

**An action research enquiry in one unitary local authority about the experiences of support
available to parents and mainstream secondary schools for children with a diagnosis of
autism**

by

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Abstract

The number of children with autism has steadily risen in recent years (Fombonne, 2005) and with the first parliamentary Act to identify a specific disability group (Autism Act, 2010), momentum has gathered in reviewing and refining service delivery to, and for, families of children with a diagnosis of autism. This thesis is an account of an episode of collaborative action research, undertaken by an educational psychologist in her employing local authority, which explores the perceptions of key stakeholders (adults in schools, and parents of children with a diagnosis of autism) about existing services available to parents and schools staff to support children with autism.

There were two central strands to the research. Firstly, questionnaires (n=223) were distributed to all the parents known to the Local Authority to have a child aged between 2-16 years of age with a diagnosis of autism. This questionnaire sought to elicit information about parental experiences of support available to them following diagnosis and to identify their subsequent family needs. Data would inform service planning. The data elicited from the questionnaires indicated that parents of children of secondary-age felt less supported by external agencies and professionals compared to experiences of support and practices available to children reported by parents of primary-age or younger. Data also indicated that parents felt the practices in secondary schools were less inclusive than those experienced during primary schooling.

Secondly, head teachers or deputy head teachers and SENCos from all the mainstream secondary schools (14) within the local authority took part in interviews to clarify the nature of support available to pupils with a diagnosis of autism and ascertain school staff needs with regard to external support in facilitating the inclusion of this group of pupils. Data from the head teacher and SENCo interviews indicated staff would routinely deploy between 6-14 strategies to facilitate the inclusion of children with autism into mainstream schooling. School staff also indicated there were inadequacies in the dialogue between professionals in school and external service provider/agencies and the training and knowledge of school staff.

The findings indicate the need for EPs and other professionals to take a fuller account of parents' differing and changing needs throughout the assessment and intervention process and ensure EP practice provides carefully calibrated advice, knowledge and understanding of autism.

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Chapter One

Overview of Thesis

1:1 Introduction

This study is an investigation into parental accounts of their perceptions of services available to them following their child's diagnosis of autism spectrum disorder (ASD) and of secondary school head teachers' and SENCos' accounts of the types of support available to children with a diagnosis of autism in mainstream secondary schools. The study was completed in a unitary local authority located in the Midlands. In order to safeguard confidentiality the Local Authority will be given the pseudonym of 'Midtown' through the remainder of this thesis. While the action research project which forms the focus for this thesis is on-going, this thesis documents a first full action research cycle which took place between June 2010 and January 2012.

This chapter will present:

- the context for the study;
- a rationale for the focus of the research, taking account of local and national developments in policy, practice and outcomes;
- the methodology; and
- an overview of the structure and remit of the remainder of the thesis.

1:2 Context for the study

In response to the National Autism Plan for Children (NAPC, 2003) which recommended the development of ASD Co-ordinating Groups to plan strategically, provide training for parents, carers, professionals and to audit and evaluate provision for families of children with autism at local levels; and in response to the revised Education Act (2004), which promoted multi-agency working, a group of professionals working in the field of autism in Midtown, formed a multi-agency ASD Strategic Group in September 2005. This group is known as the 'Strategic Group' and consists of a clinical psychologist, psychiatrist, occupational therapist, a social worker, a representative of a charitable organisation concerned with autism and an educational psychologist.

I joined the Strategic Group in December 2006 as the Educational Psychologist, in light of my specialist role and responsibilities for autism when I began working in Midtown. Currently, I work as an educational psychologist undertaking roles such as working with children with Special Educational Needs (SEN), multi-agency work and strategic work/ capacity building in organisations (DfES 2006a). As a member of the Strategic Group, I have been involved in

discussions about service planning and current models of service delivery which exist across and between the individual teams represented within the Strategic Group.

1:2:1 Rationale for the focus of my doctorate study within the local context

One of the objectives of the Strategic Group, as advocated by the NAPC (2003), was to develop a means through which to audit and evaluate services available to families. In order to consider what a service should, could, and/or must do, as a starting point, there needs to be accurate understanding of the number of individuals requiring support.

In 2009, an audit of prevalence rates of children with a diagnosis of autism within Midtown was completed by health colleagues. This audit suggested the number of children with a diagnosis of autism known to health services was 213, indicating a local prevalence rate of 5:1 per thousand within the city's child population (aged from 2 years to 16 years). Furthermore, the audit had, along with national trends (Fombonne, 2005), suggested that the number of children receiving a diagnosis had increased over time, as illustrated in Table 1:1.

Table 1:1: Number of children (2-16years of age) diagnosed with autism in Midtown between 2002 – 2009

Year	Number diagnosed per year
2002	12
2003	18
2004	26
2005	31
2006	23
2007	31
2008	43
2009	39

Whilst there has been a growth in the number of children receiving a diagnosis, there has been little or no increase in staffing capacity in Health and Education Services within Midtown (current staffing levels are indicated in Appendix 1). The strain on services for families of children with autism was compounded by local political influences which brought a number of changes to services at a local level. One of these changes included the restructuring of Children and Young People's Services into integrated teams. As such, in September 2008 the Educational Psychology Service, ASD Early Intervention Team and Specialist Advisory Teachers were amalgamated to form one single service known as the

'Specialist Teacher educational Psychology Service' (STePS). This service supports the educational needs of children with autism, and practitioners within STePS were tasked with developing 'joined-up' approaches to service delivery with social care and health colleagues. Whilst this was driven initially by government guidance (National Autism Spectrum Disorder: Good Practice Guidance - Autistic Society, 2004), it was superseded by the practical need to manage and support the growing numbers of children receiving a diagnosis. As such, education, health, social care and voluntary agencies needed to provide a clear and transparent pathway across and between services about the ways in which children and young people (CYP) and families of children with autism can be and are supported: it became the remit of the Strategic Group to construct this pathway and define operational criteria and procedures.

1:3 Clarifying the research focus

In attempting to identify current systems of referral, assessment and intervention used in Midtown across and between service, it soon became apparent to the Strategic Group that the nature and duration of support from different agencies was extremely variable and that not all families received the same level of support or entitlement, thereby raising concerns about:

- inequalities in the type and nature of support, in which some families receive a high level of support whilst others with comparable needs receive none:
- the relationship between professionals and families (particularly between professionals and parents/carers) which could be negative: and
- the difficulties providing appropriate levels of support following diagnosis to the families as they transfer between agencies, and in maintaining appropriate content and duration of support for parents/carers, particularly as children progress through the education system.

Further discussions in the Strategic Group highlighted that whilst parents required on-going professional input immediately following diagnosis, there were also frequent requests for further specialist input or advice from professionals such as those represented in the Strategic Group, when there were difficulties in the child's educational placement. In light of the disproportionate number of children with autism receiving fixed or permanent exclusions from school compared to other children or SEN groups (DfES, 2010), I felt this reported need for continuing access to 'expert' support required further exploration.

In light of these concerns surrounding parental experiences of support and educational practices in school, which coincided with the research phase of my doctoral study, I agreed to undertake an investigation into each of these areas:

- parental experiences of support:
- secondary school staff expectations for and experiences of Local Authority and other agency support for their schools' endeavours to offer effective, inclusive provisions for students with an autism spectrum disorder.

1:4 Rationale for the focus of my doctorate study within the national context

Whilst there is a clear need to identify accounts of support from service users at a local level, i.e. in Midtown, current research endorses the relevance of this study within a national agenda.

Following a radical change in policy in 1978 (The Warnock Report, DES, 1978), decisions determining how children's special needs should be identified and provided for became based upon very different criteria, operationalised through different procedures, reflecting a significant change in public values. Whereas special education had been aligned closely with diagnosis of a handicapping condition or disability, with the nature of the disability largely determining the type and often location of special educational provision, the Warnock Report formed a watershed: decision making, regarding the level and nature of needs and provision, became largely dissociated from questions re: whether or not a child should be 'ascertained' as having a disability (such as 'educational subnormality', 'maladjustment': being 'delicate', blind/visually impaired; deaf/ hearing impaired, and so on).

The Warnock Report was concerned with the functional impact of any 'disability of mind or body' a child may present, and of the fact that children with a common area of disability were not a homogeneous group, but would express considerable diversity of abilities and needs. The new generic category of 'special educational needs' was established with a 'special educational need' defined in pragmatic terms as a 'learning difficulty' which required that 'special educational provision' (i.e. provision additional to, or otherwise different from, that which was normally available) should be made. It was argued that both children who had a disability, and other children may present with 'special educational needs' during their childhood: in some cases, SEN would be severe and persistent, requiring special educational provision (SEP) throughout their statutory education: in other cases SEN would be transient and/ or vary in their nature and severity as children progressed through their schooling.

The Warnock Report (DES, 1978) had also given impetus to the expectation created by the 1944 Education Act, which had established that, where possible, 'special educational treatment' (SET) should be made in mainstream schools. The Warnock Report further emphasised this expectation that children with SEN should, where possible, be 'included' in mainstream schools.

Following successive Acts of Parliament and related guidance (DfEE, 1997) 'Excellence For All Children: Meeting Special Educational Needs'), children with special educational needs were afforded a right to "inclusive education". This saw the concerns of special education shift from 'integration' to 'inclusion', reflecting a fundamental change in perspective. Inclusion moved away from a 'deficit' model, where difficulties were located within the child, to a 'social' model, where barriers to learning were considered to exist in the structures of schools themselves and, more broadly, in the attitudes and structures of society (Daniels and Garner, 1999). As such, policy sought to change curriculum demands and educational culture so that schools could fully and holistically accommodate diversity, including the 'special' needs presented by CYP with low incidence, complex needs (DfES, 2004a).

The UN Salamanca Statement (UNESCO, 1994) strengthened the position of inclusive education and the rights of children, placing educational reform within a broader social agenda. It promoted the 'participation of parents, communities and organisations of people with disabilities in the planning and decision making' (UNESCO, 1994, p. ix) to enhance inclusive experiences. This is discussed further in Chapter Two, Section 2:5, as is the shift from the pre-Warnock focus on 'handicapping conditions' or disabilities, to generic SEN, and the developing advocacy of disability rights and expectations for both effective inclusive provisions and access to evidence-informed, specialised provisions to address particular needs which characterise children (and adults) with particular disabilities/ conditions (such as ASD).

In the UK, whilst inclusive education continued to be a primary concern (NAPC, 2003; DfES, 2002; DCFS, 2007) policy reform has seen a greater push for inclusion at a societal level. With specific reference to ASD (the focus for the current study), the Autism Act, (2009) became the first ever disability-specific law in England to define what services should be made available to families and children with autism. This Act did two key things: firstly the Government was required under the Act to produce a strategy to transform the services available to adults with autism, and secondly to provide guidance to local authorities and health providers on how this strategy should be implemented. This guidance was made available in 2010 and set out actions to increase awareness and understanding of autism,

establishing a clear and consistent pathway for diagnosis, and improve access to services which are relevant to an individual's identified needs and priorities.

Whilst the changes in policy summarised above conceptualised children with special educational needs in a more positive light, the general principles of both 'integration' and 'inclusion' have presented many challenges, with philosophical ideals often viewed as dogma and concerns re: whether the needs of vulnerable children/ those with SEN/ children and young people with autism are adequately met. Indeed Baroness Warnock highlighted her reservations and misgivings about the logic of integration/ inclusions ideals, suggesting in a "Special Educational Needs – a new look" pamphlet (2005), statements and any further moves towards inclusion should be abandoned, arguing that.....

“The concept of special educational needs, has on balance, been unhelpful.....(the) expectation among some professionals and parents that ordinary schools can or should make appropriate provision for this group of pupils (pupils with SEN) has been a 'disastrous legacy'. (Warnock, 2005,p.3)

Whilst concerns about the legacy of Baroness Warnock's 1978 report were voiced a number of years ago, (Parliamentary Inquiry into SEN, 2005) at the time my own research study was being dated (Dec 2010- Oct 2011) little has changed with regard to the inclusion agenda for children defined as having special educational needs (The House of Commons Education and Skills Committee for Special Educational Needs, 2006). In response to government concerns regarding the effectiveness of the assessment and provisions for special educational needs, and in particular, a reported lack of parental confidence in Local Authority practices within this domain, the government commissioned the Lamb Inquiry (2009) which led into a more comprehensive review of practices (Support and Aspirations, DfE, 2011) to ensure that the needs of the child are at the forefront of provision available in schools, ensuring equity and access in response to need, rather than parental capacity to 'fight for resources' (DfE, 2004).

1:5 Research design

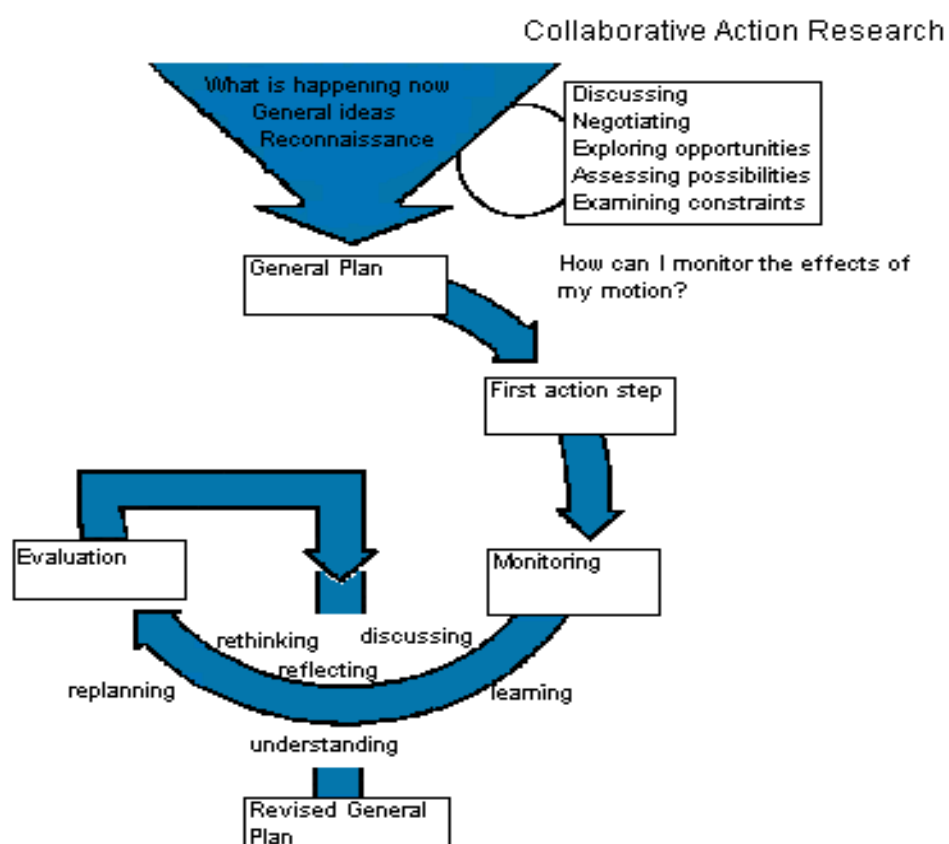
This research study is located within a social constructivist paradigm, in which my role as researcher assumes a position that people actively construct their social world (Becker 1970) and that multiple interpretations and perspectives on situations and events will be constructed. I have chosen to use both qualitative and quantitative data collection methods (Denscombe. 2007) within a Collaborative Action Research methodology (Reason and

Bradbury, 2001) to understand these social constructions, and harness this emerging knowledge and understanding to inform developments to practices and service delivery.

The principles behind collaborative action research, as defined by Reason and Bradbury (2001) include “practical issues”; “participation and democracy”; “human flourishing”; and “knowledge-in action”. The “knowledge-in-action” refers to the cycles of action and reflection which occur during each phase of research and are used to inform subsequent cycles of action. This process of reflection and action is shared with stakeholders, such as school staff and parents, and reflects the participatory and democratic nature of the enquiry. This involvement and participation can lead to “human flourishing” in which participants help construct the social world in which they must function and as such can create a world which enables them to grow and flourish (Reason & Bradbury, 2001).

This study comprises one turn of the ‘plan, act, observe and reflect’ cycle, as illustrated in Figure 1:1.

Figure 1:1: The action research cycle (adapted from Stephen Kemmis’ (1985): Action Research Planner



1:6 Research plan

There were two broad aims of the project. Firstly, I sought to develop an awareness of perceptions and needs of those (parents/carers and members of leaderships teams in secondary schools) who experience current practice in relation to support for CYP with ASD, and secondly to ensure that the quality of service available to both schools and families was equitable and meaningful. There were two central strands to the study addressing these broad aims:

- firstly to elicit, and abstract key trends within parents' accounts of their experiences and perceptions of service delivery and of the support available to them pre and post diagnosis: and
- secondly to understand head teachers' and SENCos' perceptions of support available to secondary school staff for the inclusion of children with a diagnosis of autism.

In light of these broad aims, a number of research questions were identified, as presented in Table 1:2. These questions were generated in light of the literature review which shaped and refined the initial plans for the study design and identified what data to elicit from whom and through what methods.

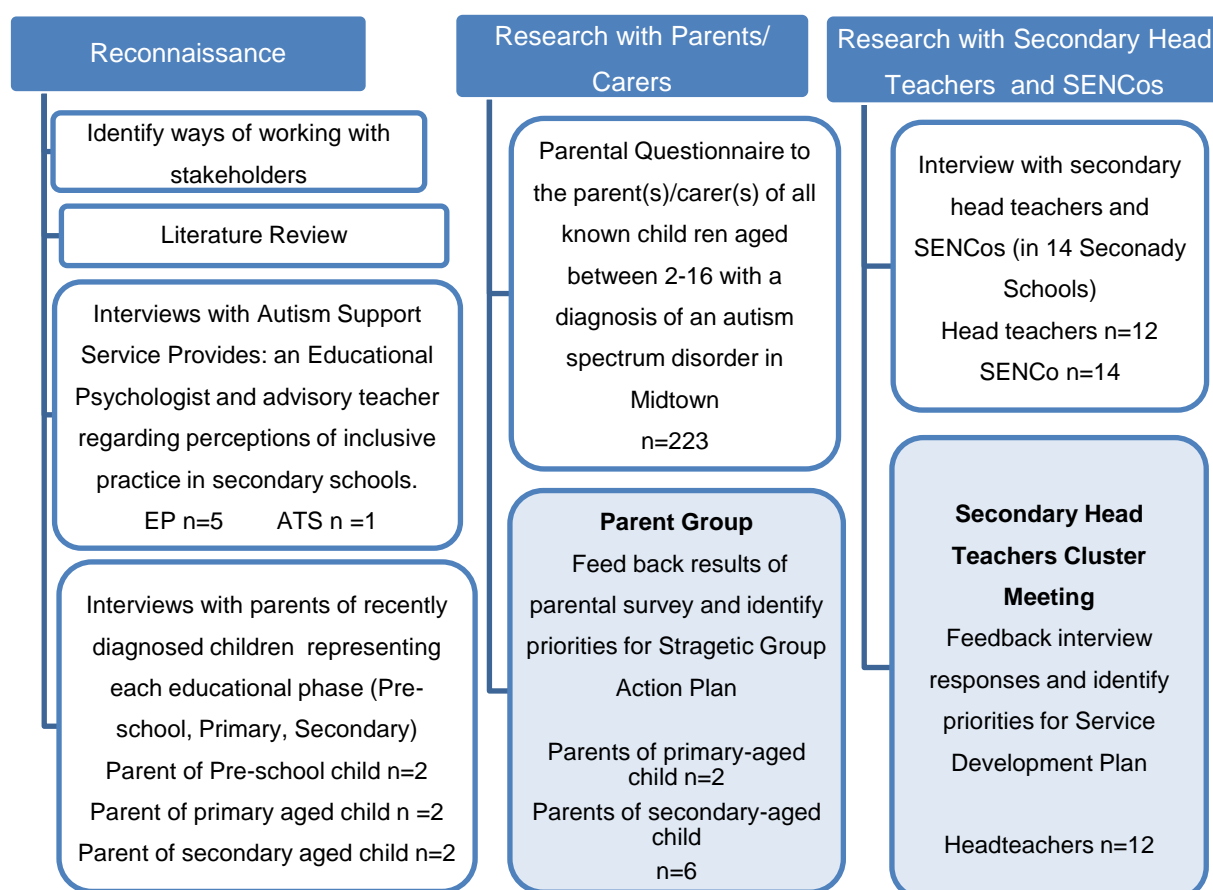
Table 1:2: List of Research Questions

	Research Questions	Key sources which informed focus of each research question
Parental experiences (Research Strand 2)	1. What support and information are available to parents/carers following a diagnosis of autism?	Literature Review: Humphries, 2009, Jones et al, 2009 Parent Interview
	2. What do parent/carers value about current service delivery from education, health and social care agencies?	Literature Review: Minnes & Steiner, 2008
	3. What could education, health and social care agencies do to improve the service available to parents/ carers pre and post diagnosis?	Literature Review: Rowlandson & Smith, 2009; Minnes & Steiner, 2008; Parsons et al, 2009 Parent Interview
	4. What support do parent/carers require in the future?	Literature Review: Symes & Humphrey, 2011 Parent Interviews
	5. What do educational providers do to facilitate access to education for a child with an ASD?	Literature Review: Renty & Roeyers, 2005 Casework: Interviews with EPs and Advisory teacher

Secondary Schools (Research Strand 3)	1. What do secondary schools currently do to ensure the inclusion of children with ASD?	Literature Review: McGregor & Campbell, 2001; Emam & Farrell, 2009
	2. What current practices of support from educational professionals (specifically support from STePS Service) are valued?	Literature Review: Glashan et al, 2004; Humphrey's & Lewis, 2008 Casework: Interviews with EPs and Advisory teacher
	3. What external support do schools need if they are successfully to provide an effective inclusive education for children with ASD?	Literature Review: Parsons et al, 2009; Emam & Farrell, 2009; Glashan et al, 2009; Humphrey, 2008 Casework: Interviews with EPs and Advisory teacher

These research questions were addressed through two strands of data collection, drawing on different participant groups which are represented in Figure 1:2.

Figure 1:2 Summary of the research process in relation to the different participation strands



1:6:1 The different strands of data collection

The reconnaissance phase of this study, of which the Literature Review reported in Chapter Two comprised one key strand, was followed by three scoping exercises which were

cumulatively used to shape and inform the research design and subsequent lines of enquiry. The first scoping exercise entailed undertaking an in-depth literature review of parental views about inclusion for children with Special Educational Needs (SEN) in general, and ASD in particular, and investigating their reported perceptions of satisfaction in relation to service delivery and the subsequent needs parents considered that they needed from service providers.

The second scoping exercise consisted of gaining the views and knowledge of school EPs and an advisory teacher for autism within Midtown Local Authority about the practices and philosophy surrounding ASD provision in each mainstream secondary school in the city.

The final scoping exercise consisted of interviewing three parents to gain insight into their current experiences of the referral, assessment and intervention pathway.

The information elicited from these three 'reconnaissance' activities was used to shape the research questions for the remaining two research strands, and the design of the questionnaire to be used within the 'Strand 2' city-wide parental survey.

As Figure 1:2 illustrates, the second strand of research following the reconnaissance phase explored parental perceptions and experiences of support during and following their child's diagnosis of autism. Two hundred and twenty-three questionnaires were despatched to elicit insight into parental experiences and views of service delivery and support from professionals. Respondents were also asked to indicate whether they wished to be involved in a focus group following the questionnaire data analysis. Those who indicated they wished to be involved (23 parents) were invited to participate in a focus group to 'member check' the accuracy of the findings and the interpretation that I had placed upon these following my initial analysis, and to identify parental priorities for change within the current support system. This strand of the research is presented in Chapter Five.

The third and final strand of the research, presented in Chapter Six, reports research designed to elicit the views and experiences of secondary school staff in regard to support from STePs and inclusion of children with a diagnosis of autism into mainstream secondary school. This strand consisted of 14 interviews in all 14 mainstream secondary schools in the city with representatives of the Leadership Team (consisting of 10 head teachers, 2 Deputy head teachers and 14 SENCOs). Following the analysis of the interview data, the findings were presented to head teachers via a weekly 'heads briefing meeting' known as the 'heads cluster meeting'.

1:7 Structure of the thesis

The thesis is structured to reflect the emergent design associated with action research methodology and consists of seven chapters.

Chapter One, the current chapter, provides an introduction to the study and presents a brief summary of the research in relation to the national and local context. A description of the methodology and design is presented, locating the study overall within a constructivist epistemological paradigm, utilising an action research methodology.

The chapter provides a summary of the research questions which arose from the scoping exercise and literature search, detailing how accounts of parental perceptions of external support and school staff perceptions about inclusive practices were elicited and are subsequently presented.

Chapter Two provides a review of the literature in regard to parental satisfaction relating to inclusive practices for children and young people with SEN, and more specifically for parents with a child/ren with a diagnosis of autism. Research questions identified in Chapter One are addressed through the interrogation of policy and legislation which provides the national context which is intended to guide and shape service delivery and inclusive practices in schools. Consideration is given to the theoretical literature which frames these reported levels of satisfaction and understanding of inclusion policy. Finally, the role of an Educational Psychologist as an agent for change is discussed. In light of this literature review, possible methodological approaches were identified and discussed in Chapter Three.

Chapter Three discusses the methodological approach adopted and considers the epistemological and theoretical bases upon which the research is positioned. A rationale for the decisions made is given, along with a description of the research plan. An overview is presented regarding ethical considerations which influenced the design, implementation and reporting of this study and attention is given to the nature of the data collected and their trustworthiness.

Chapter Four provides a description and the results of the 'reconnaissance phase' (first strand of the research) of the action research cycle. It details the three scoping exercises:

- a literature review in relation to methodological approaches and research into reported levels of satisfaction amongst parents of children with SEN, and specifically autism, in relation to service delivery and inclusive practices in schools:

- the interviews with five EPs and one Advisory Teacher for children with autism to obtain their knowledge and understanding of practices in each of the mainstream secondary schools: and
- three interviews with parents of children recently diagnosed with an autism spectrum disorder, representing the three different educational phases (Pre-school, Junior and Secondary). Results from each of these activities are examined and used to inform the next stage of the study.

Chapter Five describes the actions of the second strand of the research within this study. An account is presented of the process of questionnaire design (Brace, 2004), administration and analysis of findings pertaining to parental experiences of service delivery and school practices to support the inclusion of their child. A summary of the data derived from the quantitative and qualitative analysis of the question responses is provided and discussed. Chapter Five also provides an account of the priorities identified from the parental consultation group used to review and comment upon my analysis of trends within the survey responses, and identify the next steps for refining and developing service delivery in order to better meet the needs of parents.

Chapter Six presents the actions, findings and reflections from the third strand of the research: the secondary school head teacher and SENCo interviews. Against the backdrop of literature (Jones et al, 2009, Symes & Humphrey, 2011) which reports attitudes of school staff and practices used to facilitate access to mainstream education, Chapter Six presents the research instruments used to elicit feedback from head teachers or their deputies and SENCos within Midtown, secondary schools, describing their administration, together with the findings derived from this strand of the study. Inclusive practices reportedly deployed in the 14 secondary schools are presented. Results also detail what school head teachers and SENCos report about their schools' needs from external support agencies, (namely STePS), to facilitate the inclusion of children with autism within mainstream secondary schools. The results from the head teachers' 'cluster meeting' in which head teachers were asked to identify priorities for change within the current levels of support to mainstream secondary school staff are also presented and discussed.

Chapter Seven provides an integrated discussion of all of the findings of the research in relation to the overarching research questions presented in Table 1:2. Through reflection, the findings are reviewed in light of trends abstracted from the policy, theoretical and research literature summarised in Chapter Two. Consideration is given to the consensus within and between respondent groups across different educational phases and time intervals since

diagnosis. The purpose of this discussion is to identify future actions for implementation as a result of the information abstracted from the two principal strands of inquiry. The chapter considers the original contribution this study makes to developing further understanding about support for parents, school staff and children with autism.

Appendices contain supplementary reference materials to augment the content of Chapters Three to Six. The appendices include examples of data collection instruments such as questionnaires and interview schedules, information for participants and consent forms, as well as data charts summarising raw data and coding systems.

Chapter Two

Literature Review

2:1 Introduction

This chapter examines and reviews available policy and research studies in relation to parents' perceptions and experiences of support for children with autism in school and community environments. It also examines secondary school staff expectations for and views about the support provided by external agencies such as local authority advisory teachers and EPs.

Following an initial comprehensive review which formed a key component of the "Reconnaissance phase" of this action research study, as discussed in Chapter One, Section 1:6:1, I continued my exploration and examination of the literature throughout the remainder of the research period to ensure I took account of recent publications and used these in developing my analysis and interpretation of my own research data, making reference to previous findings reported in the literature, and theoretical accounts which have sought to illuminate and explain the inter-relationship between service user experiences, perceptions and needs.

This chapter addresses:

- the nature of autism spectrum disorder, and discussion of prevalence rates;
- a review of literature pertaining to:
 - current policy and legislation which underpins inclusive practice;
 - the views held by parents about inclusion of children with Special Educational Needs in mainstream schools;
 - the views held by school practitioners about the inclusion of children with Special Educational Needs; and
 - how service delivery for children with autism is perceived by parents and school staff.

In order to identify the relevant literature I undertook a web-search using Swetswise search engine for articles published between 2001- 2012. The key words used to identify the articles are presented in Table 2:1.

Table: 2:1: Outline of literature search strategy

Key word/s	Number of articles identified	Number of articles which occur in other searches	Number of articles relevant to current study and used to inform analysis
Inclusion and Autism	150	35	32
Inclusion and parental views	53	7	12
Inclusion and teacher views	89	15	13
ASD and parental views	12	0	8
ASD and teacher views	2	0	2
ASD and Service delivery	9	0	6

From the initial search 315 articles were identified. Following an initial screening of the titles and the subsequent review of abstracts, 73 articles were read and used to inform the subsequent stages of development of argument and analysis within the following review.

2:2 The nature of autism spectrum disorder

Prior to considering parents' reported wants and/or needs, and the extent to which such provisions are available for children with autism, a necessary starting point is to clarify what we mean when we use the term autism.

Kanner (1943) identified a number of shared characteristics and behavioural traits in 11 children which appeared to differentiate them from both typically developing peers and children with psychiatric disorders. At around the same time, Asperger (1944) also identified characteristics which distinguished the group of children he was working with from others. In both these instances, it was noted by Kanner (1943) and Asperger (1944) that the children had a greatly impaired ability to develop relationships with others, difficulties with language acquisition and language use, an atypical need for 'sameness', a lack of imagination, and a marked tendency to demonstrate repetitive and/or obsessive behaviours. Following this initial 'discovery' of autism, it soon became apparent that while 'autism' as a condition existed across Europe and in the United States, there were difficulties differentiating between the parameters which defined what was, or was not autism.

There were some early attempts over the following decades to provide a meaningful definition which characterised the features of autism. Rutter (1978) suggested four criteria for defining childhood autism. These criteria recognised impairment in social development,

delayed and deviant language development, 'insistence on sameness' as shown by stereotyped play patterns, and abnormal preoccupations or resistance to change (known together as the Triad of Impairment first reported by Wing, 1981). Rutter (1978) noted that all these symptoms should have been evident before 30 months.

Whilst accepting Rutter's (1978) identification of these 'essential features' as criteria for autism, Denckla (1986) warned of the difficulties using such criteria to categorise individuals. He suggested that the degree and severity of these 'essential features' could vary greatly and may present in many different manifestations and as such permit the inclusion of children with the most subtle as well as those with the most obvious features of autism to secure a diagnosis. Considerable diversity in the strength with which any or all of the core impairments is expressed within the population of children and adults with autism is widely acknowledged.

Later attempts to define autism came from the World Health Organisation, which located autism within a comprehensive diagnostic system used to classify mental disorders: the International Statistical Classification of Diseases and Related Health Problems (ICD-10, 1992). The American Psychiatric Association developed a parallel system, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994). These diagnostic manuals described autism as a Pervasive Developmental Disorder. Table 2:2 shows the main characteristics of Pervasive Developmental Disorder.

Table 2:2 : Key characteristics of the Pervasive Developmental Disorders (developed from DSM-IV, 1994 source)

Autism	<p>Deficits in sociability and empathy</p> <p>Deficits in communicative language</p> <p>Deficit in cognitive flexibility</p> <p>Delay with speech development</p> <p>Detectable before the age of 3</p>
Asperger's Syndrome	<p>Poor social skills, lack of insight</p> <p>Behavioural inflexibility, narrow range of interests</p> <p>IQ over 70</p> <p>No delay with speech</p> <p>Motor clumsiness</p>
PDD not otherwise specified	<p>Applies to less severely affected children who do not meet the criteria for either Autism or Asperger's Syndrome</p>

The ICD criteria (ICD-10, 1992) stipulate that specific features associated with autism, must be present at or before the age of 36 months, although this developmental 'cut-off' point remains contested by some (Wing et al 2011). Wing et al (2011) argue that symptoms denoting autism may not emerge or manifest in infancy and that the difficulties may not be noted until social demands exceed the developing child's limited capacities. Wing et al (2011) suggest that if a child or adult presents for a possible diagnosis of autism, application of current criteria is reliant upon others' (and normally parents') recollection of how the child was as an infant. This information may not be known or may not be accurately recalled owing to risks of memory distortion with the passage of time. Overall this aspect of the diagnostic criteria is considered unhelpful and unreliable.

Recent developments from the American Psychiatric Association (APA) committee in its revisions of DSM diagnostic criteria have sought to re-examine the criteria for a diagnosis of autism. In December 2012 the APA committee agreed a change to the criteria for a diagnosis of autism. The proposed changes include:

- a change in sub-categories/ terminology used to describe the condition; and
- a change in the attributes/ deficits associated with the condition.

The major change to the criteria is the use of the umbrella term of "autism spectrum disorder," which will combine the separate diagnoses of autism, Asperger's syndrome, pervasive developmental disorder - not otherwise specified (PDD-NOS) and childhood disintegrative disorder. Typically the distinction between each of these sub-categories has reflected the degree of social understanding / social intent and cognitive functioning, although there is some evidence (Seltzer et al., 2004) that with sufficient support/ intervention and maturation the profile of individuals with a diagnosis of autism changes across their developmental life span and could result in children / young people / adults presenting with skill sets belonging to other subcategories of autism as they mature and learn. As such Wing (2011) advocates the grouping of the sub-categories together, arguing the concept of a 'spectrum' is the most appropriate way to define the range and changing nature of the condition and explains that perhaps the most appropriate term for the whole group of disorders might be "the autisms" (Coleman & Gillberg, in press).

However the removal of these sub-categorises has raised concerns. Attwood (2006) argues that general public perceptions of individuals with a diagnosis of Asperger syndrome are largely more favourable than their 'autistic' counterparts. Gross (1994), writing at the time when Asperger syndrome was first included in the DSM-IV (1994), argues there is a small but often misunderstood group of children who do not present with the severity of need

typically associated with autism and may be more likely to be identified as 'naughty' and 'difficult'. Gross (1994) suggests the 'Asperger' label provides 'protection' for those with 'mild' difficulties in their language and social development.

Whilst there is some opposition to the change of criteria, the APA suggest that the move to unite the different conditions under one broad umbrella term will result in more accurate and consistent diagnosis of children. Such a view is shared by professionals in Midtown, where children receiving a diagnosis are described as having an 'autism spectrum disorder'. As such, in line with local authority practices, I will use the term 'autism spectrum disorder' throughout the remainder of this thesis.

The APA committee proposes a change to the use of the 'triad of impairment' as a criterion for diagnosis and a move towards impaired social interaction and communication as a broader term, and identifying difficulties in relation to 'restricted behaviours', by which they mean "stereotyped or repetitive speech, motor movements, or use of objects, excessive adherence to routines, ritualised patterns of verbal or nonverbal behaviour, or excessive resistance to change, highly restricted, fixated interests that are abnormal in intensity or focus or hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment" (APA DSM-5 Development, 2011). Happe & Ronald (2009), drawing on developmental neuropsychological research, suggest this new classification is reasonable because the 'triad' can be separated in the representation of each trait on a different gene.

Wing et al (2011) contest this, however, arguing that whilst the different elements of autism can be 'fractioned' down, it is the lack of 'social instinct' in the individual which is the fundamental difficulty underlying all autism spectrum disorders. They suggest that social instinct comprises social interaction and social communication: one being an individual's interest and pleasure in being with other people: the other, an ability to 'converse' in non-verbal and verbal ways with others. They suggest that an individual cannot demonstrate 'social instinct' if they do not have both the attributes/ qualities associated with social communication and social interaction. They go further and suggest that the behavioural neurology of social instinct implicates the use of specific cognitive skills (Ecker et al, 2010; Yoshida et al, 2010) which are absent from or impaired within the 'autistic brain'; therefore Wing et al (2011) suggest both social interaction and social communication need to remain core features within the diagnostic criteria as without both, social instinct is impaired. Furthermore Wing et al (2011) suggest that the proposed new criteria fail to acknowledge the atypical responses of many children with autism to sensory stimuli and that, despite research evidence (Billstedt et al, 2007; Leekam et al, 2007; Dahlgren & Gillberg, 1989) which

indicates a consistent impairment with sensory input, the proposed criteria very imprecisely locate sensory difficulties as a 'restricted repetitive pattern of behaviour'.

Whilst these proposed changes to the DSM criteria appear to 'simplify' the assessment process, thereby potentially offering increased reliability to the diagnosis, Wing et al (2011) argue that many features which distinguish autism from other conditions have been lost, and that the proposed revisions may therefore result in widening the criteria, and so lead to increased diagnosis and prevalence rates (to be discussed in Section 2:3).

It is important to note definitions and diagnostic criteria for an autism condition continue to be based on phenomenology: there are no medical tests which can be undertaken to ascertain definitively whether someone has autism or not, and assessment remains reliant upon subjective data obtained from observations of the child's communication, behaviour and developmental levels, augmented by parental reports. There is also a lack of consensus about the how to define and label the various core symptoms of autism (Matson et al, 2006) and as such a number of scaling methods have been developed to aid clarity and consistency, and address these major controversies in definition and diagnosis and the inherent unreliability of subjective interpretations. Within Midtown a number of diagnostic tools (presented in Table 2:3) are routinely used to 'standardise' assessments and strengthen procedural consistency.

Table 2:3: Summary of diagnostic tools for autism (taken from Grossman, Aspy & Myles, (2009)

Tool & Author	Age	Method of Administration	Advantages	Limitations
Autism Diagnostic Interview-Revised (ADI-R) Lord, Rutter, & LeCouteur (1994)	Over 2	Structured interview: 93 items in three functional domains. Responses are coded in eight content areas	<ul style="list-style-type: none"> • Brings some degree of objectivity, standardization, and consistency to the clinical decision-making process. • Provides a structured format to help ensure that all the important types of historical information are gathered, organized, and interpreted. • Interview helps some parents have a better understanding of the factors that are being evaluated in order to reach a diagnosis. • The diagnostic tool is tied to DSM-IV diagnostic criteria and current knowledge about autism in young children. 	<ul style="list-style-type: none"> • Low reliability: Results may result in false positive and false negative identification. • Formal training and interpreting this test is expensive. • Test administration requires a great deal of time (1-2 hours) for both professionals and parents.

Table 2:3: Summary of diagnostic tools for autism (taken from Grossman, Aspy, & Myles, 2009 continued)

Tool and Author	Age	Method of Administration	Advantages	Limitations
Autism Diagnostic Observation Schedule (ADOS/ ADOS-G) Lord, Rutter, DiLavore, & Risi (2001)	2 - adult	The protocol consists of a series of structured and semi-structured tasks that involve social interaction between the examiner and the subject. Segments of the subject's behaviour are assigned to predetermined observational categories.	<ul style="list-style-type: none"> • Opportunity to observe social behaviour and communication in standardised, well-documented contexts • Use of this instrument should be accompanied by information from other sources • Interactive play-based format 	<ul style="list-style-type: none"> • Seeks to discriminate and categorise behaviour based on a pre-determined checklist • Requires additional resources
Childhood Autism Rating Scale (CARS) Schopler, Reichler, & Renner (1988)	2 and over	15 items are rated on a 7-point scale based on observation, parent report, and other records Yields a total score with three classifications: Not autistic, mild or moderately autistic, or severely autistic	<ul style="list-style-type: none"> • Brings some degree of objectivity, standardization, and consistency to the clinical decision-making process • Provides a structured format for gathering and recording information • Useful for children as young as age two • Adequate sensitivity and specificity provides a measure of severity of the symptoms of autism • Training materials for administering and interpretation are readily available 	<ul style="list-style-type: none"> • There may be false positive and false negative test results • May not fully reflect current information about cognitive and social development in young children
Diagnostic Interview for Social and Communication Disorders (DISCO) Wing, Leekam, Libby, Gould, & Larcombe (2002)	All ages and all levels of ability	Semi-structured interview schedule Respondents are parents or other caregivers. Provisional diagnostic algorithms are provided for autism; responses on specific items are used to assist in diagnosis of autism.	<ul style="list-style-type: none"> • A detailed developmental history is taken • Use of a semi-structured interview to elicit information about the individual's past history up to current day to day functioning. • In-depth neuro psychological assessment is carried out with the focus child or adult 	<ul style="list-style-type: none"> • Parents recollections of child's development may be inaccurate and therefore affect the reliability of data. • May incorrectly identify autism in children with more severe cognitive deficits who do not have autism • Time consuming to administer

As illustrated in Table 2:3 there are a number of different diagnostic tools available to clinicians. Some (e.g. ADI-R, ADOS, CARS) utilise pre-constructed criteria of social and behavioural responses to provide qualitative scores assigning a child to a specific category,

while others (e.g. DISCO) rely on parental accounts, recollections and frequency of behaviour to determine whether a child has autism. Goldstein et al (2009) suggests there is a need for different assessment strategies and instruments to reflect the different skills which emerge at different ages and sequential development stages as people with ASD move through the lifespan. Furthermore NICE guidelines (2011) also state that an assessment for an Autism Spectrum Disorder must include both interactions with and observations of the child by clinicians and data gathering from parents/carers to obtain a full developmental history.

Whilst these diagnostic tools are intended to 'standardise' assessments, there are a number of inconsistencies arising from their use, particularly as each diagnostic tool utilises different data collection processes, so data cannot be validated across or between tests (Robson, 2002). Stoesz et al (2011) highlight such difficulties and suggest that the normative information obtained through some assessment measures, particularly those used for Asperger's Disorder, are limited, with evidence for the reliability and validity for each instrument, relatively poor.

It is noteworthy that whilst there have been improved transparency and rigour in both the use of explicit diagnostic criteria and multi-method approach to assessment inherent in each, along with consideration of different data sources (as illustrated in Table 2:3), reliability is still far from assured. Hence, diagnosis/ lack of diagnosis represent working hypotheses which will, in many cases, need to be revisited at intervals across the lifespan developmental process.

Matson et al (2006) suggest there are various approaches which can be used to establish more reliable results. They argue that a 'test-retest' approach could enhance reliability, whereby two administrations of the same test could be completed with a time interval of about 2–3 weeks. The gap in administration would be long enough to ensure to control for practice effects, but short enough to reduce risks that the symptom patterns will have changed over the interim. They also suggest that inter-rater reliability could be used as a means to check the concordance of independent raters' observations and scores. Whilst these approaches would increase the reliability of assessment data, they would prove extremely time consuming, and within Midtown, likely to be judged problematic, and clinicians unlikely to be afforded the time to undertake such rigorous assessments.

2:3 National Prevalence Estimates

Prevalence refers to the total number of cases of a condition in a given population at a specific time (The Free Dictionary, 2012). As such when examining the number of people receiving an ASD diagnosis, data need to be treated with some caution as they represent a ‘snap-shot’ at a specific point in time.

An audit completed by Fombonne (2005) indicates a change in the number of children identified as having met the criteria for a diagnosis of Autism and Asperger Syndrome over the period from 1966 to 2005 in Canada (Table 2:4).

Table 2:4: Prevalence rates of ASD between 1966-2007 in the UK (Adapted from Fombonne, 2005)

	Reference	Year	Reported diagnostic method or tool	Number per 10,000
Autism	Lotter	1966	Lotter 24 Rating Scale	4.1
	Wing et al	1976	Lotter's rating scale	4.8
	Wing & Gould	1979	Kanner / Triad	4.6 / 15.7
	Baird et al	2000	ICD-10	30.8
Asperger Syndrome	Baird et al	2000	ICD-10, DSM-IV	3.1
	Chakrabarti et al	2001	ICD-10, DSM-IV	8.4
	Chakrabarti et al	2005	ICD-10, DSM-IV	11.0

The prevalence rates presented in Table 2:4 distinguish between individuals who have a diagnosis of ‘Classic’ autism as identified by Kanner (1943) and those given a diagnosis of Asperger Syndrome. It is evident from these data that the prevalence rates for the number of individuals securing a diagnosis of autism has risen seven-fold over a 30 year period, with a similar, albeit less steep gradient in the number of individuals securing a diagnosis of Asperger Syndrome; a three-fold rise over a five year period. The reasons for such dramatic increases could be attributed to a number of different factors. These include an increased awareness of the condition amongst professionals, better screening and earlier detection, and an improvement in the assessment services available and broader diagnostic categories used in diagnosis (Jordan, 2005; 2007).

Whilst the figures reported in Table 2:4 position autism and Asperger Syndrome as separate conditions, other reported prevalence rates do not distinguish between the two conditions. Wing et al (2011), suggest that the practice of categorising individuals within distinctive

subgroups of autism or Asperger Syndrome is unhelpful. They suggest that a large number of individuals present with features of both Autism and Asperger Syndrome, and that children can often be diagnosed as autistic, who, through maturation and support grow up to fit a diagnosis of Asperger Syndrome. Such developmental change renders it problematic to specify clear boundaries for these two subgroups.

In light of the variation in reported prevalence rates (Gillberg, 1990; Wing, 1998) the concept of a spectrum is considered more appropriate. Indeed the apparent rise in numbers could include the shift from recording the conditions separately to incorporate the full autism spectrum. Utilising this broad concept of an autism spectrum disorder, Baird et al (2006) reported prevalence rates which exceed those already reported.

Indeed a number of years earlier The Medical Research Council (2001) reported figures which reflected a higher rate of the condition in children under the age of eight, indicating the prevalence rate was 60 per 10,000. Maying (2004) suggests that this figure could possibly be even higher, as not all individuals with a diagnosis are known or recorded on data bases, owing to some parents withholding consent or the children and families not accessing support provisions, and so not appearing on or within auditing systems. It is probable, however, that improved childhood screening leads to increased identification rates during this phase of the lifespan which contribute disproportionately to the overall increases in population prevalence levels summarised in Table 2:4.

Baird et al (2006) identified 9-10 year-olds within the Thames region who already had clinical diagnosis of autism (255) or were judged to be at risk for being an undetected case (1515). Using clinical consensus of childhood autism and other ASDs and a sample weighting procedure, in which the researchers selected data based upon the different socio-economic stratas to represent the population proportionately, the estimated prevalence rate was 116.1 per 10,000 children. This figure should be interpreted with some caution as a narrower definition of childhood autism within the same study provided a prevalence of 24.8 per 10,000. Furthermore the number of identified cases of autism was lower for children of “less educated parents”, raising questions about parental bias in a desire, or the social capital to secure a diagnosis. Mayring (2004) suggests that to obtain a more reliable figure for the number of children with a diagnosis, data collected should use the same diagnostic criteria, the same method of data collection, and the same research population across a prolonged period of time. However, whilst there is uncertainty about the exact number of individuals have a diagnosis of autism there is no doubt that “Autism is no longer thought of as a rare disorder” (DfES, 2006a, p.2).

2:3:1 Prevalence in Midtown

In line with the rising prevalence rates nationally, the number of children receiving a diagnosis of autism within Midtown is also rising (as presented in Chapter One, Section 1:3 – Table 1:1). In 2010 health colleagues within Midtown reported the number of children and young people with an ASD diagnosis was 213 across the 2-16 year age continuum, representing a local prevalence rate of 5:1 per thousand of Midtown's child population. Clearly this prevalence rate is also susceptible to issues of reliability discussed in relation to the national estimates and it is possible the figures reflect an incomplete estimate of local data.

2:4 ASD, inclusion and policy

In order to understand what inclusion means to parents of children with a diagnosis of autism and how this understanding shapes parental perspectives on services in schools and their community, consideration must first be given to the policy and legal framework which underpins expectations for inclusive education.

2:4:1 Brief history of Special Educational Needs (SEN) Policy in England

Within the UK there has been a radical shift in the type of education available to children, and more specifically children with Special Education Needs. The Education Act 1944 established that children's right to education should be based on their age, aptitude and ability. A number of diagnostic categories of 'handicap', such as 'educationally subnormal' were used to identify the type of school a child with a disability would attend. From this premise education policy pertaining to the education of children with additional needs has evolved over time, shifting from medical and educational assessments to graduated multi-disciplinary assessment. A summary of educational policy since 1944 is presented in Table 2:5.

Table 2:5: A summary of educational policy since 1944 for children with additional needs

SEN Educational Policy	Provision
Warnock Report (DES,1978)	The Warnock Report (DES, 1978) re-categorised how children with disabilities and other additional needs were defined to encompass a broader descriptive term, Special Education Needs (SEN) and promoted the integration of these children in mainstream provisions.

Table 2:5: A summary of educational policy since 1944 for children with additional needs (continued)

SEN Educational Policy	Provision
1981 Education Act	In light of the Warnock Report recommendations (DES, 1978) the Education Act 1981 detailed Local Education Authorities (LEAs') role in identifying and assessing the needs of children with SEN and their responsibility for providing suitable provision.
1993 & 1996 Education Act	Education Act 1993 (which was subsequently consolidated into the Education Act 1996) required the Secretary of State to issue a Code of Practice on SEN giving practical guidance to <u>LEAs</u> and the governing bodies of all maintained schools about their responsibilities for all children with SEN. The Secretary of State published the first Code of Practice in 1996.
2001 Special Educational Needs & Disability Act (SENDA)	Special Educational Needs & Disability Act (SENDA) 2001 replaced the 1996 Education Act and continued to expect the education of the majority of children with additional needs in mainstream schools. SENDA made it unlawful to discriminate against or treat a disabled person less favourably because of their disability when providing education, training or other services.
Revised SEN Code of Practice (DfES, 2002)	In January 2002 a revised Code of Practice on SEN came into force which incorporated amendments from the SENDA. The revised Code of Practice stated Local Authorities must educate children with additional or special educational needs in a mainstream school unless this was incompatible with efficient education and the wishes of the parent.
2005 Disability Discrimination Act	The Disability Discrimination Act made it unlawful to discriminate or harass an individual based upon their disability. The Act detailed the duty of local authorities to take reasonable steps to ensure a disabled person is not at a substantial disadvantage in comparison with non-disabled persons.
Equality Act 2010 (further amended in 2012)	The primary purpose of the Act was to consolidate the complicated array of Acts and Regulations pertaining to the different strands of the Act. The Act made it unlawful to discriminate or harass an individual based upon their disability or persons associated with someone with a disability in relation to provisions and access to education, health, work, transport and mental health.

Over the last 60 years different governments have tried to move towards "integration", where disabled children and non-disabled children work together in the same school and where

everyone has equal opportunities. It would appear that during 1980s-1990s government policy sought to reduce the number of children attending specialist settings. Indeed this trend was cemented in the Green Paper (DfEE, 1997) 'Excellence For All Children: Meeting Special Educational Needs', which adopted the position of inclusive education, as promoted by the UN Salamanca Statement (UNESCO,1994). The education system for children with Special Educational Needs now required "an extension of the capacity of mainstream schools to provide for children with a wide range of needs". However, whilst this was the goal, in reality the immediate changes were limited. In 1981, 127,157 children were placed in segregated special schools which, over a twenty year period, had declined to 102,621 (Greater Manchester Disabled People's Magazine 'Coalition' 2001: pp. 12-16). More recent figures suggest the number of children in special schools has declined further. The National Statistics for the Department of Education, 'Special Educational Needs in England' (DfES, 2011) indicate the number of children with SEN attending specialist provisions maintained by Local Authorities in 2011 was 89,860: a figure which has remained consistent over the period from 2007 to 2011, suggesting that a significant minority of parents either want a different type of educational experience for their child, and/ or that there remain difficulties in the capacity of the mainstream education system to meet the needs of all children identified with SEN.

Thus against a political backdrop of educational reforms supporting inclusive educational provisions for children with SEN and a contingent desire to increase the number of children with disabilities who attend mainstream provisions, changes in the education of children with SEN have gained momentum (Education Act 1996, Section 316/316A). Local Authorities are required to educate all children within a mainstream school, unless to do so is judged incompatible with efficient education of the child and/or others, and/or the wishes of the parent.

Facilitating this inclusion, particularly for children with autism, the DfEE commissioned a review to clarify what is known about autism and what gaps exist in professional knowledge about effective educational interventions for children with an autistic spectrum disorder (DfEE, 1998). This review informed subsequent developments and research into provisions for children with autism (NfER, 2003, Jordan, 2006; Jones et al., 2009; Parsons et al., 2009a) which have arguably, informed subsequent developments in the education and provision available to children with a diagnosis of autism. The NfER review (NfER, 2003) identified specific difficulties with teacher knowledge about autism and skills when providing appropriate support.

In February 2004, the publication of Removing Barriers to Achievement (DfES, 2004a), built on the reform of children's services (Every Child Matters, HM Government, 2004) and set out an agenda giving all children with special needs and disabilities the opportunity to succeed. This strategy sought to address the skill set of educational professionals and provided funding to schools to improve their capabilities to provide for pupils with SEN and disabilities.

The inclusion of all into mainstream schools as promoted by the 1996 Education Act was further supported by the introduction of the Inclusion Development Programme (IDP) (DCFS, 2008), which included a four-year programme of continuing professional development (CPD) to increase the confidence and expertise of mainstream practitioners in meeting the needs of pupils with SEN in schools.

More recently autism as a specific focus for legislation and policy priorities has again come to the fore. In 2009 the Autism Act came into force. This was the first ever disability-specific legislation in England. The Act did two key things: it required the government to produce a strategy for adults with autism, and to provide statutory guidance for local councils and local health bodies on implementing the adult autism strategy by the end of 2010. Whilst the Act was focused on adult provision it also led to a review of practices for children and young people as many Local Authorities sought to provide continuity of services as individuals with autism transferred from Children's Services to Adult Services.

However, key to understanding and ensuring the policy and legislation detailed above is implemented to benefit children with SEN, and in particular, children with a diagnosis of an autism spectrum disorder, is further consideration about the nature of inclusion.

2:5 Social inclusion

Inclusive legislation is underpinned by the principles and values which inform the UN Declaration on Human Rights (United Nations, 1948). Article 23 of the UN Convention on the Rights of the Child (United Nations, 1989) with reference to disabled children states,

“a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in their community”.

Here the emphasis is on the child's right to participate in their community and upon social inclusion as a core right. However Donnelly & Coakley (2002) argue that inclusion as a rights-based approach is inadequate to address the personal and systemic exclusions experienced by many disabled children and adults. Indeed Lamb (2009) suggests that the

concept of inclusion should consider not just how much inclusion there should be, but what sort of inclusion or end point we are really aiming for.

The Local Government Improvement and Development Agency (DfES, 2010, p.10) elaborates upon this, suggesting that social inclusion is the “ability to fully participate in normal social activities and engage with political and civic life”. However social inclusion amounts to far more than this. Donnelly & Coakley (2002) suggest “Social inclusion is about making sure that all children and adults are able to participate as valued, respected and contributing members of society”. Humphrey (2008) goes further, locating inclusion as an on-going process and encompasses inclusion as the ‘presence, participation, acceptance and achievement’ of individuals. Both Donnelly & Coakley (2002) and Humphrey (2008) emphasise that participation should be valued and respected by the community in which the inclusion takes place; indeed the issue of disability and SEN moves away from the individual into the realm of collective responsibility (Tregaskis, 2002).

Humphrey (2008) argues that this value and respect for participation is reliant upon a change in attitudes. When considering inclusive practices for individuals with autism, he suggested that those who interact with individuals with ASD often come with pre-conceived ideas about autism and how individuals might behave, often construed in the public mind as ‘rainman-like’ intellectual impairment or an expectation that affected individuals might be “emotionally cut off” (Singer, 1999). Humphrey (2008) argues that this negative view of autism is likely to affect the expectations others have of the individual, although Molloy & Vasil, (2002) argue that the individual should not be ‘defined by their diagnosis’ (p.661). Thus, Humphrey (2008) and Donnelly & Coakley (2002) argue inclusion becomes a normative, value-based concept rather than a human right concern.

Roberts et al (2011) explore the issue of ‘value’ further, suggesting that this right to participate should not be governed by ‘normal’ or mainstream societal expectations and values which assume that there is only one way of doing things; rather, participation should mean taking part in a way which is meaningful to the individual, which might not necessarily be in the same way as would be the case for others. It is important to note the view of Roberts et al (2011), that, whilst traditional accounts of social inclusion refer to and reflect a single mainstream society in which everyone participates in a culturally approved way, society is, in fact, made up of different, smaller self-selecting groups which operate different values and expectations (Roberts et al, 2011). Indeed recent rhetoric assumes Roberts et al’s (2011) position, as we see the language of social inclusion used in conjunction with the term social cohesion; “Social cohesion is the capacity of a society to ensure the well-being of

all its members, minimising disparities and avoiding marginalisation” p.42 (Council of Europe, 2008).

Current data suggest that the inclusion of children with SEN in mainstream schools has progressed with limited success (The House of Commons Education and Skills Committee for Special Educational Needs, 2006). This committee (Third Report of Session 2005–06), indicated that ‘the proportion of children with statements of SEN (around 3%) had plateaued within a system still based on the original (DES,1978) Warnock framework, and suggested that ‘The Warnock SEN framework is struggling to remain fit for purpose, and where significant cracks are developing in the system—most starkly demonstrated by the failure of the system to cope with the rising number of children with autism and social, emotional or behavioural difficulties (SEBD)—this is causing high levels of frustration to parents, children, teachers and local authorities’ (Education and Skills Committee, 2006 p.12).

More recent developments question whether the way in which we identify and describe those with SEN reflect difficulties within the SEN system and inclusion. Lamb (2009) argues that

“ the current educational definition of inclusion has been postulated as an end point that the system is working towards. However there remain radically different views about what inclusion is or should entail, both philosophically and how that is worked out in practice. However if there is no consensus as to what that end point looks like, then this should make us wary of making changes to a framework.” (p.10)

Thus, against this backdrop of a policy commitment towards social inclusion, and the still very incomplete realisation of this vision, and schools’/ educational authorities’ responsibility to develop cultures, practices and policy to achieve inclusive educational environments (DfES, 2001a; UNESCO, 1994), further guidance has been created for specific educational needs groups including those with autism. Those of particular interest to my study are the Autism Spectrum Disorder: Good Practice Guidance (DfES, 2002) and The National Framework for Children, Young People and Maternity Services (DoH,2004).

2:5:1 Social inclusion policy for children and young people with autism

The Autism Good Practice Guidance (DfES, 2002) aimed to raise awareness of Autism and promote standards of support to meet the diverse needs of children with ASD. The standards included early identification and intervention for children across educational and home settings. There were two sections to the guidance: firstly an introduction to the

characteristics of autism and the proposal of what constitutes good, effective provision; and secondly the guidance provided a list of good practice which could be used as an audit tool for local authorities. The judgements made about the quality of practices and whether they were 'good' were made by the researchers, Jones et al (2006) in light of empirical research literature. Whilst these empirical data informing the guidance were drawn from evidence-based practices, Francis (2005) argues that in the absence of an aetiology-based intervention, families and professionals are exposed to diverse and sometimes conflicting recommendations; furthermore there are no robust data available to suggest that these recommendations are better informed or more effective in their outcomes than other approaches.

More recently, the Autism Education Trust (2011) undertook research to identify existing practices in those schools judged by Charman et al (2011) to be providing excellent care and education for children and young people with autism, highlighting areas of commonality and differences between practices. Based upon this understanding, a set of good practice guidelines was abstracted, with the suggestion that they could then form a framework for school self-evaluation and be used to develop country-wide training which could be delivered by local partners and accredited by the Autism Education Trust. Features of 'good practice' were identified through in-depth study of schools, including interviews with school staff and some parents and carers. Through this data collection, the authors (Charman et al, 2011) were able to categorise aspects of good practice as:

Practitioner skills

- school staff both highly trained and highly motivated in their own practices;
- training for all staff, including for support staff, was a priority for schools;
- senior school staff provided strong leadership and vision; and
- staff recognising the need for a unique 'autism curriculum', incorporating targeted curricula to develop attention, imitation, language comprehension and use and play and social skills (Dawson & Osterling, 1997).

Curriculum adaptations

- school staff provide an individualised and adapted curriculum for each pupil.

Working with others

- school staff undertake the role of 'ambassadors' for autism to raise community awareness;
- school staff have very high levels of reciprocal communication with parents and carers, and schools work in partnership with families;
- there is a considerable amount of joint working with specialist health practitioners; and
- settings are characterised by a strong commitment towards and ability to hear the pupil's voice.

Furthermore Jones (2006) also identified a set of 'good practice' standards which schools could use to evaluate their practices. These include addressing the needs of the individual children, building relationships, modifying curriculum & learning opportunities and providing enabling environments. These standards emphasise the need for practitioner skill, inclusive school practices and collaborative joint working, such as:

Practitioner skills

- staff knowledge and training, including staff characteristics and expectations for training and dissemination; and
- levels of ambition and aspiration that staff had for their pupils, through school ethos and pupils achieving key skills.

School practices

- adapting the curriculum through a differentiated national curriculum and use of autism-specific approaches, such as, treatment and education or Autism and other Communication Handicapped Children (TEACCH);
- monitoring progress through recording systems, practices and sharing information on progress; and
- broader participation of parents as ambassadors and engagement in joint activities with mainstream pupils for children.

Working with others

- involvement of other professionals, including recognising issues which require external expertise and joint working with other professionals; and
- effective communication between staff, parents and staff and staff and children

Thus the judgements made by Charman et al (2011) and Jones (2012) about what constitutes excellent care and education of autistic youngsters are highly congruent: both identify the need to "help the individual child/young person to develop skills and strategies to understand situations and communicate needs, while on the other hand adapting the environment to enable the child to function and learn within it" (Charman, 2011), while also recognising that good practice is reliant upon the skills of practitioners and their understanding of autism prior to engaging or implementing approaches (Guldborg, 2010).

The benefits of such guidance include helping to place change and support for children with a diagnosis of autism within an bioecological systems framework (Bronfenbrenner, 2005), in which, practices integrate attention to the particular needs and capabilities of the child, salient features of the child's social and physical environment, and the skills, approaches and overall contribution of practitioners.

2:5:2 Locating change within a bioecological system

Both sets of good practice guidance summarised above indicate that schools as organisations can support young people with autism better by improving their own responses to the needs of the child, and in doing so, improving the young person's microsystem and educational experiences and contingent outcomes (Bronfenbrenner 2005).

Bronfenbrenner's (2005) revised systemic, ecological model suggested the way we encounter different environments throughout our lifespan will influence our behaviour to varying degrees. The revised bioecological model positions the developing child at the centre of five interconnecting structures/ systems (the micro system, the mesosystem, the exosystem, the macro system, and the chronosystem) which interact, whereby actions which occur in one system will have an influence on different parts of the system. Bronfenbrenner suggests that each structure functions in a different way as presented in Table 2:6.

Table 2:6: Summary of the different systems within Bronfenbrenner's biological model (2005)

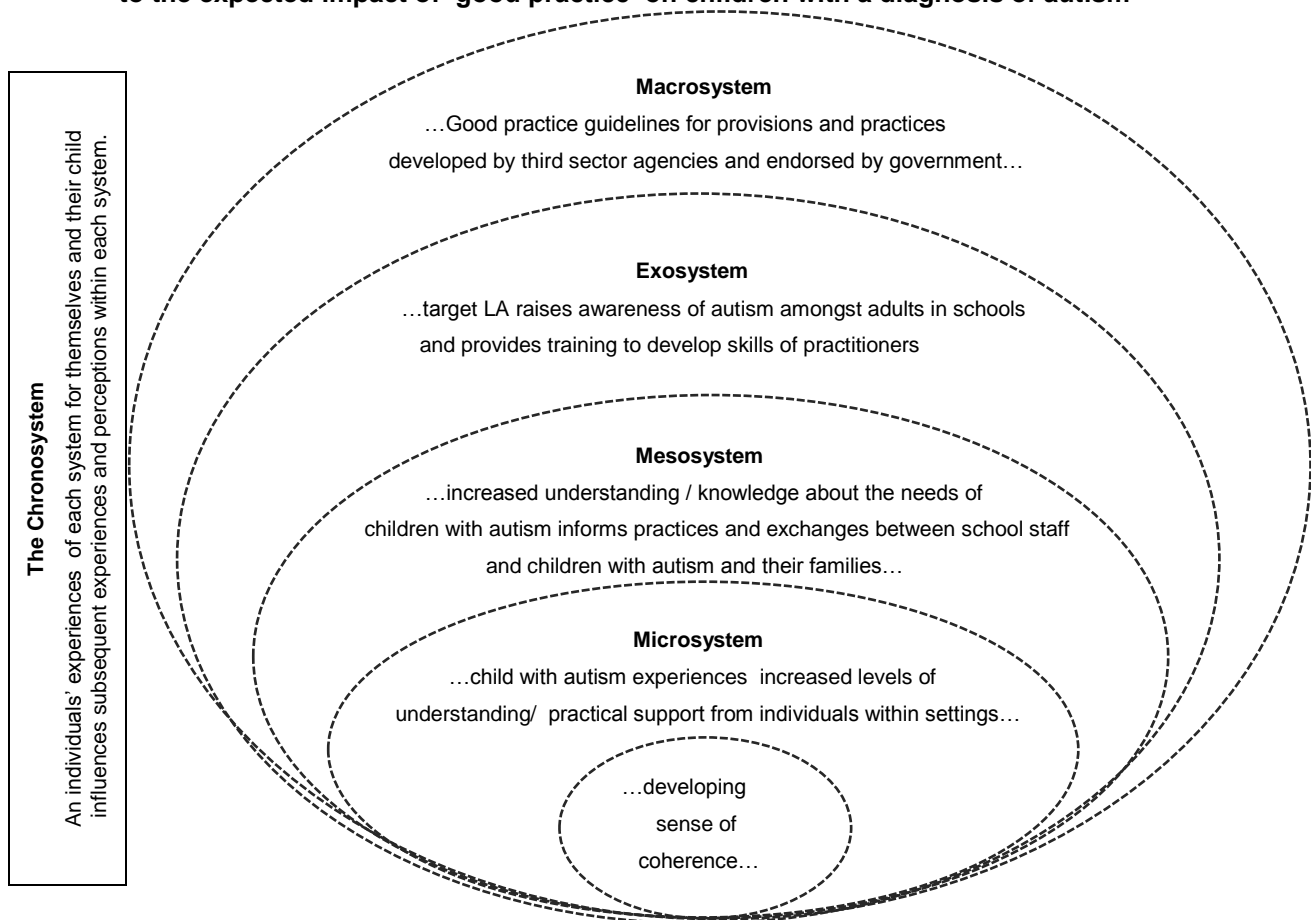
The Micro System	The micro system is the direct environment in which the individual lives. An individual's family, friends, classmates, teachers, neighbours and other people who have direct contact with the individual are included in the micro system. The theory states that the individual is not merely a recipient of experiences when socialising with people in the micro system environment, but contributes to the construction of such environment. The characteristics of the developing child are acknowledged as an important source of influence on the developing child's lifespan development through the process of ontogenesis.
The Meso System	The mesosystem involves the relationships between the microsystems in an individual's life. This means, for example, that the individual's family experience will influence responses in other micro systems, such as interactions with peers within the classroom setting.
The Exosystem	The exosystem is the setting in which the developing child does not have any active role, but where interactions may permeate their microsystemic habitat. For example, parents experiencing stress in the work place may then express the effects of such stress in the home setting in their interactions with their partner, or directly in their parenting of the developing child and/ or his/ her siblings.

The Macro system	The macrosystem comprises the superordinate culture within which the developing child and relevant micro-, meso-, and exo- systems are nested. Here cultural values reflect and influence social values, resource deployment, media representations, public policy, accepted standards and practices, so exerting considerable direct and indirect influence on the developing child, parenting practices, educational provisions and much more.
The Chronosystem	This system develops as a result of patterning of environmental events and experiences over the lifespan (such as developmental transitions childhood to adolescence; pre-school through to primary and secondary schooling) and the impact of social-historical circumstances (such as expectations for people with disability which is improved compared to the early part of the 20 th century). experience in their life. This includes environmental events and transitions in an individual's life, and this also includes the history of an individual.

In addition to the different systems described above, Bronfenbrenner (2005) also acknowledged (in his later model) the relevance of biological and genetic aspects of the person and the impact of the child's characteristics on interactions with the interconnecting systems. He identified the importance of personal characteristics that individuals bring with them into any social situation; characteristics immediately available to others, such as, age, gender, physical appearance, which may influence initial interactions because of the expectations formed by others in their social, cultural and temporal context. He also emphasised other characteristics, known as resource characteristics, which are not as immediately apparent but relate partly to the mental and emotional resources of an individual. The final addition to Bronfenbrenner's bioecological model is recognition of the differences in temperament, motivation, persistence of an individual which affect interactions with people and environmental characteristics: it is the combination of different personal attributes and experiences which leads to individuals within the same systems following different trajectories.

In relation to the current study, Figure 2:1 proposes how action starting at the macrosystem might impact upon the layers of the bioecological system for a young person with autism. The example considers how the implementation of 'good practice' for children with autism could affect each of the bioecological systems.

Figure 2:1: Illustration of Bronfenbrenner's (2005) model of bioecological system in relation to the expected impact of 'good practice' on children with a diagnosis of autism



As Figure 2:1 illustrates, the use of good practice guidelines at a macrosystemic level is intended to lead to changes in the exosystem which in turn would contribute to changes and activities within the meso- and micro- systems with which the young person with autism directly engages. It is important to emphasise that whilst events within the macro system filter down to affect the experiences of the child at the microsystem level, Bronfenbrenner (2005) also describes how the 'systems' are interconnected and the activities within the whole system are both reciprocal and multi-directional. This suggests that activities undertaken within a micro system will have an impact and contribute to activities at a macrosystemic level. However it is noteworthy that the direction of this influence is not so straight forward and often there will be a wide range of other complementary and competing influences concurrent at each systemic level which will also influence both the child's and family's engagement with and responses to Good Practice Guidelines and the implementation of the practice commended by the guidelines.

For example if children with a diagnosis of autism succeed in education and develop their skills to contribute to the communities in which they live, it could strengthen their self-esteem and relationships with others. This ability to contribute to the communities in which they live

and wider society is significant because the literature notes that young persons with a diagnosis of autism may otherwise not experience the same life chances as their peers, and as adults may be at risk of social exclusion (DfES, 2011; Reid, 2011).

It is also important in influencing social perceptions and social capital afforded to others with autism, and this, in the longer term, influencing community culture and attitudes and so, in turn, expectations of, and opportunities afforded to others with ASD. Godfrey et al (2002) observe that a likely impact of young people experiencing social exclusion is a significant cost to individuals, families and to society, reflecting how in a bioecological system a child with autism can influence the other layers. For example when a child with autism experiences the understanding and practical support from others in the micro and meso system, their understanding and sense of coherence of the social world develops. This in turn facilitates improved interactions and behavioural responses and changes the way others perceived individuals with autism. This change in perception can facilitate change at subsequent levels.

Thus the good practice guidelines proposed by Jones et al (2006) and Charman et al (2011) echo those proposed in the SEN and Disability Green Paper (DfE, 2011) and conform to a bioecological model of human development. There is growing evidence (NfER, 2010) to suggest that careful implementation of such guidance could assist those children and young people with autism to develop both personal and social capital, and therefore it is useful to consider how such guidance translates into working practices and experiences for schools and families of CYP with ASD.

The following section will consider the literature available on parental perspectives of inclusion, and will examine the relationship between these perceptions and the impact of guidelines and policies on meeting the needs of children with autism.

2:6 Parental perspectives on inclusion

Within the literature there are a number of studies which examine the views of parents in regard to inclusion. Studies pertaining to parental views of inclusion for children with general additional educational needs in mainstream schools indicate there is a lack of consensus about inclusion and the benefits it may or may not bring. Some studies (Bennett, Deluca & Bruns, 1997; Miller et al, 1992; Seery et al, 2000) indicate that parents view inclusion favourably, seeing inclusion of their child in mainstream setting as beneficial. However even within these studies there is acknowledgement of parental concerns about some aspects of inclusion, most typically relating to a lack of confidence in professional knowledge and skills.

Other research (Green & Shinn 1994; Fox & Ysseldyke 1997) suggests parents view inclusion negatively and see no merit in inclusion; whilst other accounts suggest it is only of benefit when a child attends a mainstream setting part time (Kasari et al, 1999).

Runswick-Cole (2008) suggests the views held around inclusion are complex, and that parental acknowledgement of the benefits or limitations of inclusion are constructed by the model of disability which they hold. Runswick-Cole (2008) argues that if parental models of disability locate difficulties within a medical model, confining disability to the individual, parents are likely to view inclusion differently compared to parents who view disability within a social model which locates disabling influences on a child's development within the attitudes held by society. However Runswick-Cole (2008) warns that "parents' choice of school is not only influenced by models of disability, but the choice of school, in turn constructs the model of disability" (p.179).

As such Runswick-Cole (2008) suggests, the typology of parental views on inclusion falls into three broad categories:

- those parents whose will accept nothing but mainstream schooling;
- those parents who are committed to mainstream schooling, but later change their minds; and
- those parents who never consider mainstream because they want their child to go to a specialist school.

Thus a starting point for discussion is to consider research pertaining to parental views of inclusion; in the first instance positive views of inclusion.

Leyser and Kirk (2004) sought to understand the bases for parents' views of inclusion. Via their analysis of responses (437) to a questionnaire survey, they identified that parents' view of inclusion appeared heavily influenced by the severity of their child's need: the greater the severity of need, the greater their support for inclusion. These findings appear counter-intuitive as it might be expected that parents with children with the highest needs would want increasingly specialised provision. Leyser & Kirk (2004) suggest the reason for the different levels of reported satisfaction was dependent upon a number of variables. They report that if a child was in a specialist placement, parents were more likely to view inclusion positively, suggesting there is a gap between the ideology or philosophy of inclusion and the actual reality of day-to-day practice of inclusion.

It was also noted within this study that parents of younger children gave stronger support for inclusion, although this support dwindled as the children grew older. Leyser and Kirk (2004) suggest the concerns about inclusion as the child gets older relate to social isolation, negative attitudes held by staff and peers and the quality of instruction appropriate to the child's skill level.

Leyser and Kirk (2004) further suggest the reported positive and negative parental views for inclusion were not solely influenced by the level of need or age of the child but, also by the education achievements and occupation of the respondent. They found parents who were more academically qualified were more negative about mainstream provisions and practices, suggesting that more highly educated parents brought a greater knowledge and understanding of the education system and insight into their child's needs (Runswick-Cole, 2008) which better enabled them to evaluate provisions as informed consumers/ service users.

Batten (2006) contests these findings and suggests that 'pro-inclusion' views might not be related to parental educational status or philosophical stance; rather, they argue, positive attitudes could relate to ease of access to competent specialist support within mainstream provisions. Experiences from my own practices provide a different explanation for parental views on inclusion. It appears that some parents value inclusion because they are yet to reconcile the difficulties of their child with their hopes and expectations and as such, by placing the child with significant needs within a mainstream setting they are able to fulfil these hopes and expectations, (or at least, defer acknowledgement of the full scale of their child's difficulties), thereby normalising their child (Landsman, 2005). Indeed Connor (1997) proposed that a parent's choice of mainstream schooling may often be based upon the stage of the grieving process and 'denial' about the child's level of difficulties.

Another possible explanation for the different levels of satisfaction reported by parents about their child's experiences of inclusion in mainstream education could arise from the different expectations parents assign to professionals. Jindal-Snape et al, (2005) also suggests that parents' views of inclusion relate to their belief that a teacher's knowledge will be important in his/her ability to identify a child's learning needs, and, in turn, meet those needs. Jindal-Snape et al, (2005) argue this belief, which underpins parental understanding and expectations of the professional 'expert', may be disproportionate to the reality. It is this mismatch between the belief system and reality, which could result in an individual professional being identified as lacking knowledge, and in turn, inadequate in meeting the needs of the child, rather than examining the system which constructs professionals as

'experts'. Indeed Elkins et al (2003) argued a few years earlier that a "successful system of inclusion requires that the community believe in the competence of the education system to meet the needs of all students. Parents especially have to have confidence in the capacity of the schools to understand and effectively educate their children with special needs" (p.123).

Leyser & Kirk (2004) warn that, whilst there appear to be mixed responses from parents regarding inclusion, many of these responses and identification of practices which are deemed to facilitate inclusion should be treated with some caution as much of the available data is limited to parents whose child/ren were in primary education.

Not surprisingly other research has also sought to understand parental experiences of inclusion for children with general SEN in secondary provisions. Jenkinson's study (1998) investigated factors influencing parents' choice of secondary school placement for their child with special educational needs. Using questionnaires and surveying 193 parents from a parent support group, Jenkinson reported that parents identified aspects of provision which were important factors that influenced their choice of school (this would be echoed later in the 2004 Leyser & Kirk study). These included specialist resources, curriculum, socialisation, school environment, and professional consultation and advice. Data from this study indicated a trend for students to move from the mainstream to special schools as secondary education approached. Jenkinson (1998) suggested parents chose to move a child from mainstream education to specialist placement at secondary transfer because they perceived the academic gap widened as children grew older and their child needed a curriculum which focuses upon independent living skills. Jenkinson argues that in order to address this widening gap, parents believe a special school can offer the level and quality of attention the child requires by having access to small classes and staff who have specialist training. Runswick-Cole (2008) supports this notion, suggesting that parents don't have a change of ideology about inclusion: rather the desire to move from mainstream to specialist provision is in response to the experiences of their child's increasing exclusion in mainstream schools.

A review of the studies cited above suggests there are some consistent themes across the literature in relation to what parents want for children with general SEN (Leyser and Kirk, 2004, Jenkinson, 1999). Prominent themes that emerged for parents in relation to their perception of indices of successful inclusion included positive transition experiences, a sense of personal safety, positive attitudes of the other students, the quality of learning programmes in school, and transport. It is evident that these aspects of successful inclusion have not always been available to children with general SEN. However given that much of the early policy/ legislation intended to promote and support inclusive practices (Education

Act, 1996; DfEE, 1997) provided limited guidance about how practitioners would achieve inclusive practices, it is not surprising that many schools fell short of the desired indices for effective inclusion. More recently there have been improvements in guidance and policy to facilitate inclusion (as discussed in Section 2:5) particularly for children with general SEN needs; however, what about inclusion for children with an autistic spectrum disorder?

2:6:1 Parental views on inclusion for children with a diagnosis of autism

Whilst research regarding parents' views on inclusion for children with general SEN suggests inclusion has some positive benefits (as discussed above) other research (Mesibov & Shea, 1996, Jenkinson, 1998) suggests that there is little evidence that inclusion is appropriate for all pupils with autism.

Kasari et al's (1999) study examined parental perceptions of inclusion for children who had either Down Syndrome or a diagnosis of autism. The study aimed to explore whether the perception of inclusion was viewed differently by the parents from these two specific groups.

Kasari et al (1999) noted parental values, aspirations and perceptions were influenced by the age of the child, the type of educational placement the child attended and the diagnosis/condition the child had. Whilst the majority of parents of children with Down Syndrome indicated they were generally 'pro-inclusion', over two thirds of the parents of children with a diagnosis of autism were against inclusion, citing concerns about the larger child-to-teacher ratio in the mainstream classrooms and concerns about the social rejection the child might experience. However, they found that the parents of children with autism were more positive about inclusion and likely to endorse mainstream education alongside "general education students" if they had access to an additional ASD-specific resource base to facilitate a consistent part-time placement with mainstream peers. This integrated approach to mainstream placement appeared to be a preferred option as it provided access to both specialist support and access to typically developing peers. Interestingly however, whilst parents assume this 'shared' placement provides their child with the appropriate support and access to positive role models from typically developing peers, OFSTED (2004) found that children with special educational needs attending mainstream provisions with units have limited opportunities to interact with their mainstream peers.

Further research specifically examining the experiences of families and CYP with autism was undertaken by Whitaker (2007). Whitaker (2007) was one of the first researchers, since the introduction of new policy and guidance for children with autism, to focus upon parental experiences and satisfaction with inclusion for children with autism in mainstream schools.

He sent out 350 questionnaires to the families known to Northamptonshire Children and Young People Autism Service to ascertain their experiences of inclusion in mainstream schools. Prior to exploring the findings, it is noteworthy that such a methodology has its limitations; not all children/ people with a diagnosis are recorded on service/local authority data base systems, as individuals might opt out of having their data recorded by declining services available to them. Furthermore, it is not clear from the study how individuals appeared on the databases: if the identification of families was determined by their current access to specific services, the data obtained might have been limited to the experiences and views of the most needy. Nonetheless, in other regards, the study was comprehensive in its remit, and is clearly reported.

Whitaker (2007) reports just below half of the questionnaires were completed and returned. He undertook a thematic analysis of responses which indicated a good number of parents were satisfied with inclusive practices when schools were perceived to understand the individual child's needs and make adjustments accordingly. It was noted that parents reported increased levels of satisfaction when they felt there was good reciprocal communication between school and family. Whitaker (2007) found that whilst parental responses indicated that children's learning needs were considered by parents to be typically addressed adequately, a good number of parents reported concerns about the school's role in promoting their child's social development and relationships, and the social isolation their child might experience, as noted in the Kasari et al (1999) study.

It appears concerns about social isolation are significant for many parents of children with autism. This is perhaps not surprising, given the child, by virtue of their diagnosis, will have impairment in their social functioning and may be vulnerable to either removing themselves from social situations because they find them stressful /anxiety-provoking or because they lack the social instinct that prevents them from mixing with others and parents hold their child's emotional well-being as paramount importance to them (Leyser & Kirk, 2004).

Jones et al (2009) revisited the issue of parental views on inclusion. However, unlike previous research, Jones et al (2009) examined parents' experience of support and access to educational provision which in turn facilitate inclusion. The aim of the research was to identify challenges in educating children with autism, examine the information and support given to parents, and make future recommendations. Information held on educational databases across Local Education Authorities was used to identify possible participants. Questionnaires were sent out to parents of a child with a diagnosis of autism from across the

UK. Responses were received from parents of 24 girls and 149 boys and represented a range of children from different phases of education and age at time of diagnosis.

Jones et al (2009) report that from the respondents, 34% of parents surveyed indicated they had a great deal of knowledge about autism and services available; whilst 53% reported they had 'quite a lot of knowledge.' When asked about access to specific services for families of CYP with ASD, 61% of parents reported having attended support groups. It is possible that this number does not capture the actual level of support available to families; it only highlights the uptake of these services. However this figure could equally reflect a lack of service availability, where a significant minority of parents were unable to access support despite there being a need. As such the figures need to be interpreted with some caution.

Jones et al (2009) also explored families' experiences of education. This aspect of the study can help us to understand how and why parents hold specific views on inclusion. When asked, 88% of respondents reported a positive relationship with school staff. Whilst this figure suggests the dialogue between school staff and families is generally good, this interpretation is qualified by the expressed concerns raised by parents about their ability to make requests of school staff without jeopardising relationships. It appears that parents strive to maintain a balance between active advocacy to ensure their child's needs are met and making sensitive allowances for what they can 'reasonably' expect a school to provide. It appeared, however, that whilst parents report generally positive relationships with school staff, their level of satisfaction with other services and support available is low. Parents reported a less favourable relationship with the Local Authority, with just over half of parent respondents (55%) reporting frustrations in securing provisions and being listened to. Parents considered that they had a better understanding of their child's needs than did the Local Authority professionals in many cases, so that, from their perspective, if Local Authority staff did not listen to parents, this potentially relevant information could not be harnessed to the benefit of their child. Armstrong (2005) argues that, whilst parents have been afforded the right to be consulted about their child's education via EPSEN policy (2004), the consultation process can be ineffective, as there is a relatively high percentage of disputes between Local Authorities and parents, as evidenced by the number of SEN tribunals, which suggests dissatisfaction on the part of a minority of parents of children with an autism spectrum disorder.

The apparent discord between parents and Local Authorities during the consultation process arises from the tensions of parental advocacy to secure resources to address their child's needs and the LA responsibility to reconcile the needs of all CYP within the local authority's

scarce resources. Lamb (2009) suggests that “different definitions of SEN, assessment mechanisms and criteria will align resources differently to the advantage of some and detriment of others” (p.11), and as such, parents may feel their views have not been listened to, creating a sense that parents have to ‘fight’ for provisions (Dymond & Gilson, 2007).

Data from the Jones et al (2009) survey also revealed that parents reported concerns about the training of teachers and their (teachers’) general knowledge and understanding of autism within mainstream schools, despite perceived good relationships. The concerns articulated by parents in the Jones et al (2009) study were also expressed by the teachers themselves. 32% of teachers within the sample reported insufficient knowledge or training in autism and considered that inclusion ‘did not work’. Teachers reported that the viability of inclusion as a model of education was dependent upon the severity of a child’s additional needs. That is to say, the greater the level of complexity of a child’s needs, the harder it was for staff to make adequate and appropriate adaptations to ensure the child was included in mainstream. Such a position creates a tension between what staff report they can do to facilitate the inclusion of children with additional needs (Jones et al, 2009) and what parents of children and young people with complex needs report they want (Leyser & Kirk, 2004), alongside an increasing social expectation for those who have greater severity of need to be included in mainstream schools.

There appear to be two consistent themes which have emerged from the research into parental views about inclusion and some of these have echoed concerns raised by school professionals. These concerns arise from a lack of confidence in the knowledge and the skill set of teachers, and the need for open and effective communication amongst and between educational professionals, including LA representatives and other service providers and parents. In light of these emerging themes, Jones et al (2009) highlight a number of recommendations drawn from their survey, which include a description of the type of practices which should be used in schools to support children’s needs in school as cited in the ‘Good Practice’ guidelines (Jones et al 2009), and research into the needs of parents with regard to staff training needs.

However since the publication of these studies there has been further legislation and policy (The Autism Good Practice Guidance, Jones et al, 2006; Charman, 2011; Autism Bill, 2009) specifically intended to support the inclusion of children with a diagnosis of autism. The impact of this new legislation and policy is yet to be seen, although Lamb (2009) warns:

“It is a mistake to try and claim that changes in how special educational needs have been conceptualised, and policy implemented, over the last century means that we are moving towards an uncontested notion of inclusion.” (p.12)

Indeed school professionals highlight a number of difficulties arising from inclusion, particularly for those with a diagnosis of autism. However, prior to examining the research pertaining specifically to the school staff’s perceptions of inclusion for children with a diagnosis of autism in mainstream schools, it is first worth considering how schools operate and the key factors which can facilitate inclusion.

2:7 School culture and inclusion

Prior to discussing the views of teachers about inclusion, we should first give some consideration to what we intend our schools to achieve. Once we are clear on the intended outcomes of schooling and the purpose of inclusion then we can examine how school professionals can or cannot meet the needs of CYP with autism in line with the inclusion agenda.

2:7:1 The role of schools

Roosevelt (2008) argues that education in the twenty-first century goes beyond the conventional definition of education as “the acquisition of knowledge, the reading of books, and the learning of facts”; rather, the purpose of education is to produce good citizens. Jordan (2008) supports this, suggesting education:

“is the way that citizens are taught the values, understanding, knowledge and skills that will enable their full participation in their community; it is the gateway to full social inclusion. That is why every civilised society gives all its citizens the entitlement of education” (p.11).

Similarly, Runswick-Cole (2008) reported parents identified mainstream schooling as a key pathway to inclusive experiences in adult life. With such views about the role and purpose of education, it is evident we should examine how schools deliver these objectives. One central impetus to the role of schools in developing inclusive societies is educational reform. The implementation of such externally-led reform and change has been and is influenced significantly by school culture (Fullan & Hargreaves, 1992; Hopkins, Ainscow & West, 1994; Deal, 1985; Deal & Kennedy, 1983). As such, it is important to consider how school culture

either facilitates or constrains the change processes and the development of inclusive values and practices.

2:7:2 School culture

The literature relating to school culture is located within the research field of School Improvement and a review of this literature indicates 'culture' has come to represent different aspects of school life depending on how the term is used. Thus a starting point for discussion needs to consider how the term is operationalised.

Glover and Coleman (2005) argue that culture is an overarching concept with two subsidiary areas, climate and ethos. They make the distinction between the three concepts, using 'climate' to reflect objective data, 'ethos' to reflect more subjective descriptors, and 'culture' when these two are brought together within an investigation. Indeed Donnelly (2000) suggests the formal expression of the authorities¹ aims and objectives and prescribed social reality which exists as an objective phenomenon (Hogan, 1984) only defines the concept of 'culture' in part. Donnelly (2000) argues that 'culture' is also the product of informal social interactions and processes that are inherently bound up in the organisation, reflecting the need for both objective and subjective data as a means to understand culture.

Schein (1985), considered as the 'founder' of organisational psychology, and acknowledged authority on organisational culture (although not specifically working with schools contexts) offers a helpful framework to conceptualising culture and identifying the many facets (subjective and objective) that 'make up' culture.

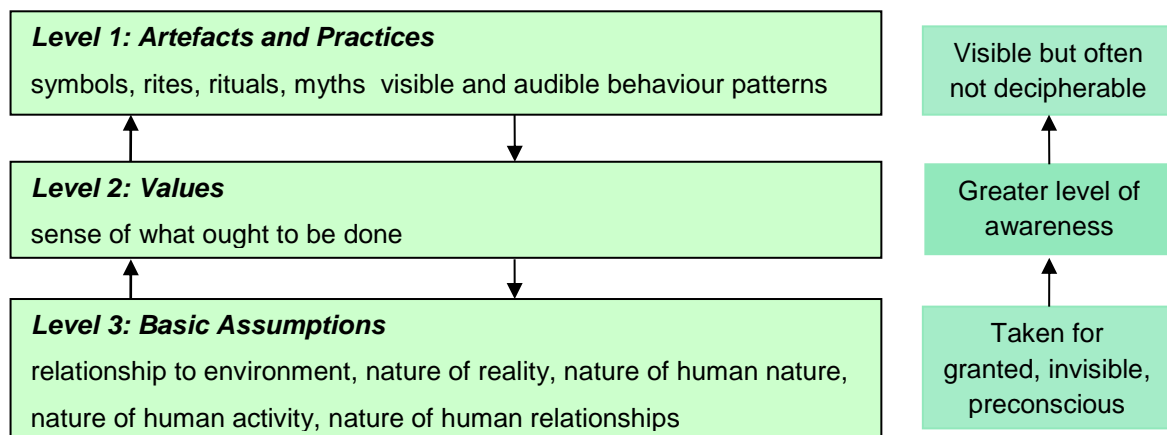
Schein's (1985) model of culture emerged from his belief that groups develop their own culture within an organisation and, that the rules and functioning of the culture often become so 'taken for granted' as to be undetectable to insiders. He (1985) suggests, however, that unless we analyse culture we cannot understand what happens in organisations, why things happen the way they do and why leaders behave in the way they do.

Furthermore he suggests that culture and leadership are two sides of the same coin and that neither can be understood by itself. This leads him to examine ways in which leaders create and sustain culture. Schein's (1985) rationale to understand culture is invaluable when considering how to change systems effectively in schools in order to improve outcomes and performance. His model is offered as a conceptual framework and operationalises the

¹ Authorities is taken to mean the organisational whole

multidimensional facets which are drawn into play when defining culture within organisations (Figure 2:2).

Figure 2:2 Schein's (1985) classification of cultural levels



Here Schein identifies three levels of interaction which are intertwined to form the culture of an organisation. At the first level (level 3) Schein (1985) describes '*basic assumptions*' as the unconscious beliefs that make teachers behave the way they do when carrying out their duties. This includes teachers' perception of the environment within the organisation and of the relationships and activities within the school. It is also influenced by their fundamental values and beliefs: their 'heart sets' and 'mind sets'. This aspect of Schein's (1985) 'culture' reflects the concept that culture comprises a multiplicity of voices with conflicting and competing discourses (McLaren, 1991); those of the unconscious, personal beliefs which may differ from organisational beliefs and practices. Indeed Erickson (1991) argues that this multiplicity of voices formulates a hybrid culture which is made up from groups of people within institutions, so that teachers' and pupils' own experiences and views of the world will impact on the way they interact.

At the second level, *Values*, Schein (1985) argues that teachers' belief about of what is right and good or desirable create their values, which in turn become unwritten rules. For example, a teacher might value and emphasise 'respect for others' as a quality they like others to demonstrate, and this then becomes a behavioural 'norm' within the classroom rather simply than a personal / professional value.

Finally these assumptions, values and behavioural norms become visible as the language, symbols and practices of the school, which are normally informally agreed and socially created and reinforced (Deal 1985). This acceptance of the language, symbols and practices of school life is underpinned by the values of educational leaders in school and again gives rise to concern about whether these values promoted in schools are borne from hegemonic

mainstream societal expectations and values which assume that there is only one way of doing things (Roberts et al, 2011).

Thus constructed culture is multi-dimensional and the values and beliefs of each group within the school will influence and be influenced, by each other. Indeed Fuller and Clarke (1994) argue that it is important for those who try and bring about change, (in this instance, improvements in inclusive attitudes and practices in schools), to recognise the way that local cultures shape and influence the change process. As such we need also to recognise that existing cultures and practices of the school and sub-groups within it can operate as a barrier to change, as well as facilitating change; teachers and pupils can resist change because they do not subscribe to the new 'values' in place, and discrepancies between published policies and the 'lived reality' of members within an organisation could militate against policy implementation.

2:8 School staff perception of inclusion for children with a diagnosis of autism

Runswick-Cole (2008) reports that whilst there has been an accelerated policy drive for children with additional educational needs to be included in mainstream education, there remains a residual belief by a majority of professionals working in schools that inclusion is not appropriate for all children (Croll & Moses, 2004), although there is a greater acceptance of inclusion for children with additional physical needs (Baker, 2005).

A study by McGregor and Campbell (2001) triggered much of the early interest in teachers' perspectives on inclusion of children and young people with autism. 49 mainstream teachers and 23 teachers from specialist provisions across schools and educational parishes in Scotland were asked to complete questionnaires which sought factual information about the teacher's experience and training, and the types of classroom support and forms of inclusion in place. Additional questions sought the teacher's attitudes and opinions to 'integration'. From the sample, 22 teachers indicated prior experience of working with children with autism and 27 teachers indicated no previous experience of working with children with this diagnosis.

McGregor & Campbell (2001) found a minority of respondents believed children with autism should be integrated where possible; suggesting that a majority of respondents did not believe children with autism should be included in mainstream schools. When these views were examined further, respondents cited a lack of appropriate staff training and confidence in their ability to meet the needs of children with autism as factors which presented barriers to successful inclusion. Whilst teachers reported concerns about their confidence and

competencies to meet the needs of children with autism, it is plausible the reluctance to include these children in mainstream classes arises from concerns about the academic skills set of this particular SEN group. Many children with a diagnosis of autism present with 'spiky' academic profiles and therefore might not be able to achieve learning outcomes or test scores comparable to their peers, resulting in depressed academic levels below national targets (Dyson & Millward, 2000; Cole, 2006). As schools are frequently measured against these national standards, teachers and school managers might oppose inclusion because of the perceived detriment effects on academic results (Dyson & Millward, 2000).

McGregor & Campbell (2001) also reported that the majority of teachers expressed concerns that the presence of children with autism may have a negative impact on other mainstream pupils because the bustle and unpredictable classroom environment could distress or confuse a child with autism. They indicated teachers felt it was difficult to accommodate the different learning styles required for many children with ASD and such accommodation might affect the learning opportunities of others. Furthermore they acknowledged that owing to their difficulties many children would require specialist teaching support at intervals throughout the day, and that the nature of this support would, in itself create a different type of segregation (Mesibov & Shea, 1996).

One year on and with no adjustment to policy, Barnard et al, (2002) also sought to understand teachers' experiences and views on inclusion of children with autism in mainstream school. A questionnaire survey was sent to five English and Welsh Local Educational Authorities. A total of 373 questionnaires were completed and returned, which represented a total pupil population of 132,646. Upon analysis it was apparent that, on average, 1 in 86 children had an educational need related to an autism spectrum disorder. Further analysis of the data indicated there were more children with a confirmed diagnosis in primary schools than in secondary schools. The higher numbers of children with ASD in primary provisions could either reflect the growth in the number of children receiving a diagnosis which had yet to filter through the educational system, or it could reflect the discrepancies between practices and organisational arrangements within secondary and primary establishments, which differentially facilitate inclusion of children with ASD, as noted by Jenkinson (1998).

With the growing numbers of children with autism in mainstream schools, it is not surprising that Barnard et al (2002) report teachers voiced concerns about the lack of specialist external support. The 2,658 teachers consulted across England, Wales and Scotland as part of Barnard et al.'s (2002) study considered that pupils with autism were not receiving the

support they needed to enable them to fulfil their potential at school. Respondents identified difficulties with teacher training, citing concerns about the extent of teachers' specific training in autism. Indeed more recent research conducted by NfER (2011) on teacher training on autistic spectrum disorders indicated continued concerns about the training experiences of mainstream teachers. 60% from a sample of 786 secondary school teachers indicated they had not received any training compared to 51% of primary teachers (sample of 989). Whilst there appear to be inadequacies and a lack of appropriate training, respondents within both studies recognised that improvements to inclusive practices in schools could be achieved with external support and resources from the Local Authority. Ironically this support has since dwindled in response to austerity measures at government and local authority level.

A study by Humphrey & Lewis (2008) examined the inclusion agenda further. Humphrey & Lewis's (2008) study, funded by Manchester Research Support Fund, sought to ascertain the effectiveness of inclusive education for children with an autism spectrum disorder. They looked at what barriers prevented the inclusion of ASD CYP in mainstream schools and how these barriers could be overcome. They also looked at the practices within mainstream schools which facilitate or constrain participation. Another aspect of this research addressed how key stakeholders perceived the inclusion process.

The research design utilised a multiple case-study design within a broad ecosystemic approach (Upton & Cooper, 1991) with four mainstream secondary schools in the northwest of England, to examine the several environmental systems which influence interactions (Bronfenbrenner, 2005). Humphrey & Lewis (2008) sought contextual information from each school, including the number children with an ASD diagnosis on roll, SEN status of children (whether School Action, School Action Plus or Statemented), the demographic information about the school and a review of existing SEN practices in order to identify their four target schools. 19 pupils with a diagnosis of autism aged between 11-17 years were identified to take part in the study. Data were obtained via interviews with students and staff, observations during classroom-based activities and free time, and a document analysis of school policy.

Having collected data, Humphrey and Lewis (2008) undertook a pragmatic content analysis (Mayring, 2004). Through categories derived from the research questions, one-quarter of the data was analysed and the categories revised. The remaining data were analysed using the revised categories. Humphrey & Lewis identified patterns within schools and across schools from pupil responses from which they argue there are a number of factors which either facilitate or constrain successful inclusion of children with autism in mainstream provisions.

These include: 'the school ethos and commitment to learning', 'communication and inclusive practices' and 'responsibility for student learning'.

Humphrey and Lewis (2008) argue, consistent with other literature (Booth & Ainscow, 2002), that the school ethos had a significant impact upon how guidance and policy are implemented and followed. They found some pupils were physically present in a school, but were not included in all aspect of school life. This level of inclusion and acceptance is found to be related to the head teacher's views on inclusion. Humphrey & Lewis note that when the head teacher promoted and valued diversity and placed less emphasis on academic performance, school staff felt supported and reported being more able to meet the needs of their pupils, thereby holding a more positive view about inclusion. Humphrey & Lewis (2008) also noted that when 'top-down' support for an inclusive ethos was not in place, many staff appeared disaffected or ambivalent, as noted also by Carrington & Elkins (2002).

Another aspect of school practices identified as either a supportive or constraining factor was the quality of general communication and communication between professionals and families, and between different professionals. This aspect of Humphrey & Lewis's work (2008) echoes findings from Jones et al's (2009) study which recognised parental satisfaction was linked to the quality of relationships between themselves and staff. When parents reported there was effective dialogue between and amongst families and professionals, inclusion was viewed more favourably. Parsons et al (2009) found a similar situation in their study, an online survey examining the views and experiences of parents of children with autistic spectrum conditions, compared to the experiences of parents of children with other disabilities. Both studies demonstrate that parents, on average, indicated positive levels of satisfaction in the level of support provided to their child. However, further analysis indicated when parents had made a request for school staff to change the provision available to their child, the level of satisfaction decreased, with a shift from feeling instrumental in decisions and processes surrounding their child, to reporting less agency in such decisions. This suggests the level of parental satisfaction is reliant on the quality of the relationship between school staff and the parents, and the extent to which parental concerns and suggestions are demonstrably heeded and acted upon.

Humphrey & Lewis (2008) also report there are a number of different aspects of current practices within the schools constraining the inclusion of children with SEN in mainstream schools. In common with earlier research (McGregor & Campbell, 2001; Barnard, 2002) Humphrey & Lewis (2008) found teachers reported concerns about differentiating work for the volume and variety of SEN within a mainstream class. Jordan (2008) raises concerns

with the way work is differentiated or changed to accommodate children with ASD. She argues that the model of 'breaking down' curriculum content into smaller steps is not appropriate for children with ASD, as they have different development and learning patterns, and as such would, in many cases, benefit from a different curriculum. Currently this is not available for many children with ASD in mainstream classrooms and to facilitate their access to learning and inclusion increasingly these students receive Teaching Assistant (TA) support, which presents with different problems. Analysis in Humphrey & Lewis's (2008) study indicates the communication between TAs and teachers was not always effective, and many TAs, in turn, reported they became the adult responsible for the 'adjustments' required for the child to access learning. The findings indicate that under these circumstances where a child has access to one-to-one additional support, teachers were less likely to take responsibility for making adjustments, suggesting difficulties in the execution of differential professional responsibilities for a child's learning, and indeed non-compliance with the SEN Code of Practice (DfE,2004). Furthermore Blatchford et al (2009) reported that pupils who received the most support from TAs made less progress than similar pupils with less TA support; in this regard therefore, there is a clear risk that so that children with autism continue to be disadvantaged compared to their typically developing peers.

Symes & Humphrey (2011) confirm Humphrey & Lewis's (2008) findings in their more recent study which sought to identify school factors which facilitate or hinder the effective support of pupils with autism. Interviews with 15 TAs from four schools indicated that at times TAs feel teachers display a lack of understanding of the needs of pupils with autism, which made it difficult to support the child. Symes & Humphrey (2011) also note that TA respondents reported teaching staff sometimes did not know how to differentiate the work at an appropriate level. It is possible that these difficulties with differentiation arise from insufficient training about autism, lack of training and/or experiences in setting work for children working significantly below expected academic levels, and/ or a lack of knowledge about the needs and capabilities of individual students.

From the literature reviewed so far, there appear to be two consistent themes which have emerged from parental and school professionals' views on inclusion. These themes indicate there are difficulties in securing appropriate education within mainstream schools for children with autism arising from the lack of confidence in the knowledge and skill set of teachers, and the need for open and effective communication amongst and between educational professionals and parents.

A review of the literature so far has centred on the views of parents and school staff, and experiences of inclusion for children with a diagnosis of autism. Whilst the literature has provided some insight into the processes and factors which facilitate and pose barriers to inclusion, there has also been growing interest in how other agencies work together to address the needs of the autistic child and family holistically.

2:9 Inclusion facilitated by services for families and CYP with ASD

In the following section the literature pertaining to support services, including statutory services, will be examined. Consideration will be given to experiences of service users and models of service delivery to support families of children with autism.

Earlier research (Feinberg & Vacca, 2000) suggests there is a great deal of variation in the type of provisions available to families, often with a child in one area or school receiving a different type of provision to a child in a different locality. Feinberg & Vacca (2000) argued that to avoid these situations, service providers have to make careful decisions about the use of finite resources and suggested models of service delivery should consider the;

- level of expertise of staff;
- type and amount of service required; and
- how services will be coordinated.

Whilst this systematic approach to service delivery appears necessary, the North West Training and Development Team (2006) argue that many services have reconfigured to ensure they address the 'Every Child Matters' (DfE, 2004) policy and the decommissioning/re-commissioning agenda to include private service providers. Such processes have resulted in a finite number (often diminishing in the stringent economic climate of the UK from 2009) of resources being allocated on 'economic' grounds rather than with a view to assuring quality of service provided. Dymond & Myran (2007) suggests that service delivery which is governed by economic factors such as budgetary constraints, rather than needs, result in service users feeling services are limited, unavailable, inappropriate, inaccessible, and difficult to obtain (Whitaker, 2002; Little, 2003), and becoming stressed by the process of 'fighting' for their child's entitlement. Indeed Dillenburger et al (2010), echoing concerns raised in the Lamb Enquiry (2009), found a number of difficulties in the way services are offered to families, and acknowledged these difficulties contributed to parental stress.

Dillenburger et al (2010) looked at the stress experiences of parents of autistic children in relation to their access to provisions for their child and the child's perceived future needs.

Using two questionnaires, the Family Autism Needs Questionnaire (FAN-Q), which sought age demographics, parental demographics, access to current provision and future needs; and the Professional Autism Needs Questionnaire (PAN-Q) which looked at professionals' perceived impact of ASD children on families, they were able to identify a number of factors outside of the immediate family environment which increased parental stress.

For example:

- 42% of parents reported they had not been notified of universal statutory services available to all;
- respondents representing both parents whose child attended mainstream school and specialist placements indicated concerns about professionals from health, social care and education having sufficient skills and abilities to meet the needs of their child;
- professional groups and parents reported a need for increased support, information and training about autism; and
- parental need for advocacy.

The authors conclude that effective communication between professionals and parents was an important factor affecting parental confidence/ satisfaction with the educational opportunities available and treatment of children with a diagnosis, as discussed earlier. They also report that whilst multi-professional support is important for parents, they concluded that the more professionals were involved in supporting the family, the higher parental stress. Interestingly the Common Assessment Framework (CAF) which was introduced as part of the 'Every Child Matters' policy (DfE, 2004) to provide a shared assessment framework for use across all children's services to help early identification of need and promote co-ordinated service provision, appears to have limited impact on participants in the Dillenburger et al's (2010) study. A possible reason for this could be that while parents still have a high level of professionals involved, and professional support might be co-ordinated through one lead professional(as required by the CAF), they might still be required to attend multiple meetings and appointments. However the North West Training and Development Team (2006) suggested a few years earlier, experiences like those described above can be avoided if public bodies are clear about what families should expect from a service, understand the number of children needing the service and have a better understanding of the gap between what is being achieved and what is required.

2:9:1 What do service users experience?

In order to understand the experiences of service users a number of researchers (Minnes & Steiner, 2009; Renty & Roeyers,2006; Dymond & Myran, 2007) have examined what parents valued about current services and what they perceived they needed.

Minnes and Steiner (2009) report a number of difficulties with the quality of service delivery in their study. They used parent groups to ascertain families' experiences of statutory support and care systems for children whose needs fall within three distinct SEN groups (children with autism, Down Syndrome and Fragile X syndrome). Using semi-structured group interviews they investigated the perceptions and experiences of negotiating and obtaining healthcare services for families with children with SEN.

Data for all three SEN groups investigated indicated a similar pattern, with parents reporting concerns about the professionals' knowledge and skills. Parents of children with Fragile X were particularly frustrated by difficulties with health professionals' knowledge of Fragile X, lack of interest in learning about the condition and a series of mis-diagnoses. This group of parents emphasised that they wanted access to parental advocacy services. This view was shared by the parents of children with a diagnosis of autism. Responses from parents who had a child with autism indicated that they believed there were increased chances of their accessing services if their child had a diagnosis; they saw health practitioners as 'gatekeepers' to such services. This perception of 'restricted' access to services without a diagnosis cemented parents' perceptions that they required better and improved parent advocacy. Indeed a recent consultation on SEN practice in the UK, 'Support and aspiration: A new approach to special educational needs and disability' (DfE, 2011), recognised the need to give parents confidence in the support they receive by giving them more control so that increasingly parents who have limited advocacy opportunities are afforded opportunities to take on this role for their child in more effective ways.

In addition to the concerns raised by parents about professional knowledge, parents of children with autism within Minnes and Steiner's (2009) study reported a sense of loneliness and isolation in the assessment and intervention services available to them. This sense of isolation appears to reflect parental perceptions they have to 'fight' for the diagnosis, and their difficulties ensuring their concerns were listened to and acknowledged. It is also plausible these experiences of loneliness and isolation arise from a lack of acceptance and tolerance by other people in the wider community; perhaps parents experience less social acceptance owing to the nature of the difficulties associated with autism. Indeed Renty & Roeyers (2006) reported parents feared the diagnosis would impact on the level of social acceptance they experienced from others, whilst other SEN groups, such as parents of Down Syndrome children, do not report a similar sense of isolation owing Down children's perceived friendliness (Minnes & Steiner, 2009).

Whilst parents across the three groups highlighted different difficulties with the diagnostic services, there was one consistent concern for each group. In the case of children with a diagnosis of Down Syndrome, professionals regularly failed to see difficulties beyond those physically presented by a child, and missed other health difficulties despite parents raising concerns. Parents with children with Fragile X or autism reported that professionals often made a late diagnosis (as late as a child's third birthday,) despite parents reporting concerns from the age of 9-13 months and 21-24 months respectively.

This research paper highlights difficulties with the level of knowledge and expertise of professionals and echoes many of the concerns discussed earlier in relation to parents' views regarding school professionals' knowledge and skills about autism. It is evident that despite numerous attempts to improve the level of knowledge and expertise of professionals through guidance and legislation, these have not had the desired impact on the experiences of families going through assessment processes, and that currently the majority of services available to families are falling short of what parents need and expect.

Indeed Kohler (1999) highlighted difficulties with the type and amount of services available to families, with parents regularly reporting difficulties securing services (speech and language therapy, respite care, extended schools) where such services are provided by different agencies. This difficulty arises because different services have different eligibility criteria and engage and communicate with parents differently. It appears that such difficulties securing support and services undermines a 'family-centred' approach to support which actively encourages parents to be involved in determining the services needed for their child. Furthermore Kohler (1999) suggests these difficulties in securing services can arise from the mis-match between what parents want and what is available.

Some research has sought to better understand this mis-match. Little (2003) completed a study which provided a better understanding of the types of service delivery available to families of children with autism, and brought greater clarity about what was needed. She completed a survey obtaining 404 responses from mothers who were raising child/ren with Asperger syndrome or a nonverbal language disorder. 52% of the sample of children were educated within a mainstream school placement. Little (2003) asked mothers to identify the resources available to their child, (from a list generated from parental comments, discussion with a paediatrician and a review of existing literature) and to rate the helpfulness of that resource. She found 10 provisions were available to 90% or more of the sample. These included: access to special education teachers, occupational therapist, Speech and

Language therapist/ teacher, medication, family therapy, psychotherapy, church groups, tutor, scouts and education advocacy.

Whilst these services were available to a wide number of respondents, the only service from the 10 consistently viewed as helpful was 'education advocacy'. Respondents were able to identify two other aspects of service delivery which were deemed helpful: smaller classes for main subjects and aid (TA support) in the classroom, both of which were widely available. Little (2003) found that which services which were judged to be helpful were correlated with the age of the child, so that those services which were judged to be helpful in the early years were less helpful as the child got older and conversely, those judged to be unhelpful became more helpful as the child got older. Little (2003) identified the need for services to be flexible so that parents could access different services relative to the child's developmental stage.

Whilst Little (2003) was able to demonstrate parents needed different things from a service at different times, other research looked for greater clarity about the specific functions of services on offer and how these were rated. Renty & Roeyers (2006), researchers from the Department of Developmental Disorders, Ghent University, sought to understand which factors influence parental satisfaction with support for their child with ASD from statutory services in Finland. Prior to exploring this study further it is noteworthy that there are a number of methodological difficulties arising from the use of questionnaire-based approaches which positively discriminate towards those who can write and express themselves by the written word. The sample used within the Renty & Roeyers (2006) study was already known to the researchers and therefore there is a potential bias in the data; for example, respondents might not record their views accurately for fear of reprisals or reduction in services/ support.

Renty & Roeyers (2006) asked parents/carers who attended a diagnostic, assessment and intervention centre in Finland to complete a questionnaire rating their level of satisfaction with the support and education for their child with autism. The level of satisfaction was measured on a 5 point Likert Scale and analysed using a simple t test. Analysis of the results indicated parental satisfaction was linked to the method of communication used between parents and professionals. Data from this study suggest parents preferred face to face contact, particularly as it afforded parents the opportunity to ask questions which could be answered by professionals promptly. Parents also acknowledged that this direct contact provided them with the opportunity to be involved in the process of diagnosis; in turn this involvement ensured greater levels of parental satisfaction.

However, it was also noted that some parents, particularly those who had a child attending a mainstream educational placement, found the professional dialogue with practitioners difficult. Renty & Roeyers (2006) described this professional dialogue as the way information is offered to families about the condition, and about the support available following diagnosis. They noted that a minority of parents reported concerns about the lack of sensitivity of professionals when sharing the diagnosis with parents. This was particularly pertinent to recognising the parents' 'emotional readiness' to understand and accept the diagnosis and what it meant for families. Furthermore a minority of parents of children who attend mainstream provision also indicated they felt overwhelmed by the quantity of information provided, reporting difficulties with the transparency of systems, and understanding schooling options and services available: difficulties which reinforce their sense of isolation (Minnes and Steiner, 2009).

Whilst Renty & Roeyers (2006) identified features from assessment, intervention and support services deemed supportive or unhelpful, they also found parental satisfaction was related to characteristics of the child. Unlike Leyser and Kirk (2004) who reported inclusion was viewed positively when external environmental factors (transition, safety, attitudes of the other students, the quality of learning programmes in school and transportation) were effectively in place, Renty & Roeyers (2006) report the child's characteristics were also influential in how a parent perceived support. They suggest when the child does not present with learning disabilities, parents perceive getting support as more difficult and they have to 'fight' for additional support and resources. It is this perceived fight for resources, parental concerns regarding the extent of difficulty their child experiences and professionals' responses to these concerns that influence the level of satisfaction.

So far the research indicates that parents want to be involved in the assessment process and desire effective communication between themselves and professionals. However Renty & Roeyers (2006) also noted parents desired a service which was timely, with many parents suggesting the time scale between initial consultation and final diagnosis took too long. Parents indicated they wanted professionals to have knowledge of services available and knowledge of the condition, consistent with Minnes and Steiner (2009) findings.

Dymond, Gilson & Myran (2007) also undertook research to ascertain parents' recommendations for improving school and community services. They suggest this research was one of the first studies to invite parents to state not only what is needed from a service, but to identify ways in which services can be improved. Having completed a wide survey (929 completed questionnaires from 3,500) parents with children aged between 2-22 years

(62% were aged between 5-13), they identified a number of recommendations comprising four themes:

- Improve the quality, quantity, accessibility and availability of services;
- educate and train professionals to work effectively with children with autism;
- increase funding for services, staff development and research; and
- create appropriate school placements and education programs for children with ASD.

They found that 62% of respondents were concerned about the quality, quantity, accessibility and availability of services. In this study, parents also reported concerns with the consistency of services available, and that those that were already available needed to improve in relation to the quality of service and/or the amount of service available. Respondents identified 29 different aspects of service which needed improving. Those which were most common included; access to Applied Behaviour Analysis (ABA), respite care, early intervention, transition support, behaviour management, sensory integration and counselling for family members. There were instances where parents reported they could not obtain services they wanted from external providers, and/or that school professionals who could provide appropriate provision were reluctant to embrace educational practices known to be beneficial for children with a diagnosis of autism, such as the TEACCH approach, or use of a classroom assistant to support aspects of school work.

Dymond et al (2007) also found that over half (55%) of parents were frustrated with the knowledge and expertise present in school staff and community service providers, again consistent with Minnes & Steiner (2009) and Renty & Roeyers' (2006) findings. Dymond et al (2007) report that parents felt health practitioners needed more training to understand the condition better and to facilitate a quicker diagnosis. Whilst parents reported a desire for greater 'general' knowledge about autism by practitioners, Dymond et al (2007) also highlighted a desire for better understanding and knowledge about 'treatments' and educational programmes to improve outcomes for children with autism. Dymond et al (2007) found that parents were aware that the type and availability of services, affecting the treatments and educational practices on offer in both the community and at schools were affected by funding constraints, emphasising difficulties with services driven by economic factors which determined resource allocation, rather than a commitment to respond to levels of need (Dymond & Myran, 2007). Despite the awareness of funding issues many parents reported a desire for more one-to-one support for their child, whilst others wanted access to trained professionals who could support the child in the home environment and provide educational programmes in school, such as Options/ Lovaas.

Dymond et al (2007) conclude that models of service delivery need to be individualised, whereby service providers move from a 'system-centred' approach to a 'person-centred' approach to ensure services available to families are determined on a case-by-case level, rather than a generic model 'one size fits all'. Such a model of service delivery would empower parents to be involved in the identification and selection of programmes and service required to meet the individual needs and provide the flexibility to access different services at different developmental stages (as discussed in Little's 2003 study). Such a flexible system would create a great deal of variation in the type of provision available to families, as proposed by 'Support and Aspiration' (DfE, 2011), which aims to provide 'parents with a real opportunity for direct control over support for their family' (p.5), albeit still within a finite budget for which parents may continue to feel they need to compete or 'fight'.

These studies indicate the types of provisions parents of children with autism want, and have gone some way toward clarifying what is valued. However, means to deliver these services is less clear. Dymond et al (2007) suggests that models of service delivery should reflect individuals' needs; however there remains the tension between being flexible and responsive to provide a service that addresses the unique needs of each individual, and the capacity to offer such services within budgetary and staffing constraints. It is noteworthy that these studies cited above have been conducted in America. Many parents involved in these studies indicate they experienced difficulties securing funding from their insurance companies to pay for treatments and interventions because autism is defined as a mental health issue and many of the interventions are located in education. It is possible that parents report the lack of services arises from the funding systems in operation in the States which is not evident within the UK as services are provided through the National Health System (NHS) and statutory services in Education (Educational Psychology Services), albeit again with finite resources and agency disputes re: prioritisation and division of responsibilities.

Unlike Dymond et al (2007), who asked parents for recommendations for an improved service delivery, Rowlandson & Smith (2009) actually implemented a new model for service delivery. They reviewed practices and services available to parents for children with a diagnosis of autism or going through the process of diagnosis on the Isle of Wight. Following an initial survey of families' experiences of service delivery, a number of negative views were reported by parents about the services available to them. These views included a prolonged and fragmented assessment process, lack of co-ordinated care and intervention, lack of co-ordinated intervention between home and school, lack of inclusive

opportunities within the local community and lack of knowledge and understanding by professionals.

In light of these concerns and in line with the National Autistic Society (NAS) National Autism Plan for Children guidance (NAS, 2003) a new assessment and diagnostic pathway was devised. Thus Rowlandson & Smith (2009) undertook a 3 year pilot project aimed at providing an holistic and co-ordinated service for families of children with autism. The project was staffed by professionals drawn from education and health services (Educational Psychologist, Clinical Psychologist, Consultant Community Paediatrician, and Assistant Clinical Psychologist), and was funded by a government grant. Subsequent funding beyond the three year period was to come from health, social care and educational budgets, contingent on evidence of improved outcomes for service users. It should be noted that the researchers were practitioners involved in the delivery of services, and so the evaluation is open to bias as participants might provide responses which they thought the researchers were looking for or which would not jeopardise access to existing services and/or prospects for future funding to support service development. It is also plausible that participants' responses could be influenced by the relationships between themselves and professionals which have already developed through previous interactions.

The new assessment and diagnostic pathway included centralising all ASD referrals within a 'Single Point of Access', developing a mechanism for gathering additional data for the initial referrals (achieved through questionnaires sent out to parents and school staff), and a subsequent 'filtering' process in which referrals requiring two or three services are assessed, to determine the most appropriate next step, whilst those requiring only one service are referred directly to that agency. Assessments were identified via monthly multi-agency meetings and completed by home/ school visits and specialist assessment. Following this assessment, parents were invited to a planning meeting to agree a plan of intervention and support for the family and child/ren.

The pilot project found that involving schools and parents directly in the process of diagnosis and intervention led to better outcomes for the parents and the child. These included the reduction in waiting times, assessment being completed in six months rather than two years, establishment of a system for gathering information about the child across settings and environments and the child's life experiences, and a multi-agency diagnosis linked to a plan for intervention and support for families and the child. Rowlandson & Smith (2009) also report there were improvements in the quality of co-ordination of support for families, school

and home and a consistent approach in the management of ASD. All these changes led to expressions of a high level of satisfaction from parents and schools.

It is noteworthy that a consistent theme has emerged across all areas of the literature reviewed in this chapter, namely the need for change: changes in policy, changes in attitudes towards inclusion, changes in school culture and values, and changes in what parents want for statutory services. However I have yet to discuss how and by whom these changes might be facilitated. One group of professionals well placed to facilitate these changes are Educational Psychologists.

2:10 The role of the educational psychologist

The application of psychology to improve the educational outcomes for the majority of pupils sees a shift away from previous ways of working, where the Educational Psychologist (EP) works with pupils identified with special educational needs, towards working at a preventative level within the context of the whole school. This shift in role enables the EP to apply their knowledge of systems and organisational psychology to support schools in their overall approach to learning and development as identified in the Current Role, Good Practice and Future Directions review (July 2000, p.10)....

“the educational psychologist will be engaged in work which goes beyond the core functions... and it is appropriate for them to be engaged in work which is aimed at improving educational outcomes through the application of psychology”.

This view was recognised in a subsequent review examining the functions and contribution of Educational Psychologists in England and Wales in light of “Every Child Matters” policy (DfES, 2004b).....

“Schools recognise that educational psychologists have a complementary knowledge base together with an understanding of school organisation and how schools work” (p.7).

Indeed this extends further with increasing recognition that EPs’ work this extends beyond schools.....

“EPs [are] more centrally placed within community contexts where schools form only one of the settings in which they work” (AEP, 2009, p.7).

The ‘Review of the Functions and Contribution of Educational Psychologists in England and Wales’ (DfES, 2006a) highlighted EPs work at levels of the individual child or family, the school and the local authority and therefore have insight into interconnectedness of these

systems as described by Bronfenbrenner (2005) which suggests no circumstance or event can be viewed in isolation but must be seen as interrelated and connected. As Figure 2:1 illustrates the child is at the centre of the bio-ecological system and interacts with several environments. This forms the child's microsystem in which the child will influence and is influenced by others (as illustrated Chapter Two, Section 5:2).

A review of current professional practices indicates that Educational Psychologists work with pupils with Special Educational Needs (SEN), contribute to multi-agency working and undertake strategic work and capacity building in organisations (DfES, 2006a). It is this understanding and contributions to all bio-ecological systems which makes the Educational Psychologist well placed to provide a constructive and insightful view of school culture and ethos and the relationship and impact it has on other ecological systems. As such EPs are in a position to affect change in communities and the service available to them and school practices. However being well placed is only part of the external change agent's ability to facilitate change. Change also requires the external agent to have expertise and skills deemed credible by those undergoing change as illustrated in Figure 2:3.

Figure 2:3: Strategies for external change agent based upon Georgiades & Phillimore (1975)

- the ability to obtain appropriate support and involvement from key personnel with the capacity to implement change,
- develop a critical mass of people in each setting to implement change;
- provide protection to the setting from stress as it undergoes change which can be achieved by follow path of least organisational resistance
- the ability to identify and work with the 'healthy' parts of the system

Thus, with the legitimacy of educational psychologist involvement in changing attitudes towards inclusion of children with autism in mainstream schools and being well place to facilitate change in models of assessment and intervention services for families of children with a diagnosis of ASD, a methodological approach that utilises both the skills of the EP and incorporates parents' and school professionals views' appears to afford an appropriate way to understand what changes are needed.

2:11 Summary

The messages abstracted from this review of research literature indicates that current policy on inclusion and legislation to protect the interests of children with autism are having a limited impact on the lived reality experienced by both parents and education providers, and contingently, on children with ASD themselves. Many parents report concerns over the quality and type of services available (Dillenburger, 2010, Dymond et al, 2007; Rowlandson &

Smith (2009) citing difficulties with the duration and process of securing a diagnosis, the lack of professional understanding of autism, school staff attitudes towards inclusion and the dialogue between parents and professions. These difficulties have consistently been noted across a number of years, despite legislation and guidance aimed at addressing these issues.

Recommendations for good practice for schools have been available for several years (e.g. DfES, 2005) and more recently (Jones et al, 2011; Charman et al, 2011). Recent research still suggests that schools and those providing statutory services to parents and children with autism are some way from offering them the kind of support they report they need (Dillenburger, 2010). Despite this guidance there continues to be concern from both parents' and teachers'/ professionals' perspectives, in meeting the needs of children with autism in an inclusive way in mainstream secondary schools than in primary and pre-school settings.

The literature review has shaped and informed overarching research questions that stemmed from evidence from research of problems of:

- inequalities in the type and nature of support, in which some children and families receive a high level of support whilst others with comparable needs receive considerably less;
- negative relationships between professionals and families (particularly between professionals and parents/carers); and
- difficulties providing appropriate levels of support following diagnosis to the families as they transfer between agencies, and in maintaining appropriate content and duration of support for parents/carers, particularly as children progress through the education system.

In Chapter Three, I explain the methodological approach chosen in order to address these research concerns.

Chapter Three

Aims, Methods, Methodology and Research Design

3:1 Introduction

Building on the literature review on inclusion and parental experiences of services to support children with special educational needs (SEN) in general, and autism spectrum disorder (ASD) in particular, this chapter discusses research paradigms and methodological practices which are relevant to educational research and applicable to the area of parental and school support for children with autism. The design of the study is then considered, with particular attention given to the justification for the choice of an action research design. Throughout each stage of the design formulation, pertinent ethical considerations are discussed. Data collection procedures are outlined and details of the theoretical framework applied during the data analysis discussed.

3:2 Focus of study

In October 2010 concerns were raised by members of a multi-professional strategic group responsible for developing an appropriate care pathway for families of children who receive a diagnosis of autism within one unitary local authority ('Midtown'). The members of this group represented education, health and social care within the city. In the process of clarifying terms of reference and understanding each other's roles it became apparent that members of this multi-professional group were concerned about unequal levels of support available following diagnosis. It was clear that the content and duration of the support available to parents/carers, varied widely, particularly as children progress through the education system, resulting in some families receiving a high level of support whilst others receive none.

In order to address these concerns, the multi-professional strategic group agreed to investigate service users' experiences expressed through parents'/carers' and schools' 'narratives' about the support received from education, health, and social care agencies. How and what views and perceptions would be obtained were then negotiated through a series of meetings.

The focus of these planning meetings and the outcomes that informed the shape of the research are summarised in Table 3.1. An overview is offered here of the main points of the procedure undertaken during the study, although these processes will be discussed in greater detail in Chapter Four (scoping exercise), Chapter Five (parental questionnaires) and Chapter Six (secondary school interviews).

Table 3.1 Chronology of meetings and their implications

Date / What	Who	What Happened	Implications for next stage / outcome
December 2010 – February 2011 Project Negotiation and Development	Strategic ASD group meeting. Professionals representing the Child and Adolescent Mental Health Service (CAMHS), Clinical Psychology, Educational Psychology, Community Paediatrics, Occupational Therapy Service, Speech and Language Therapy, Social Care Disability Team, Autism Parent Support Group, Advisory Teachers for Autism form the basis of this group.	<p>Awareness and acknowledgement that service provision across disciplines and within services had inequalities and inconsistencies in service delivery.</p> <p>Agreed to seek information re: parental experiences to inform the referral, assessment route and subsequent support/ intervention.</p> <p>Strategic group acknowledged the difficulties supporting educational placements of secondary aged children. It was noted there has been an increase in exclusion of secondary aged pupils who have a diagnosis of autism.</p>	<p>Discussion with multi-agency strategic group to provide wide scoping ideas about the focus of the research. Agreed the focus should be on exploring parents' experiences of the diagnostic process and to gain an improved understanding of secondary school perspectives and needs in supporting pupils with autism.</p> <p>Clarified with University Supervisor the suitability of researching parental experiences of support for their children pre and post diagnosis of ASD and auditing secondary school experiences as a piece for doctorate research.</p> <p>Obtained approval from Head of service to undertake research.</p>
March 2011	I met with EPs and Advisory Teachers to ascertain their perceptions of practices in mainstream secondary schools.	Met with EPs and Advisory teacher to complete a 30 minute informal discussion about perceived school practices.	Data produced from these discussions were compared with findings in the literature.
April 2011	I identified families for initial parent interviews to ascertain their experiences.	Interrogated the Midtown local authority database to identify six families who have received a diagnosis of autism in the past 3 months. Families needed to represent different educational phases.	Obtain consent from Local Authority Data Protection Officer to interrogate the Local Authority data base to identify all families known to have a child with a diagnosis of autism. Parents were identified from a three month period (January to March 2011). There were 21 families; two pre-school, 11 primary, eight secondary. Within the identified families there were 15 boys and six girls. Six families were selected based on educational phase, gender and the perception of the advisory teacher of the families' willingness to share their experiences and participate in the study.

May 2011	I undertook initial parental interviews to elicit parent/carers' experiences of their child's diagnosis of autism.	A sample of parents from six families, which, across the sample, had a child with an ASD diagnosis from each educational phase (pre-school- KS4) were interviewed to gather a narrative of each family's experiences of the assessment and intervention process.	Results of these initial interviews and comparisons between empirical data informed questionnaire design.
June 2011	I constructed and sent out questionnaires to all 223 parents of children with ASD on the Midtown database.	Questionnaire sent to all parents/carers who have a child known to have a diagnosis of autism as recorded on the Midtown database. These included parents/carers whose child attended specialised and mainstream provision across school-age educational phase (Reception- KS4).	42 questionnaires were returned and analysed using Thematic Analysis.
June -July 2011	I wrote to all secondary head teachers and SENCos inviting them to take part in the research and review service provisions and practice for children with a diagnosis of autism.	Letters of invitation sent to all mainstream secondary schools in Midtown. Educational Psychology administration team followed up the letter with a phone call to arrange interview dates.	Interview dates secured from all 14 secondary schools for me to meet with head teacher or member of the School Leadership Team and SENCo for one hour to discuss practices and support in schools.
August 2011	I analysed data from parental questionnaires and secondary head teacher interviews	Collated data and summarised findings	I disseminated findings from the parental questionnaires and secondary school interviews at the secondary head teacher breakfast briefing and parent consultation group so priorities from the findings could be identified.
September 2011	I prepared presentation of main findings for parent consultation group and secondary head teacher meeting	Parents invited to clarify priorities from the data gathered via the questionnaires. Secondary head teachers invited to clarify the priorities from the data gathered via the school interviews.	I shared priorities with the strategic group.
October 2011	I shared findings with strategic group	Presentation of results from the parent questionnaires and secondary school interview and summary of priorities identify by both parent/carers and head teachers.	Strategic group revised action plan for care pathway in light of priorities. STePs revised support available to secondary schools.

This chronology of discussion, planning and action perhaps presents a misleading picture of a neat and unproblematic process of research design and implementation. However, the process necessitated not only careful negotiation with diverse professional stakeholders, and attention to practicality, but also consideration of philosophical and methodological factors which would determine the nature and quality of the research enterprise. Prior to commencing any research, a researcher needs to consider the methodology which will be used in a study. This consists of discarding some methodological approaches in favour of others until a final appropriate research approach and design are confirmed and adopted. Whilst this appears a straightforward process, whereby the researcher selects a methodology guided by what the research intends to achieve, there are more complex processes at play than may first appear. Crotty (1998) argues a researcher has to navigate their way through the different research methods and methodologies available to them, when often there is confusion about even what constitutes a method or methodology. Within the literature some writers describe an approach as a method, whilst others define the same process as methodology. As a result of this interchange, ideas and approaches are not fixed, but are used flexibly to make interpretations of the world. Crotty suggests the researcher can navigate their way through the interchangeable terminology and research concepts by considering:

- epistemology (the study of the theory of knowledge);
- theoretical perspectives (the philosophical stance behind the methodology);
- methodology (the overarching research approach); and
- methods (the actual tools used to collect the data).

3:3 Ontology, epistemology and methodology

Researchers need to consider the nature of ontology and epistemology prior to embarking on the research design, as these philosophical factors greatly shape a research design. Ontology is concerned with the theory of being; the question of 'what constitutes knowledge', whilst epistemology is concerned with the pursuit of knowledge and seeks to distinguish between knowledge and non-knowledge in regard to the world or reality. If a researcher gives a stronger weighting to one of these philosophical standpoints, seeking either to identify knowledge or distinguish between knowledge and non-knowledge, then the chosen research questions will produce different responses. As such ontology and epistemology are interconnected: the ontological and epistemological assumptions made about knowledge and non-knowledge influence which paradigms are used to organise research.

Gadamer (1975) argues that an individual's pre-understanding of social, cultural and political phenomena defines their view of "what is 'worth' knowing, and therefore points research in a certain 'worthwhile' direction. This suggests that knowledge is not objective and that researchers make a value judgement about different types of knowledge. Kuhn (1970), meanwhile, suggests that typically knowledge is produced within 'communities' and that these communities display different social, cultural and political values which are used to validate or refute knowledge claims. It is this validation or dismissal of knowledge claims which gives rise to the criteria determining what constitutes knowledge and provides the distinction between knowledge and non-knowledge. Furthermore Kuhn (1970) argues that when knowledge cannot be validated within existing values, individuals seek to find alternative solutions to a problem. Kuhn (1970) suggests this pursuit of an answer has seen different paradigms emerge as communities seek to find solutions to problems which cannot be validated within the existing assumptions and values which operate within that community. A researcher's study choice will therefore be shaped by the community. This gives rise to the question about what communities' value and how what is valued actively shapes the research focus. Thus research becomes more than representing, reflecting or reporting on the world, but 'creates' a representation of the world based upon the social values which validate knowledge claims. Usher (1996) argues that because this knowledge is located and sanctioned in communities which operate theories of knowledge and reality of the social world, there are inherent epistemological values which cannot be ignored. Therefore a researcher needs to consider what kind of reality/knowledge is being constructed by the questions asked within the research and the methods used (Usher, 1996). If the social researcher assumes a position that knowledge is achieved through observation, where the researcher is external to the research process, these assumptions will be significantly different from those who adopt a standpoint which positions the researcher's subjectivity as integral to the research.

3:4 Hermeneutics

Hermeneutics is a position which assumes human activity has meaning and that this meaning provides insight, understanding and knowledge of the social world. For some, hermeneutics embodies a notion that knowledge is 'out there' waiting to be investigated objectively (Bleicher, 1982 p.52). While for others, particularly those assuming a postmodern position, hermeneutics is a means of providing understanding and knowledge of the human world through socially and culturally constructed concepts (Madison, 1990). Giddens (1982) argues that hermeneutics pertaining to social science research is concerned with more than just knowledge of a phenomenon; rather, it encompasses an understanding of what people do, and how people understand their world, but also recognizes that an individual's

understanding of 'their world' is not static but continually shaped and revised in light of new information, experiences and thinking. As such, individuals gain insight into their world but also provide insight into themselves. He describes this examination of human meaning as 'double hermeneutics'. This concept of 'double hermeneutics' is important to the researcher because it acknowledges the researcher is instrumental to the knowledge-making process, rather than an objective commentator, not least because the researcher brings a pre-existing understanding of the world which shapes the questions asked and the 'interpretation' process. This process of interpretation is thus inescapably governed by the researcher's own set of values, beliefs and assumptions. Indeed Ferguson et al (1992) suggest the researcher should be aware that.....

“as soon as we, as researchers, become involved in telling our stories of their stories, we present our interpretations of their interpretations. Not only are there multiple perspectives, then, but there are multiple layers of perspective as soon as one enters the reflective process of research. (p. 299).

Usher (1996) considers this further, suggesting that 'personal reflexivity', the term he uses to refer to the researcher's identity and characteristics, makes individuals select research which derives from an expression of personal interest and values, resulting in the researcher excluding other potential interpretations of knowledge and constructing knowledge from their own frame of reference and self-understanding.

Whilst in previous years, within 'traditional' positivist, experimental research, the researcher's identity has been seen as a contaminating influence on the research process, since the postmodernist movement, the researcher's identity is accepted as a resource, provided that researchers are aware of their bias, thereby ensuring a greater understanding when offering an interpretation of the knowledge they construct through the research process.

The interpretation and understanding of knowledge is shaped further by the theoretical paradigms which underpin the researcher's understanding and interpretation of knowledge.

3:5 Theoretical perspectives

3:5:1 The positivist paradigm

Positivism originates from the study of natural sciences where 'truth' can be established by uncovering laws and relationships which govern how features of the natural world behave and interact. The positivist paradigm assumes that a scientific approach can obtain objective

knowledge by separating facts from values. The use of strict rules governs the experimental process and produces a very controlled, 'clinical' approach to understanding the world (Cohen et al 2000). The application of the positivist paradigm to the natural world is generally considered uncontroversial; however, when this approach is applied to the social world, debate surrounding its suitability begins. The positivist approach assumes the researcher is separate from the research process and their role has very little influence on the research process or people involved. However, critics of positivism argue that such values fail to take into account that 'people are not just elements but social persons, acting individuals with their own wishes, perceptions and interests' (Robson 2002, p.23). Positivism assumes that the highly controlled approach used in natural science can be used to understand the social world. However, critics of this approach argue that the social world is not a phenomenon that can be measured objectively; rather it is something that is constructed in people's minds, and so needs to be defined and studied more subjectively (Cohen et al 2000).

As the current study is an exploration of parental and school professionals' experiences it is naturally positioned within a constructivist paradigm.

3:5:2 The constructivist approach

The constructivist paradigm, also known as a naturalistic or interpretative approach, believes that people actively construct their social world (Becker 1970), and that the social world should be studied in its natural state without the researcher intervening or manipulating the environment (Hammersley and Atkinson 1983). This paradigm acknowledges that there will be multiple interpretations and perspectives on situations and events and it is the researcher who must reveal these multiple social meanings and forms of knowledge constructed. Within this paradigm, it is held that the most effective way to elicit understanding of the constructed world is through the eyes of the participant (Cohen et al 2001).

Alongside the participants' multiple interpretations of situations, as discussed earlier, the constructivist view supports the assumption that the researcher's interpretation is not objective. Denzin (1989) suggests that 'all social researchers take sides and evaluators are no exceptions' (p.57). By the very nature of her subjective interpretations, the role of the researcher is constructed, enabling a responsive and dynamic interaction with 'the researched' within the contexts which form the focus of the research. This approach maximises the wealth of data collected, in contrast to the static and pre-defined positivist approach. Information that is gathered is best interpreted via an iterative process in which the respondents share their interpretation with the researcher. The researcher clarifies what

has been said and seeks to develop a shared meaning and interpretation. Here hermeneutic assumptions enable the researcher to 'create' a shared interpretation with those of 'the researched'.

However, there are difficulties with the quality, authenticity and trustworthiness of the 'created' interpretations, primarily because this 'construed' view of the world is reliant on a reciprocal interchange between the researcher and the respondent. This reciprocal exchange enables the researcher to position herself whilst being positioned by the participants (Bogdan & Biklen, 1992; Denzin & Lincoln, 1994) so that the 'stories told' are negotiated. Harrison et al (2001) emphasise that whilst we try to position ourselves 'outside' the told narratives, a brief, seemingly inconsequential comment can 'lead the others to pursue a new topic of conversation', thereby influencing the narratives shared. This 'contamination of the researcher' is inevitable as the researcher will 'dance' through the interaction, giving and taking during the conversation.

There are a small number of traditional qualitative research approaches available to the researcher within the constructivist paradigm to support elicitation of this constructed view of the world. These include the use of case studies, ethnographic studies, grounded theory (which are all summarised in Table 3:2) and emancipatory approaches.

Whilst each of these qualitative approaches could have been used to explore the research aims, there are limitations affecting the use of these approaches within this particular study. The use of a case study approach offers understanding of a phenomenon through multiple sources of data; however, the pursuit of this understanding does not anticipate the researcher's active involvement in bringing about change in the research environment, which is the primary aim of this study. As such the case study, whilst having a number of merits, was rejected because it did not capture the totality of the research aims.

The use of an ethnographical approach was also discarded as a possible research design for this study because its greatest strengths lie in the use of observational techniques and in-depth description of a phenomenon: observation was not consistent with the purposes of the study and was also judged to be too time-intensive.

Table: 3:2 Summary features and limitations of qualitative approaches (Adapted from Robson, 2002)

	Concept and methods selected	Features	Limitations
Case Study	<ul style="list-style-type: none"> • A single case or small number of related cases. • Study of the phenomena in context • Use of interviews, observations and documentation 	<ul style="list-style-type: none"> • An empirical inquiry that investigates a phenomenon within its real-life context 	<ul style="list-style-type: none"> • Does not anticipate the researcher will purposefully act to change circumstances within the research area
Ethnographic Study	<ul style="list-style-type: none"> • Focus on group, organisation or community, by immersion of the researcher in the setting. • Use of participant observation 	<ul style="list-style-type: none"> • Seeks to capture, interpret and explain how a group, organisation or community live, experience and make sense of their lives and their world 	<ul style="list-style-type: none"> • Researcher bias can affect data collected • Depends on apparent credibility of sources • Depends on study groups being representative of entire group or population studied • Requires time to build the level of trust demanded in ethnographic research; long-term studies are usually required • Does not anticipate the researcher will purposefully act to change circumstances within the research area
Grounded Theory	<ul style="list-style-type: none"> • Applicable to a wide variety of phenomena: commonly interview-based 	<ul style="list-style-type: none"> • Systematic yet flexible strategy involving detailed prescriptions for data analysis and theory generation 	<ul style="list-style-type: none"> • Grounded Theory can be reductive in the search for general patterns across a group of people. • Does not anticipate the researcher will purposefully act to change circumstances within the research area

The final qualitative research method which was considered and rejected was the use of grounded theory. Strauss and Corbin (1998) state a grounded theory approach utilises analysed data to generate a theory. Within this study, I already held some assumptions and hypotheses about existing practices and some understanding/expectations about the gaps

in provision for families of children with autism and support for secondary schools, arising from my casework as an Educational Psychologist, and my familiarity with relevant policy and research literature. I decided therefore that this approach too was not appropriate for the current study.

In pursuit of an appropriate research design that extended beyond the exploration, description and explanatory outcomes associated with the qualitative approaches discussed already, I chose to examine a research design which has been linked to influence and change: namely action research.

3:5:3 Action research

Action research is seen as a 'process by which practitioners attempt to study their problems scientifically in order to guide, correct and evaluate their decisions and actions' (Corey, 1953 p.52). McNiff et al (1996) describe action research as 'insider research' which requires action as part of the process and is driven by professionals who seek to improve practices. Carr and Kemmis (1986) define the purposes of action research as:

“...a form of self-reflective enquiry undertaken by participants (teachers, students or principals for example) in social (including education) situations in order to improve the rationality and justice of a) their own social or educational practices, b) their understanding of these practices and c) the situations (institutions) in which these practices are carried out.” (Carr & Kemmis in McNiff p.2)

Here the focus of action research is on each individual's involvement in the research process, whereby beliefs about the action needed to solve the problem are not separated from the investigation (McFarland & Stansell, 1993) and are grounded in policy reform and other types of social or systemic change (Taylor et al, 2004).

Within the literature there are 'multiple traditions of action research' (Herr & Anderson, 2010), with some writers distinguishing between different types of action research. Argyris et al (1985) describe action research as a process of Action Learning whereby the process leads to learning within organisations. This is in keeping with Lewin's (1948) notion that change is facilitated and guided by a leader. In contrast to this view Heron & Reason (2001) see action research as a process of reflection, utilising the tradition of collaboration. Whilst some writers seek to distinguish between different types of action research McNiff (2002) observes that differences arise from different researchers prioritising different aspects of the action research process.

Indeed Reason & Bradbury (2006) argue that Action Research, Participatory Action Research and Action Learning are terms which collectively refer to research which consists of:

“a participatory, democratic process concerned with (bringing) together action and reflection, theory and practice in participation with others in the pursuit of practical issues of concern to people.” (p.81).

Reason and Bradbury (2006) emphasise that Action Research provides ‘conditions for the empowerment of participants’ and draws on understanding and insight of those who experience the issue, to find solutions. It is this collaboration and involvement of those commissioning the research as participants and co-researchers alongside the teachers and parents who are key stakeholders with a high investment in the services which form the focus of this study, that is most closely aligned to the aims of this study.

3.5:4 Collaborative action research

Collaborative action research emphasises the inclusion of those who traditionally are ‘researched’ within the research process as co-researchers. The process typically requires participation and collaboration of individuals as equals in the research process to bring about understanding and change, and can be used to redress power relationships within the research process.

For some, the notion of collaborative action research is defined by collaboration in **all** stages of reflection and action but in reality the level of participation may vary greatly. Arnstein (1969) created a hierarchical ladder which attempted to identify different modes and levels of participation, ranging from the manipulation of citizens at the bottom rung to citizen control with full and meaningful participation at the top rung. More recently Pretty et al (1995) suggested that rather than representing participation as a hierarchical process, it would be more helpful to consider participation as a continuum of involvement, whereby participation takes different forms, at different times in the research process and in different situations and contexts.

It is evident from the existing research into families’ experiences of support for children with a diagnosis of autism that there have been few attempts to improve participant control and involvement in the research process. Currently the emphasis in the inclusion literature has been to understand the experiences of parents, with some attempts to give a voice to parents to share these experiences. However, there is little evidence that those participating have been empowered actually to direct service improvements. It is this lack of

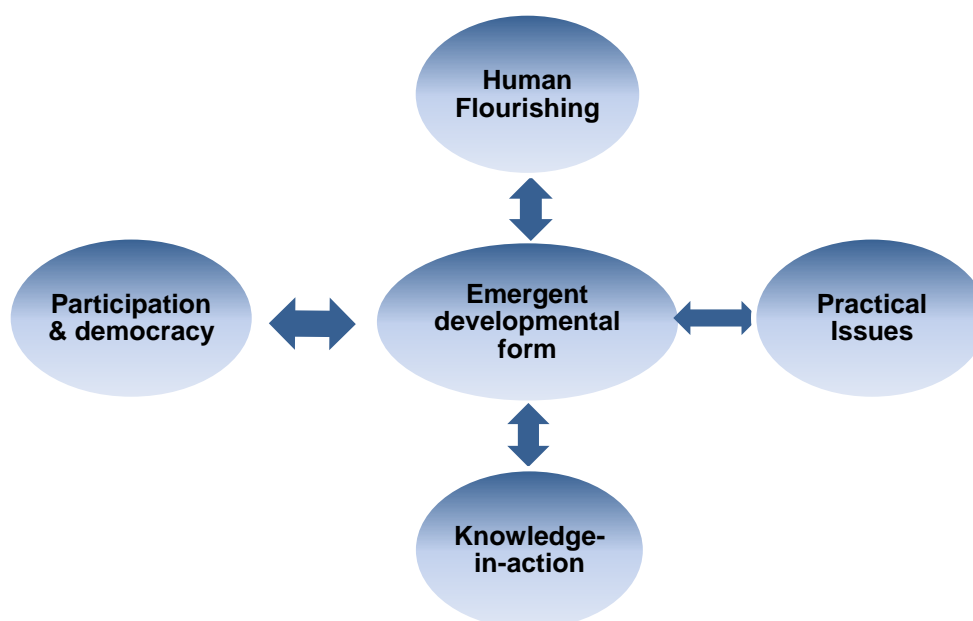
empowerment of parents/school staff as participants which has influenced my own choice of research design. Indeed Jones et al (2009) report those responding and participating in research wanted greater involvement and advocacy about decisions which affect them. As such my primary interest in collaborative action research is in its empowerment potential, which seeks to improve social situations and ensure that it is “participants’ own activities which inform the on-going inquiry” (McTaggart, 1997 p.234).

Therefore, after a thorough exploration of other research approaches, I adopted collaborative action research as my preferred research methodology, to ensure that whilst parents and school staff shared insight into their experiences with me in my role as researcher they were also afforded a means to change and shape their future experiences of support. I considered this use of an emancipatory approach the most appropriate means to ensure parents and school staff could work actively as equals in improving the delivery of the services they receive, and to be most appropriately attuned to my study aims.

3:6 Elaboration of rationale for an action research approach

From my reading about action research I have been able to identify elements of the action research approach which I believed would address the overarching aims of the study and fit with my values as an Educational Psychologist and researcher. Reason and Bradbury (2001) identify features which they associate with the action research approach, which have been influential in clarifying my own thinking in regard to this study and utilising the action research approach (Figure 3:1).

Figure 3:1 Summary of Reason and Bradbury’s (2001) Action Research Framework



Reason & Bradbury (2001) identify features of an action research process which are inter-related: however, the one which is of the greatest importance for me is '**participation and democracy**'. Within this study there were three different groups who were invited to participate:

- parents/carers of children with a diagnosis of autism;
- head teachers and SENCOs in thirteen mainstream secondary school in one unitary education authority; and
- professionals from a strategic group who were instrumental in providing the services to parents/carers and schools,

in order to ensure any changes to the current system would be attuned to the perspectives and needs of the people who use the services provided for them, and benefit from changes made in response to these views.

Reason & Bradbury (2001) also suggest that the action research process should assume an '**emergent development form**'. Given that the current study sought to understand the experiences of families with children who have a diagnosis of autism and improve services provided to families and schools, it is inevitable that the research process would be a long-term, on-going endeavour (Robson, 2002) which would be shaped and redefined by the active involvement of families and school staff as a consensus emerged about what is valued and needed by service users.

Reason & Bradbury (2001) emphasise that action research should reflect '**practical issues**', whereby the focus of the study should be located within a real life problem. Within my study the real life situation under examination is the inequality of support available to families of children with a diagnosis of autism and the support to secondary schools.

Another feature Reason & Bradbury (2001) highlight within the action research framework is '**knowledge in action**'. Here the notion of 'knowledge-in-action' relies on developing theories that are validated through practice and action (Elliott, 1991), rather than those which emerge from a theoretical interpretation of a situation. Within the current study, the aim was to develop knowledge of existing practices which support families of children with a diagnosis of autism and secondary schools and to develop improved understanding of the efficacy of the services available. This 'knowledge in-action' would serve to reform service delivery but also develop my knowledge about the most effective ways to support families. Complementary to 'knowledge-in-action' is '**human flourishing**' which emphasises the desire to improve social situations. McNiff (2002) suggests that a by-product of the researcher's 'social intent' to improve their own work should be mutual benefit for others.

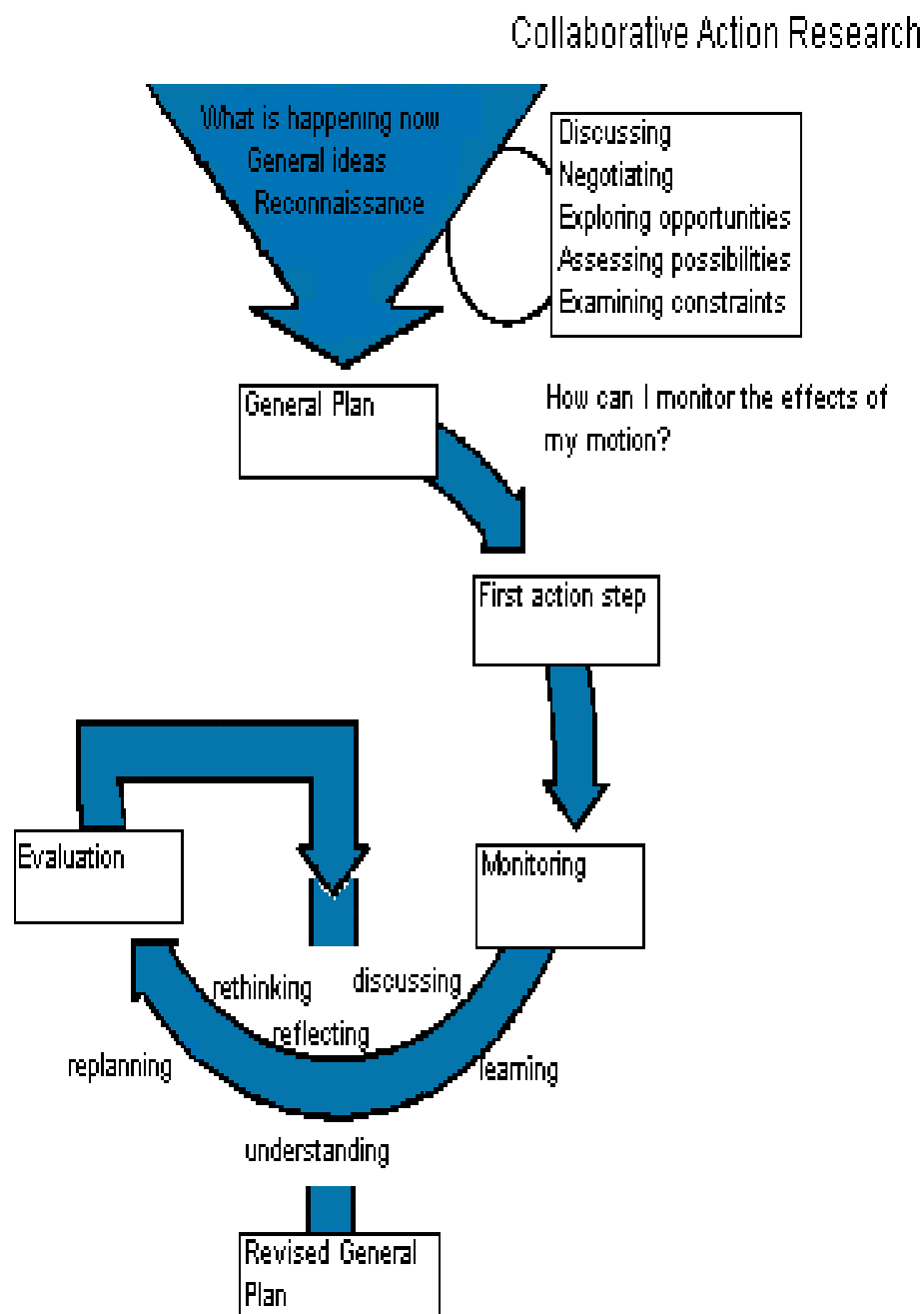
Typically the desire to change an individual's practice in order to improve 'human flourishing' arises from a mismatch between existing practices/systems and those endorsed by the researcher's own values. For me this mismatch existed between my subjective evaluation of the effectiveness of current support systems derived from my own experiences as an Educational Psychologist working with families and secondary schools. I believed that the system of support for parents/carers was influenced by the level of engagement by these service users, the type and level of pressure they could bring to bear on professionals, and which professionals were involved at the pre and post diagnosis phase. It was evident that there was a lack of rigour within the current system, so some parents/carers received a high level of support whilst others did not. Such (perceived) unequal service delivery did not fit with my professional or personal values and I believed that parents/carers should have access to a fair, equitable and transparent system. Thus to ensure the system of support available to parents/carers consistently attained these standards, the inclusion of those who used and were supported by the system, and provision of the opportunity to participate in the change process offered by an action research approach, were key considerations influencing my choice of research methodology.

3:6:1 Action research as a process

In addition to the features of action research summarised above, the methodology is characterised by a clearly defined systematic process of planning, reflecting and action. Typically the process and interplay between reflection and action is governed by a cyclical process whereby planning, intervention, data collection and analysis /interpretation occur within a specific context and inform subsequent cycles of action and reflection (see Figure 3:2).

In Kemmis's (1985) description of the action research process, he identifies the need to formulate a plan of action that is derived from a thorough exploration of opportunities, possibilities and constraints via an initial reconnaissance phase. Hammersley (2007) suggests this reconnaissance phase should be used to examine the general idea carefully by evaluating current action, identifying what opportunities and possibilities there are to develop the current action to achieve improved outcomes, and what currently prevents improvements in the action. Hammersley (2007) also argues that the reconnaissance phase should serve as a chance to learn and gather new insights regarding strengths and weaknesses of 'the action' and the techniques associated with the action. The reconnaissance phase relating to this study is described in greater detail in Chapter Four.

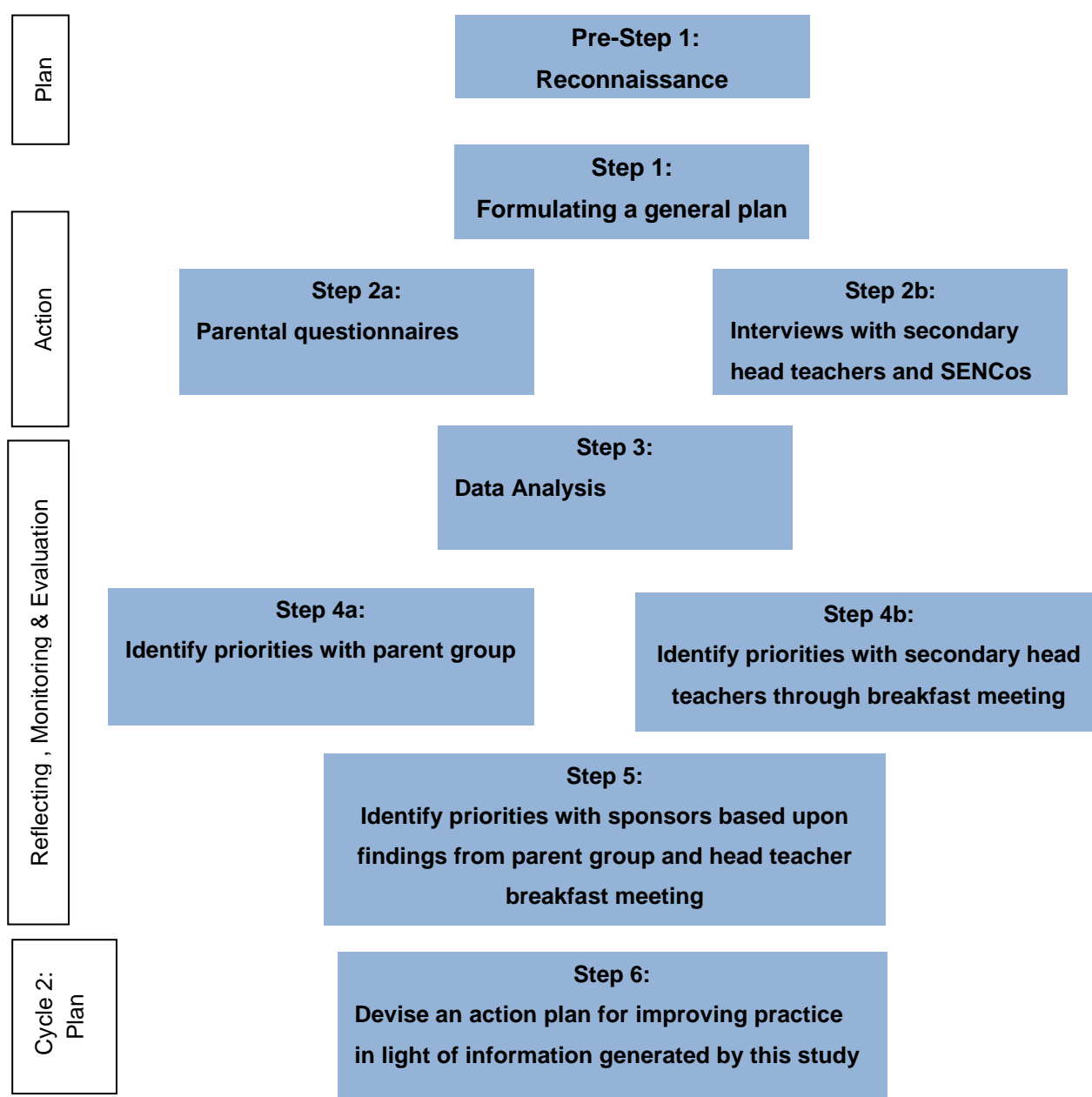
Figure 3.2: Stephen Kemmis' (1985) Action Research Planner



3:6:2 Research design

The action research approach used for this study follows Kemmis' (1985) model. For ease of reference, the stages are summarised below (Figure 3:3).

Figure 3:3: Stages of action research processes



3:7 Methods of data collection

3:7:1 Mixed methods approach

As evident from Figure 3.3, the methods of data collection were questionnaires and interviews to inform understanding of the respondents' current perceptions and experiences of service delivery. The details of data collection for each stage of the study will be discussed in Chapter Four (reconnaissance phase), Chapter Five (parental questionnaire) and Chapter Six (secondary school interviews), so the specifics of each research method and instrument have are not discussed here.

At a broader level the intended process of data collection utilised a qualitative approach, with data analysed through qualitative methods. In regard to the parental questionnaire data I planned to use quantitative methods of data analysis, in order to provide a descriptive summary of trends within this data set which will be presented in Chapter Four. The purpose of raising the matter here is to consider the use of both qualitative and quantitative approaches (a 'mixed methods' approach) in social research.

Historically qualitative and quantitative approaches have been viewed as distinct, with each approach associated with different, and perhaps incompatible epistemological assumptions. Quantitative research methods typically utilise practices from natural science, where data are gathered through 'objective' means and used to test hypotheses; such research methods are frequently linked to the positivist paradigm. In contrast, qualitative research methods typically use subjective accounts to facilitate greater detail and understanding of individuals' experiences and perceptions; here, research methods are frequently associated with the constructivist paradigm. However, more recently the use of both approaches within social research has been increasing (Cresswell & Plano Clark, 2007), as has the view that it is helpful, rather than simply muddled to use two approaches which may better be considered complementary than incompatible.

Denscombe (2007) emphasises the benefits of a mixed method approach, arguing that the researcher should draw on research tools and techniques which will work best in generating information pertaining to the research phenomenon under investigation. He considers it legitimate for researchers to draw upon elements of quantitative and qualitative approaches in order to provide this understanding.

Within my research, there are different strands of investigation which seek to understand the situation from the perspective of different sets of participants. In order to ensure the data collection process from these different sets of participants was appropriate to each strand I chose to use both quantitative and qualitative approaches, and to use both questionnaires and interviews.

The questionnaire responses were not subjected to strict statistical analysis although there were a number of questions which were analysed using descriptive statistical analysis of the frequency of responses to fixed, closed questions. Other aspects of the parental questionnaire sought in-depth descriptions and accounts, which were analysed utilising a qualitative approach.

3:7:2 Qualitative data analysis

In addition to the quantitative analysis of the questionnaires, the other data sets which used qualitative methods of data collection (questionnaires and interviews) were subjected to thematic analysis utilising two techniques advocated by Bernard & Ryan (2003) and Strauss & Corbin (1990): firstly the identification of a theme based upon repetition and the occurrence and reoccurrence of topics within the data; and secondly, an a priori approach using the prior knowledge and understanding of the research area and my own knowledge and understanding of existing practices, values and perspectives.

The records of the parent comments were examined repeatedly and organised into categories according to the content and the number of different respondents who articulated the theme. Miles and Huberman (1994) argue that such an approach enables the researcher to identify key factors, concepts, or variables and the presumed relationships among them” (p. 18). In doing so the researcher is able to “unwrap” multi-dimensional meanings and interpretations which provide greater insight into human activity.

Whilst these themes appear to ‘emerge’ from the data, it is important to acknowledge that the researcher will identify patterns and select those which s/he considers to be of relevance (Braun & Clark, 2006). This process of identification and selection of ‘preferred’ themes reflects the subjective nature of constructivist research. Herr & Anderson (2005) suggest that this researcher bias is ‘acceptable and even desirable’, although the researcher must examine the bias critically.

Within my study the identification of themes was influenced by my expectations and prior understanding derived from my casework, published literature and an awareness of the desired outcome at the end of the study. Further explanations regarding how information from each data set was analysed is provided in the subsequent chapters pertaining to each specific strand of the enquiry.

3:8 Trustworthiness and credibility

As noted at 3:5:1 above, research has historically been positioned within the positivist tradition, utilising criteria which recognise and reward objectivity. The positivist approach emphasises reliability, validity and replication of findings as a means to evaluate and validate the quality of research.

Robson (2002) refers to validity as the concern with the accuracy of the research. However, research utilising a constructivist approach is not subjected to the stringent and rigid

processes of the positivist paradigm, and these criteria for research credibility cannot be used to judge the quality of qualitative research (Bradley, 1993). Lincoln & Guba (1985) recognise the gap between the two research traditions and propose a means of evaluating qualitative research using four criteria: credibility, transferability, dependability and confirmability. The definition of these criteria is presented in Table 3:3.

Table 3:3: Criteria for robustness in qualitative research, (adapted from Bradley, 1993)

Criterion	Definition	Means to achieve criterion
<i>Credibility</i>	Adequate representation of the constructions of the social world under study	<ul style="list-style-type: none"> • Prolonged engagement in the field • Persistent observation; triangulation • Checking interpretations against raw data • Peer debriefing
<i>Transferability</i>	The extent to which the researcher's working hypothesis can be applied to another context.	<ul style="list-style-type: none"> • Provide data sets and descriptions that are rich enough so that other researchers are able to make judgments about the findings' transferability to different settings or contexts
<i>Dependability</i>	The way the researcher accounts for changing conditions in the research phenomena so that if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained	<ul style="list-style-type: none"> • Checking the consistency of the study processes • Transparent processes for coding and drawing conclusions from the raw data • Coders' knowledge and experience
<i>Confirmability</i>	The extent to which the characteristics of the data, as posited by the researcher, can be confirmed by others who read or review the research results	<ul style="list-style-type: none"> • Checking the internal coherence of the research, namely, the data, the findings, the interpretations, and the recommendations through audits of the research processes and findings

3:8:1 Credibility

Maxwell (1992) has argued that qualitative researchers need not work within the tight constraints of the positivist paradigm. Instead, Maxwell proposes that when working with qualitative data, 'understanding' is more appropriate, as noted too by Cohen et al (2001, p.106)...

“we, as researchers are part of the world that we are researching, and we cannot be completely objective: hence other people’s perspectives are equally valid as our own: the task of the researcher is to uncover these...it is the meaning that subjects give to data and the inferences drawn from the data that are important.”

A test of accuracy within qualitative research analysis therefore, becomes the ‘fit between what researchers record as data and what actually occurs in the natural setting that is being researched’ (Bogdan and Birklen 1992, in Cohen et al 2001 p.119). As such, the quality of qualitative data analysis should be considered in terms of “trustworthiness” and “authenticity” (Lincoln and Guba 1985), whereby the data analysis is authentic to the meanings given by those providing the data.

There are a number of ways to ‘authenticate’ data. Within the current study, during the process of data collection, consideration was given to validating the data. In the research interviews, I sought to understand the language used in order to facilitate my interpretations by eliciting the views of head teachers and parents and asking supplementary questions to encourage elaboration of initial responses, to help me ascertain whether my own interpretation and constructions placed upon their utterances aligned closely with their intended meaning. This conversational dialogue provided insight into the terms, expressions and vocabulary used by respondents to describe their experiences, thereby offering an increasingly credible interpretation. The interviews conducted with a small sample of parents in my ‘Reconnaissance Phase’, alongside my ‘routine’ working contact with parents in my role as an EP enabled me to ‘pitch’ the parental questionnaires using language and concepts I believed would be relevant and meaningful to them, and also, to some extent primed me, I believe, to draw inferences from their responses to open-ended questions, which were congruent with the intended meaning. Other parallel processes aimed further to strengthen the authenticity of the research findings.

McNiff (2002) suggests that the researcher should engage a critical friend or validation group to ensure the credibility of interpretation. Within this study I sought the involvement of the Head of the Advisory Service, who had accompanied me and acted as a co-researcher for the head teacher and SENCo interviews, to provide a critical view of the transcribed data. Despite the involvement of a co-researcher, interpretations of data were not entirely neutral since the colleague was also an ‘insider’, who brought her own values and practice-based perspectives to the analysis process. However, the co-researcher did offer

comments and challenge to the analysis process by reviewing my initial coding and theme identification.

As indicated above, steps taken to maximise the balance and authenticity of data analysis are described in the following three chapters, where discussion relates to the specific measures taken in respect of each data set.

3:9 Ethical considerations

The research was undertaken in accordance with commonly agreed standards of good practice such as those laid down in the Declaration of Helsinki (World Health Organisation 1996). These fundamental and widely accepted principles can be broadly categorised as: beneficence (do positive good) and non-maleficence (do no harm); informed consent; and confidentiality/anonymity. In seeking congruence with these broad principles, the research also adhered to the ethical guidelines agreed by the British Educational Research Association (BERA 2004) and the principles for ethical research set out by the British Psychological Society (BPS 2007 & 2011). Ethical consent for the planned research was secured from the University of Birmingham Ethics Committee (Appendix 2). Table 3:4 presents a summary of the broad ethical consideration for the current study, detailing possible challenges posed and the action taken in order to ensure compliance with accepted ethical requirements. In subsequent chapters I present a detailed account of the ethical considerations and action undertaken to address these for each specific stage of the research.

3:10 Limitations of the methodology

Within this research I recognise inevitable limitations which have arisen from decisions re: the research design and methods of data collection. I have achieved gains in some areas although there are some losses which are inherent in the approaches adopted. Importantly I am aware of my need to be explicit about the choices I have made and the rationale for the decision-making process to maximise the credibility of this research.

Action research as a method of social enquiry has been criticised for its lack of methodological control (Bryant, 1996) although within the current study the use of a mixed method approach has gone some way to address this potential limitation.

With regard to the focus of this study, a possible limitation could be that the views elicited via parental questionnaires and the head teacher and SENCo interviews offered broad insight into the problems, but lacked depth and/ or specificity. However, a compensatory factor is that

Table 3:4: Summary of broad ethical considerations

	Threat	Where addressed	How addressed (Action Taken)
BERA 36 - Responsibility to Sponsors	Researchers must employ methods that are fit for the purpose of the research they are undertaking. Researchers must have knowledge of alternative approaches sufficient to assure the sponsors that they have considered these, and that research needs have been properly addressed.	Research Design	Through consultation with the sponsors and my University of Birmingham research supervisor, and careful, informed consideration of possible methodologies, a thorough exploration of possible research methods were considered.
BERA 9 Responsibility to Participants	Researchers should operate within an ethic of respect for any persons involved directly or indirectly in research.	Data Collection	<p>Working with families and schools in a professional capacity has resulted in my already being perceived in a particular way by participants. This existing perception is likely to have an impact on the data sharing process. It is possible that participants would withhold information about their experiences, from fear that the service they receive would be affected by the disclosure of their experiences. Participants were reassured that information provided during the research process would be treated as confidential and not used 'punitively' to restrict access to current support.</p> <p>I bring my knowledge and experience of professional practice of working with Autism to the research. This means it is not possible to remain impartial, as existing knowledge about current practices will influence the type of questioning and the specific focus of data collection. This was redressed by seeking service user points of view and consulting with them during the research process to identify the specific and subsequent direction of the study. Consultation with colleagues and the University supervisor provided challenge to the research process and supported me in interrogating the method and process of data collection.</p>
BERA 26– Data Protection	Researchers must ensure that data are kept securely and that the form of any publication does not directly or indirectly lead to a breach of agreed confidentiality and anonymity.	Data Collection, storage and communication	Initial questionnaire responses and notes taken during the semi-structured interviews were stored in a locked drawer. Following data analysis the information was stored electronically on a password-encrypted USB device and stored in a locked office in line with other data protection practices. Following the completion of this doctoral study the data will be stored within the archives facility in the council. Participants will also be informed that their anonymous data will have also been stored electrically on the University of Birmingham network server.

Table 3:4: Summary of broad ethical considerations (continued)

	Threat	Method of Data Collection	Action Taken
BERA 18 - Children, Vulnerable Young People & Adults	Researchers must recognise that participants may experience distress or discomfort in the research process and must take all necessary steps to reduce the sense of intrusion and put them at their ease. They must desist immediately from any actions, ensuing from the research process, that cause emotional or other harm.	Design Methodology	<p>The researcher aimed to ensure the well-being of participants, providing an opportunity to de-brief if required.</p> <p>Questions were framed sensitively, and during face-to-face interviews, endeavours were made to monitor interviewees' affective state, and periodic low-key checks made that interviewees were happy to proceed.</p>
BERA 23 - Privacy	Researchers must recognise the participants' entitlement to privacy and must accord them their rights to confidentiality and anonymity.	Data Collection	<p>Questionnaires were returned anonymously, with no means of identifying which parents had responded and/or which questionnaires were returned by whom.</p> <p>Further, in reporting the research, care was taken to ensure that no setting or respondent could be identifiable.</p>
BERA 10 – Voluntary Informed Consent	Voluntary informed consent is the condition in which participants understand and agree to their participation without duress, prior to the research getting under way.	Data Collection	<p>Participants were involved in the study on a voluntary basis, and their right to withdraw from the study at any time was explained at the beginning of research activity (see Appendix 3).</p> <p>All participants were provided with a written overview of the research aims and how their data would be used both as part of the researcher's doctoral study and within the council to shape practice. Informed consent was checked orally prior to undertaking any research with all participants.</p>
BERA 13 – Right to Withdraw	Researchers must recognise the right of any participant to withdraw from the research for any or no reason and at any time.	Data Collection	Participants were informed of their right to withdraw from the study at any stage during and after the research process. They were given written instructions describing the withdrawal process (see Appendix 3).

the research provides an understanding of the situation from different perspectives, while subsequent discussion within the focus groups and cluster meeting ensured agreement about the themes and patterns across the data, thereby strengthening the confirmability of the findings (Bradley, 1983).

Another potential problem with the research methodology is how participants construe their involvement and whether they see themselves as having ownership of the problems examined and the solutions generated. To address this difficulty within the study I tried to provide a number of opportunities for parents and carers to identify specific needs and to direct subsequent actions. This was achieved by providing alternative ways to maintain involvement in the action research process beyond traditional 'face to face' contact. For example, there is now an email forum for parents with contact details promoted through the Autism Drop-in sessions. This forum is organised and monitored by parents to allow any parent to raise issues which are a priority to them, rather than just responding to issues raised by professionals: in response to this opportunity, the parents have, to date, demonstrated an interest and commitment to the project.

Further limitations of the rigour of an action research methodology arise from the flexible, dynamic, 'emergent' nature of the research process: whilst there can be a plan of intended action, the actual actions and outcomes are informed by earlier actions: therefore, in practice, the researcher's implementation of the planned steps in a neat sequence may be deflected, thereby rendering the process potentially 'messy', compared to other forms of research design, albeit more responsive to contextual needs.

In Chapters 4, 5 and 6, I present an in-depth account of the research process pertaining to three successive phases of the study and its different research strands.

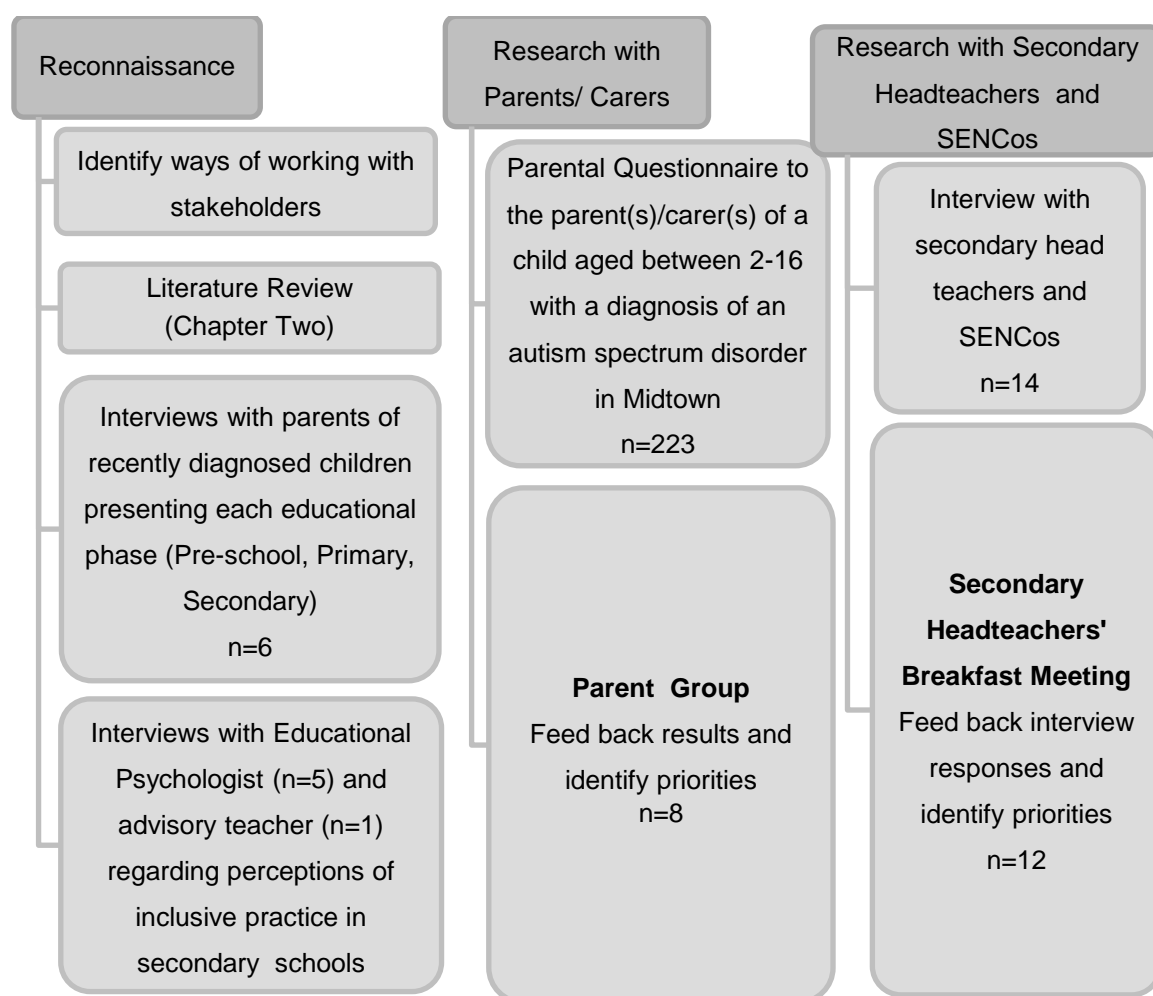
Chapter Four

Scoping Exercise and Reconnaissance Phase

4:1 Introduction

In this chapter I provide a summary of the reconnaissance phase of the research which informed the subsequent stages of the study and selection of research instruments. There were four scoping activities to the reconnaissance phase as illustrated in Figure 4:1.

Figure 4.1: The reconnaissance phase in the context of the whole study



The reconnaissance phase began with a scoping exercise which sought to:

- identify a way of working with the stakeholders (parents of children with autism, head teachers and SENCos of mainstream secondary schools, clinical psychologist, educational psychologist, speech and language therapist, social care colleagues, CAMHS colleagues and occupational therapists), that would be fit for purpose;

- inform the study by undertaking a comprehensive literature review (reported in Chapter Two and briefly summarised here in Section 4:3);
- identify parent/carer experiences of support through preliminary in-depth interviews; and
- clarify professionals' perceptions relating to current practices and systems of support.

4:2 Negotiating the research and identifying a way of working with the stakeholders

Through considering the early concerns that had been communicated prior to undertaking this research and discussions with the strategic group, consisting of an educational psychologist (EP), clinical psychologist, psychiatrist, occupational therapist, social care colleague and a charitable organisation which provides targeted support for families, it was apparent this multi-professional group would serve as sponsors of the research, in light of their shared responsibilities for providing services to families. The strategic group also recognised the duality of their role as stakeholders in the research process and system under review.

Three very broad, inter-related, over-arching questions had been mooted at meetings of the strategic group which had given impetus to the research reported in this thesis, all of which were focused upon provisions and practices within mainstream secondary schools:

- I. How effective are our services to/for children with an autism spectrum disorder from both secondary school staff and parental perspectives;
- II. What do mainstream school staff do to support children with an autism spectrum disorder following diagnosis; and
- III. How can we build on the services we currently provide?

The third of these questions perhaps provided the over-arching rationale for the study. In light of these very broad questions and purposes, the strategic group and I, in my role as both EP member of the group and researcher, acknowledged that parents and school staff were central to the research. However the strategic group also recognised that past attempts to refine service practices had not had a positive impact for families. Therefore the strategic group recognised that parents and school staff were more than a 'resource' to the research process as 'participants'; their involvement needed to be as stakeholders and as such they needed to be involved in the decision-making processes.

Through discussion with the strategic group and university supervisor and a thorough review of available methodologies (as discussed in Chapter Three) Collaborative Action Research (Kemmis, 1985) was considered to afford an appropriate methodology to support for this level of participation. Once agreement about the choice of methodology had been secured, consideration was given to how stakeholders could best be engaged in the research process

and how a process of meaningful consultation could take place. This will be discussed later in this Chapter Section 4.6.

4:3 Scoping Exercise 1 - Literature review

The first stage of the reconnaissance included a return to the literature reviewed in Chapter Two in order specifically to identify methodologies used, and identify themes and patterns derived from their use within these studies, in order to inform the choice of research design and methodology for data collection, as discussed in Chapter Three, section 3:6.

It is clear that researchers have utilised different approaches in their endeavours to understand service users' experiences of support from professionals during and following a child's diagnosis of autism. Some researchers focused on describing these experiences; others investigated the impact of the experiences; while some, tried to understand the experiences from different perspectives. A table summarising research into families' and school experiences of support is presented in Appendix 4 and illustrates the methodologies, research designs and methods of data collection which have been used to date to provide insight into inclusive practices/ attitudes and parental perceptions regarding support available to them from professionals. This review forms the academic backdrop of this study.

There are a number of similarities amongst the methods reviewed, particularly the use of survey/ questionnaire sampling to generate data.

Minnes & Steiner's (2009) study of parental experiences of negotiating and obtaining health care support for their children used a qualitative approach. They positioned themselves within a subjective paradigm utilising an ideographic method of data collection through the use of semi-structured interviews with parents within small focus groups to gain understanding of the processes families underwent in securing support from health care providers. The method of data collection via focus groups presented a number of benefits. These included the researchers' ability to provide "a carefully planned discussion (which is) designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (Krueger, 1994 p.171), thereby providing the researchers with access to 'everyday talk' (Myers, 1998). This understanding of 'real' experiences and perceptions is supported further by the group structure of focus groups, which encourages participants to produce and challenge opinions, thereby providing insight into why such views are held (Krueger, 1994). Furthermore it ensures the researcher is able to develop and begin to test shared assumptions and interpretations about the meaning of what has been and how this is reported. However the 'production and challenge of opinions' process can also be heavily influenced by the dynamics of the group. It is possible some groups might have very dominant

participants who overshadow other members of the group, so the information obtained is not reflective of the group, but is rather reflective of one or two individuals. The presence of a dominant participant would also affect upon the researcher's ability to remain 'passive' and could reinforce pre-existing power inequalities. Despite these reservations about using focus groups as a process for developing an understanding of the situation being examined, Minnes & Steiner (2009) report positive outcomes from their use of focus groups, claiming that this method facilitated the capture of meaningful and insightful data relevant to the particular problem.

Whilst the Minnes & Steiner study was located within a subjective paradigm using ideographic methods of data collection other research reflect the other end of the continuum, locating research in a positivist paradigm deploying nomothetic approaches.

Renty & Roeyers (2006) for example, utilised a nomothetic approach associated with quantitative research methods, which aimed to explore factors which influence parental satisfaction with support from statutory services. They undertook a survey and examined the data through a simple t-test. This process enabled the researchers to ascertain the difference between levels of satisfaction, and this was used to inform a hypothesis re: the relationship between parental satisfaction and type of educational provision the child received. However, as a method of data collection, there are limitations, which include the lack of depth of understanding what parents value and how educational establishments could change to increase levels of parental satisfaction.

Whilst the two studies mentioned above represent extremes along the quantitative and qualitative continuum, other research utilises both approaches. Rowlandson & Smith (2009), for example, sought to develop an holistic and co-ordinated service for children with autism in the Isle of Wight. In this three year pilot study they used both survey sampling via questionnaires to identify experiences and perceptions about current practices as an initial step, and then used semi-structured interviews to ascertain how these experiences and perceptions had changed in light of adaptations to the service available to families.

Rowlandson & Smith's (2009) use of self-administered questionnaires to survey the research population has been a popular method of data collection within the literature, not least because questionnaires provide many benefits. Oppenheim (1966) suggests the greatest benefits of self-administered questionnaires for the researcher are:

- that they can survey a large population in more than one geographical area;
- they are quick and easy to administer;

- they are relatively inexpensive to produce and administer; and
- if questionnaires are anonymous the responses are likely to be accurate.

Whilst there are benefits to this process of data collection, Oppenheim (1996) also warns there are some clear disadvantages, which include:

- researcher bias;
- low response rate;
- lack of understanding from respondents about the wording of questions;
- need for simpler questions because the researcher is not available to offer clarity; and
- the researcher cannot follow up in responses to clarify meaning or elicit further information.

In light of the limitations of data collection via questionnaires it appears Rowlandson & Smith (2009) sought to gain an increasingly robust account of parents' experiences and perceptions, using semi-structured interviews to build on the analysis of the questionnaire-based survey, and verify and extend their understanding of these experiences and perceptions. This mixed method approach, using qualitative and quantitative data collection has 'substantial advantages' (Robson, 2002). Robson suggests that the combination of ideographic and nomothetic methods of data collection reduces the possibility of the researcher presenting 'inappropriate certainty'. Robson argues one approach to data collection alone may lead researchers to what they may inappropriately consider to be a 'right' answer. The use of two or more methods of data collection, particularly methods which allow for both in-depth qualitative analysis, and the surveying of a larger number of people using a less open-ended approach to data collection, reduces the possibility that conclusions the researchers draw are 'inappropriate' or create a false picture of the 'reality' under investigation. A mixed method approach was therefore considered well suited to the purposes of the current study.

4:4 Scoping Exercise 2 – Initial parental interviews

The second reconnaissance exercise was to undertake six interviews with parents of children with a diagnosis of autism within the target authority to ascertain whether the findings reported within the literature were reflective of experiences of families in Midtown. It was evident from the literature review that findings from a number of studies conducted in very different contexts (Minnes & Steiner, 2009; Renty & Roeyers, 2006; Dymond & Myran, 2007), were consistent with the concerns raised by the strategic group and research sponsors. In order to clarify the current local picture I considered it was important to understand the whole experience for the parent(s) from the child's early development to their initial concerns and

subsequent experiences as part of the diagnostic process, and subsequent support for their child's development and education.

For the purpose of this study, the initial parent interviews served to identify central themes regarding their experiences of strengths and weaknesses of service delivery, whilst helping to identify the way parents' talked about these experiences. This understanding of parents' use of language was particularly useful when constructing the questionnaire which was used as one of the main data collection instruments within the research process (see Chapter Five section 5:2).

Within the parent interviews, I considered the semi-structured interview the most appropriate means of gathering information (the benefits of which have been discussed in Section 4:4:1) and beginning to build a detailed picture of the experiences, perceptions and accounts from a range of parents.

Bloor et al (2001) identified benefits of using interviews as a means of concentrating on certain priority topics whilst generating data (illustrative stories) and identifying everyday group language, terms and expressions. The flexibility of semi-structured interviews was advantageous, allowing me to follow up on any particular interesting issues/ comments that arose, whilst allowing the parents the opportunity to give more detailed responses (Silverman, 1993).

I now outline how parents were selected for inclusion within this initial sample.

4:4:1 Features of current sampling

The initial parent interviews utilised a 'purposive sampling' approach in which I selected participants with the specific purpose of gaining an holistic understanding of current practices within assessment and diagnosis processes for parents whose children are at different developmental stages and likely to experience and need different types of support and provision (Leyser & Kirk (2004). This approach enabled me to ensure representation of parents whose child had a recent diagnosis, whose child was at a different educational phase (Early Years, Primary and Secondary) to other participants and whose child was attending a mainstream provision.

The sampling techniques employed within this phase of the research are not without difficulties. Identifying the parents who would be invited to participate in the initial interviews through discussion with other professionals may bias the results favourably because parents

who had accepted the diagnosis are more likely to provide a positive account of their experiences. The extent to which the six parents used in the initial interviews voiced views representative of the wider experiences of parents in Midtown is difficult to ascertain because the families were relatively unknown to STePS staff because staff had not worked extensively with the parents owing to the limited time since the initial diagnosis (3 months) and the support subsequently provided. As such the sampling approach lacks the rigour of other sampling techniques. However, as Lord (1989) highlighted, research in ASD presents with methodological challenges relating to the heterogeneity of the ASD population, which will be explored in the Chapter 7. Hence, to some extent, it is argued that, however selected, so small a sample as this (six from 223) would never be representative of the target population.

4:4:2 Initial parent interview sample

The initial parent interview was primarily concerned with ascertaining the experiences of a small sample of parents, to identify strengths and any problems in the system from their perspective, and begin to compare Midtown parents' experiences with trends reported in the literature. Initially the city-wide data base was interrogated to identify the number of children who had received a diagnosis of autism in the last 3 months (January 2011- March 2011). From this data trawl 21 children were identified, data is presented in Table 4:1.

Table 4:1: Summary of data for children who had received a diagnosis during the period of Jan-March 2011

Educational phase	Boys	Girls
Pre-school	1	1
Primary age	9	2
Secondary	5	3
Total	15	6

From the sample, two families representing each educational phase were selected. This selection process was completed in conjunction with advisory teacher colleagues who were more familiar with the families and able to identify parents likely to be well placed to participate, for whom compounding factors such as recent family bereavements, court cases and the like, were not present. Following this identification process, parents were written to explaining the purpose of the research and the structure of the interview (Appendix 5). All consented to the interview. Parents were asked to identify where they would like the interview to take place; all parents requested interviews in the family home. The times were

also arranged at the parents' convenience. It is noteworthy that each parent elected to have the interview during the day when the child was attending their educational placement; therefore only mothers participated in the initial interview; reflecting the difficulties reported in Hart's (2011) study of a parental imbalance and under presentation of father's in education research.

4:4:3 Implementation of the parent interviews

The second scoping task sought to establish what parental experiences of assessment, diagnostic and support service in light of their child's recent diagnosis of autism. Each interview was conducted in the family home during the day and when all other family members were not present in the family home. This enabled the parent to provide an uninterrupted account of their experiences. The interviews lasted between an one hour and one hour and thirty minutes. The initial questions were presented in the same order because parents were asked to reflect on events in chronological order. Detailed contemporaneous notes were made and some key verbatim utterances recorded. I augmented my contemporaneous notes within one hour of each interview, to expand on any short hand/ abbreviated notes taken in situ. Table 4.2 presents the questions and provides a rationale for their inclusion in the interview.

Table 4:2: Questions parents were asked about their experiences of assessment, diagnosis and support

Question asked	Rationale for inclusion in interview schedule	Supporting Literature
When did you first have concerns about your child?	To clarify the duration of the journey parents go through as this could influence how parents construct the nature and level of support.	Jones et al, 2009
What were your concerns?	This question was intended to draw out the nature of difficulties parents experience as this could provide insight into the type of services needed	Jones et al, 2009
What happened from the point of your concerns to the entry point of your child's assessment?	It was important to identify how parents had move through the system from their first experiences of concern about their child's develop through to referral and on to assessment process to identify where the strengths and weaknesses lie.	Minnes & Steiner,2009; Kohler, 1999

Following your child's diagnosis what support did you receive?	This question aimed to clarify the nature and perceived value of the support provided and to identify whether there were differences in the type of support offered across different educational phrases. Again, this information provided insight into how the current system operates.	Kohler 1999; Little, 2003
What information did you receive about the diagnosis and support available?	Parents were asked this question to ascertain whether they had all received the information and support which is framed as an 'entitlement' within Midtown or whether there was evidence suggesting disparity in the system.	Minnes & Steiner, 2009; Renty & Roeyers, 2006
How did your child's educational placement response to the diagnosis?	To explore parents' experience of educational practitioners' attitudes towards inclusion, and capacities to accommodate the ASD child's needs.	Leyser & Kirk, 2004; Elkins et al, 2003

4:4:4 Actions undertaken to address ethic consideration prior to completing the parental interviews

In order to identify the families for participation in the initial parent interviews permission was obtained from the Head of Service and the Midtown Data Protection Officer for the researcher to access the database as a researcher, rather than a council employee. This permission was initially obtained by the Head of Service, who then referred the researcher to the Data Protection Officer to ensure the use of data was in line with the data protection protocol and practices within Midtown. The request for use of data from the Local Authority database in which families would be identified and approached for possible participation was discussed between the researcher and Data Protection Officer via a telephone conversation on 8 March 2011. The Data Protection Officer approved the use of data for this purpose because the research was linked to service improvements.

In addition to obtaining consent to access the database and the broader ethical consideration describe in Chapter Three, section 3:9, (including anonymity and confidentiality of data) I also needed to take steps to ensure the authenticity and trustworthiness of data for the specific activities in the initial parent interviews. These are presented in Table 4:3.

Table 4.3: Summary of Steps Taken to Address Threats to Authenticity and Trustworthiness

Authenticity & Trustworthiness		Threat	Method of Data Collection	Action Taken
	Robson (1993)	Dependability threat due to participant error due to tiredness/ apathy/ poor wording of questions	Initial Parental Interview	Interviews were offered and undertaken at a time of the day which was most convenient to the parents and at a venue which was most convenient to the parents, thereby reducing the impact of apathy or tiredness. The interactive nature of the interview allowed adjustments to vocabulary/ forms of expression, to ensure all respondents could engage with ease.
	Robson (1993)	Dependability threat due to subject bias (respondents telling the researchers what they think they want to hear)		The initial interviews were compared with the empirical research findings to ascertain whether there were any commonalities between the reported data and the degree of congruence was interpreted as an indicator of dependability.

4:4:5 Analysis of initial parent interview responses

Parents comments from the interviews were summarised as 'derived comments'. These 'derived comments' were analysed to identify emerging themes. The process of analysis utilised two techniques described by Bernard & Ryan (2003), firstly, the identification of a theme based upon repetition and the occurrence and reoccurrence of topics within the data; and secondly, an a priori approach using prior knowledge and understanding of the research area and the researchers' own knowledge and understanding of existing practices, values and perspectives (Strauss & Corbin, 1990). The records of parent comments were examined repeatedly and divided into categories according to the content and the number of different speakers who articulated the theme. The themes derived from this process are presented in Table 4:4.

Table 4:4: Summary of themes emerging from initial parental interviews

Question asked	Themes emerging from initial parental interviews	Example of comments	Supporting Literature
When did you first have concerns about your child?	<ul style="list-style-type: none"> Early on before the age of 2 Pre-school When he started junior school 	<p>As a baby he just didn't cry and didn't want food. I knew that wasn't normal.</p> <p>Nursery staff told me they were concerned because he found it difficult to share and have the other child close to him</p> <p>I always suspected something was wrong but it wasn't until she moved to secondary school that we really noticed how hard she found school.</p>	
What were your concerns?	<ul style="list-style-type: none"> Concerns about behavioural responses, including being passive and aggressive. Not responding to name or coping with change Constantly switching on the lights Funny about food and difficulties with sleep patterns 	<p>He finds being with others difficult and can hit out when others don't do what he wants them to do.</p> <p>It's a nightmare getting down the street he wants to stop and look at every car wheel we pass.</p> <p>She finds it difficult to understand the others and just watches</p>	
What happened from the point of your concerns to the entry point of your child's assessment?	<ul style="list-style-type: none"> Lack of acceptance by professional of parental concerns 	<p>They don't listen ...I had to wait until something went wrong</p> <p>My doctor said he'd grow out of it</p>	Minnes and Steiner, 2009; Renty & Roeyers, 2006
Following your child's diagnosis what support did you receive?	<ul style="list-style-type: none"> Lack of support following diagnosis Difficulties within family relationships accepting and agreeing the child has difficulties / stress on parents 	<p>CAMHS said she had atypical autism and just left us to it.</p> <p>The information provided during diagnosis was good but when she went to school nothing changed.</p> <p>His dad doesn't accept the diagnosis and thinks his behaviour is because I'm being soft and that he needed firmer boundaries. He says he doesn't behaviour in that way when he is with him (dad).</p>	Jones et al, 2009 Whitaker, 2002; Little, 2003; Dillenburger et al (2010);Lamb Enquiry, 2009
What information did you receive about the diagnosis and support available?	<ul style="list-style-type: none"> Limited information about what parents were entitled to. Other parents were a good source of support A sense that professionals know best 	<p>We got swept along with the diagnosis stuff we were told rather than asked what we thought</p>	Humphrey & Lewis, 2008
How did your child's educational placement response to the diagnosis?	<ul style="list-style-type: none"> Great positive and inclusive response Difficulties getting schools to recognise child was not naughty 	<p>The nursery staff were greatthey used a lot of strategies</p> <p>They make no allowances for his diagnosis and think that he is being difficult deliberately</p>	Runswick-Cole, 2008

■ Comments from parent of secondary-aged child
 ■ Comments from parent of junior-aged child
 ■ Comments from parent of pre-school-aged child

The parental feedback highlighted concerns about school staff responses to the child's difficulties and suggested a lack of understanding by school staff about the condition of autism, alongside difficulties families experienced from health care, school and other educational professionals. It appears that parents of the secondary aged boy and girl experienced difficulties with the wider family accepting the diagnosis which is not evident for the age groups. It is possible that the experiences of these two parents arise from their child securing a late diagnosis or perhaps members of the wider family had already constructed a persona for the child which does not fit with the diagnosis; compounded with changes as the child moves through the developmental lifespan.

The two parents of junior aged child had different experiences from each other. The mother of the junior aged boy found school professionals viewed her son as naughty and disruptive, whilst the mother of the girl found school professionals did not listen to her concerns or provide her daughter with support to address her needs.

4:5 Scoping Exercise 3 - Understanding inclusive practices in secondary schools: rationale for exploring practices within secondary schools

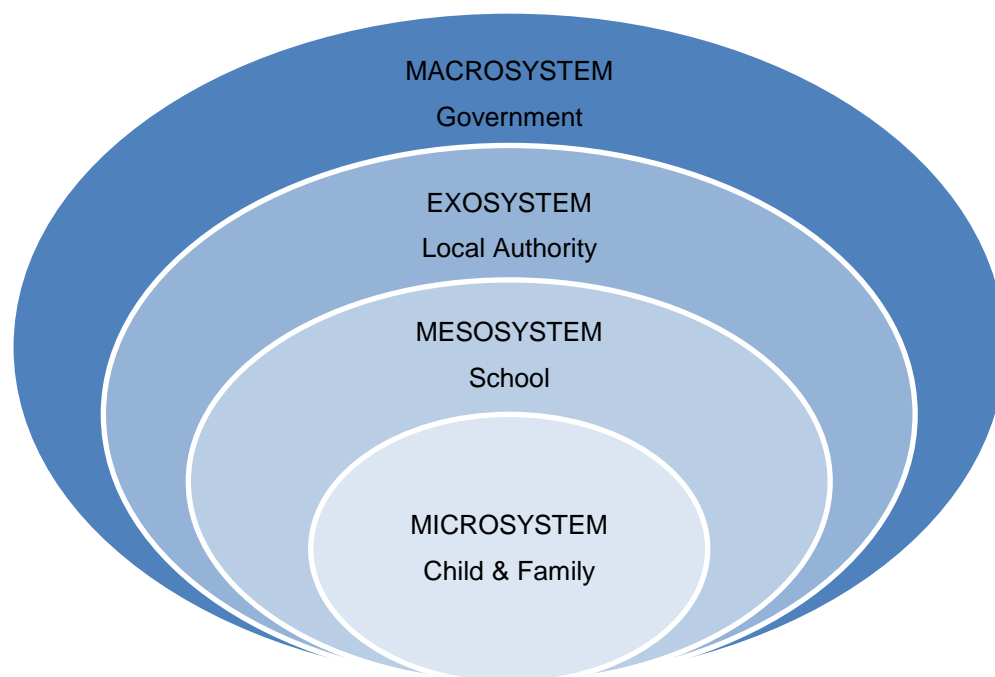
In light of the difficulties reported during the initial parent interviews in regard to experiences of school support, most notably difficulties with secondary schools' practices, and the initial concerns raised by the strategic group identifying difficulties with the way secondary schools manage challenging behaviour, meet the emotional needs, including self-esteem, difficulties and anxiety and non-attendance for children with ASD, it was agreed to explore the practices within all secondary schools in Midtown. To clarify how and what secondary schools provide for children with autism, an initial reconnaissance was completed, examining how inclusive Midtown's secondary schools are. Educational Psychologists and an advisory teacher for children with autism were asked to provide this judgement.

4:5:1 Educational psychologist and advisory teacher perceptions of secondary school ethos and practices: The rationale for consulting with this group of professionals

The third scoping exercise consisted of eliciting perceptions about school culture and practices from educational psychologists and an advisory teacher for children with autism. Educational psychologists were selected as a possible source of knowledge about provisions for children with autism because they work within different ecological system (Bronfenbrenner, 1979). These including working with differing microsystems (family homes, different schools), mediating macrosystemic influences (policy, cultural values which promote inclusion, but where social expectations for children who are 'different' may still be permeated by normative judgements of 'deviance' and contingent reluctance to embrace

disabled youngsters as valued and equal members of mainstream communities) and meso/exosystemic perspectives (working within and providing challenge to school and local authority practices). As discussed in Chapter Two: Section 9, the document, 'A Review of the Functions and Contribution of Educational Psychologists in England and Wales' (DfES, 2006a) highlighted EPs work at levels of the individual child or family,; EP school and the local authority and therefore have insight into interconnectedness of these systems (Figure 4:2)

Figure 4:2: An ecological map highlighting areas of EP practice



A review of current professional practices indicates that Educational Psychologists work with pupils with special educational needs (SEN), contribute to multi-agency working and undertake strategic work and capacity building in organisations (DfES, 2006a). It is this understanding and contribution to all ecological systems which makes the Educational Psychologist well placed to provide a constructive and insightful view of school culture, ethos, and practices within the context of other ecological systems. However it is also noteworthy that whilst EP casework is varied, it is possible that the EPs who participated in interviews might not have had recent experience of a school's additional support for children with a diagnosis of autism. To address this possible limitation of the interviews, I completed an additional interview with the advisory teacher for children with autism who works solely with staff in schools to support children with a diagnosis of autism. The process of data analysis and the results from these two activities are presented together in Section 4:5:3.

I chose to elicit these perceptions via semi-structured interviews.

4:5:2 Interview design

The use of semi-structured interviews was considered the most appropriate method of data collection as these afforded the opportunity to engage in conversations which provided a degree of flexibility in relation to the level of formality. Essentially, structured interviews use a fixed format with pre-determined questions and fixed wording, usually following a pre-set order. Smith (1995) describes these to be much like a questionnaire. The fixed nature of the structured interview can be useful in generating rich data, and facilitating both aggregation of responses and judgements re: the consistency of responses to the same question. The reported benefits of using structured interviews relate to the reliability of the data, as each participant follows the same format and gives the researcher more control over the interview.

In contrast, the semi structured interview process used in this study was judged advantageous because it afforded flexibility, allowing me to follow up particularly interesting issues which arose, while allowing the participants to give more detailed responses (Silverman 1993). Smith (1995) describes the semi-structured interview as a process of pre-determined questions that are used to guide the interview, but unlike structured interviews, semi-structured interview questions can be rephrased or re-ordered, with varied explanations which are perceived as the most appropriate means of obtaining an accurate picture of circumstances, thought and feelings within each interview.

Given the diversity of personal situations, family dynamics and the different educational phase and age of the child which could have an impact on the parental experiences of historic support from education and health services providers, I considered it important to use a semi-structured interview so that parents could describe their experiences in relation to themselves as individuals, ensuring accounts were authentic and credible. Similarly, with EP colleagues and the advisory teacher, the semi-structured interview was judged appropriate in balancing structured and consistency with flexibility and opportunities for interviewees to share conversational control, perhaps donating perspectives which I, as interviewer might not have anticipated.

4:5:3 Research underpinning interview design

The chosen interview design also addressed aspects of good interview practice. Fontana & Frey (2000) report there are a number of different ways to ensure that an interview is conducted under 'best' conditions. They suggest an interview should be conducted as simply and conveniently as possible for each individual. Individuals participating in the study should be encouraged to identify a time of the day and location which is most convenient and suitable to them (ensuring it is safe for the interviewer), (Friedman et al, 2003). Warren

(2002) also advocates preparing the individual for the interview by providing advance notice of the type of information which will be asked. Warren (2002) suggests this is particularly important when an individual is required to draw on information from memory, or where the individual does not have the information themselves, to allow sufficient opportunity for them to gather the information from others prior to the interview. Lewis (2004), meanwhile, who suggests the researcher should encourage 'don't know' responses or encourage the respondent to seek further clarification of questions asked. Lewis (2004) elaborates further and suggests that a good interview design will avoid repetition of questions, avoid closed questions and aim to provide the interviewee with the opportunity to develop an uninterrupted narrative.

With regard to these approaches within the current study I provided parents with the opportunity to identify and designate a preferred time and location for their interview. Questions were sensitively worded and interviewees were asked to identify areas of improvement in their own practice and that of external providers, thereby reducing risks of violating privacy boundaries, or make participants feel there might be repercussions because of an answer they have given (Ryen ,2002).

4:6 Implementation of educational psychologist and advisory teacher interview

This scoping exercise invited the Local Authority educational psychologist for each secondary school in Midtown to take part in a 30 minute interview with me. The interview was semi-structured and sought to obtain information re: each respondent's knowledge, understanding and perceptions about current levels of support and practices in each targeted school from the EP's perspective.

I also undertook an interview with the secondary school advisory teacher who worked with school staff to support children with autism, in order to ascertain her perceptions of current practices in each secondary school. The advisory teacher works in all schools and she was therefore able to give a more comprehensive account of practices across Midtown. Table 4.5 presents the questions asked to both EPs and the Advisory Teacher and provides a rationale for their inclusion in the interview.

Table 4:5: The list of the questions EPs and the advisory teacher were asked about their of inclusive practices

Question asked	Rationale for inclusion in interview schedule	Supporting Literature
How would you describe the school ethos with regard to the inclusion agenda?	The perception of inclusion could influence how the EP constructs the nature and level of support	Higgins, D'Alessandro & Sath (1998)
What is your perception about the organisation and leadership of the school?	This question was intended to draw out insight into the head teacher's direct involvement in the SEN system or whether a delegated model of leadership is in operation. Responses to this question were to be used to triangulate the data and responses given in the 'Strand 3' school interviews.	Haydon (2009)
How readily do the school staff with whom you work seek additional advice from you to support children with a diagnosis of autism?	This question was intended to clarify how school staff appeared to view the needs of the child and what they actively do to facilitate the inclusion of children with a diagnosis.	Carrington & Elkins (2002)
What strategies are you aware the school uses to support children with a diagnosis of autism?	This question was intended to identify a list of strategies which could then be used to triangulate responses from the 'Strand 3' school interview.	Whitaker (2007)
Do school staff implement advice (at all; with fidelity) to increase the efficacy of support for children with autism?	This question was intended to clarify whether school staff actively utilise approaches commended by the EP and/ or advisory teacher to support children with a diagnosis of autism within the mainstream secondary school.	Whitaker (2007); Jordan (2009)

These questions were considered pertinent in relation to the initial concerns raised by the strategic group and the recognition that children with a diagnosis of autism were disproportionally represented in the number of children permanently excluded from school, which in turn had an impact upon the demand for services available to parents/ carers. The

strategic group wished to clarify and identify what practices were implemented in secondary schools and how these practices translated into the type and level of support required in these schools in order to meet the needs of students with ASD. Retrospectively as the study developed, the responses from these questions were also used to triangulate data from the school staff interviews.

Comments made during the interviews with EPs and the advisory teacher were recorded as field notes (Bogdan & Biklen, 2003).

4:6:1 Process of analysis and results of the third scoping exercise: EP and advisory teacher interviews

The process of analysis utilised Bernard's (2003) technique as described in Section 4:4:5. The five EPs' and one advisory teacher's comments were anonymised and 'condensed' into themes to reflect a "general view"/perceptions held by these professionals about practices within a target school. The 14 schools were anonymised and allocated a letter for reference. The EP and Advisory teacher 'derived comments' were recorded next to the appropriate school.

A summary of these responses is presented in Table 4.6. Each school has been colour-coded using a 'red, amber, green' RAG rating approach to indicate the level of inclusive practice and response to external support, as outlined below.




- | | |
|---|---|
|  | Schools perceived as extremely weak in their inclusive practices, where SEN strategic and operational management and lack support from the senior leadership team are perceived to be low. These schools were also identified as having little or no knowledge and few skills to meet the complex needs of children with a diagnosis of autism. |
|  | Schools perceived as generally inclusive in their philosophy, but sometimes/ often experiencing difficulties meeting the specific needs of ASD children |
|  | Schools perceived as extremely supportive of children with a diagnosis of autism and operating inclusive practices |

Table 4:6: Summary of EP and Advisory teachers' perceptions of inclusive practices in the target secondary schools

School	Prevailing theme/ perception
A	<ul style="list-style-type: none"> • Willing and inclusive in nature with specialist unit, but less successful in accommodating ASD student needs in the mainstream school. • A little chaotic in providing support and utilising strategies – typically support is made available once things have started to go wrong. • Limited support from head teacher • Responsive to advice and recommendations within current resources available.
B	<ul style="list-style-type: none"> • Effective SEN provision • Limited involvement by head, who leaves SENCo to make all operational decisions • Knowledgeable and skilled staff
C	<ul style="list-style-type: none"> • Clear SEN pathway and interventions • SENCo influences wider classroom practices • Difficulties meeting the needs of ASD pupils
D	<ul style="list-style-type: none"> • Limited experience and knowledge of staff to meet the needs of all children with SEN • Difficulty meeting the large number of children with SEN • Responsive to advice
E	<ul style="list-style-type: none"> • Inclusive rhetoric but difficulties translating philosophy into classroom practice • Difficulties managing SEN provision beyond statements • Seek advice from external professionals
F	<ul style="list-style-type: none"> • Inclusive practices • Increasing knowledge base and skill set shared by all staff • Clearly identified SEN provision • Good communication with parents
G	<ul style="list-style-type: none"> • Limited SEN provision, although quick to implement advice and strategies. • Staff are receptive to inclusion agenda • Try to find own solutions to difficulties meeting the needs of children with SEN • Head heavily involved
H	<ul style="list-style-type: none"> • Difficulties managing the number of children with SEN • Receptive to external input although find it difficult to implement advice and strategies. • Many failed placements because of limited knowledge and resources
I	<ul style="list-style-type: none"> • No involvement of Head • SEN operated as “bolt on” provision • SENCo promotes inclusion agenda although this is difficult to implement across the whole school, differentiated/ target support is most evident in SEN unit/ provision. • Reactive approaches to support
J	<ul style="list-style-type: none"> • Knowledgeable and skilled staff • Clear overview of SEN provision for all types and levels of SEN • Awareness of environmental factors on successful inclusion • Highly supportive head teacher
K	<ul style="list-style-type: none"> • Receptive to external support and implements recommendations for individual children • Limited proactive approach to managing SEN in whole school • Some understanding of how children with SEN can have their needs met although experiences difficulties with children with autism.

School	Prevailing theme/ perception
L	<ul style="list-style-type: none"> • Inclusive philosophy • Supportive head teacher • Clear overview of SEN provisions • Proactive approach to support
M	<ul style="list-style-type: none"> • Head does not agree with inclusion agenda • No active support for SEN provision in whole school • High exclusion rates for children with autism • Lack of knowledge about differentiation and SEN support
N	<ul style="list-style-type: none"> • Knowledgeable staff • Inclusive philosophy from SENCo • Clear SEN provision

On the basis of the information elicited from the EP and advisory teacher interviews it appears that practices across the 14 sample schools are extremely varied. The responses for some schools indicated that the systems in place and general culture of the school were considered extremely supportive of children with a diagnosis of autism (e.g. Schools F, J, L, N), while others either have limited support from the senior leadership team and/or had limited knowledge and skills to meet the complex needs of children with a diagnosis of autism (e.g. Schools A,D,E,H,I,M). The number of schools perceived as extremely weak in their inclusive practices and providing limited provisions and support for children with a diagnosis of autism represents 50% of the sample. These findings are consistent with Carrington & Elkins (2002) and Stoll & Fink (1996) findings who also found that a high proportion of schools were limited in their ability to be inclusive, suggesting there is a juxtaposition that whilst staff hold strong positive beliefs about inclusion it does not reflect a commitment to the inclusive education.

Clustered comments from the School EP and Advisory teacher interviews indicate difficulties:

- with the level of knowledge of autism amongst practitioners to facilitate inclusion (Jones, 2009, Whitaker, 2007; Kasari et al, 1999);
- with provision mapping and providing a clear, coherent and transparent package of support Symes & Humphrey's (2011);
- establishing a sense of 'collective responsibility'(Tregaskis, 2002); and
- implementing advice for external agencies owing to difficulties with practitioner skills, funding and staff attitudes.

I recognise the identification of these difficulties with practices within all Midtown's mainstream secondary schools lacks a more comprehensive analysis of factors contributing

to the identified differences between secondary schools' inclusive practices, working relationship with Local Authority support services, and development of expertise to address the needs of students with ASD; however, this was not the purpose of this preliminary 'surface' investigation, which was simply one strand of my reconnaissance, aiming simply to set the scene for more substantial phases of inquiry presented in Chapter Five and Chapter Six.

In light of these findings it was agreed that a subsequent stage of the research should focus upon two areas of school practices:

- identification by school staff of the current types and levels of provisions made available to children with a diagnosis of autism; and
- identification by school staff of the type of service they require from external services in order to facilitate improved access to education for children with an ASD diagnosis.

It is apparent these themes and the themes abstracted from the EP and Advisory teacher interviews and literature review shared common threads and gave further direction to the focus of the study. Figure 4:3 indicates the shared themes across the three scoping exercise (presented overleaf).

Figure 4:3: Summary of the central themes across the three scoping exercises

Central themes from the literature	Central themes from EP and Advisory teacher interviews	Central themes from parent interviews
<ul style="list-style-type: none"> • Severity of need influences views on inclusion • Parents desire specialist resources, adapted curriculum, opportunities to develop socialisation skills, a positive • School environment, teachers willing to respond to advice • Parents felt authorities needed to listen to parents more • Concerns raised by parents about their ability to make requests of school staff without jeopardising relationships 	<ul style="list-style-type: none"> • Concerns re: limited staff knowledge and skills • Difficulties with the level of knowledge of autism amongst practitioners to facilitate inclusion • Difficulties with provision mapping and providing a clear, coherent and transparent package of support 	<ul style="list-style-type: none"> • Lack of acceptance by professional of parental concerns • Lack of support following diagnosis, and wanting more support • Difficulties getting schools to recognise child was not naughty

Central themes from the literature	Central themes from EP and Advisory teacher interviews	Central themes from parent interviews
<ul style="list-style-type: none"> Parents concerns about general knowledge and understanding of autism amongst teachers Teachers expressed concerns about their insufficient knowledge or training in autism Teachers report feeling inclusion 'did not work' for children with autism because of need, particularly social and behavioural needs. 	<ul style="list-style-type: none"> Difficulties establishing a sense of 'collective responsibility' Difficulties implementing advice from external agencies, owing to difficulties with practitioner skills, funding and staff attitudes. 	<ul style="list-style-type: none"> Difficulties within family relationships accepting and agreeing the child has difficulties / stress on parents A sense that professionals think they know best and do not consult parents
Central themes from the literature for parents views on service delivery		
<ul style="list-style-type: none"> Concerns about knowledge about condition amongst health care professionals. Parents desire increased support Parents desire quicker diagnosis 		



Themes across sources
<ul style="list-style-type: none"> Concerns about knowledge about condition amongst health care and educational professionals Parents desire increased support Parents consider that authorities/ professionals needed to listen to parents more Parents desire specialist resources, adapted curriculum, opportunities to develop their child's socialisation skills Difficulties with provision mapping and providing a clear, coherent and transparent package of support Lack of acceptance by professionals of parental concerns

Having completed the full reconnaissance exercise and considered the issues and concerns initially raised at the outset by the sponsors, from the perspectives of EPs, an advisory teacher and a small number of parents, the following research questions outlined in Table 4:7 were identified as the focus for the substantive inquiry reported in Chapter Five and Six of this thesis.

Table 4:7: Proposed research questions

Reconnaissance processes	Themes	Research question
<ul style="list-style-type: none"> Sponsors' concerns Initial parent interview 	<ul style="list-style-type: none"> Parents desire increased support Difficulties with provision mapping and providing a clear, coherent and transparent package of support 	<p>1: What support and information is available to parents/carers following a diagnosis of autism?</p>

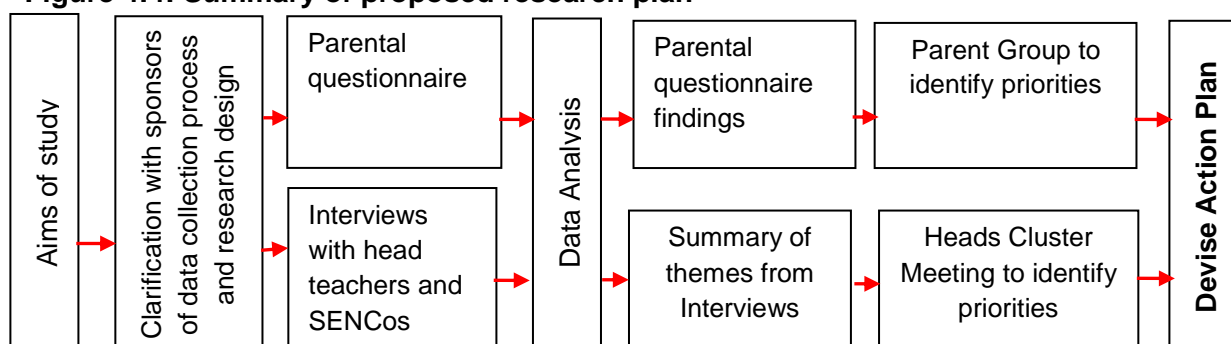
Reconnaissance processes	Themes	Research question
<ul style="list-style-type: none"> Literature review Sponsors' concerns 	<ul style="list-style-type: none"> Parents desire increased support Difficulties with provision mapping and providing a clear, coherent and transparent package of support to children and families following diagnosis Lack of acceptance by professional of parental concerns 	2: What do parent/carers value about current service delivery from education, health and social care agencies?
<ul style="list-style-type: none"> Sponsors' concerns Literature review Initial parental interview 	<ul style="list-style-type: none"> Parents desire improved access to specialist resources, adapted curriculum, opportunities to develop their child's socialisation skills Concerns about knowledge about condition amongst health care and educational 	3: What could education, health and social care agencies do to improve the services available to parents/ carers pre and post diagnosis?
<ul style="list-style-type: none"> EP and advisory teacher interviews Initial parent interviews 	<ul style="list-style-type: none"> Parents desire improved access to specialist resources, adapted curriculum, opportunities to develop socialisation skills Difficulties with provision mapping and providing a clear, coherent and transparent package of support 	4: What provision do mainstream secondary schools make available to support the inclusion of children and young people with autism?
<ul style="list-style-type: none"> EP and advisory teacher interviews Initial parent interview 	<ul style="list-style-type: none"> Parents desire improved access to specialist resources, adapted curriculum, opportunities to develop socialisation skills Concerns about knowledge about autism amongst health care and educational professionals 	5: What support is available to mainstream secondary schools from education, health and social care professionals to support the inclusion of children and young people with autism in school?
<ul style="list-style-type: none"> EP and advisory teacher interviews Literature review Sponsors' concerns 	<ul style="list-style-type: none"> Difficulties with provision mapping and providing a clear, coherent and transparent support package 	6: What could education, health, social care agencies do to improve support for mainstream secondary schools in their inclusive practices?

The reconnaissance exercise had centred upon considering how the perspectives of EPs, the advisory teacher and parents, alongside trends identified within research literature and the research sponsors' concerns should inform the remit of the next research cycle, informing the six questions outlined in Table 4:7.

4:7 Process of action research: Step two – Formulating a plan

From the reconnaissance phase of the Action Research Cycle and the identification of the research questions I then needed to clarify how these questions could be addressed. I determined that there would be two strands of data collection process; firstly an exploration of parental experiences of practices and perceived needs from statutory services within Midtown; and, secondly an investigation into the entitlement of children with ASD to high quality secondary education which presents as a particular challenge in Midtown schools. As such this forms an immediate priority and focus of Strand 3 of the current research. The plan formulation is summarised below Figure 4:4.

Figure 4:4: Summary of proposed research plan



4:8 Summary

Once the research design had been established and the method of data collection had been clarified, I began the first action steps of the action research cycle as described in Kemmis' model which is discussed in Chapter Five.

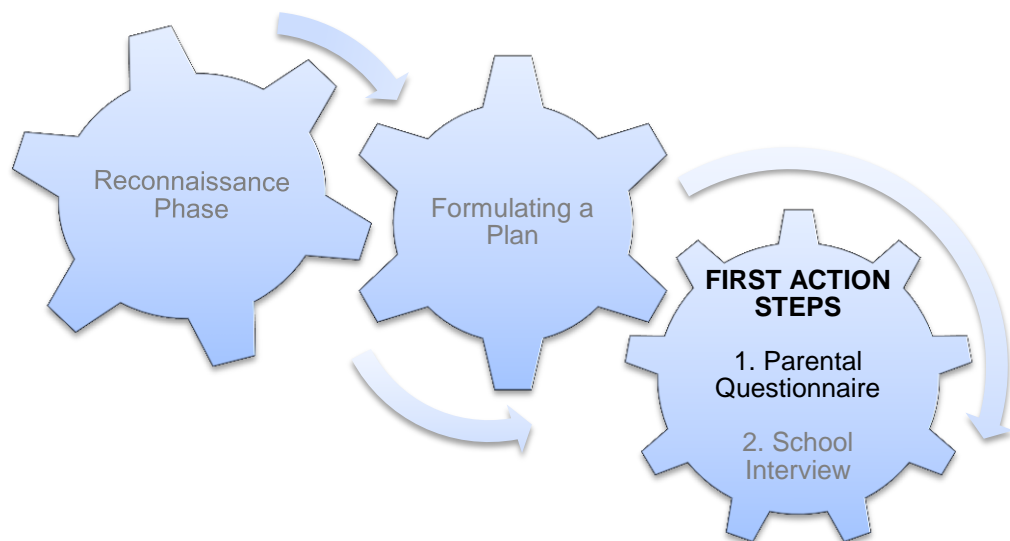
Chapter Five

Experiences of parents/carers of children with an Autism Spectrum Disorder

5:1 Introduction

Within the study so far, I have completed two stages of the action research model illustrated in Figure 5:1, as discussed in the previous chapters. The next stage of the Action Research model consists of undertaking the **First Action Step**.

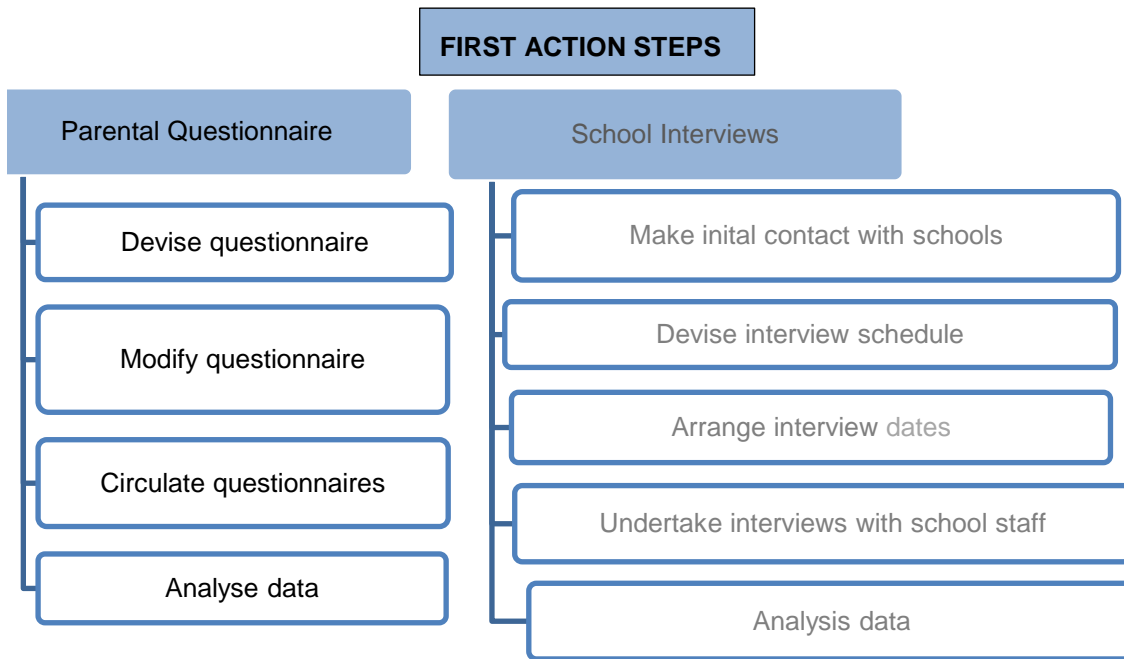
Figure 5:1: Summary of completed stages of the action research model



The first action step entailed two processes: firstly the construction and administration of a parental postal questionnaire; secondly, securing interview dates with head teachers/ SENCos in schools, devising an interview schedule, and undertaking the interviews. As further elaborated overleaf, the parental questionnaires sought to inform a comprehensive picture of Midtown parents' experiences and needs in relation to support in managing their autistic child's needs. The head teacher/ SENCo interviews aimed, in parallel, to build a comprehensive account of secondary schools managers' perspectives on the demands placed on their schools by policy expectations for inclusive special provision, and the adequacy of the support their schools received in fulfilling this obligation to children with ASD and their parents (as discussed in Chapter Six). The first of these processes (as illustrated in Figure 5:2) is discussed in this chapter.

Following the reconnaissance phase, which included initial parental interviews, it was evident there were some consistencies between the six parents' experiences, although the extent to which these applied to the wider population for each specific age group was unknown.

Figure 5:2: Research strand within the context of ‘First Step’ stage of research



To ensure a more holistic understanding of the issues relating to the services available to parents of children pre- and post-diagnosis of autism, questionnaires were sent to all the parents with a child/ren aged between 2-16 with a diagnosis of autism, as recorded on Midtown’s database.

5:2 Rationale for use of questionnaire

The use of a questionnaire-based survey was considered suitable as it enabled me to access a wide sample quickly and offered benefits described by Oppenheim (1966) (as discussed earlier in Chapter Four Section 4:3).

5:2:1 Research underpinning questionnaire design

The process of questionnaire design was governed by a number of considerations. Lietz (2009) argues the process of responding to questionnaires is complex. She suggests that a respondent needs to go through a number of different processes in order to provide a response. These includes comprehending and decoding the question which is being asked, to retrieving relevant information from the memory, where the respondent makes a judgement about the retrieved information, followed by encoding a response. The encoded response is subsequently decoded by the researcher and used to draw conclusion from the data. In addition to these complex processes, the response provided is also influenced by the respondent’s motivation and readiness to be truthful about his/her experiences. Each of these processes could potentially affect the response provided; all are integral to the ‘trustworthiness’ of the response.

Brace (2004) argues that success in eliciting a reliable answer to the question you asked is reliant on successful encoding of the question. There are a number of measures a researcher can take to ensure the 'encoding' of the question is likely to produce clarity about what the respondent is being asked. These include wording a question in language which is attuned to the respondent's language (Brace, 2004). The use of the initial parent interview had provided a means to calibrate the language used by parents, and this insight informed the questionnaire design.

Another factor which should influence the wording and construction of questions is the simplicity of the language used. Dornyei (2003) recommends that the researcher should minimise the grammatical complexity of question; this includes using the active voice, repetition of nouns and avoidance of pronouns and possessive forms. Dornyei (2003) commends deployment of approaches when constructing questions which reduce the cognitive demands placed upon the respondent and so allow them greater mental capacity to think about their response. White et al (2005) also emphasise the importance of devising questions which reduce the cognitive load, thereby enhancing the quality of understanding and response provided. White (2005) suggests this can best be achieved by using specific rather than general terms, breaking complex questions into simpler ones and providing illustrations of specific concepts.

Another factor facilitating a respondent's understanding of questions is ensuring short questions or statements are used (Holbrook et al, 2006). Indeed Brislin (1986) suggests that a short sentence or statement comprised of a maximum of 16 words can aid comprehension, whilst Oppenheim (1992) suggests 20 words per sentence ensure clarity of meaning in the question, although Oppenheim also argues that a question can consist of a number of sentences. Indeed Jabine (1987) reports longer questions lead to more accurate reporting because they convey the task is important and deserves serious effort in completing a response. A final consideration in the process of the questionnaire design within this study arose from Foddy (1993), who emphasises the importance of wording questions in ways which reduce risks of putting the respondent off, through what he describes as 'question threat'. The researcher should seek to avoid using poorly worded questions or explanations, and complex vocabulary, so that the respondent does not feel uneducated or stupid, as this would be likely to reduce willingness to respond at all, or compromise the encoding processes, whereby the answer given might not relate to the question asked owing to difficulties making sense of the question. By deploying these features within my questionnaire design I sought to increase the accuracy of the cognitive processes Leitz

(2009) described, thereby securing greater authenticity in the data collection process. This is discussed further in Section 5:8.

5:2:2 Process of questionnaire design

The process of deriving which questions would be included on the questionnaire was informed by the findings of the literature review, the preliminary parental interviews and the research aims, as illustrated in Table 5:1.

Table 5:1: Summary of questionnaire questions in the context of my existing knowledge about parental experiences

Questions asked	Preliminary parent interviews	Literature review	Research aims
1. From the support available to you and your child pre-and post- diagnosis and assessment what did you value?	<ul style="list-style-type: none"> Lack of acceptance by professional of parental concerns A sense that professionals know best 	Minnes and Steiner, 2009; Renty & Roeyers, 2006 Runswick-Cole, 2008	To elicit, and abstract key trends within parents' accounts of their experiences and perceptions of service delivery and of the support available to them pre and post diagnosis.
2. Following your child's diagnosis what do you feel you needed from support services?	<ul style="list-style-type: none"> Lack of support following diagnosis Difficulties within family relationships accepting and agreeing the child has difficulties / stress on parents 	Jones et al, 2009; Whitaker, 2002; Little, 2003; Dillenburger et al, 2010; Lamb Enquiry, 2009	
3. How could services be improved?		Dymond et al (2007)	
4. What are your experiences of school support following your child's diagnosis?	<ul style="list-style-type: none"> Difficulties getting schools to recognise child was not naughty 	Humphrey & Lewis, 2008	To understand inclusive practices within Midtown's secondary schools and identify support available to secondary school could facilitate further inclusion of children with a diagnosis of autism.
5. What support did school put into place to support your child following their diagnosis?	<ul style="list-style-type: none"> Difficulties getting schools to recognise child was not naughty A sense that professionals know best 	Humphrey & Lewis, 2008 Runswick-Cole, 2008	

The questionnaire design went through one 'revision and modification' phase before the final draft was agreed with sponsors. These amendments were made in consultation with the Head of Service, a parent of a child with autism, and the sponsors. Whilst this process of consultation was limited to one parent's contribution to the questionnaire design, I judged

that the narratives obtained through the initial parent interviews had identified the areas of difficulties and the focus for further exploration, and indeed reflected Pretty et al's (1995) notion that participation is a continuum of involvement, whereby participation takes different forms, at different times in the research process and in different situations and contexts. However had the time constraints within which the study needed to be completed been less exacting, further parental participation in the questionnaire design would have been sought via a focus group with a particular emphasis on the presentation / specific wording of the questions to facilitate their accessibility and relevance to parental experiences and the research aims.

Within this process, the first draft required the addition of a section seeking data about the educational phase and the length of time since the child was given the diagnosis. This section was added to ensure that responses could be analysed in depth, with comparisons made across educational phases and the interval since the diagnosis to gain a better understanding of the relationship between these factors and reported experiences, thereby perhaps illuminating whether/ how changes in policy may have influenced parental perspectives and experiences. A second addition to this section included a fixed choice question to gain insight into what published literature has been made available to parents. For this, the sponsors provided the list of information and support usually provided to parents within Midtown, following a diagnosis of autism.

The final questionnaire (Appendix 6) consisted of two pages divided into three sections. The first section reflected the revisions made between the first and final draft. Section 1 included the educational phase, the length of time since the child's diagnosis and identification of published literature distributed by professionals to parents\carers. Response options within this section denoted options from which respondents were invited to select.

The second section of the questionnaire sought to provide parents/ carers with the opportunity to provide their own narrative through the use of open questions. Parents were asked three questions relating to their past experiences and one question relating to future needs for the child and/or family. Questions relating to support during and post-diagnosis were explored; aiming to:

1. identify support available to families that was valued;
2. elicit suggestions for how support could have been improved; and
3. elicit what parents feel they need post-diagnosis.

The third section sought to ascertain parents' perceptions of inclusive special educational

practices within early years and school settings, and how these inclusive practices were achieved. Questions in this section aimed to:

1. identify parents' experiences and views about educational establishments' capacity to meet the needs of their child following diagnosis; and
2. identify measures in place to meet the needs of a child following the diagnosis.

The questions in this section required forced choice answers with tick boxes, augmented by two opportunities to provide an extended response. The second question provided a list of inclusive practices identified within the Code of Practice (DfES, 2001b) and the 'Matrix for Inclusion', (Midtown City Council, 2011), the Local Authority guidance to schools detailing the types of activities which should be undertaken to ensure successful inclusion of all pupils. The rationale for exploring these issues was to identify what current practices were available to children with autism in school, how these practices relate to national guidance (NAPC, 2003; IDP, 2010) and to facilitate comparisons of the range of practices within and across primary and secondary provisions.

5:2:3 Postal questionnaire sampling

The parental questionnaire used a 'convenience sampling' (Robson, 2002) approach within Midtown. All children receiving a diagnosis from the Clinical Psychology Team or from a Consultant Community Paediatrician based at the Children's Hospital are subsequently referred to the STePS team, and these children are then formally recorded on the Local Authority database. Some children also receive a diagnosis from the Child and Adolescent Mental Health Service (CAMHS). Some of these children are known to STePS, although there is no formal process for informing education services about a diagnosis of autism by CAMHS professionals. The number of children recorded on the database in September 2010 was 278 (aged 0-18 years). Of these children, 223 were recorded as of statutory school age or as pre-schoolers. (2-16 years). Questionnaires were sent to all parents/carers of the 223 children within the 2-16 age range. This included the parents/carers where children attended specialist and mainstream provisions. The sample included parents/ carers of children who underwent the assessment from different diagnostic services, represented different educational phases, and parent/carers whose children received their diagnosis at different times within the developmental trajectory.

5:2:4 Administration of parental postal questionnaire

In June 2011, the 223 questionnaires were posted to parents/carers with a child of pre-school (2-4 years) or school age with a diagnosis of autism spectrum disorder known to Midtown Education Service. Each parent/carer received a letter detailing the study aims, consent form and questionnaire (Appendix 6). Parents/carers were requested to return

completed questionnaire to STePS via an enclosed pre-paid envelope by 30 June 2011, providing a three week period to complete and return the questionnaires.

5:2:5 Data analysis: parental questionnaire

The first section of the questionnaire was constructed with pre-determined tick-box questions and respondents were asked to indicate the response options which denoted their experiences. This data was then analysed using descriptive statistics to reduce the data into a simpler summary. The number of responses for each tick-box question was recorded and is summarised in Table 5:3.

The second set of data generated by the questionnaire survey were analysed using a broad thematic analysis. Themes within the data were identified using an inductive semantic approach (Frith & Gleeson, 2004), whereby patterns and trends are abstracted from the data, rather than themes which are driven by pre-determined codes. However it is noteworthy that as both the questionnaires and interview schedules were generated from an understanding of literature findings, it is highly likely that the data analysis would reflect some of the themes evident in the literature and utilise an a priori approach of data analysis.

The thematic analysis used for questionnaire data examined what was said and moved from descriptions of experiences to patterns of semantic content on to interpretation of the significance of the patterns and their broader meanings and implications (Patton, 1990).

Braun & Clarke (2006) emphasise there is no right or wrong way to do thematic analysis but drawing on Miles & Huberman's requirements, I utilised a data reduction and data display approach as presented in Table 5:2.

Table 5:2: Summary of data analysis processes using Miles and Huberman's (1982) guidelines for qualitative analysis.

Process	Action undertaken	Outcome
Data reduction	Questionnaires were read, and responses to each question were summarised as reduced and simplified text encapsulating the essence of the comment. If other respondents provided similar comments, they were 'clustered' together under a broader heading	Q1. What parents value immediately following diagnosis: 19 different comments noted as 'codes' Q2. What could have been improved immediately following diagnosis? 19 different comments noted as 'codes'

Data reduction	Action undertaken	Outcome
	Each new concept or concern reported on the questionnaire was noted in this way so that the raw data became a refined collection of words signalling commonality of content.	Q3. Identification of individual needs: 24 different comments noted as 'codes'
Data display	'Coded' data were sorted into themes based upon the similarity of the comments.	Q1. 19 codes reduced to 5 themes Q2. 19 codes reduced to 4 themes Q3. 24 codes reduced to 5 themes

From the 223 questionnaires, 42 responses were received, (18% return rate) from a range of educational phase and time of diagnosis.

There were a number of steps taken to try and improve the response rate. These included oral reminders at the Autism Drop in centre, the CAGNAS meeting (Midtown Autism Group – National Autism Society), and requests to schools to remind parents to complete and return the questionnaires. As the questionnaires were anonymous and I was unaware which questionnaires had been returned by whom, there was no mechanism to target individual families and remind them to return the completed questionnaires. Implications of the low response rate are discussed in Section 5:8. The profile of respondents is summarised in Table 5:3.

Table 5:3: Summary of questionnaire sample

Educational Phase	Pre-school	Infant	Junior	Secondary
No. of completed responses	2	20	12	8
Percentage in relation to sample composite	4%	47%	28%	19%
Time since diagnosis	<2 years	2-3 years	3+ years	
No. of completed responses	1	9	32	
Percentage in relation to sample composite	2%	21%	76%	

This data indicates that all educational phases (pre-schools through to secondary school), were represented across the sample although respondents from the 'pre-school' group were

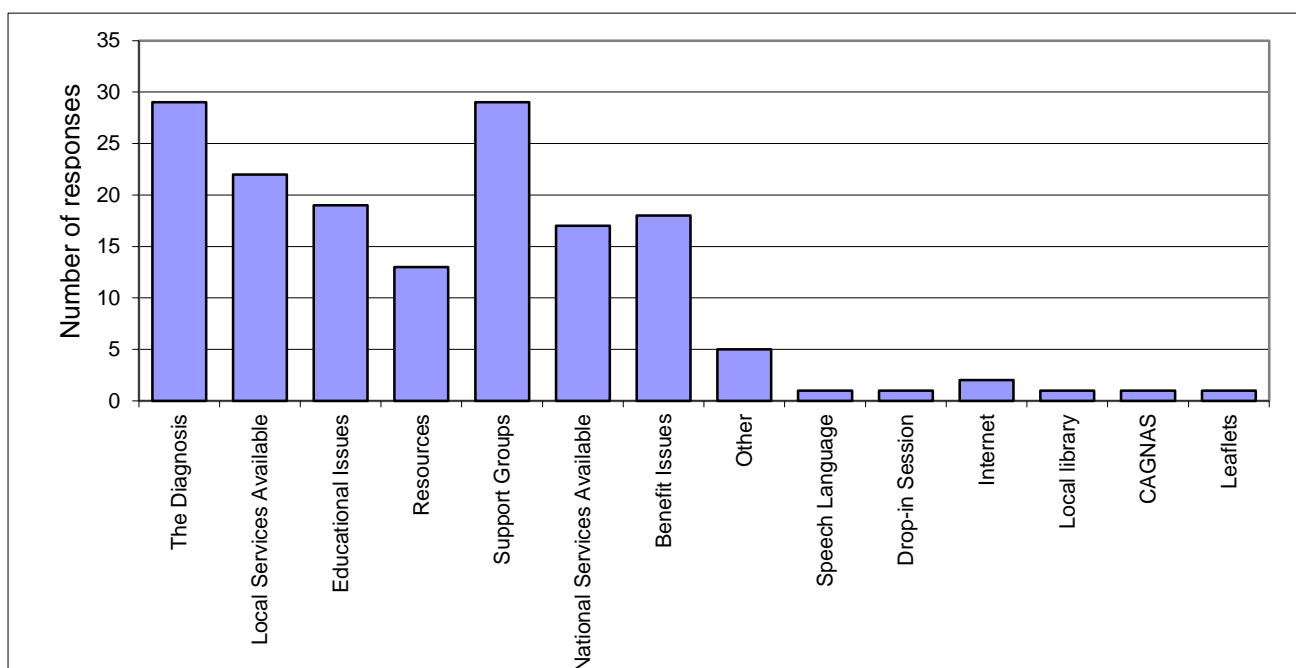
significantly low. This low response rate was also evident for children who had received a diagnosis in the last two years.

5:3 Results for Research Question 1: What support and information are available to parents following a diagnosis of autism?

Respondents were presented with a number of forced choice responses, and asked to indicate what types of information professionals made available to them at the time of diagnosis. They were asked to indicate all responses which were applicable to them. These responses are presented in Figure 5:3.

Parents across the sample indicated there was a range of information available to them immediately following the diagnosis. 69% of parents who responded to the survey had been informed about the diagnosis itself. In addition to securing information about the diagnosis, some of these parents received further information about local support services and support groups, whilst other parents received only information about support services. The majority of parents also indicated a lack of information about Speech and Language Services, with only 1 respondent (2% of sample) indicating he/she was provided with information about Speech and Language Services. This result is surprising given difficulties with speech, language and communication skills are integral to the triad of impairment which inform ASD diagnostic criteria

²Figure 5:3: Summary of information made available to families following initial diagnosis



² Educational Needs– Statutory assessment process, arrangements for support in mainstream schools

Furthermore, less than 50% of parents reported they had received information about educational support, such as statutory assessment, education placements, information about Midtown's 'Autism Drop-in' sessions, information about national services available to families or benefits entitlements. Further analysis for each aspect of 'information giving' indicates that there is disparity between parental experiences of receiving information which they consider to be adequate and appropriate, in relation to the time interval since diagnosis and the child's current educational phase (presented in Table 5:4)

Table 5:4: Percentage of respondents receiving information at the time of diagnosis

	About Diagnosis			Local Services			Educational Needs			Resources		
% of respondents	69% (n=29)			52% (n=22)			45% (n=19)			30% (n=13)		
Time Interval in years	<2	2-3	3+	<2	2-3	3+	<2	2-3	3+	<2	2-3	3+
(n=)	1	8	20	1	4	17	0	3	16	0	3	10
Education Phase	PS	P	S	PS	P	S	PS	P	S	PS	P	S
(n= /)	2	22	5	2	16	4	1	15	3	0	11	2
	Support Group			National Services			Benefit Entitlements			Other		
% of respondents	69% (n=29)			40% (n=17)			42% (n=18)			11% (n=5)		
Time Interval in years	<2	2-3	3+	<2	2-3	3+	<2	2-3	3+	<2	2-3	3+
(n= / %=)	1	8	20	0	5	12	1	5	12	0	2	3
Education Phase	PS	P	S	PS	P	S	PS	P	S	PS	P	S
(n= / %=)	2	22	5	1	16	0	1	15	2	1	3	1

It appears parents of primary-aged children who received their diagnosis more than three years ago, were more likely to have received a variety of information about the condition and support services available to them. Parents of secondary-age children or children who received their diagnosis in the past three years or less were less likely to receive comprehensive information about the diagnosis and support services available. This trend suggests 'information giving' within Midtown is fragmented and dependent upon who/ where the child receives the diagnosis (all pre-school children and the majority of primary-aged are referred to a multi-professional social and communication clinic for assessment while secondary-aged children can be referred to CAMHS or clinical psychology) 'the information

giving' is varied. Furthermore the trends indicate the quality of 'information giving' has declined in recent years.

5:4 Responses to Research Question 2: What do parent value about current service delivery from education, health and social care agencies?

Respondents were asked to expand upon their experiences of information and support available at diagnosis, and to consider the specific support they had valued? Themes derived from analysis of responses to this open question are summarised in Table 5:5.

Table 5:5: Support which was most valued

Theme	Summary of Response	Number of respondents (n= / %=)	Responses across education phase		
			PS	P	S
Professional Attitudes	• Caring attitude from Assessment Centre Staff	15 (35%)	2	11	2
	• Support from Early Intervention Team	11 (26%)	2	9	0
	• Caring attitude of Speech and Language Therapist	7 (16%)	1	5	1
	• Supportive Clinical Psychologist	7 (16%)	0	5	2
	• Responsive approach from professional	6 (14%)	1	3	2
	• Caring attitude from Paediatrician	5 (11%)	1	4	0
	• Supportive Educational Psychologist	4 (9%)	0	2	2
	• Caring attitude from Pre-school Staff (nursery staff)	2 (4%)	0	2	0
	• Caring attitude from Sure Start Staff	2 (4%)	1	1	0
Practical Support	• Support with developing ways to communicate	12 (28%)	2	8	2
	• Early Intervention Team providing knowledge about ASD	9 (21%)	3	6	0
	• Parent Partnership Advice	5 (11%)	0	4	1
	• Advice on diet from health and educational professionals	5 (11%)	2	3	0
	• Support with paperwork	3 (7%)	1	2	0
Knowledge and Expertise	• Knowledge of the professionals exceeds that generally found within the ASD field	8 (19%)	2	5	1
	• Fast referral and problems sorted out	6 (14%)	1	5	0
	• Informative assessment	3 (7%)	2	1	0
Literature	• Handful of leaflets	2 (4%)	1	1	0
Provisions	• Hanen Course (Speech and Language Course)	6 (14%)	2	4	0

Time interval since diagnosis : <2 = Less than 2 years 2-3 = Between 2 and 3 years 3+ = More than 3 years

Educational Phase : PS = Pre-School P = Primary S = Secondary

Parents reported that a supportive and caring attitude from professionals during and following diagnosis was valued, citing a range of professionals as their source of such support (illustrative comments presented in Box 5:1)

Box 5:1

“The Clinical Psychologist was immensely helpful.” (Secondary-aged child)

“Dr XX was wonderful, caring and informative. Mrs XX (Early Intervention) was my best form of support and being able to pick XX’s brains so often has been wonderful.” (Infant-aged child)

“The educational psychologist was very supportive. The report produced was extremely helpful and informative.” (Junior-aged child)

“A health visitor to come to the house would have been helpful.” (Infant-aged child)

“we need to have support available to families possibly at home where you can talk without feeling rushed.” Junior-aged child).

“A home visit from a support worker would have been really helpful. It is easier to talk in your own home.” (Infant-aged child)

It is evident from the data that parents of primary-aged children were more likely to value the support available from professionals. Some parents indicated that professional support was beneficial beyond a clinical setting, citing professionals undertaking home visits as a valued component of support.

However 19% (n=8) of responses indicated that professional support was sometimes limited (as illustrated in Box 5:2).

Box 5:2

“I found no value in the support available. The information on support mainly consists of books on autism.” (Junior-aged child)

“I didn’t receive any support. He was diagnosed by the Psychology Service and then discharged and we were sent home unsupported in every respect.” (Secondary-aged child)

Whilst some parents indicated printed information and leaflets about Autism had been of value, the remaining questionnaire responses suggested that leaflets were often provided as a substitute for other support, and their provision was therefore less highly valued.

5:5 Responses to Research Question 3: What could education, health and social care agencies do to improve the service available to parents/ carers pre- and post-diagnosis?

Parents were asked to identify what, in their view, could be improved within the current model of service delivery. Trends in response to this question are presented in Table 5:6.

Table 5:6: Ways to improve service available to parents

Theme	Summary of Responses	Number of respondents (n= / %=)	Responses across education phase		
			PS	P	S
Increased professional staffing levels	• More staff to manage work load	14 (33%)	1	8	5
	• More pre-school staff to increase the number of home visits	7 (16%)	2	5	0
	• Key worker appointed	7 (16%)	1	2	4
	• More Health visitors to visit the home and provide support in the home environment	4 (9%)	2	2	0
Local Provisions	• More places to go, and support groups within local communities	8 (19%)	0	6	2
	• Access to other parents who have CYP with ASD	6 (14%)	0	0	6
Access to Knowledge and Expertise	• Access to professionals who have experience and knowledge of ASD	22 (52%)	2	1	8
	• Support about what to do following diagnosis	15 (35%)	2	8	5
	• Professionals listening to parental concerns initially	12 (28%)	2	4	6
	• Improved access to professionals	10 (23%)	0	6	4
	• Identify agencies/ professionals who could possibly help	10 (23%)	1	6	3
	• Access to information about other services	8 (19%)	0	4	4
	• Provision of pack detailing support and professionals with specialism	8 (19%)	1	4	3
	• Prompt response from professionals	8 (19%)	0	2	6
	• All professionals to have improved understanding of Autism	5 (11%)	1	1	3
Education (schools)	• Improved funding to assist support in school	18 (42%)	0	10	8
	• School taking diagnosis seriously	12 (28%)	0	7	5
	• Schools to set up behaviour groups/training	10 (23%)	0	4	6
	• Discussions about alternative placements	8 (19%)	1	3	4

Whilst parents identified 19 recommendations to improve services and support to families, some parents demonstrated an awareness of the constraints imposed by professionals

increased caseload and the impact this had on their capacity to provide families with the level of support required (as illustrated in Box 5:3).

Box 5:3

"I know J has a large caseload and she supports me when she can, but it isn't always at the times I need it." (Infant-aged child)

"It was a long time between my initial referral to the community paediatrician and us finally getting seen and J getting his diagnosis." (Junior-aged child)

"Having a key worker would be really helpful. There's not enough people we can contact and talk to when we have a problem." (Secondary-aged child)

Parents also reported that professionals should have sufficient knowledge of autism and so remain responsive to the needs of the parent and developing child by becoming more accessible (Renty & Roeyers, 2006). It is possible that some parents want a more flexible approach to meeting professionals as often there can be unheralded and unexpected challenges and changes to a child's behaviour.

Other needs identified by parents/carers included a wish for changing perceptions in schools about the diagnosis, increasing funding to facilitate support, improved training opportunities in schools, and for professionals to afford greater priority to being less partisan when discussing the suitability of existing educational placements. Parents of children with a diagnosis of autism in secondary schools were particularly concerned about educational provisions available to their child. Eighty-seven per cent of respondents with a secondary-aged child reported difficult experiences in relation to staff understanding the diagnosis and how the condition affects behavioural, social and learning responses compared to twenty-five per cent of junior aged children (illustrated in Box 5:4).

Box 5:4

"B came across as having bad behaviour rather than poor understanding. School were rigid about any adaptations that needed to be made, thus making the environment almost impossible." (Secondary-aged child)

"Understanding, support and engagement was great in KS2 but this isn't represented across phase. Not everyone can be an ASD expert, but (to be) unwilling to learn or engage is little short of discrimination." (Secondary-aged child)

"Teachers having even the first clue about Asperger would be helpful." (Secondary-aged child)

5:6 Results for Research Question 4: What support do parent/carers require in the future?

Parents provided 80 comments about the type of support they required. These comments were grouped together based upon the similarity of the comment and clustered as four themes:

1. Practical support
2. Emotional support
3. Professional support
4. Local resources and provisions

Within each of these broad themes, responses were analysed further against the child's current educational phase and the time interval since diagnosis. Within the theme of 'Practical Support', there were 27 comments made from the 42 completed questionnaires.

Table 5:7: Trends across educational phase and time interval since diagnosis in relation to the practical support required

		Time interval since diagnoses	Practical Support Required			
			Support with toileting (No. of responses % for age range)	Explanation of where to get help (No. of responses % for age range)	Information about Benefits (No. of responses % for age range)	Signposting for practical help (No. of responses % for age range)
Educational Phase	Pre-School	2-3 yrs	1 (50%)	2 (100%)		1 (50%)
		3+ yrs	1 (50%)	1 (50%)		
	KS1 (Infant)	3+ yrs		3 (15%)		3 (15%)
	KS2 (Juniors)	2-3 yrs		2 (16%)	1 (8%)	1 (8%)
		3+ yrs		3 (25%)	1 (8%)	1 (8%)
	Second-ary	3+ yrs		3 (37.5%)		3 (37.5%)

Data trends indicate that if a child had an autism spectrum diagnosis for two or more years, parents/carers were able to identify gaps in provision and future needs. Parent stated they required advice about where to get practical support, including access to professionals who could demonstrate approaches and ensure parents were applying techniques correctly.

Parents also indicated they would like continued access to professionals who could signpost them in the direction of further assistance. It is possible that parents require further advice and support from professionals for a number of reasons. Firstly, it is likely that the process of development and maturation at different stages in the developmental lifespan will lead children to present with different challenges (Shattuck et al, 2007). For example one parent of a junior aged child wanted to know where to get help in developing her/his child's understanding of sex education and puberty. Previously this had not been an immediate concern for the parent because the child had not reached that developmental stage.

Another factor contributing to parents' need for on-going advice and support from professionals may relate to the quality of information given at the time of diagnosis. It might be that the parents were given only information considered relevant in light of the child's age and stage of development that they were given a more comprehensive briefing, but over time they forgot information which had not been of immediate relevance. Indeed Seltzer et al (2004) sought to review research literature on how symptoms of autism change across a life course. The evidence reviewed (Mawhood & Rutter, 2000; Howlin, Mawhood & Rutter, 2000) indicated age is an important predictor of changes in autism symptoms. It is noted that autism symptoms and maladaptive behaviours (behaviours such as aggression, disruptive behaviour and self-injury) often improve (reduce) over the lifespan (Tonge & Einfield, 2003) as language development improves. It is possible that some of the parental responses requesting further information relate to those families where the child has either co-morbid conditions which are consistently associated with poorer developmental and behavioural outcomes (Lord & Bailey, 2002; McGovern & Sigman, 2005).

Within the second theme, **Emotional Support**, there were 19 comments indicating what parents would like to receive from service providers (Table 5.8 presented overleaf).

Similar to findings relating to 'Practical Support', there were no comments made by parents whose child had been diagnosed within the last two years. It is possible that parents whose child has a relatively new diagnosis feel there is good support because there is a high number of professionals involved at this early stage, but when professionals do not maintain the same level of involvement owing to the demands of new cases, parents feel less supported.

Table 5:8: Responses across educational phase and time interval since diagnosis in relation to emotional support

		Emotional Support							
		Time interval since diagnosis	Counselling (No. of responses % for age range)	Family Therapy (No. of responses % for age range)	Home visits (No. of responses % for age range)	Explanation to wider family (No. of responses % for age range)	Meeting other families (No. of responses % for age range)	More support groups (No. of responses % for age range)	Local support groups (No. of responses % for age range)
Educational phase	Infant	2-3 yrs	1 (5%)					1 (5%)	
		3+ yrs	3 (15%)		1 (5%)			2 (10%)	
		3+ yrs	3 (15%)		1 (5%)			2 (10%)	
	Juniors	2-3 yrs	2 (16%)			1 (8%)			1 (8%)
		3+ yrs	3 (25%)					1 (8%)	1 (8%)
	Second -ary	3+ yrs	2 (25%)	1 (8%)					

One area parents across different educational phases viewed as useful was access to counselling; for parents of junior-age children (8-11) who received a diagnosis more than two years previously, this would comprise the additional support of greatest value. It is possible that this cohort of parents becomes increasingly concerned about school transitions and progression into adolescence, which results in a need for support in talking about these difficulties and accommodating implications of their child's life-long difficulties. Indeed Renty & Roeyers (2006) found parents were concerned with understanding schooling options and services available to them, which resulted in heightened emotional arousal and feelings of satisfaction when opportunities to explore these concerns were provided.

25 comments related to the broad theme, '**Professional Support**', that parents desired from professionals (presented in Table 5:9)

The area in most need of development is the attitude of staff in schools. Parents reported they would welcome the development of more inclusive attitudes by staff in schools and those providing support about educational placements.

Table 5:9: Responses across educational phase and time interval since diagnosis in relation to the professional support

		Time since diagnosis	Professional Support				
			Develop inclusive attitudes in school (No. of responses % for age range)	On-going Support from professionals (No. of responses % for age range)	Attendance at Annual Reviews (No. of responses % for age range)	Psychology Input (No. of responses % for age range)	Earlier support (No. of responses % for age range)
Educational Phase	Infants	2-3 yrs	1 (5%)				
		3+ yrs	3 (15%)	2 (10%)		2 (10%)	1 (5%)
	Juniors	2-3 yrs	1 (8%)			1 (8%)	
		3+ yrs			3 (25%)	6 (50%)	1 (8%)
	Second - ary	3+ yrs	4 (50%)				

For example one parent of an infant-aged child indicated that s/he would like:

“not being constantly reminded by professionals that our son should be in a special school.” (Infant-age child)

Parents also noted that input by educational psychologists would be of benefit, particularly in annual reviews. Parents of junior-aged children wanted more involvement from the educational psychologist than any other group. This is not surprising when we consider that parents are asked to nominate the secondary education placement at the end of Year 5: an extremely stressful time for any parent, but more so when the child has additional complex educational needs (Dee, 2006, Sanders & Morgan, 1997).

In contrast, parents of pre-school children or school aged children with a diagnosis within the last 2 years did not indicate any need for further / additional professional support. It is evident that the educational phase is not the sole, or perhaps the primary influencing factor in the perceived need for additional professional support. However the findings indicate there is a clear relationship between the time interval since diagnosis and the desire for additional support. In this instance the threshold for request for additional professional support appears to be two years after diagnosis, irrespective of the child’s educational phase.

The final theme, **Local Resources and Provisions**, was derived from nine comments abstracted from the completed questionnaires, indicating what parents wanted to receive in addition to the service and support already available to them (Table 5:8).

Forty-five per cent of parents from the sample who have children in the junior and secondary phase of their education indicated they required additional information about and access to different provisions. This included respite care, advice and support within the family home and activities available during summer holidays. Parents of pre-school and infant ages did not identify the desire for this type of support. As noted earlier (Chapter Four, Section 4:4:1) parents whose children are at different developmental stages and likely to experience and need different types of support and provision (Leyser and Kirk (2004), as such it is plausible that parents of older children who desire this type of support reflect the difference associated with the developmental lifespan.

Table 5:10: Responses across educational phase and time interval since diagnosis in relation to the local resources and provisions

		Time since diagnosis	Local Resources and Provisions			
			Respite Care (No. of responses % for age range)	Support during school holidays (No. of responses % for age range)	Advice in the home and school (No. of responses % for age range)	More information about different provisions made available to parents (No. of responses % for age range)
Educational Phase	Juniors	2-3 yrs	1 (8%)			
		3+ yrs		1 (8%)	1 (8%)	2 (16%)
	Second- ary	3+ yrs	1 (12.5%)		1 (12.5%)	2 (25%)

Again only parents of children with a diagnosis which was given two or more years prior to the research indicated the desire for this type of support.

The second section of the questionnaire asked parents to identify their experiences of their child's school/ nursery's capacity to meet their child's needs. The results from this section are presented below.

5:7 Results for Research Question 5: What do educational providers do to facilitate a child's access to education?

Table 5:11: Number of responses across the educational phase re: facilitating access to education

Educational Phase	No. & percentage of respondents	Facilitating factor for inclusive practices
Pre-School (n=2)	(3) 100%	<ul style="list-style-type: none"> • Support from the early years team • Small group support
Infant (n=20)	(16) 80%	<ul style="list-style-type: none"> • Additional staff • Good transition between nursery and school
Juniors (n=12)	(9) 75%	<ul style="list-style-type: none"> • Access to staff with experience of autism • Parental confidence to challenge school practice • Use of other children to support
Secondary (n=8)	(2) 25%	<ul style="list-style-type: none"> • Direct contact from autism outreach • School staff received training

Parents of pre-school-aged children indicated they were entirely satisfied with the level of support available to their child to facilitate the child's access to education, emphasising a willingness of staff to reflect upon their practices and learn new skills to ensure the child had access to appropriate support. Parents reported the learning process for staff was facilitated by specialist ASD Early Years staff who worked closely with parents and pre-school settings. Furthermore the majority of parents noted that this early support and receptiveness to developing inclusive practices remained as children moved into the infant stage of their education (illustrative comments presented in Box 5:5).

Box 5:5

"The staff at K's nursery are excellent, keen to learn, supportive and understanding and want to do everything within their power to help K." (Pre-school child)

"Playgroup went well because of the help received from the Early Years Team who supported the playgroup well." (Pre-school child)

"The staff were absolutely fantastic, understanding and sensitive to my child's diagnosis and needs. They went out of their way to ensure my child received the best support possible. They also supported me personally when the going got tough." (Infant-aged child)

"The school is very keen to help my child and we have a close working relationship" (Infant-aged child)

Here parents reported staff worked hard to meet the child's needs and suggested the process of supporting the child was eased by positive relationships between school staff and the parents. It is possible the positive accounts of support and perceived quality of provision are influenced by the quality of the relationship between school and parents.

Most parents of junior-aged children also reported positive experiences of schools working to meet the needs of their child. Three quarters of parents from this educational phase were pleased with the quality and type of provision available to their child. Again parents noted the importance of their own relationship with the staff as a key factor influencing their perception of a school's capacity to meet their child's needs.....

“ School have been supportive and have tried hard to meet my child's needs. Unfortunately at times they have got it very wrong, as have I! But we stick it all back together again between us and get on with it and try the next thing. We have got a good team of people around my child for which I am truly grateful. Their hard work, patience, support, forgiveness and care has got my son to a good place.” (Junior-aged child)

One parent stated.....

“The school has a wonderful special needs teacher who works with him during the week and focuses on his needs.” (Junior-aged child)

An overview of the responses indicates that worryingly as children and young people move through the education system there is less willingness/ capacity by schools to address the needs of pupils with a diagnosis of Autism. Parents of secondary age children are most dissatisfied with schools' responses to including their child. Only 25% of respondents (n=2) from this educational phase report positive attempts to meet the needs of the child (illustrated in Box 5:6).

Box 5:6

“I was contacted by telephone by Mrs XX who introduced herself and gave me a direct number should I have any concerns or need to contact her.” (Secondary aged child)

“Secondary school has been perfect. She is at a school with an ERF (Enhanced Resource Facility).” (Secondary aged child)

It should be noted that whilst parents' comments about the schools' capacity to meet the needs of the child indicated that parents desire more support at primary-age, there was also a desire by parents to have additional access to professional and emotional support if the child's diagnosis was given two or more years prior to this study (as illustrated in Table 5:12).

Table 5:12: Summary of data analysis for time since diagnosis and educational phase in relation to what parents want

	Practical Support			Emotional Support			Professional Support			Local Resources & Provisions		
Education Phase	PS	P	S	PS	P	S	PS	P	S	PS	P	S
Number of responses	2	15	6	0	9	8	0	18	4	0	4	4
Time since diagnosis	<2	2-3	3+	<2	2-3	3+	<2	2-3	3+	<2	2-3	3+
Number of responses	0	4	6	0	17	3	0	3	22	0	1	8

Evidently parents express concern about their ability to secure the support needed at the primary phase of their child's education and this may well contribute to the strength of negative feeling expressed by parents of secondary-aged children, as there is, over time, a growing frustration about the lack of support and the duration of its absence.

In addition to identifying practices or factors which facilitated a school's capacity to meet a child's educational needs, parents were asked to reflect on aspect of existing practices which form a barrier to the successful inclusion of children/ young people with autism. These comments are summarised in Table 5:13.

Table 5:13: Summary of responses identifying barriers to inclusion across different educational phases

Educational Phase	No. & percentage of respondents	Barriers to schools' inclusion of children/ young people with ASD
Pre-School (n=3)	(0) 0%	<ul style="list-style-type: none"> • None
Infant (n=20)	(4) 20%	<ul style="list-style-type: none"> • Lack of understanding regarding autism • Lack of staff • Staff not listening to parents
Juniors (n=12)	(3) 25%	<ul style="list-style-type: none"> • Staff attitudes can be a barrier
Secondary (n=8)	(7) 87%	<ul style="list-style-type: none"> • Schools not accepting or understanding the diagnosis • Poor LA understanding of ASD and needs of pupils • Lack of understanding regarding autism • Need training for staff • Child labelled as naughty • Staff not listening to parents • Staff attitudes can be a barrier

Parents of pre-school-aged children did not identify any barriers to the inclusion of their child, while, 20% of respondents with an infant-aged child indicated difficulties with schools making adjustments to meet the needs of the child. These comments identified barriers to inclusion arising from difficulties obtaining funding to secure adequate provision as illustrated in Box 5:7.

Box 5:7

"We (parents) asked for help and school replied no funding was available...one year he has help, the next he doesn't. We are quite upset and so is my child." (Infant-aged child)

"My son needs more one-to-one with someone who has experience of working with ASD" (Infant-aged child)

"Whoever it is that decides who gets extra funding, said no so my son misses out on extra support he needs." (Infant-aged child.)

"They want to help, but they don't have enough staff to look after him properly." (Junior-aged child)

"My child needs one-to-one but gets nothing; quite clearly because his school has no money." (Junior-aged child)

Clearly these comments suggest that many parents believe that provision of appropriate, responsive support for their child is contingent upon additional staffing. It appears these parents accept the funding constraints as a legitimate explanation for poor support and inadequate provision within schools, and that parents see the source of such constraints as residing outside the schools' control.

Other areas of concern arose for parents of junior-aged children who indicated they were dissatisfied with the schools' capacity to meet the needs of their child. A quarter of parents of junior-aged children indicated that schools failed to meet the needs of their child because of inadequate internal practices (illustrative comments in Box 5:8).

Box 5:8

"I have not seen any IEPs for over a year and have to chase up whether he has one or not".
(Junior-aged child)

"School are aware of J's autism, but nothing seems to have changed at all with his educational needs." (Junior-aged child)

However it was the parents of secondary aged children who reported the highest levels of concern about schools' capacity to meet the needs of their child. Eighty-seven per cent indicated schools did not do enough to support their child. Respondents reported their perception that, in many cases, inadequacies arose from negative attitudes held by school staff, as illustrated in Box 5:9.

Box 5:9

"School discriminates against him." (Secondary-aged child), "School staff has been completely unwilling to accept diagnosis and prefer to class our son as naughty and us as difficult parents."
(Secondary-aged child)

"They harass me all the time about our child's challenging behaviour, most of which can be explained by his diagnosis." (Secondary-aged child)

"They really don't understand Autism and are still trying to mould her into something she couldn't be."
(Secondary-aged child)

The findings indicate that the parents of secondary-age children who have an autism diagnosis are the most dissatisfied with schools' capacity to meet the needs of their child.

The main barrier identified by parents of this group is the attitude of school staff and their own poor relationships with staff. This is in direct contrast to the positive relationships reported in the pre-school and infant stages of education. It is possible these differences emerge, in part, because of the increasing social complexities of the education system (Jenkinson 1998; Vitello, 1994). In pre-school, infant and to a large extent, junior schools, children are educated in one classroom, mostly with one teacher. In secondary schools there can be 10 or more staff who teach the child, and possibly a number of different adults supporting the child in class or in small groups operating outside the classroom environment. As such, parents will inevitably find it more difficult to forge positive relationships with staff because of the number of adults involved with their child's education. The absence of a positive working relationship with one or several staff could affect parental perceptions about a school's capacity to meet the needs of their child. However, Jones et al (2006) note when parents report positive relationships with schools, they also felt compromised, finding themselves reluctant to make requests for further support for fear of jeopardising the nature of the existing relationship.

Whilst parents report concerns about the capacity of secondary school staff to support their child, these concerns must also be seen within the context of key developmental tasks of adolescence.

Within the development psychology literature, adolescence is a time of change, (social, cognitive, physical), during which a significant minority display a gradual decline in motivation to schooling, resulting in a decline in academic attainment. Eccles et al (1993) suggest the loss of motivation arises from changes in classroom organisations, task structure, task complexity, grouping practices, the locus of responsibility for learning, and quality of teacher-student and student-student relationships. As such there can be a mismatch between the needs of the adolescent and the environment, resulting in negative outcomes. It is possible parents of secondary-aged children with autism attribute their child's loss of motivation and decline in attainment to factors associated with the level of support, rather than aspects relating to adolescent development.

Whilst there are differences between parents' perception about a school's capacity to meet the needs of the child depending upon the child's educational stage, there was no difference between the experiences reported by parents whose child received a diagnosis recently or those who secured a diagnosis a number of years ago, indicating that it is the child's age and phase of education alone that are salient here.

Parents were also asked to identify specific practices school undertake to support the inclusion of their child. A summary of responses is presented in Table 5:14. For ease of reference, the data have been colour coded to distinguish between the percentage of respondents who reported schools make adequate adaptations and ensure support is available to children with a diagnosis of autism across different educational phases. The colour coding indicates the proportion of respondents confirming the use of the different strategies or provisions.

Table 5:14: Summary of adaptations undertaken and support available to children with a diagnosis of autism across different educational phases

Support and adaptations undertaken by nurseries/ schools	Pre-School (N=3)	Infants (N =20)	Juniors (N=12)	Secondary (N=8)
Held regular review meetings	(3) 100%	(16) 80%	(9) 75%	(2) 25%
Provided staff training/ awareness training for staff who would be working with child	(2) 66%	(14) 70%	(5) 41%	(3) 37%
Made adaptations to the school behaviour policy	(1) 33%	(5) 25%	(4) 33%	(0) 0%
Made adaptations to curriculum tasks	(2) 66%	(7) 35%	(8) 61%	(1) 12%
Made adaptations to the school environment	(0) 0%	(7) 35%	(4) 33%	(2) 25%
Provided additional staff to support child	(3) 100%	(12) 60%	(6) 50%	(1) 12%
Used strategies offered by other professionals/ agencies working with you and the school	(3) 100%	(14) 70%	(8) 66%	(1) 12%
Kept you well informed of progress and strategies being used	(3) 100%	(16) 80%	(8) 66%	(2) 25%
Listened to your concerns	(3) 100%	(15) 75%	(11) 91%	(1) 12%

Key

- 80- 100% Scores which reflect the majority of responses
- 51 – 79% Scores which reflect half or more of the responses
- 25- 50% Scores which reflect less than half but more than a quarter of responses
- 24% and under Scores which reflect less than a quarter of responses

Again a majority of parents report that practices at the early years and primary phases of their child's education were generally supportive. However, parental responses indicate that fewer secondary schools make adjustments to meet the needs of children with an Autism Spectrum Disorder.

Further analysis indicates a number of schools across all four phases were reported as having made use of review meetings, provided additional staff to support the child, made use of strategies commended by professionals who work alongside families and schools, kept parents informed about the child's progress and listen to parent concerns; however, in all cases reports of such provisions greatly reduced following secondary transfer.

Parents of pre-school children were particularly pleased with the ways pre-school settings tried to meet the needs of their child, with all respondents reporting that from the list of nine options available staff would undertake at least five activities to support their child. The majority of responses from parents of junior-aged children indicated schools would deploy strategies recommended by professionals who work with the school and family, and keep parents informed about the strategies used and the impact these had on progress. Three quarters of parents who had junior-aged children stated schools held regular review meetings, although one parent reported.....

“A gap of almost a year occurred regarding review meetings due to sick leave. It would have been helpful to have an alternative staff member attend.” (Junior-aged child)

Another positive action reportedly undertaken by junior school staff was to listen to parental concerns, with over 90% indicating this was their experience, suggesting that at this educational stage parents and school staff maintain positive relationships.....

“Everything is low key and informal. If I need help or have questions I just ask at school and they make the necessary changes.” (Junior-age child)

Whilst parents of children of primary-age and younger report a general sense that school staff try to develop practices to meet the needs of children with a diagnosis of autism, as noted above the same cannot be said for the experiences of parents of secondary-age children. Consistently across the responses, parents of secondary-aged children report that schools fail to make adequate adaptations or take measures to support the child in school, as illustrated in Box 5:10.

Box 5:10

“They have a poor understanding of autism. B has had no IEP/MEPs and the school were rigid about any adaptations that need to be made, thus making the environment almost impossible. Constant bad reports made school/home information sharing impossible” (Secondary-age child)

“It would have been easier talking to a brick wall. Every time our concerns were raised with school we either got ignored or told other teachers can’t be bothered.” (Secondary-age child)

“Our whole experience of secondary school has so far been relentlessly negative, undermining and almost vindictively unhelpful.”

Again a majority of parents reported that practices at the early years and primary phases of their child's education were generally supportive. However, parental responses indicated that secondary schools make fewer adjustments to meet the needs of children with an autistic spectrum disorder. There is a clear distinction between parent experiences of school practices across different educational phases, and the time interval since the diagnosis was given.

This trend is not surprising given Mayring's (2004) findings which indicated secondary school staff had difficulties differentiating work at the appropriate level and making necessary adjustments for the different groups/ types of SEN in a class, and were therefore less likely to make appropriate adjustments. Mayring (2006) also reported difficulties with school staff taking ownership of a child's learning, with many instances where teachers left the TA to differentiate learning tasks. This lack of teacher ownership for a child's learning is further compounded by the number of teachers/ adults a child encounters in the course of their week in a secondary school.

5:8 Summary of findings

It is evident a number of parents valued aspects of service delivery by school practitioners. These have previously been presented in Table 5:4 and include:

- caring attitudes of professionals;
- responsive approach by professionals;
- practice support, including developing communication skills;
- advice on diet and toileting; and
- informative assessment.

In addition to identifying valued aspects of practice, interviewees identified a number of gaps in existing provision and support, which are presented in Figure 5:4.

Figure 5:4: Key findings from parental questionnaires

- Parents received varied information at the time of diagnosis
- Parents valued caring professional attitudes, practical support, knowledge and expertise at the time of diagnosis
- Parents wanted increased staffing levels, access to knowledge and expertise, increased local provision, changes to attitudes held by professionals in schools
- Parents of younger aged children with a diagnosis of autism were more satisfied with the support available to them

- Aspects of current provision should incorporate access to professionals with more specialist knowledge of ASD, increased levels of staffing, more appropriate local provision and a change in school staff attitudes to the condition
- Gaps in existing provision included family therapy/ counselling services, support around benefits, toileting, access to more on-going professional involvement and access to activities during the summer holidays, advice for managing behaviours at home and respite care.
- Reported difficulties with school staff skills in managing and understanding autism
- Provisions and adjustments made within secondary schools vary
- There are difficulties with inclusive practices in mainstream school schools

In light of the data gathered from parental questionnaires in relation to how existing practices could be improved and what parents perceived their future needs to be, a number of recommendations were presented to a parent consultation group to ascertain which changes to service delivery were of greatest importance to them (as discussed in Section 5:5 and 5:6). These recommendations are presented in Table 5:13.

5:9 Reflections on the collection of questionnaire data

The quality, authenticity and trustworthiness of the interpretations and conclusions drawn from these data are reliant upon the trustworthiness of the research tool used to gather the data. Abrams et al (2009) suggests that whilst there are no black and white rules when it comes to assessing the 'truth' of questionnaire data, the researcher must be aware of a continuum of validity.

The number of completed questionnaires (42) represented 18% of the targeted population. Robson (2002) argues that generally, a good indicator of questionnaire validity is the number of questionnaires returned. It is noted that the number of respondents was below the expected level (typically 20-50 per cent achieved by conventional mail surveys, Frankfort-Nachmias & Nachmias 1996). Robson (2002) goes on to suggest there are a number of measures a researcher can take when seeking to address a poor response rate. He suggests that responses from later returners could be compared with earlier respondents, or contact made with non-responders to see if the researcher can turn them into responders and compare the data. Neither of these approaches could be used within the current study as there were no later returners nor was there any means of identifying which parents had responded and which had not.

Table 5:15: Summary of interview findings in relation to what schools want from advisory teachers and subsequent recommendations made

Themes	Findings in relation to parental perceived needs from health and education support services	Recommendations
Practical Support	<ul style="list-style-type: none"> • Parents report difficulties with the referral route • Families experiences of the referral processes to support agencies/ services are varied. • Parent require advice and support with daily living skills such as toileting and difficulties with restricted diets • Parents perceive school staff lack the knowledge and skills required to manage the difficulties arising from their child's autism 	<ul style="list-style-type: none"> • Ensure families understand the referral processes to support agencies/ services. • Ensure all families are provided with information about the diagnosis, support services available locally and nationally, and advice on education provisions, benefits and named professionals with a specialism in autism. • Provide access to staff who can assist with toileting and eating issues. • Develop inclusive practices in schools and ensure school staff have sufficient knowledge and skills to meet the needs of children with ASD.
Emotional support	<ul style="list-style-type: none"> • Parents want access to professionals who can assist with the changing needs of the child and family following diagnosis as children move through the developmental lifespan. • Parents report a lack of psycho-educational interventions, such as, counselling, to support families in coming to terms with the diagnosis 	<ul style="list-style-type: none"> • Provide families with access to professionals who can assist with the changing needs of the child and family following diagnosis as children move through the developmental lifespan. • Provide psycho-educational interventions to support families in coming to terms with the diagnosis.
Professional Support	<ul style="list-style-type: none"> • Parents report a lack of acceptance from professionals about their concerns for their child's • Parents want psychologist on-going involvement to ensure their received the right support • Parents report that some professionals did not have sufficient knowledge about autism and this lead to a delay in securing a diagnosis and acknowledgement of their concerns 	<ul style="list-style-type: none"> • Professionals ensure they listen to parental concerns and act upon them. • Ensure psychologist has direct and on-going involvement. • Professionals to have appropriate knowledge, attitudes and skills about CYP with ASD and strategies for managing challenging behaviour arising from the condition. • Increased training to support teachers understanding of autism and the best ways to support children with ASD.
Local resources and provisions	<ul style="list-style-type: none"> • Parents report local support services were limited and often restricted to day time provision • Respite care is limited and criteria thresholds often made it difficult to secure this type of provision • Parents indicated they wanted home visits and increased support at home and for this support to compliment what was available in schools 	<ul style="list-style-type: none"> • Improve locality support for families with ASD to include access to day and evening provision. • Provide appropriate and reliable respite care. • Provide support in the home and in school. • Increase staffing levels to respond to the families' request for more home support/visits, access to specialist health visitors and appointment of keyworkers.

Within this study the number of questionnaire responses were below the expected levels (Robson 2002), although the completed questionnaires did reflect different educational phases and different time intervals since the diagnosis. Whilst the sample did reflect different educational phases, parents/carers of pre-school children were under-represented; there is no claim that the responses provided are representative of this age group or can be generalised to other parents of pre-school children in Midtown.

Table 5:16: Number of respondents across educational phase

Educational phase	Pre-school	Infant	Juniors	Secondary
Number of respondents	2	20	12	8

Edwards (2002) argues that a response rate below 80% is likely to incur bias and a response rate below 60% is 'barely acceptable'. This view contrasts with Robson (2002) who suggests that the acceptability of questionnaire response rate is not determined solely by the number of returned questionnaires, but rather, by the degree of difference between the responders and non-responders.....

“It would be entirely feasible for a response rate of 30 per cent to lead to a more representative sample than one of 60 per cent.” (p.267)

Factors which could have contributed to the low response rate may include the respondents' inability to complete the questionnaire due to barriers such as literacy, language, or disability, or simply declining to participate.

The difficulty ascertaining the trustworthiness of data arises from how many of those who did not respond would have presented with different views. It is worth noting that some parents who chose to respond may have had an 'axe to grind' and therefore the responses might be unfairly skewed to reflect negative experiences, since those who did not respond could have held more positive views and experiences. However analysis across the data set indicates there was a mixture of positive and negative views reported from parents representing different educational phases and time intervals since the initial diagnosis was given. Most notably responses indicate that experiences deteriorate for parents as their children move through the education system, and that such differences cannot be attributed solely or predominantly to the recency of diagnosis.

Importantly, whilst the response rate was low, the views expressed in the questionnaires are generally consistent with the research literature and views expressed within the initial parent interviews: as supported by Denscombe & Aubrook (1992 p.127) I judged questionnaires to be completed “in a spirit of open co-operation, in good faith, and in all honesty”.

In light of the data gathered from parental questionnaires a number of recommendations were presented to a small parent consultation group to identify further priorities for service delivery.

5:10 Parent consultation group sample

The parent consultation group was primarily concerned with clarifying priorities for changes in service delivery in light of the trends evident in the parental questionnaire data. Parents were recruited to the consultation group via their expression of interest to be involved, which was established by their response to one of the questionnaire items which had invited all parents to indicate whether they would like to be involved in this subsequent stage of the study (Appendix 7).

From the 42 parental questionnaire respondents 17 parents expressed an interest in becoming involved in subsequent stages of the study. Each of these parents provided contact details which were returned to STePS separately from the questionnaires, to ensure confidentiality of questionnaire responses; this information was used to invite parents to a group meeting. In addition, to ensure that any parents who might not have formally recorded their ‘expression of interest’ at the time of questionnaire completion were given an opportunity to be in a consultation group, parents were informed about the proposed focus group via the Autism drop-in session and a local Autism Services Group meeting two weeks prior to the consultation group. From these invitations eight parents attended the consultation group, representing school-age children, as illustrated in Table 5:17.

Table 5:17: Parent consultation group sample

Educational phase of child	Boys	Girls	TOTAL
Primary age	2	1	
Secondary	3	2	
	5	3	8

5:11 Implementation of the parent consultation group

The group meeting took place at a council building located within the city centre at 7.30 p.m.; timing aimed to facilitate attendance by employed parents of children with autism (including fathers) , although of course their child care responsibilities will have militated against participation by many. In the event, the sample comprised seven mothers and one father.

This meeting was completed in two stages; firstly the findings from the school-based interviews were presented to the parent consultation group, which ensured parents were aware of schools' perceptions about the support they claimed to offer to children with autism, and provided me with an opportunity to validate my own 'reading'/ interpretation of 'their' data to their scrutiny, with scope for them to influence the final interpretation. It also provided parents with some insight into the difficulties school staff faced in meeting the needs of children with autism with the knowledge, support and resources available to them. This presentation of the findings sparked some interesting conversation, as a number of parents had not, for example, appreciated that information-sharing between health and school professionals may be problematic, but had assumed schools did not want to provide information or support, rather than understanding that school staff may not have access to the 'right' information required if they were to provide the most appropriate support.

The second activity within this parental consultation group consisted of presenting the findings from the parent questionnaire alongside 14 provisional recommendations for consideration. These 14 recommendations were recorded under the four themes:

- practical support;
- emotional support;
- professional support; and
- local resources and provisions

Following a presentation of the general questionnaire findings and the main conclusions, which had informed these recommendations, parents were asked to review recommendations derived from the parental questionnaires, and to discuss the extent to which these recommendations reflected their current priorities.

Each parent was then asked individually to prioritise three of the recommendations from the list. They were asked only to identify three priority recommendations (as were head teachers), in order to ensure that, alongside priority recommendations from the head teachers' group, recommendations would inform an action plan which could be realised over a two year period: the typical review cycle for a service development plan within Midtown.

Whilst straightforward to implement this ranking method was not comprehensive: it might have been more appropriate to ask parents to rate or rank all recommendations with which they agreed so that I could capture the overall strength of support for each recommendation, and use this cumulative rating/ranking to determine priorities for action.

It is acknowledged that this process of identifying priorities to be addressed in the short term has limitations, not least because the parent group composition was not representative of all parents of children with ASD; however it was clear during the discussions that parents took care to consider parental experiences and needs beyond their own. For example, one mother said.....

‘It’s not an issue for me but I know other people have had difficulties with this.’ (parent of a secondary-aged child referring to the in-class targeted support).

The difficulties in securing a representative view are also problematic because of the heterogeneity of the ASD population (Lord, 1989); however, despite limitations, this process afforded a practical initial opportunity for parents to contribute to shaping subsequent practices within Midtown.

5:12 Priorities for action

From the 14 proposed recommendations parents prioritised eleven, as presented in Table 5:18.

Table 5:18: Summary of strategies prioritised for action by the parent consultation group

Theme	Summary of Recommendations	Number of responses
Practical Support	• Ensure families understand the referral processes to support agencies/ services.	0
	• Ensure all families are provided with information about the diagnosis, support services available locally and nationally, and advice on education provisions, benefits and named professionals with a specialism in autism.	1
	• Provide access to staff who can assist with toileting and eating issues.	1
	• Develop inclusive practices in schools and ensure school staff have sufficient knowledge and skills to meet the needs of children with ASD.	5

Emotional support	<ul style="list-style-type: none"> Provide families with access to professionals who can assist with the changing needs of the child and family following diagnosis as children move through the developmental lifespan. Provide interventions to support families in coming to terms with the diagnosis. 	2 4
Professional Support	<ul style="list-style-type: none"> Professionals ensure they listen to parental concerns and act upon them. Ensure psychologist has direct and on-going involvement. Professionals to have appropriate knowledge, attitudes and skills about CYP with ASD and strategies for managing challenging behaviour arising from the condition. Increased training to support teachers understanding of autism and the best ways to support children with ASD. 	0 0 1 2
Local resources and provisions	<ul style="list-style-type: none"> Improve locality support for families with ASD to include access to day and evening provision. Provide appropriate and reliable respite care. Provide support in the home and in school. Increase staffing levels to respond to the families' request for more home support/visits, access to specialist health visitors and appointment of keyworkers. 	1 1 2 4

Once parents had individually identified their three priority recommendations these were grouped together and the three most strongly supported were identified:

- 1) Develop inclusive practices in schools and ensure school staff have sufficient knowledge and skills to meet the needs of children with ASD.
- 2) Provisions of psycho-educational interventions to support the child's needs arising from autism, and families with coming to terms with the diagnosis.
- 2) Increase staffing levels to respond to the families' request for more home support/visits, access to specialist health visitors and appointment of keyworkers.

These priorities reflect recent priorities within health and education policy. NICE (Dec, 2011) completed a scoping exercise on 'the management and support of children and young people on the autism spectrum' which would inform proposed guidelines in February 2013. NICE recognises that "early diagnosis followed by appropriate therapeutic intervention can improve outcomes in later life for most people" (p.4). These 'improved outcomes' will facilitate the quality of life experiences, the priority outcome desired from this guidance.

Education policy (Support and Aspiration, DfES, 2012) is congruent with parents' views about increasing staffing levels to respond to families' needs for more home support/visits, access to specialist health visitors and the appointment of keyworkers. The consultation document (DfE, 2011) suggests that "parents will have real choice over their child's

education and the opportunity for direct control over support for their family.....Key workers will be trained to advise families and help them navigate the range of help available across health, education and social care” (p.5).

The final priority identified by parents for immediate action was action to develop inclusive practices in schools and ensure school staff have sufficient knowledge and skills to meet the needs of children with ASD. This concern recognises the need for schools to change and build on the concept of ‘world class’ education laid out in ‘The Importance of Teaching’ white paper (DfE, 2010), and the ‘Support and Aspiration’ document (DfE, 2011), which explain that staff will need to be increasingly skilled in their practices, stating.....

“teachers and other staff in schools and colleges (will be) well trained and confident to: identify and overcome a range of barriers to learning; manage challenging behaviour; address bullying; and intervene early when problems emerge; and schools will have additional flexibility to support the needs of all pupils.” (p.58)

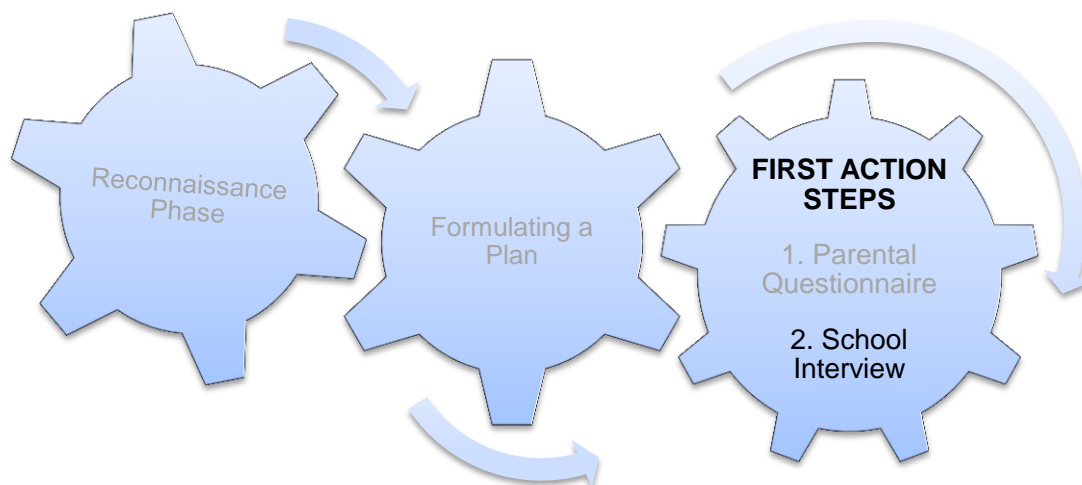
With consensus between the priorities identified by parents and policy, both recognising the need to reform services for families and children with autism, the prioritised recommendations were presented to the strategic group.

Chapter Six

Secondary school head teachers' and SENCOs' perceptions of educational practices used to support children with a diagnosis of autism

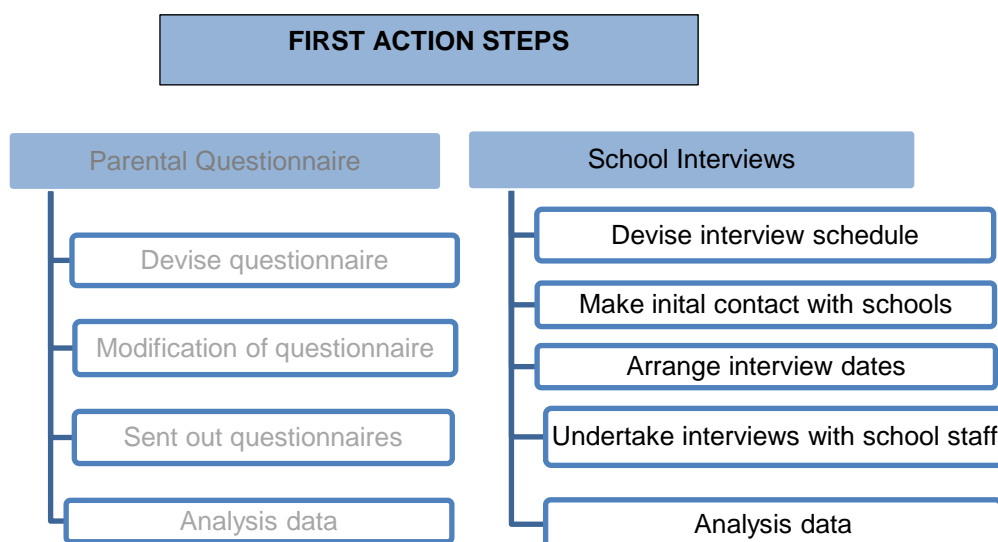
- 6:1** This chapter provides an account of the second strand of the First Action Step of the action research process summarised in Figure 6:1 below.

Figure 6:1: Summary of completed stages of the Action Research Model



The second stage comprised interviews with head teachers and SENCOs in all Midtown's mainstream secondary schools, as illustrated in Figure 6:2.

Figure 6:2: Research strand within the context of 'First Step' stage of research



The second stage of the 'First Action Steps' sought to illuminate the educational practices used by school practitioners, as reported by secondary school head teachers and SENCoS, to support children with a diagnosis of autism and to ascertain what they perceived they needed from external agencies and support services. The rationale for this activity arose from parental concerns about their negative experiences of support, particularly within secondary schools, and the concerns raised by the research sponsors about the growing number of children receiving a diagnosis of autism, and their perception that secondary school professionals had difficulties meeting the needs of this group of children: a perception based on the high number of children receiving fixed term or permanent exclusions from secondary school and the subsequent requests from parents for support from health professionals at these times.

In light of these concerns it was agreed with the sponsors that it would be helpful to build a more comprehensive understanding of school practices, so that identified difficulties with current support systems could be addressed to ensure support available to schools and families was meaningful and relevant, and facilitated improved inclusion of children with ASD in mainstream secondary schools.

Each mainstream secondary school in Midtown (n=14) was contacted and the head teacher and SENCo invited to participate in a semi-structured interview (as described in Section 6:2:2).

6:2 Rationale for using interviews

In addition to the benefits of using semi-structured interviews as discussed in Section 4:5:3, I considered there were additional benefits of using this research method to elicit information from school staff. Firstly the sample size available for the study was limited and therefore provided an opportunity to obtain in-depth understanding of what is happening in each secondary school. Secondly, the decision to use a semi-structured interview arose from the awareness that each secondary school operates differently and has different structures, systems and ways of describing what it does. For example some schools use a pastoral system which operates independently of academic aspects of school life, whilst others adopt an integrated approach. I believed it would have been difficult to establish how the systems work and who is involved in each, without face-to-face discussion.

The use of interviews as a data gathering method also afforded me the opportunity to request access to the senior leadership team and so allowed me to identify whether support/inclusion was promoted and encouraged through a 'top down' leadership approach (Dufour,

2007) . This understanding could provide me with a clearer picture of how change might occur within schools and whether the change required was in attitudes/ school culture and/ or practices. Conversely it is also important to acknowledge that head teachers may be distant to the 'everyday practices' and may not be well placed to provide an accurate account of what happens in their school or the nature of support the school receives. Indeed during the interviews where the head teacher was perceived as being 'removed' from everyday practices, as judged by the EP and advisory teacher, it was often (n=8) requested their SENCo provide an account of school practices. During the interview process at least 10 head teachers were very reliant on the SENCO to provide information and specific detail about support and school practices for accommodating and addressing the needs of students with ASDs).

Given the diversity of schools within the study, I considered it important to utilise a semi-structured interview format, in order to combine consistency of format and topics addressed with flexibility which would allow respondents to describe their own school's practices and experiences in relation to each school as a unique entity, ensuring accounts were authentic and credible. Questions asked in the interviews were identified using an a priori approach based on the literature review and comments noted in the parent interviews/ questionnaires. Further collaboration between myself as researcher and the head teachers and SENCos in regard to the interview process could have been achieved if, in addition to sending head teachers the interview questions prior to the interview, they had been invited to add any further questions or issues they wished to explore within the research. (It is acknowledged, however, that while this iterative review of the interview remit, and invitations for head teachers and SENCos to offer alternative questions formed part of the interview process, respondents' uptake of this opportunity may have been limited by the restricted time available during interviews for interviewees to marshal their thoughts and take a more proactive role

A further limitation of the interview design, and inclusion of the head teacher and SENCo in a single joint interview is the threat to authenticity of response by either party, in light of influence of the presence of the other. Here, it must be acknowledged that the influence or social desirability effects may have constrained or distorted each respondent's account.

6:2:1 Sampling: mainstream secondary schools

As the focus of the study was to gain greater understanding and knowledge of professional practices and support for children with an ASD diagnosis in mainstream secondary schools and to ascertain training and support needs for colleagues in secondary schools, all 14

mainstream secondary schools in Midtown were approached to participate in the interviews. This utilised a ‘purposive sampling’ approach. I requested head teachers and the school SENCoS participated in the interviews. All schools agreed to participate in the interview and 85% (n=12) of schools made the head teacher or an alternative member of the Senior Leadership Team and SENCo available for the interview and 14% (n=2) of the interviews were conducted with the just the school SENCo (as illustrated in Table 6:1).

Table 6:1 Summary of the sample participating in school interview

School	A	B	C	D	E	F	G
Staff Available	Head / SENCo	Head / SENCo	Head / SENCo	Head / SENCo	Deputy Head / SENCo	Head / SENCo	Deputy Head / SENCo
School	H	I	J	K	L	M	N
Staff Available	SENCo	SENCo	Head / SENCo	Head / SENCo	Head / SENCo	Head / SENCo	Head / SENCo

The schools (H and I), which did not have representation from their senior leadership team had already been judged by the school EP and Advisory teacher as establishments with limited support from the senior leadership team (as noted in Chapter Four, Section 4:5:2): it is perhaps not surprising that senior staff declined to be interviewed in these schools.

6:2:2 Implementation of mainstream secondary schools interviews

Following the initial invitation to participate in the study, schools were then contacted by the STePS administration support staff and interview dates were secured. Schools were asked to host the interview, ensuring an appropriate venue for the interviews. All interviews were conducted within the head teacher’s office. Staff from each school were provided with a copy of the questions prior to the interview so that they could collect necessary information. The interviews lasted about one hour and were completed over a five week period. Prior to asking the specific questions pertaining to school practices on inclusion and ASD provisions I undertook a general preliminary welcome and sought school-specific information about the demographics of the school population, the way general SEN support is organised and the main strengths and challenges facing each school. The specific questions asked during the interview and the rationale for their inclusion are presented in Table 6:2.

Table 6:2: Questions used in the school staff interviews and a rationale for their inclusion in the interview

Question asked	Rationale for inclusion in interview schedule	Sources of supporting literature and data
1. What arrangements and adjustments do school staff make to increase access and inclusion to mainstream schooling for Children and Young People with ASD?	In light of parental concerns about the nature of support available to children with ASD in schools, I wanted to clarify the specific range and type of provision available in the school	Literature Review: McGregor & Campbell, 2001; Emam & Farrell, 2009
2. What is the school's experiences of support from the Specialist Teacher Service?	This question sought to explore the school's self-evaluation of the strengths and weaknesses of the support currently available / provided to the school.	Literature Review: Glashan et al, 2004; Humphrey's & Lewis, 2008 Reconnaissance Phase: Interviews with EPs and Advisory teacher
3. What external support does a school such as yours need if it is to provide an effective inclusive education for children with ASD?	This question was intended to draw out the gaps in existing provision and provide information re: whether these gaps contribute to the range of negative parental experience.	Literature Review: Parsons et al, 2009; Emam & Farrell, 2009; Glashan et al, 2009; Humphrey, 2008 Reconnaissance Phase: Interviews with EPs and Advisory teacher
4. How do rate your school's capacity to meet the needs of CYP with ASD on a rating scale of 1-5 (1= low, 5= high)?	This question sought to explore senior staff school self-evaluation of the quality of their practices. This could be used to gauge the organisation's receptiveness and capacity to change.	Literature Review: NAPC, 2003; DfES, 2002; DCFS, 2007; Godfrey et al (2002)
5. How do you rate your school's ability and capacity to fully include CYP with ASD into wider aspects of school life on a rating scale of 1-5?	This question sought to identify the level of self-awareness schools have about their practices. It could be used to gauge the organisation's attitudes to inclusion.	Literature Review: Godfrey et al (2002)

The Manager of Advisory Teachers for Children with Autism and I were present during each interview, and detailed contemporaneous notes were made and some key verbatim utterances recorded. We individually augmented our own contemporaneous notes within one hour of each interview, to expand on any short hand/ abbreviated notes taken in situ and then met to assimilate the two sets of notes to produce a single set of notes for each school. These notes were then reduced into 'derived comments'. This approach has been described in Chapter Four section 4:6:5. The interview pro-forma, examples of the recorded notes from the interviews and examples of the interview data analysis are presented in Appendix 8.

6:2:3 Interview data analysis

Once the data had been reduced to 'derived comments' and themes identified using the approach to qualitative analysis previously outlined in Section 4:6:5, members of the wider Educational Psychology Team were given a number of comments/ phases, extracts and asked to place these selected extracts under the proposed 'themes' which appeared most appropriate for the comment. This process of checking my interpretations of data enabled me to verify whether themes I had constructed/ abstracted were robust. Robson (2000) argues this team analysis approach provides the researcher with an opportunity to gain many interpretations of the data and therefore reduces risks of researcher bias.

6:3 Results for Research Question 1: What arrangements and adjustments do school staff make to increase access to and inclusion in mainstream schooling for children and young people with ASD?

The practices within each secondary school as reported by the Senior Leadership member and/ or SENCo were recorded during the interviews. Data pertaining to each school's practice are presented in Appendix 9, while a summary providing an overview of the number of strategies used across all schools and descriptive data are provided here (Table 6:3).

Table: 6:3: Overview of the number of strategies used in each school and descriptive data

School & Age range	Number of strategies used	Ofsted rating	EP rating of inclusive practices	School & Age range	Number of strategies used	Ofsted rating	EP rating of inclusive practices
A (11-16)	10	Satisfactory	Weak	H (11-16)	8	Satisfactory	Weak
B (11-19)	14	Outstanding	Satisfactory	I (11-16)	8	Satisfactory	Weak
C (11-16)	8	Satisfactory	Satisfactory	J (11-19)	15	Good	Outstanding

D (11-19)	8	Satisfactory	Weak		K (11-16)	7	Inadequate	Satisfactory
E (11-16)	9	Outstanding	Weak		L (11-19)	8	Satisfactory	Outstanding
F (11-19)	14	Good	Outstanding		M (11-16)	6	Good	Weak
G (11-19)	11	Outstanding	Good		N (11-19)	9	Satisfactory	Outstanding

The analysis summarised in Table 6:3 showed that schools deployed between six and 15 different strategies or types of support. Those schools OFSTED rated 'outstanding' used 9, 11 and 14 strategies, compared to schools rated as good which typically deployed 6,14,15 (15 used within an Enhanced Resource Facility) and satisfactory schools who self-reported deploying 8, 9,10 (10 were used within an EFR) and one inadequate rated school using 7 strategies. It was apparent that the number of strategies used within schools appear to relate to the number of pupils with SEN (Appendix 10). For those schools rated as satisfactory by OFSTED inspectors there were above the national average of children on the SEN register. It is possible these schools cannot resource the type of support promoted by good practice guidance (Charman, 2011; DfES, 2001a; TDA, 2004) and meet the diversity and range of needs for all SEN pupils (Humphrey & Lewis, 2008).

At a very superficial level these summary data suggest there is a discrepancy between the practices valued by OFSTED and the EP perceptions of schools' working culture, ethos and practices for supporting students with ASD. It appears that those schools which were rated highly by OFSTED are not held in equal esteem by professionals who have sustained working relationships with the schools. It is possible that such data suggest that OFSTED assessments are driven by academic indicators, rather than prioritising schools' delivery of inclusive provisions for pupils with special needs. Indeed William (2012) argues that school inspectors' judgements should be subjected to an evaluation of reliability because the short, snapshot observations of lessons cannot possibly afford a reliable measure of the impact teachers have on pupil progress or the provisions they make available to pupils with special educational needs.

However, whilst there are possible difficulties arising from the reliability of OFSTED inspectors' judgments, other interpretations of this apparent discrepancy need to be acknowledged: educational psychologists/ advisory teachers could, for example, provide relatively unreliable, and superficial judgements based on their own relatively distant working

relationships with schools and/ or a self-serving bias which could lead EPs to 'blame' schools for their own unrealistic expectations and/ or ineffective practice.

The new framework for school inspection (OFSTED, 2012) indicates for September 2012 'inspectors [will] focus sharply on those aspects of schools' work that have the greatest impact on raising achievement' (p.5). This new guidance indicates judgements will be based upon:

- the achievement of pupils at the school;
- the quality of teaching in the school ;
- the behaviour and safety of pupils at the school; and
- the quality of leadership in and management of, the school (p.6).

However inspectors are also instructed to consider:

- the extent to which the education provided by the school meets the needs of the range of pupils at the school, and in particular the needs of disabled pupils³ and those who have special educational needs (p.6).

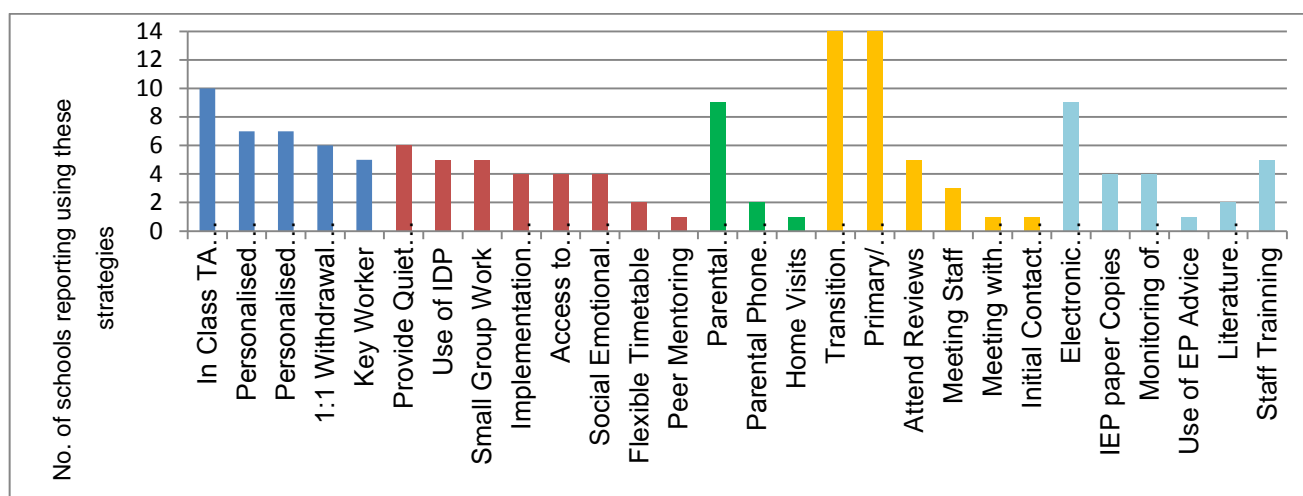
Therefore, future OFSTED ratings may afford higher priority to addressing those aspects of school effectiveness which form the central focus of this study.

For the purpose of this study the interview data have been summarised as an aggregate response from all 14 schools. It was reported by staff that there were 29 different strategies or adaptations made to school practices to ensure the inclusion of children with ASD. These are listed in Figure 6:3.

Across all schools, interviewees stated they provided a "*transition package*" and primary and secondary liaison for children with autism. However, the interviewees indicated that this provision varied.

³ For the purposes of the Equality Act 2010.

Figure 6:3: Current school practices and adaptations made to meet the needs of children with ASD



Themes:

- Individual support
- Environment change
- Parental involvement
- Consultation
- Information giving/ sharing

For some schools (n=7) the transition and liaison process was part of typical practices for all children as they move between primary and secondary schools. However 50% of schools offered more than the typical package of transition support and information sharing with primary schools as illustrated in Box 6:1.

Box 6:1

“We offer an extended transition package. If the child needs to familiarise themselves with staff and school beyond our typical transition support we offer more time here and they do extra visits.” (School F)

“They come and take photos of the school and a member of our staff can walk them around the buildings and give them more time to ask questions and become more familiar with the place.” (School M)

“we make contact with our primary feeder schools in April and get a list of children who will need additional transition support. This means they can have extra visits which can be arranged throughout the summer term if needed.” (School A)

Another strategy which was reported by SENCos/ head teachers to be frequently deployed was the use of TA support. In seventy-one per cent (n=10) of schools, ‘in-class’ TA support was made available to children, which included support in small ‘low ability’ groups, whilst 42% (n=6) of schools made TA support available to specific targeted individuals with autism. Schools staff were clear they would use both types of TA support and the decision to use

one over another was very much related to the individual needs of the child. Some schools also acknowledged that whilst they would have liked to have used more 'in-class' TA support, there were financial constraints.....

"We provide TA support in most lessons, although resources need to be distributed across different year groups so it isn't always possible to have the TA where he/she is needed most. As you know in the end it comes down to money." (School C).

Of the SENCOs/ head teachers who indicated they made use of 'in-class' TA support, 50% reported that staffing and financial constraints limited the type of support available.

Despite the financial concerns about the way pupils could be supported, 50% (n=7) of head teachers/SENCOs reported they provided pupils with a personalised '*package*'. When asked to elaborate upon this, respondents indicated there was no standardised approach, and that they provided strategies which they considered were appropriate to the individual; this could include a mixture of the strategies cited above or other measures recommended by health or education professionals.

Analysis of other strategies used in schools to meet the needs of children with autism indicate that 67% of schools (n=9) reported involving parents, as indicated in Box 6:2.

Box 6:2

"I phone parents before the child is due to start to introduce myself so we have already had contact before the transition meeting with parents." (School L)

"we invite parents in to progress meetings and they are included in setting the IEP targets." (School G).

It was unclear from the interview data whether this parental involvement was specifically for children with a diagnosis of autism and / or was additional to the level of parental involvement typical of practices for other SEN groups. It was however evident that SENCOs/ head teachers felt parental involvement was defined as making contact with parents and inviting them in to school. There was limited acknowledgement of how parents may be able to contribute to the meetings they had been invited to or contribute to/ negotiate the types of provision their child would access in school. It appeared that many respondents who reported

involving parents lacked a genuine means for parents to be involved in equal partnership, particularly in decision-making.

Another popular strategy used by school practitioners to facilitate the inclusion of children with autism was 'information sharing'. 78% (n=11) of school SENCOs/ head teachers reported deploying this as a means toward promoting staff involvement and responsibility for making appropriate and reasonable adjustments.....

"We put the IEP (Individual Education Plan) on the drive and staff are expected to look at the information. This way we can keep the information up to date and distribute it quickly." (School F)

Interviewees in other schools also emphasised the collective responsibility of school members to make adjustments to classroom practices. Some school head teachers/ SENCOs reported circulating paper copies which detailed the individual's needs and approaches known to be effective, for example.....

"Staff have access to hard/ paper copies of IEPs and information about the child which is stored centrally in the staff room. If new information is received about a child, this is added to the central copy, but individual staff also receive paper copies for their own reference." (School I)

Whilst the schools in this sample were able to identify specific aspects of their practices and how they distribute relevant information about a child's educational needs and provide an overview of strategies which could be used, there was a strong sense that the schools described the SEN system rather than practices specific to children with a diagnosis of autism. Furthermore school professionals were not able to explain if or how they monitored the effectiveness of their chosen SEN strategy, or whether it had a significant impact on the experiences of children with a diagnosis of autism.

In addition to these strategies a number of SENCOs/ head teachers reported deploying strategies which address environmental facets of school life. 35% of respondents (n=5) reported they make use of the Inclusion Development Programme (IDP) to identify appropriate strategies and develop knowledge and skills in classroom practitioners. Strategies identified from the IDP included promoting the use of quiet work spaces (42%, n=6); providing learning opportunities within small groups (35%, n=5); and providing a "social

emotional curriculum” (28%, n=4); deploying a key worker (35%, n=5) who becomes the adult who meets with the child on a daily basis and is the first point of contact for the child and school staff. Interestingly only two SENCos/head teachers (14%, n=2) reported utilising a flexible approach to timetabling, where children with autism attended lessons appropriate to the child’s academic, social and emotional skills.

There were a number of strategies which were used by only two or three schools. These included undertaking home visits, using peer mentoring, homework club, using advice from the educational psychologist and meeting with the SENCo of the primary school. Each of these strategies provides different benefits:

- Home visits afford parents with an opportunity to talk freely in their own homes (as noted in 5:4).
- Peer mentoring provides opportunities for the child with deficits in social functioning associated with their condition, to foster social skills in naturally occurring situations, thereby increasing the opportunities for the child to practise these in ‘real’ situations, and negotiate the social complexities of secondary schools (Jenkinson, 1998 Leyser and Kirk, 2004). Furthermore, locating support within ‘typically’ developing peers enables schools to develop the collective responsibility that is central to an inclusive philosophy (Tregaskis, 2002).

It appears that, whilst these strategies were not widely used, they are likely to have a significant impact on the child’s experience of mainstream education and inclusion.

6:3:1 Results for Research Question 2: What are schools’ experiences of support from the Specialist Teacher Service?

Where a pupil has an ASD diagnosis, his/her school has access to the Specialist Teaching and Psychology Service (STePS) advisory teacher for children with ASD. During the interviews Senior Leadership Staff (consisting of head teachers or deputy head teachers) and/ or SENCos were asked to describe the specific support they received from the advisory teacher. The responses were clustered together based upon the similarity of content and recorded under a broad thematic heading. The results are presented in Table 6:4.

Table 6: 4: Summary of schools' experiences of support from the Specialist Teacher Service

	Theme	Responses	(N=)	% of schools
Experiences of support to Schools	Direct work	• Pre-arranged 1:1 sessions with individual CYP	4	28%
		• Child seen in class	5	35%
		• Observations of CYP and feedback given	5	35%
		• Attending and contributing to annual reviews and Multi-Element Plan meetings	7	50%
	Training	• Provision of training for specific members of staff	6	42%
		• Modelling approaches via 1:1 tutorials	6	42%
		• INSET training	9	64%
		• Providing strategies for managing behaviour	11	78%
	Consultation	• Verbal feedback regarding 1:1 sessions	3	21%
		• Consultation with school staff	6	42%
		• Summary of involvement via reports	6	42%
		• Information-sharing based on primary school experiences	9	64%
		• Clarification of the nature of support	10	71%

These findings indicate that overall, advisory teachers undertake 14 activities to facilitate the inclusion of children with ASD; however the range of activities is limited to direct work, training and consultation. Data suggest the most common activities undertaken are 'providing strategies for managing behaviour', 'clarifying the nature of support' available to schools and 'information sharing'. These activities support the development of practitioner skills promoted by the Charman et al (2011) good practice guidelines, as teachers are informed about the need for a unique 'autism curriculum' and supported in providing it. Some respondents indicated that they were able to negotiate the nature of support offered by the advisory teacher, whilst other schools claimed to have been presented with a pre-determined list of activities from which they could select. It appeared that this negotiation process was governed by the preferences of the individual advisory teacher, again suggesting inequality within the existing system of support.

Following the identification of the nature of activities and support available to schools, interviewees were asked to comment on the strengths and limitation of the support available (Table 6:5)

Table 6:5: Schools' overall rating of strengths and limitations of advisory teacher support

	Responses	(N=)	% of schools
Limitations of support available	• Limited access to STePS staff	10	71%
	• Limited expertise in advice offered	6	42%
	• No depth to reports	4	28%
	• Nothing was valued	1	7%
Aspects of support that were valued by schools	• 1:1 support for CYP	11	78%
	• Brief ASD training to whole school	7	50%
	• Support for staff in developing skills and confidence in managing challenging situations	6	42%
	• 1:1 time-limited interventions with CYP	6	42%
		2	14%

Interviewees acknowledged that the role of the advisory teachers for CYP with ASD had been supportive, albeit with evidence of diversity in the roles and responsibilities undertaken by specific advisory teachers; this accounted for the mixed responses, as illustrated in Box 6:3.

Box 6:3

"It was helpful getting training to all staff about the basics of autism." (Head teacher School D)

"Some of the training is helpful, but many staff felt it was telling them what they already knew....the school needed to know how to manage some of the behaviours, but this information was lacking." (Head teacher School H).

Other schools recognised casework as an important and valued aspect of support from the advisory service, as illustrated in Box 6:4.

Box 6:4

"I can call E (advisory teacher) when things are kicking off, and she comes over to help us sort the problem and models some of the approaches we can use in a 'real' situation" (SENCo School J).

"She comes and does 1:1 work and always finds time to talk to us about what she has done." (SENCo Secondary School L).

"J will see them in class so can see the type of things they are doing and she then gives us ideas about what we need to do to manage the situation." (SENCo School H).

"It's helpful to talk through strategies and get ideas about the ways we can manage J's behaviour". (SENCo School E).

Another perceived benefit of the support available was the attendance of a specialist teacher at annual reviews and meeting with parents. 50% of respondents valued this aspect of service delivery: for example.....

“I value their attendance to annual review meetings, particularly when parents can be challenging. They are able to give a professional opinion and answer parents’ questions there and then. It also helps when we think about the suitability of the school placement and what is needed for the child.”
(Head teacher School A).

Whilst SENCOs/ head teachers were able to identify aspects of current practices and support from the advisory teachers which they valued, there were a number of perceived difficulties, as illustrated in Box 6:5.

Whilst one school reported a positive and speedy response, another school just a few miles away did not report receiving an equivalent level of support, again highlighting inequalities within the current system. It is possible that some schools received different response time and services in light of how the advisory teacher perceived the school’s practice. It is possible that those schools which were rated by STePS staff as ‘poor’ in their capacity to meet the needs of children with ASD received a quicker response because the placement is more likely to break down; differences may therefore reflect planned differentiation of practice.

Box 6:5

“I think that the written feedback is poor. The reports we receive are little more than a description of what was said during the meeting. They don’t offer any advice or strategies and you never know when you are going to see the teacher again (SENCo School B).

“much of what is written down is what is already known – there are limited strategies and I feel my staff have better knowledge than some of the advisory teachers.” (Head teacher School K).

“Staff in the ASD team need to have the appropriate knowledge and skills to provide schools with the advice and support.” (SENCo School M).

“staff from STePS need to be properly trained and have the appropriate knowledge and expertise.....there is no point coming and telling us what we already know.” (SENCo School D).

“they are never in and you leave a message and they get back to you a week or so later; by then things have blown over and already started to settle.” (Headteacher School I).

6:3:2 Results for Research Question 3: What external support does a school such as yours need if it is to provide an effective inclusive education for children with ASD?

Whilst SENCos/ head teachers were asked to identify features of current practices which were valued and aspects which were perceived as difficult, they were also asked to identify features of support they would like. These are presented in Table: 6:6, which is divided into sections (a-c), each followed by brief elaboration and exemplar quotations.

Within the responses a number of schools indicated they would value further professional involvement. Whilst the question centred on provisions from the autism advisory service, school staff generally recognised they wished also to be involved in improved two-way information sharing with colleagues from Child Adolescent and Mental Health Services (CAMHS) (Box 6:6).

Box 6:6

“we take the time to fill in the paperwork but we never know the outcome of our input unless parents tell us.” (SENCo School E)

“it would be nice to know what happens to our views and comments when we have filled in the paperwork.” (School C)

“I would like CAHMS to come to meetings and take part in discussions, rather than telling us what should or should not happen for a child” (Head teacher School K).

Table: 6:6a: Services/interventions schools wanted from external agencies in addressing and meeting the needs of CYP with ASD

Clustered Responses	Summary of Responses	No. of schools
Professional involvement	• Depth and rigour of knowledge and support so schools are confident in the “expert’s” skills	10
	• Clarity about who and why a CYP is targeted for involvement	9
	• Improved information sharing with CAMHS – currently schools report providing information to CAMHS professionals but receiving little information back.	8
	• Support in determining whether a pupil with autism is appropriately placed	8
	• Improved communication between health and education professionals – where there is evidence of mutual respect for professional opinions	7
	• All correspondence and contact with STePS staff to be formally recorded	6
	• Schools wish to negotiate the type of support provided by advisory teachers to support pupils with ASD	5
	• Outline of provisions/ support available to schools	5
	• Equitable services	2

Whilst views about practices within services other than the autism support service were unsolicited, it is evident that staff in a number of schools felt strongly about the process of diagnosis within CAHMS, from which they reported they frequently felt ‘excluded’, so that their professional opinions were peripheral to the narratives provided by families in informing diagnoses. Such limited involvement is likely to have significant impact on the interactions within and between the different ‘systems’ (Bronfenbrenner, 2005): teachers may respond differently to the child depending upon their views about the ‘reliability’ of a diagnosis, which will, in turn, influence the experiences of that child, potentially resulting in individuals within the same systems following different trajectories. Additionally, of course, accuracy of diagnosis of a number of disorders requires that reliable accounts of the child’s presentation in different contexts (normally home and school) be considered by physicians (APA, 2000).

The comments expressed by interviewees reflect the difficulties reported within the literature surrounding the professional dialogue amongst and between different professionals (Minnes & Steiner, 2009).

Interviewees also identified a number of other provisions and practices which they required from advisory teachers, as illustrated in Box 6:7.

Box 6:7

“some clarity about why one child gets support while another one doesn’t. The support needs should be agreed with the schools rather than schools being told what X will have.” (Head teacher School F)

“an outline of the different types of support that are available to schools and the child.” (Head teacher School I)

“[Specialist] teachers doing direct work, working with the child and modelling approaches with the child and school staff.” (SENCo School C),

“Access to experienced staff who can deliver social skills training to address the core difficulties. My staff aren’t as knowledgeable and lack the confidence to try....some are worried they might be getting it wrong.” (Head teacher School G).

School staff cited a desire for additional practical support from advisory teachers to facilitate their inclusion of children with autism. It is possible that interviewees are aware of the lack of specialist external support (Barnard et al, 2002) available to schools, and like their counterparts (parents), recognise that school staff require different things from a service at different times (Little, 2003).

Other aspects of a service school staff reported would be of benefit included support for families, as summarised in Table 6:6b. One interviewee indicated.....

“it would be helpful if the advisory teacher attended meetings so they can answer parents’ questions about the type of provision we should be putting into place” (Head teacher School I),

whilst another suggested.....

“parents can sometimes be very confused, particularly if they have received their child’s diagnosis from CAMHS. It would be good if the advisory teachers could be available to support these families and provide support networks for them.” (SENCo School F)

Table 6:6b: Services/interventions schools wanted from external agencies in addressing and meeting the needs of CYP with ASD

Clustered Responses	Summary of Responses	No. of schools
Practical support for schools and families	<ul style="list-style-type: none"> Increased access to teachers who can undertake more direct support 	12
	<ul style="list-style-type: none"> Delivery of specific interventions by advisory teachers 	10
	<ul style="list-style-type: none"> Modelled approaches to school staff 	7
	<ul style="list-style-type: none"> Quick response from the STePS team, particularly when behaviour quickly escalates 	7
	<ul style="list-style-type: none"> Support for the transition of a pupil with autism between school 	6
	<ul style="list-style-type: none"> Provide appropriate strategies relevant to the individuals needs rather than generic strategies 	6
	<ul style="list-style-type: none"> More observations in class to inform consultations 	6
	<ul style="list-style-type: none"> Early support and observations to prevent the breakdown of placements 	5
	<ul style="list-style-type: none"> Direct support for class teachers 	4
	<ul style="list-style-type: none"> Social skills training resources provided by advisory teachers 	4
	<ul style="list-style-type: none"> Facilitate meetings between schools and parents 	3
	<ul style="list-style-type: none"> Contribution to the setting and review of Multi Element Plan targets 	3
	<ul style="list-style-type: none"> Parental support where parents can get together to meet 	3
	<ul style="list-style-type: none"> Maintain links with parents and families 	2
	<ul style="list-style-type: none"> Advisory teachers to support staffs early contact with parents 	2

Another, focusing on the potentially disorienting and disabling effects of secondary school transfer, explained.....

“It’s always helpful if a [specialist] teacher has been involved and can support the family through the transition from primary to secondary school” (SENCo School C).

It is possible that respondents felt that the school’s relationship with parents benefits from support by ‘experts’ who can address parental apprehension and reassure parents about schools’ practices and ability to promote the child’s social and academic development (Kasari et al,1999; Whitaker,2007).

The final theme derived from the interviews indicated school staff desired improved access to training, advice and resources (as noted in Table 6:6c).

Table 6:6c: Services/interventions schools wanted from external agencies in addressing and meeting the needs of CYP with ASD

Clustered Responses	Summary of Responses	No. of schools
Training, Advice and Resources	• Awareness-raising for classroom practitioners	7
	• Professional discussions about provisions, strategies and recommendations	6
	• Access to resources which are loaned to schools to address the needs of CYP with ASD	6
	• Support in implementing the Inclusion Development Programme	4
	• Appropriate and expert advice	4
	• Support via external agencies working with school staff to develop skills	4
	• Reading lists	3
	• ASD awareness-raising amongst peers in school	3
	• Advice and support regarding access to extended schools	1

School staff reported it would be useful to have further knowledge and resources available for children with a diagnosis of autism (Box 6:8).

Box 6:8
<p>"We currently provide art therapy which we fund. It would be good if other professionals could provide activities as part of an extended schools agenda." (SENCo School H)</p> <p>"access to different resources which could be lent out." (SENCo School J)</p> <p>"I don't mind finding things out for myself but there are so many books on autism it's difficult to know which ones are any good....it would be helpful if there was a reading list which we could use to develop our understanding." (SENCo School E).</p>

Such comments appear to indicate 'willingness' by school staff to develop their skills and practice. Indeed 30% of respondents indicated a desire to develop their own understanding of autism and the most appropriate way to support children, through their own reading, further training or working alongside more experienced colleagues. It is possible that respondents in this study reflect a shift in attitudes arising from policy and guidance (NAP-C, 2003; Jones et al, 2011), although it is important to emphasise this shift in attitude is not

evident in either parental experiences (as discussed in Chapter Five section 5:4) or the literature which so frequently locates ‘knowledge, training and support’ with external agencies (Barnard et al, 2002): a division of labour which is further entrenched by difficulties with the quality and quantity of training available to teachers, particularly during the initial teacher training phase (NfER, 2011).

6:3:3 Results for Research Question 4: How do you rate your school’s ability and capacity to meet the needs of children with ASD on a rating scale of 1- 5?

In order to understand the schools’ self-evaluation of their capacities to meet the needs of children with ASD, school staff were asked to rate their school on its ability to meet the needs of this population, using a 5 point Likert scale (where 1 was least able to 5, most able).

Table 6:7a: Summary of self-rated capacity scores

	Successfully meet the needs of CYP with ASD				
Rating scales	1	2	3	4	5
	Least able ←————→ Most able				
Responses (n= %)		1 (7%)	1 (7%)	12 (85%)	
Schools		G	K	A,B,C,D,E,F,H,I,J,L,M,N	

School G’s low (2) rating appears at odds with the OFSTED rating of the school as ‘Outstanding’, but perhaps more congruent with the rating suggested by the EP (Satisfactory) during the reconnaissance phase of this study. While interviewees rated this school’s capacity to meet needs as low, they demonstrated awareness about ASD pupils’ difficulties, and identified a lack of knowledge and skills amongst staff and a need for further training.

In contrast, another school (K) rated by OFSTED as ‘inadequate’ felt their practices were satisfactory, again reflecting the views held by the school EP. There was congruence between schools’ self-rating scores, OFSTED ratings and the rating from the school EP for schools ‘F’ and ‘J’, whilst the remaining schools’ (A,B,C,D,E,F,H,I,J,L,M,N) self-rating scores correlate with OFSTED rating only, perhaps having taken the OFSTED rating as a reliable benchmark. It is noteworthy that a majority of schools (85%) rated their inclusive practices positively, but this did not reflect parental experiences of inclusion at secondary schools (as noted in Chapter Five section 5:6). A possible explanation for this mis-match between school

perceptions of inclusive practices and parental experiences could arise from different expectations about what ‘inclusion’ means, and the goals parents/ teachers were aiming for (Lamb, 2009).

6:3:4 Results for Research Question 5: How do you rate your school’s ability and capacity fully to include CYP with ASD in wider aspects of school life on a rating scale of 1-5?

In addition to rating schools’ practices to meet the needs of children with autism, interviewees were also asked to rate the school on its capacity to include CYP with ASD fully in wider aspects of school life, such as after-school clubs and trips. Again interviewees were asked to use a 5 point Likert scale (where 1 was least able to 5, most able).

Table 6:7b: Summary of self-rated capacity scores

	Fully include pupils in the wider aspects of school life				
Rating scales	1	2	3	4	5
	Least able ←————→ Most able				
Responses (n= %)			1 (7%)	11 (78%)	2 (14%)
Schools			G	A,B,C,D,E,I,J,K,L,M,N	H,F

Interestingly whilst the majority of schools’ self-ratings here were consistent with their self-rating scores for ‘meeting the needs of children with ASD’; two schools, (H and F) felt practices supporting the ‘wider’ inclusion of children with autism exceeded their capacity to meet the pupils’ individual needs. School H was judged by the school EP as weak in its inclusive practices for children with ASD, while it was rated ‘satisfactory’ by OFSTED. This apparently inflated self-evaluation could reflect the impact of a ‘top-down’ leadership (Dufour, 2007) where the school leadership is unaware of the gap between policy/ espoused theory and ‘lived realities’ or policy in action (Fuller and Clarke, 1994).

School F also reported the highest rating possible for its inclusive life. This school was rated as ‘good’ by OFSTED and ‘outstanding’ by the school EP. There appears to be consensus about this school’s practices from those who are most familiar with the school. Furthermore this was the only school to highlight the desire to increase the ‘extended schools’ agenda for children with ASD, reporting using art therapy as a means to secure access to a broader experience of school life beyond the traditional curriculum.

Whilst these two schools (H and F) reported their practices were exemplary, the majority of respondents (78%) felt their school was able to include children with ASD in wider aspects of school life with a reasonable success rate (rating themselves as 4). Again this self-rating indicated dissonance with parent questionnaires data. Similar to how interviewees rated the schools' capacity to meet the needs of children with ASD, it is possible that school staff and parents have different ideology about 'inclusion' and the criteria against which success should be judged (Donnelly & Coakley, 2002; Humphrey, 2008). This mis-match between parental experiences of inclusion in wider school life and school staff self-rating scores could also be influenced by policy. The new OFSTED framework (OFSTED, 2012), indicates that schools will be judged on their ability to "meet the needs of the range of pupils at the school, and in particular the needs of disabled pupils and those who have special educational needs." (p.6), although it does not locate 'judgements' within the context of an inclusive agenda where the child's needs implicitly include access to "normal social activities" (DfES, 2010).

6:4 Reflections on the collection of interview data

The quality, authenticity and trustworthiness of the conclusions drawn from these data are reliant upon the trustworthiness of the research method used. Whilst interviews were used to obtain data, the researcher's ability to account for the trustworthiness of the data can be more problematic (as discussed in Chapter Three, sections 3:4 and 3:5:2). Steps taken to maximise the trustworthiness of data included:

- use of two or more analysts in the interpretation of data (Clarke, 1999); and
- undertaking member checks, whereby participants were given the opportunity to review the researcher's interpretation of the data (Koch, 1994; Lincoln & Guba, 1985).

As discussed in Section 6:2:3, the interviews were completed with a colleague, a Team Manager from the Advisory Service, and field notes were written up separately and then assimilated to form a single record of each interview. Mayes & Pope (1995) argue that reliability is enhanced when more than one skilled qualitative researcher is involved in the analysis process, stating....

"a sound justification for having two researchers analyse the data, enables themes, codes and categories identified by each researcher to can be compared and differences discussed."

The second strategy used, 'member checking', consisted of stopping at intervals throughout each interview to ensure the data recorded as field notes reflected the comments and views

expressed through the interview, ensuring accurate representation of the ‘narratives’ told during the interviews. Parahoo, (1997) argues this approach minimises researcher bias and can be useful in determining the trustworthiness and credibility of data collected.

6:5 Summary of findings

It is evident a number of advisory teachers’ practices are valued by school practitioners. These have previously been presented in Table 6:4 and include:

- 1:1 support for students;
- ASD training to all school staff;
- support for staff in developing skills and confidence in managing challenging situations; and
- 1:1 time-limited interventions with CYP.

In addition to identifying valued aspects of practice, interviewees identified a number of gaps in existing provision and support, which are presented in Figure 6:4.

Figure 6:4: Summary of findings for head teacher and SENCo interviews

- Support and advice offered by the advisory service was varied across Midtown
- Aspects of current provision should incorporate access to professionals with more specialist knowledge of ASD, increased levels of staffing, more appropriate local provision and a change in school staff attitudes to autism
- School staff require additional training on autism
- Respondents indicated school staff didn’t always have the understanding of autism and the skills to manage complex needs, including challenging behaviour arising from the diagnosis
- Across the 14 secondary schools provisions and adjustments made to facilitate a child with ASD access to school was varied

In light of the data gathered from school interviews a number of recommendations were presented to head teachers at a ‘Breakfast Meeting’ to ascertain which changes to service delivery were of greatest importance to them. These recommendations derived from the school interview data (as discussed in Section 6:3:2) are summarised in Table 6:8.

Table 6:8: Summary of interview findings in relation to what schools want from advisory teachers and subsequent recommendations made

Theme	Findings in relation to what changes school want for the services provided by the advisory teachers	Recommendations
Professional involvement	<ul style="list-style-type: none"> Schools reported a desire for improved information sharing with CAMHS schools report providing information to CAMHS professionals but receiving little information back. Advisory teachers lack the depth of knowledge required to support schools in the inclusion of children with ASD. School staff require support in determining whether a CYP are appropriately placed Negotiate the level and focus of involvement with CYP with ASD 	<ul style="list-style-type: none"> Establish a clearer pathway to collaborative information sharing with CAMHS. Develop the depth and rigour of knowledge and support so schools are confident in the “expert’s” skills of external professionals. Support schools in determining whether a CYP is appropriately placed within existing school placement. Improve school staffs’ ability to negotiate the level and focus of involvement with specific individuals.
Practical support for schools and families	<ul style="list-style-type: none"> Schools want advisory teachers to undertake more direct support Direct support for class teachers from advisory teachers. Support schools in the transition processes from primary to secondary schools Schools want early support and observations to prevent the break-down of placements Contribution to the setting and reviewing of Multi Element Plan targets Parental support network Facilitate meetings between schools and parents 	<ul style="list-style-type: none"> Increased access to teachers who can undertake more direct support Strengthen support with primary to secondary school transfer Ensure Advice teachers are available to contribute to the setting and reviewing of Multi Element Plan targets Ensure schools to have access to information regarding parent support networks Facilitate meetings between schools and parents when difficulties arise (including the potential break-down of school placements)
Training, Advice and Resources	<ul style="list-style-type: none"> Support in implementing the Inclusion Development Programme ASD awareness training amongst peers Awareness training for all classroom practitioners Advice and support regarding access to extended schools Appropriate and expert advice Access to resources which are loaned to schools to address the needs of CYP with ASD 	<ul style="list-style-type: none"> Support school with the implementation of the Inclusion Development Programme Provide ASD awareness training amongst peers Provide awareness training for all classroom practitioners Provide advice and support regarding access to extended schools, including access to advisory teachers who can deliver some of the activities Strengthen advisory teachers knowledge about ASD advice to manage complex needs Ensure advisory teachers can provide resources on loan to meet the needs of child with ASD

6:6 Head teachers' breakfast meeting sample

All secondary head teachers across Midtown convene a monthly cluster meeting which forms a peer support group. I chose to use this meeting to share the findings derived from parent questionnaire and the school-based interviews and the provisional recommendations for service development, as this enabled me to make use of a pre-existing meeting to communicate with all the head teachers, thereby reducing the demands on head teachers' time to attend yet another meeting. I deployed a 'convenience purposive sampling' approach, although such sampling resulted in SENCos being excluded from the opportunity to influence the recommendations and identify priorities. I recognise that this was far from ideal; however as a full-time EP I was constrained by the amount of time I could invest in the process, and the use of the breakfast meeting afforded me an imperfect, but low (time) cost 'single hit' with a significant stakeholder group, and also provided me with an opportunity to undertake some member checking (albeit incomplete) with my school-based interview sample.

I was afforded an hour at the start of the meeting to share the findings with head teachers via a Powerpoint presentation. The first 15 minutes provided an overview of the parental questionnaire findings. Head teachers were invited to comment upon the findings as they were presented. The findings from the school-based interviews were presented in 20 minutes and the remaining 25 minutes were given over to head teachers to identify their priorities for change from the provisional list of recommendations (Table 6:9). Again during the latter stage of the presentation head teachers were invited to share their thoughts and ideas within the group: a process facilitated by myself.

The presentation aimed to give head teachers insight into parental experiences of support in general and support within schools. The findings relating to parental perceptions of declining support within secondary schools appeared to shock a number of head teachers. Once the findings from the parent questionnaire had been shared with head teachers, findings from the school-based interviews and the related provisional recommendations for service development were then presented.

Eleven head teachers participated in this meeting. Head teachers representing Schools C, D and N did not attend.

6:7 Implementation and analysis of feedback from the head teachers meeting

The head teachers' meeting took place at a council building located within the city centre during the school day. Following a presentation of the main research findings in relation to parental experiences of support and school-based interviews, head teachers were presented

with a list of 15 provisional recommendations (Table 6:9). They were asked to review these recommendations and provided with an opportunity to discuss whether these recommendations did indeed reflect and potentially address their concerns and priorities for service improvement. Following this discussion, which provided clear overall endorsement of the face validity and credibility of the research findings and the acceptability of the provisional recommendations, head teachers individually identified three priorities, so that the new STePS action plan could address the difficulties and development priorities which were judged most relevant in the short term. These are presented in Table 6:9.

Table 6:9: Suggested strategies prioritised for action from school-based interview findings by head teachers

Themes	Recommendations	Number of responses
Professional involvement	• Support schools in determining whether a CYP is appropriately placed within existing school placement.	0
	• Establish a clearer pathway to collaborative information sharing with CAMHS.	3
	• Develop the depth and rigour of knowledge and support so schools are confident in the “experts skills” of external professionals.	5
	• Improve school staffs’ ability to negotiate the level and focus of involvement for specific individuals.	6
Practical support for schools and families	• Strengthen support with primary to secondary school transfer	0
	• Ensure schools have access to information regarding parent support networks	1
	• Ensure advisory teachers are available to contribute to setting and reviewing of Multi Element Plan targets	2
	• Provide increased access to teachers who can undertake more direct support	3
	• Facilitate meetings between schools and parents when difficulties arise (including the potential break-down of school placements)	4
Training, Advice and Resources	• Support school with the implementation of the Inclusion Development Programme	0
	• Provide ASD awareness training amongst peers	1
	• Provide advice and support regarding access to extended schools, including access to advisory teachers who can deliver some of the activities	1
	• Strengthen advisory teachers’ knowledge about ASD advice to manage complex needs	2
	• Provide awareness training for all classroom practitioners	2
	• Ensure advisory teachers can provide resources on loan to meet the needs of child with ASD	4

As noted above, respondents were not asked to rate all recommendations, and again it is acknowledged that failing to ask them to do so prevented my apprehending the level of

importance given to each recommendation. Within the constraints of the 'top three' ranking exercise which was adopted, the most strongly supported recommendations include:

1. Improve school staffs' ability to negotiate the level and focus of involvement for specific individuals;
2. Develop the depth and rigour of knowledge and support so schools are confident in the "expert's" skills of external professionals;
3. Ensure advisory teachers can provide resources on loan to meet the needs of child with ASD; and
3. Facilitate meetings between schools and parents when difficulties arise (including the potential break-down of school placements).

However, beyond using ordinal data to present these recommendations, I am unable to identify whether the priority which secured the strongest support did indeed represent a shared priority for action by secondary head teachers in Midtown.

The first priority discussed related to the desire to improve school staff ability to negotiate the level and focus of involvement for specific pupils. This aspect of the study does not wholly align with existing research. A number of studies (Symes & Humphries, 2011; Humphreys & Lewis, 2008) have sought to identify barriers to inclusion and consider the impact of internal school practices on experience of inclusion. However, unlike research into parents' experience, which frequently examines how support from professionals in education, health and social care can be improved, research into what school staff want from external agencies is lacking. Indeed it appears the way schools are supported by external agencies, particularly those funded by Local Authorities, has not been seen to have significant impact on school practices, or in turn worthy of research, although school staff have indicated the desire to access to specialist advisory support (Barnard et al, 2002). It is possible head teachers recognise the important role advisory teachers play in supporting the inclusion of children with autism, but feel current support is too prescriptive, not allowing for the individual needs of the child or accommodating differences between schools. It appears that school staff, like parents, want flexible support indeed reflecting new government policy (DfE, 2011) proposing the "transfer (of) power to professionals on the front line and to local communities so that professionals can innovate and use their judgement;...(to) give parents and communities much more influence over local services" (p.5).

Another priority discussed (for STePS to develop the depth and rigour of knowledge and support so schools are confident in the "expert" skills of external professionals) is consistent with other research findings. For example, Barnard et al (2002) and Dillenburger et al (2010)

found parents require improved knowledge amongst professionals about autism to facilitate the referral, assessment and diagnosis process. Similarly, school staff have in previous research (Minnes & Steiner, 2004), indicated concerns about the lack of specialist external support available to children, although these concerns have generally centred on the access to advisory teachers, rather than their particular skill set.

This study provides a different understanding of school experiences of support from external agencies. The Midtown secondary staff were clear they want support, and for this support to be provided by highly skilled professionals. It is possible that school staff locate this need for improved knowledge and skills amongst advisory teacher because of the increasing complexities of children with autism who can present with co-morbid conditions (NICE, 2011), or the impact of new policy, the Education: Special Educational Needs Co-ordinators Regulations (DfE, 2009) which has led to significant improvements in the skills of SENCos to meet the needs of children with autism and as such require advisory teachers to have knowledge and skills which surpass the knowledge derived from the new SENCo qualification.

The final two priorities identified by head teachers indicated a desire to access equipment and resources so that the child's needs can be met, suggesting there are difficulties with funding or knowing what equipment would be beneficial; and finally school staff expressed a need for advisory teachers to facilitate meetings between schools and parents when difficulties arise, including the potential break-down of school placements.

Whilst head teachers and SENCos had raised concerns about the level of knowledge of advisory teachers, paradoxically they also recognise that advisory teachers' skills extend beyond knowledge about autism, and appear to value the consultation and conciliation skills of advisory teachers. Miller (2003) suggests the tensions between parents and schools are inevitable given the limited attempts to "arrive at shared definitions of problematic situations, particularly in the case of difficult behaviour." (p.72). Miller states that, within schools, shared-meaning is 'derived during a process of socialization into an institution. To members of the institution they become part of the shared, taken-for-granted, common-sense knowledge (Berger and Luckmann 1966)" (p.72). However parents are not privy to these institutionally constructed meanings and have different perspectives which can impede effective working relationships between themselves and schools. As such, "teachers perceive it to be impossible to feel a unity of purpose and action with parents over the difficult classroom behaviour of their children; a barrier perceived and attributed to the parents" (p.73).

Furthermore Miller (2003) acknowledges that when these tensions between schools and parents occur “effective mediation by an external person or body is sometimes the best or only hope for conciliation and agreement on ways forward” (p.77), reinforcing the value head teachers place on the conciliation and consultation skill set of the advisory teachers in which head teachers define the advisory teacher as an ‘expert’ who can influence parents because of the way parents construct the concept of external professional support (Jindal-Snape et al, 2005).

The priorities identified by head teachers relate to how support services should operate within schools and emphasis the role of external professionals in developing schools’ own capacities to meet the needs of children with autism via training and consultation. However, current priorities do not seek to address how systems within schools, such as staff culture and school policy and procedures influence inclusive experiences. Indeed Cox (1993) suggest “whether or how the changes are implemented depends to a large extent on the perceptions and attitudes held by those working in the organisation” (p.19). As such it is important to emphasise that whilst actions which seek to address the priorities identified by Midtown head teachers are intended to change and improve schools’, families and ASD pupils’ experiences of support, in turn, improving inclusion and classroom practices, this change process can be limited because system change will be governed by internal and external processes, each exerting a different direction and degree of influence (Bronfenbrenner, 2005).

Having identified the priorities from the parent consultation group and the priorities from the head teacher breakfast meeting these were presented to the strategic group (sponsors) for discussion and action planning. This phase of the Action Research process does not form the substance of this current thesis. At the time of writing and submission, (October 2012) planning is in progress.

Chapter Seven

What has been learnt from this study?

7:1 Introduction

One motive for selecting collaborative action research methodology was to afford parents and school staff, who comprise the primary users of STePS' services, an opportunity to influence service developments, so these would be appropriate to their needs. In the spirit of collaboration, following elicitation of their experiences and views, and analysis of trends within the data corpus, I needed to offer parents and school staff an opportunity to consider and comment on the findings in an authentic way, and go on to identify necessary developments, in order to ensure these developments would indeed be relevant and meaningful to them. This final chapter considers how findings from Chapters Five and Six can be used to shape service delivery and identify priorities for future provisions. I also acknowledge some of the limitations of the study and outline the contribution this study can make to the corpus of knowledge about service provisions from health and educational for children with a diagnosis of autism.

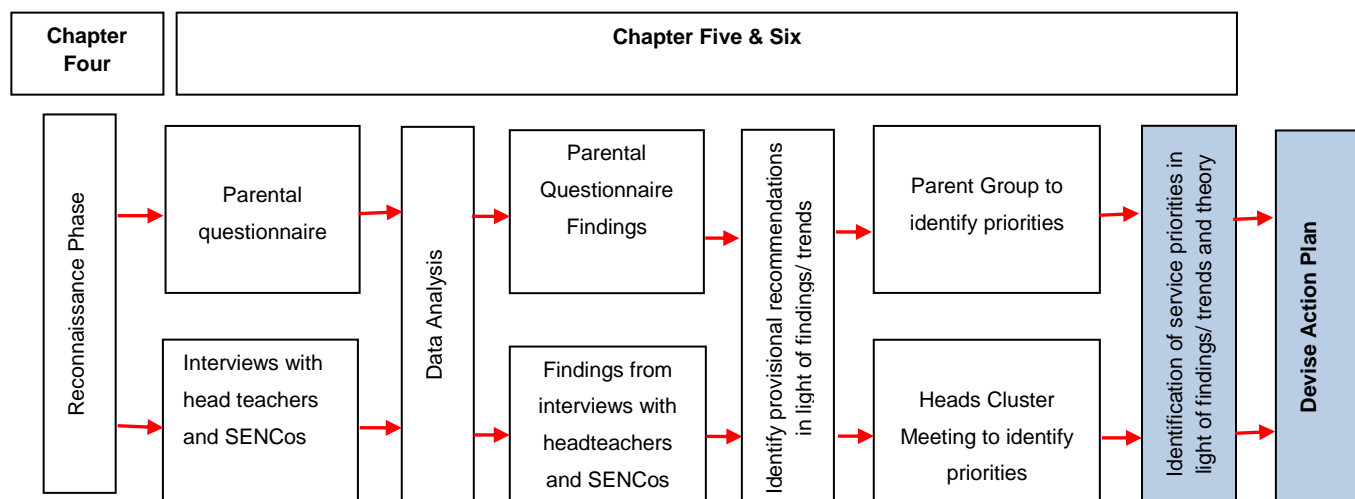
7.2 Review of action taken

As illustrated in Figure 7:2 the findings from the research activity reported in Chapters Five and Six were analysed, consistency with the literature identified, and a list of provisional recommendations constructed in light of this process.

The collaborative processing of the research findings was mediated within a small group of parents and a head teachers' breakfast meeting. The priority recommendations thus derived, and their relationship with findings from the action steps presented in Chapter Five (Section 5:10) and Chapter Six (Section 6:5) were subsequently presented to the strategic group/ research sponsors.

Figure 7:1 outlines the six key actions aimed at developing an informed understanding of parents' and school staff perceptions and experiences of service delivery. The reconnaissance activities afforded some insight into the parents' experiences of assessment and support available during and following their child's diagnosis, and perceptions of external agents in school practices to facilitate inclusion of children with autism. The scoping exercises were precursory activities to facilitate the design of the parental questionnaire.

Figure 7:1: Stages of action research processes



7:3 What have I learnt about the type of service parents want from health and educational service providers?

Table 7.1 summarises the findings from the parent questionnaires which were presented in Chapter Five, which are re-presented here for ease of reference.

Table 7:1: Key findings from parental questionnaire

Key findings from parent questionnaires
<ul style="list-style-type: none"> • Parents received varied information at the time of diagnosis • Parents valued caring professional attitudes, practical support, knowledge and expertise at the time of diagnosis • Parents wanted increased staffing levels, access to knowledge and expertise, increased local provision, and changes to attitudes held by professionals in schools • Parents of younger children with a diagnosis of autism were more satisfied with the support available to them • Aspects of current provision should incorporate access to professionals with more specialist knowledge of ASD, increased levels of staffing, more appropriate local provision and a change in school staff attitudes to the condition • Gaps in existing provision included family therapy/ counselling services, support around benefits, toileting, access to more on-going professional involvement and access to activities during the summer holidays, advice for managing behaviours at home and respite care. • Reported difficulties with school staff skills in managing and understanding autism • Provisions and adjustments made within secondary schools vary • There are difficulties with inclusive practices in mainstream school schools
Prioritised recommendations
<ol style="list-style-type: none"> 1. Develop inclusive practices in schools and ensure school staff have sufficient knowledge and skills to meet the needs of children with ASD. 2. Provisions of psycho-educational interventions to support the child's needs arising from autism and families with coming to terms with the diagnosis. 2. Increase staffing levels to respond to the families' request for more home support/visits, access to specialist health visitors and appointment of keyworkers

These key findings provide some insight into the valued aspects of service delivery for parents alongside identified gaps between what is wanted and what is available. Abstracting these findings completed the 'first action steps' within the collaborative action research approach and the emphasis moved to the 'Reflection, Monitoring and Evaluation' cycle of Kemmis' (1985) model where gaps in existing provision were explored in greater depth and consideration given to how these findings could shape practices and service delivery for parents in Midtown.

Parents were able to clarify aspects of service delivery which they wished to prioritise for targeted action (discussed in Chapter Five section 5:10 and Chapter Six section 6:5). It was evident there were shortcomings in the range of services available to families and schools, and that both parents and school staff sought a more individualised approach. Indeed NICE guidance (2011) suggests that,

“Treatment and care should take into account the needs and preferences of children, young people and those who care for them. Children and young people with autism and their families and carers should have the opportunity to make informed decisions about their care and treatment in partnership with their healthcare professionals.” (p.6)

Such a position advocates a shift in control and power dynamics between service users and providers, which is congruent with parental and school professionals' wishes elicited within the current study, but presents challenges for service providers in balancing equality of opportunity and access to support and services, against differentiated provisions to accommodate individual needs/ preferences.

Whilst I am aware parents require developments to existing provision available, I must consider how change can occur. Mackrell & Peacock (2006) suggest that in order to effect change and promote new approaches, consideration and understanding must be given to the aims, practices and constraints of working environments. This is a significant undertaking as the strategic group works across different organisational bodies, with different funding streams and different priorities; as such the working environment is complex. It is clear that some of the desired changes to service delivery are easier to implement than others: some pertain to a specific organisation within the diagnostic and intervention pathway, while others pertain to the wider system and model of service delivery. Moreover, implementation of all desired developments may be constrained by funding. Under these circumstances further negotiation with service users and service providers is required. Indeed in recent years

policy has tried to achieve this position by proposing “parents have access to transparent information about the funding which supports their child’s needs” and providing parents with “the option of a personal budget for all families with children with a statement of SEN or a new ‘Education, Health and Care Plan” (DfE, 2011, p.8).

However, whilst this new policy (DfE, 2011) appears to be congruent with what parents want, suggesting an ‘evidence-based’ approach to policy-making, Wesis & Bucuvalas (1980) warn the relationship between policy and evidence-based practice should be treated with some caution. They suggest that any link between policy and research evidence is often fuelled by politicians watching the polls or their backs, rather than obtaining a rich understanding of research, so that “they [policy-makers] discuss broad purposes, not specific decisions, specific aims or specific content of research studies (Weiss & Bucuvalas, 1980, p.156).

7:4 What have I learnt about the type of support service school staff want/need?

Head teachers’ and SENCos’ experiences and perceptions of support for schools were also examined and findings presented in Chapter Six. A summary of these key findings are presented in Table 7:2.

Table 7:2: Key findings from head teacher/ SENCo interviews

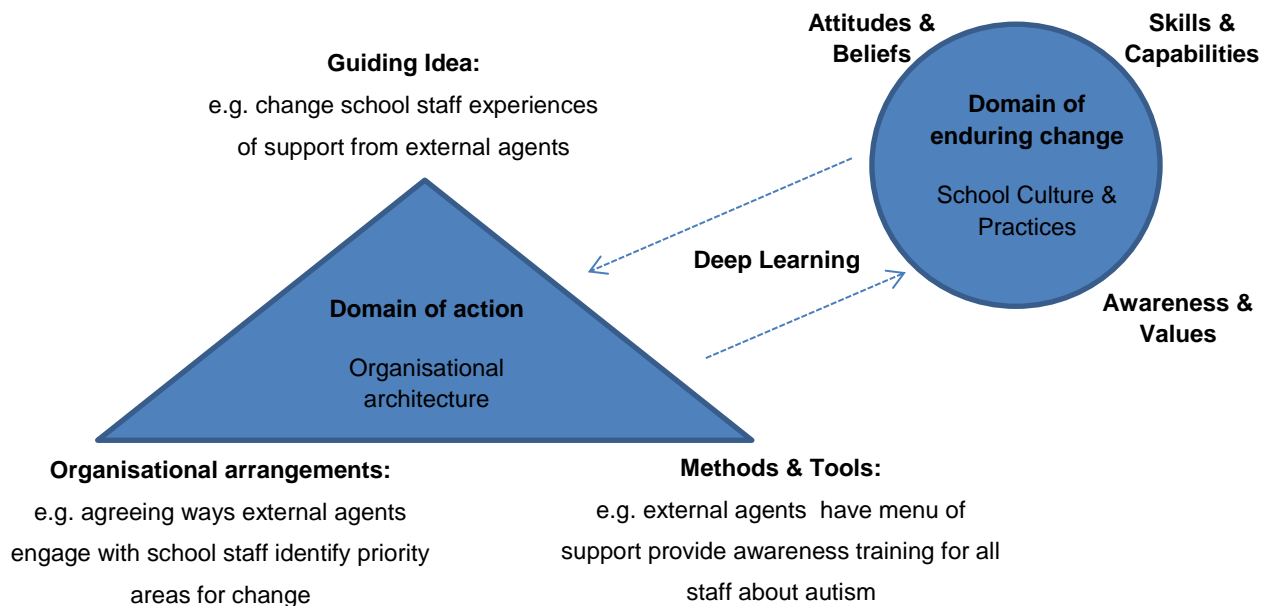
Key findings from head teacher/ SENCO interviews
<ul style="list-style-type: none"> • A majority of schools provide a variety of strategies to facilitate the inclusion of children with autism into mainstream schools • Schools recognised the need for awareness training for all classroom practitioners • Schools reported a desire for improved information sharing with CAMHS: schools report providing information to CAMHS professionals but receiving little information back • Some school staff perceive advisory teachers to lack the depth of knowledge required to support schools in the inclusion of children with ASD • Schools seek greater scope to negotiate the level and focus of involvement with CYP with ASD
Prioritised recommendations
<ul style="list-style-type: none"> • Improve school staffs ability to negotiate the level and focus of involvement for specific individuals • Develop the depth and rigour of the knowledge and support which support services can be dependent upon to offer, so school staff are confident in the “expert” skills of external professionals • Support staff should facilitate meetings between schools and parents when difficulties arise (including the potential break-down of school placements); and • Ensure advisory teachers can provide resources on loan to meet the needs of child with ASD

Findings from the school-based interviews (summarised for ease of reference in Table 7:2) identify that a support service should be flexible to meet the individual needs of the organisation and child. This is consistent with what parents want and recent proposed policy (DfE, 2011) which aims to provide greater control to front line professionals in determining the type of support they provide and children, parents and schools receive.

The findings from this strand of the study also indicate that school staff were aware of their own need to improve the knowledge of school practitioners through activities such as training. School staff indicated training, and subsequent improvements in school practices arising from this training, could be provided by an external agent. Cunningham & Davies (1985) suggest such a view of training arises from an expectation that 'experts' can transplant their knowledge and skills to parents/ school staff to bring about change. However Georgiades & Phillimore (1975) argue that training alone perceived as a mechanism of change or a means to enhance practice should be viewed with caution. They suggest change is best achieved when organisations evaluate their own cultures and practices, rather than expecting external services to contribute to 'bolt-on' training. Indeed Kirkpatrick (1994) suggests that training maybe one necessary condition for development and change, but it is unlikely to be a sufficient condition. Despite this, head teachers/ SENCos and parents value the role of training and the 'transplant' model of knowledge as a mechanism of change; creating unrealistic expectations about the impact of training on organisational cultures. As such the recommendations identified by head teachers and parents seem more closely aligned with functional integration rather than with the school transformation which is at the heart of inclusion.

With this 'functional integration' in mind head teachers and parents continue to locate effective inclusion in the practise and training of external agents. One external agent well placed to facilitate organisational change is the educational psychologist. It is documented that schools value their relationship with their EP (Ashton & Roberts, 2006; Farrell et al, 2006) and this relationship can be used to encourage school staff to reflect upon their practices. Indeed Tajik (2008) suggests that through knowledge of the school and an understanding of its working practices, educational psychologist "can create an environment of trust, cooperation, and collegiality in the school by encouraging dialogue and exchange of views, ideas, and expertise" (p.254). Furthermore this cooperation and trusting dialogue can create an environment in which 'deep learning' can occur, resulting in long-term change. Senge et al (2000) suggest that the foundations of 'deep learning' or 'organisational architecture' reside in agreed tangible actions which reinforce organisational attitudes and skills, as illustrated in Figure 7:2.

Figure 7:2: Organisation learning model



Based on Senge et al (2000) and Arbuckle (2000)

Whilst Senge (2000) provides a conceptual framework for understanding organisational change it is also important to recognise the ‘model of development’ or ‘deep learning’ is also influenced by the ‘level of pressure and support from the external source.’ (Tajik, 2008, p.253). The nature/ intensity of this ‘pressure and support’ is further influenced by the roles assigned to the external change agent. Tajik (2008) suggests there are three roles: a facilitator (the external agent is equal to others in the change process- Richert et al., 2001); a critical friend (to mirror teachers’ actions in order to engage the teachers in systematic and critical analysis- Richert et al., 2001); and a technical expert (someone who takes on the role of solution giver/ adviser-Reid, 1990).

Findings from this study appear to suggest that school staff assign STePS professionals either the role of ‘facilitator’ and/ or the role of ‘technical expert’. However the assignment of these roles to the external agent, or the degree of ‘pressure and support’ brought to bear on schools will not themselves be sufficient to create long term, sustained change to practices.

It would be remiss not to acknowledge that currently the ‘change agent’ role is donated to STePS professionals by school staff by providing a prescribed commissioning brief. It is evident that in order to facilitate change STePS staff will need to engage more fully in the consultation process in which the expectations are clarified, the role and ways of working are

negotiated and consultants and consultees create a shared, realistic vision of outcomes arising from undertaking the change tasks.

Huffington (1996) defines consultation as:.....“A process involving a person who is invited to help a client with a work-related issue. The client can be an individual, a group or an organisation.” Importantly Huffington focuses upon the voluntary nature of the process where the consultee invites the consultant into the problem. This voluntary nature enables the consultees to feel in control of the situation and helps to mediate more responsive collaborative working. Furthermore, she suggests that consultation covers a range of activities, from non-directive counselling to more directive activities, such as giving recommendations. Similarly, Schmidt and Johnston (1970) propose a continuum of consultation styles, at one end a non-directive, client centred style, and at the other, a directive, consultant-centred style. Huffington (1996) proposes a consultant should be skilled in moving along the continuum according to the specifics of the request made and the different stage of the change process.

Whilst the role of the external change agent is often donated and governed by the nature of dialogue between schools, Ainscow (1998) argues that, schools are idiosyncratic communities and whilst outsiders can be involved in the change process, change has to come from within the community. Indeed Greenwood et al (2002) indicate that innovations introduced by external agents succeed less often than those internally initiated and implemented by schools, often because the former cannot be sustained after the external agents leave the school; an argument which emphasised the importance that change should be owned by those implementing the change to ensure it is embedded and sustained over time.

The use of collaborative action research methodology within the current study is propitious to the ownership of the change processes by utilising a series of action research cycles, of which data collection, analysis and processing with stakeholder representatives is just the first cycle. McNiff (2002) suggests that, such is the speculative nature of action research that it will often generate more questions than answers “as one question is addressed, the answer to it generates new questions” (p.2). As such the findings from this study and any immediate actions taken to address the concerns raised should be viewed as an initial action research cycle only from which subsequent research cycles continue to develop in order further to refine services/ support.

7:5 Implications for educational psychology practice and wider applicability of findings

At the outset of the research project the data collection aimed to offer an improved understanding of parental experiences of the referral, assessment and intervention processes for children with autism and to identify the practices available and needed in order to support the inclusion of children with a diagnosis in mainstream secondary schools. It was noted the findings reflect data collection at a particular place and time, with a specific cohort of participants and cannot be seen typical of all the parental experiences of children with autism in Midtown or representative of current secondary school staff practices and attitudes, as these are dynamic and change in response to new situations and policy.

It is important to emphasise the purpose of this study was not only to understand parent and school staff experiences of support for children with autism but to inform directions for change in order to improve practices and to refine the STePS support system to ensure it was 'fit for purpose', albeit for this specific cohort of participants at a specific point in time. As such it was never intended for these findings to be generalised; rather this study sought to provide an effective framework for consultation with key service user groups (parents and senior staff in secondary schools), and for collaborative reflection processes, and identification of priorities for action which were endorsed by these service user representatives.

However, whilst generalisation of these findings was not a primary purpose of the study, these findings do hold relevance to policy and practices beyond the immediate study. Educational Psychologists could use these findings to improve the ways they engage with parents and school professionals and construct their role as 'agents of change'. This might include reflecting upon how change processes occur with different stakeholders and how the roles assigned to those seeking change are negotiated. It would be important for EPs to recognise their responsibility to involve all those undergoing the 'change process' and ensure they bring sufficient challenge to existing practices (as discussed in Section 7:4.) It is noteworthy that this task of offering constructive challenge of the status quo in the role of critical friend expected to become increasingly difficult for EPs as schools become independent of the authority through the academy/ free schools agenda and the decommissioning from Local Authority control of many of the universal service providers, of which Educational Psychology Services form part.

Beyond facilitating the 'change process', the findings also indicate the need for EPs and other professionals to take fuller account of parents' differing and changing needs

throughout the assessment and intervention process, and contingent differences in the nature of support they require from professionals. A clear implication for EP practice is to develop skills in providing carefully calibrated advice, knowledge and understanding of autism relevant to parents' differing needs and the different stages of the diagnostic process, demonstrating awareness of the different states of 'readiness' to accept and understand the diagnosis (Connor, 1997).

In addition to the findings holding relevance to EP practice, the theoretical arguments derived from these findings can be applied to other 'cases' which share some of these characteristics.

The findings from this study converge with findings reported in similar studies (McGregor & Campbell, 2001; Humphrey & Lewis, 2008; Symes & Humphrey, 2011; Minnes & Steiner, 2009) and provide a legitimate claim to the theoretical generalisation for findings attesting to:

- the nature of and bases for difficulties many parents experience as their autistic children progress from primary to secondary schooling (Leyser & Kirk, 2004; Jenkinson, 1999; Kasari, 1999);
- the challenges secondary schools experience in developing a fully inclusive philosophy and practices, whilst also developing the 'disorder-specific' knowledge, understanding and expertise that is necessary in order to fully accommodate the needs of students with ASD (Whitaker, 2007; McGregor & Campbell, 2001; Humphrey & Lewis, 2008; Barnard et al); and
- the difficulties with external professionals and schools face in mediating working relationships which best facilitate the application of the external professionals' expertise to the needs of the organisation (Miller, 2003; Jones et al, 2009; Kirkpatrick, 2002).

In light of proposed changes to the SEN system (DfE, 2011) and the decommissioning of services so that parents and schools (through academy status) can purchase individualised services relevant to their perceived needs, it will be all the more important for local authorities and service managers to consider how services can remain appropriate to service users' needs.

The findings from this study provide some insight into perceived gaps in existing provision and in line with previous research, notably Jones et al (2009), McGregor & Campbell (2001)

Dymond et al (2007), could be used when constructing new services and support to parents and schools

Furthermore the findings from this study are also relevant to policy makers. The over-arching themes reflect concerns about professional dialogue with families, staff training and knowledge and the desire for a needs-led service model. Whilst inclusion has been a priority since the late 1970s and numerous legislation and policy incentives have been produced to promote inclusion in general and more recently, specific policy and legislation for children with a diagnosis of autism (Autism Act, 2009; NICE Guidelines, 2011; Autism Strategy, 2010) the difficulties with parental levels of satisfaction and confidence in the systems remain largely undiminished. Thus this study indicates that there is a mismatch between espoused policy and its translation into effective practice. As such these findings indicate the need to sustain research into the relationship between policy and practice.

However since the completion of this thesis a number of steps have been taken to address the recommendations identified and the mis-match between policy and practice. These include:

- improving the knowledge and expertise of school staff through the identification of an ASD champion in each secondary school. These individuals received ASD-specific training from the advisory teachers and serve as 'in-house experts' so that other practitioners are able to access support and advice from professionals within their own school and with increasing responsiveness, with the longer term aim of facilitating a change in attitudes about a school's capacity to meet the needs of children with a diagnosis of autism. The role of 'ASD champion' is currently being extended into all primary schools;
- The advisory teachers have identified a 'Menu of Support' which is used to provide examples of the type of work they can undertake, although much of the casework is negotiated via a termly planning meeting (as used by Educational Psychologists) where schools can consider the need of individuals and groups of children within the school;
- introduction of a parent email used by parents to facilitate their communication with professionals and to raise areas of concern which are presented at the strategic group for discussion/ action;
- parent representation at the strategy group so that parents are able to raise areas of concern and work with professionals to achieve a service which they consider increasingly 'fit for purpose'; and

- commissioning of Occupational Therapist and Speech and Language Therapist services via the Local Plan (DfES, 2012)

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Appendices

2 educational psychologist providing 40 hours a year in ASD development/ strategic work

3 full time specialist advisory teachers providing 4440 hours a year in direct casework, training and support/ advice for schools and parents for school age children (4-16 years)

2 pre-school support worker providing 2960 hours a year in direct casework, training and support/ advice for local authority and private pre-school provisions.

1 speech language therapist providing 1160 hours a year to pre-school children in specialist and mainstream settings in the local authority and private sector.

2 clinical psychologists provide 1665 hours a year (children aged 9-16years) to ASD assessment and intervention work.

1 consultant community paediatrician 900 hours to diagnosis children through a specific diagnostic centre (children aged 2-8 years)

CAMHS and Social Care practitioners who have a generic casework in which they will have children who have a diagnosis.

This totals 11165 hours a year, 214 hours a week is available to support CYP and families from the 11 different professionals with a specific role and function of supporting children and families with a diagnosis of autism.

Dear Parents/ Carers,

The specialist teaching and Psychology Service (STePS) is currently reviewing the services offered to families following their child's diagnosis of Autism. We would very much value knowing about your experiences. It would be really helpful if you could complete the enclosed questionnaire and return it in the stamped addressed envelope. Your responses will help us to plan future effective provision for families of children with Autism Spectrum Disorder in Midtown.

Your responses will be treated as strictly confidential and will be anonymous. Should you wish to withdraw from this study you can do so in the following way. On the front of your questionnaire is an additional piece of paper which provides a unique number for you. Detach this paper and keep it safe. You will need to refer to this should you want to withdraw. If you would like to remove the data from the study then phone STeP and quote the number from your questionnaire. Your data will be removed from the study.

All data will be anonymous and a collective response will be summarised in a written document. This information will be shared with parents via the CASNAS, parental autism drop in sessions and shared with service commissioners from social, health and education sectors.

In addition to the questionnaire there is an additional letter enclosed with a separate stamped addressed envelope seeking parental interest in being involved in the planning process of provisions for families with children with autism. If you wish to become involved then please complete the form and send it back. It is crucial you do not enclose it with your questionnaire.

Appendix 4: Summary of literature research into families' and school experiences of support

Study	Focus	Methodology	Findings
Bernard et al (2002)	A survey of teachers views on the number of children with autism and the provisions available to them to support those children.	Quantitative – survey sampling Questionnaires were sent to 5 English and Welsh Local Educational Authorities. A total of 373 questionnaires were completed and returned	Upon analysis it was apparent that 1 in 86 children taught have an educational need related to autism spectrum disorder. There were also more children with a diagnosis in primary schools than in secondary schools. Teachers reported concerns about lack of specialist support and would welcome training and advice from the LEA. There were also concerns about the training of teachers and general knowledge and understanding of the condition. Teachers report that inclusion as a model of education is dependent upon the severity of need. 32% of schools who reported insufficient knowledge or training in autism felt that inclusion did not work.
Jones et al 2009	Parents experience of support and access to educational provision.	Quantitative – survey sampling 173 questionnaires were completed and sent out to parents across the UK. The sample included responses from parents of 24 girls and 149 boys.	Parents felt authorities needed to listen to parents more as they generally have a better understanding of the child. Concerns were also expressed about parent's ability to make requests of school staff without jeopardising the positive relationships with schools.
Leyser and Kirk (2004)	Parents perception of inclusion	Quantitative – survey sampling Questionnaire sent out to parents	Parents see the benefits of inclusion as improved social and emotional outcomes for the child.
Minnes and Steiner (2009)	Investigate the perceptions and experiences of negotiating and obtaining healthcare services in Canada	Qualitative – semi-structured interview with parent focus group	Parents report a number of concerns and researchers suggest the need for enhanced services to include education of professionals and creating a centre which offers service-related information for parents.
Renty & Roeyers (2006)	Factors which influence parental satisfaction of support for their child with ASD from statutory service in Finland.	Quantitative – survey sampling Questionnaire completed by parents. Satisfaction was measured on Lickert 5 point scale and analysed using a simple t test.	There was greater satisfaction amongst parents whose children attended specialist provision. Parents also acknowledge that the child's characteristics would also influence how parents perceive support. If the child doesn't present with learning disabilities, getting support was seen as more difficult to obtain.
Rowlandson & Smith (2009)	A 3 year pilot project on the Isle of Wright aimed at providing a holistic and co-ordinated service for families of children with autism.	Quantitative and qualitative Survey sampling via questionnaire and semi-structured interviews	Responses indicated that involving schools and parents directly in the process of diagnosis and intervention led to better outcomes, reduction in waiting times and a consistent approach in the management of ASD.
Whitaker (2007)	Parental experiences and satisfaction with inclusion of children with autism into mainstream schools	Quantitative – survey sampling 350 parental questionnaires were sent out. A themed analysis was used on the data.	Parents were satisfied with inclusion when parents perceived schools to understand their child's needs and made adjustment accordingly. Increased levels of satisfaction were also linked to reciprocal communication between schools and parents. Parents reported concerns about schools' role in promoting social development and relationships.

Dear Parents/ Carers,

The specialist teaching and Psychology Service (STePS) is currently reviewing the services offered to families following their child's diagnosis of Autism. We would very much value knowing about your experiences. It would be really helpful if you could complete the enclosed questionnaire and return it in the stamped addressed envelope. Your responses will help us to plan future effective provision for families of children with Autism Spectrum Disorder in Midtown.

Your responses will be treated as strictly confidential and will be anonymous. Should you wish to withdraw from this study you can do so in the following way. On the front of your questionnaire is an additional piece of paper which provides a unique number for you. Detach this paper and keep it safe. You will need to refer to this should you want to withdraw. If you would like to remove the data from the study then phone STeP and quote the number from your questionnaire. Your data will be removed from the study.

All data will be anonymous and a collective response will be summarised in a written document. This information will be shared with parents via the CASNAS, parental autism drop in sessions and shared with service commissioners from social, health and education sectors.

In addition to the questionnaire there is an additional letter enclosed with a separate stamped addressed envelope seeking parental interest in being involved in the planning process of provisions for families with children with autism. If you wish to become involved then please complete the form and send it back. It is crucial you do not enclose it with your questionnaire.

Yours sincerely

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Yours sincerely

Dear Parent

I am an Educational Psychologist who works part time at the Midtown Council within the Specialist Teachers and Psychology Service (STePS). I am currently undertaking my doctorate study in Educational Psychology. I have a specialism in Autism and work with the specialist placements for children with Autism within Midtown.

As part of my role I am currently working with Health professionals to identify an appropriate pathway for children who are referred for assessment, diagnosis and intervention. In order to shape practices in Midtown it would be really helpful to understand the experiences of those who have gone through this process. Therefore I would like to opportunity to meet with you to discuss your experiences of support from your initial concerns through to current support available to you and your child from both health and educational professionals.

The information you provide will be used as part of the research component of the Doctorate Study at the University of Birmingham and will inform subsequent stages of auditing autism practices and provisions for families of children with autism within Midtown. Following data analysis practices within Midtown will be reviewed and developed in conjunction with families to help shape a new model of support and service delivery.

The information you provide with be made anonymous and treated as confidential unless the information you share puts yourself or others at risk of harm. Naturally during this interview you can withdraw from the process at anytime and should you decide later that you no longer wish for your comments to be included in this study then you can contact me and request the information be withdrawn. This research forms part of my doctorate study at the University of Birmingham and the information obtained throughout the study will be stored by the University.

If you would like to take part in this study then please phone the STePS admin team providing your details so that I can make arrangements to meet with you.

Clarify background information- pregnancy, early milestones

Identify initial concerns. Who had these, what were they?

Next steps: how did things process-

Referral process- who referred the child for diagnosis? How was this agreed? How was information shared with parent?

Use of salmon line – identify how parents felt at each stage of the process of diagnosis.

Discuss each rating individually- why have the parent rated the phase of diagnosis in this way- what were their experiences of professional attitude and demeanour, specialist knowledge and ability to impart this to parents in a meaningful way, understanding of the process and subsequent stages.

From the support provided by professionals was most helpful/ valued ? which service and why?

What was least helpful and why?

What would have been more helpful?

Following diagnosis what support was made available? Who informed parents about this support ? how did parents access it?

What services are valued?

What do parents need now from services?

What have been parent experiences of support within educational placement? What if anything changed following the diagnosis?

What parents feel is needed in school to support their child?

What arrangements and adjustments do school staff make to increase access and inclusion to mainstream schooling for Children and Young People with ASD?

We provide extra transition where we meet with the primary school staff on a number of occasions. Our staff go over to observe the child in their primary class on a number of occasions so that the child sees a familiar face. On occasions we have taught alongside primary teachers so that the child experiences support in a familiar environment and again gets use to our staff.

We make early contact with our primary feeders so they can alert us to any child who might come to us prior to formal allocation of places.

When we know a child is coming to us we contact parents to provide a named contact for someone in school: that might be a key worker or head of house.

We provide TA support in all lessons for the first half term which is then reviewed. The nature and intensity of support is based on the individual needs. All students on the SEN register have a key worker.

We also provide information to all staff about the individual child and the strategies to use. Staff have access to electronic information. This information is updated on a fortnightly basis. Information includes the use of strategies to use with the child as promoted from primary staff, statement objectives/ strategies, IEP targets, other personal or relevant information which will help teachers teach the child.

We include parents in the induction process very early on. Once we know a child is coming to us we contact parents and invite them to a parents evening for children with SEN (general)

The curriculum is adapted to the individual child's needs, for example, we provide some children with extra support via nurture group, booster sessions literacy and numeracy groups, time out cards, quiet work space LSA's also meet weekly to discuss the behaviour of children.

- Individual support
- Environment change
- Parental involvement
- Consultation
- Information giving/ sharing

What is the school's experiences of support from the Specialist Teacher Service?

We have received training in different departments

In-class support

Whole-school training (awareness raising)

1:1 work to identify strategies

1:1 work modelling strategies to school staff

Observations in class

Feedback on observations about class teachers practices and ways of managing difficult behaviour

Comments about school placements

Advice on strategies being used in school

- Training
- Consultation
- Direct work

What external support does a school such as yours need if it is to provide an effective inclusive education for children with ASD?

Advice about classroom practices

Strategies relevant to the individual child rather than generic strategies

Training

Negotiation of the work undertaken and focus of intervention and support

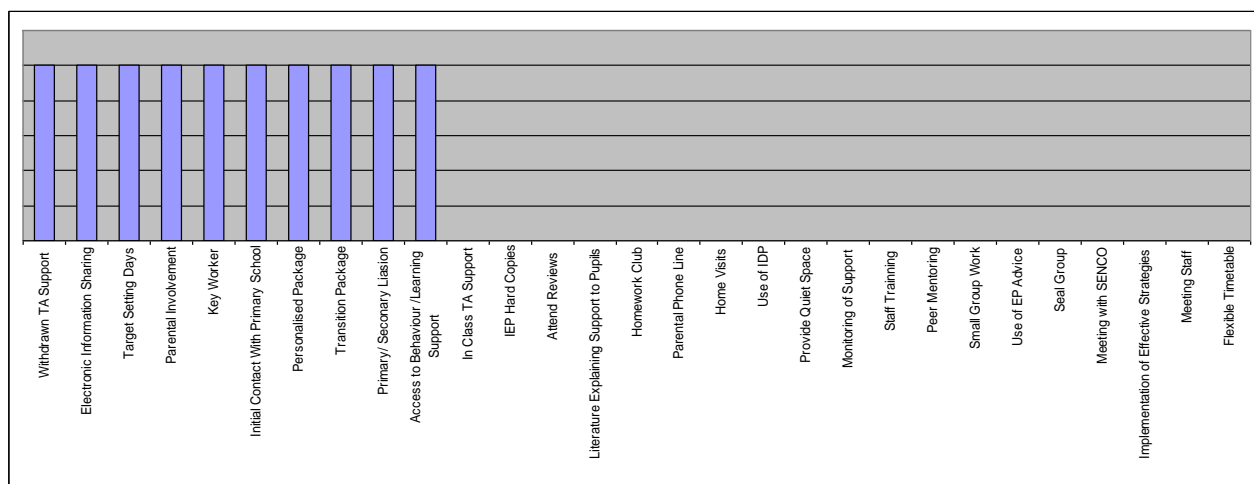
STePS staff to have good ASD knowledge

■ Professional involvement ■ Practical support for schools & families ■ Training, Advice & Resources

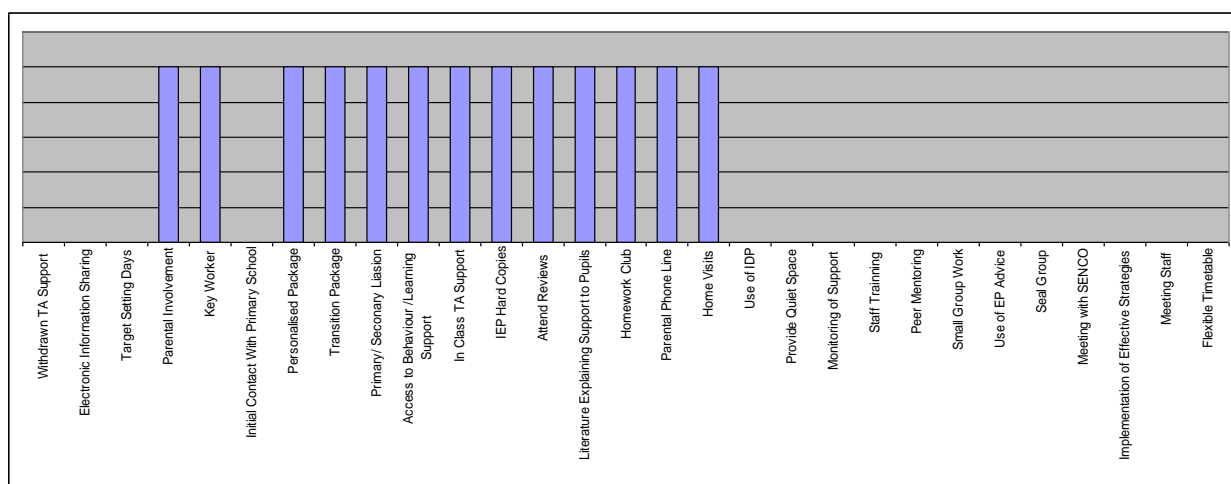
Appendix 9: Individual school democratic data

School & Age range	No on roll	Ofsted rated	Demographics	School & Age range	No On roll	Ofsted rated	Demographics
A (11-16)	735	3	Below average sized secondary school Most pupils are from minority ethnic group Above average free school meals Above average no. of SEN	H (11-16)	882	3	Above average sized comprehensive school Most pupils are of White British backgrounds Average no. of pupils from minority ethnic backgrounds Above average free school meals Above average no. of SEN pupils Above average no. of EAL pupils
B (11-19)	1377	1	Above average sized comprehensive school Most pupils are of White British backgrounds. Small no. of pupils from minority ethnic backgrounds Below average free school meals Below average no. of SEN pupils	I (11-16)	949	3	Above average sized comprehensive school Most pupils are of White British backgrounds. Small no. of pupils from minority ethnic backgrounds Below average free school meals Above average no. of SEN pupils Below average no. of EAL pupils
C (11-16)	623	3	Smaller than average sized comprehensive school Most pupils are of White British backgrounds. Small no. of pupils from minority ethnic backgrounds Above average free school meals Above average no. of SEN pupil	J (11-18)	1265	2	Above average sized comprehensive school Most pupils are of White British backgrounds. Below average no. of pupils from minority ethnic backgrounds Above average free school meals Above average no. of SEN pupils Above average no. of EAL pupils
D (11-19)	1234	3	Above average sized comprehensive school Most pupils are from minority ethnic backgrounds Small no. of pupils from White British backgrounds Above average free school meals Above average no. of SEN pupils	K (11-16)	897	4	Above average sized comprehensive school Small majority of pupils are of White British backgrounds. Above average no. of pupils from minority ethnic backgrounds Above average free school meals Below average no. of SEN pupils Above average no. of EAL pupils
E (11-16)	808	1	Above average sized comprehensive school Most pupils are of White British backgrounds Average no. of pupils from minority ethnic backgrounds Below average free school meals Below average no. of SEN pupils Above average no. of EAL pupils	L (11-19)	1483	3	Above average sized comprehensive school Most pupils are of White British backgrounds. Average no. of pupils from minority ethnic backgrounds Below average free school meals Above average no. of SEN pupils Average no. of EAL pupils
F (11-19)	1174	2	Above average sized comprehensive school Most pupils are of White British backgrounds Small no. of pupils from minority ethnic backgrounds Below average free school meals Above average no. of SEN pupils	M (11-16)	1350	2	Above average sized comprehensive school Most pupils are of White British backgrounds. Below no. of pupils from minority ethnic backgrounds Below average free school meals Below average no. of SEN pupils
G (11-19)	1496	1	Above average sized comprehensive school Most pupils are of White British backgrounds Average no. of pupils from minority ethnic backgrounds Below average free school meals Below average no. of SEN pupils Above average no. of EAL pupils	N (11-19)	1014	3	Average sized comprehensive school Most pupils are of White British background Small no. of pupils from minority ethnic backgrounds Well above average no. of SEN pupils. Below average free school meals

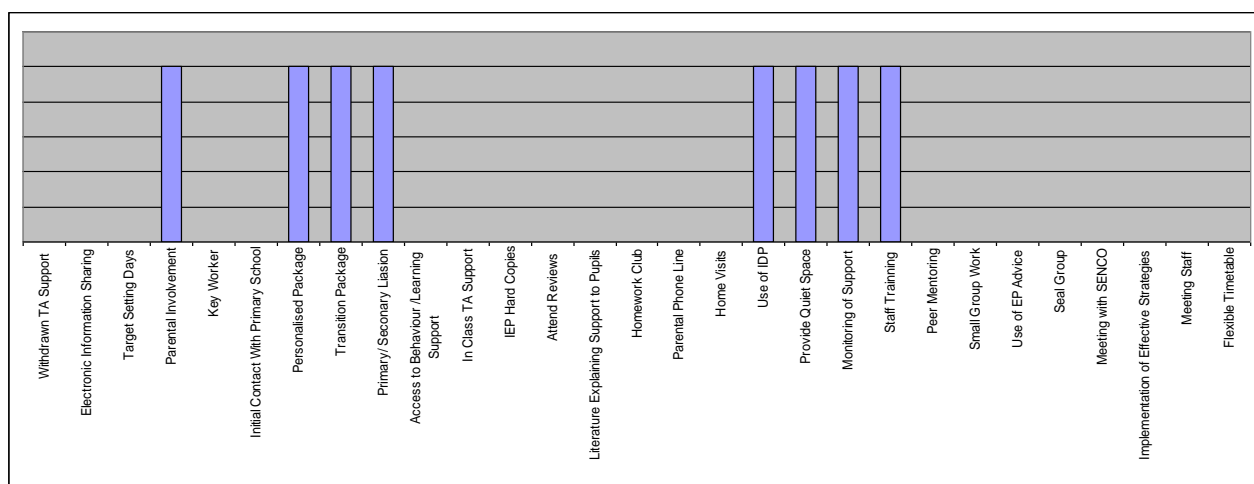
School A



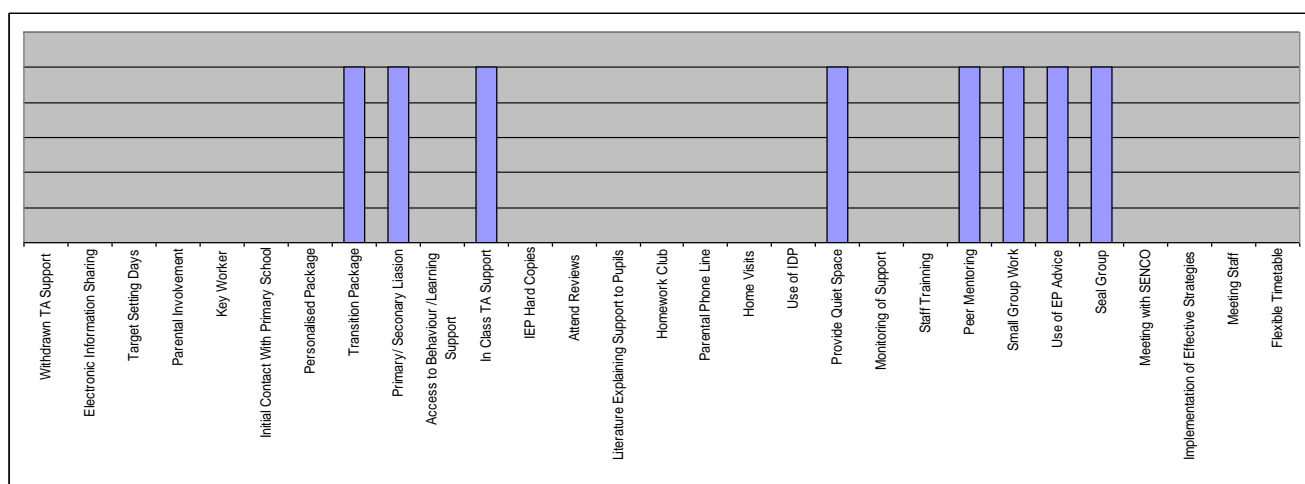
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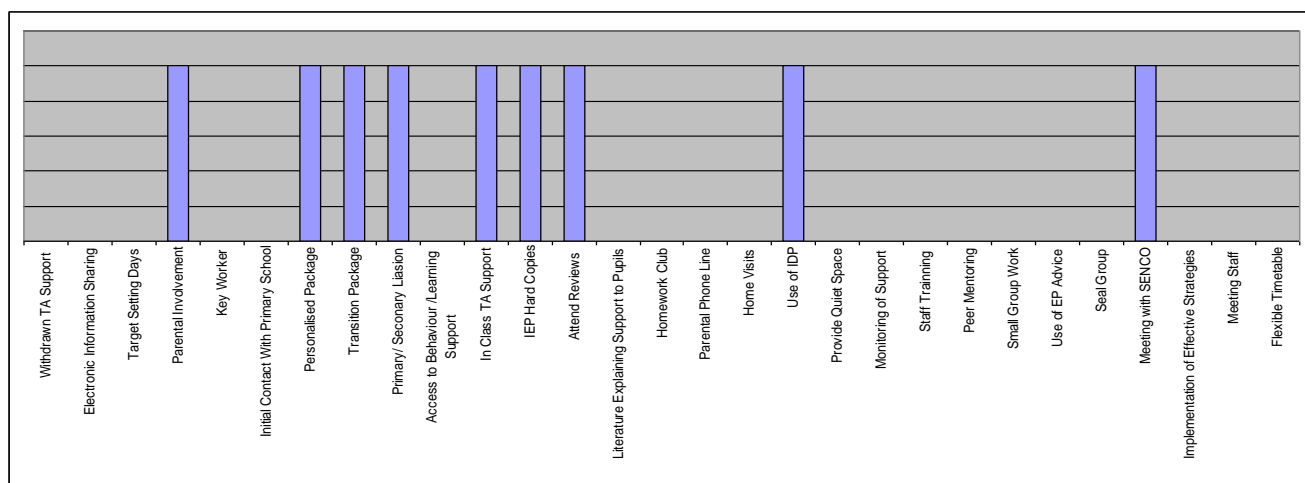
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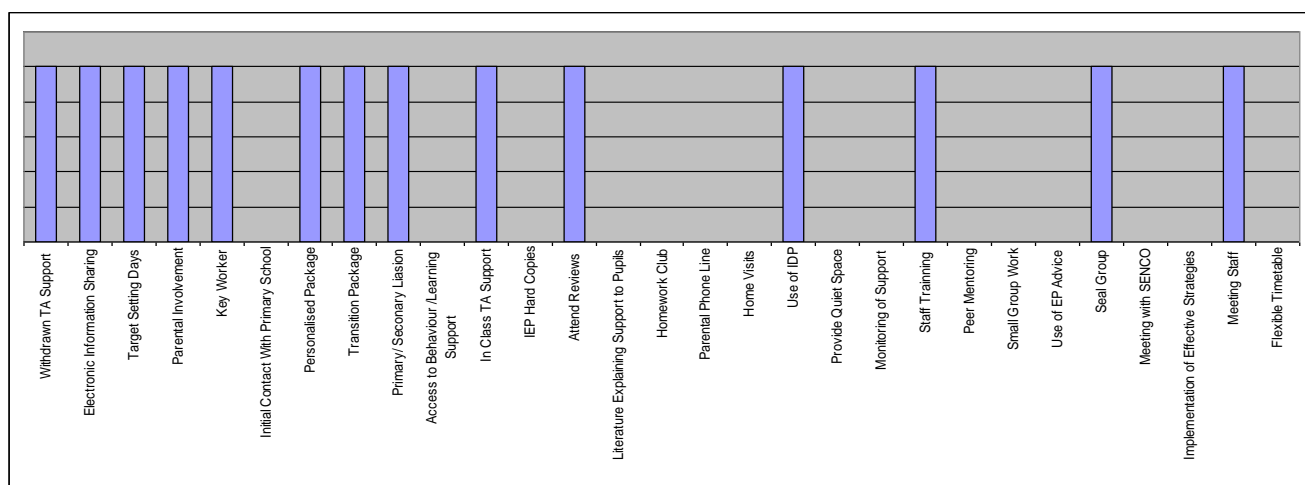
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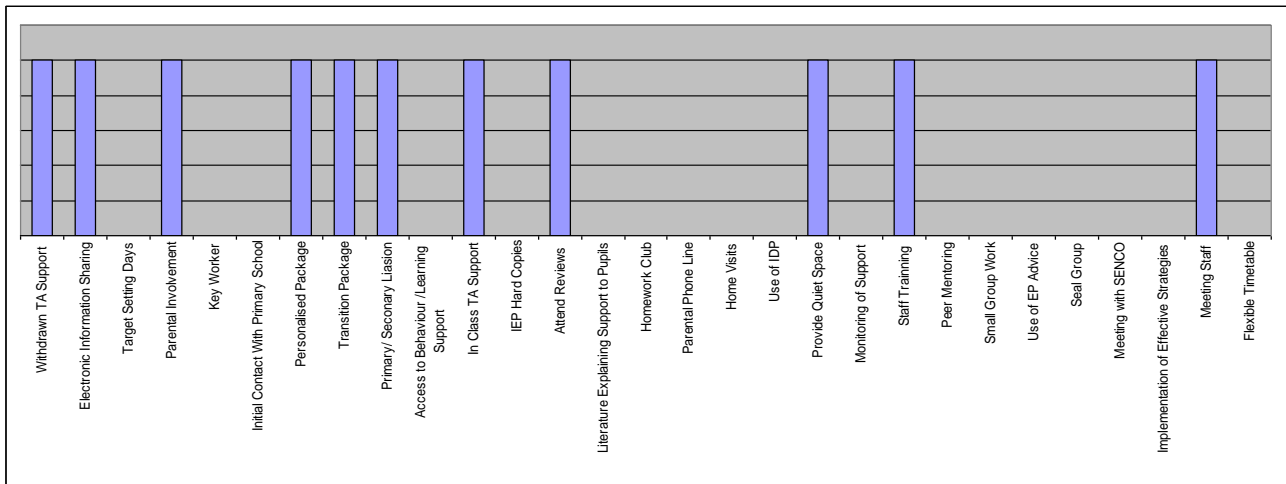
School E



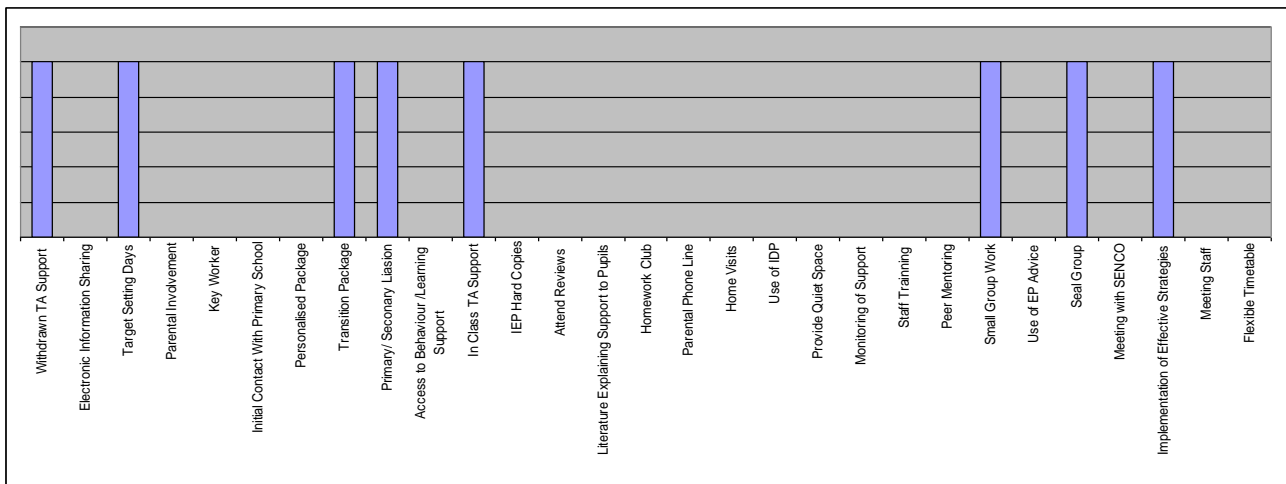
School F



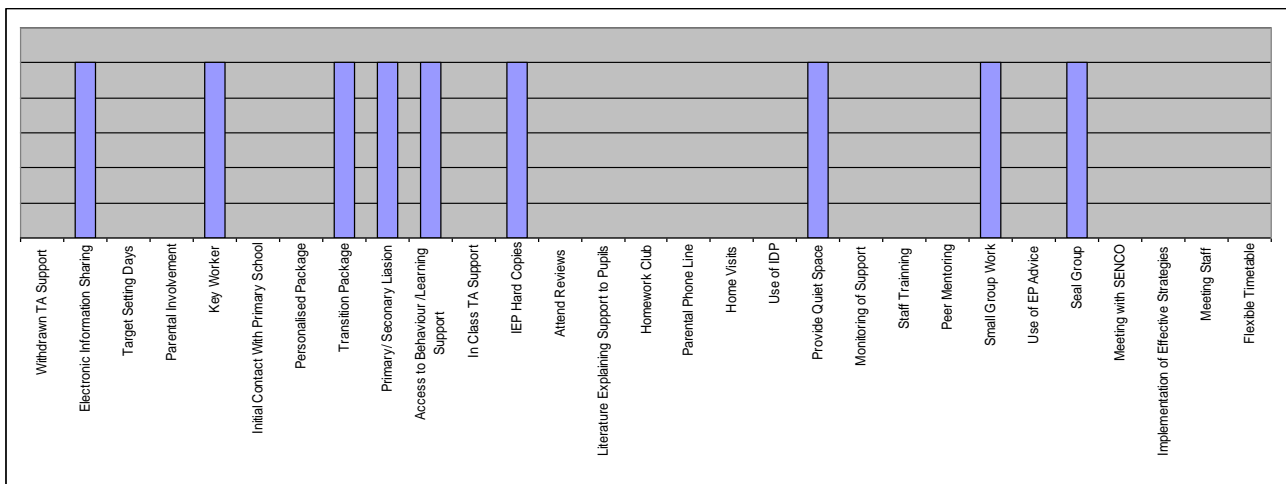
School G



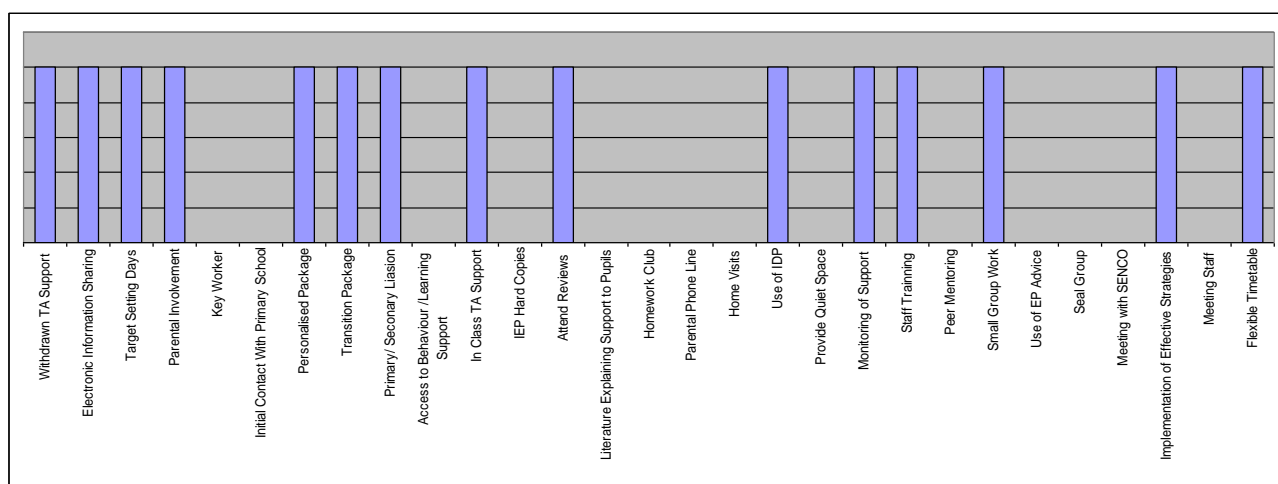
School H



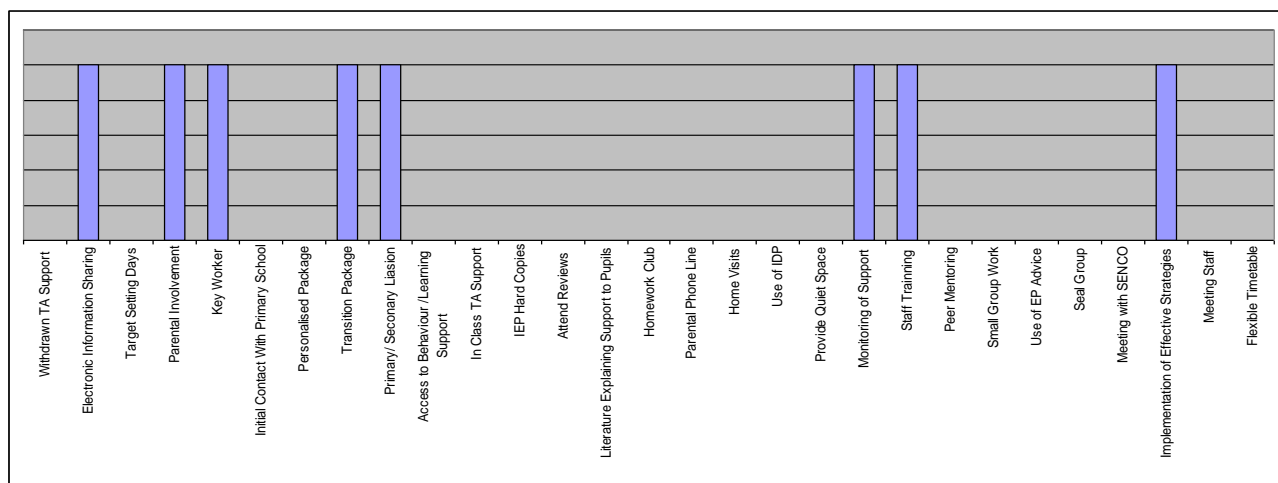
School I



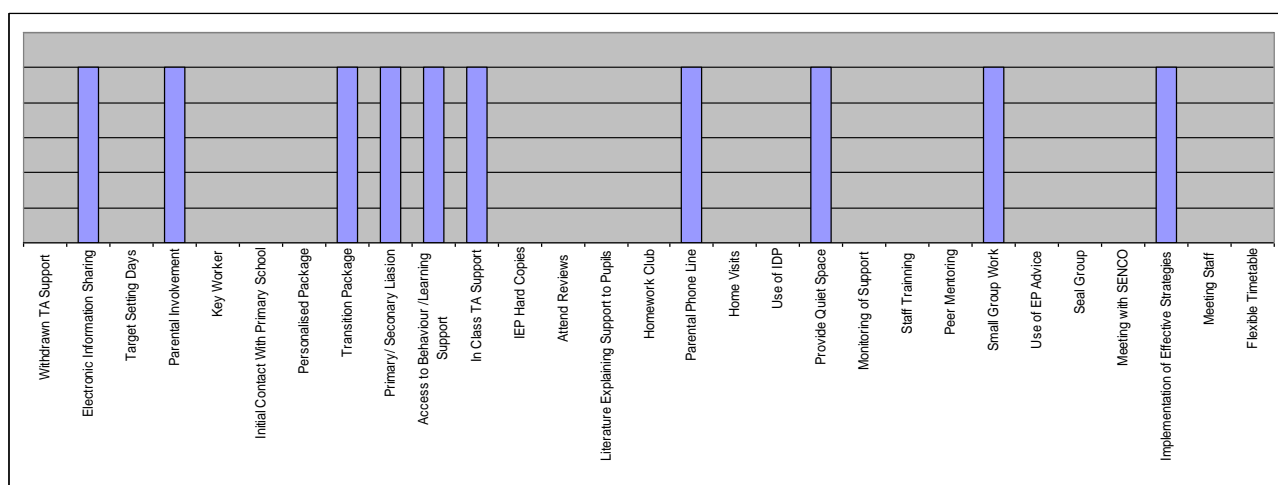
School J



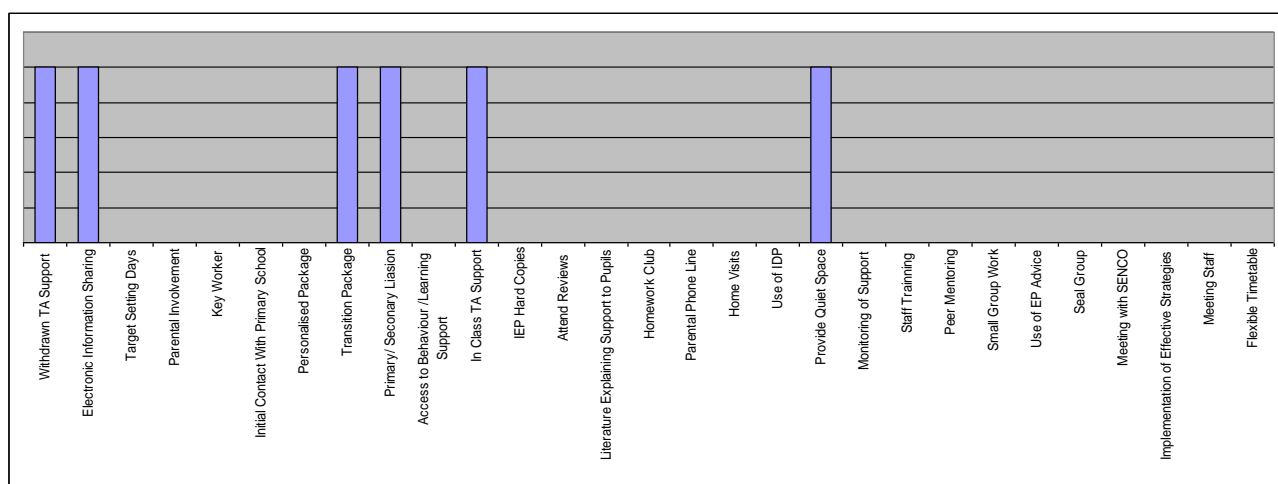
School K



School L



School M



School N

