflexivity: a topic which is expanded on in Chapter 4. Therefore, I understand the importance of ongoing self-questioning regarding my position and the importance of being neutral in situations that could bring out a partiality that could negate the value of this thesis. Nevertheless, I appreciate the benefits that my experiences on placement have given me and in particular the exposure to PPPs. In this respect, I hope to allude to some of these experiences to highlight salient points made throughout this study. At the same time, I appreciate the importance of the researcher being detached in order to stay impartial and at all times, attempted to stay in this mind-set – the challenges of being detached are further discussed in Chapters 4 and 6.

Finally, I would like to underline my reasons for undertaking this study. Over and above the need to fulfil criteria to become an accredited EP and to contribute to the evidence-base of my current placement in south east England, I have undertaken this research to satisfy my personal need to understand the ways in which people, specifically parents and professionals, work best in order to help children. This need arises mainly from my dissatisfaction regarding several parent-professional collaborations I have experienced and in particular, the consequences this can have on the focus child. I still remember vividly the shocking exposé of Victoria Climbié (Great Britain Home Office, 2003) – a girl failed by both her carers and the professionals involved in her case – and more recently, 'Baby P' (www.telegraph.co.uk, 2009) – a child whose tortured life revealed the inadequacies of the current system of parent-professional support. Whilst it is optimistic to expect this study, on its own, to change the way in which parents and professionals relate to each other and the children in their care, I hope to add evidence to the current knowledge base that will enrich the understanding of the government, Children's Services – including EPs, social workers and health professionals – and parents regarding the way in which PPPs can evolve in order to safeguard the child.

1.6 Overview of the study

This study is set out in eight Chapters. This Chapter has provided an introduction to the study. Chapters 2 and 3 present a review of literature pertaining to the history and development of PPPs, the associated surge in parental power as well as a more specific review of the ways in which PPPs relate to supporting families of children with ASD. Chapter 4 outlines the research context and describes the methodology employed in this study. Chapter 5 presents research findings. Chapter 6 offers discussions of these findings. Chapter 7 outlines the strengths and limitations of this study and

Chapter 8 offers recommendations for future practice in PPPs and some overall conclusions.

CHAPTER 2: THE MOVE TOWARDS PARENT-PROFESSIONAL PARTNERSHIPS

2.1 *Introductory comments*

This Chapter sets out the historical context in which to understand how Parent-Professional Partnerships (PPPs) have evolved to be as they are today. This review, where possible, refers to the four key features highlighted in Chapter 1 as being the fundamental characteristics of a PPP, namely: confidence, involvement, empowerment and valuable contact.

Reference is made to the theories, government policy documents and resulting legislation that have shaped PPPs as well as to criticisms that suggest PPPs are still very much in favour of professionals over parents. A background to PPPs is presented before a more detailed consideration of the literature on PPPs.

2.2 *Background*

Before the mid-1970s, the English education system was characterised by divisions between parents and professionals, not partnerships. Vincent (1996) described parents as powerless during this period and believed that parents were openly discouraged from becoming involved in the education of their child and from having contact with education professionals. This was a point neatly illustrated by notices outside the school gates, during the time, that read: *"no parents beyond this point,"* (Vincent, 1996, p1).

Parent-professional divisions extended to most areas of education, including, for example, the right to state a preference for a school for a child, decisions over curriculum and input into any interventions to support a child – policy dictated that such issues were at the sole discretion of professionals. This last issue was a particularly controversial one for children with Special Educational Needs (SEN). Indeed, parents of children with SEN arguably had the least power. At that time, SEN was viewed as a health abnormality – these children were viewed as educationally subnormal (ESN) – with the result that the child was typically supported by professionals in either hospitals or special schools (http://inclusion.uwe.ac.uk) with no parental input (Marshall, 2008). Accordingly, parents had no right to access mainstream education for their child because of his/her SEN and the power was in general in the hands of professionals.

This enforced segregation was consistent with the prevailing medical model that highlighted a child's difference rather than normality and specifically considered this difference to be a product of the child (Sturt, 2009):

> *"Children were given medically diagnosed categories with the emphasis on deficit rather than potential," (Sturt, 2009, p1).*

This deficit was normally in the form of low Intelligence Quotient (IQ) scores assessed and provided by Educational Psychologists (EPs) (Tomlinson, 1981). The thinking around the "deficit model" has subsequently been viewed as flawed (www.parliament.uk, 2005) with findings that it creates a negative portrayal of an individual's needs and negative impact on the way in which such children are supported (ibid). Additionally, the use of IQ tests has also been viewed as culturally biased to Caucasians and therefore producing over-representations of SEN in what had been considered minority groups such as black children (Coard, 1971). Nevertheless, at the time, parents' roles would not have enabled them to voice effectively issues around the appropriateness of these or other tests. Indeed, it can be surmised that parents were very much passive in the operations that took place around their child's education; they were mute bystanders rather than active voices. In contrast, professionals appear to have been key to the decisions made around these children despite the new evidence that such decisions were not either always accurate or appropriate. Parents' roles may have continued to remain passive were it not for the simultaneous occurrence in the mid-1970s of an educational crisis and an economic recession with its associated pressures on government finances, which together brought about a change in both the roles of parents and professionals in services for children.

The educational crisis arose primarily out of a number of influential studies that found schools and education professionals were failing children: in particular, they were failing to achieve satisfactory targets and supporting teachers who were considered to be irresponsible and unaccountable (for example, Cox and Dyson, 1969; DES, 1972; Cox and Boyson, 1977; Taylor, 2008). Literature called for a new approach that would afford children greater educational opportunities through improved access to the curriculum (ibid). Crucially, this emerging school of thought found a voice at the political level through the Prime Minister of the time, James Callaghan, who described the education service as if it was failing the nation in his Ruskin College speech of 1976:

> *"I am concerned on my journeys to find complaints from industry that new recruits from the schools sometimes do not have the basic tools to do the job that is required... how much of the criticism about basic skills and attitudes is due to industry's own shortcomings rather than to the educational system?" (Callaghan, 1976; cited in The Guardian, 2001, p1).*

In this quote, Callaghan openly identifies the failings of the prevailing educational system and the fundamental impact that they have on the UK economy.

Coincidentally, a series of psychological theories highlighted an alternative way to view both children's development and more specifically, the roles of parents and professionals.

2.2.1 Socio-cultural theory

Socio-cultural theory (Vygotsky, 1978) claimed that cognitive development is determined by society and culture and effectively that our view on the world is determined by our interactions with others. In a practical context, such as one where I am engaged in a meeting with a parent, this can mean that my interactions with parents and theirs with me co-constructs my new thinking related to those people (Choo, 2004).

2.2.2 Systems theory

Closely linked to socio-cultural theory was the systems theory (Bronfenbrenner, 1976, 1979), that proposed that children learn best in an environment where they are supported by all appropriate "systems", for example, their school, their family, their community: in effect, professionals, parents and friends. Pertinent to this study, systems theory highlighted the importance of interactions between different systems (Bronfenbrenner, 1979; Ringness, 1970) and therefore the importance of relationships between systems, such as parents and teachers (ibid). In effect, the theory identified that a child's capacity to learn is influenced not just by the school and parent but by the quality of these school-home interactions (Hutchins and Sims, 1999).

2.2.3 Behaviourism

Behaviourism was popular in the 1970s (Sturt, 2009). Behaviourists rejected the medical model view that a child's SEN was an intra-individual deficit and instead believed that behaviours could be modified, for example by a teacher – this was known as operant conditioning (ibid). Although it has its critics (ibid), behaviourism arguably, enabled a more positive view of a child's needs and reinforced the idea that a child was not predisposed to end up in either a mainstream or special school.

2.2.4 Attachment theory

Bowlby's attachment theory (Bowlby, 1971) proposed that a child's bond with or attachment to his/her parents determined his/her overall life development, including cognitively, emotionally, physically and socially (ibid). This finding emphasised, *inter alia*, the importance of familiarity of parents with their child and of the active role of parents in education and specifically in their child's educational development.

The first example of an education programme that recognised the contribution of parents and arguably, showcased the value of the aforementioned psychological theories was the Head Start Programme. This was established in the USA in the 1960s and was designed to support the transition between pre-school and junior school for children from low income families. A long-term study (Oden, Schweinhart and Weikart, 2000) showed that Head Start had succeeded in helping participating young children achieve greater school success and avoid crime as they grew up (ibid). Despite some contrary claims that results were only short term (Lee and Loeb, 1995), extensive evidence suggested that the most successful outcomes were experienced by children whose parents were actively involved in their children's educational intervention plans (Stearns and Peterson, 1973; Goodson and Hess, 1975). The value of the Head Start Programme is perhaps best illustrated by the fact that not only does it still exist in the USA but that it has since been replicated in several countries, including in England where it was introduced in 1998 as "Sure Start". Sure Start is a national initiative focused on children up to the age of four and their parents in economically disadvantaged areas. The aims are to increase child development and parental employment (Moss, 2004) mainly through the co-ordination of child care and support services (ibid).

The recognition of the value parents could bring to child development was assured in England not so much by the emerging theoretical thinking but by necessity arising from the economic difficulties of the time (high inflation, stagnant growth and weak government finances). The policy response to these economic difficulties, most notably propounded by the later Thatcher government, was, *inter alia*, to introduce a market-based approach to all aspects of government provision, including education (Gillard, 2007; Sexton, 1977). The aim was to improve the quality and reduce the cost of provision. In education and following this economic-rationalist model (Choo, 2004), this meant parents were to be treated as consumers of education. As a result, parents were for the first time to be given the rights to make demands of their child's school and their voice would have to be listened to (Munn, 1993). Thus, the 1970s marked a turning point: now, parents had become an integral part to any educational policy reform and the move towards partnerships with professionals had begun.

2.3 The Warnock Report and the Importance of PPPs

The Warnock Report (DES, 1978) was arguably the catalyst for the changing of both parental and professional roles, initiating as it did the moves towards PPPs (O'Connor, 2008). As such, the report demands consideration. The Warnock Report commissioned in 1974 by the then Education Secretary and future Prime Minister, Margaret Thatcher aimed to review and provide recommendations on provision for children with SEN. However, in so doing, the report made a defining contribution to the emerging thinking on PPP.

A key area for change was to include parents in the assessment and supportive processes for children with SEN. The report felt that this inclusion would enable a more objective understanding of the child's needs. Chapter 9 of the report, entitled "Parents as partners" makes reference to the importance of parental input to providing appropriate support for children:

> *"... the successful education of children with Special Educational Needs is dependent upon the full involvement of their parents: indeed, unless the parents are seen as equal partners in the educational process the purpose of our report will be frustrated. But the parents with whom we are at present concerned (mainly, though not exclusively, those of more severely handicapped children) have burdens to bear of which other people may have no conception. It is therefore an essential part of our thesis that parents must be advised, encouraged and supported so that they can in turn effectively help their children," (DES, op. cit, paragraph 9.1).*

This was to lead to a widespread appreciation of the value that parents could bring to professionals and to the educational process for children with SEN:

> *"The report created a turning point in public and professional opinion, saying parents of disabled children had vital information about their offspring that must be incorporated and used in the assessment, placement and educational process," (http://inclusion.uwe.ac.uk, p1).*

A central recommendation of the report was therefore that professionals should accept the input of parents: "[professionals should] take note of what they [parents] say and how they express their needs and treat their contribution as intrinsically important," (DES, op. cit, paragraph 9.6). Moreover, Warnock emphasised that this should extend to all professional organisations within the system of education:

> *"Both parents and teachers may need the help of other professionals in their endeavours. At every stage of our discussion, the contribution of parents and non-teacher professionals to the education of the child has been at the front of our minds," (ibid, paragraph 1.5).*

Warnock emphasised the importance of information-sharing between professionals, especially teachers, and parents. The parent-professional relationship relies on *"information and advice from the school about its objectives and the provision being made for their child"* as well as the *"insights that his parents, from their more intimate experience of him, are able to provide,"* (ibid, paragraph 9.19). Warnock stressed that professionals have a responsibility to build on this shared information by creating support programmes for children that extended to both the school and home environments:

> *"These teachers will be responsible for devising programmes which are suitable for the parents to carry out. They will help parents to work with their children. By working directly with the children they will themselves provide a model of how such programmes can be effectively carried out," (ibid, paragraph 9.14).*

One of the report's core recommendations was that Local Authorities (LAs) should identify children with SEN and provide them with a Statement of Special Educational Needs in order to "include" all children (that is, provide equal access to opportunities, including within education). It should be the responsibility of professionals to detect, assess and provide for children with SEN, using the support of parents. In Chapter 14 of the report, Warnock also stressed the importance of EPs being involved in these interactions and taking on a more advisory role regarding the development and provision for children. In part, this marked a shift in their role from mainly IQ testing children believed to be ESN to a wider remit enabling them to respond to a child and family's wider concerns. For example, EPs were encouraged to become actively involved in providing practical advice and guidelines for children in school settings (Quicke, 1984).

The report encouraged parents to become more actively involved in supporting their child's educational needs. The report guided parents and professionals to view their relationship as a "partnership": *"[it is] a partnership, and ideally an equal one,"* (DES, op. cit, paragraph 9.6). To create this partnership, the report recommended that parents have a "named person" whose role was to liaise with them to allow their views to be heard and disseminated at a wider level (ibid, paragraph 5.72).

The Warnock Report was to become embedded in government policy following the election of the Thatcher government in 1979. Warnock's thinking was reflected in the Education Acts that have followed between 1980 and 2009 (Cole, 2005). These Education Acts gave rise to increased parental rights within the educational context (Gillard, 2007), regardless of whether the children had SEN. One of the effects of this was that the generic parental role changed from a relatively passive bystander in the world of education to an active member of the processes by which children's education took place.

2.4 The rhetoric and reality of PPPs in the post Warnock Era

Following the Warnock Report, government policy promoted a market-driven approach whereby parents had relatively greater rights in determining their child's education and professionals were encouraged to work more closely with parents to achieve these rights. However, the extent to which parents felt a part of a PPP, in practice, is debateable. Indeed, literature suggests that even more than 30 years after the Warnock Report and despite the rhetoric, parents and professionals have still not fully cultivated a relationship founded on the four qualities discussed in Chapter 1: confidence, involvement, empowerment and contact.

2.4.1 Parents' rights in the face of professional bureaucracy: the 1980s and 1990s

Following the Warnock Report, new legislation increased the focus on PPPs and the importance of parents' rights within the educational setting and professionals' responsibilities to facilitate these rights. The political rhetoric enshrined in the education acts during this time was impressive, seemingly delivering on so many of the recommendations provided by Warnock. For example, with every passing Act, there appeared to be another right or extension of rights given to parents that helped them to become more active participants in education. The 1980 Education Act (DES, 1980) gave parents the right to be represented on school governing bodies. The 1981 Education Act (DES, 1981) gave parents new rights in relation to special needs. Local Education Authorities (LEAs) were to identify the needs of children with learning difficulties; they were to have assessment procedures for ascertaining these needs; and were to produce statements of SEN specifying how these needs would be met. The 1986 Education Act (DES, 1986) granted parents the right to equal representation with LEA governors in school governing bodies, as well as access to a range of issues such as exam results, criteria for admission and curriculum. Parents also had the right to detailed annual reports on their children whilst parents of children with SEN had the right to statements which described the support their children required (Gillard, 2007). By 1988, the 1988 Education Reform Act (DES, 1988) further entrenched the role of parents in the reform of schools and in the process of raising educational standards through greater involvement in decision making and governance of schools. These rights increased in 1991 with the "Parents' Charter" (DES, 1991) that gave parents the right to information about schools and their performance. Of note was that the Special Educational Needs Code of Practice, passed in 1994 (Department for Education/DfE, 1994) and later revised in 2001 (DfES, 2001a) that focused on the importance of PPPs and the individual education plans for children with SEN that were drawn up with collaboration with parents.

There was evidence that the legislation improved parents' position in the education settings and did increase their role within this setting. For example, there were findings that some parents of children with SEN did become directly involved with professionals in assessment, diagnosis and in some cases, were even supported to become teachers of their own children (for example, Daly, Addington, Kerfort and Sigston, 1985; Dessent, 1984; Pugh, 1981; Newson and Hipgrave, 1982; Mittler and McConachie, 1983; Wolfendale, 1983; Cunningham and Davis, 1985). There was also the emergence of PPP-based support programmes for families. For example, there were *"family centres,"* (Wolfendale, 1986, p32) based in pre-schools that encouraged parents to participate in school practices with staff (Tizard, Mortimore and Burchell, 1981). Some of these school practices included reading programmes such as the Portage Programme (Wolfendale, 1986) which were designed to encourage parents and professionals to work jointly to support children's reading development. There were also seminal reading projects including those in Haringey and the Hackney Parents and Children and Teachers (PACT) (Griffiths and Hamilton, 1984) and paired reading projects which were based on encouraging parents to come into primary schools to hear their children read (Stierer, 1984). Similar schemes proliferated across the country. By 1997, there were family literacy courses (where children and parents could learn together) in more than 60 LEAs (Gillard, 2007).

The reported successes of PPPs were balanced by findings in the educational legislation at the time which still seemed to favour professionals' views over parents' views. For example, despite the 1980 Education Act (DES, 1980) allowing parents to express a preference for a child's school, there was a still a caveat allowing LEAs to overturn a preference on the basis of inefficient use of resources. Whilst this was revised by the 1988 Education Act (DES, 1988) that did allow greater freedom of selection, there was still the proviso that the school, in question, could only accept the child if it had room to provide for the child's age and aptitude. Indeed, even in the 1996 Education Act (DfE, 1996), professionals could override a parents' choice for mainstream provision for SEN children solely on the basis of their superior knowledge and expertise (Paige-Smith, 2000). Even today, parents can argue for a chosen provision but there can be *"strong and clear reasons for going against what parents want,"* (DfES, 2001c, p12). This can include situations where the parent's preferred provision would be *"incompatible with the efficient education of other children,"* (DfES, 2001c, p9). Similarly, Wolfendale (1986) found that the decision making processes in programmes of professional and parent provided support such as Portage were still characterised by professionals as the *"senior partners,"* (ibid, p33) who made the *"executive decisions,"* (ibid): a point reflected by Lissner (1995) who added that professionals could be over-confident of their own skills and not those of the parents which had the potential for misunderstanding from both parties. The Inner London Education Authority (ILEA) identified some of the difficulties professionals felt they experienced when working with parents (ILEA, 1984). One teaching provision asserted that there are *"parents who don't care,"* and that *"you never get to see the parents you should see,"* (ILEA, ibid, paragraph 3.1.5).

These comments suggest that the divisions between parents and professionals were very much still entrenched within society, at this time. Findings suggest that professionals were still very much at the forefront of PPPs and certainly not discussing children's provision on equal terms (Dale, 1996) as per the goals of the PPP, recommended by Warnock. Additionally, there is an implicit suggestion that professionals did not always encourage parents to access the rights available for them. For example, Echols and Willms (1995) found that the middle and professional classes were typically the parents most likely to exercise the choices available to them as opposed to parents of other socio-economic backgrounds. The suggestion here is that only those individuals adequately articulate to voice their criticisms capitalised on any opportunities to support their children – a finding observed in personally experienced placements where those parents who are less articulate have more difficulties in accessing professional support and obtaining their goals. Such findings led Edwards, Ezzamel and Robson (2005) to conclude that:

> *"Individual parental power ... was more myth than reality," (ibid, p747).*

2.4.2 Parents' rights in the face of professional bureaucracy: since 2000

Under the Labour government, elected in 1997, there were further drives towards promoting PPPs fuelled by the Special Educational Needs Code of Practice (Code of Practice; DfES, 2001a) and the Special Educational Needs

Disability Act (DfES, 2001b). These underline the importance of viewing the child not from solely the needs perspective but as a whole child and therefore one whose family is an essential influence. The Code of Practice underlines more clearly than most other legislation the need for professionals to contact, empower, and involve parents with the implicit suggestion that parents will feel more confident of their role in education.

> *"Parents ... have a critical role to play in their children's education. ... It is therefore essential that all professionals (schools, LEAs and other agencies) actively seek to work with parents and value the contribution they make. The work of professionals can be more effective when parents are involved and account is taken of their wishes, feelings and perspectives on their children's development. This is particularly so when a child has Special Educational Needs. All parents of children with Special Educational Needs should be treated as partners. They should be supported so as to be able and empowered," (DfES, 2001a, paragraph 2.2).*

It is also clear in the Code of Practice that parents should also treat professionals with similar respect and have a responsibility to communicate with them (ibid). However, there is less emphasis on professionals' rights than there is on parents' – possibly in view of the findings of professionally top heavy parent-professional relationships. Instead, it is clear that professionals need to engage in more parent-friendly practices. The Code of Practice recommends that professionals take account of parents' feelings regarding their child and to be aware of and accommodate parents' needs, including, for example, being flexible when arranging interventions and timeframes for meetings (ibid).

These recommendations have been extended by the 2004 Children Act (DfES, 2004b) which again underlines the importance of valuing parental contributions, involving families in the process of support, such as by keeping up regular contact between them and professionals; empowering parents and professionals to come to key decisions about future provision and inspiring confidence in roles, whether they are parental or professional. The Act also promotes the need for greater inter-agency collaboration, regardless of parental input. The Act refers to the importance of all professionals making more effort to communicate and network with each other and with parents (ibid). This has been described as Multi-Agency working and can be viewed as a more extensive version of PPPs, emphasising as it does the importance of a wider set of inter-agency collaboration over and above parent-professional partnerships (ibid; DfES, 2004c, 2004d).

In response to an increased focus on PPPs, there are more PPP-style services in which parents and professionals are engaged. Parents can now access extended schools. These are wrap-around services based on the Sure Start initiative described earlier (Scott, O'Connor and Futh, 2006). They provide parents and children with support beyond the school day (between 8am and 6pm). Parents can also access parenting support opportunities (National Remodelling Team, 2006) that can provide education on how to develop parenting skills and promote family health, as well as offering crèches for children and job advice for parents (Lloyd, 2008). There is also access to family-learning sessions which enable children to learn with their parents (National Remodelling Team, op. cit), access to adult-learning opportunities (ibid) and quick referrals to specialist agencies, such as EPs (ibid; www.dcsf.gov.uk, 2009).

There are also designated Parent Partnership services (DCSF, 2007) which are monitored by the LA. These aim to promote parents' confidence in their relationships with professionals (ibid). They aim to achieve this by providing parents with a variety of supportive structures. They offer information on parents' rights, roles and responsibilities within the statutory assessment process (ibid); offer support during the statutory process, including before and after a tribunal and can direct them to relevant agencies, such as EPs and seek feedback on the provision of their service from parents (ibid). Feedback provides an important input into developing funding and budgeting plans, maintaining adequate resources and staffing and also allowing programmes to be flexible and responsive to local changes (www.parentpartnership.org.uk, 2009).

Some of the PPP style services available have made a difference to the parent-professional dynamic. For example, personal experiences on placement as a trainee EP showed that being able to access a multitude of views from both parents and professionals have helped to provide quick and holistic understanding of the child's needs. In the case of one girl with Autistic Spectrum Disorders (ASD), a PPP approach that addressed her whole needs led to GCSE grades that far exceeded her original predicted grades. At the same time, it helped teaching staff and parents appreciate the many ways in which this girl could be better supported at school to assist her progress. For professionals, in particular, it is recognised that PPP programmes can benefit them as well as parents. One PPP in Lancashire supporting children with ASD showed how professionals valued the insights provided by parents, especially in terms of their *"intimate knowledge of their child's strengths and weaknesses, likes and dislikes and strategies used at home which work during more difficult times,"* (www.teachernet.gov, 2009, p1). This information helped them develop and improve provision for these children and families, making them feel more, involved, empowered, contacted and confident of their own role therein (ibid).

The increases in parental rights have also led to parents feeling more confident to raise their concerns: indeed literature shows that a greater number of concerns are raised by parents than professionals (Nind, 2002; Wolfendale, 2002; Hunter-Carsch, 2001; Pinkus, 2003; Todd, 2003; Duncan, 2003; Rogers, Tod, Powell, Parsons, Godfrey, Graham-Matheson, Carlson and Cornwall, 2006). However, some of these concerns imply outward criticisms of professionally made decisions – a point that implies a lack of confidence for these very professionals. In particular, Asthana (2007) found that an increasing number of parents are appealing against LAs for refusing their first choice of educational provision for their child. Additionally, as provided in the Code of Practice, parents can and frequently do, contest the statutory assessment process (House of Commons Education and Skills Committee, 2006). In my own personal experiences, some parents are happy to be vocal with their dissatisfaction with the process and outcome of statutory assessment and are fully prepared to take the case to tribunal if required. This suggests that parents have become sufficiently confident and empowered to challenge professional decision-making. Indeed, part of the reason for their confidence is the encouragement and reassurance of other parents of their situation (www.healthtalkonline.org). In effect, parents can use their power to discredit professionals – this is a reflection of the potential for PPPs to empower parents whilst simultaneously disempowering and arguably creating an adversarial relationship rather than a true partnership.

Given this indictment towards professionals, it could be argued that professionals, if not losing their rights, are then, at the very least, forced to be more accountable. Indeed, professional accountability – the need to justify opinions and decisions made in the field – has become increasingly more dominant in educational legislation (DfES, 2001a, 2001b, 2001c, 2003a, 2004b, 2004c, 2004d). Arguably, this has made some professionals feel more vulnerable to public opinion (Reith Lectures, 2002). Even current day ministers such as Edward Milliband agree that professionals need to be given more *"space"* in order to work more effectively (Milliband, 2008, p4): a suggestion that professionals are in some way restricted by the current need for accountability to the public and perhaps, even worried and frustrated by parents' challenge to their professionalism. For example, one key change has been the increased administrative workloads, especially for Special Educational Needs Co-ordinators (who are responsible for supporting and recording provision for children with SEN in schools) (DCSF, 2009b; Dyson and Gains 1995; Stakes and Hornby, 1997).

Nevertheless, amid the benefits of the modern day PPPs, there are also clear challenges. Amongst several issues, Webster et al (2004) found that despite the use of a parent-professional collaboration known as the South West Autism Project (SWAP) and to a lesser degree the Applied Behaviour Analysis (ABA) programme, there were still family concerns that they were not taken seriously and that support was delayed. Similarly, families were upset about the delays in the statutory assessment process. At a broader level, Abbott et al (2005) felt that whilst such collaborations can make a positive difference to families in terms of managing children's complex healthcare needs, it can still fail to provide families with emotional support, with families feeling that they had *"no* *one to turn to for such support,"* (p236). This can include the practical difficulties of attending meetings with professionals especially if they cannot be as flexible as professionals in their time-scales (Hodge and Runswick-Cole, 2008). This suggests that there still needs to be more development in parent-friendly programmes to address this gap in PPP provision: there are still challenges to meeting the requirements of a PPP.

Additionally, it appears that despite over thirty years of legislative stipulations and associated interventions, parents are still not being involved in PPPs in that their wishes, feelings and perspectives are not extensively sought or addressed (House of Commons Education and Skills Committee, 2006):

> *"Too often...problems arise because parents feel ignored or that their views and preferences are not being given proper consideration under the current system," (House of Commons Education and Skills Committee, 2006, p37).*

This is a finding also reflected in the more recent Bercow Report (DCSF, 2008) and the Lamb Inquiry (DCSF, 2009a). These findings collectively suggest that parents' contribution to PPPs and education, in general, though theoretically powerful, remains in practice, marginal, relative to professional view points or what O'Connor (2008) calls the hierarchy of knowledge. In effect, PPPs seem to remain professionally top heavy. This is supported by additional evidence that professionals prefer *"to remain secure within their own habitus of 'expert',"* (Hodge and Runswick-Cole, 2008, p641) providing opinions which are expressed as absolute (Hodge, 2006; Runswick-Cole, 2007).

Perhaps, this is not a surprise as it could be argued that the whole rationale of a PPP has been *"designed by professionals for professionals,"* (O'Connor, op. cit, p265). There is also the point that some parents may not wish to be as involved as others in the PPP. This point has been suggested by Hartas (2006) who identified that whilst some parents want an interactive relationship with professionals, some may prefer the popularised model of a market-driven relationship where they are a consumer and others may wish to be passive recipients of services. Such findings underline the fact that not only are there gaps in perceptions between parents and professionals but also between parents themselves over what constitutes an effective PPP. Arguably, the procedure of collecting multiple perspectives is always going to present itself as methodologically challenging (Gray, 2001), an issue further discussed in Chapter 4; nonetheless, this would suggest that the value of both parental and professional contribution to PPPs and more broadly, education has yet to be properly recognised.

2.5 Summary

This Chapter has considered the developments that have taken place to shape PPPs. Whilst evidence suggests that parents have taken on a greater role in the educational arena, there are still findings identifying their weak position relative to professionals. This is especially true in some areas of SEN, such as the statutory assessment process and in parent-professional meetings. Some researchers such as Hodge and Runswick-Cole (2008) imply that parents are still in weakened positions relative to professionals and that more parent-friendly measures need to be implemented before the goals of PPPs are realised and specifically, parents and professionals are on the same level. This appears to be especially true in terms of gaining parents' perspectives on the quality of PPPs.

The next Chapter considers in detail the needs of families of children with ASD and the extent to which a PPP can meet these needs.

CHAPTER 3: PARENT-PROFESSIONAL PARTNERSHIPS AND AUTISTIC SPECTRUM DISORDERS

3.1 Introductory comments

The previous Chapter demonstrated the positive contribution that Parent-Professional Partnerships (PPPs) can make to child development and highlighted some of the challenges in achieving an effective PPP. However, to understand the full impact of a PPP on children with Autistic Spectrum Disorders (ASD), it is important to extend the review of this evidence base. This entails a more detailed review of the needs of a child, including the characteristics of ASD, before greater consideration of the needs of parents and professionals who care for and support children with ASD. Finally, there is a review of existing PPPs for families of children with ASD and a discussion of the extent to which these PPPs empower, involve, promote effective contact and raise the confidence of parents.

3.2 Characteristics of ASD

It is important to understand the profile of a child with ASD as their presentation can help explain any challenges that parents and professionals need to address when supporting these children.

ASD is a triad of core impairments in social interaction, communication and behavioural flexibility (American Psychiatric Association/APA, 2000). A child with ASD can show different levels of need within each of component of the triad, hence it is a spectrum (ibid).

The difficulties a child can experience when placed in social situations can include difficulties in using appropriate non-verbal social communication such as eye-contact, facial expressions, body postures and gestures (ibid). Children with ASD can also show a lack of interest in sharing enjoyments or achievements with those around them and a lack of reciprocal communication (ibid) such as playing with other children and a lack of imaginative play. Bejerot (2006, pp64-65) highlights the continuum of social needs that these children may present as varying from *"aloofness and indifference to active but inappropriate social approaches"*.

Children with ASD can present with marked communication difficulties. The APA describes these in terms of a delay in the development of spoken language (APA, op. cit); difficulty in initiating or maintaining a conversation with others and stereotyped and repeated language. Again, these communication needs exist on a continuum that can range from a total absence of any communication be it non-verbal or verbal (with the exception of disturbed behaviours) (Bejerot, 2006) to fluent communication but typically used in an ego-centric manner to explain things of interest to the speaker (ibid). Echolalia (repeating back utterances) is also a common communication nuance (Carlson and Moses, 2001).

Behavioural difficulties can present as rigid and sometimes obsessive behaviours (Harris, Best, Moffat, Spencer, Philip, Power and Johnstone, 2008). These can be typified as restricted and repetitive interests and behaviours (ibid) which have been described as Obsessive Compulsive Disorder (Bejerot, 2006). This is a description disputed by Baron-Cohen (1989) although Bejerot cites what can be described as obsessive-compulsive tendencies that include *"repetitive ordering, hoarding, touching, tapping or rubbing and self-damaging or self-mutilating behaviours,"* (Bejerot, op. cit, p71).

Alongside the triad are comorbid features, including an inability to deal with over-stimulation or under-stimulation (Rutter, 1966), for example excessive noise or silence; in some cases the presence of Attention Deficit Hyperactivity Disorder (ADHD) (National Institute of Mental Health/NIMH, 2003); and difficulties with imagination that can co-create problems with empathising with others (Macintosh and Dissanayake, 2004). Asperger's Syndrome exists on one end of the spectrum and can be viewed as a less severe form of ASD (Connor, 1999). It differs from other ASDs by its relative conservation of language and cognitive development (Akshoomoff, 2006). Debate is still ongoing as to the position of one other ASD, High Functioning Autism (HFA) (ibid) and whether Asperger's Syndrome is a form of HFA or a separate disorder (Frith 2004; Macintosh and Dissanayake, 2004).

In practice and for young children with ASD, these difficulties can often manifest themselves in lifestyle difficulties that encompass the greater part of each day and therefore impact on the families and extended community around them. Social play can be halted because the child is distracted by their repetitive behaviours or compulsive tendencies (Peeters, 1997; Veale, 1998) whilst the introduction of a new game can cause anxiety to a child with ASD who prefers restricted and repetitive interests (Harper, Symon and Frea, 2008). As Harper et al underline, *"without interventions that focus directly on social and play skills within the context of the classroom, children with Autism continue to exist in isolation even though they are within a rich social environment,"* (ibid, p816). Not surprisingly, there is a high risk for any child with ASD to experience chronic loneliness, alienation, social anxiety, such as bullying and low self-esteem (Jobe and White, 2007) despite findings that these are not necessarily the desired states for these individuals (ibid). Moreover, the delays children with ASD experience in domains such as language and social interaction can impact negatively on their cognition leading to further delays in achievement scores (NIMH, 2003). Some parents feel that these children's needs cannot always be met by schools (Batten, Corbett, Rosenblatt, Withers and Yuille, 2006).

The difficulties that children with ASD face can become more pronounced over time and therefore can contribute to increased levels of stress for families (Li-Ching, Harrington, Louie and Newschaffer, 2008). Adolescence is a crucial period when many kinds of social behaviours are developed and a time when these individuals can become more keenly aware of their relationship difficulties (Tse, Strulovitch, Tagalakis, Meng and Fombonne, 2007).

ASD presents to parents and professionals as a diverse spectrum of needs. Current figures suggest one child in every 100 is diagnosed with ASD (National Autistic Society, 2009). However, it is believed that many cases remain undiagnosed (Baron-Cohen, 2009) which if addressed would increase this prevalence figure.

3.3 Implications of ASD for parents and professionals

In considering the implications of ASD for families, it is evident from the literature that families can feel anxious, disrupted and stigmatised by those around them. These stressful feelings can occur both in and out of professionally-based services. They can occur during the diagnosis process but also during those times where professional support is less available, such as evenings, weekends and holidays. These are issues that clearly can affect parents and so require further examination. In considering these implications and in keeping with the area of this study, reference is also made to the professionals' role in the family and the extent to which they help parents and themselves to address the child's needs. These discussions can help to outline the issues that PPPs should be exploring and supporting.

3.3.1 The challenges of the diagnostic process

Most ways to diagnose ASD comply with broad governmental recommendations (DfES, 2002) and involve parent and professional-led checklists (Baron-Cohen, Allen and Gillberg, 1992; Baron-Cohen, Cox, Baird, Swettenham, Drew, Nightingale, Morgan and Charman, 1996; Robins, Fein, Barton and Green, 2001; Berument, Rutter, Lord, Pickles and Bailey, 1999; Rutter, Lecouteur and Lord, 2003; Gray and Tonge, 2005; Swinkels, Dietz, van Daalen, Kerhof, van Engeland and Buitelaar, 2006) whereby parents and professionals compare observed behaviours of the child with the formal criteria for ASD (for example, the International Classification for Diseases/ICD-10, World Health Organisation, 2007). What this might entail is summarised in the National Autism Plan for Children (National Initiative: Autism Screening and Assessment/NIASA, 2003) which is accessible to all LAs. It recommends a

Multi-Agency approach to diagnosis with clear time-frames for assessment; the promotion of training of professionals in the knowledge and awareness of ASD; the active involvement of families in care planning and procedures and the creation and implementation of national networks of support for ASD.

However, my personal experiences identify that PPPs are rarely involved in the diagnosis; instead, most processes involve just a few single agencies meeting to discuss the child's presentation, such as GPs, Speech and Language Therapists, Educational Psychologists (EPs), Psychiatrists and Clinical Psychologists. It is also evident that it is still the professionals who make the final diagnosis (Baird, Charman, Baron-Cohen, Cox, Swettenham, Wheelwright and Drew, 2000). Moreover, it is clear that despite or possibly because of their involvement, many parents find the diagnosis process very traumatic (Jupp, 1992). Perhaps this is hardly surprising given that parents naturally want their children to be healthy and happy and to progress easily into adulthood (Benderix, Nordström and Sivburg, 2006). However, it seems that their unease during this time is not addressed by the very professionals that are contributing to their traumas.

Large scale evidence (n=>100) from Mansell and Morris (2004) and Oberheim (1996) shows that parents in the UK find the diagnostic process for ASD and by default the professionals, slow, chaotic, and badly handled. These results were mirrored by a smaller set of four interviews conducted with parents in Wales by Midence and O'Neil (1999). Findings prompted Mansell and Morris (2004) and Brogan and Knussen (2003) to emphasise the importance of early and speedy diagnosis to reduce parental stress. Additionally, Hodge (2006) found that some professionals do not involve parents in the final decision-making process that determines whether their child has ASD, a finding prompting him to imply that parents therefore feel confused about how decisions have been reached. It is also true that the language used by professionals is not always open and that this can create further confusion for the parents involved. For example, Brogan and Knussen (op. cit) found that parents were more satisfied with professionals who allowed them to ask questions at disclosure.

3.3.2 Parental anxiety

Given their familiarity to the child – a point raised in Chapter 2 (section 2.2) – it is no coincidence that it is parents who are usually the first to recognise that their child is displaying ASD (Gray, 1994). However, this identification can also be pre-empted by a general parental anxiety over their child's behaviour (Howlin and Moore, 1997). This anxiety can often be exacerbated by the feeling that they are in some way responsible for their child's behaviours (Midence and O'Neil, 1999). Significantly, such stresses are found to be higher in parents of children with ASD than those parents with other developmental difficulties. For example, research shows that parents of children with ASD more frequently report indicators that their children have diminished quality of life and have higher levels of concerns about their child's well-being than do parents of children with ADHD or children with a normal trajectory (Li-Ching et al, 2008). The stresses parents can present and arguably need to discuss at a PPP can include: difficulties with child-care; difficulties in maintaining job; child's absences from school; diminished participation in activities and in community life (ibid); and financial stresses (McCubbin, Cauble and Patterson, 1982). Of the latter finding, research suggests that it is public contact and family outings that can be particularly challenging for families of children with ASD because of the odd behaviours displayed by children with ASD (Bouma and Schwietzer, 1990; Gray and Holden, 1992; Howlin, 1988).

These stress factors can produce a range of severe problems for parents, (Blacher and McIntyre, 2006; Schuntermann, 2002) such as depression and dysphoria (Wolf, Noh, Fisman and Speechley, 1989) and disruption to family life (Dunn, Burbine, Bowers and Tantleff-Dunn, 2001). In addition to the impact on the parent and on the family, high levels of stress can impact negatively on the ability of the parent to engage with their child with ASD (Konstantareas, Homatidis and Plowright, 1992). Irrespective of the source of this reduced involvement of parents with their children with ASD (for example, the nature of the ASD, difficulties with engagement, parental stress etc.), this difficulty may also extend to the interventions given to the children (for example, Boyd and Corley, 2001). A relative lack of involvement with the intervention may exacerbate the stress-related problems experienced by the parent (Lecavalier, Leone and Wiltz, 2006; Osborne, McHugh, Saunders and Reed, 2008). I have also observed that whilst parents value the professional support given to children, it can be sometimes very painful for them to witness their child at the hands of so many relatively unfamiliar and wide ranging professionals. In one case, a parent, known to me on placement felt that their child was being seen not so much as an individual but a range of different parts, each of them belonging to the remit of a specialist professional. This is an argument frequently voiced by researchers who equally discuss the child as *"disassembled"* and in need of being put back together (McKnight, 1995, p45) – a rather harsh and challenging prospect for arguably both new and experienced parents.

Furthermore, the stresses of ASD that are experienced, seemed to fall more on mothers than fathers (Hastings, Kovshoff, Brown, Ward, degli Espinosa, and Remington, 2005, Hastings, Kovshoff, Ward, degli Espinosa, Brown and Remington, 2005; Lecavalier et al, 2006). Additional data suggests that mothers take more responsibility for liaising with professionals than fathers (Vincent, 2000). Whilst it has also been found that the stress between them is equal but manifested in different ways (Hastings, Kovshoff, Ward, degli Espinosa, Brown and Remington, 2005), there is, nonetheless, a paucity of literature on the coping mechanisms of fathers of children with ASD relative to mothers (Rodrigue, Morgan and Geffken, 1992; Phares and Compas, 1992; Cassano, Adrian, Veits and Zeman, 2006). This could lead to fathers being neglected in research studies (ibid) and neglected in supportive programmes (Altiere and Von Cluge, 2009).

3.3.3 Family disruption

One other area PPPs should consider is that of the family disruption common to some homes of children with ASD. For example, parents can experience difficulties trying to discuss their child's autistic behaviours with even members of their own family in order to avoid any "blame" being attributed to the parents (Gray, 1994). Other difficulties relate to the way in which to deal with the siblings of children with ASD. Some studies suggest that having a child with ASD in the family places other siblings at increased risk of externalising and internalising adjustment problems (Bågenholm and Gillberg, 1991; Gold, 1993; Rodrigue, Geffken and Morgan, 1993). Gold (1993) found higher levels of self-reported depression in siblings of boys with ASD compared to siblings of normally developing boys. However, this finding was limited by the greater proportion of adolescents in the group of siblings of children with ASD. Nevertheless, an increasing volume of literature emphasises that siblings of children with ASD can often become marginalised as a result of the attention spent on the child with ASD (Reed, 2007): this can place parents in a stressful position when trying to tend to the differing needs of the family.

These findings highlight the importance of a PPP providing emotional support not just to the parents but also to the children with possibly tailored interventions for siblings on ways in which to address their own needs safely and positively. In all credit to the government, professionals are directed to liaise closely with parents so that the home environment supports any intervention in the school or pre-school setting and vice versa (DfES, 2002). More pertinently, it stresses that families affected by ASD (including siblings and the extended family) should be able to access support for their emotional and material needs from professionals with knowledge of ASD and family support (DfES, 2002). However, there are still clear demands for more emotional support for families; these demands are raised by both families and professionals (Abbott et al, 2005).

3.3.4 *Social stigma*

In addition to feelings of anxiety and disruption, Revill (2007) identified that families can be stigmatised because of a child's supposed differences to other children:

> *"For most families, the biggest impairment of all lies in the inability of others to accept their children, and to accept that they have particular educational needs that don't slot neatly into any easy category," (Revill, 2007, p1).*

Revill argued that this is even more apposite to those families on low income, attributable in part to difficulties such families often face in articulating their concerns and in financing the strategies to address them (ibid) – a point that has been raised in Chapter 2.

Social stigma can lead to feelings of exclusion from mainstream society and services for the child with ASD and for the family unit as a whole (Petrie, Knight, Zuurmond and Potts, 2007). Shelley (2002) finds that families universally feel that these problems were particularly apparent in holidays and out of school time, and as a result parents found their children were difficult because there was an absence of activities specifically for them. Where there were activities, many families felt disrespectful attitudes and a lack of understanding from members of the public (ibid).

Personal experiences when on placement as an EP suggest that families can feel threatened by what they consider a lack of understanding or consideration on the part of community figures. Likewise, they feel that there is little that they can do to address this problem. The goals of a PPP are to help parents feel confident yet these examples suggest that confidence can be very low on the part of some families, especially during out of hours times, such as after-school, holidays and weekends. Arguably, professionals have tried to stem this problem with the use of wrap-around services (see Chapter 2) that extend the school day so as to provide support between 8am and 6pm on a daily basis during the school week. Personal experiences show that there are also holiday schemes set up by professionals but these vary across Local

Authorities (LAs) and most demand payments and are not guaranteed to accommodate children with Special Educational Needs (SEN). Those that do, for example some London boroughs, cannot accommodate every child with SEN during the holidays, which means that there will always be pressure on parents to accommodate children on their own. Some parents that I have engaged with complain that what they would really like, is not so much, a designated provision for the summer months but some form of guaranteed outreach support that they could turn to if necessary that could help them cope with any feelings of stigma and help increase their child's sense of inclusion in the community.

3.3.5 The challenges of ongoing support

It is recognised by the government that it is important that professionals support parents of children with ASD (DfES, 2002). In particular, they should maintain their partnership with parents with regards to planning for and implementing provision following diagnosis:

> *"To offer no intervention once children have received an ASD diagnosis is no longer a defensible option for service providers," (Webster et al, 2004, p26).*

DfES (2006b) emphasises the importance of professionals communicating to parents their specialist skills and knowledge. However, there are challenges in providing this support. First, not all professionals have the necessary skills to communicate their knowledge effectively:

> *"Many professionals (e.g. health visitors) leading training on parenting skills are very knowledgeable about parenting, but aren't skilled adult tutors," (DfES, 2006b, p50).*

Second, professionals can often, in seeing themselves as the experts, fail to acknowledge the importance of parental knowledge which can, in turn, lead to an impaired relationship between parent and professional (MacNaughton and Hughes, 2001):

> *"The more that staff proclaim their professional expertise, the more likely they are to dismiss or ignore parents' untrained and unprofessional knowledge of their children as inadequate, misguided, or just plain wrong," (MacNaughton and Hughes, 2001, p1).*

This finding can explain recent evidence that parents do not obtain enough satisfactory advice and support in their parenting role (Social Exclusion Unit, 2000). This can lead to differing viewpoints between the parents and professionals about areas of support such as provision for the child (Connor, 1997). Third, there can be an inadequacy of professional support for parents, which can damage the parents' trust in the professionals' understanding of their child's needs (O'Connor, 2008; Brogan and Knussen, 2003). There can even be a fear from parents that their views and attitudes once given, will offend professionals (Runswick-Cole, 2007; Hodge and Runswick-Cole, 2008). Arguably, a lack of trust can challenge the mutual confidence that is necessary, between these parties to establish an effective PPP.

If parents do not feel confident in interacting with professionals, the professionals in turn may have less confidence in parental ability to support their children. Kontoniemi, Poikonen, Lerkkanen, Poikkeus, Niilo and Kikas (2007) report that professionals would have more confidence in parents if they opened up about the needs of their children. Research shows that a lack of parental confidence in professionals can lead to frustration, stress, depression, helplessness, and overall dependence on service providers, such as the professionals in a PPP (Brookman-Frazee and Koegel, 2004). Equivalently, research highlights that too often professionals are over-confident of their own skills and not those of the parents which can lead to misunderstanding from both parties (Lissner, 1995).

A lack of confidence is frequently cited as a frustration for both parents (Essex and English, 2001; DCSF, 2009a) and professionals (Preece and Jordan, 2007). Sadly, evidence suggests that PPPs are often characterised by a lack of confidence between the parties but more commonly from the parents towards the professionals (DeMyer, 1979). DeMyer (ibid, p177) found that parents whose children experienced the diagnostic process of ASD *"named* *three times as many complaints about professionals as admired qualities"*. These complaints included professionals appearing impatient, taciturn and using big words without providing explanations. Also, parents reported feeling especially angry when professionals failed to listen or believe what they said (ibid). More recent work by Billington et al (2000) found that one family of a child described as being autistic became *"disaffected with professionals"* who mostly *"failed to address [their] conflicting feelings,"* (p62) and did not appear to value the observations they made. Instead they describe feeling disempowered, a feeling which was compounded by the focus on his *"impairments, difficulties and problems,"* (ibid, p62). Similarly, Hodge (2006) reported that parents in the UK were often not happy with the imbalanced focus on a child's difficulties as opposed to strengths. Hodge also commented that the US system placed a greater emphasis on a child's abilities and was less open to this criticism. One explanation for this discrepancy could link into additional findings that both parents and professionals feel that teaching professionals require more training in SEN than they currently have (House of Commons Education and Skills Committee, 2006). This deficit in training has been described as applicable to all levels of the teaching scale, including trainee to fully qualified teacher (ibid). It is also acknowledged that without this training, teaching professionals will not confidently be able to carry out their role in supporting children with SEN, such as ASD. This suggests that more support is needed for professionals to understand the needs of families. Given the findings, perhaps this support is best provided at the level of teacher training although it also seems wise to provide more rigorous continual professional development (CPD) to address ongoing concerns. Currently, the government is promoting CPD in schools via its Inclusion Development Programme (IDP) (www.standards.dcsf.gov.uk). The IDP aims to increase the confidence and expertise of school staff, such as teachers and teaching assistants, in areas of SEN. Incidentally, 2009 is the year in which the IDP focuses on ASD. However, any successful findings that have resulted from the work undertaken by the IDP are limited, possibly due to its recent implementation (DCSF, 2009c).

3.3.6 Schools and the problem of inclusion

Educational policies towards supporting children with ASD and SEN more generally have evolved significantly since the 1970s. Most notably, educational policies direct LAs towards a policy of inclusion, whereby all children, where possible, should be educated in the mainstream (DfES, 2001a, 2001b). This is a positive response to the fact that they are not, as was the historical belief (see Chapter 2), educationally sub-normal and in need of only health support, but in reality, were capable of and had the right to an inclusive education. Moreover, their needs in the mainstream are, where possible, accommodated – for example, many children with ASD will require the curriculum to be taught more explicitly than a normally developing peer. They may require *"detailed and structured questions in order to complete any 'problem solving' exercises,"* (DfES, 2003b, p44), prompts to help them focus on work-demands and links between their work and their personal interests in order for them to make more sense of the task in hand (ibid). Where standard mainstream provision is insufficient, the child can be offered more intensive support via a funded statement of SEN. This can provide them with access to support over and above what is typically offered by mainstream provision: this can include additional support from specialist professionals (www.nas.org.uk).

Such findings suggest that professionals are positively involved in the lives of children and families and moreover, contributing in a constructive way towards these individuals' wellbeing. However, research still suggests that despite such support, the children themselves are not always fully included in mainstream activities. Indeed, Revill (2007) found that 21 per cent of children with ASD will end up excluded from school at some point in their lives, either for a fixed period or permanently. This is higher than the rate of exclusion as a whole (www.autismeducationtrust.org.uk). Such findings question the success of any input professionals and parents are providing for these children and the extent to which the PPP concept is actually working to engender a better and more inclusive future for these children.

There are additional services that similarly posit the PPP approach and have a relatively better record for inclusion: two popular ones are EarlyBird and EarlyBird Plus.

3.3.7 EarlyBird and EarlyBird Plus and limited data-sets

EarlyBird and EarlyBird Plus are two options that adopt the PPP approach and are available to parents of children with ASD. Other support groups include the Bexley LA Parents of Autistic Children Training and Support (PACTS), a home and nursery based programme that offers professional support for families to help support children's daily life skills, such as communication and social skills; and the ASD Monitoring and Support Group, on which this study is based. The EarlyBird and EarlyBird Plus Programmes were developed by the National Autistic Society (NAS) and are the most common programmes reliant on PPPs for families of children ASD.

Both programmes support families whose children have received respectively a diagnosis around the age of four years – the typical age for diagnosis (Rhoades, Scarpa and Salley, 2007). The programmes address the needs of both home and school settings by training parents together with a professional (such as a teacher or EP) who is working regularly with their child. Both aim to focus on the context of the child, namely, parents and other family members. The programmes teach about ASD before considering how to develop communication or manage behaviour (key areas of difficulty for children with ASD). A key principle of the programmes is the need to build confidence in both parents and professionals so as to encourage the teams to work jointly in favour of the target child. The programme spans a three-month period with parents being committed to weekly training sessions (3 hours) or a home visit, plus continual support with their child (www.nas.org.uk; Connor, 2008). Training involves professionals supporting parents to understand the causal basis of ASD and its presentation; to create interactions for the child to develop communication and to address behavioural difficulties (ibid). Some strategies include Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) (see Chapter 1) and the Picture Exchange

Communication System (PECS) where pictures are used as a form of communication. EarlyBird is used for pre-school children and EarlyBird Plus is used for children aged between four and eight years. All children must have a diagnosis of ASD (www.blackburn.gov.uk).

Both programmes claim to increase the knowledge, skills and understanding of the participating parents which in turn lead to improved social and communication behaviours in their children (NAS, 2007). Shields (2001) identified that these programmes were popular with parents. Hardy (1999) found improved child behaviours, particularly increased communication and social engagement and lowered parental stress levels following eight weeks of the programme. However, the research methodologies used by Shields and Hardy are open to question – Hardy used a data-set of only 30 families and restrictive measurement tools (time durations of physical contact between child and parent and child and toys and the number of words used by parents in exchanges with their child). Engwall and MacPherson (2003) identified improvements to parental stress-load and child behaviours following participation in EarlyBird and EarlyBird Plus, although they also relied on a small data-set of 24 families with only parent-reported data. Morris' (2002) and Shields and Simpson's (2004) studies also showed similar improvements in parental stress and child behaviours. However, both used only parent-reported data, limiting the scope for findings. Even more recent studies such as Whitaker's (2007) offer vague reportage with findings linked to broad and methodologically limited postal questionnaire.

Finally, the reality is that not all parents can obtain access to this provision (Evans, Castle, Barraclough and Jones, 2001). Evans et al identified that EarlyBird and EarlyBird Plus provision is irregular and not fully developed. There are only a limited number of NAS branches nationwide which can provide this support (www.nas.org.uk) and personal experience identifies that not all LAs are willing to fund this provision and if they do, it is very much limited to a small number of families.

3.4 Summary

This chapter has identified a number of criticisms of existing programmes for ASD. Several of these criticisms concern the design of current programmes for ASD. Some parents feel that the help they require is beyond the scope of current ASD provision. For example, parents would like more support in the holidays and at weekends (Shelley, 2002; Petrie et al, 2007). Without this support, there is arguably a lack of wrap-around care for these individuals. Parents would also welcome support that enables their emotional needs to be addressed (Abbott et al, 2005). Additionally, research findings identify the need for more focus on the provision for siblings of individuals with ASD (Reed, 2007); the importance of providing quicker and more consistent diagnosis procedures (Mansell and Morris, 2004; Brogan and Knussen, 2003; Oberheim, 1996; and Hodge, 2006) and more training for professionals, to feel themselves, more equipped to support families (House of Commons Education and Skills Committee, 2006).

There are also criticisms that suggest that parental perspectives on PPPs still need to be more extensively sought and recorded in the process of supportive programmes for ASD (Frederickson et al, 2004; O'Connor, 2008).

These criticisms are referred to again in the next Chapter which considers the methodology adopted in this study.

CHAPTER 4: METHODOLOGY

4.1 *Introductory comments*

This Chapter sets out the research questions of the study; the chosen theoretical and conceptual framework; an overview of the Monitoring and Support Group (MSG) in the focus Local Authority; the research design; data analysis and the procedure for data collection. It then moves on to consider issues of validity and reliability; the position of the researcher and ethical implications of the study.

4.2 *Research questions*

This study aims to explore the perspectives of both parents and professionals involved in the subject Parent-Professional Partnership (PPP). The specific questions that it attempts to address are as follows:

1. How confident are parents and professionals, respectively, when supporting the needs of children with Autistic Spectrum Disorders (ASD) and to what extent is their respective confidence influenced by the PPP?

2. How involved are parents in the PPP?

3. How empowered are parents in the PPP?

4. Is contact between parents and professionals in the PPP valued by both parties?

These research questions have, so far, been discussed with reference to the existing literature. They are now discussed with reference to the existing research paradigms that have been employed to explore PPPs and to the research paradigm selected for this study. This information helps put the study in perspective in terms of its structure and approach. In this way, issues of validity and reliability will be explored so as to maintain the robustness of this study.

4.3 Theoretical and conceptual framework

4.3.1 Philosophical concerns raised in previous research into PPPs

Literature suggests that an important weakness in past research on PPPs, such as EarlyBird, arises from philosophical weaknesses in the ontological and epistemological perspectives employed. The ontological perspective in these studies appears to be that truth revolves around facts not opinions and as such their epistemology should be solely Positivist. Whilst a Positivist would believe that this enables a measurement of success via numerical data, it avoids a deep analysis of the attitudes and feelings of those involved. The absence of this Interpretivist epistemology could lead to a unilateral view of PPPs. For example, parents and professionals may assume that their only purpose in a PPP is to create a value-added system of support where success is measured by numbers and feelings are ignored and avoided, marginalised and discounted. This is unlikely to be the view of the government – as evidenced by the increasing body of educational legislation emphasising the role of parents as well as children and common usage of phrases such as "Every Child" and "Every Parent" in government literature. Similarly, it is unlikely to be the view of parents, as evidenced by the increasing body of literature that highlights the need for their greater involvement in their child's development (for example, House of Commons Education and Skills Committee, 2006; Abbott et al, 2005). Nevertheless, it would appear that research in PPPs has yet to catch up with the thrust of policy.

4.3.2 Chosen philosophy: the use of Pragmatism

To begin to address some of these concerns, and improve our understanding of PPPs, this study considers both the perceptions of participants and the outcomes of PPPs. As such, the overriding ontology is that facts and opinions both have a place in this research and as such force the need for both Positivist and Interpretivist epistemologies. There is a debate as to whether this mixing of epistemologies is theoretically valid. Indeed, purists would argue that philosophies such as Positivism and Interpretivism exist as single entities and cannot be mixed because each views the truth and knowledge in different ways. Positivism is based on the idea that that which is real is based on that which can be experienced – and that research involves observation and statistical measurement of data; in line with this, it also necessitates that the researcher is neutral throughout the research process (Finlay, 2002). In contrast, Interpretivism believes that all knowledge is a matter of subjective interpretation and this is normally understood by relating these interpretations to themes that recur in the data-sets; as it necessitates subjective interpretation, it is a given that the Interpretivist research is more likely to become less detached from the research process than the Positivist researcher. However, and given the polarised views of interpretation in both Positivism and Interpretivism, Pragmatism argues that truth is a hopeless pursuit as knowledge is always changing and exists merely as a product of our time (Denscombe, 2007). This is the Pragmatist theory and is the one that serves the purposes of this study well, challenging as it does the traditional philosophical debates over dualisms such as Positivism and Interpretivism and instead enabling us to view reality as a more fluid and accessible place where both theories can co-exist. Indeed, Pragmatism is a popularly chosen philosophy to explain the changing natures of truth and knowledge accepting as it does the opportunity to mix and adapt epistemologies (Denscombe, 2007).

As this study aimed to consider both perceptions and outcomes of a PPP, the Pragmatist theory was used. Denscombe identifies five core ideas of Pragmatism:

1. "Knowledge is based on practical outcomes and what works; the key criterion for judging knowledge is how useful it is perceived to be and how well it works when applied to some practical problems;

2. Research should test what works through empirical enquiry;

3. There is no single best scientific method that lead the way to indisputable knowledge;

4. Knowledge is provisional, what we understand as truth today, may not be seen as such in the future. Knowledge is seen as a product of our times. It can never be absolute or perfect because it is inevitably a product of the historical era and the cultural context within which it is produced. The quest for absolute truth is consequently seen as a hopeless cause;

5. Traditional dualisms in the field of philosophy and science are regarded as not helpful; in particular, there is scepticism about the distinction between quantitative and qualitative research but there is also a rejection of distinctions like facts/values, objectivism/subjectivism and rationalism/empiricism,"

(Denscombe, 2007, p117).

Key to these ideas is the argument that the focus of any Pragmatist research should be on whether the research methodologies employed answer the research questions presented (ibid). In Denscombe's words *"what answers my question?"* (ibid, p117) is the guiding principle within Pragmatist research. In practice, this means that the traditional paradigms of research, Positivism and Interpretivism, are brought together and emphasis is placed on elements of each which can be combined to good effect (ibid). Ultimately, Pragmatism revolves around the idea that the *"end justifies the means,"* (Doyle, Brady and Byrne, 2009, p178) and in this sense, Pragmatism is a very practical "friend" of the researcher.

4.4 Merits of the chosen theoretical paradigm

The strengths of Pragmatism revolve around its inherent flexibility. Pragmatism enables the "best bits" of other philosophies to be used and explored, enabling research to be less restricted and free of the limitations around which the research process is commonly placed. The fact that Positivist studies should rely only on data that is measured restricts the opportunities to make interpretations on that data; instead, the researcher must only state what is real as viewed through the narrow and tinted view of a rigid philosophy. Instead, Pragmatism searches for a *"meaningful consensus"* in pluralistic settings such as Positivist and Interpretivist contexts (Parker, 2006, p572).

These very strengths can also be viewed as weaknesses (ibid). It is claimed that Pragmatism is an *"anti-philosophy"*, reducing as it does the traditionally held philosophical and ethical disputes (Johnson and Onwuegbuzie, 2004, p18) which have arguably produced the most robust results. Pragmatism rejects the notion that there must exist dualisms such as Positivism versus Interpretivism. Instead, Pragmatism claims that both can be integrated and used as a methodological approach. In this way, it could be implied that Pragmatism lacks robustness, being as it can be a watered down and mixed version of philosophies that make no attempt to negotiate, rationalise and justify these disputes. Indeed, Pragmatism has been criticised as being unable to clearly describe the practical methodological principles and corresponding conceptual frameworks for research (Ulrich, 2007). This can limit the ethical rigour of the work carried out (ibid). To address these limitations, I consistently accounted for the validity and reliability of my study through ensuring reflexivity via a research diary (see Nadin and Cassell, 2006).

4.5 Overview of the chosen PPP

4.5.1 The ASD Monitoring and Support Group

The MSG aims to support those involved in educating and caring for children with ASD as well as the child, itself. The MSG provides training to both schools and families. Also, it gives families ongoing support, including via a three monthly telephone call. This support is reviewed in professional team meetings six times a year. In this respect, the MSG can be considered to provide both interventions and reviews of these interventions, in effect, monitoring and support.

In contrast to behavioural support programmes such as Applied Behavioural Analysis (ABA) and the Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) which ultimately reframe a child's behaviours (www.researchautism.net, 2009), the MSG has a systemic approach, aiming to provide to parents and professionals the resources and strategies to support the child, without trying to change the child.

In line with a PPP (see Chapter 2), the professional members of the group are wide ranging, including those from both Health and Children's Services – for example, Paediatricians, Speech and Language Therapists, Clinical Psychologists, Educational Psychologists (EPs), specialist ASD teachers and Social Care Workers. Any parent can become a member of the MSG providing that their child has received a diagnosis of ASD. Their children must be primary school aged, between four and 11 years.

The MSG offers flexible training programmes for parents and professionals in ways in which to support children with ASD. Training which can be both online and face-to-face regularly takes place to support teachers and related staff, such as teaching assistants, as well as parents, to understand and use appropriate strategies to empower and progress children with ASD, for example, the use of social stories and visual time-tables. These usually take place in the school settings and on a fortnightly basis. Also, there are more informal meetings where parents and professionals can share information and strategies to support their child with ASD. Strategies can include anxiety-reducing strategies and visual communication strategies. These usually take place on a monthly basis.

Also, the MSG provides specialist resources and equipment; regular forums to discuss and address parents' and professionals' challenges; advice; and for parents, a professional contact who will telephone all parents every three months to offer further guidance and support. The professional contact is known as the key contact. This role is a key element to the group. The key contact can be any one of the listed professionals from this multi-professional team. The key contact can give advice at any time, over and beyond that provided in training sessions. The key contact will usually provide this advice in the three monthly telephone calls – for example, ways in which to help a child feel more sociable and included within the family and school settings and ways in which to reduce the stress load for parents and family members.

For the purposes of this study, the PPP is considered to be the interaction that parents have directly with the MSG, as well as with the in-school professionals, who have also had training from the MSG.

At the time that this study was conducted, the MSG had been in operation for two years. At the same time, there were 39 parents involved in the group and 15 professionals.

4.5.2 Sample

Twelve people, six parents and six professionals, were selected for this study. The original number was 14 but one parent and one professional were unable to attend the interviews.

The 12 people sample was selected, at random, from the MSG. Probability sampling was used. This involved random selection (Bryman, 2004) of the participants in the group so that every seven participants were selected. This selection was carried out by an office administrator in order to ensure impartiality on the part of the researcher. The sample was contacted by the office administrator and given an information form (see Appendix I) and a consent form (see Appendix II) about the research.

Once consent forms were returned, they were given interview dates. Before, during and after the interview, each participant was reminded of the fact that they would be audio-taped and of their ethical rights (see section 4.10 below): specifically, their right to withdraw from the research.

In the case of the parents, all were mothers who had children under 12 years of age with a diagnosis of ASD(2). Apart from one parent, all children were educated in mainstream settings. In the exceptional case, the child was educated in a special school setting. All parents had been involved in the group for over a year by the time of the interview five children were boys, one child was a girl. All parents presented as healthy and articulate.

In the case of the professionals, all were women. They included the co-ordinator of the group and key contacts for parents in the group. In the case of key contacts, there was a range of professions, including: EPs, Language Learning and Support Services staff and Specialist Teachers.

All parents who took part in the study were women and in my opinion presented as articulate. All lived in statistically the most affluent area within the LA. My review of the literature did not find any studies, either on a national level or specific to the LA, that identify a comprehensive profile of a "typical" parent of a child with ASD. However, LA data suggests a prevalence of ASD amongst less affluent families. Arguably, my sample of parents was somewhat atypical of my own experiences of working within this LA: for example, I have worked with a number of fathers and also, with parents who themselves, experience learning and/or communication difficulties (who could be viewed as

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(2) With the exception of the child of Parent 4 who had been described as having ASD tendencies.

less articulate), neither of whom were represented in my sample. Nonetheless, I do not believe this compromised the validity of my random sampling procedure.

4.5.3 Strengths and weaknesses

Sampling can pose several challenges which can bias the selected sample. In my research, alternative sampling methods such as purposive sampling (Cohen, Manion and Morrison, 2005) and opportunity sampling (ibid) were rejected in order to minimise the risk of obtaining a biased sample. It was instead felt that random sampling enabled all participants to have an equal chance of being selected from the population.

4.6 Research design

4.6.1 The mixed methods approach

In keeping with Pragmatism and as discussed, this study employed a mixed methods approach. Mixed methods designs combine both Interpretivist and Positivist approaches: effectively generating qualitative and quantitative data (Creswell, 2003). This is useful because it captures a wide range of information about people's beliefs, attitudes and intentions from a wide perspective.

Mixed methods research requires a research design that clearly specifies the sequencing and priority that is given to the quantitative and qualitative elements of data collection and analysis and an explicit account of the manner in which the quantitative and qualitative aspects of the research relate to each other. Mixed methods research also has a heightened emphasis on the manner in which triangulation is used. Triangulation in this respect can be construed in one of two ways: either as a means to seek convergence among qualitative and quantitative methods (Creswell, 2003), or as way to provide different perspectives on a subject (Woolley, 2009). In practice, triangulation can show how qualitative data can complement the quantitative data by providing an interpretive aid to understand the statistical patterns that emerge – in effect, it allows the meanings underlying the statistical data to be accessed (ibid).

4.6.2 Research tool

The research tool reflects the strengths of the mixed methods approach, drawing on ways to elicit both qualitative and quantitative data related to the PPP.

4.6.2.1 The semi-structured interview schedule

In line with the research objectives to explore parents' and professionals' perceptions of PPPs and drawing on the fundamental principles of Interpretivism, one of the aims of the research tool was to ask questions that invited parents and professionals to describe actual experiences that they had lived through in the context of a PPP. To effect these requirements, a semi-structured interview schedule was used (see Appendix III). This enables, as Marshall and Rossman (1995) state, participants' perspectives rather than researchers' perspectives to unfold. In practice, the semi-structured interview can also generate a vast amount of information that can create a richer data-set than that necessarily generated via structured interviews.

The semi-structured interview schedule was adapted from an unpublished study by Davis and Oland (2007) that considered the EarlyBird Plus programme. Davis and Oland sought to address a number of issues raised by the literature on PPPs, in particular the lack of confidence that parents and professionals had in each others' abilities to work together to support a child; the frequency with which these interactions took place; the value of the contact between parents and professionals and the sense of goal-achievements that they experienced. These exhibit considerable overlap with my research own questions on confidence, involvement, empowerment and contact, albeit that my questions were refined to reflect my view of the major concerns raised in the literature. For example, as the literature identified a greater number of concerns raised by parents than professionals (Nind, 2002; Wolfendale, 2002; Hunter-Carsch, 2001; Pinkus, 2003; Todd, 2003; Duncan, 2003; Rogers et al, 2006), my interview schedule was comparably longer for parents than professionals. Also and in contrast to the schedule from Davis and Oland (op. cit), questions around contact were more open and general, in order to elicit as rich a data-set as possible.

Semi-structured interviews were designed to elicit responses to be analysed thematically in response to the four main research questions that explored the four identified features of a PPP: confidence, involvement, empowerment and contact. The research had been planned originally to prevent the problem of researcher effects – the possibility of affecting parent responses (Sims-Schouten, Riley and Willig, 2007), such as by non-verbal cues and gestures – by ensuring that parents interview each other and the researcher adopts a background role whilst making notes. However, practical considerations meant that all interviews took place in a one-to-one setting with the researcher and hence, the research was unable to minimise researcher effects. However, and as demonstrated by my reflexive diary, I was aware of the potential for bias in my research and therefore at all times, strove to be neutral in my own role. Also, and to promote validity, I ensured that each interview was audio-taped and then transcribed by the researcher.

4.6.2.2 Likert Scales

In line with the Positivist paradigm, a Likert Scale was used to measure parents and professionals' confidence in various aspects of the PPP. The questions were about parents and professionals' confidence in each other and schools to support the needs of the child. The questions asked were as follows (the full schedule is included in Appendix IV):

1. "I am confident that I am managing the needs of my/the child."

2. "I am confident that other parents involved in the group can manage the needs of their child."

3. "I am confident that the professionals involved in the group can manage the needs of my/the child."

4. "I am confident that the schools involved in the group are managing needs of my/the child."

The Likert Scale responses ranged from 1 to 9 rather than the more normal 1 to 5 to allow for a wider variation in response. The middle number 5 was used to denote indecision whilst the first 4 numbers and the last 4 numbers were both, respectively, variations of agreement and disagreement on the subject of inquiry. In keeping with the triangulation feature of a mixed methods design, the scales considered areas that had been referred to in the interview schedule, specifically the confidence participants had in schools, professionals and parents. Essentially, this meant that the taxonomy was determined by the qualitative research tool.

4.6.3 Strengths and weaknesses of research design

There are several benefits to using a mixed method design (Greene, Caracelli and Graham, 1989; Koch and Rhodes, 1979; Paul, 1996). Rossman and Wilson (1991) summarised these advantages, describing three broad reasons for linking qualitative and quantitative data: (a) to enable confirmation or corroboration of each other via triangulation; (b) to elaborate or develop analysis, providing richer detail; and (c) to initiate new lines of thinking through attention to surprises or paradoxes, providing fresh insight. Thus, mixed methods add to the research toolbox by facilitating a synthesis of traditions and providing the opportunity to maximise the potential of both qualitative and quantitative methods, thereby minimising the restrictions of each tool. In addition, a mixed methodology design enables respondents to have the opportunity to use multiple approaches in answering research questions, rather than being restricted to the researchers' choices.

In this respect, mixed methods research rejects dogmatism (Johnson and Onwuegbuzie, 2004). In so doing, mixed methods research is an expansive and creative form of research, not a limiting form of research. Johnson and Onwuegbuzie describe it as *"inclusive"* (ibid, p17). As mentioned, the inherent challenges to using a mixed methods design relate mainly to the philosophical debate of the use of two traditionally contrasting methods: quantitative versus qualitative and specifically, the need to account for the unintentional effects resulting from combining data collection methods (Mingers, 2006; Teddlie and Tashakkori, 2003). As mentioned, this is an area that was addressed by a reflexive account of any challenges faced during the research process.

The use of a semi-structured interview enables the researcher to adapt the questions posed and/or prompt new questions and/or lines of questioning where parents and professionals were leading the interviewing. Employing a face-to-face mode of interviewing as opposed to alternative interview forms such as telephone or on-line interviewing also means that issues can be more easily probed in depth (Rossi, Freeman and Lipsey, 1999). This enables the participants to elaborate on their individual concerns (Banister, Burman, Parker, Taylor and Tindall, 1996) and to avoid feelings of being pre-judged. In this case, the research tool has a high validity as the respondents' meanings may emerge with little direction from the interviewer. However, there are associated weaknesses. The use of probing questions in my research, such as question 1 around "How well do you think the educational professional has managed the needs of your child?" could reveal a rich data-set but could also place both cognitive, emotional and time demands on both the interviewer and respondent. In the latter case, the respondent could feel quite emotionally "drained" especially if questions were set around feelings, attitudes and beliefs personal to them (British Psychological Society/BPS, 2006), as was the case with this research.

Similarly, the success of the tool relies on the skills of the interviewer and in particular, the ability of the interviewer to think of questions that are useful during the interview and also the articulacy of the respondent. Moreover and despite all attempts to avoid forming prejudgements, the interviewer can, even if unintentionally, present non-verbal signals or cues that can guide the respondent to answer in a specific way. Whilst my research tool was intended to be valid, this validity was somewhat compromised in that the tool was not standardised and therefore cannot easily be replicated. Furthermore, the richness of the data did become burdensome and unwieldy especially when attempting to focus on relevant areas. These issues were again addressed through the use of reflexivity and continual checks with colleagues and supervisors.

Use of Likert Scales did enable me to use a standardised research tool to obtain a set of responses that could be ranked in order of how many agreed or disagreed with statements regarding the level of confidence parents and professionals had in each other and the group and the levels of variation within these responses of agreement and disagreement. This permitted a fuller understanding of the experiences of both parents and professionals rather than the relatively looser interpretation given by the Interpretivist treatment of data as detailed above. There are other strengths. Likert Scales are easy to use and respond to, placing little cognitive demand on the respondent (Van Laerhoven, Van der Zaag-Loonen and Derkx, 2004). This is of benefit especially in a study such as this one, where there were arguably cognitive and labour demands placed on respondents via the qualitative research tool. It was easy to deliver a Likert Scale of 9 Likert choices compared to the delivery of a long questionnaire (ibid). Likert Scales also have the advantage that they can cope with different strengths of opinion (Hayes, 2000) as well as with someone who has no opinion at all on a topic (ibid). As such, the data generated can be thorough (ibid).

There are weaknesses associated with the use of Likert Scales. For each respondent, scores on the scale only have meaning relative to the scores obtained from other respondents. Data produced is therefore best treated as ordinal (Coolican, 1999). Also having an undecided score, in this case, number 5, is ambiguous (ibid) as it is vague whether the number implies a neutral position (that is, no opinion) or an "on-the-fence" position (ibid) with the respondent *"torn between feelings in both directions,"* (ibid, p140). In this respect, work from qualitative data, the descriptions of the experiences felt in a PPP, could in some ways explain, expand or clarify any of these indecisions. However, more typically, it is found that what people say during attitude tests, such as the Likert Scales, does not necessarily correspond with what people actually do (Hayes, 2000). As such, the "real" understanding about people's belief systems – in effect, their version of the truth – could sometimes be limited.

Nonetheless, for the purposes of this study, the strengths of the Likert Scales appear to outweigh the weaknesses. In particular, it is one of the only few tests that enable attitudes to be measured. Measuring attitudes is an important element in addressing the research objective. Moreover, it is one of the simplest and most accessible tests to use. This is pertinent given the fact that the Likert Scales were conducted alongside a comparatively demanding semi-structured interview. It was therefore important that the scales did not overload the participant. Given its simplicity, this was unlikely and therefore warranted its full use. Moreover, it enabled quick and ordered quantitative data. Again, from a researcher's point of view, this was practical given the longer amount of time used to analyse qualitative data.

4.7 Data analysis

4.7.1 Thematic analysis

In line with the Interpretivist tradition, I employed a Thematic Analysis (TA) to draw out the participants' understandings and perceptions of the PPP. Use of TA meant that I could identify, analyse and report patterns (or themes) within the data. Carrying out TA tends to involve 6 or 7 different stages that tend to be fairly comparable in most research methodologies (for examples, see

Hayes, 2000; Lacey and Luff, 2001; Boyatzis, 1998). Hayes' approach to TA was very similar to that employed in this data analysis(3). Herein, data, once collected (the interview transcripts) (stage 1) was read carefully for items of interest (stage 2); these items are organised into or coded as bundles which represent shared ideas(4) (stage 3); examined and identified as themes at either a surface (semantic) or more detailed (latent) level(5) (stage 4); re-examined against the original data-set (stage 5); given a name, definition and supporting data from the original data-set (stage 6); and selectively reported (stage 7). The need for selection in stage 7 arises out of the practical difficulties (particularly unwieldiness) of reporting every quotation (Hayes, 2000).

In practice, the TA was a lengthy and recursive procedure of examining the transcripts and looking for common themes in the language used. This necessitated the reading and re-reading of the transcripts and coding key themes. An example of a coded transcript is in Appendix VI. To limit subjectivity (a common criticism of interpretivist approaches) and again given the small data sample, I identified themes in terms of instances where two or more of the six parents and professionals had given the same type of response, for example at least than two participants mentioned their concern regarding the diagnosis process used to identify ASD. The emerging themes were then presented in the form of direct quote examples to enable the reader to evaluate the theme-descriptors (that is, whether a summary phrase that was used to describe a certain theme was justified by the examples quoted). A brief discussion of the themes then followed which acted to consolidate the overall meaning of the data(6). This enabled substantial data reduction which made it more visually accessible to the reader than alternative presentations such as free-flowing paragraphs.

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(3) The only adaptation was at stage 4 which in my revision requires either a semantic or latent thematic analysis as required by Braun and Clarke (2006).

(4) This can be described as coding (Bryman, 2004).

(5) My research considered themes at a latent level. Braun and Clarke (2007, p84) describe this approach as examining "the underlying ideas, assumptions, and conceptualisations and ideologies that are theorised as shaping or informing the semantic content of the data."

(6) These discussions are further extended in Chapter 6.

Again, given the small sample size, my TA was described in depth (the latent level) (Boyatzis, 1998) although detail was limited to individual words and phrases rather than the non-verbal gestures that would characterise Interpretative Phenomenological Analysis. However, this amount of analysis was still able help me to identify the underlying structures behind attitude and belief systems around the PPP (ibid); effectively, some of the processes at work in a PPP. These types of findings can help to build theories (Fitzpatrick and Boulton, 1994); in my case, as to how and why the PPP does or does not effectively support parents. Additionally, it presented me with wider issues as to how these parents and professionals made sense of and addressed their lives (Bryman, 2000) as TA can elicit *"reconstructed counts of connections between events and contexts,"* (ibid, p413). Moreover, the instruments commonly used in such a TA (semi- or unstructured interviewing and participant observation) were open enough compared to alternative tools (for example, experiments and closed questions) to enable me to have an active role in the research to explore these connections further, for example, asking further questions for purposes of clarification.

4.7.2 Statistical analysis

In my Positivist approach, I aimed to measure the amount of confidence parents and professionals had in the PPP using numerical data from a Likert Scale questionnaire. Whilst there were other areas I looked at qualitatively (contact, empowerment and involvement), I felt that confidence was a more familiar issue and a best fit measure to identify overall perceptions of the processes of the PPP.

Statistical analysis (using the Mann-Whitney U Test) was based on the need to identify any difference between the respective responses of parents and professionals to questions of confidence. I hoped that this statistical data would enhance any descriptive findings from the interview that related to either a sense of unity or disharmony within the PPP.

Differences between groups were identified by the Mann-Whitney U test. Mann-Whitney U tests are non-parametric tests to assess whether two independent samples of observations are drawn from different distributions. The Mann-Whitney U test tends to be used to test for differences in medians so is appropriate for this study. The test involves the calculation of a statistic, called U, whose distribution under the null hypothesis is known. In the case of small samples, the distribution is tabulated. The procedure for running the tests and the tabulated distribution were taken from Clegg (1983).

The assumptions of the Mann-Whitney U test is that if there is no difference between the scores of the two groups of individuals – the null hypothesis – that is, if all scores are placed in rank order in one combined list, the group membership will be intermingled. If there is a significant difference between the groups, then the ranks will be in groups according to a group membership and the null hypothesis can be rejected.

4.7.3 Strengths and weaknesses of data analysis

There are challenges to using TA. First, there is little agreement about how it is operationalised (Attride-Stirling, 2001) which limits validity, (Braun and Clarke, 2006). Second, and in line with the lack of clarity about what TA actually involves and its associated processes (Dixon-Woods, Agarwal, Young, Jones, Sutton, 2004), there is confusion especially on issues of data collection and analysis (Attride-Stirling, 2001). At the analysis stage, I found it hard to know how to identify themes in any systematic way and subsequently, used a recursive process of revisiting my themes to check that they still appeared valid. In line with this argument, Silverman (1993) warns the researcher about selecting a particular line of argument and then choosing quotes from interviews to support the theme. Third, TA can lead to rather soft, subjective analyses, with the researcher seeking data that support preconceived ideas. Whilst this approach is an accepted part of a TA (Bryman, 2004), it is nevertheless, time-consuming and can create an anxiety about the rigour of the work undertaken (Dixon-Woods et al, 2004; Lacey and Luff, 2001). Fourth, the flexibility of TA can often lead to a laissez-faire attitude on the part of the researcher (Antaki, Billig, Edwards and Potter, 2002) to the point that *"anything goes"* (Braun and Clarke, 2006, p78). This underlines the need for clearer and more concise guidelines around the process of TA (ibid).

To address these issues, I referred at all times to existing guidance to conduct good qualitative research at both the level of data collection and analysis (for example, Elliott, Fischer and Rennie, 2000; Parker, 2004; Seale, 1999; Silverman, 2000; Yardley, 2000; BPS, 2006). I also followed the recommendations (ibid) to always try to be transparent in my research, using my supervisors and colleagues to check data throughout collection and analysis and to stay reflexive using an account of my experiences in analysing data.

There are several strengths in using the Mann-Whitney U test. First, it accommodates for the fact that this study uses ordinal not interval data and as such does not like other tests (such as the T or the Wilcoxon test) assume that there is equidistance between each Likert item. Second, it is more robust than alternatives such as the T test, as it does not use outliers, dispensing with mean figures. However, as with most small sample size research studies, the Mann-Whitney U test has limited power in terms of efficiency in reporting significance and this has to be acknowledged. Despite this inherent weakness, it was felt that the value of any findings would be enhanced by their triangulation with qualitative findings. As such, limitations would, where possible, be addressed.

4.8 Research method – procedure for data collection

Qualitative data was collected from face-to-face semi-structured interviews with parents and professionals and quantitative data from Likert Scales were applied to the same participants immediately following the delivery of the interviews. In this respect, both sets of data were obtained from the same visit and hence matched the requirements of mixed methods design. All of the participants were interviewed in a meeting room in the council's offices on a one-to-one basis with the interviewer. The interviews with the parents took on average 40 minutes and the interviews with the professionals took on average 20 minutes. Unintentionally, the parents were both interviewed in the morning and the professionals in the afternoon. At all times, attempts were made to make the participants feel at ease (for example, comfortable lighting, space and air).

4.9 Validity, reliability and position of researcher

4.9.1 Validity

It is important to consider validity – the issue of whether an "indicator" (Bryman, 2004, p72), or the research tool, actually measures the concept it is designed to measure (ibid); essentially, does the tool capture the "truth"? Three issues of validity are considered.

First, in a TA, validity is easily influenced by researcher bias because the meanings of utterances are profoundly shaped by the way in which something is interpreted to be said and indeed, the extent to which the researcher decides to show what and how data is relayed (Bailey, 2008). Several researchers recognise the problem with this form of limited validity (for example, Braun and Clarke, 2006). In particular, they emphasise the considerable degree of latitude researchers have when selecting the themes which are considered important to the research. For example, the researcher can choose to select certain themes over others for any reason. Braun and Clarke (2006) show how the research on representations of lesbians and gay parents on 26 talk shows (conducted by Clarke and Kitzinger, 2004) identified not necessarily the most prevalent themes but the ones that captured elements that met the requirements of the research objectives. In this way, the researchers could be viewed as consciously overlooking or ignoring the more common themes in order to satisfy their personal demands. Effectively, by constraining TA to specific research objectives, the participants' lived experiences may not be captured.

This has, to some degree, been an issue in my research which has also selected themes more on the basis of capturing important elements about the parent-professional partnership as opposed to reflecting a blanket coverage of every area important to parents and professionals. However, and without trying to be defensive, it is important to be open to the fact that the validity that we associate with quantitative analysis is not so appropriate to TA; rather it is more important to understand the participants' version of the truth:

> *"Unlike researchers who are quantitatively oriented, many "qualitative researchers" would claim that they are not interested in the truth. Rather, they would inquire into a respondent's version of the truth," (Moret, Reuzel, van der Wilt and Grin, 2007, p25).*

Furthermore, it is important to acknowledge that the very act of engaging in Interpretivist research necessitates some subjective interpretations to be made (Henning, van Rensburg and Smit, 2004) – this in itself means that the research is neither value – nor bias-free (ibid) and therefore validity will always be limited in such a paradigm.

However, I did try to minimise the propensity towards bias by the use of face validity (Bryman, 2004) in the sense that I checked my findings with others in the field. In this instance, I chose supervisors and related mentors who had extensive experience in psychology and research. They looked at my work revising where necessary. This is an acceptable way to establish validity, albeit at the very minimum level (Bryman, 2004). An additional or alternative approach would have been to ask the respondents, themselves to check my findings from the TA. This is useful but the respondents' time did not enable them scope to make these revisions.

A second compromise to the validity in this study is that the sample size is small and therefore it is difficult to generalise findings. Some researchers (for example, Stake 1995) argue that generalisation need not be the primary aim of research whilst Wolcott (1995) argues that attempts to generalise should be the remit of the reader and therefore not the aim of the researcher. This study, similarly, adopts both views on generalisations: it accepts that findings have a relevance to the way in which PPPs operate but not that these findings should necessarily be considered typical of a normal population.

Third and finally, validity in quantitative testing and in this case, statistical analysis, is comparatively free of difficulties. This is because the research tool, the Likert Scale, is a standardised measurement tool. However, the validity of the tool, rather than the statistical forms of analysis, may be difficult to demonstrate. This is, in part, because the statements within the Likert Scale were "chosen" by me and therefore may carry an inherent subjective bias. This could distort or challenge the "truth" that is being sought. Nevertheless, Dyer (1995, p131) states that such scales "*do not need to be factually accurate – they simply need to reflect one possible perception of the truth... [Respondents] will not be assessing the factual accuracy of each item, but will be responding to the feelings which the statement triggers in them*". Keeping this in mind, I felt that the questions that I chose for my scales maintained their essential validity.

4.9.2 Reliability

Two areas of contention in respect of the reliability of TA are discussed. First, there is a lack of coverage in the literature of ways in which to carry out a TA. This can mean that "anything goes" and as a result, it can be challenging to make a proper assessment of the robustness of the procedures that have been followed. This was not helped by the fact that not all my interviews (this includes the Likert Scales) could take place on the same day; in fact, some participants were interviewed in one week and others were interviewed in the following week. As such, there may have been variations in the way that I facilitated interviews or followed up on more probes or used different probes to elicit more information. Future researchers wishing to repeat the study with different participants and/or in another location or organisation may struggle to do this as they have insufficient knowledge of how the work in the original project was carried out. Thus, any comparisons that are ultimately made between the findings of the two studies may be unsoundly based. Second, and in line with this lack of coverage, researchers looking to design their own projects with the help of insights from accounts of previous work tackling a related area may find little assistance in my research and be forced to rely on the advice given in general research texts on qualitative methods.

However, and again in line with my aims to be reflexive, I tried to always demonstrate how I used and interpreted my data both within the writing of the thesis and in the reflexive diary. I used my diary to make my interpretations more plausible and me more visible. I have also ensured that I appended one of my coded transcripts within the study to ensure that others could follow my thinking. This aimed to fulfil Nightingale and Cromby's direction to ensure that I explored *"the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research,"* (Nightingale and Cromby, 1999, p228).

4.9.3 Position of the researcher: multiple roles and partiality

In keeping with the need for reflexivity, it is important to recognise my own multiple roles in the study. In so doing, this can help to clarify the way in which my thinking has developed and specifically, how my own perspectives arising from these different roles have influenced my results. These roles included: the "student", analysing, criticising and recording literature; the "interviewer", questioning and testing participants; "sympathetic listener"; the "trainee EP", working with parents and professionals to support the needs of children; the "observer" of PPPs who has become concerned that some PPPs are not necessarily equipped to support the needs of families (for example, those in the case of Victoria Climbié (Great Britain Home Office, 2003)); and the "non parent" who has not experienced the process of nurturing a child either with or without ASD and therefore cannot truly empathise with this process.

Taking each of these in turn:

"Student": as a student, I may have had a natural bias towards favouring existing research findings. However, I believe that the findings set later in this

study both confirmed certain themes already identified and added to the existing research base by bringing new insights into the processes and outcomes of PPPs.

"Interviewer": as an interviewer, I felt upset by the emotional discourses of parents. In contrast, I felt comfortable listening to the more rational responses of professionals. This was probably because I was familiar with and attuned to their specialised language and factual type accounts. To address this, I always thematically analysed and identified the themes separately for each of the parents and professionals transcripts. Finally, the standardisation within the Likert Scale questions served to regulate any bias too.

"Sympathetic listener": as a sympathetic listener, I was drawn into parents' and professionals' dialogues. On three occasions, mothers became upset: two cried and became angry. There was a sense from all three that they had, or indeed in one case continued to, feel very much alone, isolated and vulnerable – an area I return to in Chapters 5 and 6. If I had remained detached – and avoided responding to these mothers' emotions – I would have felt insensitive. However, to attempt to address issues around partiality, I made reference to these occasions in my diary.

"Trainee EP" / "Non-parent": as a professional and non-parent, who values loyalty amongst my professional colleagues, I did not want to upset or frustrate the network around me. This made me uncertain and tentative about the questions that I asked participants especially when they became emotional. Similarly, I was anxious about the findings generated by my work: there is the possibility that these findings present a rather negative view of PPPs and I must trust that if so, this will be accepted as a constructive rather than accusatory criticism.

"Observer": media influences have made me sceptical of the PPP process. Regular monthly supervision helped me review this scepticism so I could keep it in check.

4.10 Ethical Issues

BPS guidance was used regarding ethical principles for conducting research with human participants (BPS, 2006).

4.10.1 Informed consent

An information form (see Appendix I) and a consent form (see Appendix II) were sent to the sample. Prior to each interview, the researcher highlighted the rights of the participant in regard to confidentiality, transcripts and the right to withdraw at any time. After the interview, these rights were reiterated to ensure parents and professionals still agreed to be part of the project (as recommended by Miller and Bell, 2002). In particular, at this stage of the project, participants were reminded of their right to withdraw from the project. It was also made clear that any withdrawal would not affect their access to the MSG or any other service available to them.

4.10.2 Confidentiality

As this study was a sensitive topic, it was made clear to participants that the data generated during the project was to be used only for the purposes of the research project. It was also stated that the presentation of data would only use anonymised participant responses via pseudonyms.

4.10.3 Protection from harm

It was made clear to the participants that the researcher would not give advice about ASD during the interview. It was also made clear that I was not a qualified EP and therefore, not in a position to advise parents/carers or professionals on specific details. However, participants were informed that any concerns they may have could be discussed with other qualified professionals. I made this information clear to the participants face-to-face before the interview. I also ensured that in the event of any anxiety, there was support from me and from impartial professionals in the surrounding offices.

4.10.4 Detachment

The BPS makes reference to the importance of maintaining personal boundaries (ibid). Whilst this typically refers to the avoidance of sexual and romantic involvement (ibid), it can also be argued that boundaries can describe the detachment that some researchers consider is an important consideration during the research process. For example, Yu (2008) argues that during Positivist research, involvement and subjectivity on the part of the researcher can bias results and hide the truth (ibid). In contrast, Interpretivists believe that truth is a subjective experience and can only be understood by subjective interpretations. Therefore, the involvement of the researcher can be difficult to prevent and is arguably necessary in the research process (Kelliher, 2005).

As this is a mixed methods research study, I sought to keep detached during the quantitative part of my research by following the same administrative format for each participant – that is, reading the questions for the Likert Scales and writing down given responses. Any possible involvement on my part was recorded in my reflexive diary. For the qualitative element of the research, I did not try to become unnecessarily involved in the research, but sought clarification on issues that arose during the interviews and in line with the TA, made my own interpretations of the data. However, to keep my thinking transparent and to check the accuracy of my interpretations, I logged these experiences in my diary and used supervision with colleagues to confirm face-validity of my findings.

4.11 Summary

This Chapter has detailed the theoretical and conceptual framework, methods and instruments that were used to gather the data. It has also considered my research position and ethical considerations.

The following Chapter will detail the results, including the details of the participants and the themes which were reported.

CHAPTER 5: PRESENTATION AND ANALYSIS OF FINDINGS

5.1 Introductory comments

The primary aim of this study was to explore the perspectives of parents and professionals as regards to the underlying processes and outcomes that form the basis of their Parent-Professional Partnership (PPP) within the context of the Autistic Spectrum Disorders (ASD) Monitoring and Support Group (MSG). As discussed in Chapter 4, this study considered the interaction that parents had directly with the MSG, as well as with the in-school professionals, who have also had training from the group.

Specifically, the study aimed to identify these perspectives in relation to four research questions set out in Chapter 4; these explored the key features by which a PPP should operate: raising confidence, positive involvement, parental empowerment and contact between parents and professionals. These research questions are used in this Chapter to outline the results that were generated in the study. As outlined in Chapter 4, these results identify the processes and the outcomes of the experience of participating in a PPP.

To recall the sample selected for this study. There were 12 participants. Six were parents, six were professionals. All were women. The sample was randomly selected. All participants were interviewed in an office in the Children's Services. All had children that were aged between four years and 12 years. All interviews followed the structure stated in Chapter 4. The small sample size meant that findings are limited in generaliseability.

5.2 Qualitative results

5.2.1 How confident are parents and professionals, respectively, when supporting the needs of children with ASD and to what extent is their respective confidence influenced by the PPP?

5.2.1.1 Parents

Theme 1: Parents are not confident that schools have enough knowledge and understanding of ASD

Reference 1: "The knowledge base of the teachers in the school and including the SENco [Special Educational Needs Co-ordinator] ... just rubbish," (Parent 5).

Reference 2: "Well if you're talking about the school; it's been complete crap!" (Parent 5).

Reference 3: "A complete lack of knowledge that the headmaster actually said that he leaves those sorts of things to the SENco and it's a school of 240... about 220 children, so there's no excuse in my view but no ... very very poor understanding," (Parent 5).

Reference 4: "It would seem from the conversation that I've had with them is that the heads often take themselves out so they're not part of the training," (Parent 5).

Reference 5: "A lot of the staff aren't particularly familiar with Autism anyway ... it's like we almost have to be the experts for the teachers," (Parent 6).

Reference 6: "It is the school that need more help than I do," (Parent 4).

Reference 7: "You see the teacher my daughter has at the moment doesn't actually believe that Autism exists," (Parent 6).

Reference 8: "I don't think anyone who's been with X [her child] really has been trained, you know, sufficiently to really understand what's going on, you know what I mean?" (Parent 2).

Reference 9: "At the school, they really didn't understand what her needs were," (Parent 2).

Reference 10: "What I would like is for some parental support group ... going in to the schools to actually help with the teachers ... but yes, if they could come and talk to the teachers ... then they'll know how to deal with X [her child]," (Parent 6).

As shown, parents were very vocal and expansive about their criticisms of schools. Indeed, four out of the six parents, interviewed, made it clear that they were not confident of some of the schools' abilities to support their children with ASD. Specifically, they highlighted school staff's lack of knowledge and skills in ASD. Parent 5 stated that the staff at the school showed *"very very poor understanding"* of ASD which suggests that they are not accessing or engaging with the support from the MSG. This is borne out further by the comment:

> *"The knowledge base of the teachers in the school and including the SENco ... just rubbish,"* *(Parent 5).*

Parent 4 took this thinking one step further, suggesting sympathy for teachers: *"they need more help than we do"*, a comment supported by Parent 6's comment that "we" – the parents – have to be the professionals to help the teachers (reference 10). The use of the word "we" suggests that she identifies herself with all parents and she feels that collectively, there is anxiety about the competencies of the school professionals.

It is interesting to note that all school-based professionals including the SENco and head teacher, as well as health professionals receive a lot of criticism. These criticisms towards the health professionals are consistent with the literature (see Chapter 3) although the negative comments about the SENco are new to the evidence base and to my professional experiences as a Trainee Educational Psychologist (EP).

This indirect criticism of the MSG – whose role is to train school-based professionals – is reinforced by direct complaints regarding the MSG from Parents 2 and 5 (references 4 and 8) who feel that the training is ineffective.

Parent 5's criticisms imply a lack of respect for any of the school staff, from head to teacher. However, her criticisms are focused on the head teacher. It was apparent that she is angry at what she considers to be the head's lack of engagement with ASD and families of children with ASD; the statement that *"he leaves that to the SENco"* and heads *"take themselves out of the training"* suggests that she views head teachers as marginalising those families of children with ASD.

Parent 6's comments are illuminating, as they, in part, help to explain Parent 5's criticisms of her school's tendency to marginalise ASD. Parent 6's comments reveal a belief that her school does not understand ASD: teachers are not familiar with ASD and one teacher does not believe that it exists (references 5 and 7).

<u>Theme 2: Parents not confident of professionals ability to support the ASD diagnosis process</u>

Reference 1: *"To actually get him diagnosed was an absolute nightmare – I felt that we were passed from pillar to post. He went into playschool when he was 2½ and from the moment he was in playschool, the playschool teacher picked up that there was a problem. Because he was my first child, I suppose, I did not necessarily think there is something wrong here. So it took from the age of 2 to the age of 5 to actually get someone to diagnose him and in that respect I do not think there is the support there is not there at all in this area," (Parent 3).*

Reference 2: *"He was seen by the Educational Psychologist at play school who agreed that there was a problem but they also did a quite openly say that he is not in school and he is way down the pile so he wasn't priority," (Parent 3).*

Reference 3: *"I mean I think that's a huge thing when people still say that they get given a diagnosis and then get waved off," (Parent 5).*

Reference 4: *"Yes, it goes back to diagnosis ... Yes, your son has got Asperger's so they give the label then walk away. That's kind of the long and short of it," (Parent 5).*

Two parents related a lack of confidence to the professionals involved in the ASD diagnosis process. The MSG itself is not intended to include parents whose children have not yet received a diagnosis of ASD. However, this lack of inclusion can create a situation in which some parents requiring support must wait, in some cases for years, to access the support. Nonetheless, the challenge of diagnosis was a dominant issue in the transcripts and one that has effected a sense of powerlessness in some parents (see section 5.2.3 of this Chapter). It is therefore an important consideration for parents when discussing the PPP.

The parents' comments here described the process of ASD diagnosis as if it was a series of conflicts, where they had to challenge the professionals for a diagnosis and then come to terms with the diagnosis on their own – an internal conflict. Parent 3 described the process of the diagnosis as a *"nightmare"* (reference 1). Her lack of confidence is perhaps best underlined by her account of an EP who told her that her son was not a *"priority"* for diagnosis (reference 2). The implicit reason for this apparent lack of concern on the part of the EP was that the child was not yet of school-age (reference 2). Whilst it is true that most diagnoses of ASD occur at around the age of four years, it is also true that some children can be diagnosed before this age (Chapter 3). However, Parent 3's comment is made more striking by the apparent "laissez-faire" attitude of the EP, that is described by the parent, which if true, is no way to engender a positive partnership with this parent.

It is worth noting that, although not common enough to be a theme, Parent 6 did state that she felt that she had no support from the health services even after the ASD diagnosis. She said:

> *"Medical. I've had nothing medical at all. When we moved here, the school nurse turned up and said "Oh, I hear you have a child with Autism." And then went wittering on about something totally unrelated and it was like she had no idea what Autism is. But no, we've had no medical intervention whatsoever," (Parent 6).*

Coupled with the comments related to the ASD diagnosis process, it would seem that the health teams are especially viewed negatively by parents.

Theme 3: Parents are not confident of the MSG's knowledge and skills of ASD

Reference 1:	*"I'd like ... more professional support from people who really do understand the condition and who aren't just sent off on a course – they really understand the condition and really understand her as a human being, not just the condition. It affects people in different way – it's a very broad spectrum as you know and she's her own individual but somebody who can really support her as a human being so, so she can grow up to be independent and self-supportive and feel that she has some value cos she does yet it's for her to help her find what her talents are and what exceptional thing she can be or do," (Parent 2).*
Reference 2:	*"The speech therapist comes in and talks to him for about half an hour once a year ... which is nothing," (Parent 6).*

Two of the parents felt a lack of confidence in the MSG's own knowledge and skills in ASD. Parent 2 specifically targeted this at the professionals providing training sessions in the MSG meetings (reference 1) whilst Parent 6 felt that there was a gap in speech and language expertise as her son was only visited once a year for input which she felt he required more regularly. Whilst the low number of comments in this theme, suggests that the four other parents in the sample were confident of professionals' knowledge and skills in ASD, the extensive criticisms of the MSG expressed by Parent 2 are illuminating. There is a clear sense that she feels that professionals do not personalise their support to her needs (reference 1) (a theme also raised in section 5.2.4 of this Chapter). Her comment that their knowledge was little less than that which could be accessed by a textbook is particularly sharp and suggests not only a lack of confidence for the professionals but also a lack of respect.

These comments are initially quite shocking, revealing as they do, the dissatisfaction of some parents. Whilst it can be very challenging and given my experiences, sometimes impractical and unrealistic, for professionals to ensure that every parent receives the right amount of and type of support, it is evident that Parent 2, in particular, feels that her daughter's needs are not being recognised. She describes her daughter's situation (reference 1) as one where she has been forgotten about as an individual and provided with generalised support. Literature makes reference to the importance of providing for individual needs (e.g. DfES, 2003a). Here, one of the key problems appears to be a perceived deficit in knowledge and skills in ASD to fulfil these needs – an area, interestingly, which is recognised and acknowledged by the professionals themselves (see theme 9 below).

Theme 4: Parents are confident in their key contact

Reference 1: *"It is good, it's like a safety net. I can phone them and they will respond to you," (Parent 3).*

Reference 2: *"We had a problem with the school at the beginning of this year and I was able to contact X [her key contact], so umm in those terms, it was quite a big support that I knew I'd be able to phone her and that she's be able to help me to deal with it," (Parent 5).*

Reference 3: *"It's a phone-call – that's all you need," (Parent 1).*

Reference 4: *"[I'm] slightly more relaxed about it [her son's ASD], slightly less stressed about what he is going to do because there is someone you can speak to and who will understand that you are not completely mad," (Parent 5).*

Reference 5: *"I mean they have been ready to listen and they haven't given the impression that they think we're wrapping him in cotton wool," (Parent 1).*

Reference 6: *"If there's a crisis, you can say 'well, hold on a minute. This was flagged up or you should have done this'. You can say, 'help' or 'thank you'. It's nice to say 'thank you' and we generally do," (Parent 1).*

Reference 7: *"It's good to know it's there," (Parent 2).*

Reference 8: *"Because you know these professionals are involved and that they are saying 'yes try it'. They've given us the courage to say 'yes try it, we're sure he can cope with this once things are in place'. It gives you more confidence um and I've lost track. It gives you the confidence to know that there are people there and that it gives you the confidence to know that my son has the right to this education and you've got the right to seek it out and say 'well I just need you to do this little bit for you' – it's a huge thing for our son and will get him where he needs to be," (Parent 1).*

Reference 9: *"For us, it just felt like we had some support and understanding which we weren't getting from school so yeah it's like having someone on your side, if you like," (Parent 5).*

Reference 10: *"She's really good ... she's really good. She phones up about once a term; talks about whether I've got any issues to take back to the group and I tend to tell her how we're going; if we've got any problems; academically and she takes back to the group," (Parent 6).*

Reference 11: *"I think in our own mind, we know that he's being properly monitored and that there are professionals that are keeping an eye on him, on how he's doing. I know he's doing well and I still think it's because he's doing well that it's ... I would imagine that when you think of an autistic child or when you see an autistic child and then you see my son that's a very good example of how well an autistic child can do in a mainstream school given the right support and yes it's to do with the ASD group and the fact that they put it all together and we can say that a particular thing we're worried about ... I can say to X [her key contact] 'you know this isn't happening' or 'this seems to be a problem' and she will act upon it and find somebody who can so that that's very much a positive thing," (Parent 1).*

Five of the parents were confident in their key contact. There is a feeling that the contact gives them reassurance (Parents 1, 2, 3 and 5; references 1, 3, 4 and 7) to help them feel secure in themselves. As parents can often feel insecure in their parenting (Midence and O'Neil, 1999), this finding served to highlight some of the good the key contact role is providing.

Parents' sense of confidence extended to a feeling of being independent. In Parent 1's case, she felt that the three monthly telephone call is in itself, was enough to help her support herself and her family (reference 3).

There is also a sense that parents felt comfortable with their key contacts as if there was a sense of trust between them. Parents 3 and 5 (references 1 and 2) discussed how they felt that they could ring their contacts to inform them of any problems that they were facing and moreover, their contacts could support them with resources, where necessary. There is a sense that some of these parents, such as Parent 6 (reference 10), valued the listening ear provided to them: just feeling 'heard' was an adequate element of PPP provision.

Even Parent 2, who did not appear to value the PPP, acknowledged the benefits of knowing that a system of support existed.

Theme 5: Parents feel reassured by their interactions with other parents in the MSG

Reference 1: *"Yes there are benefits to it because if you do have particular problems – we have always had problems with his aggression and that is something that I have talked to them before about and also because it is also done in a very informal way you do meet there are other parents there, and there was a lady I was talking to a couple of meetings ago who has an older boy that had the same sort of problems so she had obviously gone through it. So that it is also meeting other people there that have had the same problems and perhaps giving you different ideas of how to deal with things. So in that respect it is quite useful," (Parent 3).*

Reference 2: *"It has been good and it's good for information um from other parents who have not the same issues but similar issues so 'Have you read about this?' or you usually get a wider sense of what's available to other people as well,"(Parent 1).*

Reference 3: *"So some parents say that they feel that they don't feel understood and it's only when they meet parents who are in a like minded situation that they can filter through their own experiences," (Parent 5).*

Reference 4: *"I think that probably the main thing is just to have time to talk with other professionals and with other parents as well," (Parent 5).*

Reference 5: *"I get [from the training sessions] contact with other parents ... that's quite a big thing actually because the ... people are talking about the same stuff that you're going through," (Parent 5).*

Three of the parents discussed how meeting with other parents had given them the opportunity for empathy which had built up some confidence in their own abilities as parents. As the MSG organises these meetings, it is suggested that they are, in part, responsible for some of the confidence that parents express. Parents 1, 3 and 5 believed that their interactions with other parents had meant that they could share anecdotal stories about their children (references 1, 2, 3 and 5) which could help them feel more understood. Parent 5's comment (reference 3) was particularly pertinent as it reaffirmed the importance of feeling understood – a clear need for parents of children with ASD (as identified in Chapter 3):

> *"So some parents say that they feel that they don't feel understood and it's only when they meet parents who are in a like minded situation that they can filter through their own experiences," (Parent 5).*

Parent 5's comment suggested that she valued the meetings as they could help her access other parents' views and thoughts easily.

Parents also recognised the value of being able to share supportive ideas for their children (references 1 and 2). For example, Parent 3's comment (reference 1) identified the value in being able to learn from parents, alternative ways to view her situation, whilst Parent 1 (reference 2) provided the concrete example of being able to benefit from another parent recommending to her, a book to read.

The literature has noted the contributions parents can bring to other parents (for example, see www.healthtalkonline.org). It is reassuring, therefore, that the value of these contributions is being recognised and addressed by the MSG.

Theme 6: Parents' confidence is helped by their familiarity with their children

Reference 1: *"We get along all right, we know his quirks, so we just treat him accordingly," (Parent 4).*

Reference 2: *"We could communicate with him – we're his mum and dad and we knew what was going on but you couldn't, you wouldn't leave him there [with the professionals], they wouldn't have a clue what he was doing," (Parent 1).*

Findings suggested that two of the parents were confident that they had adequate intimate knowledge of their children which could be used to support their child. Parent 4 described how she could understand her child on the basis of his *"quirks"* (reference 1) whilst Parent 1 would not wish to keep her son alone with professionals because they *"wouldn't have a clue what he was doing,"* (reference 2).

The benefits of parents' familiar knowledge of children is well documented (for example, Bowlby, 1971; DES, 1978). However, it would appear, given findings from theme 1 and Parent 1's comment, that this knowledge is not being used gainfully by the professionals, despite recommendations and directions from government to capitalise on parents' familiar knowledge of their children (Chapters 2 and 3). However, it is also striking that four of the parents interviewed did not mention having any confidence related to their own familiarity as parents. Instead and as shown by theme 1, most parents preferred to discuss the lack of confidence that they had in professionals.

Theme 7: Parents' confidence is helped by them being proactive in seeking out support

Reference 1: *"I think we're more confident. I mean we've always been fairly confident that yes our son has ASD and uh uh uh we as parents we need to know how to make things easy for him so we've been quite proactive in finding out what's better for him, for us and not sitting back thinking this is too hard now," (Parent 1).*

Reference 2: *"I think we're fine actually. We've read books on it all. As you do," (Parent 5).*

Reference 3: *"You just have to find all these different routes to find his way in. So, not bad yes, I think we're pleased," (Parent 6).*

Reference 4: *"I mean I try to access what information I can myself but I mean I have a positive attitude towards her," (Parent 2).*

Four of the parents interviewed felt that their confidence was in part due to their abilities to be proactive. There is a sense from Parents 1, 2, 5 and 6 that they have a positive and realistic outlook regarding their and their child's position. This is a healthy response as it avoids the feelings of blame that literature has identified as common to parents of children with ASD (Gray, 1994). The responses also show that they are happy to self-initiate – Parent 1 discussed how she did not want to *"sit back thinking this is too hard now,"* (reference 1) whilst Parent 5 considered her position as a parent *"fine"* and Parent 6 was *"pleased"* with her efforts to *"find all these different routes"* to help them and their child. However, it is striking that none of the three parents mentioned the support from the PPP; instead they focused on what they have done such as book reading. Once again and in line with themes 1 and 3, this could suggest that parents do not feel that their confidence is attributable to the PPP but more to their own attitudes and motivations.

5.2.1.2 Professionals

<u>Theme 8: The Multi-Agency (MA) element of the PPP increases professional confidence</u>

Reference 1: *"Because we're coming together, working in a MA way, we're bringing aspects of our expertise together and helping us to sort it out cos normally in the past we would have done individual visits etc or focused in the schools or bit of training and overlapping and you get more coherence, training or working together – that benefits every one," (Professional 5).*

Reference 2: *"I think it's been good having multi-professionals; I think that's been really good, sharing ideas especially things like planning training, being able to call on speech and language therapy, LLSS and other medical people to help with developing the training and to help with running the training and discussion within the group; you know it's just good to have people's perspectives," (Professional 4).*

Reference 3: *"It's good to have a range of people with different perspectives and different understandings and different things that they can bring to it [the MSG]," (Professional 6).*

Reference 4: *"You can direct them [parents] to other people with another story to tell," (Professional 3).*

Reference 5: *"Getting together on a regular basis every six weeks with other colleagues from other professions, getting a full rounded picture of what's going on with the children referred to in the group; multidisciplinary training now – using everybody's skills," (Professional 1).*

Reference 6: *"I think there are a lot of benefits for parents and for myself as well being a part of it because it's multi-agency; you've got a lot of experience to draw on from other people, and you can also call upon them. If you go in and you think 'Oh actually, I think it's a speech and language or LLSS' you could call on them as well. You can have them from that point of view," (Professional 2).*

Reference 7: *"If I've been in a school with a child, or in a meeting or I've been this key contact and made this telephone call that actually there is somewhere to go with that, what's happened. I've got somewhere to go. I've got people to talk to about it or I've got someone to talk to about doing a bit more work around an area," (Professional 6).*

Reference 8: *"I don't feel alone in it either, which is lovely," (Professional 6).*

All six of the professionals found the MA element of the PPP increased their own sense of confidence in their professional practice. In contrast with the following theme, this suggests that they preferred working in a joined up rather than single agency way.

There is a feeling that they and parents both benefit from the shared expertise that characterises MA working. For example, Professional 6 discussed the way in which the MA element of the PPP allowed the MSG to have *"different perspectives"* and *"different understandings"* (reference 3). These different perspectives are important parts of providing parents with the range of information that they need to empower them to make informed decisions and so appears to be a key benefit of the PPP.

Moreover, there was a sense that professionals felt that they did not have to know everything; instead they could draw on other agencies' expertise. For example, Professional 6's comments (references 7 and 8) suggest that she had used the MA to pool advice and guidance. There is an implication that this helped her to feel professionally competent but also at a personal level, a part of a supportive group: her comment *"I don't feel alone,"* (reference 8) highlights the strength she derives from the MA element of the group. The implication is that this, in turn, inspires a sense of confidence and empowerment in the parents.

Professionals' comments further suggest that the use of MA working speeds up the support that they can provide to parents because *"you get more coherence, training or working together – that benefits every one,"* (Professional 5, reference 1). Professionals can use the MA route to refer parents to other agencies that may provide them with support (Professional 4, reference 2), thereby providing them with an efficient route to support.

MA working has become a popular topic in areas of educational research (Abbott et al, 2005; Booker, 2005; Edwards, 2004; Leadbetter, 2006) despite the fact that there has, arguably, been as much critical as positive commentary as to its viability in the Children's Services (Sloper, 2004; Booker, 2005). These comments suggest that there is strong support for inter-agency collaboration, at least within the MSG. However, it is interesting to note that parents, in contrast with professionals, did not comment on the use of the MA approach. This would suggest that this form of collaboration has not necessarily been a clear feature in their experiences within a PPP. Indeed, the interviews suggested that parents are more familiar in dealing with just one professional rather than several from different agencies.

Theme 9: Professionals in the MSG do not feel confident of their own knowledge of ASD

Reference 1: "You have to give the appearance of being confident," (Professional 2).

Reference 2: "I myself would probably say that I don't feel fantastically confident even though I'm quite experienced," (Professional 6).

Reference 3: "I've only recently in the last three years got the post grad diploma in Autism," (Professional 5).

Reference 4: "I don't think I ever feel very confident" (Professional 6).

Reference 5: "I always think there's more I don't know and more I need to learn," (Professional 6).

Reference 6: "I obviously seek advice and support," (Professional 2).

Reference 7: ***"I wasn't very confident at all three years ago but because I've done a lot of shadowing as well, I've shadowed people umm and done a few courses and worked with schools now with ASD so moderately confident," (Professional 4).***

Reference 8: ***"I myself would probably say that I don't feel fantastically confident even though I'm quite experienced," (Professional 6).***

Reference 9: ***"I don't feel that confident in managing any child because that's because things unexpectedly can happen," (Professional 5).***

Here, there is a clear sense that professionals were uncertain, almost arguably, confused, by their position as a supportive partner to parents; at points, their views on their confidence were contradictory, for example Professional 6 (reference 2) recognised that her experience should mean that she was confident of her ability to support families but she did not feel that she had this confidence and more worryingly, given her experience, had never felt this confidence. Meanwhile, Professional 2 (reference 1) felt that she had to give the appearance of being confident, suggesting that the appearance of confidence is a coping mechanism for the confidence she feels she lacks. Professional 5 (reference 9) appeared to be anxious of the *"unexpected"* and not adequately confident to deal with this.

There is an awareness of the need to address this gap in their professionalism. They recognised, for example, the importance of continual professional development (CPD) (see comments from Professional 4, 5 and 6) (references 3, 5 and 7) although in most cases, what training these professionals have received may be deemed questionable given their lack of self-confidence.

Comments about the importance of CPD are raised in Chapter 2 and the process of updating skills and knowledge are clearly important to these professionals. However, it also seems that the confidence with which this skill set and knowledge-base are received is even more important, given the fact that it can both enable and disable a professional's feeling of adequacy (Chapter 2) and in this case, could lead to a delay in support being provided to parents.

Theme 10: Professionals in the MSG are not confident that schools fulfil their role in supporting parents

Reference 1: "I think (talking of confidence) it changes on the school, as much as anything; I mean their ability to be flexible. I mean I should be confident to transition children successfully into secondary cos that's mostly what I'm doing ... but some large secondary schools are less willing to be or less able to be flexible about the needs of these young people and that makes it quite hard actually," (Professional 1).

Reference 2: "TAs [teaching assistants] need to experience it; they need to feel that they can actually see how something works rather than it being just a knowledge base," (Professional 6).

Reference 3: "I do think there is a fundamental; something to do with getting on with what is going on for the child where you do need to have the kind of knowledge base because when you're thinking about how a child might interpret the information that they're being presented with, you need to have someone just standing up about Autism more broadly," (Professional 6).

Reference 4: "I've had some involvement with someone who is experiencing very high levels of anxiety around situations like going into assembly, doing specific pieces of work in the classroom and because he was functioning fairly well in the classroom setting and appeared to be doing fine in assembly, nobody was saying there was a problem at all apart from the parents who were getting huge levels of fall out at home, huge levels of anxiety and anger and frustration which I think is very difficult to manage and so it was quite important somehow that we communicate that whilst this child might be trying to conform all the time in that situation so if someone in assembly says 'would anyone like to put their hand up?' he might put his hand up even though that's causing him a high amount of distress and that's about a fundamental understanding about the way in which some autistic children might behave," (Professional 6).

Reference 5: "There is still room for expansion as well. We're looking at secondary schools; the older children," (Professional 2).

Reference 6: "The schools had taken an entrenched position and the possibilities you had for turning it around were much smaller, much slimmer," (Professional 3).

Reference 7: Professional: "Some large secondary schools are less willing to be or are less able to be flexible about the needs of these young people and that makes it quite hard actually."
Interviewer: "What would you attribute that to?"
Professional: "Certainly attitudinal and certainly attitude at the top; cos I mean I think a lot of the time, subject teachers are quite willing to be inclusive and helpful but sometimes they don't feel that they have that ability to change things."
Interviewer: "So we're talking more about senior management?"
Professional: "Yeah senior management team and this particular one who's out and moved into a special provision; it was definitely attitudinal from the top," (Professional 1).

Reference 8: "Some of the schools use this (visual strategies), some don't," (Professional 3).

In contrast to professionals' views of themselves but consistent with five of the parents interviewed (theme 1), four of the professionals were very clear that they were not confident of schools' abilities to support parents' needs relating to their children. Whilst arguably, it is down to the MSG to ensure that the schools have the training that they need, Professionals such as 1 and 3 (references 1, 6 and 7) suggested that school staff needed to change their attitude before being in a position to effectively access this training. In line with parents' comments (theme 1), Professional 1 (reference 7) suggested that senior management figures could restrict the ways in which a school could support families of children with ASD. Professional 1 did not explain to any extent her reasons for this comment and as such, the reader can only assume that the attitudes which these senior management staff have negate and limit the value of the contribution of the PPP towards supporting families of children with ASD. Also, comments (Professionals 1 and 3; references 1 and 6) suggested that there needs to be greater flexibility on the part of the teachers; the implication possibly being a greater openness to supportive strategies, such as the visual strategies which some schools use and some do not (reference 8). This last point underlines the inconsistency in approaches used by schools and staff therein and the need therefore for greater standardised practice in terms of PPP support. However, there was also the implication from Professional 3 (reference 6) that there could be factions formed in schools, with some taking *"entrenched positions"*. This suggests that there is the possibility that any efforts to support schools have to be taken carefully and cautiously so as to avoid potential tensions. This point highlights the difficulties professionals in the PPP can experience: whilst they recognise the need to improve whole school thinking regarding ASD support, they identify the potential for animosity and therefore, a mutually destructive rather than constructive relationship.

In a contradictory way, it is interesting to note Professional 1's comment (reference 7) that "subject teachers are quite willing to be inclusive and helpful but sometimes, they don't feel that they have the ability to change things". This could suggest that school professionals, require more training from the

MSG, especially in terms of feeling that they can make a positive difference for children with ASD. Clearly, achieving the balance between getting schools "on-side" and avoiding tensions is both difficult and fine.

Theme 11: Professionals believe that parents have some confidence in them

Reference 1: *"There's still a long way to go but I now feel that there is; whenever I'm dealing with a parent, even in a conflict situation because I've picked it up ... at a high level, it might be parents who don't know us but there's more confidence that [the county] are doing something for their children with Autistic Spectrum Disorder and that tends to actually make/ allows parents just to have a little bit more trust," (Professional 3).*

Reference 2: *"I had a lot of positive feedback ... some dads in particular as well who have the different sort of opportunity to access it in a different sort of way and not just through the monitoring group courses or you know groups really but also through the ASD online training really as well. I just think that they feel that they are connected to some sort of network in a way that they possibly didn't feel as well," (Professional 6).*

Reference 3: *"The parents have said to me that they really appreciate being contacted," (Professional 4).*

Reference 4: *"Parents, suddenly, certainly, when I have rung them are very pleased to be rung and made contact with," (Professional 6).*

Reference 5: *"Not all parents are ready to go to them," (Professional 2).*

In contrast to parents' views of professionals (theme 1), four professionals felt that parents were confident in the abilities of the professionals to support the needs of children. However, they still understood that there needed to be further work into improving their confidence. Professionals described some parents as showing positive feelings towards the MSG including: trust, appreciation, pleasure and positive feedback (references 1, 2, 3 and 4). Within these specific comments, there was a sense that parents enjoyed the fact that professionals were proactively helping them by initiating contact with them – a theme that is further discussed in section 5.2.4 in this Chapter.

Of interest were the feelings that fathers of children with ASD had expressed (reference 2). Professional 6 recounted the appreciation shown by fathers towards the PPP, stating that they had, expressed a sense of involvement in the PPP via the online training programme sessions. This is pertinent given findings that fathers can feel isolated by rather than included in supportive PPP structures and this can lead to fathers feeling like a forgotten parent (Altiere and von Kluge, 2009). Professional 6's point made it clear that there were ways to include fathers in PPPs and that this PPP has, at least, according to Professional 6, successfully achieved this. As such, Professional 6's point underlines the importance of providing to parents a choice of ways in which to be supported, that is, parents do not need to feel obliged to attend face-to-face meetings, they do have the option of alternative mediums, such as online training. This finding is not highlighted in the current literature on PPPs and so adds some value to the evidence-base.

5.2.2 How involved are parents in the PPP?

5.2.2.1 Parents

Theme 12: Parents require more support to develop children's social interaction skills

Reference 1: *"There is a real concern ... people can't really empathise with them because they are not in the same situation as you," (Parent 3).*

Reference 2: *"We love our son to bits. It's easy for people to say 'Oh he's s a naughty boy' [mother cries] when he was in reception, it was very hard," (Parent 1).*

Reference 3: *"It's very tricky cos her sister is super-bright, super-able in everything, popular at school, invited everywhere, brilliant social life; and Y [her daughter] ... doesn't want to invite friends home because she says 'X will take her friends away'. She doesn't want her friends to become friends with X because they'll want X more," (Parent 2).*

Reference 4: *"X's [her daughter] at that stage where she just wants to be friends with normal people certainly normal looking people. Do you understand? So that is what I would like. It's possibly an impossible thing to ask for I mean how can she feel more comfortable to learn skills and to integrate well into our community?" (Parent 2).*

Reference 5: *"The social skills ... that's the thing she could really, really deal with," (Parent 2).*

Reference 6: *"The friends that she had were never really friends; they tolerated her and accepted her to some degree, but they never invited her round to their houses, to parties but, apart from that, she was pretty isolated. What I'd really like in a way is a how can we improve relationships where she is so she feels a part of a community. At the moment, she wants to walk to the shops but there's no one she can walk with – you can't knock on the door and say do you want to.*

It's heart breaking and she's pretty much isolated in that community – there are other kids that have special needs but they are very different – she has cerebral palsy, she can't walk, she can't make herself understood to X [her daughter] and X is at that stage where she just wants to be friends with normal people," (Parent 2).

Reference 7: *"I went to one meeting which was supposed to be 'Everyday problems with your child' ... I went with my husband because we felt that we could really do with every day things that are happening ... there wasn't anything that was really helpful or meaningful to us and we just thought 'forget it' and I kept on trying to draw the conversation into something that was helpful for us but the two women that were running it didn't really have anything more helpful to suggest that I hadn't already thought of myself," (Parent 2).*

Reference 8: *"Yes, I mean when you see M [her son], he's a bubbly 8 year old, curly haired, very very attractive to look at. The amount of people that have said that over the years, I've said 'ooh, that's his saving grace'. He's a very likeable little boy. He's very attractive to the eye and people think 'oh isn't he a cutie' which is fantastic but I always think 'if he wasn't always such a cutie to look at how much difficult life would be for him' which is really sad I think but it's so true. But it's very much, it's a society thing," (Parent 1).*

Reference 9: *"What I really want is a child who feels confident to and you know somebody who's happy, really, someone who has friends, has a social life. I honestly don't care whether she, well you know, can read or write; I couldn't care less; I want her to be able to feel happy with herself and the most important; for me, the thing about happiness, the thing that will bring her happiness is social relationships, that is the most important thing," (Parent 2).*

Reference 10: *"In some ways, life is more difficult than school life because school life is very much an ordered life," (Parent 1).*

Three of the parents expressed their concerns regarding their child's lack of social development skills and the equivalent lack of professional involvement to address this need. General comments related to the way in which these children desired a sense of inclusion, what Parent 2 described as being *"friends with normal people,"* (reference 6) and others described in terms of empathy (reference 1) and in Parent 1's case, just a sense of acceptance and almost openness (reference 2).

Parent 1 implied that the community around her son; in her example, the school community, were not maybe as open as they could have been to her son's needs, seeing him as *"naughty"* and perhaps not as a child who needed social support. There was an implication here that schools had not necessarily been as "ASD-friendly" as they could have been – too readily viewing a child as poorly behaved rather than in need of support. Perhaps, there is also, in this respect, a feeling that schools are again too easily influenced by the medical/deficit model (Chapter 2, section 2.2) viewing a child's issues as being their fault and not questioning other reasons for them, such as the challenges presented by ASD. Parent 1 also rather painfully discussed how one of the reasons she felt that her son has coped had been due, not so much to internal coping mechanisms but his good looks (reference 8): the implication being that he would not have coped without these looks.

Parents felt concerned by the wider levels of society and their attitudes towards them and their children. For example, Parent 2 explained how her daughter desired a *"normal"* social life but felt challenged by the community in which she lived and the lack of inclusion she felt within this very setting (references 4 and 6). There was also a sense that Parent 2 was in a state of despair, viewing as she did her child's social needs, as unrealistic:

> *"It's possibly an impossible thing to ask for I mean how can she feel more comfortable to learn skills and to integrate well into our community," (Parent 2).*

Additionally, Parent 3 talked generically of "people" not understanding her son's needs (reference 1). There is an implication that the parents take some of these attitudes personally, almost feeling attacked and judged by the society around them. This is reinforced by the sense of despair in Parent 1's statement that *"in some ways, life is more difficult than school life because school life is very much an ordered life,"* (reference 10). There is by implication a sense that her life and that which she shares with her family is an antithesis to that of the school setting: where school is ordered, her family life is less ordered and perhaps confused and disrupted by what she considers to be other people's misconceptions and misunderstandings of the needs of her child.

Also, it appears that more support is necessary to help families include their children in their settings. Some parents, such as Parent 2 (reference 7) did not feel that enough support was available from the PPP to address these areas of need. Her criticism that the training sessions on social skills lacked application to her family's needs suggests that future support planning needs to take into account more explicitly the importance of differentiation and personalising support to address family's needs and manage their expectations.

It is evident in the literature that there are many families who experience notable difficulties in feeling that their children are accepted by society (for example, Revill, 2007). Furthermore, it is identified that many of these experiences occur in public and family outings (Bouma and Schwietzer, 1990; Gray and Holden, 1992; Howlin, 1988) with families complaining that there is inadequate PPP style support to provide for their needs when out in a family context (Shelley 2002; Petrie et al 2007).

Theme 13: Parents need more help to develop their child's communication skills

Reference 1: *"He is often saying 'but you said' and so it is phrasing things right and giving him time to adjust to change. Just being aware that he likes his routines and his order," (Parent 4).*

Reference 2: *"[She] hasn't ... really learnt 'this is how I have a conversation with somebody' and how this impacts on her life out of school time," (Parent 2).*

Reference 3: *"He goes off and seems as if he's not actually concentrating," (Parent 5).*

Reference 4: *"He won't necessarily listen to what anyone else is saying but we do have to go over and over the same things," (Parent 3).*

Reference 5: *"One of the things is in the morning; she just doesn't stay on target and I just hate being a nag; a policeman, you know kind of thing and how can I help her? She can do it but she just goes into her dreamy little world and does her own sort of thing," (Parent 2).*

Reference 6: *Parent: "Well, there are times when I need to repeat myself several times; times when I need to understand her point of view, look into her eyes and say 'whatever'. Usually, it's something I've asked her to do several times that she hasn't done, for instance."*
Interviewer: "Morning routine?"
Parent: "Yeah. The morning routine or the night time routine, either one of them."
Interviewer: "Beginning and ending of a day."
Parent: "Yeah, beginning and ending of the day."
Interviewer: "That can be quite a problem, can't it for a number of children with Autism."
Parent: "Usually, well for me it is, because 25 past 8, her taxi's there," (Parent 2).

Reference 7: *"His ability to hold a conversation, you know back and forth ... It's improving but it's not like his peers. He may ... he'll talk about something he loves and he won't pick up that the person he's talking to hasn't got any real interest in like the 'Thunderbirds' or what he watches in TV," (Parent 1).*

Five of the parents felt that more professional involvement was needed to address their child's communication, specifically, the way they express themselves in the company of others both verbally and non-verbally (such as facial and bodily gestures).

Many of the parents (Parents 2, 3 and 5; references 3, 4 and 5) felt that their child had particular difficulties concentrating: what Parent 2 (reference 5) describes as *"she just doesn't stay on target"*. This lack of concentration was described by parents in terms of frustration. For example, Parent 3 (reference 4) says *"We do have to go over and over the same things"* and Parent 2 who says *"I just hate being a nag ... how can I help her?"* (reference 5).

There were also reported difficulties from Parent 1 related to her child's tendency towards egocentric conversation (reference 7) whilst Parent 3 described her daughter's tendency to *"not necessarily listen to what anyone else is saying"* (references 4). Whilst these are common characteristics of children with ASD, they can impact negatively on the development of appropriate social communication (ibid). Despite the fact that one of the key goals of the MSG is to address and help parents support their children's communication and interaction (Chapter 4, section 4.5) the parents in this sample did not express any satisfaction that this goal has been achieved.

<u>*Theme 14: Parents require more support to reduce child's behavioural problems*</u>

Reference 1: *"I think that certain areas, more free time, play time and lunch time and they don't get any support. And that is where a lot of his problems come up," (Parent 3).*

Reference 2: *"Teachers are not there all the time – this [behavioural problem] is happening at break times on the playground, circle time," (Parent 2).*

Reference 3: *"Social problems – aggression. His ... he did it a couple of months ago he had to – he went through a spell where he was constantly in trouble fighting, he tried to escape from school, and it is all in the lunchtime," (Parent 3).*

Reference 4: *"[It is the] kind of unstructured time that I would think that probably a lot of kids with ASD struggle with which is where there doesn't seem to be the support," (Parent 3).*

Reference 5: *"Where she is now, they'll say 'put your hand up if you don't like X' and she's [her daughter] learning that sort of thing," (Parent 2).*

Two of the parents felt that a greater amount of professional involvement was needed to support the behavioural needs of their children with ASD. In line with their responses to questions of confidence (theme 1), they felt that support was needed in schools, especially during unstructured times, such as break and free time (references 1, 2, 3 and 4) to support these behavioural needs.

Parents described these behavioural needs in different ways: Parent 3 wanted help to address her child's aggression (Parent 3; reference 3) whilst Parent 2 wanted professional involvement to reduce her daughter's risks of being bullied (reference 5). There is a sense, especially in references 1, 2 and 4 that, their children are vulnerable and in need of greater supervision.

The literature identifies that children's behaviours if not addressed appropriately can become challenging for family members (Bouma and Schwietzer, 1990; Gray and Holden, 1992; Howlin, 1988). For the child, it can cause isolation and associated social difficulties (Harper et al, 2008) that have already been described (theme 12). However, these findings also raise the importance of safeguarding children – a key theme of the "Every Child Matters" agenda (DfES, 2003a) and one which is clearly needed in some of these children's cases.

Theme 15: Parents require more support to help child's transition into adolescence

Reference 1: *"Obviously as he [her son] gets physically bigger it's quite a worry cos he's not violent at all, thankfully but you know, if he gets cross you know and starts pushing, then it's quite a worry how he's going to be," (Parent 6).*

Reference 2:	*"It does worry me now because he is quite a big boy and he is quite strong that you can't physically make them do anything anymore so and as he gets older that will be less and less the case," (Parent 3).*
Reference 3:	*"Last term, I actually said he's different than other kids and he wants to know if he's ever going to be clever; is there some sort of book he can read so he can understand what Autism is and that it can introduce to him that he is different. So I've asked her for that about a month ago and I haven't heard anything back," (Parent 6).*
Reference 4:	*"It's going to become more of an issue soon because he's going into year five and so is the secondary school issue. I would definitely like more information about where to go for the secondary school," (Parent 6).*
Reference 5:	*"The one time she did say 'oh, why don't you try social story; a sort of visual timetable' ... I just don't think it'll work because she'll forget to look at it. She'll think it's babyish ... that sort of thing is too different to teenager, too babyish," (Parent 2).*

Three of the parents mentioned their need for further professional involvement to address their child's transition to adolescence. There is a sense that parents were worried about the challenges their children will face as well as present to their families and the wider community, such as school.

Specifically, there was a sense from Parents 3 and 6 (references 1 and 2) that they felt threatened by the prospect of their sons' increases in physical strength and how this strength could be used to challenge their parents and take control of a situation. Parent 6 mentioned not knowing how her son was *"going to be"* when he begins his adolescence and at the same time, she desired information from the PPP regarding suitable provision to accommodate his future needs (reference 5). Similarly, there was a sense from Parents 2 and 6 that the PPP needed to be more involved in providing information regarding ways in which to support their children's needs during their adolescence (references 3, 4 and 5). However, in Parent 2's case, she required support to be more differentiated to suit her daughter's age-range, feeling that the type of support provided for her daughter, such as the "social story" (a visual support strategy) was too *"babyish"* for her (reference 5). In contrast, Parent 6 (reference 3) felt that despite her being proactive and asking the MSG for a book to explain to her son about his needs, the MSG had not delivered any support, prompting concerns as to what she could do to help her child.

Comments show that it is important to these parents to gain help for their children at all times but arguably, adolescence is one of the most crucial periods of time where a child's social behaviours are developed and when these individuals can become more keenly aware of their relationship difficulties (Tse et al, 2007). The findings raise the issue of whether the MSG has addressed the importance of differentiating their recommended strategies in an age-related way to avoid youngsters' feelings of being "baby-ed" and accommodate the different developmental milestones along a child's trajectory. The findings in this study would suggest that there is also a lack of such differentiation in this PPP.

Theme 16: Parents need more support for siblings of children with ASD

Reference 1: *"It would be nice to have some sort of support for them, to give them time out and meet other children who are in the same situation because they become almost carers/siblings as carers. The older one does particularly ... he shouldn't have to be; he's 12 and it's embarrassing to have a brother who's a bit weird so you know he needs time from being this," (Parent 6).*

Reference 2: *"She has a sister. Well her sister's nine. It's very tricky cos her sister is super-bright, super-able in everything, popular at school, invited everywhere, brilliant social life; and X [her daughter] doesn't want to invite friends home because she says 'Y will take her friends away'. She doesn't want her friends to become friends with Y because then they'll want Y more," (Parent 2).*

Reference 3: *"Autism brings its own difficulties ... in some ways, family life is more difficult because although family members know him very well, reasonably well, they're in this little bubble whereby that he's fine. So if we go to family do's, they all expect us to be there. But sometimes it is right to say, no. It's not going to be appropriate for M [her son], he's going to stress out – we'll all stress out. We'll all have an awful time so we made a pact. Sometimes we'll go, we'll go; sometimes only two of us will go; me and my husband or my daughter and I so, uh, in some ways life is more difficult than school life because school life is very much an ordered life," (Parent 1).*

Three of the parents were concerned about the position and wellbeing of their other children, the siblings of their child with ASD, as well as the effect that siblings could have on the child with ASD. It was apparent that more professional involvement to support families around these issues would be useful.

Comments from Parents 1, 2 and 6 suggested that they felt that having a child with ASD could be divisive, almost segregating the family. Parent 1 described how only *"two of us will go"* (to a family function) (reference 3) sometimes her and her husband or her daughter, but not always as a whole family because that could lead to an *"awful time"* as her child with ASD will *"stress out"*. Similarly, Parent 2 felt that her daughter with ASD was threatened by her normally developing sibling who was described as if she was her sister's rival (reference 2). For example, her daughter with ASD does not wish to take her friends home, for fear of losing them to her sister. In contrast, Parent 6 felt that her other children had to develop roles not as siblings but as carers – a divisive move that stopped them being a normal brother or a sister (reference 1). Parent 6 also felt that her children could find their brother with ASD *"embarrassing"*.

It appears from these findings that coping with these divisions between the siblings can be challenging for the family as a whole. However, there seems very little input from the PPP into how to support siblings and it is certainly not mentioned as an issue to address by the professionals. This is despite the fact that it is evident from the literature that siblings are at risk of being marginalised as a result of the attention spent on the child with ASD (Reed, 2007; Bågenholm and Gillberg, 1991; Gold, 1993; Rodrigue et al, 1993). The findings from this study, although small-scale, do suggest that families are still challenged by the family dynamics of supporting a child with ASD and do require more support and guidance.

Theme 17: Parents want more support to increase societal and familial understanding of ASD

Reference 1: *Parent: "It doesn't challenge my confidence, it just means you're confronted with it more; if you try and explain to people that we won't be going because that's not something that M [her son] will enjoy and we're not going to make him do something ... there is no point in making him do something that he's going to get so, so stressed out about. If it's important, then we'll do it but if it's not vitally important then we'll take the other route."*
Interviewer: "But sometimes other people don't see it – is it? – a problem with society?"
Parent: "Yeah and family people who know him but they well will forget. And I'll say you should think about it and they say 'Oh yes'." (Parent 1).

Reference 2: *"Although family members know him very well, reasonably well, they're in this little bubble whereby they think that he's fine. So, if we go to a family do, they all expect us to be there but sometimes, it is right to say no, it's not going to be appropriate for M [her son], he's going to stress out – we'll all stress out. We'll all have an awful time so ... sometimes, we'll go, sometimes only two of us will go," (Parent 1).*

Reference 3: *"In some ways, life is more difficult than school life because school life is very much an ordered life," (Parent 1.)*

Reference 4: *"And I haven't really had a sense of being understood as having a particular child with her particular sense of psychology and you know, particular idiosyncrasies and us as a family with our dynamics," (Parent 2).*

Two of the parents felt that they were misunderstood and there was an absence of support available to address this feeling. Parent 1 described the difficulties in gaining her family's understanding regarding her and her son's needs. She spoke about how family outings could be challenging because of people's expectations that her son is *"fine"* (reference 2). There is a sense that Parent 1 is continually trying to cope with this but that her strategies are ultimately divisive as she resorts to separating up her family into who will attend an outing and who will not. She spoke of how their life as a family was disordered and as she contrasted it with school (reference 3); we can only infer that there is somehow a routine lacking from their familial life. Similarly, Parent 2 discussed the difficulties of being understood as a family with their *"dynamics"* (reference 4). Again, Parent 2, consistent with some of her other comments (see section 5.2.1.1 of this Chapter), suggested that the misunderstanding she receives is related to a lack of personalised support for her and her family.

Again, the need for personalised support is referenced (see Chapters 2 and 3) but in these cases, seems limited.

5.2.2.2 *Professionals*

Theme 18: Professionals are responsive to parental needs around behavioural problems

Reference 1: *"I know that X [the MSG co-ordinator] is keen to look at, you know, at the options; do training around that and behaviour and things like that," (Professional 2).*

Reference 2: *"Nor are all practitioners all comfortable with behaviour and the issues I get are all behaviour," (Professional 3).*

In contrast with parental views, two of the professionals (Professionals 2 and 3) recognised the need for increased amounts of PPP support to families and schools in relation to behaviour management strategies. Professionals believed that they were responsive to parental wishes in relation to behaviour management strategies. Whilst professionals acknowledged that there were behavioural problems (reference 2) and that it was important to develop strategies within the PPP to address them (reference 1), the fact that only two of the six professionals referred to this issue, suggests that it is not necessarily that high on their agenda or necessarily a common goal for the PPP.

Indeed, Professional 3 stated that not all professionals are "*comfortable*" with dealing with behavioural difficulties (reference 2). This is a pertinent comment that highlights that there may be a tendency for professionals to shy away from dealing with behavioural issues: a personally made observation of some professionals, mainly health professionals, who are not necessarily trained in and feel challenged by ways to promote appropriate behaviours. However, given the parents' comments about behavioural difficulties (theme 14) there is a strong argument for addressing behavioural issues more explicitly within the PPP. This seems especially true in light of the existing literature that underlines the anxieties parents have around behaviour (Howlin and Moore, 1997).

Theme 19: Professionals are responsive to parental needs around children's communication skills

Reference 1: *"I kind of recommend the use of visuals a lot so um, you know things like having symbols," (Professional 4).*

Reference 2: *"I think the general principles are very much the same: visual approaches, whether they feel they are necessary or not, it is, children need some method of being informed and that could be print ... social stories ... some children, obviously you've got children with very severe developmental delay who are, who haven't got any communication at all and [then you might start] them with the picture exchange communication," (Professional 3).*

Reference 3: *"I have used MAKATOn and symbols and whatever level they're at," (Professional 2).*

Reference 4: *"I'd be supporting staff in schools with a child with ASD, I'd be recommending the use of visuals," (Professional 5).*

Reference 5: *Professional: "You know I use a lot of visuals when I'm talking and trying to communicate with the children."*
Interviewer: "Is it a strategy you'd be advising to somebody else to be using?
Professional: "Absolutely," (Professional 6).

In contrast with parents' views, (theme 13), five of the professionals felt that they used and promoted social communication strategies to both families and schools, discussing at length their use of and recommendations of visual support strategies, such as social stories, to develop children's social interactions.

This difference in parent and professional opinion on the use of social communication tools is more striking than the difference highlighted above regarding behavioural problems and could suggest that parents are not accessing the support provided as effectively, perhaps, as it was intended or the support is not necessarily as useful to parents as they would like it to be. For example, the use of visual support may be regarded as unsuitable and inappropriate given the age ranges and needs of these parents' children. This is a point raised by Parent 2 (theme 15, reference 5) who discussed how the social story technique, a popular visual communication strategy was not suitable to her child's age and was considered too "*babyish*" for her child. It is also possible that families would like their children to learn how to use verbal rather than visual communication; a point that recalls Parent 2's comment (theme 13, reference 2) that her daughter *"hasn't ... really learnt this is how I have a conversation with somebody".*

Verbal communication strategies for children with ASD are not commonly reviewed in the literature, although this could be due to the more successful outcomes identified in the use of visually-based resources (Beck, Stoner, Bock and Parton, 2008). Also, it is difficult to identify ways in which these professionals could provide support in addressing verbal communication without adopting a behavioural approach, such as Applied Behavioural Analysis (ABA) which has a lot of criticism because of its focus on reframing and changing a child's behaviours (see Chapter 1).

5.2.3 How empowered are parents in the PPP?

5.2.3.1 Parents

Theme 20: Parents have had difficulties coming to terms with their child's ASD diagnosis

Reference 1: *"I mean I have a nursing background so I know what the diagnosis meant but having said that it probably took us about six months to expect that it was a permanent feature and that it wasn't something you could grow out of and you could cure overnight," (Parent 5).*

Reference 2: *"Because he was my first child, I suppose I did not necessarily think there is something wrong here," (Parent 3).*

Reference 3: *"I would say the first time when we were told you know we think he has ASD, that he we think he has by my doctor although not in so many words but I came out of that room feeling that it was just me being a bad parent, that was why he was the way he was so there was no sort of anything going on from that, that was just, which was a really bad start and when you start from that point, obviously you are very ... ," (Parent 3).*

Reference 4: *"I think it would have been good to have contact [during diagnosis] cos I think at that point we would have been able to talk us through stuff," (Parent 5).*

Two of the parents discussed the diagnostic process in very negative terms. Their views highlighted their sense of disempowerment and specifically, vulnerability, throughout this process. Their comments suggest that they would welcome some support and guidance whether from the PPP or otherwise, to come to terms with the diagnosis process.

Parent 5's comments revealed her sense of disbelief regarding the ASD diagnosis, once obtained:

> *"I mean I have a nursing background so I know what the diagnosis meant but having said that it probably took us about six months to expect that it was a permanent feature and that it wasn't something you could grow out of and you could cure overnight," (Parent 5).*

This sense of disbelief is common amongst parents of children with Special Educational Needs yet still is striking here, given this parent's open admission of knowledge and understanding of the diagnosis prior to it being obtained. These findings prompt the question of how other parents, who may not be so skilled and informed in the area of ASD, may react to the news of a diagnosis of ASD.

Finally, parents' vulnerability was also expressed in terms of feeling isolated. For example, Parent 5 described how she would have valued emotional support from the PPP at this time:

> *"I think it would have been good to have contact cos I think at that point we would have been able to talk us through stuff," (Parent 5).*

Literature states that it is beneficial for parents to be involved in every step of the process of diagnosis (Osborne and Reed, 2008; Schuntermann, 2002; Stoddart, 1999), yet it seems that in the cases outlined this parental involvement has not been evident. With regards to the length of time it takes for the diagnosis process, it is clear that parents are dissatisfied that the procedure takes so long. Again, this is a long-standing issue of concern (Mansell and Morris, 2004; Brogan and Knussen, 2003). In this case, an early and speedy diagnosis has not been given to at least one of these parents.

Even though the PPP is not responsible for the diagnosis procedure, it may be beneficial, given parents' anxieties regarding their experiences of diagnosis, to offer some emotional support at an early stage. This would be in line with their role of supporting parents to address their feelings of competency and success.

5.2.3.2 *Professionals*

Theme 21: The MA element of the PPP empowers professionals to empower parents

Reference 1: *"Because we're coming together, working in an MA way, we're bringing aspects of our expertise together and helping us to sort it out cos normally in the past we would have done individual visits etc or focused in the schools or bit of training and overlapping and you get more coherence, training or working together – that benefits every one," (Professional 5).*

Reference 2: *"I think it's been good having multi-professionals; I think that's been really good, sharing ideas especially things like planning training, being able to call on speech and language therapy, LLSS and other medical people to help with developing the training and to help with running the training and discussion within the group; you know it's just good to have people's perspectives," (Professional 4).*

Reference 3: *"It's good to have a range of people with different perspectives and different understandings and different things that they can bring to it [the MSG]," (Professional 6).*

Reference 4: *"You can direct them [parents] to other people with another story to tell," (Professional 3).*

Reference 5: *"Getting together on a regular basis every six weeks with other colleagues from other professions, getting a full rounded picture of what's going on with the children referred to in the group; multidisciplinary training now – using everybody's skills," (Professional 1).*

Reference 6: *"I think there are a lot of benefits for parents and for myself as well being a part of it because it's multi-agency; you've got a lot of experience to draw on from other people, and you can also call upon them. If you go in and you think 'oh actually, I think it's a speech and language or LLSS you could call on them as well. You can have them from that point of view," (Professional 2).*

Reference 7: *"If I've been in a school with a child, or in a meeting or I've been this key contact and made this telephone call that actually there is somewhere to go with that, what's happened. I've got somewhere to go. I've got people to talk to about it or I've got someone to talk to about doing a bit more work around an area," (Professional 6).*

Reference 8: *"I don't feel alone in it either which is lovely," (Professional 6).*

In line with findings in theme 8, all six of the professionals were confident of MA working and specifically its ability to empower parents. This included the opportunity to share expertise (references 1 to 7) and to work in the company of others, for example *"I don't feel alone,"* (reference 8). Professionals felt that MA working sped up the process of support for parents (reference 1) and that empowered everyone (ibid).

As mentioned in theme 8, MA working has become a popular topic in areas of educational research (for example, Abbott et al, 2005; Booker, 2005; Edwards, 2004; Leadbetter, 2006) and one that clearly has a lot of meaning for all of the professionals involved in the MSG.

5.2.4 Is contact between parents and professionals in the PPP valued by both parties?

5.2.4.1 Parents

__Theme 22: The key contact reassures parents__

Reference 1: *"It is good, it's like a safety net. I can phone them and they will respond to you," (Parent 3).*

Reference 2: *"We had a problem with the school at the beginning of this year and I was able to contact X [her key contact], so umm in those terms, it was quite a big support that I knew I'd be able to phone her and that she's be able to help me to deal with it," (Parent 5).*

Reference 3: *"It's a phone-call – that's all you need," (Parent 1).*

Reference 4: *"[I'm] slightly more relaxed about it [her son's ASD], slightly less stressed about what he is going to do because there is someone you can speak to and who will understand that you are not completely mad," (Parent 5).*

Reference 5: *"I mean they have been ready to listen and they haven't given the impression that they think we're wrapping him in cotton wool," (Parent 1).*

Reference 6: *"If there's a crisis, you can say 'well, hold on a minute. This was flagged up or you should have done this.' You can say, 'help' or 'thank you'. It's nice to say 'thank you' and we generally do," (Parent 1).*

Reference 7: *"It's good to know it's there," (Parent 2).*

Reference 8: *"Because you know these professionals are involved and that they are saying 'yes try it'. They've given us the courage to say 'yes try it. We're sure he can cope with this once things are in place'. It gives you more confidence um and I've lost track. It gives you the confidence to know that there are people there and that it gives you the confidence to know that my son has the right to this education and you've got the right to seek it out and say 'well I just need you to do this little bit for you' – it's a huge thing for our son and will get him where he needs to be," (Parent 1).*

Reference 9: *"For us, it just felt like we had some support and understanding which we weren't getting from school so yeah it's like having someone on your side, if you like," (Parent 5).*

Reference 10: *"She's really good ... she's really good. She phones up about once a term, talks about whether I've got any issues to take back to the group and I tend to tell her how we're going; if we've got any problems; academically and she takes back to the group," (Parent 6).*

Reference 11: *"I think in our own mind, we know that he's being properly monitored and that there are professionals that are keeping an eye on him, on how he's doing. I know he's doing well and I still think it's because he's doing well that it's ... I would imagine that when you think of an autistic child or when you see an autistic child and then you see my son that's a very good example of how well an autistic child can do in a mainstream school given the right support and yes it's to do with the ASD group and the fact that they put it all together and we can say that a particular thing we're worried about ... I can say to X [her key contact] 'you know this isn't happening' or 'this seems to be a problem' and she will act upon it and find somebody who can so that that's very much a positive thing," (Parent 1).*

In line with theme 4, five of the parents felt that the key contact role reassured them. It gave them a feeling of security (references 1, 2 and 7) and a sense that they did not need to seek out support proactively (reference 10). There was also a sense of trust between parents and the key contact (references 1 and 2). Some parents felt that their contacts could support them with resources where necessary (ibid) or just listen to their needs (reference 10).

Theme 23: Meetings give us a chance to obtain information

Reference 1: *"It's nice to know that, every now and then, you're asked to do a group and some of them you will do because you can and some of them you think 'well, we've passed the time when we used to see the stuff' but it's nice to know that it is there and you know," (Parent 1).*

Reference 2: *"It has been good and it's good for information um from other parents who have not the same issues but similar issues so 'have you read about this?' or you usually get a wider sense of what's available to other people as well," (Parent 1).*

Reference 3: *"I've got information ... I've been to a couple training sessions and done various things. It gives me information," (Parent 5).*

Two of the parents felt that the contact between them and professionals was beneficial in bringing them information related to their needs as parents. They mentioned the benefits of being able to share information to gain a *"wider sense of what's available,"* (Parent 1, reference 2). This seems particularly important as it highlights the way in which the meetings are acting like forums with the emphasis on collaborative learning and every one being in a position to access some help if needed.

For some parents, such as Parent 1 there seems to be a sense of relief that the meetings exist and are available.

<u>Theme 24: Parents value contact with other parents</u>

Reference 1: *"[There is] contact with other parents ... That's quite a big thing actually because the ... people talking about the same stuff you're going through," (Parent 5).*

Reference 2: *"Yes there are benefits to it because if you do have particular problems – we have always had problems with his aggression and that is something that I have talked to them before about and also because it is also done in a very informal way you do meet there are other parents there, and there was a lady I was talking to a couple of meetings ago who has an older boy that had the same sort of problems so she had obviously gone through it. So that it is also meeting other people there that have had the same problems and perhaps giving you different ideas of how to deal with things. So in that respect it is quite useful," (Parent 3).*

Reference 3: *"It has been good and it's good for information um from other parents who have not the same issues but similar issues so 'have you read about this?' or you usually get a wider sense of what's available to other people as well," (Parent 1).*

Reference 4: *"So some parents say that they feel that they don't feel understood and it's only when they meet parents who are in a like minded situation that they can filter through their own experiences," (Parent 5).*

Reference 5: *"I think that probably the main thing is just to have time to talk with other professionals and with other parents as well," (Parent 5).*

As mentioned in theme 5, parents welcomed the opportunity to meet other parents. Parents 1, 3 and 5 believed that their interactions with other parents meant that they could share anecdotal stories about their children which could help them feel more understood. Parent 5's comment (reference 4) was particularly pertinent as it reaffirmed the importance of feeling understood – a clear need for parents of children with ASD. Parents such as Parent 3 also welcomed the ease at which the meetings enabled her to meet parents (reference 2) and the supportive strategies that they could share (reference 2, reference 3).

Theme 25: Contact is not always flexible to parents' needs

Reference 1: "There are people it doesn't work for you know. Some things aren't tailored for their needs. But that's certainly something the group needs to be aware of because if they're not meeting your needs, then they're not supporting ASD are they?" (Parent 2).

Reference 2: "What I would like is if I've got an issue that I could phone up and talk to somebody and say 'how do I work this out? How do I deal with this?' that's what I'd really like," (Parent 2).

Reference 3: "At the moment, I've got to wait for someone to call me and frankly when she has called me and I've had issues to deal with it seems that what they're really more interested with is issues with the school or the sort of education side of it rather than the daily life," (Parent 2).

Reference 4: "If it could just be more about the human being rather than the boxes that are to be ticked and more about the um the things that matter to us rather than the things that seem to matter to the group or the things that seem to matter to the ticking of the boxes, the sort of categories," (Parent 2).

Reference 5: "They have an agenda but it isn't mine," (Parent 2).

Reference 6: "I kept on trying to draw the conversation into something that was helpful for us but the two women that were running it [the PPP meeting] didn't really have anything more helpful to suggest that I hadn't already thought of myself. I didn't really have the sense that this was someone who really understood Autism or the issues we were dealing with and maybe the fact that they'd never met her or don't know her – it might have something to do with it, I don't know but I didn't have the sense that they had more to offer than I'd read in a book or you know," (Parent 2).

Reference 7: "They keep telling me to go to their things but it's always on a Friday so we never go along to them cos I can't do Fridays," (Parent 6).

Reference 8: "What I would like is for some parental support group that was a bit easier to get to," (Parent 6).

Reference 9: "We sort of look at the internet, trying to work out our own answers to the problems," (Parent 6).

Two of the parents suggested that the contact between them and professionals was not always flexible to their needs.

From the above, it is evident that Parent 2 felt strongly that despite receiving contact, she still believed that it was not the right kind of contact because she felt that it did not help her support her or her child's needs.

Parent 6 also raised the point that contact between parents and professionals was still not as flexible as she would like it to be. She said:

> *"They keep telling me to go to their things but it's always on a Friday so we never go along to them cos I can't do Fridays," (Parent 6).*

As a result, she felt that she could be isolated from support (reference 9).

Given the importance that the key contact and regular telephone call clearly plays in these parents' lives and the difficulties that at least Parent 6 experiences in making face-to-face meetings, there may be a greater need to explore ways in which to further use telephone communication to enable even greater flexibility to families.

Over and above this, it is clear that the PPP understands the importance of contact between parents and professionals and from this evidence is achieving their goals of ongoing communication and interaction.

5.2.4.2 Professionals

Theme 26: Key contact quickens the support professionals can provide

Reference 1: *"I think you can pick up on things much quicker as well, slipping or something's changing or not quite right after that phone call," (Professional 4).*

Reference 2: *"The youngsters are picked up quicker if there are difficulties that we try and pick them up sooner rather than letting them build up to a bigger problem and hopefully getting in quicker you know kind of stops the blowing out of proportion," (Professional 4).*

Reference 3: *"They've got a key contact and there is a support network around them, for some of the parents that is very part of that ... there is somebody you can ring," (Professional 2).*

Reference 4: *"We know the parents made contact with the parents and there is a sort of cyclical feedback into that group as to what's happening, what's going well, what might be about to become a big issue, what is already a big issue or what successes there have been. And I think that parents, suddenly, certainly, when I have run them are very pleased to be rung and made contact with and pleased to tell the good things as well as the not so good things," (Professional 4).*

Reference 5: *"Since I have been a key contact for some of the children that I've got in my patch, I've learnt a lot more about it and a lot more about managing the child's needs but through a range of ways really: working alongside the schools and alongside the parents and facilitating communication between them," (Professional 6).*

Reference 6: *"I think that the fact that there is the parent phone call – that is fantastic – it does pick up issues much more quickly. It does make parents feel very supported and that's great if parents feel supported," (Professional 1).*

Four of the professionals felt that one of the most important aspects of the MSG key contact was that it provides quick and effective support for families. These professionals refer to the way in which the key contact role has quickened their interactions with parents and other professionals and in so doing, sped up the support provided to parents. Professional 4's comments were especially pertinent as they described the way in which the key contact role could facilitate *"cyclical feedback"* (reference 4). The implication is that the communication between the two parties allows both parents and professionals to voice and address concerns simultaneously allowing the process to be recursive and therefore a more positive and constructive use of time for all parties. Professional 6 (reference 5) felt that her role as key contact had helped her to learn more about how she could manage the needs of children with ASD – a benefit, professionally, as well as one of value to the parents.

Theme 27: Key contact reassures parents

Reference 1: *"It's so nice that somebody else has done the contacting rather than feel that they have to do all the work and that's been they've found that really reassuring," (Professional 4).*

Reference 2: *"I think that parents, suddenly, certainly, when I have rung them are very pleased to be rung and made contact with," (Professional 6).*

In line with parents' views, professionals identified their role as key contact as offering to parents a sense of security and support. There is a sense here that the key contact role engenders both parents and professionals, almost acting like the "glue" that binds them into their partnership and facilitates interactions.

It appears that the professionals identified that parents felt more valued by the fact that the professionals were initiating contact with them, rather than the other around. Chapter 3 referred to the ways in which parents could feel neglected by professionals. In this instance, it would appear that both parents and professionals felt that the role of the key contact allowed both of them to feel recognised and valued. This not only underlines a key benefit of the PPP but also at a simpler level, the value of a three monthly telephone call.

Theme 28: Key contact is a way to share information

Reference 1: *"I feel like it creates a kind of grid within which there is much more communication between everybody: parents, the schools, the EPs, every service that is involved with those children," (Professional 4).*

Reference 2: *"I just think that they [the parents] are connected to some sort of network in a way that they possibly didn't feel as well. I think you can pick up on things much quicker as well, slipping or something's changing or not quite right," (Professional 6).*

Reference 3: *"I mean I think for the child themselves, they don't realise the support they're getting but certainly the impact it has on the parents; for some parents to know that they can access training; they've got a key contact and there is a support network around them. For some of the parents, that is very part of that ... there is somebody you can ring," (Professional 2).*

Both Professional 2 and 6 (references 2 and 3) described their role as providing a supportive network to parents whilst Professional 4 (reference 1) felt that the key contact role enabled parents and professionals to fit into a *"grid"*. This networking acts to disseminate information which professionals believed had concrete value. For example, Professional 2 (reference 3) discussed the ways in which the key contact role allowed her to discuss any forthcoming training events on the calendar.

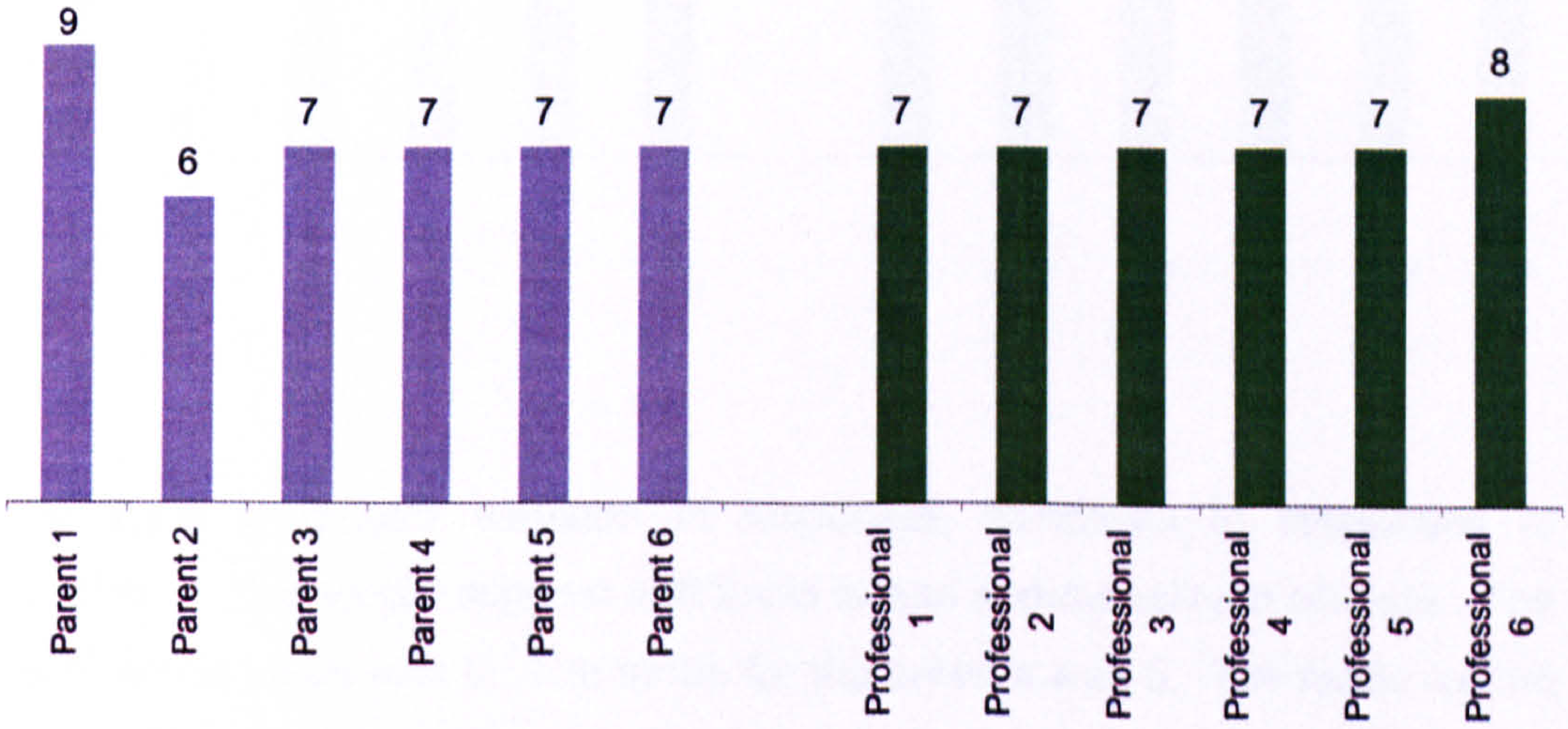
5.3 *Quantitative results*

In line with the requirements of the research tool – to adopt a mixed methods approach – quantitative data from Likert Scales questions were asked to all participants immediately following the delivery of the interviews. This was to enhance findings relating to perceptions of confidence in the PPP.

Professional and parental responses to each question are shown together to show any consistency in attitudinal response. As set out in Chapter 4, the responses can range from 1 to 9 and denote levels of agreement to the question posed. One means completely disagree; 2 means strongly disagree; 3 means disagree; 4 means disagree more than I agree; 5 means undecided; 6 means agree more than I disagree; 7 means agree; 8 means strongly agree; and 9 means completely agree. The findings are presented graphically for each question answered.

5.3.1 *Question 1: "I am confident that I am managing the needs of my/the child?"*

Figure 1: Responses to Likert Scale question 1

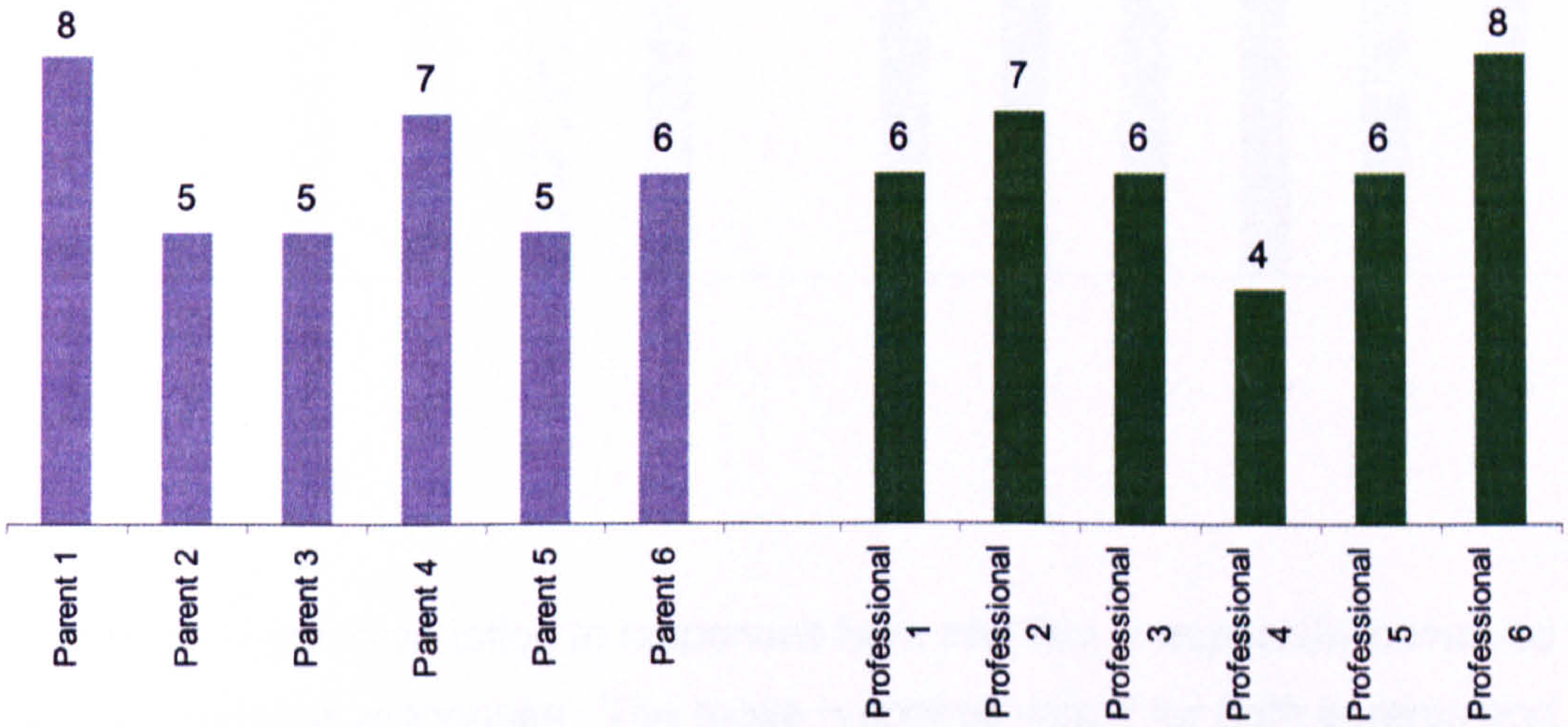


Descriptive statistics show that the mode response was 7 for both parents and professionals. This suggests that parents and professionals, on the whole, agree that they are confident that they are managing the needs of the child.

The null hypothesis in a Mann-Whitney U test that the two samples are drawn from the same distribution cannot be rejected. The U-statistic is 16 and the critical value to reject the null at the 90 per cent confidence level for a two-tailed test is 9. Accordingly, the test shows that there is no significance difference between the professional and parental groups. From this, we can suggest that there is a level of agreement between the two groups.

5.3.2 *Question 2: "I am confident that the parents involved in the group can manage the needs of the child"*

Figure 2: Responses to Likert Scale question 2

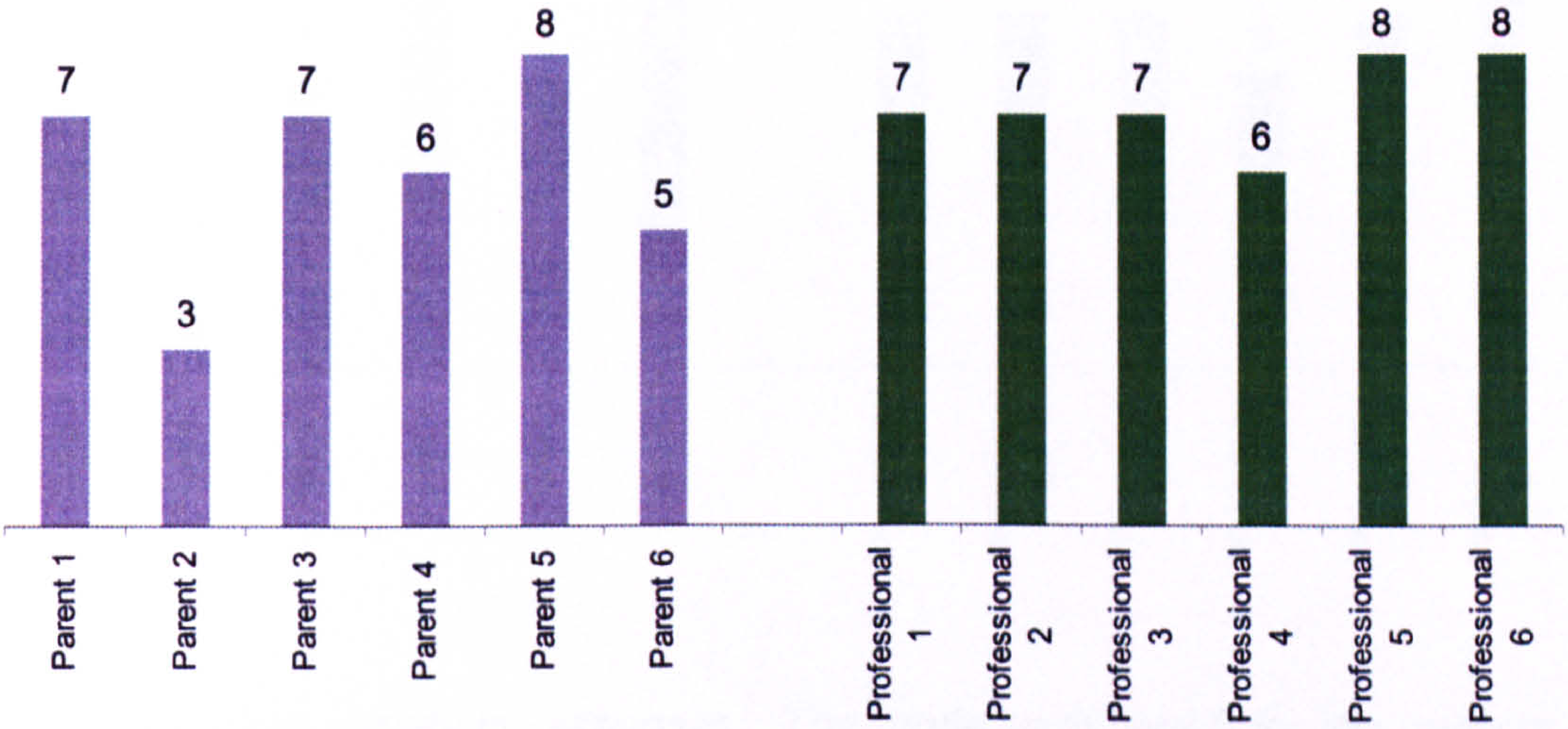


Here there is greater variation in responses compared to responses to question 1. This would suggest that there is less commonality in attitude. The overall mode value was 6. The mode for the parents was 5. The mode for the professionals was 6. Whilst this denotes that there was more agreement than disagreement, it is comparatively less specific value and shows the possible ambiguity in attitude to parents managing the needs of their children.

The null hypothesis in a Mann-Whitney U test that the two samples are drawn from the same distribution cannot be rejected. The U-statistic is 15.5, and the critical value to reject the null at the 90 per cent confidence level for a two-tailed test of 9. Accordingly, the test shows that there is no significance between the professional and parental groups in terms of difference of their ranked responses. From this, we can suggest that there is a level of agreement between the two groups.

5.3.3 *Question 3: "I am confident that other professionals involved in the group are managing the needs of the child?"*

Figure 3: Responses to Likert Scale question 3

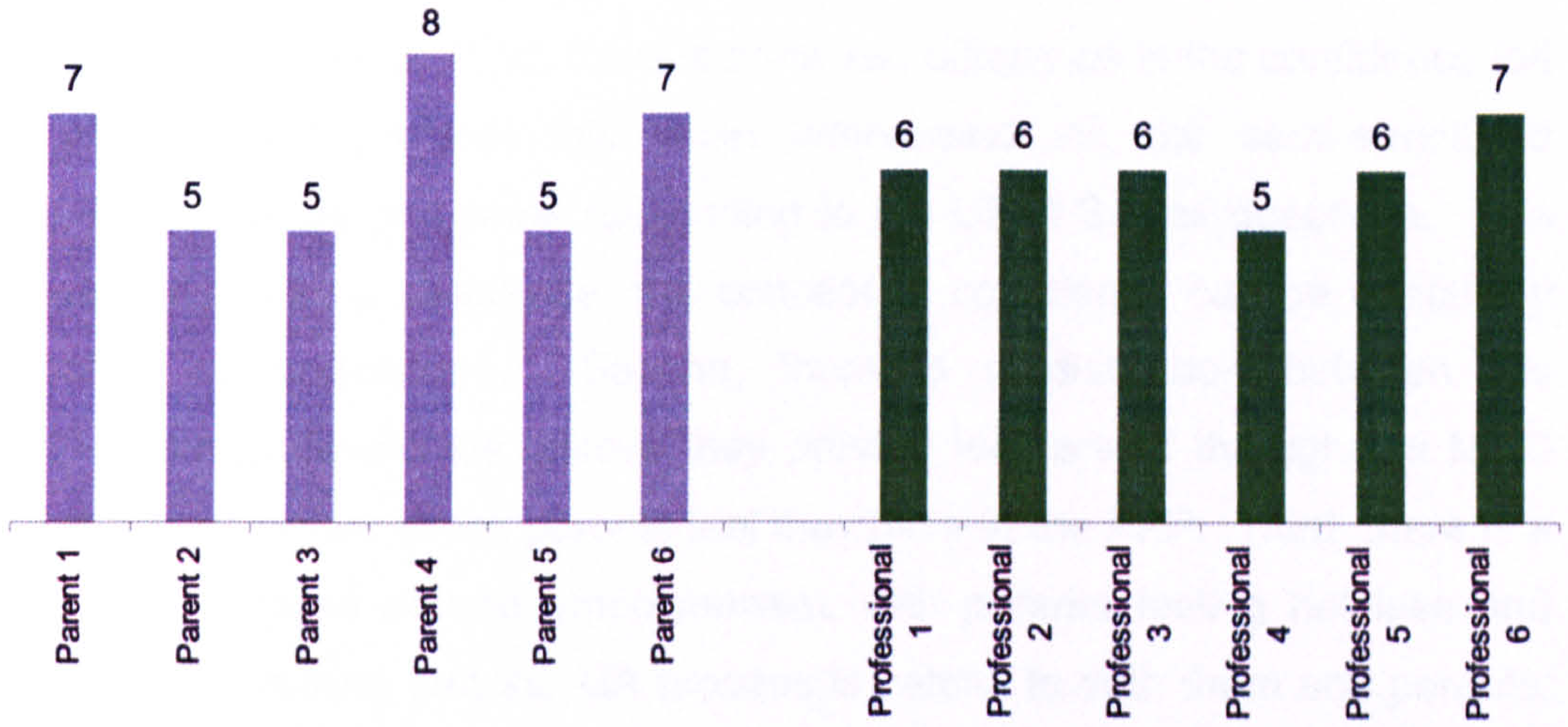


Again there is some variation in responses here and this is especially observed within the parental responses. The mode response was 7 for both parents and professionals. This shows that there is some measure of agreement from parents and professionals in the group that professionals can manage the needs of the child. Yet, the parents' responses show a very spikey profile with some extreme differences in scores – Parent 2 scored professionals 3 whilst Parent 5 scored professionals 8. Clearly, there is a wide variation here.

However, reflecting the small sample size, the null hypothesis in a Mann-Whitney U test that the two samples are drawn from the same distribution cannot be rejected. The U-statistic is 10.5, and the critical value to reject the null at the 90 per cent confidence level for a two-tailed test is 9. Accordingly, the test shows that there is no significance difference between the responses of the professional and parental groups. From this, we can suggest that there is a level of agreement between the two groups.

5.3.4 *Question 4: "I am confident that the schools involved in the group are managing the needs of the child"*

Figure 4: Responses to Likert Scale question 4



There was some variety in responses. The mode here was 5 for the parents and 6 for the professionals. This suggests that parents and professionals are somewhere between undecided and agreeable as to whether schools can manage the needs of children. This is the lowest score in the quantitative data results. This suggests that schools invite the least amount of confidence from parents and professionals in terms of support for children.

The null hypothesis in a Mann-Whitney U test that the two samples are drawn from the same distribution cannot be rejected. The U-statistic is 17.5, and the critical value to reject the null at the 90 per cent confidence level for a two-tailed test is 9. Accordingly, the test shows that there is no significance between responses of the professional and parental groups. From this, we can suggest that there is a level of agreement between the two groups.

5.4 Summary of findings

The findings illustrate a wide-ranging set of responses between parents and professionals. However, it is clear that there are both consistencies and inconsistencies between the findings in this study and those discussed in Chapters 2 and 3.

Summarising the main points from each research question in turn, the following is of interest. First, there is a marked difference in the confidence felt by parents and professionals when interviewed via the semi-structured interview schedule and when responding to the Likert Scales questions. This raises questions as to whether the concept of confidence can be effectively identified or understood. Second, there is a distinction between the involvement professionals believe they provide for parents through the MSG and the involvement which parents feel they have in the PPP. Third, there is a difference in ideas around empowerment, with parents feeling helpless and professionals feeling that the MA process is helpful to both them and parents. Finally, there is some agreement on the efficacy of the role of the key-contact with parents and professionals equally valuing the contribution this makes to the support and monitoring element of the MSG.

To appreciate these similarities and variations, it is important to discuss the findings in greater detail and with reference to the literature. Chapter 6 presents this discussion.

CHAPTER 6: DISCUSSION

6.1 Introductory comments

The research questions adopted for this study were designed to explore parents' and professionals' perspectives on the processes and outcomes of one Parent-Professional Partnership (PPP) that provided for children with Autistic Spectrum Disorders (ASD) and their families. This Chapter considers the extent to which these questions have been answered. In keeping with the research methodology, this section discusses findings that are considered to be most thematically and statistically relevant.

6.2 Discussion of findings

6.2.1 How confident are parents and professionals, respectively, when supporting the needs of children with ASD and to what extent is their respective confidence influenced by the PPP?

- There are inconsistencies in the degree of confidence felt by both parents and professionals.

- Parental confidence is largely derived from their own knowledge and skills rather than from the PPP.

- Professional confidence seems to reflect the impact of the Multi-Agency (MA) approach that is embedded in the PPP's set up rather than a reflection of their own knowledge and skills.

- Professionals have some confidence in meeting parents' needs.

- The contribution of schools is a major obstacle to delivering the objectives of the PPP. Anecdotally, this appears to be, at least in part, a reflection of the attitudes of schools.

6.2.1.1 There are inconsistencies in the degree of confidence felt by both parents and professionals

A two-fold inconsistency emerged in the research. First, the Likert Scale data for individual participants did not always triangulate perfectly with the themes that emerged from the interview transcripts of the same individual. Second, there was a variation in views around confidence across the participants: some participants were confident, some were not.

The mode values in the Likert Scale data denoted positive feelings about every agency. Parents and professionals expressed confidence about each other and schools. However, on closer inspection, there tended to be quite a lot of variation around the mode values. In response the questions as to whether parents were confident in professionals, responses ranged from 3 to 8 whilst parents' responses to questions of confidence in schools ranged from 5 to 8. Professionals showed less variation in their responses with the exception of questions of confidence in parents which range from 4 to 8.

However, the TA would suggest a lower degree of confidence than suggested by the Likert Scales. The TA painted a significantly more negative picture of confidence than the Likert Scale questions. For example, whilst Parent 4 rated her confidence in schools as a 7 she believed that they needed "*more help than I do," (Parent 4)*. Parent 6 rated her confidence in schools as a 7 but showed a lack of confidence in schools in the TA. She said:

> *"You see the teacher my daughter has at the moment doesn't actually believe that Autism exists," (Parent 6).*

> *"A lot of the staff aren't particularly familiar with Autism anyway ... it's like we almost have to be the experts for the teachers," (Parent 6).*

Similarly, professionals rated their own confidence in themselves highly on the Likert Scales but revealed some lack of confidence in their knowledge and skills of ASD in the Thematic Analysis (TA). Professional 6 rated herself as very confident of managing the needs of a child with ASD but in interview stated "*I don't think I ever feel very confident*".

These inconsistencies between statistical and thematic data are new to the evidence base. There could be several explanations for this. Is the discrepancy attributable to the research design in that the use of a statistical measurement and the use of semi-structured interview questions will ultimately lead to different results? If so, participants may possibly have felt that they were restricted by the closed Likert Scale questions and their answers may not have been a true reflection of their feelings but the closest approximation, whereas their responses to the relatively more open style questioning in the interviews, may have enabled a wider scope for revealing their true feelings. Alternatively, is this inconsistency merely a reflection of their changing attitudes towards the PPP? Either way, it would be interesting to explore this discrepancy more widely as this could help to resolve these tensions.

6.2.1.2 Parental confidence is largely derived from their own knowledge and skills rather than from the PPP

TA identifies that parental confidence was largely derived from their knowledge and skills than from the PPP. The confidence they expressed was directed more at themselves than the contribution of the PPP. For example, two parents felt confident that their intimate knowledge of their child could address some of their needs whilst four parents felt that they were confident of their ability to seek support proactively for them and their children, if necessary. These findings reflect those of the Warnock Report (DES, 1978) that underline the value of parental knowledge and skills in supporting a child and equally the recent findings from Asthana (2007) that identify parents ability to seek out support where appropriate. Nevertheless, these comments do not reflect the impact of the PPP, suggesting that parents would have been confident without its existence.

Other contributions to parental confidence revolved around the contacts provided with professionals from the Monitoring and Support Group (MSG) and other parents. These issues will be picked up in more detail in the discussion of the research question on contact but I will comment on them briefly here. Parents were jointly in agreement that they felt reassured by the presence of the key contact in the PPP, the professional who contacts them every three months. This finding does show that in respect of the key contact, the PPP is fulfilling the government aim to provide some element of trust between parents and professionals (DCSF, 2008; DCSF, 2009a).

Parents also appreciated the contribution the PPP makes by allowing the opportunity to meet other parents via the training sessions and meetings that are held by the MSG. The interactions that they have with other parents seems to provide them with a sense of assurance in their own knowledge and skills as well as a chance to give and provide information that can help children and families. The importance of such parent-to-parent interactions is not new to the literature (for example, www.healthtalkonline.org) but does reinforce the point that the collaboration between parents can be equally as important to issues of confidence as the collaboration between parents and professionals. It is important to underline that in this instance, this collaboration has been a product of the PPP and clearly one that they have effected successfully.

The literature has also highlighted other sources of confidence: *inter alia*, the knowledge and skills of professionals (DCSF, 2008, DCSF, 2009a) and the strategies provided by the professionals (ibid). However, parents made very little comment on these areas during the research. Instead, two parents clearly stated a lack of confidence in professionals' knowledge and skills in ASD:

> *"I'd like ... more professional support from people who really do understand the condition and who aren't just sent off on a course – they really understand the condition and really understand her as a human being, not just the condition," (Parent 2).*

> *"The speech therapist comes in and talks to him for about half an hour once a year ... which is nothing," (Parent 6).*

Parents' perceived lack of confidence in professionals' skills and knowledge will not reassure them of the support they can receive: we also know that if true, a skills and knowledge deficit in professionals can lead to a weakened system of support for the child (DCSF, 2008; DCSF, 2009a). Therefore, it would appear that this is an area which will need to be addressed by the PPP; this is especially appropriate in the light of the following findings.

6.2.1.3 Professional confidence seems to reflect the impact of the MA approach that is embedded in the PPP's set up rather than a reflection of their own knowledge and skills

The confidence professionals claim is that which emerges to a significant extent from their joint working with other professionals: the MA system. It is recognised that there are several benefits of MA working for professionals (for example, DfES, 2004b, 2004c, 2004d) and in the present sample, professionals attribute these benefits to their ability to share and gain knowledge and understanding of ASD (see Chapter 2, section 2.4.2) – yet at the same time, their comments also highlight that they need to know more on this very area (theme 9).

Indeed, it would seem that professional confidence in the PPP was more appearance than reality. On the whole, professionals seem to feel that it is their role to appear confident but their comments reveal a sense of anxiety related to their job. Professional 2 says candidly "*You have to give the appearance of being confident,*" whilst Professional 6 says that "*I myself would probably say that I don't feel fantastically confident even though I'm quite experienced*". This comment is then reinforced by the rather numbing "*I don't think I ever feel very confident*". There is also a clear sense that professionals lack confidence in their knowledge and skills in ASD. Professional 6 says "*I always think there's more I don't know and more I need to learn*".

Within these comments, there is a suggestion that professionals can feel that it is difficult to be challenged in a work context. Professional 5 finds it hard to work with unexpected issues whilst Professional 6 comments that her lack of knowledge is in part related to a need for more training. There is a suggestion that some professionals need further training if not to extend their knowledge base then to raise their self-esteem. It is also fair to add that addressing the unexpected can be challenging, as my own professional practice as a trainee Educational Psychologist (EP) has revealed, new situations can arise unexpectedly and it cannot always be a given that people can and should immediately know what and how to act. Nevertheless, this finding is an interesting one since there is very little in the current literature base on the lack of professional confidence in themselves: in fact, the reverse is typically true with there being more discussions on the over-confidence of professionals (Lissner, 1995). However, the literature does make clear that a perceived inadequacy of professional support for parents can damage the parents' confidence in the professionals' understanding of their child's needs (O'Connor, 2008; Brogan and Knussen, 2003). This suggests that, whilst MA working may be a useful and supportive professional tool for the PPP, there remains a recognised need for further continual professional development: this has been a recently recognised area of need, highlighted by the Lamb Inquiry (DCSF, 2009a) and the Inclusion Development Programme (DCSF, 2009c).

6.2.1.4 Professionals have some confidence in meeting parents' needs

Notwithstanding the above, professionals expressed some confidence in meeting parents' needs. This related to their ability to provide regular contact with parents and comments related to parents' positive feedback around this contact. This is a point that reflects parents' own positive feelings towards the key contact role and in this sense, there is a clearly identified shared understanding of at least one of the benefits of the PPP.

Interestingly and given the findings that fathers tend to be marginal in PPP research (Altiere and von Kluge, 2009), Professional 6 felt confident that fathers in the group had been identified and supported. This suggests that the PPP is succeeding at including what has been considered a neglected parent.

However, it was clear and in line with popular stereotypes of males and females (Brody, 1999), that fathers preferred the more peripheral and circumspect route into support groups, favouring the more individual and distant online training programmes than the face-to-face styles meetings that characterise other areas of the PPP and which, interestingly, mothers seem to enjoy (see section 6.2.4 of this Chapter). However, given the absence of fathers in this study, this finding would have to be further clarified from them to improve its credibility.

6.2.1.5 The contribution of schools is a major obstacle to delivering the objectives of the PPP. Anecdotally, this appears to be, at least in part a reflection of the attitudes of schools

TA shows that both parents and professionals express very little confidence in the ability of schools to support the needs of their child with ASD. However, whilst it is beyond the scope of the present study to corroborate these findings, the anecdotal evidence herein is revealing. Equally, these findings are important as we know from systems theory the quality of these school-home interactions (Hutchins and Sims, 1999) can determine a child and family's wellbeing and this wellbeing in this study seems to have been reduced. Criticisms included schools' lack of ASD awareness; their apparent lack of knowledge and skills in ASD and an inflexible attitude regarding training (for example, Professional 1 talked of how secondary schools were *"less willing to be or less able to be flexible about the needs of these young people,"* whilst Parent 5 (reference 4) noted that *"heads often take themselves out so they're not part of the training"*). The latter point highlights that both parents and professionals felt that the weaknesses of these schools related primarily to the attitudes of senior management. This included head teachers and Special Educational Needs Co-ordinators (SENcos) to which Parent 5 alludes.

There is a suggestion here of criticism of the school culture and in these cases, a specific criticism of the vertical or hierarchical system of governance. It appears that the lack of senior involvement with ASD within the schools could be having deleterious effects on all other staff. Professional 6 made the comment that teaching assistants needed more practical experience of using ASD supportive strategies (reference 3) whilst Professional 6 would like *"someone just standing up about Autism more broadly,"* (reference 4) as if a healthy representative or advocate for ASD is absent from the school system. Whilst the findings that criticise schools' lack of expertise are not new to the evidence base – indeed they have been further clarified only recently by the Lamb Inquiry (DCSF, 2009a) – the specific criticisms of the senior management and particularly, the head teachers and SENcos appear to be new findings. These new findings do question the extent to which the roles of heads and SENcos are being operationalised in relation to meeting both parents' and professionals' needs.

6.2.2 How involved are parents in the PPP?

- A significant number of specific needs identified by parents are not being addressed by the PPP.

- Some needs identified by parents relate to specific contexts whereas the PPP make generalised identifications of needs.

- Lack of resources is not identified as a key concern in promoting involvement (in contrast to my own experiences as an EP).

6.2.2.1 A significant number of specific needs identified by parents are not being addressed by the PPP

The TA suggested that parents' wishes have not consistently been accommodated by the PPP. It identified a number of specific areas where parents' have identified the need for further support but where this has not been forthcoming, at least, from the perspectives of parents. These areas include: support for their child's social interaction skills, communication skills, behavioural problems and transition to adolescence and provision for siblings. These are all key areas of need for families of children with ASD (for example, Midence and O'Neil, 1999; Bouma and Schweitzer, 1990; Gray and Holden, 1992; Howlin, 1988; Jobe and White, 2007). Interestingly and with the exception of issues around siblings and adolescence, they are also issues that the PPP states that it addresses as part of their MSG training programme. However, and in contrast to the parents' views, professionals do feel that they are aware of and attempting to address certain areas of a child's development. Specifically, they highlight their involvement within areas of communication and behaviour development.

This discrepancy raises the question as to why parents and professionals have a different perspective as to the support given and received. There is, of course, the possibility that parents have not made their wishes clear to the professionals in the PPP – possibly as a result of ineffective contact or concerns that they cannot make their requests known due to a lack of opportunity to relay their concerns and needs or a fear of offending professionals. Since parents have clearly identified their confidence in the role of the key contact in the PPP, we can only assume that the contact between them is at least satisfactory. However, it is still possible that this contact has not provided sufficient opportunity for them to make their needs clear: some parents may not find enough time to commit to expressing their concerns – a known area of difficulty for parents of children with ASD (Hodge and Runswick-Cole, 2008). Others may feel anxious about offending professionals (ibid) as they may feel that any offence will restrict further opportunities for support (Runswick-Cole, 2007). There is also the possibility that professionals are just not listening to the parents or not asking the right questions to elicit the true perceptions and wishes of these parents (Squires, Farrell, Woods, Lewis, Rooney and O'Connor, 2007).

What is clear is that parental involvement does not appear to have been optimised in this PPP. This is consistent with past research findings that too often parents do not feel that their voice is being either heard or addressed in a timely manner by professionals (Webster et al, 2004). Other research has shown that parents of children with Special Educational Needs (SEN) in general can feel ignored (House of Commons Education and Skills Committee, 2006). The Bercow Report (DCSF, 2008) is especially interesting as it identified that some parents felt that professionals did not truly understand a child's needs, sometimes taking for granted that they should be able to communicate with others. Perhaps this is one reason why parents do not feel that their needs are being met.

6.2.2.2 Some needs identified by parents relate to specific contexts whereas the PPP make generalised identifications of needs

Parents' identified needs extended to most settings in and outside the school. Whilst parents desired more in-school support including help to reduce issues such as bullying and absconding (theme 14) and behavioural difficulties, they also focused on support for the home and wider community. This included: issues around support to help a child understand routines such as morning and night (theme 13); social interaction, communication, friendships; addressing the difficulties of social stigma and families' expectations and provision for adolescence and siblings. Whist the professionals recognised the need for support in areas of behaviour and communication, they did not appear to identify the need for specific support within the home, school and community setting.

The importance of addressing needs within contexts is not new to the evidence-base. Socio-cultural theory (Vygotsky, 1978) and systems theory (Bronfenbrenner, 1979; Ringness, 1970) show how the world around us shapes our perceptions and indeed life. It is also clearly identified that children with ASD express needs in all of these contexts (for example, Revill, 2007; Tse et al, 2007; Bejerot 2006; Connor, 1999). Several PPPs do appear to work with these theories in mind. For example, EarlyBird and EarlyBird Plus do take into account the importance of working with families in the schools and homes (Rhoades et al, 2007). It appears that this direct 'hands on' support or at the very least, support that is more meaningful in home, school and community contexts, is what the parents in this study desire but are not necessarily receiving.

6.2.2.3 Lack of resources is not identified as a key concern in promoting involvement (in contrast to my own experiences as an EP)

In direct contrast to my own experiences as a trainee EP, neither parents nor professionals mentioned having any concerns regarding limited resources to carry out their roles and to meet parental needs. This is somewhat surprising as I have experienced several situations where parents have frequently complained that they lack supportive resources for their child (for example, visual timetables and social stories) as well as findings in the literature that emphasise the importance of PPPs providing supportive resources to families of children with SEN (www.parentpartnership.org.uk). This absence suggests that the PPP is effectively fulfilling its requirements to provide resourced ASD support for families.

6.2.3 How empowered are parents in the PPP?

- Parents have a sense of helplessness at the diagnosis stage.

- Despite this feeling of helplessness, empowerment is not identified as a key issue for either parents or professionals.

- Professionals believe that MA working means parents have the support they need to be empowered.

- The father's voice is absent.

6.2.3.1 Parents have a sense of helplessness at the diagnosis stage

It was very clear in the transcripts that parents were frustrated by the diagnosis process and the support that they received at this time. Support during diagnosis is not part of the remit of the MSG: the MSG is explicitly designed to cater for those with an existing diagnosis. However, this theme is particularly striking in that I did not ask any explicit questions about the diagnosis process in the interviews; instead, I asked one general question about the support that parents felt that they had received since diagnosis. Despite this, parents consistently referred to their frustrations throughout the process of diagnosis, and this was particularly focused on the lack of professional support available to address these frustrations. Their recollections of these times coupled with the repetitive nature of their recollections paints a picture of parents as helpless in the PPP rather than empowered.

The frustrations highlighted by parents included that professionals devoted only a minimal amount of time to their case and that their case was handled insensitively. One parent who had been a nurse and was arguably familiar with process of diagnosis and the impact it can have on the family felt upset by the handling of her child's diagnosis. There is a sense that the professionals involved in the diagnosis process did not identify that these children were more than case work. This is pertinent given the extant findings that parents have a tendency to blame themselves for their child's diagnosis (Gray, 1994) and therefore need to be dealt with sensitively and moreover are in need of emotional support (Abbott et al, 2005). In the words of Parent 3:

> *"I would say the first time when we were told you know we think he has ASD, that he we think he has by my doctor although not in so many words but I came out of that room feeling that it was just me being a bad parent, that was why he was the way he was so there was no sort of anything going on from that, that was just, which was a really bad start and when you start from that point, obviously you are very ... ," (Parent 3).*

Whilst not flagged directly by the TA, past research has shown that the effects of this sense of helplessness can be for parents to seek to become more than a parent – possibly they feel a need to be a *"para-professional"* (Hodge and Runswick-Cole, 2008, p640), knowing more than professionals in order to feel powerful (ibid). Ultimately, the disproportionate weighting of power between parents and professionals can be a barrier to a partnership (ibid). In the context of diagnosis, it can even be argued that little has developed from the 1970s style partnerships where professionals not parents were in charge.

6.2.3.2 Despite this feeling of helplessness, empowerment is not identified as a key issue for either parents or professionals

It was interesting that despite the focus on parent empowerment in the literature and the helplessness described during the diagnosis phase, neither parents nor professionals made reference to "power", "empowerment" or their synonyms during the interviews. This could indicate that neither group recognises a need for parents to be empowered. Indeed, parents' discourse revolves not so much around the drive for individual power but around their desire to be passive recipients of support delivered by the professionals. Hartas (2006) reports similar findings: that some parents may actually wish to be passive in the process of parent-support. The findings in this study would suggest that the latter description is true of these parents. This can be a useful in shaping the future provision of the PPP so that it responds more directly to the needs of parents and children rather than indirectly trying to negotiate too much interactivity.

6.2.3.3 Professionals believe that MA working means parents have the support they need to be empowered

Professionals discuss MA working as if it is a tool to support both them and parents. In their view, MA working can accelerate the support provided to parents (Professional 5); share expertise and be used to refer parents to other agencies that may provide them with support (Professional 3). Whilst these benefits of MA working are reported in the literature (DfES, 2004b, 2004c, 2004d), parents' are relatively less praising of their experience of MA working. They neither mention the term "MA" nor explicitly refer to any way in which they have benefited from the process apart from in their positive descriptions of their contact with other parents.

Parents' lack of engagement with the MA model suggests that they are either not that familiar with the way in which it works or else do not identify any personal benefits. Literature identifies that parents can often be dissatisfied with the process of MA working (Abbott et al, 2005). It also seems that, in this case, they may be unaware of its existence.

6.2.3.4 The father's voice is absent

The fathers' voice did not emerge in the TA. What references there are to fathers are vague with the exception of Professional 6's description of fathers taking part in the online training programmes. In this instance, it would appear that yet again, there is little of their character or opinion in this study. The extent to which they are therefore a powerful presence in the lives of children with ASD is debateable without further input from fathers as to the role that they feel they fulfil within the PPP.

6.2.4 Is contact between parents and professionals valued?

- Contact is valued by both parents and professionals but needs to be more tailored and flexible.

- Responses are inconsistent with views on confidence, involvement and empowerment.

6.2.4.1 Contact is valued by both parents and professionals but needs to be more tailored and flexible.

Parents and professionals both felt that the contact between them within the PPP was valued. It seems that the value enshrined in this contact is very much one located in the positive effects to wellbeing and the effective route to receiving information. In the interviews, most participants felt they benefited especially from the knowledge of the key contact and from the support network they offered. From parents' comments, it also appears that the links between professionals were strong as parents reported that they could use the key contact to access information related to a range of resources very quickly and effectively.

However, findings suggest that not all parents felt that their contact with professionals was tailored to meet their personal needs. Some felt that there was little flexibility in terms of meeting schedules or necessarily the subject matter of the training (Parents 2 and 6). Some parents felt frustrated at not being able to share information with professionals about their children (for example, Parent 2), and they also described a reluctance on the part of professionals to share information with them (Parent 2). In the latter case, there was evidence that professional contact with parents was marked not by an openness and affability that characterise effective PPPs (DfES, 2001a) but an unwillingness to discuss and sometimes avoidance of personal issues. This identifies the importance of personalising contact with parents.

6.2.4.2 Responses are inconsistent with views on confidence, involvement and empowerment

It is interesting that, broadly, the comments around contact are significantly more positive than those on the other research questions around confidence, involvement and empowerment. This suggests that, in general, the PPP has created an effective system of contact between parent and professional: a central aim of PPPs. However, this finding is striking as it is inconsistent with the more negative perceptions around the PPP as a whole.

The findings also highlight the usefulness and benefits of the simple device of a telephone as a means to create interaction. This is not explicitly referred to in the literature and so is unique to the evidence base. Arguably, given its benefits, it may be useful to consider the extent to which telephone contact can be used more extensively as a way of providing remote contact between parents and professionals; for example, it could be used instead of certain face-to-face meetings via a conference call.

CHAPTER 7: THEORETICAL AND METHODOLOGICAL LIMITATIONS

7.1 Introductory comments

The Chapter considers the strengths and weaknesses of the chosen methodology.

7.2 Detachment

I recognised that my epistemological stance as a Pragmatist meant that I had relative freedom regarding detachment compared to, for example, Positivists that should remain wholly detached from the participants. Indeed, my very use of a mixed methodology: using a combination of elements of Interpretivism and Positivism meant that I could employ the "best bits" of each approach. For example, Interpretivism enables the researcher to get involved because it emphasises the importance of truth being a subjective experience (Guba and Lincoln, 1998; Mcmillan and Schumacher, 2001). However, my use of Positivist approaches by way of the Likert Scales meant that I had to attempt to maintain neutrality in order to keep the tool standardised (Finlay, 2002; Yu, 2008). Sometimes, this was very difficult as parents, in particular, became emotional on the subject of their experiences and this at times moved me. However, I feel that by keeping a reflexive diary, in which I described any possible partiality, and by discussing issues with my supervisor and colleagues, I was able to make balanced and reasoned interpretations of my data-sets.

In addition, I did not feel that such feelings of partiality would always negate the research process. Indeed, I felt that, at times, they were a necessary feature – to have attempted to redirect participants' prompted or unprompted accounts of their "lived experiences" solely to retain my own sense of detachment may have risked damaging participants' own interpretations of their experiences. Indeed, it can be argued that this process of "offloading" is a necessary one to aid an individual's capacity to make sense of and come to terms with issues of conflict (www.asd-forum.org.uk).

7.3 Limited sample size and quantitative data

With only six of each of parents and professionals, the sample did not lend itself to rigorous statistical analysis. On the other hand, a larger sample size, whilst enhancing the validity of the statistical tests, would have made analysis of the qualitative data significantly more cumbersome, given the resulting volume of the interview transcripts subjected to Thematic Analysis (TA). Nevertheless, it would have been of interest to check the statistical results generated in this study with those of a larger cohort, to check generaliseability of findings. Likewise, with the benefit of hindsight it would have been beneficial, for the purpose of consistency, to extend the Likert Scales questions beyond an assessment of confidence to encompass the other identified key characteristics of a Parent-Professional Partnership (PPP), that is involvement, empowerment and contact.

Nonetheless, I feel that for the purposes of the study, namely to explore parents' and professionals' perspectives of the PPP, the quantitative data collected were useful in gaining an insight into the views of the participants and into the inconsistencies within and between the parents' and professionals' groups. Of particular interest was the finding that there was a striking and largely inexplicable discrepancy between Likert Scale data for confidence compared to thematically analysed data for confidence.

7.4 Use of Pragmatism to determine epistemological and ontological position

The adoption of Pragmatism enabled significantly greater freedom in research design than alternatives such as critical realism. In particular, it allowed the use of a mixed methods design, encompassing both qualitative and quantitative data-sets. However, Pragmatism is considered an *"anti-philosophy"* (Johnson and Onwuegbuzie, 2004, p18) and as such, lacks the same rigour and therefore essential credibility of other theoretical designs. In particular, this is reflected in the question of partiality and detachment discussed above.

For the purposes of this study, the flexibility of Pragmatism outweighed its inherent theoretical weaknesses. The first step to address such weaknesses is to recognise them and I have already set out the lengths I went to, including a research diary and supervision, to achieve this.

Future work into PPPs may wish to address these methodological challenges differently. There is scope to explore PPPs by using a solely Positivist approach. If carried out on a sufficiently large scale, this could derive a vast amount of valuable statistical data related to the full range of outcomes of a PPP encompassing confidence, involvement, empowerment and contact as well as other characteristics. In contrast, a solely qualitative research design could be used to emphasise the more subtle areas of parent and professional discourse – such as the way in which they pause in their conversations, the shifts in emphasis, any tears or anger. This enables scope for discussions into these subtle areas. Naturally, this approach would also carry potential for subjective bias. Finally, it may be worthwhile using the same approach as I used but extending the study to include school-based data. This would be useful given the findings that there was an essential lack of confidence in the contribution of schools to the PPP.

7.5 The sample

The parents sample was, though randomly selected, only female and in my opinion presented as articulate. As discussed in Chapter 4, my personal experience in placements in the Local Authority identify that this sample is not necessarily representative of other parents of children with Autistic Spectrum Disorders (ASD). For example, I have worked with fathers of children with ASD and parents who find it difficult to express their needs around their child with ASD because of their own learning needs. Therefore, this sample, coupled with its small size, does arguably limit the generaliseability of findings. Whilst, future work in the area of PPPs could account for this limitation by ensuring a larger and more representative sample size, the samples in my study still make up a significant percentage of the cohort within the target PPP:

in fact the six parents represent around 15 per cent of the number of parents in the group whilst the professionals represent 40 per cent of the group.

Therefore the findings, whilst lacking generaliseability to Local Authorities (LA) nationally, do have some applicability to the target LA in this study. In addition and given the overlaps between the PPP and Multi-Agency (MA) work, these findings could also inform MA teams in related fields, for example they could be used to resolve tensions that may appear during joint meetings in Sure Start centres or, at a more general level, they could be used to ease parent and professional tensions that can appear during the statutory assessment process.

7.6 The challenges of the semi-structured interview design

The semi-structured interview approach was selected in order to elicit a wide range of views. However, information, especially from the parents, sometimes took on a narrative theme – often during the interviews, it was clear that parents wanted to divert away from the questions on the interview schedule so that they could concentrate more on related personal anecdotal issues. Whilst the semi-structured interview enabled this form of diversion, it was sometimes challenging to redirect parents back to the given schedule. However, whilst, as discussed, these diversions could impact on issues of partiality it was important to give scope to participants' feelings: in effect, this is a basis for any Interpretivist research. As such, ultimately I felt that it was important to enable these diversions.

However, I did not feel that the semi-structured interview was always sufficiently flexible to capture participants' real interpretations of their experiences of supporting a child with ASD, in effect, their version of the truth regarding their own perceptions of the PPP. This is mainly because it did, albeit loosely, attempt to structure and therefore limit parents' responses. As such, parents' narratives could not necessarily be retold as sincerely as I would have liked. Given the importance of parents' experiences, future studies could work more around a life history method (Bryman, 2004) and use unstructured interview techniques to elicit more detailed information on parents' experiences and specifically, their connections to changing events and phases (ibid) such as the ASD diagnosis process.

It is also worth mentioning that it was only when I reviewed the transcripts that I realised that there could have been some additional follow-up questions that could have clarified and extended the generated discourses. For example, following comments around the tensions within the school and parental relationships, I could have asked "when has there been a time that schools have supported you?". This form of solution-focused questioning (Ajmal and Rees, 2001) may have helped to identify any positive features of the relationship between schools and parents and more usefully, what areas of support were effective and should be increased within the current provision.

CHAPTER 8: RECOMMENDATIONS AND CONCLUSIONS

8.1 Introductory comments

This Chapter considers some specific recommendations for improving the effectiveness of Parent-Professional Partnerships (PPPs), drawing on the PPP used for this study, before presenting some final conclusions.

8.2 Recommendations – raising confidence for parents and professionals

8.2.1 Increasing opportunities for parental involvement in the PPP

In this study, it emerged that parents felt that their familiarity with their children meant that they were often best placed to make sense of and meet the needs of their children. However, they did not always feel that their needs were addressed. This is the case despite the existing theoretical and empirical literature which has highlighted the important role of parents in informing professionals of their and their child's needs during the Autistic Spectrum Disorders (ASD) diagnosis process and existing government policies which underline the need for parental input into educational provision (for example, O'Connor, 2008; Runswick-Cole and Hodge, 2008; DfES, 2004b, 2004c, 2004d).

It would appear that, at least in the case of the PPP used in this study, there is still some way to go to make genuine parental involvement a reality. Means to promote increased involvement could, at its simplest, involve increasing forums and meetings, whether or not face-to-face, in order to identify parental needs and issues. More refined approaches to information-seeking could include the use of parental diaries or logs into the ongoing support process. The use of computer-based logging and communications could serve to enhance this method further. Used in this way, issues of concern could be identified and addressed more quickly and effectively than is possible via the three monthly phone calls or other existing means. Also, this technique would be more tailored to and inclusive of fathers.

8.2.2 Increasing training opportunities for professionals

Although perhaps merely a reflection of the intimacy of parents with their child, it was apparent that parents felt that their knowledge and understanding of their children's needs were superior to that of professionals. Professionals did not acknowledge such an imbalance but nonetheless did identify a lack of confidence in their own skills and expertise to support families of children with ASD.

Parents' perceived superior knowledge and understanding could be viewed either as a positive affirmation of their role or as evidence that professionals need to further update their own knowledge and understanding to a level that could be considered "specialist", as targeted by the DfES drive towards maintaining and improving professional expertise (DfES, 2006b).

There is also the possibility that the focus should not necessarily be on whether professionals have this expertise but rather on, whether they are communicating this expertise sufficiently effectively for it to make sense to the intended audience, in this case parents (ibid; DCSF, 2009c). Perhaps more emphasis should be placed on the communication styles adopted by professionals in PPP organisations. This could also serve to allow professionals to feel more confident of their skills in supporting families of children with ASD.

8.2.3 Increasing professional involvement to promote inclusion via Community Psychology

The findings identify the need for more support at home and community levels. This could be facilitated by the use of the Community Psychology model (Mackay, 2006). Community Psychology can enable Educational Psychologists (EPs) to provide parents with more meaningful support so that they actually go into the community, be that the home or any other relevant setting to work collaboratively with parents to meet their needs. This can include identifying and adapting any existing support measures (Squires et al, 2007) and seeking parental views on how they could be more involved the family's life.

From a professional perspective, the role of community psychology is also appealing. It would enable EPs to extend their role in different areas and respond to widespread community needs at a first-hand and grass-roots level (Stringer, Powell and Burton, 2006) although this would have to be achieved in a way that still gave EPs time to support needs in the school settings.

8.2.4 Improving emotional wellbeing

All of the parents in the study identified the need for increased emotional support. Some parents discussed their feelings in terms of emotional anxiety about their children and themselves as parents. A majority expressed the distress they felt during the diagnosis phase and in coming to terms with the diagnosis. Most parents also recounted that the traumatic experiences during diagnosis left them with a residual anger levelled at the professional services in general, including but not specifically the PPP. Notwithstanding this, in some cases, parents recognised that the PPP could offer help in the way of follow-on support. Other authors have highlighted this emotional distress that can be caused by ASD (for example, Howlin and Moore, 1997; Midence and O'Neil, 1999; Abbott et al, 2005), yet there still seems to be a gap in provision to support this distress.

Whilst in this study it was evident that professionals wanted to provide more support for family anxieties, none mentioned the importance of "talking to someone". This suggests there could be a niche for more "talk-based" therapies for some of these parents. Research conducted by Rhodes (2000) and Wheeler (2001) identified the benefits of solution-focused brief therapy as a way to improve carers' strengths, change negative perceptions, challenge patterns of blame and support positive attachment. Given these findings, perhaps the PPP could function more as an "ambassador" figure or advocate for parents to seek this therapeutic support via agencies such as an Educational or Clinical Psychologist.

8.2.5 Improving wider recognition of ASD

Half of the parents interviewed would have valued more help and support for their families. They felt that their families did not always understand their child with ASD and in some cases, felt marginalised and/or unaware of the realities of being with a child with ASD. A clear concern was around siblings of children with ASD and how they felt alienated and sometimes troubled by being with a child with ASD. For example, one mother was aware that her daughter with ASD liked to compare herself unfavourably with her younger sister without ASD.

Existing literature highlights some of the difficulties for families coping with ASD but there is a paucity of research on siblings of those children, although what exists shows that siblings can become marginalised by the presence of another child with ASD (Bågenholm and Gillberg, 1991; Gold, 1993; Rodrigue et al, 1993). However, there is very little information on ways in which families can positively include its members whilst at the same time, ensuring maximum support for the child with ASD. More research in this area would be illuminating especially in terms of highlighting strategies to support the wellbeing of siblings, perhaps in the form of a sibling-support group that runs on similar lines to the PPP.

8.2.6 Raising the role of telephone communication between professionals and parents

It is interesting to note that both professionals and parents felt that the role of the key contact, particularly the three monthly telephone calls from the professional to the parent, made a positive difference to the process of support. Whilst contact between parents and professionals is identified in the literature review to be a benefit in any type of PPP, there is little or no evidence, specifically underlining the advantages of the regular telephone contact between both parties.

This finding illustrates that even simple procedures can make a positive difference to inter-agency networking and the success of a PPP. It may be worthwhile, therefore, to explore the extent to which telephone communication can be further employed to benefit PPPs. Perhaps, it could be beneficial to consider the use of extended forms of telephone communication, such as conference calls, to act as virtual meetings. This would not only serve as a way to provide greater flexibility of choice on behalf of parents and professionals accessing Multi-Agency (MA) services but also dove-tail neatly into the government scheme to encourage more virtual MA practice (DfES, 2004b).

8.2.7 Quality control

Some form of quality control could be used in future work around PPPs, to ascertain to what extent parents and professionals are working in synchrony. This could perhaps be operationalised using rating scales. As demonstrated by the use of Likert Scales in this study, rating scales are very quick and easy to use. In this context, they could help to identify areas where a partnership is not working as effectively as it could.

Other services already use rating scales in this way. For example, the NHS use electronic rating scales to measure the quality of their service (www.nhs.uk). Regular use of such a device should help consistency and transparency of service delivery – a remit of the current children's service legislation (DfES, 2004b).

8.2.8 Increasing research into PPPs

Further research into PPPs could use a larger scale study than that employed in this study. It would be useful to compare all PPPs in all Local Authorities

(LAs) or those in a cluster, for example, LAs in Central England. Given the extant number of participants that this would involve, the research would be most efficiently achieved by a questionnaire approach which could still employ Likert Scales. The advantage of this would be that the study would capture a large number of participants in a quicker time than a solely qualitative or mixed methods approach. Alternatively, a large research group, such as EPPI (eppi.ioe.ac.uk), could perform a mixed methods research into some or all of the LAs.

8.2.9 Eliciting schools' views

Results showed that neither parents nor professionals appeared confident in the schools' ability to perform their duties of care regarding children with ASD. It would seem that some school professionals did not attend training. Without training, school professionals will lack the necessary skills and knowledge to support children and families effectively. However, co-operation from schools is a vital component of the Monitoring and Support Group (MSG) delivering its objectives. It was also interesting to note that the focal point of criticism of schools was on head teachers and Special Educational Needs Co-ordinators. This suggests that there needs to be better relationships between these individuals and the parents and professionals in the MSG. Also, schools need to understand and take more seriously their role in delivering the PPP-based provision. Eliciting the views of school professionals could be a useful way to ensure that their needs are not being overlooked, their agenda is being addressed and they understand their responsibilities. Gaining their perspectives is also important for the purposes of triangulation of findings in respect of the school role.

8.2.10 Eliciting children's views

Eliciting children's views could help to focus more directly on the child's role in the PPP. It would be interesting to identify whether they feel that they experience any benefits from the PPP. Given their communication skills, this may be more challenging to gauge for primary school aged children and such research would have to ensure that alternative ways, other than oral interviews, to seek their views were applied. This could include visual means such as emotions cards – these are visual aids that can help children with social and communication needs to express themselves and their emotions, such as sadness and happiness (see www.asdfriendly.org).

8.3 Final conclusions

This study has shown that the contact parents and professionals share in the PPP is valued. Their contact benefits their sense of wellbeing and also their sense of responsibility in their role. Contact is one key marker of a successful PPP and in this respect, the LA has achieved at least one objective. Valued contact is a fundamental starting point in fulfilling the remaining objectives of the PPP, namely to build confidence, empowerment and involvement. The use of online diaries and the implementation of Community Psychology are examples of ways to encourage parents and professionals to enhance contact further in order to pursue these wider objectives. Over and above this, I have highlighted other recommendations that could bolster the effectiveness of this PPP, such as a focus on continual professional development. However, I have identified a number of areas where further research would be beneficial in informing improvements in the operation of the PPP.

It is very important that these areas of need are addressed. They represent issues of conflict for the parents and professionals that stifle their ability to effect positive change for themselves and the children for whom they are responsible. It is clear that the professionals in this study are aware of at least some of these issues and moreover, are willing to address them positively. It is also fair to underline that their PPP is still in its infancy and any tensions can still be attributed, at least in part, to this. Nevertheless, the study has shown that there are potentially significant benefits from the PPP approach. The study has also shown that in terms of progress over the years, parents are no longer prepared to be silent and passive in the face of their child-care. They have a voice even if this voice does not appear always to be heard.

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APPENDIX I: INFORMATION SHEET

University of
BRISTOL

Norah Fry Research Centre
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Bristol, BS8 1TX

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PARTICIPANT CONSENT AND INFORMATION SHEET

Invitation

You are invited to participate in a research study into parent and professional partnerships in the [name of Local Authority] ASD monitoring and support group. One of the objectives of the study is to see how we can best develop current provision for children with ASD in the county.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you agree to participate in this study, you will be asked to sign the attached Participant Consent Form.

The researcher

The research is being conducted by Anna Read. Anna is currently undertaking a doctorate in Educational Psychology at the University of Bristol. As part of her doctorate programme, she is on placement with [name of Local Authority] Children's Services. Anna has agreed to conduct this evaluation of the Council's ASD Monitoring and Support Group as an input into a review of this programme that is currently being undertaken. It will also form the basis of Anna's doctoral thesis.

Answering your questions

1. 'What is the purpose of this study?'

The purpose of this study is to examine parent and professional partnerships in the [name of Local Authority] ASD Monitoring and Support Group. A parent-professional partnership refers to the ways in which parents of children with ASD work together with professionals, such as educational psychologists, teachers and support workers, in providing care to the child. Effective parent-professional partnerships have been shown to have dramatic beneficial impact on the development of children. This study focuses on such partnerships within the context of the [name of Local Authority] ASD Monitoring and Support Group.

One of the objectives of the study is to see how we can best develop current provision for children with ASD in the county, and also possibly for similar programmes across the rest of the country. Additionally, it is hoped that these findings will be useful for schools when they consider the types of support they would like to use to meet the needs of children with ASD.

2. 'Why have I been invited to participate in this study?'

You have been invited to participate in this study because you are part of a parent-professional partnership. This is the first time that a review of the [name of Local Authority] ASD Monitoring and Support Group has been undertaken since it was established last year. Your views and experience are valued and may help us to find ways to further improve the service offered by the Group.

3. 'What does this study involve?'

This research involves your participation in a short interview of about 30-40 minutes that is audio-taped and transcribed to ensure that data is authentic. The interview will seek to understand your experience and opinions of the parent-professional partnership from your viewpoint within the Group. You will also be asked to provide ratings on a scale of 1 to 9 of certain aspects of such partnerships.

All data is kept anonymous so at no time will your responses be identifiable.

4. 'What are the risks associated with this procedure?'

For most participants, there are no foreseeable risks to participating in this study. Some items will relate to personal and/or professional concerns you may have regarding your own, and/or your family's well-being in relation to the support provided by the ASD support group. However, you do not have to complete these items if you do not want to, or continue participating in the study if these items upset you. You have the right to withdraw from the interview at any point and will be reminded of this right throughout the interview. All information provided to the researcher is completely confidential.

5. 'Will I benefit from this study?'

Yes. We hope to ensure that you are being offered the best possible support for your child. One of the key objectives of this study is to see how [name of Local Authority] County Council can further improve the quality of the support it provides to children with ASD and their parents through the ASD Monitoring and Support Group.

If you wish, you will be updated regularly of research findings.

6. 'What happens if I don't want to take part in the study?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. This will not affect your right to continue to use the ASD Monitoring and Support Group.

7. 'How will my confidentiality be protected?'

All participants will be given pseudonyms to ensure that the responses of all participants will be completely confidential. Only the researcher will have access to the information that is provided, although anonymous summary data and conclusions will be shared with the Council.

The consent forms will be stored separately from the interview transcripts, notes and tapes so that there is no direct connection between a participant's name and any interview responses, which will be anonymous. The transcripts, tapes and related materials will be stored in a locked cabinet for 6 years, after which they will be destroyed. This is a requirement of the British Psychological Society which governs the conduct of psychological research in the UK.

I will write a final written report to be sent to the group at the end of the study. I also plan to discuss/publish the findings with [name of Local Authority] Children's Services and Bristol University in the form of a report. In any publication, information will be provided in such a way that you cannot be identified.

If they wish, participants will be kept regularly updated on progress made in the study through verbal feedback from ASD monitoring and support co-ordinators.

8. 'What should I do if I want to discuss this study further before I decide?'

When you have read this information, I will discuss it with you, if you wish and answer any queries you may have. If you would like to know more at any stage, please do not hesitate to contact me at The Norah Fry Research Centre, 3 Priory Road, Bristol, BS8 1TX, 0117 331 0987.

9. Who should I contact if I have concerns about the conduct of this study?'

This study has been approved by the Norah Fry Research Centre Ethics Committee, 3 Priory Road, Bristol, BS8 1TX, part of the University of Bristol. Any participant with concerns or complaints about the conduct of this study should set out their concerns in writing to the above address.

10. 'What if I don't want to know the outcomes of the research?'

It is entirely your decision as to whether or not you decide to be told the results.
This will not affect the treatment you receive now or in the future.

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.

APPENDIX II: CONSENT FORM

University of BRISTOL

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Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web: www.bris.ac.uk/Depts/NorahFry/

Consent form for Interview

I consent to the information that I provide in this interview to be used/ published as part of a research study.

....

I understand the information will be used:

1. To inform [name of Local Authority] Children's Services.
2. For publication in journals, textbooks or similar publications. In which case I understand that:
    a) The material will be published without my name attached and every attempt will be made to ensure my anonymity.
    b) The material may be published in journals world-wide which are distributed mainly to psychologists but are seen by many non-psychologists, including journalists.
    c) The material may also be placed on a world-wide web site.
    d) The material may also be used by book publishers.
    e) The material will not be used for advertising or packaging.

Data Protection Act

I understand that data collected about me during my participation in this study will be stored in a locked cupboard and that any files containing information about me will be made anonymous.

I agree to the University of Bristol and [name of Local Authority] Children's Services recording and processing this information about me. I understand that this information will be used only for the purpose of this study and my consent is conditional upon the University of Bristol and [name of Local Authority] complying with their duties and obligations under the Data Protection Act.

Name of person being interviewed

....

Signed .... Date ....

I consent to being taped during the interview, as part of the research study.

....

APPENDIX III: INTERVIEW QUESTIONS

Parents

1. Which professionals have you had contact with since your child's diagnosis?
2. What other support have you had since being on the programme?
3. How well do you feel supported?
4. How often do you communicate with a professional with regards to the ASD monitoring and support group?
5. What effects has this had on your attitude towards your son/daughter's ASD?
6. How well do you think the educational professional has managed the needs of your child?
7. How confident are you in managing the needs of your child?
8. How do you communicate with your child?
9. What have been the benefits of the programme?

Professionals

1. What were your previous experiences in managing and supporting ASD?
2. How frequently do you communicate with parents?
3. How confident are you in managing the child?
4. What communication strategies do you use with the child?
5. What have been the benefits of the programme?

APPENDIX IV: LIKERT SCALE QUESTIONS

Parents

1. "I am confident that I am managing the needs of my child?"

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

2. "I am confident that other parents involved in the group can manage the needs of their child."

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

3. "I am confident that the professionals involved in the group can manage the needs of my child"

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

4. "I am confident that the schools involved in the group are managing needs of my child"

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

Professionals

1. "I am confident that I am managing the needs of the child?"

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

2. "I am confident that the parents involved in the group can manage the needs of the child"

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

3. "I am confident that other professionals involved in the group are managing the needs of the child?"

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

4. "I am confident that the schools involved in the group are managing the needs of the child"

9	8	7	6	5	4	3	2	1
Completely Agree	Strongly Agree	Agree	Agree more than I disagree	Undecided	Disagree	Disagree more than I agree	Strongly disagree	Completely disagree

APPENDIX V: RESEARCH DIARY

21 October 2007

Decided on the issues in the county – and have come up with an appropriate area for thesis – how parents are supported by professionals but specifically those parents of children with ASD.

ASD seems really prevalent here but there are also difficulties with supporting it – get the feeling it's a hot topic. This should not be surprising, I guess, given the government focus on ASD (e.g. DfES, 2004a, 2004b, 2004c, 2004d). However, it seems that here, professionals are concerned about the extent to which families are able to support their children with ASD, as well as themselves. I also get the impression that some professionals are not always sure, themselves, of the support available for these parents and children. This lack of information may be at odds with their professional role which is to provide guidance to parents etc. (e.g. Squires et al, 2007) but I think that it is difficult for professionals to know everything and it is also unrealistic (Milliband, 2008). I'm aware that I will need to bear this in mind when I begin research as it is possible, given past experiences, that I will identify that parents do not feel that professionals are adequately informed. I must make sure that I do not judge this finding as an example of professional incompetence and instead, explore the issue more extensively in line with the literature and other research.

30 October 2007

Chatted to quite a few teachers, TAs and EPs today about the group – the ASD Monitoring and Support Group, as it is formally known. Some people seem to only just be getting to grips with it but maybe that's not surprising as it's only been around for a year or so. Teachers aren't necessarily familiar with it. I asked one how they refer to the group and they confused it with another group. Another teacher seemed to think that EPs referred children and parents to the group which apparently isn't true – schools can refer. Not sure what the teachers do know so it may be interesting to find this out.

This thinking made me aware of how important it is to remember that the group is in its infancy. Some people will not necessarily know about it and what it represents. Moreover, this is not necessarily the fault of the group. It cannot be expected to suddenly become widely familiar to the LA, even though this could be a goal. However, on this note, I became aware of how important it is for me to remember that the group's infancy means that I should also not expect or assume that it will be fully functioning as a model of excellence. I hope that I do not, therefore, jump to negative conclusions if all of its goals are not necessarily being met.

15 November 2007

Feels a long time since thinking about the research but my research proposal is looming so I have been doing a lot of thinking. My placement experiences make me feel that some parents are not aware of the existence of the group but would really appreciate it as a support for them. I know one child I work with who has ASD only just recently diagnosed is proving challenging for family and school. Parents seem to be really anxious and unsure of how to support him whilst school want to exclude him. I think in his case, he and family would really benefit from the group as they could give them all some strategies which seem really useful.

Have also read up on some stats around ASD – really shocked that it has such a high prevalence – still questioning whether this is because this is a true representation, or whether diagnosis hasn't always been accurate. I am not sure.

Feel like I need to get more views on ASD and supportive mechanisms – also surprised at how little research there seems to be on parent and professionals perspectives – actually there seems a real lack of professionals' ideas on it.

Also there is a lot of statistical analysis but not much qualitative work. Again, I think perceptions may be a lot more important for my study than just stats although I think I will run this by my tutor.

26 February 2008

It's taking ages to sort out who, how and when I am going to research. Am lucky I have some excellent secretaries to help with the process of sampling. I think given the difficulties of selecting my sample: i.e: biased; not necessarily representative etc. – means that I will need to carry out a randomly selected sample/probability sample. Am not totally comfortable with this way of working, as I am a little anxious that I may not get a representative sample, this way either. This seems especially possible given that there are few parents in the group: i.e. 39 parents and 15 professionals. What worries me is that I will end up with an all female sample and possibly ones from the same socio-economic background. Both seem probable given some verbal feedback from other professionals who have had contact with the group. They have, for example, stated that most are women and tend to be "middle-class" Caucasians.

Not really sure how I address this if the sample is narrow. Part of me feels that this is the representation of the group and so should be accepted as such; part of me worries that there will be parents I have missed, especially fathers.

However, I think the lesson here for me is to ensure that I do make it clear in my thesis what I have achieved in my methodological approach and what I am unable to achieve: in effect, the strengths and weaknesses. Hopefully, this will balance out my concerns.

May 2008

It's been a long time but think I have sorted out my samples and begin to interview next week. I am preparing myself for these interviews by going back over the existing research that I have reviewed regarding PPPs and looking at associated methodologies. I have also re-acquainted myself with the BPS code of practice (BPS, 2006) to ensure that I follow ethical issues regarding informing parents and professionals of their right to withdraw.

I am concerned that some parents may find the process of talking about their child, difficult so have arranged a very comfortable room for the interviews. I guess I am trying to be as "humanistic" as possible as recognise that the attachment parents have to children (Bowlby, 1971) is very different from my own, as a non-parent. I think it makes me realise that parents need a different kind of approach from me than maybe the one I would give to my non-parent friends or even the professionals in the group.

<u>June 2008</u>

Have done my first week of interviews with both parents and professionals. Am really exhausted and have a headache! It's very hard to keep positive when you are spending all day asking questions and trying to look for probes to respond to that can help stimulate and take the discussions forward. Also, it's hard when parents – in my case anyway – get emotional.

Have been upset myself at how tearful and in one case, angry some of the parents got. They all seemed to respond very sensitively to questions of diagnosis of ASD – it seems a really contentious area and one that is incredibly emotive for these parents, yet strangely, it doesn't seem to have been mentioned all yet by the professionals – not sure why there is this discrepancy. O'Connor (2008) mentions how professionals can get lost in their "hiatus" of expert and I wonder if this has happened.

Nevertheless, I enjoyed interviewing the professionals – they are very friendly and also factual and direct – it seems easier to understand and identify their view points; then again, that is probably because I work in the same area as them and we speak the same "language". However, they are not emotional which does make them stand out from parents. They seem to want to support parents. I get the feeling they recognise that there are things they need to do to take the support forward yet it is still early days – I hope I can reflect that in my study, I guess, in my discussions.

27 June 2008

Have conducted my last interviews. The same as before can be said of this week. A lot of emotion from the parents and more direct and factual information from professionals. I am concerned about how critical most of the parents' comments are: there is a lot of negative feeling towards the diagnosis process but also to schools and more broadly to professionals. However, I feel that in some respects, there is a sense that parents are not necessarily looking for support but the magic solution to all of their problems. This seems true in cases where parents want support almost 24 hours a day including the weekend. Part of me appreciates this need but the remaining part makes me question the extent to which they NEED this help or just WANT this help. I feel that given this dilemma, I need to analyse more carefully my themes and try my best to minimise any biased interpretations. It will be revealing to consider the themes when they are identified.

12 August 2008

Have been ploughing through the transcripts from the interviews. They are so revealing. It seems that there are some interesting consistencies and tensions between parents and professionals which aren't really revealed as clearly in the Likert Scales. I get the feeling that there is also a lot of misunderstanding; for example, professionals say they offer communication support yet parents do not seem to acknowledge this support, saying that they need more support in this area. They do, however, both agree that more needs to be done to improve behaviours of the child. It seems, though that parents have a lot more stress than has been acknowledged or identified by professionals. I can't say that I even noticed the extent of this stress on placement which makes me question my own competency as a professional. It reminds me of the need to ensure that I do communicate with parents in a way that identifies their needs (DfES, 2002).

24 August 2008

Finding it hard to keep up momentum here with the Thematic Analysis – it is taking a long time. Find myself going back into the data time and time again – it is very much a recursive approach which I know is supposed to be part of the process (Hayes, 2000) but it is easy to lose focus when the data is so dense. I have tried to stay "fresh" during the analysis by taking regular research breaks – a very healthy strategy offered by my supervisor. I have also used my time with my supervisor to talk through the themes that I have collected to ensure face validity. However, the whole experience makes me realise that TA is very time-consuming and can be frustrating. This seems especially true when trying to code. I have, for example, found some really revealing comments but have not been able to find any repetitions of these comments that justify calling them a theme. As a result, some of my data is perhaps not as interesting as I would have liked it to be. However, I think that these reflections make me realise that it is important to try and aim for a balance in my work and one that captures the "truth" of people's comments but not at the expense of credibility.

20 October 2008

Have taken a break from analysis to concentrate on literature review. It is very interesting to experience the different demands that the research process places on me – the analysis was very labour intensive and involved a lot of detail and careful attention to every word but the literature review feels more cognitively demanding – feel like I have to be very critical of myself – bit like a court barrister arguing every toss of the coin. However, like the TA, it can be hard to keep focus and the research breaks are very beneficial!

2 November 2008

Am enjoying the literature review – seem to have amassed a lot of information on parent-professional partnerships not sure how to approach the actual structuring of my review – do I adopt a historical perspective? A thematic perspective? Sometimes, I wish I had done a grounded theory thesis then I wouldn't have to write a lit review – or so I have been told. However, I think that this just underlines how easy it is for the researcher to see the grass on the other side as always "greener". I think it also makes me realise the importance of "stepping back" to get a proper insight into the way I am working.

Nevertheless, I understand the need for a good review of the PPPs as what I have read has already helped me to appreciate the different demands placed on family and professionals and the ways in which this can and in some cases, cannot be addressed.

16 February 2009

Managed to give in and talk through my introduction with supervisor – I think she's pleased but I know I need to change perspective. I've concentrated on ASD and not PPPs – as she said, I need to know whether what I've written answers the research question – don't think it does at the moment. I think this is a sign that my chosen area of research is dense and I have to be careful to avoid getting "carried away" by the option to write about everything to do with PPPs. My supervision certainly highlighted that for me.

12 March 2009

Am enjoying the studying part of the research but I forget sometimes how it can help me on practice. I feel like I should now be more aware of the ways in which I can promote a PPP. As a result, I am taking greater steps to consider the way in which I communicate with parents and trying to ensure that I use my interactions with them to identify more clearly their needs.

14 March 2009

Have a done another swap with my working pattern – now on methodology – thought it may be a nice break or maybe cognitive break, at least, to concentrate on another area of the thesis that may involve different things to the literature review. It seems to have paid off: for some reason, I feel like I am racing through my methodology. Am a little bit stuck on the theory of Pragmatism – part of me feels a bit of a fraud for using a theory that seems so new to the research arena and also is described as an "anti-philosophy"! However, I know that the theory is well-researched. I think that I just need to have more confidence to try something "different" but at the same time keep reflexive about it.

28 April 2009

My meeting with my supervisor has gone really well. She has given me really useful pointers about my work so far which have felt like really useful guides to keep me going which right now I really need!

In general, I think the content of my work seems ok in both literature and methodology chapters but I need to change the style a little: think it should read as a punchier more refined piece. Need to sort this out by June.

12 May 2009

Have gone back to intro and I think, I have finally "cracked it"! Made it relevant to PPPs at last and I have to admit, it really reads better. Am annoyed though as it totally reads differently to the way it was a few months ago. Basically, I don't think there is a single word that I have not changed! I guess these frustrations are part of the process yet they still frustrate.

29 May 2009

Trying frantically to sort out my discussions and analysis sections. Can't sort out the right structure.

I know I should ensure that I check all of this with my supervisor – I will do this. I just wish that I was able to solve these problems on my own a little more than I seem able. I guess that this is a "confidence" issue and hopefully not a bad one considering the value of supervision.

1 July 2009

Sometimes, I feel like you just have to "get on with it" and this is what I am doing and have been doing for the last week or so. I think I may have discovered what I actually need to write in my discussions and results.

Hope they make sense. Really want to capture the perceptions of parents and professionals in my work and not my own. So I am going to use as many relevant quotes as I can in my findings and then give only brief discussions on what they can tell me about the PPP. Will leave the other things like what the findings tell me about the wider context, e.g. political etc. to the discussions section.

Whilst I feel now more "on top", I am still shattered and have realised that I have to go back and "revisit" my transcripts for more coding – basically, I think I have forgotten or overlooked quite a lot of salient points so I must try and identify them before I forget or lose patience. Sometimes, it is hard to even consider going back to the analysis process again yet I recognise that I need to do this not just for personal satisfaction but also to ensure that I truly capture the "voice" of parents and professionals.

2 July 2009

Am actually enjoying the coding process – although think I may be alone in this! Find it quite therapeutic and time does seem to go very quickly during the process. Also, it is nice to use some coloured pencils on my work! I enjoy findings pattern in my data especially when a pattern occurs more than twice and in some cases, occurs for every parent or professional.

It's really interesting but practically everyone in the MSG has mentioned how great the key contact role is – makes you think that something simple like a phone call makes a huge, huge difference. I now have to make sure that is really highlighted in my data as I do think it is very valuable – also it doesn't seem to have been identified in the literature so seems really new to the evidence-base.

Am getting stuck, however, with how little information there is from professionals versus parents on questions of empowerment. It seems strange but whilst parents talk about how they don't feel empowered and only parents empower them, professionals talk quite a lot about the powers of Multi-Agency working as if it is a miracle cure for empowerment – yet it isn't mentioned by the parents! Not sure where this point may be leading but it does need some discussion.

27 August 2009

It is nearing the end of the summer holidays and I would be lying if I said I was comfortable with my thesis work so far. All I can think of is how much I have to do and how little time – this seems especially real now I know I start full time work in less than a week.

Am trying to "knuckle down" but am getting myself tied into knots. I have noticed that as my panic rises, so do my e-mails and phone-calls to my supervisor. Luckily, she is very supportive. I think that the fact that I have had her there to support me has really made me appreciate the value of a "critical friend". Not only has she reassured me – a necessary part of this process, but also she has been able to guide me by giving me information that I would just not have been guaranteed to consider, such as reports and different perspectives. This has been a real bonus and it makes me hope that as a qualified EP, I can continue to have similar supervision.

11 September 2009

Have just come back from work and am back doing my thesis. Luckily, I have combined this work with a phone call to my supervisor who has really cheered me up and basically chivvied me along. I really needed chivvying along so I am totally grateful to her. I am even more grateful to my wonderful fiancé!

This is a hard process – it makes me realise only now that it has practically swallowed me this whole two years. Sometimes, I cannot believe that it has been two years. Sometimes, it feels like only yesterday; other times, it feels like my life.

I do worry about whether I have done justice to the people I have worked with and for the professionals and families. When I think about it in detail, I worry about what they will think of my work and whether it does match their attitudes and views. In a way, I hope it does because I don't want to be too revolutionary but in other ways, I do want it to be new, wholesome and fresh ideas that can help bring about some positive changes.

APPENDIX VI: EXAMPLE OF CODED TRANSCRIPT (PARENT 6)

Int. 6. & Parent.

Parent interview 6

[redacted]

m. speech

R: Does he have a diagnosis of Autism?

P: Midrange.

R: Midrange; ok and how old is he?

P: He's 9

R: He's 9. When was he first diagnosed with ASD/

P: I think he was first picked up as a possibility at 4 and then got the final diagnosis and statement at 4 and a half.

R: Ok so ; which professionals have you had contact with since [redacted] diagnosis?

[speech is a key problem for both the parents and professionals] — SPEECH was a prob

third

P: We used to live [redacted] and thankfully for us he was referred to a speech therapist in [redacted] cos he wasn't speaking at about 3; but the speech therapist was a friend of ours in the church who said well I don't think this is just a speech problem; I think it's autism. she referred to him to the ep who then set the ball rolling; ~~so when he~~ had his diagnosis; that was it from then but she then referred us to the early birds in [redacted] which was fantastic…absolutely brilliant but in terms of professional since then, nothing, really..

EARLY BIRD

R: So actually since his diagnosis, you've had the early birds but that's it?

P: That's it.

R: Have you had ep input?

P: no; we've had ..when we moved here; the case worker wanted to review his statement and redo it and I think she met him once and then rewrote it. But no, we've had no more ed psych or anything.

R: But you're part of the ASD monitoring and support so someone has referred you? DO you know?

— LACK of KNOWLEDGE

P: I don't know; I've brought along the latest letter. Cos they keep telling me to go to their things but it's always on a Friday so we never go along to them cos I can't do Fridays but I have just filled in their questionnaire thing they're doing. I presumed the

Fri [illegible] [illegible] day

lack of flexibility.

info.

can there be more?

school referred us to the monitoring group. **[can there be a greater flexibility with time-frames??]**

[redacted]: Right Ok. So, with in the group; is they're a contact for you; someone who calls you?

[redacted]: Yeah we do; she's really good; I think she's called [redacted]y; I think that's her name: she's really good. She phones up about once a term; talks about whether I've got any issues to take back to the group and I tend to tell her how we're going; if we've got any problems; academically and she takes back to the group but I don't actually get any other feedback but that. This last term, I actually said he's different than other kids and he wants to know if he's ever going to be clever: is there some sort of book he can read so he can understand what autism is and that it can introduce to him that he is different. SO I've asked her for that about a month ago and I haven't heard anything back. **[importance of growing self-awareness and in particular awareness of a difficulty comes through here and meets the diagnostic criteria for ASD development – see Trevarthen ..work around 'what do I do if I have..ASD? are important for children and families – where are they in [redacted]?')**

[redacted]: do you think that the training sessions that the group provides would help to answer those questions?

[redacted]: Yes they probably would if they did an evening one that I could get to but they only do Friday and I can't do a Friday because my husband's a minister and Friday is our Sunday, basically. But the **early bird course we did in [redacted]was absolutely fantastic. WE met together every week as a support group and** they were brilliant. I really miss them. When I moved here, I phoned up the ep and said is there a support group I could join and she said there wasn;t so I said I'd set one up and she was really keen and sent letters to school but nobody was particularly interested so I gave up on trying to do it so I gave up on trying to do it. But she was really keen on having a support group but we needed a professional to come and help set it up.

[redacted]: do you think it's met some of the needs?

[redacted]: Not all of them.

[redacted]The second question's difficult given what you've just said. I will ask. What other support have you had since being on the programme? I suppose this can be support that goes beyond the professional: could be informal: part of the school: could be brother or sister.

[redacted]: We have a speech therapist that comes in once a year to look at [redacted]and give hhis INA some further advice. What else have we had? I mean I'm in a very fortunate position int hat we live in [redacted]and the school has an Autism specialist in the secondary school so in that sense the secondary school are our support system and they're really good and also in our primary school there are 4 other children with autism and the parents have made a little group together to try and support each other cos we know each other really

Act is VALUED

clusive

need more info

↓

pus

li

early bird

Contrast 1:1 as + msa

needs more input + confide

School - base

trying to be proactive

parents value eachother's support.

she values school in contrast with others.

well: it's a very small school wi[illegible] high Autism number so informally, we're supporting each other and we have my older son is at secondary school so we have contacts there as well; but no formal other support. These would be really good if it was another day.

[redacted]

R: Ok, how often do you communicate with the group and how well do you feel supported?

P: What professionally?

R: Well you can use both. How well do you think you are supported professionally?

unknown.

P: I think if I have a problem the school are really good would fight my corner. And I think the college, [redacted] college are really good as well and that's probably where [redacted] gonna end up and actually his caseworker has been quite good when she's met with me with the statement but I haven't seen her since but she has been quite good in saying what she thinks is working. But in terms of general ongoing support, it's what we've been trying to do ourselves really; there hasn't really been any …yeah, but not bad in that sense.

R: You drew the line between professional and I guess personal; do you feel less personally or more personal support.

emotional?

P: **less personally supported; it is something that is needed as an issue to be addressed, desperately.** (where can the parents go?)

need personal support

R: I'm getting that feeling from other parents that have been less forthcoming than yourself so it's quite interesting for me to have you vocalise that. Would you mind expanding that?

P: Yeah I feel that the early bird support I **did in [redacted] was fantastic in setting me up because otherwise the diagnosis was your son has autism, off you go..basically which is the experience that other parents I know in school have had in [redacted] cos they've done the whole thing in [redacted]...here's your diagnosis, off you go; nothing like this is what you do; short stories; anything like that; it's beginning.** They've been doing picture time-tables: social stories; courses on this thing so it's beginning whereas I've had all that previously and I'm sort of relying on that really: what I've been **through and how to cope with behaviour and things like that but for those who have not had that unless they talk to other parents that know how to deal with these things, they have nothing**. SO whenever; I mean I phoned up my old support workers back in [redacted]... "Help, what do I do, cos he's doing this!" and they're brilliant. **They sort of destructure what is behaviour is, go back and try to work out**

isolation vulnerable?

hard to go back

emotional

this still true?

what the origin is and go from there. (this is what she wants from ASD group - that psychological perspective that accompanies time, personalising the issue and coping with parents' needs – sounds like we are getting there but need to work on this bit harder)

R [redacted]: I'm not sure whether I'm right but it's an emotional issue for you, personal support.

P [redacted] Yeah. I think it has to be because **it's hugely** difficult coping with a child with Autism cos although he's not particularly severe.

coping strategies ↓ answered

R [redacted] I mean is it… I don't know, you'll have to tell me if I'm right or wrong but from what **you've said I understood** that some of your experiences that you said it's a case of 'he's **got autism**' and it's down to you to deal with it. Do you also feel it's down to you to sort of **rationalise and understand it. Do you think that maybe** someone's attributing everything to you? Do you feel that?

P [redacted]: **Um, no. I wouldn't have said so; I think it's probably, particularly in terms of the** schools and things: **I mean a lot of the staff aren't particularly familiar with Autism anyway and I'm not saying that as a negative** cos when I did my teacher training there was **virtually** nothing on autism at all…we had an afternoon. (this is a government issue)

Just training of teachers

R [redacted]: We had an hour.

P [redacted] **so it's not a negative on theirs but it is like we almost have to be the experts for the teachers.**

parents versus school.

school needs training

R [redacted]: No-one's blaming you for your child's autism, are they?

P [redacted]: No.

R [redacted]: Cos sometimes that's come out…

P [redacted] I haven't personally felt that, no

R [redacted]: But what you do feel then is a lack of support for the issues you're having to deal with on a day-to-day basis and is that coming through every area that could be helping you? School? Speech and language? Monitoring group? Medical panels?

P [redacted]: **Medical . I've had nothing medical at all. When we moved here, the school** nurse **turned up** and said "Oh. I hear you have **a child with autism." And then went** wittering on **about** something totally unrelated and it was like she had no idea what autism is. **But** no, we've had no medical intervention whatsoever but have I felt it in all areas? No. I think **the primary** school have been very **understanding actually mainly because** he is the third child in the series. It was harder for the oldest one that's gone through and she's had to fight all the battles really. And so for [redacted] coming through, it's been much easier.

[redacted] What could they do this group to help you more, on a personal basis?

medical model regarded.

— flexible

P: What I would like is for some parental support group that was a bit easier to get to and possibly going in to the schools to actually help with the teachers. The college have done that; they've done some training for the teachers of the primary schools but yes, if they could come and talk to the teachers.. they know how to deal with [redacted].

help schools.

A: Emotional support. Is that something you'd like more of?

P: Yeah, very much so.

emotions.

A: Nurturing support?

P: Yeah.

A: I know it's a difficult issue and many people find it difficult to talk about..

A: The next one is about communication. I'm not sure how you're gonna answer this one. But if I was to ask you about frequency. How often do you think you communicate with professionals with regard to the group?

P: About once a half term, I guess one of these..

[shows list of training sessions available]

A: SO that's kind of written communication

P : And about twice a year, I get a phone call from [redacted] the case worker.

A: And do you communicate back at all ? *{ this could be an action that needs to be encouraged – parents ringing the professionals.....}*

P: No. Well, I had a questionnaire with this last one but that's the first opportunity I had to communicate back.

would like an opp. to ring . . .

A: What effects has that had towards your attitude towards [redacted]'s ASD?

P: I think it's put it more back on us as a family rather than trying to rely on outside support, I suppose.. we are sort of looking at the internet, trying to work out our own answers to the problems.

forced independence v helped

A: Is that good or bad?

P: Not good, because we aren't the experts at all and there's to be more answers out there than we have thought of or discovered. It's going to become more of an issue soon because he's going into year 5 and so is the secondary school issue. I would definitely

transition issues.

like more information about where to go for the secondary school;? Where would be best for him? *{why isn't this advice available???!!]*

[redacted]: How well do you think educational professionals have managed [redacted]'s needs?

P: [big pause]. Speech, I've been really disappointed with cos he was having monthly speech therapy in [redacted] **and he's had, in terms of actual speech therapy**, he's had **nothing .** A speech therapist comes in and talks to him for about half an hour once a year **[this speech input is a big issue...is it common???]** which is nothing. ***His INA is relied on to do most of the support for him.*** **HE's very fortunate in that the teacher he has this year** is absolutely fantastic and has had three years with another child with Autism **[importance of teacher's experience in teaching children with ASD and other related needs???]** and his progress has been fantastic this year. His previous **teacher knew nothing and he sat in the corner**, basically and was left to it. So mixed in **terms of the** professional.

Speech not good

Speech

teacher's experience is important

[redacted]: How about teachers?

P: It depends which teachers. You see the teacher my daughter has at the moment doesn't actually believe that autism exists [redacted]]. She thinks she's just naughty so I'm thankful he doesn't have her **but the teacher he has at the moment** is **absolutely brilliant**, superb. She includes him because he is now desperate to **be included** and wants to be independent and she is really good at including him at the level ~~he is~~ and encouraging him to be independent and this has given him confidence to do things within **the classroom** but also she's really good with the other children in the classroom in helping him to accept [redacted] and they are really good, the other kids, really good [**important point about inclusion]**

inclusion

Inclusion.

[redacted]: Good environment?

P: Yeah, brilliant.

[redacted]: How confident are you in managing [redacted]'s needs?

P:Um ~~not bad. He's difficult.~~ I'm probably less confident about the older he gets..puberty and everything [what's available for different dev milestones??] cos I think **phew!** ~~Cos um I have~~ **a child who's 12 at the moment and he's just going through it and** he's bad enough and he hasn't got the autism so at the moment, the level we're at, fairly confident. Obviously as he gets physically bigger: **it's quite a worry cos he's not** violet at **all, thankfully** but you know, **if he gets cross you know and starts pushing, then it's** quite a **worry** how **he's going to be. But** at the moment, **going day to day**, we're fairly **confident that we can cope with most of his behaviour** problems; **it's** ~~more~~ **academically**, how far's he going to get and have we got the ability to find the way ~~in to bring his~~ ability out really cos like with reading, he was getting nowhere at all and had plateaued for ages until we just tried a different route in and he's gone like that (points upwards) so it's

problem with puberty

concerns about adolescence.

size.

academic.

experiment!

really hard to sort of …**you just have to find all these different routes to find his way in.** So, not bad yes, I think we're pleased… experim

[redacted]: And how do you communicate with him?

Verbal is good

P: He's not bad. We used social stories and we used to use a lot of picture… social stories.

[redacted]: PECS visuals.

P:Yes. A lot of those. And now, his verbal communication is pretty good and actually he can say what he's feeling a lot..

emotionally aware.

[redacted] Really? Great.

P: Yeah. He's really good. [praisse] and saying why he's been like he is and things like that . So, in actual fact, not bad but we do tend to revert to the **picture**, pecs if it's getting desperate and we can't work out what's going on here.

visuals.

[redacted]: would that be every week?

P: no, no no. Very rarely really, no. Only if he's really really distressed and we're trying to work out why he's so distressed.

[redacted]: So once a year?

P: **Yeah, once every couple of months.** So we're just trying to work out what the issue is here and he just finds it easier to see it visually.. which space and why?

[redacted] And he communicates quite a lot with you verbally?

P: Yes.

[redacted]: Does he need quite a lot of repetition or emphasis?

P: In terms of us communicating to him, yes, he does need quite a lot or repetition to give **him time to process** what we're trying to say. Yeah

[redacted]: And what have been the benefits of the programme?

P: Um..

[redacted] Be honest, it's all confidential

not personalized.

P: A lot of what they've been covering in the adverts that they've sent, I've thought well there's not a lot of point in me going to that because I've done that and I've done that with the Early birds so even if I couldn't get to it, there wouldn't be a lot of point. So, if

Not tailoring 2 needs

you haven't done any of that, it probably would be beneficial because it's covering the basics that I did in the early birds.

R [redacted]: But for you at the moment…

P: not a lot of use

importance of siblings.

R [redacted]: Ok.

P: What I haven't covered is peers…cos I've got..not peers, siblings ..cos I've got two children . one older and one younger and I think it's really hard on them.

Imp. of siblings?

R [redacted]: That's interesting

P: **It would be nice to have some sort of support for them, to give them time out and meet** other children who are in the same situation because they become almost ***carers / siblings as carers]*** The older one does particularly. He's really good if [redacted]'s distressed in getting all out of it.

sibling supp?

R [redacted]: But you feel he shouldn't have to be ?

P: He shouldn't have to be; he's 12 and it's embarrassing to have a brother who's a bit weird so you know he needs time from being this…

stigma?

R [redacted]: That's really interesting ….that you've highlighted that.

P:There must be other siblings around here.

R [redacted]: There's a growing amount of research into sibling situations. Such a lot of time has been focused on the individual child

P And now the parents but they're forgetting that.

sibling

[redacted]

[redacted]

[redacted]

[redacted]

is this covered?

Links into lit review in this area