A study of the experiences and perceptions of parents of Black and Minority Ethnic pupils statemented with autism in relation to the educational support provided for their children and for themselves.

by

Sheladevi Nair

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ABSTRACT

This study investigates the experiences and perceptions of parents of Black and Minority Ethnic (BME) pupils statemented with autism of the support they receive for their child in education and for themselves. These perceptions are explored alongside the views of stakeholders in education who work to support these pupils and parents. The study expands upon the work of Perepa (2008) who investigated the cultural influences on the understanding of appropriate social behaviour by BME parents of children within the autism spectrum in a London borough. Since then there has been minimal research on BME parents’ experiences of having a child with autism in education, so this study addresses a gap in research. A qualitative case study approach was adopted using in-depth interviews with participants from one selected local authority in Wales. An interpretivist approach was used to gain an understanding of the researched phenomena within a cultural context. The data was managed for thematic analysis using the qualitative analysis software tool, NVivo. The findings reveal that BME parents receive support from the providers within education rather than from their own ethnic communities. They show a preference for mainstream education, although evidence here suggests that there are fewer specialist resources in these schools compared to special schools. The findings also reveal that their culture, religion, education and socio-economic backgrounds influence BME parents’ ability to access and utilise educational support services. They feel that their ethnicity and cultural needs are not always taken into account in the ‘culturally-blind’ system which appears to be implemented within education, and their expectation is that society should provide them with more support. It is anticipated that these findings would be taken into account by policy makers and contribute to further research in Wales.
DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signature of author ............................................................

Date .................................................................

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by citations giving explicit references. A list of references is appended.

Signature of author ............................................................

Date .................................................................

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be made available for consultation within the university library and for photocopying or for inter-library loan for the purposes of consultation and for the title and summary to be made available to outside organisations.

Signed .................................................................

Date .................................................................
DEDICATION

To all parents who are ‘living with autism’

Despite the amount of care and love that these parents provide for their child with autism, they face many difficulties. It is recognised that supporting parents and their children in education will assist in lifting the strain that is felt by them in their lives.

*Every time the mind gets 'disturbed' it loses its stamina. But as it gains in poise and equilibrium, it is progressing towards serenity – Santi (peace).*

_The Bhagavad Gita: Chapter 16, page 782_
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ABBREVIATED TERMS

AET
Autism Education Trust

AN
Additional Needs

APA
American Psychiatrist Association

ASD
Autistic Spectrum Disorder

BERA
British Educational Research Association

BME
Black and Minority Ethnic communities

CoP
Code of Practice

CPAG
Cross Party Autism Group

CPD
Continuous Professional Development

DDA
Disability Discrimination Act

DH
Deputy Head

DSM
Diagnostic and Statistical Manual of Mental Disorders

EALAW
English as an Additional Language Association of Wales

EHRC
Equality and Human Rights Commission

EMAS
Ethnic Minority Achievement Service
EO
Executive Officer

GP
General Practitioner

HA
Head of Achievement

HV
Health Visitor

ICD
International Classification of Disease

ICO
Information Commissioner’s Office

ITET
Initial Teacher Education Training

ITT
Initial Teacher Training

LA
Local Authority

LEA
Local Education Authority

mps
mainstream primary school

mss
mainstream secondary school

NAfW
National Assembly for Wales

NAS
National Autistic Society

ONS
Office of National Statistics

PDD-NOS
Pervasive Developmental Disorder-Not Otherwise Specified

PLASC
Pupil Level Annual School Census
**PM**
Project Manager

**QTS**
Qualified Teacher Status

**SaLT**
Speech and Language Therapist

**SEN**
Special Educational Needs

**SENCo**
Special Educational Needs Co-Ordinator

**SENDA**
Special Educational Needs and Disabilities Act

**SENTW**
Special Educational Needs Tribunal of Wales

**ss**
special school

**SST**
Specialist Support Teachers

**TA**
Thematic Analysis

**TC**
Transitional Co-ordinator

**TDA**
Teacher Development Agency

**UNESCO**
United Nations Educational, Scientific and Cultural Organization

**WAG**
Welsh Assembly Government

**WHO**
World Health Organisation

**WG**
Welsh Government
Chapter One

Introduction
1.0 Introduction

Autism is defined as.

A lifelong developmental disability which affects how a person communicates with, and relates to, other people (Evans, 2011: 6).

Autism is part of a range of related developmental disorders known as Autistic Spectrum Disorders (ASD) which begin in childhood and last through adulthood (Jordan, 2006; Frith, 2008; Evans, 2011). The American Diagnostic and Statistical Manual of Mental Disorders in its fourth edition (DSM-IV) (APA, 2000) and the European International Classification of Disease in its tenth edition (ICD-10) (World Health Organisation (WHO), 2007) outlines the essential features of ASD as the difficulties in social communication and interactions, repetitive behaviours and the inflexibility of thoughts by individuals with autism.

The term ASD has been adopted in the literature to refer to the group of developmental disorders that includes autism, Asperger’s syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (Wing, 1996; Frith, 2008). According to the ICD-10, a child may be diagnosed with PDD-NOS if the child shows some behavioural features of ASD but does not meet the full criteria (WHO, 2007). The three conditions share similar characteristics, as mentioned above, during its early onset and therefore it is difficult to distinguish one from another. While there are studies that have used the term ASD as a whole, this study will use the term autism to explore the experiences and perceptions of parents of a child with autism and will not include those with Asperger’s syndrome.

Autism encompasses learners who are high functioning but show delay in language during their early development, to those with profound learning difficulties who also experience delay and difficulties in language. The level of severity of autism can therefore vary greatly, with some individuals with autism being able to “live relatively independent lives”, whilst others may need a “lifetime of specialist care and support” (Evans, 2011: 6).

The intensity of learning difficulties within education tends to increase with the severity of the condition, for example, a pupil at the severe end of the spectrum may tend to exhibit more extreme difficulties in social communication and interaction (Frith, 2008; Jordan,
Jordan (2006) states that those on the severe end also have less verbal ability, increased self-injurious and aggressive behaviours compared to those on the milder end of the spectrum. It is therefore essential that individuals with autism are provided with tailored support and resources to enable them to meet their full potential. The education system therefore has a key role to play in supporting both pupils with autism and their families. Research to date has highlighted isolation of parents of children with the condition (Huws, Jones and Ingledew, 2001), difficulties in getting support for pupils (Jones et al., 2009) and relating to the lack of funding (Chamba et al., 1999; Jordan, 2006).

However there has been limited research which investigates the experiences of Black and Minority Ethnic (BME) families of children with autism as they negotiate their way through the education system. It should also be recognised that the UK is likely to see an increase in BME populations. Predictions made by Emerson and Hatton (1999) identify that by 2021, one in ten young people with learning difficulties will belong to a non-White ethnic group. In line with these author’s predictions, there appears to be a need to explore support services for these communities in education. This study will therefore explore the perceptions and experiences of BME parents as they reflect upon their personal journeys through the education system.

This chapter begins by explaining key terminology used within this study. This is followed by an overview of my reasons for choosing this area of study, an outline of the aims and specific research questions of the study and an examination of the wider policy context which frames this study.

1.1 Terminology used in the study
There is a debate by many local authorities (LAs) in the UK as to which term may be more appropriate to use when addressing the needs of those on the spectrum, ASD or Autism Spectrum Condition (ASC) (Jones et al., 2009: 12). Literature has suggested that “currently some local authorities have opted to change to the term ASC” since they suggest that “some individuals with autism … do not see themselves as disordered” (Jones et al. (2009: 12). Since these feelings are also reflected in the wider concerns of some individuals and support organisations such as NAS Cymru in Wales, who may feel a negative connotation to the term ‘disorder’, the term autism which is used within this study will be referred to as a ‘condition’ rather than a ‘disorder’ within this thesis. Nevertheless,
the abbreviated term ASD and the term ‘disability’ have been used when cited as such in the original sources quoted.

With the use of the abbreviated term LEA in the study, it is also noted that in May 2010, there was a notification to integrate the functions of the LEA and “Children’s Services Authority” within legislations and replace them with the term Local Authority (LA) in Wales (Welsh Assembly Government (WAG), 2010a). Hence, this study will retain the abbreviated term LEA in research prior to this but otherwise use LA. Similarly, it is recognised that the Welsh Government which was formerly known as the Welsh Assembly Government is often referred to as the National Assembly for Wales.

The abbreviated term ‘BME’ is used to represent the Black and Minority Ethnic and is the official term that is used within research in the UK. Additionally, while the term ‘community’ is used when referring to BME as a whole category, ‘communities’ is used to differentiate participants’ ethnic identities within this study. It is acknowledged that research in England by Corbett and Perepa (2007) and Perepa (2008) who examined the access of services by BME parents of children with autism from a cultural perspective, also used the term ‘community’ when referring to the individual minority ethnic groups in their research. Therefore, I have chosen to use the abbreviated terminologies ‘BME, community and communities’ in this study. When referring to support in education, this study will take into account formal or specific intervention programmes such as those provided by speech and language therapists. In addition, support also includes informal support that is provided to pupils with autism and their parents, such as, support from the health visitor (White and Hastings, 2004; Benson and Karlof, 2009).

1.2 Aims of the study

In view of defining the aims of this study, it would be necessary to recognize that the core element that is explored is the importance of BME parents' voices which is recognised and elicited through qualitative interviews. This concept of voice is defined by Bogdan and Biklen (1998: 204) as a way of “empowering people to be heard who might otherwise remain silent” and this concept of voice is further elaborated upon in the methodology chapter. The voices in this study as seen through parents’ experiences may provide valuable insights which could be used to inform future policy development. Since this study seeks to develop a greater understanding of the experiences and perceptions of
parents of children with autism, the selected design of the research is a qualitative interpretive approach. It is noted that the explanations offered by Perepa (2008) provide the rationale for adopting the qualitative approach in this study. The author has highlighted that the qualitative method facilitates in-depth understanding of experiences of individuals regarding a phenomenon. Furthermore, the use of the qualitative approach, particularly in the area of Special Educational Needs, has increased in recent years (Lichtman, 2013; Reid, 2012).

Based on the concept of voice, the aim of the study is to examine the experiences and perceptions of parents of BME pupils statemented with autism of the support that they and their children receive in mainstream and special schools in an urban city area within one Local Authority in Wales. To understand the experiences of BME parents, this study also explores the perceptions of relevant stakeholders, comprising key personnel in education and relevant support organisations, of the support that they provide for BME pupils with autism and their parents.

The reference to pupils’ Statement relates to a legally binding document that describes the SEN of particular pupils and the type of support and placements that they may need in education (National Assembly for Wales (NAfW), 2002; Education Lifelong Learning and Skills Committee, 2006). It is recognised that for some pupils with autism who are being taught in mainstream schools, their needs can be met without a statement (Jones et al., 2009). According to Jones et al. (2009), this would be achieved by staff in schools devising an Individual Education Plan in consultation with specialist professionals such as, the Educational Psychologist and the school Speech and Educational Needs Co-ordinator (SENCo). The authors also explain that where there are pupils with the condition who may need more assistance than the school can provide from its own resources, these pupil might need to secure a statement in order to obtain the needed support.

Jones et al. (2009) go on to say that if the needs of the pupil with a statement cannot be met in a mainstream school, then a placement in a resource-based unit within a mainstream school or a special school might be required. Prior to gaining a statement of SEN or autism, a statutory assessment would need to be conducted with these pupils to determine the most suitable provision to meet their individual needs. It is also recognised that stakeholders have a duty of care for appropriate standards when considering provision of services in education for pupils and their family from BME communities (WG, 2011). A
community is defined by Bartle (2007) as a social group, living and interacting in a specific locality. The author goes on to include other aspects of a community such as, bringing together common interests, and often having common cultural, religious, customs, traditions, beliefs and historical heritage.

It is recommended that members within a community should be provided with support so that they can take control of their needs (Duffy, 2009). In order to be able to make decisions and improve one’s quality of life, Duffy proposes that people within a community should have information to ensure that they are connected to people from other communities. The proposition by Duffy yet again highlights the duty of care and the need to share experiences among professionals, as well as with parents and carers within education.

As highlighted in the literature review by Corbett and Perepa (2007) and Perepa (2008), there has been little research into parents of children with autism from BME families. These researchers have stated that those from BME backgrounds faced difficulties in relation to their disability and their ethnicity. Arising from these studies, there is a suggestion that (Perepa, 2008) more research in the education needs of the BME communities needs to be explored. My own experience as a teaching assistant in special and mainstream schools and my own ethnicity also provided my interest in selecting the area of focus in this study.

1.3 The background and position of the researcher

I first became interested in autism when I worked as a teaching assistant at various special and mainstream schools. My personal experiences in supporting pupils with autism in classrooms and coming from a BME background myself led me to want to explore the experiences of BME parents. My interest in pursuing research was also influenced by earlier research in similar areas which led me to explore BME parents’ experiences and perceptions of a child with autism in education.

My first experience was in a mainstream secondary school where I supported a fourteen year old pupil with autism from a non-BME background. I had the experience of being in a position of having to support a learner when I had no previous training in supporting such a pupil and it was a difficult experience. Unlike mainstream school, my experience of
supporting pupils with autism in special schools was not the same since I had specialist support from professionals at the schools. Further, this experience in turn, led me to work in a special school for approximately two years. Over the years, I have been able to gain experience for the whole range of the spectrum from very young to those in adulthood. My experiences and settings were based on mainstream and special schools and therefore the reason for my study related topic. While working in schools, I also thought about the difficulties that pupils and their parents from BME background may experience in education.

In one special school that I worked in, the staff-pupil ratio was high with four staff to eight pupils in each classroom and with some pupils having one to one support. The school was well equipped with specialist staff to support the pupil’s needs. The staff in the special school included speech and language therapist, occupational therapist, physiotherapist, a nurse and a visiting doctor, all in one premise. The teaching staff at the special school regularly attended workshops and skills training in autism, in and outside school premises. I also noticed that teaching staff would often speak to the parents about their child’s progress and achievements. The staff were also seen to provide parents with useful information that would relate to their children’s education and to find out from the parents if there was anything in particular that they needed to know about their children.

At another specific level when it concerned BME pupils, some of the teachers and teaching assistants were often seen to be making an effort in their communication with the few BME pupils who did not speak English but rather their own home language. My experience of working with staff at the special school, in the way they related to the pupils’ parents also gave rise to my interest in the experiences and perceptions of these parents in my study. In my view, my own experience as a teaching assistant and a researcher coming from similar background as the BME parents becomes important in my exploration of their experiences and perceptions of a pupil with autism in education.

My interest in autism also arose when I was invited to attend the forum of the Cross Party Autism Group (CPAG) in 2011. The forum which was held at the National Assembly of Wales was based on issues affecting people with autism and their families in Wales. The discussions and ideas that were raised at this forum about the experiences of parents and stakeholders provided a key catalyst that reaffirmed the need to explore the BME focus in my study.
Additionally, my interest in the experiences of parents from BME communities, stems, at least in part, from the fact that I myself am from a minority ethnic background. I come from Malaysia and am myself a child of immigrant parents, whose origins are in Kerala, a state in southern India. I was brought up embracing the Hindu faith and have in my life experienced the cultures, beliefs and traditions as practiced in my native home in Malaysia. Malaysian society is a multi-cultural society which comprises three major ethnic groups, namely the Malay, Chinese and the Indian group. The Malay community, the indigenous group are Muslims, whereas the immigrant Chinese community are mainly Buddhist and with others among them following the Christian and Islamic religion. Further, the Indians who are the minority migrant group include those, the majority of whom practice Hinduism and with the rest practicing Christianity, Buddhism and Islam as their preferred religion. Therefore, as a child of migrant parents in a largely Islamic population in Malaysia, I was aware of the different cultural practices within the diverse multi religious and ethnic communities. This makes me particularly sensitive to the position of BME groups in Wales.

It is also important to mention that I am able to speak several BME languages which include a few Indian dialects such as Tamil and Malayalam as well as the national language of Malaysia which is known as Bahasa Malaysia. Although my education has been through the medium of English, I speak Malayalam, Bahasa Malaysia and English with members of my family in Malaysia. Furthermore, as someone who has settled in Wales, I am presently involved in a community setting which comprises people who are migrants from India and who speak Hindi and English, and my association with this community has enabled me to understand basic Hindi and gain an understanding of a local BME group. My knowledge of Asian languages and customs proved to be significant when undertaking the data collection for the study, as explained later in methodology chapter.

As I progressed in my study, I became aware that my own ethnicity and background would be factors to consider when exploring the views of parents who were from similar backgrounds. Having come from an Indian background, I was mindful of some of the shared cultural practices that would be experienced by some parents in this study. On reflection, there were some cultural familiarities wrapped within my own Indian customs and traditions, such as remembering how my grandmother would not directly have eye
contact with another person of the opposite gender when having a discussion with them, which placed me in an advantageous position as a researcher when interviewing BME parents in their own homes. So, when I carried out this research I became aware that I had to understand my own experience not only as a child of an Indian migrant but also of a minority group in Malaysia and a member of a migrant BME community in Wales. Therefore, I needed to recognise my ethnicity during the research process and reflect upon it. Although I had to ensure that the captured data and analyses were not overly influenced by my own experience and ethnicity, I believe that my background and position as a member of a BME community in Wales, facilitated the research and enabled particularly rich data to be collected.

1.4 Educational needs of pupils with autism

The concept of a ‘spectrum’ proposed by Wing and Gould (1979) offered the first theoretical explanations of autism based on a triad of impairment. The triad comprises three areas of difficulties that individuals with autism experience, namely, social communication, social interaction and social imagination or flexibility of thought and which are the main criterion for a diagnosis of autism in the UK (Frith, 2008, Osborne and Reed, 2008).

Wing and Gould’s notion of the triad of impairment has been included and adopted within the two accepted diagnostic systems, the DSM-IV and the ICD-10 (APA, 2000; WHO, 2007). It is also noted that the current updated DSM-5 includes only two criterion for ASD within its manual, combining the former first two of the triad to merge, under the heading of, Social and Communication Deficits and with the second criteria under the new heading of Repetitive and Restrictive ‘Behaviors’ (APA, 2011). Although the change is acknowledged, the idea of the triad has influenced thinking on how individuals with autism should be guided or nurtured within schools in the UK.

In view of the differences in needs of pupils with autism in education (Wing and Gould, 2011), they will each need “explicit” teaching in all aspects of the triad of impairment (Jones et al., 2009: 13). This refers to the particular style of teaching that is focused on areas of learning and development that typical pupils may acquire naturally through experience (Jones et al., 2009). In addition, the condition of autism may co-exist with other learning difficulties such as dyslexia and dyspraxia and therefore create additional
concerns for these pupils in education (Frith, 2008; Heap, 2010). Therefore, the need of these pupils at any one time may depend on the demand made on the pupil in education and how the pupil’s need is met within this environment (Jordan, 2006). Although there may be communicative differences between pupils with autism and typical pupils in education, these differences may not lead to some pupils with autism receiving a statement of SEN if they are accommodated in a supportive environment within the school (Jones et al., 2009).

Other areas of need for pupils with autism may include supporting them to develop their social understanding, enabling them to engage more effectively with their peers and others around them (Jordan, 2006). There may be a need to teach pupils with the condition, both verbal and non-verbal communication so that they may be able to convey their needs to others and for the sharing of information (Wing, 1996; Bogdashina, 2006).

1.5 The context of the study

Wales is a small country in the west of the mainland of the British Isles. It is bordered by England to its east and the Atlantic Ocean and Irish Sea to its west and is largely mountainous (Williams et al., 2007). A recent statistic on the UK population census figures by the Office of National Statistics (ONS) showed that the total population of Wales was 3,063,456 and with the majority of the population being located in the south of the country (ONS, 2011). Based on the estimates of prevalence rate of 1 in 100 for autism in the UK (NAS, 2008), it can be noted that there are approximately 30,000 people with autism in Wales. Further, the ONS statistics also showed that out of the total population of Wales, 140,203 (4.6 per cent) are from BME background (ONS, 2011). Therefore, in using the same prevalence rate, it can be noted that there are approximately 1,400 people from BME backgrounds and 28,600 people are from non-BME background with autism in Wales.

Like many other countries, the demography of Wales is changing with increasing numbers of immigrants, giving rise to increasing language, ethnic and cultural diversity. Historically, most of the immigration into Wales since the nineteenth century has been into the south of the country, as mentioned earlier, due to the nature of trade and industry (Williams et al., 2007). The authors suggest that the long history of BME settlement and
the diverse nature of settlement pattern of this community from north of Wales are noticeably different from the pattern in south Wales.

There are five cities in Wales, namely, Cardiff which is the capital, Swansea, Newport, Bangor and St David (WAG, 2010). The official languages in Wales are English and Welsh and with twenty-one (21) per cent of the population speaking Welsh. Thus, Welsh is a minority language of Wales and is unique compared to the rest of the UK (WAG, 2010; Welsh Government (WG), 2011). Wales is becoming a bilingual country through its national action strategy, laith Pawb which means the Welsh language is also ‘everyone’s language’ (WAG, 2003). The equal status for Welsh and English in the delivery of public services is provided by the Welsh Language Act of 1993 (Welsh Language Board, 2001). This equal status is reinforced by the Government of Wales Act of 2006 which states that Welsh Ministers are required to adopt a strategy setting on how they propose to promote the use of the Welsh language (NAfW, 2006a: Part 4.5, section 78: 7). More recently, there has been a new strategy for the promotion and strengthening of the position of the Welsh Language in the community, to increase in the number of people who both speak and use the language (NAfW, 2012: section 78).

It is further recognised that Wales does not only have two official languages but is host to a number of different languages and cultures (WG, 2011). This includes the languages of migrants who have been settled in Wales for over a century and those who have settled in recent years and who are referred to as BME in this study. In the case of those who are neither English nor Welsh speaking, there is no similar legal requirement for the use of their own languages. However, it has been acknowledged that there is a need for BME languages in the delivery of services in Wales (WAG, 2010). For example, the SEN Code of Practice (CoP) (NAfW, 2002) provides that resources such as translated information material to be made available for the BME communities in their own different languages, which would include, among others, Chinese, Pakistani and African languages. Whilst this would provide a more inclusive approach, the ‘practical realities’ and resource implications of providing materials in over 117 home languages need to be acknowledged (WG, 2011).

One aspect of this study explores the ability of BME parents, who are the children of migrants who have lived in Wales all their lives or those who have newly settled in Wales, to use the English language. For parents who are able to use English, it would enable them
to better access the available support services that are provided for their child and for themselves. The importance of BME languages becomes relevant in the geographical context since cities that have high BME populations are in the south of Wales and Map 1, which is the latest official available map, shows the distribution of BME pupils in schools.

Map 1: Distribution of BME pupils in schools in Wales

Source: (EALAW), 2003
Earlier research identified that there is a lack of centrally held government statistics for the prevalence of autism in different ethnic groups in the UK (Corbett and Perepa, 2007; Perepa, 2008; Jones et al., 2009). However, recent available data on minority ethnic pupils with autism within education in Wales is provided by the Pupil Level Annual School Census (PLASC, 2011), as presented in Table 3.

There are presently twenty two LAs in Wales. The Children Act of 2004 gave LEAs the responsibility for children’s services which included the educational achievement of children in their care. The responsibilities of the LAs also included attendance and advisory rights in relation to the employment of teachers, and in relation to the dismissal of any staff. Within Wales, there are 23 nursery schools, 1,435 primary schools, 222 secondary schools and 43 special schools and, of these 467 primary schools and 56 secondary schools were Welsh medium schools (WG, 2011).

There are several types of schools that exist for pupils with autism in Wales (WAG, 2008; Withers, 2009). These include LA maintained mainstream primary and secondary schools which may or may not have a specialist resource-based unit within the school for the purpose of including pupils with SEN. The primary school comprises infant school for children aged five to seven and junior school for those aged seven to eleven and the secondary schools admit pupils at eleven until statutory school leaving age at seventeen (WAG, 2008). In a mainstream school where there is a specialist resource-based unit, some pupils with SEN which include autism may spend most of their time in the unit while others would spend most of their time in mainstream classrooms but have access to the provision within the unit (WAG, 2008). There are also special schools, both day and residential which provide education for children with SEN. Further, there is also the Pupil Referral Unit which accommodates children who are not able to attend a mainstream or special school for any period of time for reasons such as illness or if they are not permitted to attend school due to bad behaviour, as well as those with bad behavior associated with their disability (NAfW, 2002).

The total numbers of pupils in all LA maintained schools in Wales is recorded as 394,432 (ONS, 2011). Of this total 367,174 (93.1 per cent) pupils are from White ethnic backgrounds and 27,258 (6.9 per cent) pupils are from BME background. The White ethnic category includes pupils from White British, Irish Traveler and Gypsy Roma groups
while the BME category comprises pupils from Asian, African and Afro-Caribbean, Chinese and other ethnic groups (ONS, 2011). It is noted that within the data of the Welsh Government (WG), the term Asian refers to those from Indian, Pakistani and Bangladeshi backgrounds and the term Black refers to those from African and Afro-Caribbean backgrounds (WG, 2011). Further, of the total number of 394,432 pupils in all maintained schools in Wales, the number of pupils with SEN is 99,774 (25.3 per cent) of which 3,445 (3.4 per cent) pupils are recorded as with ASD. The data in Table 1 show that within these schools in Wales, 13,393 pupils are statemented with SEN of which 2,326 pupils are recorded as with ASD (PLASC, 2011).

Table 1: SEN pupils with and without statements in LA maintained primary, secondary and special schools in Wales.

<table>
<thead>
<tr>
<th></th>
<th>Primary School</th>
<th>Secondary School</th>
<th>Special School</th>
<th>All maintained Schools (Primary, secondary and special school)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEN</td>
<td>54,826</td>
<td>40,767</td>
<td>4,181</td>
<td>99,774</td>
</tr>
<tr>
<td>ASD</td>
<td>1,289</td>
<td>1,299</td>
<td>857</td>
<td>3,445</td>
</tr>
<tr>
<td>Total numbers of pupils with SEN/ASD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With a statement</td>
<td>4,118</td>
<td>5,290</td>
<td>3,985</td>
<td>13,393</td>
</tr>
<tr>
<td></td>
<td>702</td>
<td>796</td>
<td>828</td>
<td>2,326</td>
</tr>
<tr>
<td>Without a statement</td>
<td>50,708</td>
<td>35,477</td>
<td>196</td>
<td>86,381</td>
</tr>
<tr>
<td></td>
<td>587</td>
<td>503</td>
<td>29</td>
<td>1,119</td>
</tr>
</tbody>
</table>

Source: Pupil Level Annual School Census (PLASC), January 2011

Table 1 also shows that the number of pupils who are not statemented with SEN within these schools is very high with 86,381 pupils and of which 1,119 pupils are with ASD. The needs of pupils without a statement may be met within the school’s own resources, with or without intervention of a professional service from outside the school.

The SEN CoP in Wales provides the guidelines to support pupils who may have specific needs (including disabilities) and their families in education (NAfW, 2002). Some examples of support for these pupils within the guidelines may include support within the school premises such as, among others, specialist teachers, speech and language therapists and teaching assistants in the classrooms. These pupils may also have access to support from outside the school premises such as, among others, health visitors or home visits provided by support workers from parent support charitable organisations (NAfW, 2002; WAG, 2008). Although the SEN guidelines state that there should be provision of specialist support available for all pupils with specific needs including for those with a disability, services of this nature is generally not adequate in Wales (WAG, 2008).
1.5.1 Data on BME pupils in education within the selected LA in Wales

The number of BME pupils in schools in the selected LA rose from 5,729 (10.9 per cent) in January 1999 to 12,554 (25.3 per cent) in January 2010 (WG, 2011). Further, this change in data shows that the numbers of BME pupils has doubled more than a decade ago within education in this region compared to the rest of Wales. With regard to the BME communities, an earlier study carried out by the English as an Additional Language Association of Wales (EALAW) explored factors such as socio-economic backgrounds and levels of education that impact on the achievements of these different communities in Wales (EALAW, 2003; WAG, 2007). Through interviews with pupils, parents and teachers, the study identified over 15,000 BME pupils from 100 different backgrounds who used over 90 different languages. In addition to this data, the Ethnic Minority Achievement Service (EMAS) have stated that there are 117 home languages spoken within this LA such as Bengali or Sylheti, Urdu, Punjabi, Gujarati, Arabic and Somali which are the most prevalent languages (WG, 2011). These above statistics show that there are so many BME pupils and such a variety of them and so little research about them further justifies the need for more research about their education.

Table 2: Pupil population in maintained schools within the selected LA

<table>
<thead>
<tr>
<th></th>
<th>Primary school</th>
<th>Secondary school</th>
<th>Special school</th>
<th>Total numbers in maintained schools</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of pupils</td>
<td>20,945</td>
<td>20,674</td>
<td>443</td>
<td>42,062</td>
</tr>
<tr>
<td>White British</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(75.4)</td>
<td>15,738</td>
<td>16,668</td>
<td>335</td>
<td>32,741</td>
</tr>
<tr>
<td>Minority Ethnic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(24.6)</td>
<td>5,207</td>
<td>4,006</td>
<td>108</td>
<td>9,321</td>
</tr>
</tbody>
</table>

Source: WG, 2011

The data in Table 2 shows that the total number of pupils in maintained primary, secondary and special schools school within the selected LA is 42,062 comprising 32,741 from a White British background and 9,321 from a minority ethnic background (WG, 2011). In all the categories, the BME population is an important component to the overall school population, with a relatively substantial proportion in all schools. A record by PLASC (2011) of statemented pupils with SEN including ASD within the selected LA is shown in Table 3.
Table 3 also shows that from the total school population of 47,469 pupils, 246 were statemented with ASD. Of these 246 pupils, 181 are from White backgrounds and 65 from BME backgrounds (PLASC, 2011). The data shows that there are different BME categories which comprise Pakistanis, Bangladeshi, Afro-Caribbean, Somali, Arabs, mixed and others, thus indicating that there are different communities within the BME community itself.

Interestingly for the categories of Indian and Traveller/Romany, the number of pupils with ASD is reported as ‘0’, although the total numbers within these two categories are given as 756 and 289 respectively to the categories as shown in Table 3. There appears to be no reason given to the Indian categories although it could be linked to their attitudinal differences about disability (Niner, 2004). However, there is no recorded data for the Traveller/Romany category.

1.6 Theoretical framework for the study

One factor which may impact on the type and availability of support is how individuals with a special educational need are viewed. It is useful to consider the contribution of models of disability and how these may impact upon the development of educational policies. Although the medical model is not used in this study, it is necessary to acknowledge its elements, which stress the importance of ‘curing’ the disability (Wall, 2006; Cole, 2008). For example, if there is no cure found for a child with a disability then the child would be sent to an institution or even kept out of sight. Likewise, the deficit model focuses on the
difficulties of the child and how to provide the child with support. However, the
deficit model is criticised on the basis that it continues to see the disability of
child as a “problem” that “needs to be fixed” to enable him or her “to function
normally in society” (Robertson, 2010: 2).

Alternatively, the concept of the social model of disability suggests that those with a
disability are faced by the barriers and attitudes in society (Union of Physically Impaired
Against Segregation (UPIAS), 1976; Oliver, 1996). The concept suggests that the
individual with a disability must adapt to the way in which society is constructed, rather
than suggesting that society needs to change in order to recognise the individuals’ needs in
society (WHO, 1992). However, the affirmative model, which developed from the
criticism of the social model of disability, suggests a framework for the understanding of
the basic needs of individuals with a disability beyond just providing them with their day
to day needs (Swain and French, 2000; Cameron, 2008, 2011). In addition, this thesis will
also explore parents’ experiences and perception through the ‘culturally-blind’ theoretical
framework in the literature review as well as in the discussion chapter. The concept of
‘culturally-blind’ translates to where different life experiences, based on skin color,
culture, religion and sexuality, are ignored by those who would want to see everyone as the
same (Castro, 2005). These theoretical frameworks will be explored in its relevance to
recognising the BME communities as a unique group within society and this will be
discussed in the literature review chapter.

1.7 SEN on inclusion and support policies in the UK

While this section refers to the literature on policy, as well as providing a historical
perspective of support in education in the UK, it is found to be appropriate to be placed in
the introductory chapter in order to provide an understanding of the framework for the
study. It is for this reason, it is useful to begin the discussion by referring to a key policy
document, namely, The Warnock Report of 1978 which redefined the population of pupils
with learning difficulties by bringing to light the term, “Special Educational Needs” (SEN)

The Education Act of 1981 states that, “a child has special educational needs if he has a
learning difficulty, which calls for special provision to be made for him (cited in Gibson
and Blandford, 2005: 10). The Warnock Report removed all categories of using labels in
relation to children’s disabilities, such as ‘maladjusted’ and ‘uneducable’ by replacing
them with the term SEN, and integrating these children into mainstream education (cited in
Topping and Maloney, 2005).

During the 1990s, the Government in the UK adopted the 1994 United Nations
Educational, Scientific and Cultural Organisation (UNESCO) Salamanca Statement which
encouraged educational and social inclusion of children and adults with SEN (UNESCO,
1994). The term ‘inclusion’ refers to the social and moral grounds for educating children
with SEN which was seen as an important part of building an inclusive society
(Department of Education and Employment (DfEE), 2001. The key principle of the
Salamanca statement is that,

All children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognise and respond to the diverse needs of students, accommodating both different styles and rates of learning and ensuring quality education to all (UNESCO, 1994: 11).

The Salamanca statement’s definition of inclusive education intended to respond to pupils’ diversity by increasing participation of pupils. When an educational setting is genuinely inclusive, all pupils regardless of their needs may be provided with a fair opportunity to learn with their peers and be educated in full-time mainstream school (Booth and Ainscow, 2002). This also includes pupils who have difficulties for different reasons in mainstream education such as, those from minority ethnic backgrounds who may be excluded or at risk of being marginalised.

The Special Educational Needs and Disabilities Act (SENDA) of 2001 stated that it was unlawful for those who provide education, to discriminate against a child with a disability (Disability Discrimination Act (DDA), 2005). The Act also specified that all children with a full range of SEN should be taught in mainstream schools unless it was against the wish of the parents. The SENDA also required service providers to make reasonable adjustments for those with a disability, in making changes to the way services are provided to them (DDA, 2005). It is noted that the SENDA was modified and became Part 4 of the Disability Discrimination Act (DDA) of 1995.
Moreover, the recent Equality Act (HM Government, 2010) has replaced all former existing equality legislation such as the Sex Discrimination Act of 1975, the Race Relations Act of 1976 and the DDA of 1995. The DDA was intended to reduce discrimination against those with disabilities in areas such as, education and employment. Following the Equality Act of 2010, educating children with Special Educational Needs (SEN) in mainstream schools became a legislative provision (HM Government, 2010).

Additionally, in order to obtain funded educational support for a child with a special need, it is necessary that the child should be provided with a statement of SEN by the LEA which is presently referred to as the LA. If parents of a child with SEN feel that their child’s needs have been discriminated against, they can make an appeal to the SEN Tribunal which is a statutory body that provides possibilities of resolving conflicts between the parent and LEA (DDA, 1995: part 4). Similarly, in Wales, these conflicts are resolved by the SEN Tribunal for Wales (SENTW) (WG, 2011a). The discrimination may range from inadequate educational provision for children in mainstream schools to parents’ choice of school for their child (NAfW, 2002). Since the early nineties, there were more than 25,000 registered appeals out of which 4,950 appeals (19.8 per cent) comprised pupils within the autism spectrum (Runswick-Cole, 2007). It is noted that, the basic provision provided by the tribunal system in the UK for BME and non-BME pupils is generally the same although language and cultural concerns can influence the take-up of services (NAS, 2002, 2003; Lindsay and Shah, 2009). Further, if there are behavioural concerns of pupils within the classroom, the tribunal may suggest “reasonable adjustments” to be made within the school policy such as providing disability training for staff (HM Government, 2010).

The SEN CoP (DfEE, 1994) was the first clear guidance in the UK of how schools should respond to the needs of pupils who were not making progress in the classroom (Peacey, 2005: 3). It is noted that the development of the SEN CoP in England (Department of Education and Skills (DfES), 2001) and in Wales (NAfW, 2002) are similar. The SEN CoP in Wales states that,

> A child must not be regarded as having a learning difficulty solely because the language or form of language of the home is different from the language in which he or she is taught (NAfW, 2002: paragraph 1.3).
The above quote refers to children who do not speak English as their first language. These children are often silent or very quiet in school as they adjust to the rhythm and flow of a new language and adjust to a new environment (NAfW, 2002). The SEN CoP also provides that the quiet phase experienced by these children should not be “equated with learning difficulties” by professionals who engage with them in education (paragraph 5.16). It also states that parents “hold key information” about their child and therefore play a vital role in their child’s education (paragraph 2.2). The details on the specific SEN CoP guidance for pupils, parents and for professionals in education who provide support for pupils with autism and their parents are further discussed where relevant in other chapters.

In England, documents such as, Removing Barriers to Achievement (DfES, 2004a) and Every Child Matters (Children Act, 2004) have contributed to the view that parents are important in the educational success of their children. However, it was the Every Parent Matters (DfES, 2007) that placed importance on the guidance for parents’ and carers’ role in the development of every child. The intention that was stated in the Every Parent Matters document was to open a “national debate with parents, children and young people as well as service planners, commissioners and providers as to how parents can be best supported and engaged” (DfES, 2007: 1). The statement in the document affirms that parents should be given greater attention in public policy decisions since they are important ‘stakeholders’ themselves.

Although, there is no equivalent to the Every Parent Matters document in Wales, there appears to be guidance with reference to giving voice to all parents and carers within the SEN CoP (NAfW, 2002). The need for this voice is recognised in the SEN CoP which states that, in those instances where there is a “lack of a means of communication, the LEAs should ensure that parents and relevant professionals are provided with access to signers or interpreters and translated information material” (NAfW, 2002: paragraph 4.25: 35). These resources would, for example, ensure that “early concerns may be shared about the child's behaviour, health and development” (paragraph 4.25: 35). In addition, it is also stated that “bilingual support staff, teachers of English or Welsh as an additional language may be able to help and their support should be enlisted from the outset” (paragraph 4.25: 35). All these specific resources and facilitators of support highlight the fact that the SEN CoP recognises the importance of parents’ role in supporting their children in education.
The Welsh Assembly Government (WAG) also published the world’s first government action strategy for autism namely, the ASD Strategic Action Plan that was launched in April 2008 by the charity, Autism Cymru. The charity is recognised as the world’s first Government Action Strategy for autism (WAG, 2008). The Action Strategy included provisions for raising awareness of autism within Wales at a local level by improving delivery of services and support for individuals with ASD which included those from different ethnic backgrounds (WAG, 2008). The WAG also recognised that LA and other agencies have a duty to work together to provide continuing professional development across a range of SEN including autism. The ASD Strategy Action Plan is important since it was considered timely in relation to this study in Wales and is elaborated upon in the literature review chapter.

Further, in another initiative, the Welsh Local Government Association (WLGA) (2011), in its policy document entitled, The Equality Improvement Framework for Wales, acknowledged the diversity of the population in Wales. The framework within the policy document referred to those listed as ‘protected characteristics’ under the Equality Act and these include, among others, age, disability, gender, race, religion or belief (WLGA, 2011: 8), thus recognising diversity. On the one hand, it is also noted that the subsequent improved version of the WLGA (2011) included assisting LAs in their delivery of services with a view of improving people’s lives and meeting their needs. On the other hand, although both the government strategy and initiative acknowledged that those from BME background may have unique needs, the documents did not mention the provision of specific services for parents of pupils with autism from BME backgrounds.

In England, the launch of the recent SEN Government Green paper, entitled, SEN and Disabilities (DfE, 2012) unveiled proposals for the reform in education and health for children with SEN. This Green paper was intended to reinforce the strategic role of LAs in working together with a wider multi-agency framework to incorporate education, health and social care by 2014, thus recognising that the need for SEN support is not only within education. Similarly, a recent consultation document in Wales, entitled, Forward in Partnership for Children and Young People with Additional Needs: Proposals for Reform of the Legislative Framework for Special Educational Needs presented a review of the existing SEN framework with a view to make changes where necessary (WG, 2012). This document follows the earlier review of SEN framework by the Education, Lifelong, Learning and Skills (ELLS) Committee (WAG, 2007) which had identified that the
“existing system was too bureaucratic and not sufficiently child-centred” (WG, 2012: 2). Further, the proposal intends to be more person-centred in nature with the use of the new term “Additional Needs” replacing the terms “Special Educational Needs” and “Additional Leaning Needs” (WG, 2012: 8). The proposal will also include “an increased emphasis on improved information services and networks of support” for parents and carers (WG. 2012: 8). The proposed change within the SEN framework would further recognise that these children and young people may have needs that might be met by the social services, health service or in education.

Following, the above references to policies, the next section will review the educational provision with regard to the BME community.

1.7.1 Educational provision recognising BME community

In the UK, the early Swann Committee Report of 1985, titled, Education for All, referred to research carried out on the educational attainment of BME pupils. The findings of this report which focused particularly on Afro-Caribbean and Asian pupils, found that a small group of teachers’ attitudes could have influenced negative views of pupils’ abilities based on their ethnic origin. Other contributing influences for teachers’ attitudes were linked to pupils’ language and religion and how that impacted on their educational attainment.

When addressing the needs of BME communities, research states that the notion of the ‘colour-blind’ approach which is “services offered on the same basis to all” (Raghavan and Waseem, 2007, p. 30) may not be recognised as appropriate. This is because the BME communities may have needs that are not similar to dominant non-BME community in the UK and may therefore need services that would take into account their cultural and religious sensitivities (Mir, Nocon and Ahmad, 2001). In the context of education policies, such a policy which treats everyone equally may not recognise that there could be differences in the needs of all within society. This criticism of this notion will be explored through the perceptions of BME parents in this study to determine whether in their views, more should be provided for them which includes taking into account their ethnicity and culture. The research exploring the notion of the colour-blind approach to policy and its relevance to recognising the different BME communities as a unique group within society will be discussed in the literature review chapter.
1.8 The rationale for the study

The rationale for this study emerges from the review of research literature in relation to parents’ experiences and perceptions of a child with autism since they are regarded as having a unique lived experience of their child. As highlighted by Corbett and Perepa (2007) and Perepa (2008), there has been little research into parents of children with autism from BME families. Corbett and Perepa (2007) in their findings stated that individuals with autism from BME backgrounds faced difficulties in relation to their disability and their ethnicity. The authors went on to add that it was important that these communities are provided support, in terms of being sensitive of their cultural and religious basis. Further, Perepa (2008) recommended that there needs to be more research in the educational needs of the BME communities and on the impact of autism on family members particularly parents.

With the demography change through migration, larger proportions of BME communities are seen settling in both England and Wales. There has been some emerging academic research concerning various aspects of autism in relation to these communities. It has been acknowledged that while the BME communities are not the same as the indigenous dominant White community, they are also not homogenous between and within themselves (Lloyd and Rafferty, 2006).

Finally, my own experience as a teaching assistant in caring for children with autism in schools and my own ethnicity also provided the basis in selecting the area of focus in this study. This rationale which is explained in detail in the literature review chapter thus forms the basis for formulating the three research questions which are identified below.

1. What are the experiences and perceptions of BME parents of the support they and their children with autism have received via the education system, relevant support organisations and their families and wider BME community?

2. What are the perceptions of key personnel in education and relevant support organisations of the support provided for BME children with autism and their parents?

3. In what way do BME parents and stakeholders identify improvements for the future?

The next chapter reviews the literature that guided the study.
Chapter Two

Literature Review
2.0 Introduction
The review of literature in this chapter provides the basis to explore the research questions that are placed in an appropriate context, thematically in a chronological sequence. The chapter begins by exploring existing research which considers the cultural context relevant to identifying BME parents’ perceptions concerning support services. Following parents’ perceptions, the literature then discusses the provision of SEN support in education which covers also the range of resources and interventions. The chapter will then explore specifically the role of BME parents in relation to the social model of disability and related sociological theory.

There has been evidence of studies focusing on autism since the 1990s, which includes research carried out with parents of children with autism. These include studies on the clinical aspects of autism measuring parents’ levels of stress (Gray, 1994; Tams, 1998; Hutton and Caron, 2005; Cassidy et al., 2008; Lee, 2010) and the psychological wellbeing of parents (Beale, 2007).

There is currently limited research about the experiences and perceptions of parents of pupils with autism with respect to support in education (Gray and Garand, 1993; Jones et al., 2009). There has however been research that has explored the impact autism has on individuals, parents and families (Williams, 1997; Guralnick, 2005; Lawson, 2009). Much of the research around autism in the UK has been conducted with the White population and by White researchers (Perepa, 2008; Jones et al., 2009). Additionally, it is noted that there is limited research on Black and Minority Ethnic (BME) parents especially regarding their ability to take up services and in their experience in caring for a child with autism (Beale, 2007; Corbett and Perepa, 2007; Perepa, 2008; Jones et al., 2009; Lee, 2010).

It is appropriate to refer to a definition for ethnicity since this study, which explores the experiences and perceptions of BME parents of educational support services. A definition of ethnicity by Scott (2006) is,

A self-conscious and claimed identity that is shared with others on the basis of belief in common descent that may be linked to country of origin, language, religion or customs, and may also be shaped by contact with others (Scott, 2006: 69).
The definition by Scott provides a basis that reflects a sense of belonging to a distinctive social group through their similar identities. However, some researchers have used the term ‘ethnic’, to refer to those from BME backgrounds who may often share a common cultural identity but which may include marked characteristic differences such as, among others, place of birth, physical appearance, first language, religious beliefs and cultural practices (Modood et al., 1997; Mink, 1997; Mackintosh et al., 1998). Although an ethnic identity of a group may often be expressed by its group members, the “opinions of members change” or evolve over time “from generation to generation” (Modood et al., 1997: 14). It is noted that, although the study is about the perceptions of BME parents, it does not explore the theoretical or social context of ethnicity, focusing rather, on what the parents in this study express as their own understanding of their ethnicity.

2.1 BME parents and autism

A useful source of basic statistics was provided by the National Autistic Society (NAS) study entitled, *Make School Make Sense* which was conducted by Batten et al., (2006) through a survey on autism and education in the UK. Corbett and Perepa (2007) used the statistics from the NAS survey, as explained in the next section, of families describing themselves as non-White British. Corbett and Perepa investigated the experiences of these families of children with autism, whom they referred to as the BME group. They found that the key concerns for these families was in relation to them not being aware of autism, not knowing their rights and not knowing what services are available to them, and therefore highlighting that the needs of BME families are not always met.

2.1.1 Review of studies on support services for parents

Studies have found that most parents of a child with a disability from a non-western background had little information about disabilities (Fazil et al., 2002; Bywaters et al., 2003). Fatimilehin and Nadirshaw (1994) in their study compared Asian and White British parental ways of thinking about a disability. The authors suggest that in instances where there is less information about a disability, some Asian parents tended to turn towards spiritual explanation while White British parents sought a medical explanation for the disability. There are also studies suggesting that parents experience negative attitudes from their families and their wider ethnic communities which may in turn lead them to
isolate themselves and withdraw from family, religious or social events (Fatimilehin and Nadirshaw, 1994; Bywaters et al., 2003).

The views of parents have been accepted by professionals as being an important aspect during the process of diagnosis of their child (DfES, 2001; NAfW, 2002; Jones et al., 2009). There is evidence that parent support groups can be an important source of support to parents during and after the diagnosis of their child (Bitsika and Sharpley, 2000; Osborne and Reed, 2008). In exploring the views of parents of children with autism in their use of support groups in the UK, Mandell and Salzer (2007) found that parents’ continued involvement in the support groups reflected a certain amount of perceived benefits. These benefits were in relation to their need to share their personal experiences with other parents in similar circumstances and in the knowledge that they are not alone.

An earlier study by Chamba et al. (1999) explored housing for disabled children in Bradford. This study used a questionnaire in which 2,500 parents responded of whom 600 were from BME backgrounds. Some Asian parents were less likely to access support groups due to their difficulty in communicating and accessing information in English. The study also found that in some people with Asian cultural backgrounds, having a child with a disability is often perceived negatively as a punishment by God. Thus, both Chamba et al. (1999) and Bywaters et al. (2003) argue that service providers should take into account cultural perspectives when providing non-judgmental support services for those in need from BME communities. Further, when Chamba’s findings were later compared to the needs of White parents, it was found that parents of children with a disability from both White and BME backgrounds had the same pressing concerns relating to more funding needs for their child’s future as their top priority.

As mentioned earlier, in the UK, a large survey on autism and education was conducted in 2006 by the NAS, a British charitable organisation for people with ASD in consideration of improving their lives. This survey which was conducted by Batten et al. (2006) obtained its statistical data through questionnaires with a relatively large sample of 1,271 parents of school-age children with autism and through in-depth interviews with 25 children with autism across England and Wales. Of the sample, 70 (5 per cent) were parents who described themselves as from a non-White British ethnic background. The findings of this study showed that the choice of school for parents was limited by a lack of
appropriate placements for their child in their local areas and therefore they did not receive adequate support in choosing a school for their child.

The parents in Batten et al.’s study highlighted the importance of the need for a parents’ lobby. For example, the voices and concerns of parents are conveyed to charity organisations that would then highlight these concerns to the Government or to the appropriate providers. The statistical data from the questionnaire in relation to these pupils in schools also revealed that “41 per cent (10 children) of the children” who participated in the study were “bullied at school” (Batten et al., 2006: 3) and “as much as 1 in 5 children with autism being excluded from school” (Batten et al., 2006: 43). In addition, they identified a shortage of Speech and Language Therapists (SaLT) due to lack of funding which is similar to the findings in the Autism Education Trust report (Jones et al., 2009).

Corbett and Perepa (2007) in a journal paper entitled, Missing Out, used the NAS statistics by Batten et al., 2006, to investigate the experiences of seventy (70) BME parents of children with autism from Asian, Afro-Caribbean and Somali backgrounds. Corbett and Perepa found that research on these families has been “neglected” and that autism impacted on their lives because these communities may not have had knowledge of the condition and of the relevant available services (Corbett and Perepa, 2007: 8). According to the authors, this experience by parents isolated them from the education system. It is necessary to note that the findings in this paper were based on a questionnaire sample of 70 parents of children with autism from BME background, out of an overall relatively large sample of 1,367 parents of school-age children. While the overall response rate was high, it should also be noted that only five per cent of parents were from the BME group. Although the response rate provides valuable insight, its validity is questionable as to whether the views of the small sample are represented within the findings of the study.

Following the paper by Corbett and Perepa (2007), an important study exploring the perception of BME parents, White British parents and professionals, of the social difficulties faced by children with Autism Spectrum Disorder (ASD), was conducted by Perepa (2008) within a borough in London. The author particularly explored parents’ views on ASD and social behaviours from different cultural contexts through the use of questionnaires and interviews. The author used questionnaires with 89 parents and professionals and interviews with 63 parents from four different ethnic backgrounds namely, Somali, Asian, Afro-Caribbean and White British. Perepa’s findings showed that
parents attached more importance to teaching personal social skills such as encouraging communication through eye contact and gestures compared to that of professionals who attached more importance to social rules and instructions. He also revealed that the ethnicity of BME parents could influence how they perceived their child’s condition.

Perepa suggested that these parents seem to believe that religion has an important role in the acceptance of ASD with the need to develop information material to address their beliefs. The need for support for such material should also be provided by organisations that work in collaboration with the local religious heads. He proposed the need for “organisations to work in collaboration with the local religious heads” and to develop information materials to support these communities (Perepa, 2008: 322). Although, the study did not particularly focus on education, it has generated a better understanding about the social behaviours and needs of different BME communities living in the UK. The study by Perepa is particularly important since the author’s personal experiences and future recommendations provided the basis in selecting the area of focus for this study.

2.1.2 The role of parents
Research examining the role of parents has acknowledged the wealth of knowledge that each parent has regarding their individual child through their ‘lived experiences’ (Modood et al., 1997; Tams, 1998; Fombonne, 2005). The role of parents is further acknowledged in the SEN Code of Practice (CoP) which also recognises that, “parents have a vital role to play in supporting their child’s education” (NAfW, 2002: paragraph 1.5: 2). The experiences of parents are regarded as an important role in supporting children with autism in education (NAfW, 2002). It is also acknowledged that parents are usually the first to recognize the early signs of the condition (Dobbins and Abbott, 2010; Michael and Lesley, 2010) and therefore through their experience may be involved with a variety of roles in the life of their child.

In a recent British Educational Research Association (BERA) research paper on parent-school relationships in the UK, Crozier (2012) referred back to the recommendations made in the early Plowden Report (Central Advisory Council for Education (CACE), 1967). In reflecting on this report, the author stated that the recognition of the importance of BME parental role and their involvement in the schooling of their children within the Report did not make a difference since parents were “usually kept at the school gate” (Crozier, 2012:
According to Crozier’s findings, when some parents get involved in the schooling of their child, they were seen by teachers as “interfering” with their responsibilities and this “have led to tensions” (2012: 3) due to teachers’ professionalism being questioned. Similarly, the findings by Lareau (2000), who examined the role of parents in their relationships with schools, also reflected the British Educational Research Association (BERA) research paper by Crozier (2012). Similarly, both Lareau and Crozier found that working class parents were less likely than middle class parents to get involved in their children’s education, and that when they did; it was generally in non-academic activities. According to the authors, parents from working class backgrounds tend more often to believe that academic matters should be left to teachers. These findings would be useful in providing a basis for developing the methodology for this study, since it is expected that BME parents would come from different socio-economic backgrounds.

The emphasis on home language in the UK has also been reported in an early educational research on the education of migrant children in schools (Swann Committee Report, 1985). The Swann Committee Report, titled, *Education for All*, was carried out on the educational attainment of BME pupils and focused particularly on Afro-Caribbean and Asian pupils. It was found that a small group of teachers’ attitudes could have influenced negative views of pupils’ abilities based on their ethnic origin. Other contributing influences for teachers’ attitudes were linked to pupils’ language and religion and, how that impacted on their educational attainment. It is further stated that since there was very little research on the BME community, the concerns relating to them were hindered and not implemented in policy (Swann, 1985).

The Swann Committee report also identified that children who are brought up using their own home language may need to be given opportunities to speak in the language that they are taught or learn at school if they are to develop verbal skills. Additionally, parental involvement in the school needs to be an integral part of everyday school life, particularly if the child has a disability. While it is recognised that parents appreciate being listened to, the communication between parents and schools may become difficult if the schools do not understand or value parents’ views (Ward et al., 2004). It is believed that the main reasons for conflicts between schools and parents of a child with a disability are the difference of views of the parent and the school, of the child’s needs (Ward et al., 2004).
Another point to note is that disability research has mainly involved in seeking the views of the experiences of mothers rather than fathers (Llewellyn et al., 2010). An early meta-analysis across 20 studies involving 190 parents was conducted by Feldman (1994). Within the sample of these studies, only two fathers were included, despite the term “parents” being used in the majority of studies. Evidence from this study also shows that, although the invitation to participate in the study was addressed to all BME parents, only mothers with the exception of three fathers agreed to take part in this study. The researchers do not explain the reason for the non-participation of the fathers in their analysis. The experience of parents in their effort to obtain a mainstream school placement for their child with autism rather than a special school has been explored by Reid (2012). Reid’s findings raised suggestions of how schools, professionals and parents might work together in order to better support these children and their parents. As a result, there is a gap in the literature of the experiences of fathers who may face their own unique experiences and who may not be provided with a voice.

2.1.3 Parents’ responses to diagnosis of autism

The time period of recognition between initial signs of the condition and diagnosis should be shortened as an immediate priority since it would be followed by the appropriate support for the child with the condition (Daley, 2004). This is because the period before diagnosis is often a time of confusion and self-blame for parents since it was found that children were often misdiagnosed and parents was often given false reassurances by General Practitioners and health workers during this time (Midence and O'Neill, 1999). Research has also confirmed that parents’ tend to feel isolated due to their difficulties in understanding autism, resulting in them not wanting to explain their child’s condition to others (Dumas et al., 1991; Gray, 1994).

Midence and O'Neill (1999) in their pilot study using interviews explored the experiences of four families of children diagnosed with autism from a White British background in north Wales. The authors found that parents often felt relieved once their child obtained a diagnosis, since it would provide an explanation for their child's behaviour and to enable them to access available support. Moreover, the lack of physical signs of autism can lead to some parents disbelieving that anything is wrong (Midence and O'Neill, 1999; Lauchlan and Boyle, 2007).
The increase in the numbers of children with autism attending mainstream pre-school or nursery schools in an English county have indicated that parents want this option to be available for their children. Whitaker (2007) explored education provisions for youngsters with ASD in mainstream classroom. The author sent a postal questionnaire to every parent of the 350 children with ASD attending mainstream schools in the county of which 175 parents responded. The purpose of the questionnaires was to explore the similarities and differences of variables such as parents’ experiences, views, attitudes and levels of satisfaction. The finding showed that just over half of the parents who responded were satisfied with the provisions that their child received in their schools, the reciprocal communication between home and school and including the role of the school in prioritising and promoting social development and social relationships within the schools. However, the study by Whitaker did not differentiate the ethnicity of the parents.

Research evidence also show that diagnosis usually occurs later in children from BME backgrounds compared to those from non-BME backgrounds (Perepa, 2007; Jones et al., 2009) thus making it difficult for parents of these children to obtain support at an early stage (Dobson and Upadhyaya, 2002; Corbett and Perepa, 2007). According to the the views of these researchers, this delay may be linked to cultural differences and language difficulties experienced by BME parents when explaining their children’s difficulties to professionals during diagnosis (Dobson and Upadhyaya, 2002; Daley, 2004; Corbett and Perepa, 2007; Perepa, 2008; Jones et al., 2009).

Since the present study is based within a cultural context, focusing on interviews with BME parents of children with autism, the following section will explore the relevance of cultural influence for parents from BME backgrounds.

2.1.4 Relevance of cultural influence for parents

Culture plays an important role on a person’s perception of the world in terms of how their values such as morals and ethics are seen among those persons within a similar community (Hofstede, 1980; Diller and Moule, 2005). Diller and Moule (2005) refer to culture as aspects of lifestyles and learned traditions that are shared by members of a particular group, defined by language, habitual ways of thinking, feeling and behaving. An earlier definition of culture is that it is “not genetically inherited, and cannot exist on its own, but is always shared by members of a society” (Hall, 1976: 16). Hall’s definition of culture
appears to fit the individual in a social context since culture is passed on from one generation to the next through socialisation between individuals.

The first clinical study in the UK that explored the perceptions of people from Asian cultural backgrounds towards ASD was conducted in Bradford by Dobson and Upadhya (2002). In their research, the authors specifically concentrated on awareness of the condition and aspects of language and did not consider any cultural differences. They found that there were members from the Asian communities who had misconceptions about ASD and who considered that the condition could be contagious. In spite of their findings, it is noted that their research was not conducted with family members who had experience of the condition. Hence, it is important to understand family attitudes towards ASD, to be able to develop support that is culturally sensitive and appropriate for them.

Daley (2004) explored the interpretation of the traits of autism by 95 families of children in Urban India. The findings in these studies showed that there were parents who were not worried that their sons did not speak by the age of four, due to a belief that boys may speak later than girls. Further, there were parents who held the view that their sons did not speak due to them being unintelligent and that they would get better with age. Daley (2004) proposed that these different interpretations could have an impact on whether or not, BME parents consider the need for these behaviours to be addressed by providing professional support in education. However, the experiences of BME families in Daley’s study may be different compared to that of the experiences of BME families who have settled down within a White community in the UK.

There was conflicting evidence by Beresford et al. (1996) as to whether some BME parents gave more attention or support to the care of their disabled children than parents from White ethnic backgrounds. According to these authors, some service providers held the view that BME parents preferred to take care of their own concerns within their own families rather than depend on external support (Beresford et al., 1996). However, Flynn (2002) pointed out that the view taken by service providers in Beresford et al.’s study is questionable. Flynn stated that the low uptake of services may be related to services not being appropriate, rather than due to parents being satisfied with their situation. Flynn goes on to state that it is more likely that parents may question whether their culture, religion and language will be appreciated by professionals who provide support for their child. Another question was whether there was a possibility of having a carer from a
similar ethnic background to their own, to support their child for short breaks (Flynn, 2002).

In focusing on ethnicity and improving service provisions for parents from south Indian communities, both Perepa (2008) and Dobson and Upadhyaya (2002) revealed similar findings. The authors found that south Indian parents were under-represented in support groups and lacked awareness about available support services. Further, the importance of ensuring that service provision provided for these communities are made suitable for the needs of different BME cultures is also recognised (Raghavan and Waseem, 2007; Perepa, 2008). For example, the needs of these communities could be by linking community groups and religious organisations; or by providing a single point of contact for each of the BME communities, so that their concerns around support services may be interpreted, translated and understood in the particular communities’ preferred languages. However, some BME parents have reported that people with disabilities are not included within their society in their native countries and that this practice continues to be followed by those who had migrated into other countries (Bywaters et al., 2003). It is useful to note that not all BME people are migrants and that they may well be second or third generation migrants who may not have language difficulties.

As shown above, language is one of the difficulties which has been identified in research (Whitaker, 2002; Dobson and Upadhyaya, 2002; Daley, 2004; Corbett and Perepa, 2007; Perepa, 2008; Jones et al., 2009). The role of translators may be relevant when BME parents of children with a disability are unable to voice their concerns due to their lack of communication skills in the English language. Raval (1996) suggests that translators may make the link between two different languages and cultures within services and provide some support which may or may not always be clear to the parent. In some cases, family members may be seen interpreting information from one language to another (Perepa, 2008; Jones et al., 2009), although this may be perceived as unethical and unprofessional by social science researchers (Shah, 2001). Shah (2001) suggests that the reliance on family and siblings should be avoided, due to the possible biases within the family. She goes on to say that if early identification is not acted upon and translators are not provided, it could result in some BME parents’ voices not being heard.

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An earlier study by Shah (1995) who interviewed Asian parents of children with severe learning difficulties in Birmingham and Manchester also drew attention to the cultural barriers. Shah concluded that,

In the case of many Asian children, because of the language difficulties they or their parents may experience, access is further denied (Shah, 1995: 93).

The author stated that for Asian children, “their effectiveness will be judged on how these services respond to their needs in respect to ethnicity, culture, religion and language needs and to their individual needs” (Shah, 1995: 94). According to Shah, there is often an assumption by service providers that Asian parents do not have a positive or encouraging attitude towards disability because of their religious or superstitious beliefs. Shah’s findings also suggest that many Asian parents do not tend to make future preparations for their child with a severe learning disability and this according to her may be due to their naivety of their child’s condition.

There were also parents of severely disabled children from Pakistani and Bangladeshi communities in the UK who kept their child away from social events since they felt a sense of shame (Fazil et al., 2002). This was because their children displayed behaviours such as: tantrums, aggression, poor eye contact and poor social and communication skills. Wilder et al., (2004) argues that some of the displayed behaviours, as listed by Fazil et al. (2002) may be rooted within the Pakistani and Bangladeshi communities’ cultural differences. Similarly, some Asian children often avoid eye contact with adults or respond
to a teacher’s question with silence, out of respect for the adults (Corbett and Perepa, 2007). Such displayed behaviours in pupils may be interpreted differently by staff at school, since they may not be aware of the child’s cultural signifiers. Alternatively, the child’s avoidance of eye contact may be attributed to the child’s difficulty in social skills and communication and thereby treated as a possible characteristic of autism (Wilder et al., 2004). Apart from cultural influences, religious concerns have also been explored in the literature and these are discussed next.

2.1.5 The influence of religion in the context of autism as a disability

Religion and beliefs are two aspects that have been explored within the context of BME parents (Modood et al., 1997; Chamba et al., 1999; Bywater et al., 2003). Religion can help some parents to cope with the diagnosis of their child’s disability in a better way by providing an explanation for the condition which may reduce their stress (Tarakeshwar and Pargament, 2001). While this is so, it may also create difficulties in the process for others if the explanations that are offered in a religious context are not sensitive to cultural concerns (Chamba et al., 1999; Miles, 2002; Bywater et al., 2003). While some parents may associate their child’s disability as due to the will of God as a negative experience (Bywaters et al., 2003; Gabel, 2004; Shaked and Milu, 2006), others may positively perceive the disability as a gift from God (Skinner et al., 2001, cited in Dyches et al., 2004).

In view of the influence of religion, while some BME families may accept western medical explanations, many of them may find consolation in their own religion (Fatimilehin and Nadirshaw, 1994; Bywaters et al., 2003). Although, these families say that they have found comfort in their religion, this is more in their faith rather than in the places of worship (Raghavan and Small, 2004). Bywaters et al. (2003) who studied Bangladeshi and Pakistani families’ experiences of a child with a disability indicated that most often, mothers of these children accept that they are given special responsibilities, to look after their child, by God. Nevertheless, many mothers are still blamed or stigmatised by their communities for their child’s disability (Gabel, 2004; Jegatheesan, Miller and Fowler, 2010; Richardson and Fulton, 2011; Kim, 2012).

While religion and beliefs may provide an explanation about the disability, there are some from Pakistani and Bangladeshi communities who may rely on religious healers from their
own local mosques for an explanation of their child’s condition (Bywaters et al., 2003; Raghavan and Waseem, 2007). There were also parents who have pointed out that the birth of a child with a disability either encouraged greater faith or resulted in a complete loss of faith (Fatimilehin and Nadirshaw, 1994; Raghavan and Small, 2004).

There is also a widespread belief among Asian communities that the disability is seen as a punishment emanating from the spirits, an evil eye or sins of their previous lives (Chamba et al, 1999; Aminidav and Weller, 1995; Gabel, 2004; Crabtree, 2007; McCabe, 2008). Interestingly, it is argued that the idea of disability as a punishment is not an Islamic belief (Begum, 1995) since similar beliefs and attitudes are found amongst many religious believers including Christians (Katbamna, Bhakta and Parker, 2000). In comparing beliefs of Asian and White British parents, the implication was that all information given to the Asian parents about autism was in English and from a Western perspective (Mockett, Hackett and Theodosiou, 2009). The way information is provided to parents and, the unusual relationship between disability and the influences of religious beliefs, may partly account for the low take-up of services by BME communities (Bywaters et al., 2003). These reasons by Bywaters et al. (2003) further place emphasis on the need to consider the wider cultural aspects of the lives of BME communities. Since the role of parents is the focus of this study, it is necessary to examine literature on research concerning the experience of all parents, both from White and BME communities, within education.

2.2 Parental participation with support services

Research has shown that following the educational initiative of Every Child Matters: Change for Children by the government in England (Children Act, 2004), the number of reported cases of autism has increased. However, information regarding the needs of parents of a child with autism was seen to be lacking. Chakrabati and Fombonne (2005) suggest that due to the increase of autism in children, parents of these children may also often require medical and social support. According to these authors, the support could be from various specialist professionals such as psychologists, psychiatrists and Speech and Language therapists and from a network of family and community members.

2.2.1 Available support services for the need of parents

Parents of a child with autism generally use services so that they can gain help for their child, however they often find it difficult to obtain these services (Hutton and Caron, 2005;
Jones et al., 2009). Research has focused on a variety of formal and informal support that may be available to parents and their children with SEN (White and Hastings, 2004; Benson and Karlof, 2009). The formal type is provided by legislation or statutory agencies through support which can take the form of specific intervention programmes, organised parent support groups within schools and any other involvement from professionals. These could include speech and language therapy, psychological services, occupational or physiotherapy services, social emotional services, interpreter and transportation provided by the LA (Benson and Karlof, 2009).

On the other hand, informal type could be gained through support provided by charitable organisations that could include the provision of respite care or short breaks and via parent and carer support groups. It could also include support provided by close family members such as from spouses, siblings, grand-parents and those from the wider community (Benson and Karlof, 2009). One useful support by these organisations is their involvement in supporting parents in the filling in of forms such as when claiming disability benefits and family tax credits which are seen by parents as a daunting process (Richardson and Fulton, 2011). In addition, the home-school liaison was proposed to encourage parents to interact with school about any concerns that they may have for their child and themselves (Blair and Bourne, 1998). This interaction could be useful for parents who did not speak English, when provided with a translator (Raval, 1996). Such variety of support can be helpful for parents and carers in terms of adapting to their child's diagnosis and gaining order in their lives (Gray, 2002).

In Wales, a feature of support at various times during school life may also include specialist and outreach support teams and social services (WAG, 2010b). According to WAG (2010b), outreach support teams provide advice to people in a community without them having to look for it. Another area of concern for BME families of a child with autism is the need for respite care. A study examining this concern in Wales found that BME carers who experienced respite services spoke about the difficulty of accessing the service but there was no indication of the socio-economic background of the carers in the study sample (London Economics Wales, 2010). The study also showed that services were often not culturally appropriate due to, “the use of male staff for female care recipients and of meals that were not religiously appropriate” (London Economics Wales, 2010: 30). It is noted that there is the need to consider that the interest of the child within the context of
their culture and community as proposed within the SEN CoP (NAfW, 2002: paragraph 5.15).

Although little research has been carried out to investigate how parents and families of children with autism support each other, studies addressing the experiences of parents of children with other developmental disabilities indicate many benefits of such support (White and Hastings, 2004). It is also recognised that BME parents in the UK may often not have families living nearby as they would be first generation migrants who would be living within a community of other migrants in similar situations (Chamba et al., 1999; Raghavan and Waseem, 2007).

According to Hatton et al. (2004), BME parents receive little informal support from their extended families despite their high support needs and in their difficulties in receiving specialist support elsewhere. Hatton et al.’s study comprised two phases, the first phase of which involved in-depth interviews with 26 south Asian parents of a child with severe learning disabilities. In the second phase, a further 136 parents of children with similar disabilities including re-interviewing the 26 parents who participated in phase one. The findings showed that these parents found it difficult to obtain information about available support services for their child. The study also found that parents had awareness of general health services, such as the family doctor or dentist, although their knowledge about specialist support services such as speech therapy and psychiatry was lower. The authors also stated that some Asian parents expressed the belief that they should bear full responsibility for their child and therefore were reluctant to seek help from their extended family. Hatton et al.’s findings are also similar to that found in other studies (Chamba et al., 1999; Perepa, 2008).

An example of support that is offered within education in the UK is the parent-focused Early Bird programme (Evans, 2011). The Early Birds programme aims to support parents of children with SEN which includes autism in the period between diagnosis and starting at school so that they become confident in supporting their child’s social communication and appropriate behaviour (Shields, 2000; Birkin et al., 2008). The programme provides a three month period of group training skills sessions for parents whose children are under five and with a diagnosis of autism spectrum disorder (Evans, 2011). Although an early evaluation of the Early Bird programme in the UK reported an improved outcome for parents of children with SEN, it is suggested that some children with autism do not receive
a diagnosis until they pass the age of five (Richardson and Fulton, 2011). Therefore, there may be some parents who are excluded from this programme as a result of not meeting the specific inclusion criteria because their child may be too old or because their child’s behavioural developmental abilities maybe either too severe or not severe enough.

However, the Early Bird programme was criticised for its inflexibility when applied in other countries (Anderson et al., 2006). In their argument, the critiques indicated that the skills within the programme did not accommodate the cultural values and the language barriers faced by minority ethnic caregivers. Anderson et al.’s study appears to pose the question as to whether it may be relevant to consider evaluating the Early Bird programme in the UK with regard to its present diverse multi-cultural society.

The development of new technology creates another approach to interact, understand and appreciate the voices of researchers and the participants (Huws, Jones and Ingledew, 2001; Arthur et al., 2012). Huws, Jones and Ingledew (2001) in a study analysed postings of messages of an email group that was set up for parents of children with autism. The authors found that many of these parents were seen to make sense of autism by participating and sharing similar experiences with each other and this helped them to reduce feelings of isolation among themselves. The findings in Huws, Jones and Ingledew’s (2001) study were similar to that of findings of a later study by Fleischmann (2004) who explored parents’ use of internet as a resource. Fleischmann stated that although the internet enabled the voices of parents to be heard, there were some parents who felt frustrated when they had to provide explanations for their child’s behaviour to members of the general public. In addition, research by Sharpe and Benfield (2012), which explored students’ experiences through technology-mediated learning, gave a perspective of the use of the internet as a useful resource in learning and teaching (cited in Arthur et al., 2012). Although new technology may provide opportunities to parents, it may not be the same for parents whose first language is not English and whose understanding of autism may be based around their own cultural and religious beliefs (Richardson and Fulton, 2011).

In highlighting the voice of parents, a viewpoint of a prominent BME parent activist, highlighted the need for culturally appropriate services to meet the growing needs of ethnic minority communities across the UK (Corea, 2002). This parent recommended that SEN teachers from BME backgrounds would provide better support since they may have a
greater awareness of the culture of the families concerned (Corea, 2002). Although this parent stated that support for children with autism is being denied in education, there is no research-based evidence of this parent’s statement and therefore this could be an expression of his personal life experiences of caring for a child with autism. While the literature surveyed has provided an understanding of the range of support for parents in general, it also highlights research on the perceptions of BME parents in the way that they view such support.

The next section will explore the historical perspective of autism and highlight the provision of specific support for pupils with the condition in education, including the policy framework for SEN in Wales.

2.3 Autism and inclusive education

The term autism, which is derived from the Greek word “autos” to mean “self”, was first used in a clinical setting to describe the strange or unusual behaviours of children, who seemed enclosed in their own world (Reber, 1985). Autism was originally described in 1911, by psychiatrist, Eugen Bleuler who perceived it as a key symptom of schizophrenia, a mental disorder which often features social withdrawal (Frith, 2008). It is now known that autism is not a mental illness and is not caused by bad parenting but the causes of autism are still unknown (Wing, 1996; Skuse, 2000). The condition is four times more prevalent in boys than girls (Wing, 1996; Jones et al., 2009; Autism Cymru, 2011) and does not distinguish between race and ethnicity (Frith, 2008; Jones et al., 2009). The current estimated prevalence rate for autism is 1 in 100 (Wing and Gould, 2011; NAS Cymru, 2012).

Some children with autism are reported as developing speech normally for a period of time and then regress or lose the skills that they have developed (Jordan and Powell, 1995; Dobson and Upadhyaya, 2002). There are also a small proportion of individuals with autism who may have ‘savant’ skills which is a phenomenon referring to exceptional skills in areas such as, memorising the entire pages of the phone book or playing a musical instrument at a young age without any training (Wing, 1996; Skuse, 2000; Frith, 2008). However, there is no single theory that provides a sufficient explanation to the phenomenon (Hou et al., 2000). While there is no cure for autism (Rutter, 2005; Frith, 2008; Wing and Gould, 2011), research has revealed that early behavioural interventions
can positively impact on thinking and language development (Grindle et al., 2009). The condition of autism is usually seen at an onset age of three years (Wing, 1996; Frith, 2008). However, due to better diagnostic tools and awareness, diagnosticians are now able to identify the condition as early as fourteen to eighteen months of age (Frith, 2008; Wing and Gould, 2011).

Historically, both Leo Kanner in 1943 and Hans Asperger in 1944 offered the first theoretical explanations of autism and Asperger’s syndrome respectively (Frith, 2008). Research into a possible explanation for autism can be seen in the early work of Kanner (1946) who, while looking for the evidence of heritability in autism, assumed that behaviours of autism stemmed from the lack of warmth and emotions showed by the mothers of these children. This led to the “refrigerator mother” theory which blamed mothers for the behaviour of their children. One criticism of this view was by Eisenberg (1957) who argued that autism is a biological condition and not the result of unloving parent-child relationships. Additionally, Rimland (1964), a research psychologist and a parent of a child with autism, criticised the “refrigerator mother” theory on the grounds that there was nothing more than anecdotal evidence from Kanner’s small sample of parents of eleven children with severe behavioural difficulties. Despite being criticised over his early comments, the work of Kanner is still useful today, in terms of identifying the main characteristics of autism namely, the “desire for aloneness”, the failure to relate to others and the obsessive need for repetition (Kanner, 1943: 222).

2.3.1 Understanding the needs of pupils with autism

Wing and Gould (1979) in their explanation of the triad of impairment refer to impaired communication experienced by individuals with autism, poor social interactions and repetitive behaviours and the inflexibility of thoughts by individuals with autism. The triad has remained the main criterion for a diagnosis of ASD in the UK in order to determine educational resources for pupils with the condition in education (Frith, 2008, Osborne and Reed, 2008).

The difficulty associated with social communication refers to difficulties with verbal and non-verbal communication, ranging from concerns with developing speech, and the repetitive use of language, which is also referred to as echolalia (Wing, 1996; Bogdashina, 2006). Research has revealed that restricted and repetitive behaviours constitute a major
barrier to learning and social adaptation (Leekam, Prior and Uljarevic, 2011). These authors suggest that early intervention may be necessary to address certain behaviour patterns before they become deep-rooted in individuals with the condition.

Additionally, individuals with autism may not fully understand instructions and could interpret questions in a literal way (Plimley, Maggie and Morgan, 2007). For example, in school, when a pupil with autism is asked if he or she can pass a book they may reply ‘yes’ without understanding that the request has a basic social assumption. As such, it would be necessary to explain to the individual, the use of such non-literal expression in simple language so that they would be able to understand (Bogdashina, 2006). Lawson (2009), a researcher who has autism herself and who is also a parent of a child with autism, states that individuals with the condition may have limited eye contact, which may stem from the difficulty of not being able to listen and look at the same time because of sensory overload.

Another aspect within the triad relates to social interactions or forming relationships which can range from being withdrawn to simply not fitting in (Wing, 1996). For example, individuals with autism may seem insensitive to the feelings of others which can lead to difficulties with making friends or to being bullied (Corbett and Perepa, 2007; Jones et al, 2009). Further, some children may like physical contact, although they rarely initiate it themselves and teaching social skills to them may help socialising and making friends (Wing, 1996). These children may also have difficulties in understanding the rules of turn taking where they are required to work together in groups (Plimley, Maggie and Morgan, 2007).

The third concern within the triad relates to developing flexible thinking and understanding (Wing, 1996). Since individuals with autism experience a genuine lack of appreciation for the feelings and thoughts of others, they may interpret the feeling of being upset in others as amusing, which in turn can appear unkind or rude on their part (Baron-Cohen et al., 2009). Further, difficulties may also be evident in the individual’s resistance to change and their inability to communicate with others due to distress in crowded environments. For example, in a school environment pupils with autism may find it hard to cope with changes to their timetable (Jones et al., 2009).

With the growing numbers of pupils with ASD in mainstream schools, a high level of expertise and skill is required in educating them (ACCAC, 2000; Barnard et al., 2002).
This is because it is reported that all pupils within the autism spectrum have different individual needs (Barnard et al., 2002). In an academic or educational environment, research suggests that professionals need to be made aware of the triad of impairment so that they would be able to recognise the characteristics of pupils with autism and address their concerns and needs (Jones et al., 2009; Wing and Gould, 2011).

Wing and Gould (2011) in presenting at the fourth International Autism Conference held in Wales revealed that the triad of impairment did not take into account the gender differences of the needs of children with the condition. Wing and Gould (2011) added that the individual need of pupils with autism therefore places a responsibility on all teachers, whether in mainstream or special schools. In an inclusive setting, a pupil with autism may become agitated in a classroom, due to his or her inability to communicate or to express what he or she wants. For instance, when a pupil is seen misbehaving, it may be important for the education providers to think about what may explain the pupil’s behaviour (Schopler, 1995). In addition, the pupil’s behaviour may be due to sensory difficulties that the pupil may be experiencing in the classroom, such as the level of noise or bright lightings within the particular classroom. These explanations of autism within the triad help to understand the support that would be needed for pupils.

For a child who has English as a second language, taking into account their specific cultural and religious needs may add another layer of challenge, since the identification of their specific needs may go beyond the triad of impairment. Corbett and Perepa (2007) in their study, found that schools are challenged with communication issues related to English as a second language. According to these authors, these schools were challenged “to look at its system of communication throughout all classes and within the whole school environment” (Corbett and Perepa, 2007: 22). For example, these schools used ‘Boardmarker Symbols’, a type of visual communication tool, in the entrance and classrooms in schools and received advice from the local authorities and special educational needs advisory teachers.

2.3.2 Range of support for pupils with autism in mainstream and special schools

There is currently a range of existing provision in the UK to meet the varying needs of children across the autism spectrum (Jordan, 2006; Guldberg, 2010). For example, pupils
with autism may attend mainstream nursery schools, mainstream primary and secondary schools, special schools and residential schools where there is choice of support and care that is available 24 hours a day or with a 52-week placement (NAfW, 2002, 2006; Jones et al., 2009). In addition, parents are able to choose a day school or residential independent school which are not maintained by the LA, at their own expense or apply to the LA for an independent school placement where the fees may be paid by the LA. However, the practices within these schools may vary with the experiences and expertise of the staff and for this reason it is not possible to account for the best type of placement for a particular child (Jordan, 2006).

Over the last decade, there has been an expansion of the range of educational provision, typically for pupils with more complex needs who attend a specialist school for autism which are either run by the LA or an independent organisation (NAfW, 2006; Jones et al., 2009). There are pupils who may attend mainstream primary or secondary schools with or without autism specialist resourced provisions attached (Whitaker, 2007). Although there are a range of educational provisions for pupils with autism, this study mainly highlights the different provisions that are provided for these pupils. It does not aim to further explore or evaluate them as its focus is to explore the experiences and perceptions of parents of a child with autism in an education setting.

The SEN CoP in Wales identifies the right for children with SEN to be educated at a mainstream school where possible, for the LA to offer advice and information to parents and a means of providing services to them and resolving their disputes (NAfW, 2002). Within the SEN CoP, it is stated that those who provide services in education have a duty to inform parents when the provision of SEN is made for their child and that schools have the right to request a statutory assessment of a child, if needed. There are day-care settings specifically for children with SEN provided by LAs such as in nursery schools within mainstream schools and family centres. In addition, there are also other registered day-care providers, which include playgroups and accredited child-minders, working as part of an approved network (NAfW, 2002: paragraph 4.2).

While there are pupils with autism who are educated in mainstream schools, a significant proportion of them attend special schools (Jordan, 2006; NAS, 2008). Within mainstream schools, pupils with autism may attend resource base units while others may attend a number of lessons in a mainstream school when appropriate but then again are educated in
the resource base for the rest of the time (WAG, 2008). It is further noted that resource-based units within mainstream schools may or may not include autism specific support. The argument is that low teacher-pupil ratio and lack of resources in mainstream schools may influence the amount of support that may be offered in these schools (Jordan, 2006).

On the other hand, in special schools there are available resources that are provided for pupils with SEN and this is because the schools specifically provide for pupils with severe learning difficulties or physical difficulties. Additionally, the high teacher-pupil ratios enable the schools to be able to provide for its pupils. However, there are some special schools that specialise specifically to accommodate pupils within the autistic spectrum. The argument may be that in special schools, due to the level of severity of pupils and high teacher-pupil ratios, a range of additional communication tools and support programmes are put in place (Jones et al., 2009). According to Jones et al. (2009), communication tools such as TEACCH and PECS tend to be offered in special schools rather than in mainstream schools since there is usually more space to accommodate these pupils in these schools.

The Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) programme was first founded and imported into the UK by Schopler and Reichler (1971) and used for children with autism. The programme is a structured and organised teaching intervention to help these children to focus and learn (Mesibov, Shea and Schopler, 2004). The Picture Exchange Communication System (PECS) on the other hand is a positive behaviour strategy training which was first developed by Frost and Bondy in 1985. It uses picture symbols to teach a child who is non-verbal or with very little speech skills, to initiate communication (Frost and Bondy, 1994). The range of support also includes Applied Behavioural Analysis (ABA) which is an approach that is used to teach social and behavioural skills to individuals by breaking down large tasks into more manageable tasks in order to make it easier for these pupils to achieve certain goals in their learning (Lovaas, 1987), although it may not be offered in mainstream and special schools due to its cost (Grindle et al., 2009). Other forms of support include the use of personalised social stories or comic strip conversations which provide a visual approach to the understanding of specific situations to develop greater social understanding for those with autism (Gray and Garand, 1993; Gray, 2000). In addition, the Circle of Friends is another approach that is used mainly in mainstream schools as a way of promoting the inclusion and interaction of pupils with autism with their peers (Whitaker et al, 1998).
These interventions are presented merely to show what is available within the education system in terms of support rather than supporting the child and thus reinforcing the objective in this study which is about the experiences of BME parents.

Individuals with ASD are provided with a network of education and health professionals caring and working with them and their families (WAG, 2010b). For example, specialist professionals such as Educational Psychologist, Occupational Therapists, Physiotherapists, and support groups from charity organisations are able to support children with the condition to manage the difficulties that they may experience (NAfW, 2002; WAG, 2010b). These professionals may offer advice on behaviours of children and support these children with their physical difficulties through the use of exercise and advice on appropriate diets (WAG, 2008; Jones et al., 2009).

The specific provision provided by Speech and Language Therapists (SaLT) are also seen as useful particularly for pupils with autism since their work is concerned with disorders of speech, language and communication (Jones et al., 2009; WAG, 2010b). However, Lindsay et al. (2002) stated that in England, the services provided, particularly by SaLT is not adequate in many areas. Similarly in Wales, the Welsh Assembly Government in 2003 recognised this concern and published the consultation document entitled, Working Together-Speech and Language Services for Children and Young People, which recommended for the provision of service needs such as, among others, training, recruitment and retention of SaLT (WAG, 2008). However it was found that even after recruiting more SaLTs, the situation did not improve but got worse since these professionals had large caseloads and were not supported adequately by assisting staff (Jones et al., 2009). According to Jones et al. (2009), due to the inadequacy of staff, only parents who could afford these professional services chose to employ these therapists and support assistants, privately.

With regard to practices within schools in England and Wales, specifically for pupils with autism, it is unusual that schools adopt or follow any one type of support or approach (Jones et al., 2009; O’Sullivan, 2009). In recognizing these differences, it is possible that some schools may use a number of approaches, as well as therapies, depending on its available funding. Support and therapy also include, among others, makaton signing and symbols, play therapy, art therapy, music interaction therapy, sensory therapy, massage therapy, computer assisted learning, daily life therapy and drama therapy (Jordan, 2006).
Another aspect of support in the literature draws upon the word transition which means the movement from one phase to another (Jones et al., 2009). In an education or school life context, this move might mean travelling home to school, such as the move from early year’s provision to primary, primary to secondary education or leaving school and moving into higher education or from one classroom setting to another (Jones et al., 2009). It is important to recognise that according to the authors, these moves within education could have an impact on the lives of pupils with autism since they have difficulties with change in their routines, which in turn can cause anxiety (Jones et al., 2009; Withers, 2009; Wing and Gould, 2011). Although, it is suggested that with appropriate planning and support in education, individuals with autism may experience as smooth a transition as possible (Her Majesty's Inspectorate of Education and Training (Estyn), 2007; Withers, 2009), there is no evidence in research to show that there is that planning and support.

Following upon transition, it is useful to explore literature reflecting upon the professional ability of staff in schools including teachers’ perception of pupils’ ethnicity in a school environment.

2.3.3 The challenges in providing inclusive practices in education

Like many countries, the population demography in the UK is changing and therefore ethnicity is seen as an important social factor which should be taken into account when planning societal structures such as the education system. One of the challenges in education is to ensure that teachers and teaching assistants are knowledgeable about autism and also trained to deal with a culturally diverse population in schools which include BME pupils with autism.

In Wales, there is provision for practising teachers to gain SEN qualifications or to specialise in particular subject areas such as supporting children with specific learning needs such as, in dyslexia and autism, through the Masters programme in SEN (WG, 2011b). It is noted that these qualifications and programmes are all compatible with the Qualified Teacher Status (QTS) Standards (WG, 2009). These standards provide for teachers’ need to “understand the diverse learning needs of learners … whatever their individual aspirations, personal circumstances or cultural, linguistic, religious and ethnic backgrounds” (WG, 2009: Section 1.1) and “to understand their responsibilities under the
SEN Code of Practice for Wales” (S 2.6). It also requires the teacher to “establish a purposeful learning environment where diversity is valued” (S 3.3.1) and to “recognise and respond effectively to social inclusion” (S 3.3.14).

It is also noted that in UK, there were also studies that explored the importance of the teaching from the perspective of race and ethnicity. Lander (2008) in a conference paper entitled, *Race, Culture and All That* explored racial perceptions of student teachers from White backgrounds who were preparing to teach in secondary schools. The author found through interviews with student teachers and tutors that teachers in the Initial Teacher Education (ITE) were not trained adequately to support ethnic minority pupils in schools. These findings are an important aspect of support in education and therefore will be explored in preparing the methodology and the data analysis that will emerge. These findings are particularly useful for my study when examining the role of teachers, as perceived by BME parents, in supporting their children with the condition in schools.

In a more developed study, Lander (2010) again when exploring race equality issues with teacher education tutors in ITE through interviews with them, found that the issue with respect to race and equality was not evident in their initial planning to teach. This study, which was based in England within a mainly ‘White English teacher’ education setting, showed that teacher education tutors, particularly in the ‘White’ areas, lacked knowledge and experience about ethnic diversity. The study highlighted the importance of Continuing Professional Development (CPD) services about concerns related to race, culture and ethnicity in education and also provides an insight into the perception of ‘White’ teachers in a culturally diverse education setting. Further, Lander (2011) in a journal paper exploring race equality issues proposed that teacher training programmes need to develop a framework to be aware of issues of race in an education setting.

A later paper by Smith and Lander (2012) explored the effects of teacher ethnicity during the course of initial teacher training in England. The authors observed that, in reality, although many ‘White’ teachers may see no difference between their culture and that of the minority ethnic groups, the viewpoint of the White dominant culture in a society tend to prevail and become an accepted view.

Earlier research in England has showed that teachers’ training in autism was inadequate in England (Batten et al., 2006; Jones et al., 2009). In Wales, there is no requirement in the
Initial Teacher Education Training (ITET) to undertake any training in autism although there is some evidence of Continuous Professional Development (CPD) services (NAS Cymru, 2006, Evans, 2011). The Welsh Government commissioned a review of the ITET in 2005 to advice on what could be done to ensure that the needs of schools in Wales are met in terms of trained teachers (WG, 2012). The focus of the review explored the need for providing appropriate training for teachers in their ITET.

A review led by Furlong, Hagger and Butcher (2006) which became known as the Furlong Report, found that the ITET provision “did not adequately prepare or support trainees in the areas of equality and diversity, behaviour management and SEN” (Furlong Hagger and Butcher, 2006: 4). In the light of the Furlong Report, the Welsh Government (WG) then included measures to improve schools by strengthening the quality of CPD provision in schools based on teachers’ appraisals on their strength and difficulties (WG, 2012). However, it was found that the appraisals by trainee teachers did not always lead to the identification of their individual needs but rather through reports made by institutional inspections (HMCI, Wales, 2012). A follow up report was then presented by Tabberer (2013) who found that trainee teachers in Wales were seen to be making good progress, had good knowledge and knew how to conduct themselves professionally. The recommendations from this report were to strengthen the importance of teaching as a profession and encourage a stronger culture of CPD in the schools, in order to ensure that the competence and knowledge of these teachers were continuously enhanced.

2.3.4 Policy framework for SEN in Wales

In Wales, the policy framework within education is regulated by the National Assembly unlike in England where regulations are made by the Secretary of State (DDA, 2005). An important starting point is to make reference once again to the framework in England where the Autism Act of 2009 which looked beyond the school setting, was introduced in Parliament (HMSO, 2009). This Act required the government to produce an Autism Strategy with supporting statutory guidance, which was followed in 2010. Although, debates and proposals are put forward by the charity, such as National Autistic Society (NAS), only section 6 of the Autism Act extended to Wales which related to the view of promoting services and support for all adults with autism (House of Commons, 2009). However, the guidelines in this Act in England did not specifically relate to those from BME communities.
In Wales, the same debate was taken up by the *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales* which is discussed briefly in the introductory chapter. The ASD Plan was launched in April 2008 and its key role was to improve the provision available to individuals with autism and their families. From a resource point of view, during 2008 to 2011 total funding of £12.5m was allocated to support the implementation of the ASD Plan (Welsh Government (WG), 2010). The funding was also partly allocated to Local Authorities (LAs) for the support of services to meet the needs of individuals and their families, for the ASD Plan during 2011 to 2012. Since then, there has been a national ASD implementation manager based in the Welsh Government to drive forward in the delivery of the ASD Plan.

An evaluation of the Plan was carried out by the Welsh Government after three years with an aim to provide an account of its progress (2011b). This covered areas such as, among others, the level of specified funding for autism in Wales, awareness-raising, training, developments specifically for adults and context of research into autism. The evaluation drew on research from two NAS surveys, namely, *I Exist: The Message from Adults with Autism in Wales* by NAS (2008) and *The Life We Choose: Shaping Autism Services in Wales* by Evans et al. (2011)

The I Exist survey (2008) explored the support experienced by adults with autism and their carers in Wales and there were 132 responses from this survey of which 87 of those who responded were women. Qualitative interviews were also conducted with nine adults with autism and these interviews were carried by an experienced researcher in English except for one which was conducted in Welsh. Those who responded were also asked to take photos of people and places which meant something to them, using a disposable camera that was provided to them by the researcher. Bilingual questionnaires were also sent to the executive members of the social services and local health boards in all 22 local authority areas in Wales and only half of them responded. The findings of the survey highlighted that the LAs were not structured to meet the needs of people with autism since it was found that most LAs provide services through learning disability or mental health groups, even though autism does not fall under either of these groups.

The second NAS survey entitled, *The Life We Choose* (Evans et al., 2011) examined the views of people with autism and their families in Wales. Even though 490 people
responded to the survey, 75 participants were excluded due to the fact that they were not individuals with autism and did not receive any services in Wales. Therefore, the responses were from 415 individuals with autism and their families. The findings of this survey highlighted that the level of support provided to parents varied depending on their geographical location. For example, there were differences seen in the provision of support in the north and south of Wales. In addition, areas where there were larger population of BME pupils such as in south of Wales, were found to provide the same support for both BME and non-BME pupils in education and thus not providing cultural specific support to those from BME backgrounds.

According to Evans et al. (2011), in the first three-year implementation phase, the Welsh Government (WG) recommended that there would be funding and support for local authorities to undertake several actions across Wales. These actions included mapping prevalence, identifying gaps in services, developing local action plans to meet local needs, forming stakeholder groups which also include individuals with autism and their families and appointing a named lead within each local authority. Since then, over 250 awareness raising and training courses were delivered in Wales and over 5,000 stakeholders attended these courses. There were also five web-based awareness raising booklets aimed for practitioners and families and an on-line resource for people with autism, their parents and carers and professionals.

With regard to awareness-raising translated booklet within the selected LA in this current study in Wales, it was noted that there are over 117 home languages, however, only the most prevalent of the community languages, which include, Bengali or Sylheti, Urdu, Punjabi, Gujarati, Arabic and Somali, are recognised. Therefore information about autism is translated in only these languages (WG, 2011) and as a result there appears to be a ‘double-dose’ of exclusion for those who cannot speak these particular main home languages.

In 2010, the Wales Autism Research Centre (WARC) established the Research Policy Practice Hub which was dedicated to studying autism and promoting scientific research and good practice in Wales. In schools within Wales, staff are required to take into account the way they organise and teach their lessons (NAfW, 2002). For example, a teacher may use a visual timetable and simple drawings of the activities with a pupil with autism so that he or she may know exactly what is taught and when they will be doing such
activities. In addition, the teacher may also have to take into account the pupil’s language learning needs. The home languages of BME pupils are used extensively but it is not frequently recognised or supported in school (EALAW, 2003).

In addition, a bilingual information site (www.awares.org) was set up by Autism Cymru (WG, 2010) although only a few main languages were provided within this site. From 2011 a web-based ASD e-resource which includes e-learning was established and a national co-ordinator was appointed to deliver these initiatives. It is worth noting in this regard that the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales states that “the range of services, including advocacy services for individuals from Black and Minority Ethnic Communities is generally poor in Wales” (WAG, 2010: 7). However, it is useful to note that the Wales ASD Plan is important and is considered timely in relation to when this study commenced.

Other reports, entitled, ‘A snapshot of specialist autism education provision in Wales’ (Withers, 2009), studies exploring the needs of siblings of children with ASD (Petalas et al., 2009) and of aging adults with autism (Stuart-Hamilton et al., 2009), did not particularly focus on the needs of BME communities. It is also necessary to point out that the Cross Party Autism Group (CPAG), a charity which was established in 2002, provided a forum in the National Assembly for Wales has been helpful in raising awareness of autism over the years. Their focus has been upon highlighting the experiences of individuals with the condition and informing parents of the provision of educational services in Wales (Withers, 2009; Evans, 2011). Although, these reports, studies and forum referred to the BME communities as part of the society in Wales, their debates and sources of information did not specifically focus on the needs of these communities.

More recently, Routledge collated and showcased a number of published researched articles on autism (World Autism Awareness Day Article Collection, 2014). These articles focused on all aspects of autism, including education, health, social care and behavioural science. Although some of the articles related to understanding autism in multilingual and multicultural contexts and how teachers empathise and facilitate motor skills development of pupils with the condition (Todd, 2012).

Following the review in this section covering the area of support for pupils with autism which also includes the policy perspectives on BME languages in Wales, the next section
will examine the literature which specifically highlights research on the language needs of these communities.

### 2.3.5 Language support for BME pupils with autism

The inflow of migrants into the urban areas in Britain during the sixties till the eighties for the purpose of employment and education resulted in changes in its demographic composition (Hatton and Price, 1999). According to Hatton and Price (1999), these changes were expected to have implications on public policies. Although a large number of migrant children were admitted into the schools in the UK, very little was known about the education of these children and their communities (Swann Committee Report, 1985; EALAW, 2003).

In the UK, the class system was traditionally divided into three broad categories, the upper class, the middle class and the working class (Horvat, Weininger and Lareau; 2003; Ball, 2003). According to Horvat, Weininger and Lareau, and Ball, the upper class would consist of people with inherited wealth and who would usually be people may have sporting life which may involve hunting and horse riding for leisure. Further, that the middle class may include those who make up the majority of the population who comprise of professionals such as lawyers, doctors, academics and those from business backgrounds. Finally, the third category is the working class group comprising mostly of agricultural and factory workers. Thus, the language acquired by children from higher socio-economic or from wealthier background are more likely to be exposed to the English language through newspapers, books, movies, home environment and social circles. Alternatively, children coming from lower socio-economic background may have less of a chance to have such facilities and social networking (Ball, 2003; O’Sullivan, 2009). The above explanations may provide a basis for explaining the influence of the socio-economic background of BME parents in this study particularly with regard to their ability to use language for the purpose of obtaining relevant support for their child.

In the case of migrant communities who settle in the UK, they bring with them a language that is different from the language of the place that they reside in. Therefore, the need to enable communication between English and the language of the migrants is vital to enable their voices to be heard. Within education in the UK, there is a variety of translated material provided for parents and their children in several main BME languages such as
Bengali, Urdu, Gujarati, Arabic and Somali (EALAW, 2003; EMASS, 2004). The theoretical ideas provide a frame of reference for the purpose of understanding the experiences and perceptions of BME parents and of stakeholders within the context of this study.

The relevance of aspects of race in the UK was brought to the public domain in the Macpherson Report (1999) which raised issues relating to racism and prejudice in the context of policing. Further, another study by O’Neale (2000) entitled, *Excellence Not Excuses* explored services for ethnic minority children and families by reporting on aspects of race, ethnicity and education. This study gave a different perspective unrelated to racism and prejudice, was based on investigations by the Social Services Inspectorate which was carried out between December 1998 and July 1999. In comparing to White families, O’Neale found that individuals from Pakistani, Bangladesh and the Caribbean families faced difficulties in accessing services due to English not being their first language.

From a policy perspective, the Race Relations Amendment Act (2000) emphasised that LAs and schools should strategically view how their resources are used to support all their pupils and to ensure equality of outcomes. A major strategy to put an end to social inequality and regional differences for children from minority ethnic backgrounds was the establishment of the Ethnic Minority Achievement Services.

Following Section 11 of The Children Act of 1989, about safeguarding and welfare, more grants were made through the Minority Ethnic Achievement Grant (MEAG) in 1999 to local authorities for the purpose of meeting the Additional Needs (AN) of minority ethnic pupils from age 3 to 18 (cited in Tickly et al., 2002). Further, the Race Relations Act of 2000 specified that the MEAG was intended to narrow the achievement gap for the minority ethnic pupils and to meet their particular needs. This therefore highlights that there was help provided for these communities.

The Ethnic Minority Achievement Service (EMAS) referred to earlier, is a UK government funded initiative that forms part of the key delivery mechanism for English as a Second Language (Department for Children, School and Families (DCSF), 2007, 2009). This service which is the same in England and Wales advises staff at school on the provision of support for those with English as an Additional Language (EAL) and not for disability of
pupils (EMASS, 2004; EMAS, 2009). EMASS and EMAS are similar in terms of the services they provide but are stated differently depending on their location, for example, EMASS is used within Milton Keynes and EMAS is used within the council in Bath and the latter is the acronym that is used in Wales. In schools, the Ethnic Minority Achievement Service (EMAS) coordinators are usually the first point of contact for Ethnic Minority groups who newly arrive into the UK (EMASS, 2004).

Research has also shown that an aspect of educational support in Wales is the lack of services for children and young people with autism whose first language is Welsh. Roberts and Miller (Welsh Language Board, 2001) identified the need to improve access to Welsh medium or bilingual training for teachers across Wales. The inability of the families to access services may be referred to as language barriers due to their lack of use of English language (Bywaters et al., 2003). While there is this inability among Welsh people with their native language, this may be even more so for the non-Welsh speaking families and this would include parents of children with autism.

The literature also shows that there is a lack of studies exploring the cultural aspects of parents and their children with autism (Dyches et al., 2004; Perepa, 2005; Corbett and Perepa, 2007). Dyches et al. (2004) noted that there was scarcity of knowledge on how BME parents from different communities view autism and the difficulties that these parents experience in raising a child with the condition. Furthermore, Mockett, Hackett and Theodosiou (2009) stated that much of the material available for parents are still written in English and from a Western perspective. These authors who explored different beliefs of Asians and White British families suggested that the different beliefs of these families could be linked to support for ‘culturally appropriate’ services which is defined by Barns (2006: 4) as services that “recognise ethnic, cultural and religious diversity”. Mockett, Hackett and Theodosiou (2009) therefore propose that changes need to be made when designing and delivering services including translated information material for families and children from different ethnic groups.

The need to provide for translated materials in BME languages and the need to be aware of the differences arising from BME communities’ religious perspective of autism were also identified in the AET report (Jones et al., 2009). These identified shortcomings in the way support is provided, were regarded as being due to the inadequate research into BME families of children with autism (Jones et al., 2009). While on the one hand the AET
The report recognised that support was an important area of concern to be examined, on the other hand it also highlighted that the special needs of the BME communities needed to be taken into account. Conversely, the report did not give a breakdown of the different composition of the sample and therefore could be considered as an ‘ethnically blind’ report.

As mentioned earlier in this chapter, it is necessary to take into account that the literature surveyed so far is thematically based on ideas that were explored in earlier research in relation to the phenomena that is explored in the study. In order to further explain the perceptions of BME parents, relevant theoretical models are used to make sense of the phenomena that is explored in this study. These are discussed in the next section.

2.4 Theoretical perspectives in understanding BME parents’ experiences

There are different disability models that have influenced the basis for provision of support in education, namely, the medical, the deficit and the social model (WHO, 1992; 2007). The medical model of disability defines people with disabilities by their medical condition. The model considers that the inherent characteristics in individuals with disabilities need to be overcome to be part of society (Wall, 2006). However, in the deficit model, disabled people are interpreted as unable to carry out their activities of daily living because of the deficits which they possess (Dyson, 1990). According to Dyson (1990), an important factor within the deficit model is the belief that it is the impairment which is permanent in disability due to the loss of the function of a part of the body, which causes the inability of the individual to function normally. It is in this sense that people who have impairments are generally regarded as ‘disabled’ and who have been considered unable to function independently in, for example, education and employment. The approach however is to provide for intervention to achieve the ideal of ‘normality’ in those individuals with the impairment so that their lives would be more comfortable.

Critiques of both the medical and deficit models which focuses on the difficulties of the child, gave rise to the social model (Oliver, 1996) which has been conceptualised within the Fundamental Principles of Disability (Union of the Physically Impaired Against Segregation, 1976). However, the social model of disability is placed in the direct experience and understandings of those who are
disabled themselves and therefore concerns marginalisation and discrimination directly faced by them (Terzi, 2010) and this is elaborated in the next section.

2.4.1 The relevance of the social and affirmative models of disability in education

The social model of disability states that disability is about the way society is organized or structured (Matheson, 2008) and looks at ways of removing difficulties that restrict choices for an individual with a disability. The outcome is that these individuals may feel self-sufficient and equal in society (Oliver, 1997; Jordan, Jones and Murray, 1998; Jordan, 2006).

The Union of the Physically Impaired Against Segregation (UPIAS, 1976) provides a distinction between impairment and disability. According to the UPIAS document, impairment refers to “having a defect in a body part” while disability refers to “the exclusion of people from mainstream social activities by contemporary social organisation” (UPIAS, 1976: 31). The social model of disability consider people with disability as individuals who are treated equally and with access to a wide range of education, and have a right to be involved in all walks of life within society (Kellett, 2008, cited in Matheson, 2008).

In the context of education, if teachers have strategies or approaches to include pupils with autism in learning then these pupils may be successfully included into society since they are not incapable of learning (Jordan, 2006; Jones et al., 2009). In speaking about individuals with autism, Aylott (2004), state that their main difficulty is in understanding a social world within which there is social and attitudinal barriers. The quality of lives of these individuals can be changed positively if their difficulties are ameliorated (Jordan, Jones and Murray, 1998; Jordan, 2006).

However, critiques of the social model of disability from the latter part of the twentieth century focused largely on the absence of feminist perspectives, the exclusion of individuals with learning difficulties and issues of race (Lloyd, 1992; Crow, 1996). It has also been argued by feminist critics that the social model of disability has been largely explored by disabled male academics (Thomas, 1999; Oliver, 2003) and did not address
concerns of the wider experiences of individuals with a disability such as in “issues raised in theoretical debates around sex and gender” (Thomas, 1999, cited in Barnes and Mercer, 2004: 11).

An idea that may also explain the social context of pupils with a disability in education is with regard to social disadvantage experienced by many pupils (Lansdowne, 2009). Lansdowne (2009) stated that pupils with disabilities are more likely to be vulnerable to physical and sexual abuse, live in poverty and have limited access to education. They may often experience social discrimination which may not be as a result of their medical condition that they face but rather to attitudinal behaviours in society.

Another framework which emerged from the criticism of the social model of disability was the affirmative model which includes ideas within both the medical and the social models of disability. The affirmative model is defined by Swain and French (2000) as “being different and thinking differently about being different, both individually and collectively” (Swain and French, 2008: 185). Swain and French (2008), state that in exploring the relevance of the affirmative model sociological research on disabilities in individuals has gone beyond the social model.

Swain and French (2008) make the point that having impairment is regarded by societal practice as an unusual or unfortunate abnormality but, in fact, it is a relatively common part of human life. They further state that disability, “far from being tragic, could be an experience that is valuable” and that an individual’s disability is not only about his or her “negative” experiences (Swain and French, 2000: 571). According to Swain and French, the affirmative model challenges the view of the disability as a personal tragedy and places importance on “disabled individuals’ own lifestyle, culture and identity” (Swain and French, 2000: 578). Blandy (1989) who explored disability issues in art education also argued that the affirmative model does not stigmatise people because these individuals are regarded as those who are able to think, speak and write for themselves and therefore should not be stigmatised by society. Finally, Eisenhauer (2007), also an advocate of the affirmative model, stressed that “disability is a cultural rather than a personal limitation” (Eisenhauer 2007: 19).

In further explaining the affirmative model, Cameron (2008) argues that society should just accept individuals’ disabilities by accommodating and providing for them so that they
become part of an inclusive society. Cameron (2011) goes on to propose that society has a duty to be sensitive and appreciate these individuals’ disabilities by providing them with medical, therapy and social support to improve their mental well-being. For example, with regard to autism, it would be necessary to recognise that when providing support for individuals with the condition, their difficulties in understanding and predicting other people’s intentions should be taken into account (Baron-Cohen et al., 2009). Although the social model of disability places the responsibility upon society and not on the individual (Oliver, 2003), the affirmative approach appears to take into account the relevance of the holistic need of individuals with a disability (Cameron, 2011). The literature so far points towards clarifying the aims of the study to explore the experiences and perceptions of BME parents from the perspective of the affirmative model. Additionally, in view of the context of this study, it is also relevant to explore the literature that explains the rationale for policies based on the ‘colour-blind’ concept which is regarded as providing support for all on the same basis.

2.4.2 ‘Colour-blind’ and ‘culturally-blind’ theoretical frameworks

The concepts of ‘colour-blind’ and ‘culturally-blind’ refer to how, within a multi-ethnic or multi-cultural society, the diversity and uniqueness of particular ethnic and cultural groups are overlooked, especially by policy-makers. When reviewing the literature on the support of BME children and their parents in education it became clear that these conceptual frameworks were relevant to this study as I critiqued the extent to which policies either recognised or overlooked BME needs.

In explaining from a historical perspective, Cross et al. (1989) stated that the concept of ‘colour-blindness’ was used in America to refer to the failure to acknowledge the racial divide between the White and the Black society. However, over time the concept evolved and was used to explain the basis of policies that aimed to remove notions of racial discrimination. Mir, Nocon and Ahmad (2001) and Lall and Gillborn (2004) proposed that the effective way to deal with inequalities is to address the differences rather than ignoring them. These authors argue that ‘colour-blindness’ ignores the cultural values and beliefs of individuals and their families; and therefore may fail to acknowledge that the differences within a multi ethnic society could reflect a particular group’s cultural differences. These authors also suggest that it is likely that, by default, policies may result in services that are seen to be geared towards the dominant White community and thus seen as neglecting the
needs of the minority ethnic communities. Mir, Nocon and Ahmad (2001) also argue that services that are delivered by treating everyone the same, regardless of their ethnicity, are in line with the ‘colour-blind’ basis of public policies, as outlined later by Raghavan and Waseem (2007).

Further, Lloyd and Rafferty (2006) in an evaluation of several reports which surveyed minority ethnic groups in education stated that service providers may need to acknowledge that migrants from different countries who reside in the UK have unique cultural differences between and within each group. They argued that these communities are not homogenous and therefore suggested that a ‘colour-blind’ or ‘culturally-blind’ approach to policy making would not be appropriate.

The need to recognise the uniqueness of BME communities was highlighted by the SEN Code of Practice in Wales (NAfW, 2002: paragraph 4.25: 35) and in England by Raghavan and Waseem (2007) through their questionnaire-based survey which was conducted in Bradford. The study drew attention to what the authors termed, the ‘colour-blind’ approach to policies and which is defined as “services offered on the same basis to all families” (2007: 30). The authors mapped out service use among young people with mental health problems and learning disabilities from Pakistani and Bangladeshi communities. Their findings showed that these communities were using their GP services for health care and social services for benefits but were reported not to be accessing mainstream learning disability services. Further, these families also reported barriers to participation, such as their difficulties in language, lack of awareness of services together with a lack of culturally sensitive services which in turn made them unwilling to use these services. Raghavan and Waseem’s study also indicated that many individuals were worried about what others within their own community would say if they found out that they had a person with a disability in their family, which is similar to the findings of other studies such as Beresford et al. (1996) and Bywaters et al. (2003).

According to Fryberg (2010), the idea of colour-blindness is regarded as an ideology that suggests that in order to end discrimination all individuals within society should be treated equally without regard to race, culture or ethnicity. However, the author states that the colour-blind approach would create a society that does not acknowledge racial experiences and, importantly, rejects individuals’ cultural heritage as well as their uniqueness in diversity. An alternative approach is a multicultural perspective which acknowledges and
celebrates racial and cultural differences. Fryberg (2010) goes on to state that to move away from colour-blindness into multiculturalism, would involve a process of change in society that would not be easy, but necessary. However, underlining the complexity of this issue, it can be noted that the term ‘multicultural’ itself in the UK has been criticised for its limitations in addressing the actuality of diversity; and even for reinforcing cultural divides and inciting racial hatred (Thapar, 2014).

From the point of view of policy, it is useful to recognise that the Race Relations Amendment Act (2000) has ensured that public authorities have a duty to take steps to improve services provided to minority communities in the UK. However, Gillborn (2004), in his study which explored details of BME education projects, found that the support provided for them was aimed in a general way to provide for all in society rather than being directed to an audience of BME heritage. According to him, there is a misconception that the BME communities can benefit under a common policy of support that is for all. The study shows that despite an overall improvement in educational standards in England since the late 1980s, there remains inequality in terms of attainment between White pupils and their peers of Bangladeshi, Pakistani and African-Caribbean heritage. This finding would seem to support the argument for a change from a colour-blind to a multicultural approach within education policy.

Within the literature, the terms ‘colour-blind’ and ‘culturally-blind’ appear to be used interchangeably. Further, definitions of ‘cultural blindness’, are noticeably absent within the academic literature. However, according to Castro (2005: 336), the term ‘culturally-blind’ relates to how different characteristics such as, skin colour, culture and religion, are ignored by those who would want to see everyone as the same and do not acknowledge that people of other cultures have differing needs. This is highlighted as “the phenomena in which some people will say that they are culturally-blind, as a compliment” (Castro, 2005: 336). From both a ‘colour-blind’ and a ‘culturally-blind’ perspective, the dominant society often only sees things from the perspective of their own culture. Whilst, the term colour-blindness encompasses culture and ethnicity and is not simply about race and colour, ‘culturally-blind’ was considered a more appropriate term for this study. The focus is on culture and ethnicity as opposed to colour.
2.5 Scope for the study

The literature review reveals that much of the research in England and Wales so far has been wide in scope, focusing not entirely on the BME community particularly where it concerns supporting children with autism and their parents in education. In addition, it has included aspects of public policy which have identified the unique lived experiences and role of parents and relating to those who provide professional support for these children. There is also literature that has explored the principles of inclusion for those with special needs, particularly when requiring educational services to be provided through mainstream schools (UNESCO, 1994). At the same time, there is a need to provide for children with autism in terms of special assistance that is likely to be available only through special schools where there are specialised resources to meet their needs. This subject is raised in the research to explore how parents relate to the principles of inclusion where policy provides that they have a choice in the school that they want their child to attend (DfES, 2001; NAfW, 2002).

While there may be a lack of information among some BME parents of children with a disability in relation to support services, there may also be a lack of knowledge of BME needs by service providers in education (Chamba et al., 1999; Fazil et al., 2002). This is because service providers explain their role through the ‘culturally-blind’ approach where support is given on the basis that the condition is similar to all ethnic groups which include both BME and non-BME communities, as also suggested in the literature (Mir, Nocon and Ahmad, 2001; Raghavan and Waseem, 2007).

Researchers in the field have also critiqued a general lack of studies within culturally and linguistically diverse families of children with autism (Dobson and Upadhyaya, 2002; Perepa, 2008, Lee, 2010). It is noted that there is not much research on how the BME families understand autism, including difficulties that they face in obtaining services in education. While some concerns could be regarded as universal and not only unique to the BME community, it is necessary to highlight that there are several difficulties that are faced by these communities which include delayed diagnosis, lack of specialist knowledge on the part of professionals and scarcity of information and resources in different BME language. With the demography change through migration, larger proportions of BME communities are seen settling in both England and Wales. It has been acknowledged that while the BME communities are not the same as the indigenous dominant White
community, they are also not homogenous between and within themselves (Lloyd and Rafferty, 2006).

The major strategy in Wales which lies at policy level, the Autism Spectrum Disorder (ASD) Strategic Action Plan has clearly shown that there is a need to examine this position with regard to the BME communities in education. The strategy suggest that support services for families with autism, from different cultural backgrounds do not currently exists within Wales and therefore that it is important to prioritise research and data collection within this area to inform Welsh policy. Further, the views of parents of children with autism are to some extent determined by their common perceptions of cultural values which include, identifying their child’s disability as a passing condition and perceiving their child’s disability as God's punishment or as a gift from God. The literature review suggests that BME communities’ concerns are not adequately addressed within research in autism and education particularly within the selected Local Authority (LA) in Wales.

As highlighted by Corbett and Perepa (2007) and Perepa (2008), there has been little research into parents of children with autism from BME families. Corbett and Perepa (2007) in their findings stated that individuals with autism from BME backgrounds faced difficulties in relation to their disability and their ethnicity and that it was important to provide support that acknowledges their social, cultural and religious needs. Further, Perepa (2008) recommended that more research on the educational needs of these communities needs to be carried out, particularly on the impact of autism on BME parents. Although, it is noted that the studies did not focus specifically on education and explored both the experiences of BME and non-BME parents, my thesis builds on their ideas and recommendations. It is however recognised that there would be contribution to research from this study on the role of parents of children with autism from BME backgrounds.

Finally, my own experience as a teaching assistant in caring for children with autism in special and mainstream schools and my own ethnicity also provided the basis in selecting the area of focus in this study. In my view, the area of study in education is an original contribution to new knowledge. Further, the selected LA was chosen as the location in this study since there are no studies that are specifically examining BME parents’ experiences within Wales. Therefore this study fills the gap that is identified in the review of literature.
Based on the literature review it is appropriate to restate the research questions that are explored in this study.

1. What are the experiences and perceptions of BME parents of the support they and their children with autism have received via the education system, relevant support organisations and their families and wider BME community?

2. What are the perceptions of key personnel in education and relevant support organisations of the support provided for BME children with autism and their parents?

3. In what way do BME parents and stakeholders identify improvements for the future?

The next chapter examines the research design and methodology that guided the study.
Chapter Three

Methodology
**3.0 Introduction**

The literature reviewed in the previous chapter showed strong preferences towards the use of qualitative approaches in studies which have similar aims to this study. For example, several studies that have explored in-depth experiences and perceptions of parents of a child with autism in a clinical setting (Tams, 1998; Dobson and Upadhyaya, 2002; Beale, 2007; Lee, 2010) and cultural setting (Corbett and Perepa, 2007; Perepa, 2008) have obtained their data through the use of interviews. Further, it is also noted that some of these studies have used the qualitative interpretive approach in their analysis of the data to make sense of parental experiences. Since this study is also exploring similar parental experiences, I have been influenced to adopt the qualitative interpretive approach to explore the appropriate research design and methods in this study.

**3.1 The research design**

The design in this study includes several approaches for the collection of data and the selection of the appropriate tool for analysing the data. A qualitative interpretive case study was adopted to explore the experiences and perceptions of the parents in view of providing explanations to these phenomena. The nature of the enquiry of this study is also a relevant aspect in choosing an in-depth case study method since it focuses on a number of parents from the Black and Minority Ethnic (BME) community within one selected Local Authority (LA) in Wales. Moreover, the qualitative approach was selected since its basis lies within the interpretive paradigm in terms of relating to the interaction of people and in the description of their lived experiences (Bryman, 2008; Lichtman, 2013).

The research questions that are identified in the literature review chapter of this study make it appropriate to take into account the ethnicity of the parents. It is important to note that this study does not focus on the perceptions of other close family members such as grandparents, uncles, aunties or siblings. Although, these family members may provide some care for the child with the condition, they may or may not have the knowledge of the condition. It is argued that, the exploration of different experiences and perceptions of BME parents from different cultures is best achieved through their own lived experiences (Willig, 2005; Bryman, 2008).

The other aspect of the study includes an exploration of the perceptions of key personnel in education and relevant support organisations, referred together as the stakeholder group,
who provide support to a child with autism and their families, on similar questions. The
method for the collection of data was designed to provide the basis for the analysis in this
study. Here, primary data was obtained from BME parents and stakeholders using
interviews as the main method of data collection, while secondary data was obtained from
official statistical data and documentary evidence. The statistical data shown in the
introductory chapter is merely to present the contextual background and is not for the
purpose of any statistical analysis. In addition, the justification for the choice of a case
study in the selected LA using a qualitative enquiry approach is provided. Further, the
interview method used in data collection is explained with the discussion of the interview
schedules that are administered in the study. The data analysis using the thematic
approach which is facilitated by the NVivo qualitative software is also discussed after
which details of issues relating reliability and validity, and ethical considerations are
provided.

3.2 Cultural consideration and research reflexivity

In this study, it may be useful to note that before the interviews commenced, a few of the
parents who were from a Muslim background asked me what my religion was. This
question from the parents gave me the feeling that they may have felt comfortable to talk to
an interviewer from a similar background and probably sensed a trust in me since, being
from an Asian background, I looked like one of them. Further, Perepa also stated that it is
important to “establish personal rapport and build the trust” when researching minority
ethnic communities (2008, p. 331). It is acknowledged that Perepa’s study (2008) has been
crucial in determining the scope of this study and reference to his work is made widely in
this thesis since he explored the views of BME and non-BME parents. It is also recognised
that his study did not specifically focus on education but on these parents’ views of social
behaviours of children with Autism Spectrum Disorder (ASD) within different cultural
context.

I was aware of the potential of this influence, when I was greeted by some of the
participants in an Islamic way at our interview meetings, I responded back accepting their
greeting in a similar manner. I was comfortable in my response since I had previously
lived in a country, where the main religion is Islam. Further, I was able to understand
some Urdu words, which is the Pakistani language and this was very helpful in terms of
making sense of two of the participants who spoke Urdu when they were not sure of
English terms during the interviews. Another aspect to be noted is that, I am a woman from a BME background and that ten out of the eleven participants in this study were also women themselves.

In order to place myself in the study, a useful way is in understanding research reflexivity which is defined as a position of “being able to locate oneself in the picture” and to gain an understanding as to how one’s own self influences certain actions (Bolton, 2009, p. 14). Bolton explains that reflexivity is about exploring one’s own role as a researcher, when evaluating the extent to which the researcher could be detached in carrying out a particular study. The author further explains that the researchers’ own experiences allow them to critically examine themselves in relation to those being studied as they both become engaged as co-researchers. This allows the researchers to understand and get an insight into this joint effort in the course of the analysis through different and differing views of participants. In this study, my position becomes relevant as seen by Bolton (2009) and research reflexivity would have to play a vital part in the analysis and discussion of the findings.

Finlay (2002) suggests that in some cases there may be an influence of power emerging during the research process that may give rise to uncertainty of the researcher’s own position which could in turn result in researcher bias. For example, in this study it is proposed that there would be interviews with some stakeholders who may have authority in policy and in such cases it is possible that the stakeholder may dominate the interview session. Further, since I come from an Indian background which is similar to the background of the BME parents whom I intend to study, there would be a relationship between the participants in the research and myself. In addition, there was the possibility that I would potentially become part of the research process.

While Bolton (2009) and Finlay (2002) provide different perspectives into the awareness of the researcher in constructing meaning during the process of reflexivity, Etherington (2006) proposes that it is important to make a distinction between the ideas of ‘reflection’ and ‘reflexivity’. The idea of reflection relates to “a state of mind” in research which refers to what researchers would do to make sure that their “own experiences and interpretations do not influence the analysis and findings in research” (Etherington 2006, p. 28). The idea of reflection is about listening and being flexible in using the interview schedule and valuing what participants say (Roulston, 2010). For practitioners, reflection
is about making an idea clear within themselves about the phenomenon and involves recalling about “who said and did what, how, when, where, and why” (Bolton, 2009, p. 4) and this might lead to insights about something not noticed in time.

On the other hand, reflexivity is “a technique” in research which involves the researcher to think from within his or her own experiences and to provide information on “what is known” and “how it is known” and therefore creating “transparency” (Etherington 2006, p. 3). In exploring the advantages of using reflexivity with participants who are also her students, Etherington states that reflexivity addresses both the ethical concerns and power relations between the researcher and the researched. She also states that awareness of ‘self’ is a core idea within reflexivity in terms of how the researcher may influence the way research is carried out. Thus, the technique of reflexivity is useful to be taken into account since the focus of this research is on the experiences of BME parents and who are similar to the researcher’s background in this study.

In reflecting upon my own experiences, the idea of reflexivity as explained by Etherington (2006), Bolton (2009) and Roulston (2010) becomes relevant for this study. It is useful to note that these authors suggest that reflexivity is about devising questions that takes into account the researcher’s own thoughts about his or her experiences. Further, the idea of reflexivity is also encouraged by Bolton (2009) who suggests that, in conducting a study, researchers should continuously reflect back upon their own personalities and to be aware that, as far as possible, their own bias is not brought into their work. Therefore, my part as the researcher is vital in the research process, in terms of my own personal role or of my experience and with my own reflexivity that I bring in to my role in research.

The reflexive approach which is taken up by emancipatory research has its roots in Disability Studies (Oliver, 1992; 1997; 2003). Oliver, in his seminal paper defined emancipatory research as “the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs” (Oliver, 1992, p. 110). The author argues that “oppression” that is faced by those with disabilities should be taken up openly through a political agenda by rejecting the disability as impairment (Oliver, 1997, p. 25). Oliver also emphasised that the role of research is to ‘liberate’ people with a disability which is seen as a form of social discrimination. However, this study does not ‘liberate’ BME parents of their child’s autism but has the purpose of giving these parents a voice. The phenomena that is explored here is based on listening to the voices of BME parents as an “active
accommodator” (Corbett, 1998, p. 59) and thus a message as told by a marginalised group.

In the process of designing the interview schedule for BME parents, it was necessary to ensure that the data that is captured would appropriately answer the research questions explored in this study. This had to take into account the perceptions of these parents in relation to support in education, support from relevant charitable organisations and support from family and the wider BME community. Following upon the design, I have selected the interpretive approach to answer the research questions by focusing on examining and understanding the researched phenomena through the views of the participants as expressed during the interview phase of the study.

The understanding of experiences and knowledge within research may be also explained through the ideas held within philosophical research paradigms.

### 3.3 Interpretivist research paradigm

The interpretivist paradigm refers to the understanding the meaning of an action or idea from an individual’s point of view (Blaikie, 1993; Hammersley, 2007; Cohen, Manion and Morrison, 2011; Lichtman, 2013). The idea within the paradigm consider that expressions of human behaviour are socially constructed (Seale, 2004) and that people actively construct their social world (Hammersley, 2007; Cohen, Manion and Morrison, 2011). There is also the held view that the most effective way to elicit understanding of the constructed meaning of an event is through the ‘eyes’ of participants or of those who are being researched (Cohen, Manion and Morrison, 2007). This includes the acknowledgement of the influence of the participants’ own background and experiences of the event (Creswell, 2003, p. 8).

The role of the researcher in using the interpretivist paradigm which is qualitative in nature is to interpret the subjective meaning of the actions within the social world (Kvale, 2007; Denscombe, 2007). The subjective interpretation is most effectively achieved through a variety of research methods, such as interviews and observations, in order to gain different perspectives of the phenomenon that is being studied (Robson, 2004). The paradigm uses an inductive reasoning approach that is exploratory in nature and based upon the evidence that is provided and to detect patterns that may contribute in developing new ideas (Punch, 2009).
The interpretive paradigm has been criticised on the grounds that interpretation of meaning is made by those involved in the study for example, the researcher and the participants (Miles and Huberman, 1994). A further criticism was that detailed knowledge can only be gained about the aspects of the phenomenon observed or discussed (Cohen, Manion and Morrison, 2007). The findings will only refer to the information provided at the time of the research, by the participants involved, and, therefore cannot be generalised. Despite these criticisms, the interpretive paradigm was thought to be appropriate for this study because it enables an understanding of the experiences of participants as they perceived it. Since this study is adopting the qualitative interpretive approach, the rationale for a qualitative case study is discussed next.

3.3.1 Qualitative approach using case study

There has been an increase in qualitative research conducted over recent years in the area of Special Educational Needs (SEN) such as those researched by Dobson and Upadhyaya, 2002; Corbett and Perepa, 2007; Jegatheesan, 2009, Lee, 2010), particularly in documenting stories of individuals with disabilities. Jegatheesan argues that this approach should be broadened to consider the socio-cultural contexts in which disability exists. Additionally, the qualitative method “enables the voice of the participant to be heard" (Grieg and Taylor, 1999, p. 46) and is of relevance in this study where the focus is on BME parents of a child with autism, in terms of what they had to say about their lived experiences. The strength of qualitative in-depth analysis is suitable as a method within a case study which would also enable to take into account everyday social life experiences and therefore would be suitable as a method in this study.

The decision to select the case study approach as opposed to any of the approaches within the interpretivist paradigm is that case studies result in thematic analysis, rather than the detailed and descriptive analysis associated with ethnographic studies. Similarly, the Interpretive Phenomenological Approach (IPA) was not adopted since it is an approach to psychological qualitative research (Robson, 2004).

Case studies have their antecedents in, among others, the disciplines of Sociology, History and Psychology and are frequently used in both quantitative and qualitative studies (Stake, 1995, 2000). The use of case study as a research method is highlighted as “adopting an
interpretive approach to data information” (De Vaus, 2001, p. 10). This view corresponds with the basic aim of this study which is to explore the research questions through the ‘eyes’ of the participants.

The case study is defined as,

An empirical enquiry that investigates a contemporary phenomenon … within its real-life context and which … relies on multiple sources of evidence (Yin, 2009, p. 18).

In commenting on the definition of case study by Yin, Simons (2009) argues that it is difficult to differentiate between the “phenomenon and context in real-life situations” (Yin, 1994, p. 20) due to many variables of interest, for example, relying on numerous sources of evidence and techniques during the collection of data. The appealing feature of a case study is that it has the ability to draw on many sources to capture a bigger picture of what is investigated (Simons, 2009). It is argued that while a case study can give valuable insights for the researcher (Stake, 2005; Simons, 2009; Yin, 2009), there are many preconceptions about the use of case studies. This may be in relation to the method as being too subjective or with regard to a small sample size for it to infer any relevant information.

Simons (2009) reviewed the literature on the case study method and found that there were different perspectives that emerged from it. These perspectives included Stake’s (1995) idea that case studies tend to use the qualitative enquiry method. Another perspective based on the definition by MacDonald and Walker in 1975 as described by Simons, offered the possibility that one can generalise the findings from a particular in-depth case “to yield insights of universal significance” locked in time and circumstances (cited in Simons, 2009, p. 20).

One advantage of case study is that the data produced “may form an archive of descriptive material sufficiently rich to admit subsequent reinterpretation” (Yin, 1994, p. 24). A further advantage of the case study approach is that it can be undertaken by a single researcher (Gillham, 2000; Denscombe, 2007) and also provide insights into other similar situations and cases, thereby assisting interpretation of the insights (Denscombe, 2007). It is also important to consider some of the limitations in doing a case study to make sure that they are recognised prior to the study so that appropriate ways can be considered to deal
with them (Denscombe, 2007; O'Sullivan, 2009). The main concern in using the case study approach is with regard to the opportunities for generalisation (Schofield, 2000; Denzin and Lincoln, 2011; Yin, 2009). However, Yin (2009) suggests that case studies can be generalised to theoretical propositions and not only represent a sample in the study population.

Interestingly, Flyvbjerg (2006) highlights some common misunderstandings about case study research and provides an explanation about the issues underlying these misunderstandings. On the misunderstanding that theoretical knowledge is more valuable than practical knowledge, Flyvbjerg explains that in the study of human affairs, practical knowledge or context specific knowledge would also be valuable. When referring to another misunderstanding that one cannot generalise from a single case, Flyvbjerg argues that an in-depth case study enables one to understand complex issues that are explored in understanding a phenomenon. This, he argued, would provide an understanding of practical knowledge for its ideas to be generalised. He further explained that generalizations based on large samples are overrated and the strength of a single example is undervalued in research. Another misunderstanding was that case study confirms the researcher's preconceived notions and to this Flyvbjerg argued that there is no greater bias in case study towards confirming preconceived notions than in other forms of research.

It is also useful to be aware of earlier research that pointed towards the diversity of minority ethnic communities that is also continuously changing (Gunaratnam, 2003). Research about an ethnic group therefore cannot be generalised since there could be differences within the different ethnic groups and which has been referred to in other studies (Lloyd and Rafferty, 2006; Perepa, 2008). Gunaratnam states that some of these differences could be based on social class, language, gender, history of settlement, economic status, and religious beliefs. According to the author, these differences, in turn, may affect the way BME families respond to having a child with a disability. The author further asserts in the context of methodology in research, the background of the interviewer could include the bias of the participants. In view of this, there could be concerns of interpretations of what is recorded in the data of an interview where the people give their opinions when questioned by an interviewer from another ethnic background (Gunaratnam 2003, 54). Therefore, the researcher, when engaging with these communities, need to be aware of the impact of these differences on them.
An important aspect within this case study is concerned with ‘giving voice’ to BME parents. Bogdan and Biklen (1998) define giving voice as “empowering people to be heard who might otherwise remain silent” (p. 204). Moreover, Mazzei and Jackson (2009) state that qualitative researchers have been trained to recognise the importance of voice and to be able to “free” or enable the genuine voice of those being studied so that it would be possible to relate to the “truth about the self” (p. 1). The mention of ‘self’ by these authors can be associated to the voices of BME parents in this study who have experiences in caring for a child with autism. While the desire to give voice by some can assume several troubling truths or concerns (Kincheloe and McLaren, 2000; Ashby, 2011), Bogdan and Biklen (1998) affirm that to some extent the voices allow people's stories to be told. It should also be acknowledged that the data that is obtained in this study is not only derived from the voices of the participants but also through the researcher’s own perspective and interpretation of the data.

In addressing the research questions within the design of this study, one Local Authority (LA) of relevance was selected as the case and within this case a qualitative enquiry approach was adopted. In this case study, the ‘voices’ of BME parents as well as relevant stakeholders are explored.

Following the discussion and rationale for a case study, the instruments used for data collection within the case study is presented next. Further, in order to place the sampling frame in context, details that are relevant to all participants, both BME parents and stakeholders will be presented in separate tables later when discussing the study sample.

3.4 Data collection: Interview as a method

As the case study does not recommend a specific research method, an in-depth interview was selected as a tool for data collection in this study. Silverman suggest that the interview method is a way of asking people to talk about their lives (Silverman, 2007; Roulston, 2010). The interview method was selected as the most appropriate method to gather data and to answer the research questions in this study compared to using a questionnaire which would not have elicited the in-depth information that was required for this study.
An interview is by one definition,

... a conversation between two partners about a theme of mutual interest (Kvale, 2007, p. 11).

Kvale describes the exchange of ideas and one in which particular knowledge of interest is constructed. Interviews are considered as a suitable method when the aim of a study is to understand individuals’ experiences and perceptions and where inferences can be made about the individuals’ opinions and feelings (Silverman, 2007; Mason, 2002; Denscombe, 2007). Moreover, many interpretivists have recommended using interviews as an instrument for data collection (Creswell, 2003; Robson, 2004; Langdridge, 2007).

The advantage of using an interview approach is that the data that is generated from the interview can be aimed to elicit rich, detailed information for analysis (Thomas, 2009, Yin, 2009; May, 2010). This approach is usually carried out by asking questions or probing through the use of open-ended questions (Lichtman, 2013). Yin (2009) suggests that this kind of interview is often conducted face-to-face since the approach would most likely position the participant in front of the interviewer during the interview. In this case, the tool that is used for the in-depth interviews is a simple tool, the researcher’s own conversation skills.

However, the disadvantage of interviews may be that the analysis of data can be difficult and time consuming (Denscombe, 2007; May, 2010). Further, there may be difficulties of interviewer effect, where the data from interviews are based on what people say rather than what they do and this cannot be assumed to reflect the truth (Lichtman, 2013). A criticism may be that, the use of interview as a method, may lead to potential interviewer bias, and therefore giving rise to the lack of validity of the data (Mason, 2002). This could be, according to Burgess (1984), the rules of proper interview behaviour, is to be friendly but not over-sociable, in order to overcome difficulties associated with such ‘bias’ (p. 101).

### 3.4.1 Semi-structured interviews

A semi-structured interview was selected for this study and conducted with a sample of eleven BME parents, eleven key personnel in education and five key personnel from relevant support organisations (May, 2010). In a semi-structured interview, the interviewer knows the areas he or she wants to cover with the interviewee, but allows the interviewee
the choices to take different paths and explore different thoughts and feelings (Denscombe, 2007). The questions are devised not in a detailed form in order to allow the researcher to give space for the interviewee to speak around the raised questions, including digressing during an interview. Semi-structured interviews may involve open-ended questions which may require a detailed response from the interviewees, as well as some closed questions which may be in the form of multiple choice or just a ‘yes’ or ‘no’ answer from the interviewee (Bryman, 2004; May, 2010). The interview schedules that were developed for this study begin with closed questions and then move towards open-ended questions. This is in view of assisting the participants to become more comfortable and familiar so that they may respond openly to the questions that are posed to them (Flick, 2011).

In describing the strengths of interviews, the face-to-face nature of semi-structured interviews can provide insight into the non-verbal signs which can be lost in a written response (May, 2010). This view is shared by Arksey and Knight (1999) who stated that interviews are powerful instruments that can explore individual’s personal understanding of the situation and to make clear what has been implicit. This is particularly true in the case of semi-structured interviews, which were used in this study since most of the BME parents voiced their worries by openly talking about their difficulties when the questions were raised by me. The flexibility of semi-structured face-to-face interview was particularly essential for this study since the interview gathered personal information from BME parents who had different levels of ability in the English language.

A weakness of the face-to-face semi-structured interview is the possibility that participants could be influenced by the researcher's language, gender or ethnicity and the amount of information that is shared during the interview (Denscombe, 2007). Further, there may also be the possibility of the participants being affected by the researcher's appearance during the interview with participants and which were also highlighted in Perepa’s (2008) study. This in turn suggests that in an interview, participants may or may not be comfortable in giving their response to the questions that are asked if the interviewer came from a similar background as theirs. Similarly, the interviewer may also be concerned of likely bias arising from the background of the researcher.
3.4.2 Elite interviews

The elite interview which is unstructured in nature is also selected as an approach within this case study. The elite interview is defined as an interview with “a group of individuals, who hold, or have held, a privileged position in a society” (Richards, 1996, p. 199). It is about the expertise in specific knowledge that they may have that the researcher wants to explore. This knowledge as expressed by the elite is obtained through face-to-face interviews using instruments such as interview schedules that usually contain open-ended questions. These interview schedules are designed to recognise the role of the elite during the interview and this is by allowing the participant to reflect and express themselves in their own ways usually recognising that they possess specialist knowledge that is relevant to the research.

Smith (2006) maintains that by using elite interviews, the researcher needs only a list of topics to be covered and with no order in the topics. In using this approach, while there is the power relationship between the interviewer and the interviewee (May, 2010), there may also be the possibility to reproduce this power relationship between the researcher and the participant and with the researcher leading the interview (Fontana and Frey (2000). Regardless, according to Smith (2006), elite interviews are usually used with individuals who are of high positions in authority who are capable of providing answers with insights into what is being studied or investigated. In using this approach, it is the interviewee who may prefer to articulate his or her views without being constrained by the questions within an interview schedule (Aberbach and Rockman, 2002). Thus, there may be power interactions where the researcher is talking to those who have high status and who may direct the interview rather than be led by the researcher (Gillham, 2001; Smith, 2006).

The difficulty faced by the researcher when using such interviews is that the interviewee may not “submit to being interviewed where the interviewer directs a series of questions at them” (Gillham, 2001, p. 64); although the use of the approach with people of authority can be particularly informative in terms of uncovering information that would not have been exposed using structured or semi-structured interviews (Smith, 2006). Nevertheless, both semi-structured and elite interviews allow participants to speak their mind and develop better ways of discovering a phenomenon (Denscombe, 2007).

In this study, a separate elite interview schedule was devised and used with three
participants who held high positions in authority and who have prominent roles in relation to policy in education and in leading relevant support organisations. The interview schedule for this category of elites was therefore designed to recognize that they were in the category of elites in this study. For the others within the stakeholder category, who did not hold positions in authority, such as, teachers, teaching assistants and EMAS advisors, the use of interviews provided a slightly different way of collecting data. In this study, elite interviews were used with three selected stakeholders exploring their expertise and their role in supporting pupils with autism and their families and this added depth to the study.

3.4.3 Conducting interviews from a distance

In addition to semi-structured and elite interviews, an online web-based interviewing technology was used with a staff at a national society in the UK. The use of the web-based approach was convenient since I was living in Wales at the time of interview. This was because interviewing the staff in a traditional face-to-face context would have been costly and time demanding.

The advantages in conducting a web-based interview is that its availability is inexpensive and easy-to-use and therefore offering researchers several benefits in terms of its cost, geographical flexibility and it is easy to and ease of installation (Kazmer and Xie, 2008; Sharpe and Benfield, 2012). In this study, I conducted the web-based interview with one participant through audio and video digital approach, thereby enabling me also to see non-verbal cues which was similar to the face-to-face interviews that were carried out with the rest of the stakeholders. According to Booth (2008), where the interviews are conducted using only the audio approach, the non-verbal cues would be lost thereby highlighting the advantage of audio and video digital approach. However, the disadvantage of using a web-based interview is that there may be time delays in the conversation which can break the flow of an interview (Booth, 2008). In using online interviewing, the researcher needs to be aware that if the technology fails, it can result in disconnection problems and loss of data (Kazmer and Xie, 2008).

While the possibility of using a focus group was considered, I decided against using the approach since I experienced difficulty in getting a group organised as the majority of the parents were not in favour of it. Hence, the method adopted in this study was by the use of
interviews with participants which included both parents and stakeholders.

For all BME parents who participated in the study, an information sheet on autism and a covering letter were provided and a copy of this is shown in Appendix 1. In addition, a copy of an information sheet was also provided for participants from the stakeholder group (key personnel in education and relevant support organisations) during the interview and a copy of this is shown in Appendix 2. The purpose of sending out these information sheets and covering letters to parents and stakeholders was to explain to them the purpose of the study and to seek their participation. In addition, before the interviews commenced all participants were given an opportunity to discuss the ethical considerations of the research before they were asked to sign a consent form. A copy of the consent form that was used for both the BME parents and stakeholders is shown in Appendix 3. Further, the ethical considerations are discussed later in this chapter.

3.5 Interview schedules

There were three interview schedules devised for the study, one schedule was administered with the parent group and the other two with the stakeholder group namely the elite and non-elite schedules and these are all shown in Appendices 4, 5 and 6 to the respective order of the schedules. The two interview schedules within the stakeholder group comprised two categories of participants, firstly, key personnel in education and relevant individuals from support organisations and secondly, with people who were in high positions in authority and who had privileged insights in relation to what was being studied. As such, it was found necessary to separate these two groups of stakeholders and thus acknowledging the privileged and power relationships within those from the elite group (Richards, 1996; Fontana and Frey, 2000). In view of this, separate schedules were required to be administered even within this stakeholder group and the design of the schedules is discussed next.

3.5.1 Design of the interview schedule for BME parents

In designing the parent interview schedule, I took into account the need to include questions that explored parents’ experiences of support for themselves and their child within education and within their own communities and to take into account the need to record the interviews using a digital recorder. May (2010), states that it would be advantageous that all interviews are recorded, since this approach provides a detailed data
of the actual interviews; and thus assist in the process of transcription and subsequent analysis. This was especially important since in this schedule, some of the questions included within the interview schedules were aimed to take into account the sensitive nature of the experiences explored. Further, it took into account that, while using a semi-structured face-to-face interview, it was possible during the actual interview to modify the wording of the questions according to the responses of the interviewees.

It was planned that the questions within the interview schedule should start with easy questions to help participants become relaxed and familiar with the interviewer and thus be able then to be more open and honest in their responses to questions (Denscombe, 2007; May, 2010). In keeping with both Denscombe and May’s proposition, the first part of the interview schedules for parents in this study started with a preliminary data sheet with closed questions to capture the personal details of the parents then led to more open-ended questions (as shown in Appendix 4). This data sheet, in the first part of the same schedule, included relevant information about the child with the condition and information regarding the ethnicity of the participant and the length of their stay as migrants in the UK, as shown in the description of BME parents in Appendix 7. A revised interview schedule for parents used in this study is shown in Appendix 4 following the pilot study which is explained later in section 3.6.1 (See Appendix 8 for original version of the interview schedule for parents).

The design of the second part of the interview schedule for the parent group were based on ideas that were raised in the literature and previous researchers’ work and was divided into the main section headings, namely, support in education, support from relevant charitable organisations and support from family and the wider BME community. This part of the schedule contained open questions, to enable the participants to talk about their experiences of their lives. For example, the first question was “Can you tell me your story about your child?” This question allowed most the participants to give a meaningful account of their experiences to date and being “reflective of underlying thoughts” (Lichtman, 2013, p. 143) about their experiences without being constrained (Wengraf, 2001). This type of question was intended to capture and elicit thoughts about the provision of educational support that they may have received for themselves and for their child with autism in education. Further, the sub-questions included participants’ perceptions on the provision of support, diagnosis and of the support provided by professionals in education and from relevant charitable organisations.
The schedule also included questions that related to exploring BME parents’ perceptions in a cultural context and thus enabled most parents to respond to questions that were applicable to their communities. I was able to gather data about these parents’ socio-economic backgrounds by requesting for their address in the first part of the interview schedule. The interviews with these parents were arranged and took place in their homes between June 2010 and April 2011 and each of these interviews lasted for approximately an hour. The focus of questions on parents’ perceptions was further extended to bring in relevant stakeholders’ perceptions in education.

3.5.2 Design of the interview schedules for stakeholder group

It was acknowledged that the design of the interview schedules that were used for both the stakeholder and parent group would be different. The key point here was that the questions within the schedule for the stakeholder group focused on the provision of support rather than the experiences of support. In addition, an important part of data collection within the stakeholder group required that data had to be obtained through elite and non-elite interviews schedules as explained earlier in the chapter. The questions within these schedules were unstructured and semi-structured respectively in its nature.

The interview schedules for the stakeholder group contained two parts, the first part containing closed questions regarding personal details about the background and role of the stakeholder and the second part containing specific questions regarding their views on the provision of support. The second part of the schedule which contained open-ended questions, in turn comprised three sections, firstly, to explain in their own words, details of the support that were provided by them for BME pupils with autism and their families. The second part contained their perceptions on provision of training available to address BME needs in education. The final section of the schedule comprised questions on stakeholders’ perspectives of the range of support and good practice in line with the needs of BME pupils with autism and their families. The questions to each group of participants were broadly categorised within the framework of the research questions that were explored in order to obtain relevant data for the study.

In view of the need to differentiate the two categories of stakeholders, namely the key personnel in education and those from relevant support organisations, the interview schedules were modified accordingly to reflect the differences. Additionally, an elite
interview schedule was administered with three key personnel within the stakeholder group who had expertise and insights within the field of autism. The elite interview schedule contained eight questions which explored the participants’ perceptions of the support that they provide for pupils with autism and particularly in their experiences in relating to BME parents. On completion of the interview schedules for the stakeholder group, the participants were contacted to arrange for interviews that were conducted in their places of work, from September 2010 till October 2011. In order to ensure that the interview schedules would be able to sufficiently capture the required data and also as suggested by researchers (Oppenheim, 2000; May, 2010), both the schedules were piloted.

3.6 Piloting the interview schedules
The interview schedules for both parents and stakeholder groups were piloted in this study in order to ensure that the design of the schedules could be improved if any clarification was needed (Oppenheim, 2000; May, 2010). Piloting can help us not only with,

... wordings of questions but also with, procedural matters such as the design of a letter of introduction and the ordering of question sequences (Oppenheim, 1992, p. 47).

The use of piloting in research is an important validating process in terms of the clarifications and judgments that are made from the findings from the pilot study (Oppenheim, 2000; Bryman, 2006; Denscombe, 2007; May 2010). Hence, piloting the interview schedule aimed to see whether additional questions or changes were necessary to enhance the content of the research instruments and define a more coherent design before the start of the full-scale study (Cohen, Manion and Morrison, 2007; Thomas, 2009; May, 2010). In order to ensure that the interview schedule could be used as an instrument to collect data, the interview schedule that was devised in this study was firstly piloted with one parent from a BME background and secondly with an individual from the stakeholder group.

3.6.1 Piloting the parents’ interview schedule
The original interview schedule used in the pilot contained three parts covering questions relating to the awareness of autism, support at school and support within the community (Appendix 8). There were important lessons learnt from the pilot interview which took place in the participant’s house. One aspect was that it was an interview that I found
difficult to complete because the parent’s son, who had been diagnosed and statemented with autism, was present in the same room. After the first part of the questions within the schedule had been administered and on entering the second part on support at school, the participant’s son, who was also in the room, began to show anxiety. Here, I realized that the timing of the interview should be scheduled when the child is not with the parent at the same time.

Before the pilot interview, I was assured by the parent that his child would not be in the house during the proposed interview period, which was in the early evening. However, a few minutes into the interview, the child was dropped at home by someone else and this took me by surprise. However, I continued and this may not have been an appropriate response on my part as the researcher since it had in fact altered the setting of the interview. Further, at this point in time, when the child entered the room and showed anxiety, I should have stopped the interview and rearranged for another date and left the home. The interview was however abandoned at this stage and, when the participant when contacted after two weeks for a new date, they did not agree to any further meetings.

This experience was an important aspect for ensuring that the process of interviews in the future should avoid similar situations from arising and to ensure that the child would not be in the house during the interview. A suitable time would be when the child was in school and the interview time should preferably be in the morning. This was the important lesson learnt in this pilot study. While this pilot indicated that timing is important in arranging for an interview exploring questions in research of this nature, there were other aspects that arose during the pilot, which also required that I subsequently revised some of the questions in the schedule. These included the adoption of prompts in view of getting the participant to talk more on particular aspects of the questions and thereby encouraging them to talk about their lived experience. These prompts were added after some of the other initial interviews were discussions with the supervisors. It was necessary that this interview schedule, as the principal research instrument in my study, would be able to capture a coherent picture of the difficulties and perceptions of the parents. Therefore, it would be necessary to design an interview schedule that is flexible enough to take into account the changing circumstances that could emerge during the phase of the research. For example, this could be by introducing prompts, skipping questions that may not be relevant for particular participants, and allowing participants to speak freely within the framework of the interview schedule.
It was also noted during the pilot that, although the participant’s first language was Urdu, he could speak English but took longer to phrase the answers in English, since he was thinking in terms of his first language before giving an answer in English. Therefore, I had to explain each question clearly and slowly in order to give some time before the participants answered the questions. It became clear from undertaking the pilot interview that when interviewing BME parents, it may be necessary for me to be prepared to explain the questions further to them. Some of these points were useful in formulating not only the revised interview schedule but also in organizing the actual interviews that would have to be carried out in the study. The relevant changes were then made to the interview schedule and subsequently the parents who agreed to participate were contacted for the interviews with these points in mind. Additionally, with regard to the format of the actual parent interview schedule, it was noted that some questions were generating similar answers, for example reflecting on the same issue more than once. In view of that a few questions in the interview schedule were merged together to form fewer questions in the revised schedule.

3.6.2 Piloting the stakeholder interview schedules

Similarly, a pilot was conducted with a specialist teacher who was the first person to agree to be interviewed from the group representing key personnel in education. This participant had difficulties answering the questions although the questions were explained by me. This was partly because she worked as a specialist teacher on a part-time basis and was not familiar with the broad range of questions and topics covered. She therefore was not able to provide the answers to many questions within the schedule. For example, one set of questions contained within the main schedule comprised aspects relating to the statementing process, support in mainstream schools, support in special schools, another on additional support and one on training needs.

In recognizing this weakness in the schedule, I held discussions with the supervisors and it was then decided that the main schedule needed to be separated out by adapting the questions to the different categories of professionals. It was decided to adapt the main interview schedule to best fit the categories of participants. For example, the teacher in the special school was asked questions relating to support that is provided in that school setting. Thus, useful lessons were learnt on the design of the interview schedule in order
that the data collected through the interviews would be directly relevant to address the research questions.

Following this pilot, some changes were made in relation to clarity of the questions. A number of prompts were included and some changes were made to the interview schedule where questions were merged together so that the questions became more focused. An elite interview format was also developed for three participants who held high positions in authority within the selected LA. As a result of this pilot, it was decided to devise two schedules. The first schedule which was semi-structured was adapted accordingly for key personnel in education and relevant support organisations. The second, a less structured schedule comprising eight questions was designed to specifically elicit the views of individuals who held high positions in authority. The next section explores the basis for the selection of the sampling frame and the sample in the study.

3.7 Sampling frame and sample selection

For this study, the sampling frame had to include participants who would be able, from their involvement in the area of study, to reflect the objective of the research and one which would provide a useful sample for any research. The sampling frame in this study included, firstly, a directory for schools in south Wales which had information on primary, secondary and special schools in three LA areas that could potentially be targeted for the study. These areas were initially selected and identified because of information relating to the demography of BME population in them. The purpose of this sampling frame was therefore to determine the size of the parent group from these communities who had children with autism in these schools. In addition to the directory, another source for identifying a sample of parents was the university tutors at the institution where the research was undertaken, who have close links with partnership schools where trainee teachers are placed for school experience. These tutors had relevant information with regard to possible BME and SEN populations. A third source was from an official in the LA who provided me with a list of names of primary, secondary and special schools with information regarding pupils with SEN.

The technique of the selection of the sample from this sampling frame will be explained before discussing the actual experience that I had in obtaining the sample in this study. Thus, while the initial challenge is to obtain enough for a sample, the approach had to
explore avenues to get sufficient participants for the study to be robust in its findings. The approach was to adopt the purposive sampling approach to select those from the categories that would reflect the purpose of the study. Using this approach, the participants were “hand-picked” for the research, since the method was most likely to produce the most valuable data (Denscombe, 2007, p. 17).

The build-up of the sample was a little difficult throughout the early phase of the study and the research journey was an experiential one. The initial process of recruiting participants involved posting out 200 letters to all primary and special schools within three selected LAs in Wales. Due to the low response from schools, discussions were held with supervisors, following which emails were then sent out to the same schools. In addition, several visits were made to schools although this produced a lower rate of response than that I had hoped for. There were eleven schools which responded to the emails and staff in these schools were followed up by telephone calls to clarify the study sample.

However, some of the staff in these schools were apologetic, giving reasons such as, they could not accommodate me in their school, they were getting ready for the school inspections or the school did not have any pupils from BME backgrounds. It was found that only one school had a pupil with autism who met the study criteria and the parent of the pupil was contacted through the school. It is relevant at this point to note that this parent was used as a pilot interviewee for this study since the parent lived outside the LA which was eventually selected for the study. However, after discussions with the supervisors, it was decided to focus the study within one LA and this was partly due to time and travel costs, together with the fact that local university tutors that I came into contact with were starting to provide contacts with schools in this specific LA.

Since I had difficulty finding suitable parents for the study and as an added approach to increase the numbers, it was also noted that there was another approach, the snowballing technique that could be used in gaining more BME parents to participate in the study. Literature on research methods pointed out that the snowballing technique could be applied and through which more participants are likely to “emerge through a process of reference from one person to the next” (Denscombe, 2007, p. 17). Denscombe (2007) indicated that this technique can be useful for gathering a reasonable sized sample. In addition to the one BME parent who participated as a pilot interviewee, there were three other parents who met the criteria for the study. Following the identification of the three parents, I initially
decided to use the snowballing sampling method. This was because of the expectation that the selected parents would in turn assist in identifying other BME parents in a similar situation.

However, the snowballing technique was not successful in gaining the anticipated numbers of participants since it was found that these parents were not aware of other BME parents of a child with autism. It was found that the four parents, who responded to the invitation, had no contact with anyone else who had a child with the condition and therefore this did not help in the recruitment process. The difficulties experienced in identifying participants highlighted levels of isolation that some of the parents were experiencing. In view of this, the method was not successful in gaining the anticipated number of parents.

Finally, with the support of the LA, a list with names of fourteen schools comprising seven maintained primary schools, three maintained secondary schools and four special schools within the selected LA was obtained. I then contacted the head teachers of these fourteen schools through a formal letter giving information about the study and asking permission to do the research and for the purpose of contacting BME parents who fulfilled the criteria of the study. Following a positive response from these schools with information on the numbers of these pupils, parent information packs were posted to the schools. In some cases I personally handed these information packs to the schools. The information packs included information about the study, a reply slip which requested information such as parent name, address, telephone number and a stamped envelope with my address on it. It was agreed that the school would distribute these information packs to the relevant parents. From the list of schools that was provided by the LA, I received the reply slips from eight BME parents who agreed to participate in the study. In addition, the names of three parents provided with the assistance of the university tutors brought the total of the sample to eleven. The process of sample selection for the study highlights the challenge of conducting research with families who find it difficult to engage with mainstream services.

As stated above, the selection of BME parents were made possible with the help of the university tutors who were based at the university where my research is based and also from the list of schools that were provided by the selected LA. Therefore the recruitment of participants through the use of purposive sampling enabled the inclusion within the study of participants from schools within the selected LA where there were BME pupils
with autism.

The recruitment of key personnel in education, which is the other core group of participants in the study, included specialist staff at school such as the EMAS advisors and health professionals such as the Speech and Language Therapist (SaLT). There were also participants from relevant support organisations who included personnel from the national society, the national charity and parent support groups. The recruitment of stakeholder group was made possible through the advice of the supervisors, the LA staff and through contacts with schools. The fact that I had worked as a teaching assistant within the same LA earlier, helped to re-establish contacts and negotiate access to some schools and personnel.

3.7.1 The BME parents study sample

The sample which was eventually obtained, as shown in Figure 1 below, comprised eleven BME parents.

![Figure 1: The selected BME parent group](image)

The two English mothers were included since their children were of dual heritage origins and therefore were likely to have been influenced or even immersed in BME cultures and languages from a very young age. Therefore, these mothers were included to represent the BME community since they have close knowledge and experiences in relation to the relevant BME communities.
Out of the selected BME parent group, eight of the parents followed Islam as a religion while the remaining three parents followed Christianity. In understanding where these participants came from and the nature of their religion, allowed an insight into the origins on their experiences and perceptions about autism.

All parents had more than one child and each parent had one child statemented with autism except for one parent who had two children statemented with the condition. In total, the children comprised seven boys and five girls. All the children had been diagnosed and statemented with autism by a specialist and their ages ranged between five and eighteen. Seven out of the twelve children attended special school and four children attended mainstream schools that had a resource-based unit attached to them. Finally, one individual who was eighteen years old at the time of the study was in full-time residence. The profile of BME parents is shown in Table 4 below.
Table 4: Profiles of BME parents (The pseudonyms that are used for parents and their children in this table are culturally appropriate)

<table>
<thead>
<tr>
<th>Parent (P)</th>
<th>Mother’s (M) occupation</th>
<th>Father’s (F) occupation</th>
<th>Child/age</th>
<th>Ethnicity</th>
<th>Religion</th>
<th>Severity of child’s condition</th>
<th>Type of school</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1- Lim (M)</td>
<td>home-maker</td>
<td>Spouse-unemployed</td>
<td>Lee (10)</td>
<td>Chinese</td>
<td>Christian</td>
<td>mild</td>
<td>special school (ss)</td>
</tr>
<tr>
<td>P2- Nazia (M)</td>
<td>home-maker</td>
<td>Spouse-doctor (FT)</td>
<td>Ani (8), Ali (5)</td>
<td>Pakistani</td>
<td>Muslim</td>
<td>Ani- (non-verbal), Severe Behavioural Difficulties (SBD) Ali- mild with some behavioural difficulties</td>
<td>Both are in ss</td>
</tr>
<tr>
<td>P3- Mina (M)</td>
<td>teacher (PT)</td>
<td>Spouse-retired businessman</td>
<td>Mahmud (18)</td>
<td>Pakistani</td>
<td>Muslim</td>
<td>SBD</td>
<td>Residential school</td>
</tr>
<tr>
<td>P4- Fante (M)</td>
<td>home-maker</td>
<td>Spouse-Full-time student, employed (PT)</td>
<td>Bini (4)</td>
<td>African</td>
<td>Christian</td>
<td>SBD</td>
<td>ss</td>
</tr>
<tr>
<td>P5- Tammy (M) - Tariq (F)</td>
<td>employed (PT)</td>
<td>Spouse-businessman (FT)</td>
<td>Nina (12)</td>
<td>M-English F-Pakistani</td>
<td>M-Christian F-Muslim</td>
<td>mild</td>
<td>Resource-Based Unit (RBU) in mainstream secondary school (mss)</td>
</tr>
<tr>
<td>P6- Shara (M), Adeo (F)</td>
<td>home-maker</td>
<td>Spouse-unemployed</td>
<td>Adi (5)</td>
<td>Both African</td>
<td>Both Muslim</td>
<td>SBD (non-verbal)</td>
<td>ss</td>
</tr>
<tr>
<td>P7- Anne (M)</td>
<td>employed (PT)</td>
<td>Partner-employed (FT)</td>
<td>Canna (9)</td>
<td>M-English F- Afro-Caribbean</td>
<td>Both Christians</td>
<td>mild</td>
<td>mainstream primary school (mps)</td>
</tr>
<tr>
<td>P8 - Amin (F)</td>
<td>Spouse-home-maker</td>
<td>lecturer (FT)</td>
<td>Yusuf (7)</td>
<td>Pakistani</td>
<td>Muslim</td>
<td>Severe with some behavioural difficulties</td>
<td>RBU in mps (Welsh school)</td>
</tr>
<tr>
<td>P9 - Bibi (M)</td>
<td>Works in a sundry shop (PT)</td>
<td>Partner-employed (PT)</td>
<td>Din (9)</td>
<td>Pakistani</td>
<td>Muslim</td>
<td>SBD</td>
<td>mps</td>
</tr>
<tr>
<td>P10- Riza (M)</td>
<td>home-maker</td>
<td>Spouse-doctor (FT)</td>
<td>Zul (14)</td>
<td>Pakistani</td>
<td>Muslim</td>
<td>SBD</td>
<td>ss</td>
</tr>
<tr>
<td>P11- Jamilla (M)</td>
<td>Radiographer (PT)</td>
<td>Spouse-doctor (FT)</td>
<td>Irwan (15)</td>
<td>Pakistani</td>
<td>Muslim</td>
<td>SBD</td>
<td>ss</td>
</tr>
</tbody>
</table>

Parent-participant by Default anonymised as ‘PPD’ (M) | Charity | Not asked | Not given (10) | White | Christian | Not given | ss |
The parental sample represented a range of socio-economic backgrounds and this was in reference to their occupations and where they lived. A description of BME parents as shown in Appendix 7 show that there were six parents who had settled within the selected LA for at least five to ten years, four parents who have lived in south Wales all their lives and with one having lived in the UK for more than twenty-five years. In all, there were seven parents who were migrants in Wales and the remaining four were children of migrants. It was noted that three of the mothers worked part-time and the rest of them were not in employment, hence the mothers provided majority of the child care. All parents in the study spoke and understood English but spoke their ethnic languages at home with their children and within their communities except for one who spoke English, Welsh, Pakistani, Urdu and Punjabi. Interestingly, this parent, who is from a Pakistani-Punjabi background, identified himself as “Welsh”, having lived in Wales all his life. This is the only parent whose children attend a Welsh medium school and spoke Welsh at home. While some parents were fluent in English, others had just enough of the language to engage with the interviewer and that made it easier for the interpretation of BME parents’ responses. All parents in the study had friends who were mostly from mixed backgrounds.

A description of BME parents is shown in Appendix 7

As a researcher from a BME community, I initially believed that it would be straightforward to obtain my sample but this was found not to be the case. It is necessary to note that during the initial selection phase before the interviews were carried out, some others who might have been in the sample when they were contact indicated that were reluctant to participate. This could have been due to inhibitions that could be linked to aspects of their culture which was also referred to in Perepa’s study (2008).

3.7.2 The stakeholder study sample

In addition to the sample of parents, a sample of individuals who provided educational support to pupils in south Wales was also selected. The selected individuals within the stakeholder group were interviewed since they would have had close contact and a longitudinal understanding of the child’s development in an educational setting. In addition, they would have further understanding of the child’s development through their meetings with parents. The stakeholder sample comprising sixteen participants, were categorized into two groups namely, key personnel in education and relevant support
organisations. A diagram in relation to these groups is shown in Figure 2.

**Figure 2: The selected stakeholder group**

Figure 2 shows the sample of the selected participants from both key personnel in education and relevant charitable support organisations of which the latter group shown in Figure 2 is shaded blue. The information regarding their roles and position is taken from the first part of the interview schedule with regard to personal details and background about participants from the stakeholder group (as shown in Part 1 of Appendix 5).
<table>
<thead>
<tr>
<th>Table 5: Profiles of stakeholders (key personnel in education and relevant support organisations)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>(i) KEY PERSONNEL IN EDUCATION</strong></td>
</tr>
<tr>
<td><strong>Participants’ status</strong></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Teaching Assistant</td>
</tr>
<tr>
<td>Teaching Assistant</td>
</tr>
<tr>
<td>Teacher</td>
</tr>
<tr>
<td>Deputy Head</td>
</tr>
<tr>
<td>Special Educational Needs Co-ordinator</td>
</tr>
<tr>
<td>Specialist Support Teacher</td>
</tr>
<tr>
<td>Specialist Support Teacher</td>
</tr>
<tr>
<td>Local Authority Officer</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
</tr>
<tr>
<td>Ethnic Minority Achievement Service</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>(ii) RELEVANT CHARITABLE SUPPORT ORGANISATIONS</strong></td>
</tr>
<tr>
<td>Executive Officer of a national autism charity</td>
</tr>
<tr>
<td>Project Manager of a national society</td>
</tr>
<tr>
<td>Chairperson of a parent support group</td>
</tr>
<tr>
<td>Developmental Manager (DM) of a parent support group</td>
</tr>
<tr>
<td>Transitional Coordinator (TC) of a national society</td>
</tr>
</tbody>
</table>
The first group consisted of eleven key personnel in education. They comprised one Special Education Needs Co-ordinator (SENCo) at a mainstream primary school and one deputy head of a special school who had a role equivalent to that of a SENCo. There were two specialist teachers in resource-based units in mainstream schools, a teacher in a special school and two teaching assistants, with one based in a resource unit in a mainstream secondary school and the other in a special school. The sample also included a Speech and Language Therapist (SaLT), two Ethnic Minority Achievement Service (EMAS) advisors and a LA manager who was the Head of Achievement for Schools and Lifelong Learning. Unlike staff at school whose daily work is based in the school, the work of these personnel was not always based at the school. For example, they might offer advice to staff at schools and families about assisting children with communication difficulties and language issues. They might also be involved with other professionals in assessing and diagnosing individuals with various difficulties including autism and this work might be in schools or out of schools such as in hospitals or within the communities.

The second group consisted of five representatives from relevant support organisations. This group comprised the Executive Officer (EO) of a national autism charity, a Project Manager (PM) of a national society, two officers from parent support groups and the Transition Co-ordinator (TC) of a national society who is based in London. It is necessary to note and emphasise that in one of the support organisations, which is a charity, the person who was interviewed stated that she was also a parent of a child with autism but from a non-BME background. The interview which is presented later in the study with this person has therefore to be seen from an aspect which reflects upon the person in the organisation. As such, the views of this participant will reveal two roles and therefore the view of this person as a parent has been noted in the study with the need to take into account the ethical rules of this study. The perspective of this person as the parent is provided in this study by the use of the pseudonym, similar to other parents who were chosen for the study. This participant is therefore also a parent-participant by default (PPD) and not by choice and therefore the pseudonym “PPD” is given to this parent.

The following sections discuss the roles of key personnel in education and relevant support organisations that formed the samples within the stakeholder group in this study.
3.7.2.1 Key personnel in education
The role of a SENCo is particularly to work with schools and the children within schools who have SEN (Clarke, 2008). The SENCo is required to work closely with specialist teachers to provide teaching support to mainstream and special school teachers who teach children with SEN (DfES, 2004). It is stated that specialist teachers are also required to work with the SaLT who provides therapy advice that may be implemented to support the school where appropriate, for example, when they offer advice to parents of a child with SEN (Lindsay, Pather and Strang, 2006). One of the selected participants in this study was a Pediatric SaLT and had supported children with autism for eleven years in a number of different schools within the selected LA and therefore could be considered a specialist in the field of autism.

The role of teaching assistants within the primary school setting is to support pupils or groups of pupils who may need extra support to complete tasks in the classroom (O’Sullivan, 2009). Their role includes assisting the teacher in setting up equipment and getting things ready for lessons. Others who were involved in the study included professionals working with the LA. The LA is a local authority in England and Wales that has responsibility for education within their area. It is necessary to note that there was one LA manager within the selected LA who had expertise in the area of SEN. Although this participant did not have a direct role in supporting pupils with autism, this person had oversight of all the processes in relation to the required support for SEN pupils.

Further, the two EMAS advisors who were interviewed worked in partnership with schools and within the selected LA in Wales to raise the attainment of minority ethnic pupils, through training, support and guidance. Their specialism supports children who are learning English as an additional language. Although the EMAS advisors do not have specific training in autism, they have worked with BME pupils with SEN. Another participant within the stakeholder group was also a parent of a child with autism and who offered valuable insights in her role as a parent, although this participant was not from a BME background. For ethical considerations related in this study, the identity of this stakeholder was subsequently made anonymous, since the person also provided information about her experiences as a parent. Further, as a stakeholder, this person was also engaged in supporting other parents in similar situations.
3.7.2.2 Key personnel from relevant support organisations

Within this category, the Executive Officer (EO) of a national charity for autism in Wales was interviewed since his role was to promote and establish high quality services for people with autistic spectrum disorders living in Wales. This interviewee had been the EO for a national charity for ten years and before that he was EO of a regional charity in England. He has had experience working with children with learning disabilities and children with ASD within schools and on hospital wards and therefore is considered an expert with regards to services for autism. Another interviewee was the Project Manager (PM) of a national society who had an important role in the implementation of the ASD Strategic Action Plan under the direction of the relevant local authorities across Wales. He had previously been a Governor at a special school within the selected LA. Both the national autism charity and the national society are funded through voluntary contributions, charity events and also from funding by the government.

In addition, two participants or representatives from two parent support groups (Charity A and Charity B) were interviewed. One participant was the Chairperson of Charity A, a self-funded charity run entirely by parent volunteers of children with special needs but not exclusively autism. The service of Charity A also offers support to the children’s siblings and families. Similarly the other participant was the Development Manager (DM) of another parent support group (Charity B) which offers various support to parents which includes completing the paperwork for proposed statements and in getting parents’ responses to the LA. However, the service of Charity B is not entirely a self-funded charity and it obtains some financial support from individuals, local groups, Trusts and Funding Bodies and also from the selected LA. Both the services offer independent and confidential advice. The above information is drawn from the literature taken from the information material that was provided to me by the interviewees.

The final participant within the support organisation category was the Transition Coordinator (TC) of a national society and who was based in London. The national society is a British charity organisation for people with autistic spectrum disorders (ASD) (NAS, 2006). The TC, who was based in London was selected to participate in the study since the local person from the same national society within the selected LA did not respond to repeated requests for an interview from me and my supervisor. This person was an important participant since the society is a key charity concerned with autism especially
since it provides the Early Bird training which aims to support parents in the period between diagnosis and pre-school placement. The Early Bird programme offers support to parents by providing them with information about autism and appropriate skills in managing their child's difficulties as well as to enable parents to establish good practice in handling their child at an early age.

3.8 Recording and transcribing interviews

All interviews were recorded using a digital audio-recorder and later transcribed word-to-word to provide a full verbatim data including non-word sounds, such as ‘hmm’ and ‘urh’ and pauses and tone of voice which is not possible by taking field notes (Gray, 2004). The advantage of using an audio-recording is that it allows the researcher time to concentrate on the interview process and responses (Bryman, 2004; Willig, 2005). In this regard, the use of a recording device for the interviews ensured that the data description was accurate and transcription could be validated (Robson, 2004).

The notion of a verbatim transcript was criticized by Poland (1995), since it could encourage the belief that, what is said and heard through the tape is the truth, an idea that comes from the positivist paradigm where the truth is a form of unquestioned authority. According to Poland, an interview is a “lived experience” and it is therefore impossible to have a truly “verbatim” account (1995, p. 292). Further, the researcher may often pick up different meanings each time the recorded passage is listened to, when providing an interpretation of the data through just listening and making notes (Robson, 2004). Additionally, when aspects of feelings are expressed through intonation of voices, pauses, signs or laughter, they are not easily translated in writing then there is a tendency that the feelings may be shaped by researcher’s biases (Robson, 2004).

However, Gray (2004) argues that audio recording can assist interpretation as it allows the interviewer to concentrate on the conversation. The author pointed out that the non-verbal gestures by participants can be noted and recorded during the interview, rather than spending time looking down at the notes and writing down what is being said. In this study, I took breaks while transcribing the interviews and this went on for several weeks, and these breaks were useful to reflect so that I was not overburdened.

Another difficulty may be that participants may find the audio-recorder inhibiting and not
wish their conversation to be recorded (Arksey and Knight, 1999; Robson, 2004). In this study, all participants during the interview agreed to the audio-recording, although one participant did let me know that she was a little uncomfortable about the interview being recorded. However, I assured her that everything that was recorded would be kept completely confidential and that she had the right to withdraw at any stage of the interview. Following this assurance, the interview was able to take place and the transcription was carried out. A sample interview transcript of one BME parent’s interview can be found in Appendix 9.

3.9 Analysis of interview

There are different analytical methods within the qualitative paradigm such as, among others, Interpretative Phenomenological Analysis (IPA), Grounded Theory and Thematic Analysis (Braun and Clarke, 2006; Langdridge, 2007). The IPA is a qualitative analytical approach developed specifically for psychological research (Beale, 2007; Lee, 2010; Smith, Flowers and Larkin, 2010) and therefore not adopted in this study. The Grounded Theory (GT), on the other hand, is similar to the IPA method since it is based around developing theoretical insights that explain the findings within the data (Glaser and Strauss, 1967; Strauss and Corbin, 1998). Since GT made use of analysed data to generate a theory which is not the objective in this study, it was not used. Another analytical method, namely, the Thematic Analysis (TA), is similar to the GT, in that, both these methods aim to summarise and organise themes across the data through the process of data coding. However, while the GT aims to develop a theory from the data, the TA seeks to summarise the data but not necessarily with the aim of generating a theory to explain the findings within the data (Boyatzis, 1998; Braun and Clarke, 2006).

Boyatzis (1998) identified two levels used in TA within which themes are identified, namely, at a semantic and latent level. At the semantic level, the themes are identified and provided with clear meanings of the data and not exploring beyond what is said by the participant. In contrast, TA at the latent level goes beyond the semantic level of the data where the identified underlying ideas and broader assumptions are explained and theorised. It is noted that the use of TA typically focuses on one level (Braun and Clarke, 2006) and for this study; interviews were selected as a method to capture the parents’ stories or experiences to confirm with their semantic level of language and knowledge. During the interviews, the selected parents were, from time to time requested to recount specific
situations and to keep within their lived experiences. The interviewer’s lead provided the insight into the semantic knowledge of these parents’ experiences. Therefore, the strength of TA as a method is seen as suitable to address life experiences of these participants’ within an everyday social context since these descriptions are all grounded in reality (Denscombe, 2007; Langdrige, 2007).

However, the use of TA is critiqued by Flick (2009) who stated that the approach can be time consuming. In relation to this study, the time is justified by the rich data it produced and the ability to understand the perceptions of individuals within different communities. Despite the criticism, the TA was selected for this study since it allowed the use of various methods in the design of the research and because it engages the researcher in the analysis of the findings based on the research questions.

The process of analysis in this study adopts Braun and Clarke’s (2006) six phases of analysis. These phases include the researcher familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and finally producing the report. In this study, I began by importing all relevant interview transcripts into the qualitative computer based software, NVivo and organising them into the relevant parent and stakeholder categories. I used the software to facilitate in the reorganisation of the developed codes and categorising them into relevant themes.

The NVivo software is used to preserve interview transcripts and to hold on to the uniqueness of participant’s contribution (Bazeley, 2007). The use of the software was also acknowledged to be able to assist in making qualitative analysis “more accurate, more reliable and more transparent” (Gibbs, 2007, p. 11). In addition, the software allows interview transcripts to be coded, themed, and location of quotations to be saved in various ‘nodes’ or spaces which can be revisited easily at any time (Bazeley, 2007). The software therefore facilitates in producing “a rich and detailed, yet complex account of data” (Braun and Clarke, 2006, p. 78).

Following the importation of data, I read and re read the transcripts to examine and familiarise myself with the data. A list of themes were generated, cross-checked and compared for similarities and differences. This is for the purpose of making sure that the codes which did not emerge again in other interviews were either kept aside to form sub-themes or discarded (Willig, 2005; Johnston, 2006; Arthur et al., 2012). The themes were
later reviewed and modified accordingly until all data was integrated into one summary list to include the experiences and perceptions of the participants. The analysis contained the key themes and sub-themes together with verbatim quotes in view of capturing participants’ voices in this study which were derived from the interviews with them, based on the research questions. A snapshot of a sample of themes and sub-themes coded and contained within NVivo showing the software working sequence is shown in Figure 3 below.

**Figure 3: A snapshot of themes and sub-themes using NVivo**

Figure 3 show ‘parents’ understanding of autism’ and ‘pre-school experience’ as the main themes and containing sub-themes such as among others, past support experiences, acceptance, early suspicion and denial. These are all coded in multiple ‘nodes’ which are storage spaces for ideas (Langdridge, 2007; Bazeley, 2007) and a click on a particular ‘node’ will open up its contents. An example of the contents within the sub-theme ‘acceptance’ is shown in Figure 4 below.
This process of arranging the themes and sub-themes together with the links to the information of the source provides the facility to retrieve the data with ease. The researcher also has the opportunity to link some ideas in a ‘memo’ which is a workspace for storing any emerging data that needs clarification and this storage space is used for the purpose of facilitating the researcher’s thoughts about a particular data (Johnston, 2006).
In terms of its flexibility, it is possible that even after the coding of interviews is completed, NVivo allows the possibility to locate any information about the source and about where a relevant quotation may be located (Bazeley, 2007). This is because information of the source is always preserved in NVivo and thus adding to the transparency of the data management in the research process.

The next section discusses the importance of reliability and validity of the research process within the framework of this study.

### 3.10 Validity and reliability of research

Validity refers to how well research, through the administered instruments, actually measures what it is set out to measure and how well the findings reflect the truth it claims to represent (Robson, 2004). Reliability on the other hand, may be defined in relation to the number of times that a particular set of research findings can be repeated and how accurately these findings would be replicated in an identical piece of research (Joppe, 2000).

Since qualitative research emphasises the importance of validity, Denzin and Lincoln (2011) suggest two ways in which validity can be established by the researcher through the use of triangulation. This is firstly by using data triangulation where data is collected from different contexts or settings and over a period of time. Secondly, through the use of methodological triangulation where the researcher may use more than one method of obtaining information in view of increasing or lending weight to the validity of the findings (Denzin and Lincoln, 2011). In view of exploring the nature of validity in this study, the questions within the semi-structured interview schedule were designed to capture data on participants’ experiences and perceptions and how they have made sense of these experiences (Kvale, 2007; Dillman, 2007).

The data in this qualitative study is captured through the use of digital recordings and subsequently transcribed. While the transcripts of the data are intact in the digital recorder, the interpretation that is provided in this study can be explained by the idea of reflexivity which has been discussed earlier in this chapter. It is also important to recognise that my understanding of the customs of the participants added to the strength of the analysis in this study. This is validated by the fact that all parents interviewed in the study also invited me to contact them again if need be and this comment from parents is reflected in the analysis.
of the transcripts of the interviews.

In research where social phenomena are examined involving people, the question of ethics is invariably raised and this is discussed next.

3.11 Ethical considerations

Ethics may be defined as, “a set of values by which a particular group or community decides to regulate its behaviour in order to distinguish from what is acceptable or what is not, in search of their aims” (May, 2010, p. 41). In view of the need for ethics, this study had to ensure that there was no deception of parents in the purpose of the study, which was made clear to all those who participated. The process of research ethics that was adopted in this study is considered next.

3.11.1 Ethical consent

Prior to the commencement of this study, ethical approval was gained from my University’s Ethics Committee and this permission was in line with the British Educational Research Association guidance (BERA) (2011). Since the data would include confidential information obtained from participants regarding their personal lives, there would have to be a more secure basis that would ensure limited access to this data to only those directly involved in the study.

Further, in relation to the need to ensure proper and secured management of sensitive data from staff at schools about children with autism, I was made aware by an official in the selected LA of the requirement that, I obtain the status of Data Controller issued by the Information Commissioner’s Office (ICO, 2012). This was a legal requirement since I would be handling sensitive data of individuals. In addition, the management of this data had to be identified as being properly controlled. I then applied and obtained this status, for which an annual fee had to be paid, with effect from January 2011 and has been extended as required by the rules of the issuing authority for another year ending January 2015.

An important aspect of ethical consideration was related to the fact that the participants who participated in this study were not the children with autism but rather their parents. Therefore, since I was not exploring the experiences of these children, there was no need to
obtain permission to speak to them. There would have been other issues to consider had I wished to speak to the children themselves and that need did not arise since I only spoke to the parents and service providers in education.

In order to carry out research on a target population, it would be necessary to negotiate access so that the appropriate instrument of data collection can be administered without any objections. A code of ethical practice makes researchers aware of their obligations to their participants and also to areas that could be of concern about what is acceptable (Frankfort-Nachmias and Nachmias, 1996). In view of carrying out the principle of ethics in this study, each participant was required to sign a form consenting to the interview (see Appendix 3).

Following this discussion of ethical consent, the next two sections will consider firstly, the principles of anonymity and confidentiality and secondly, the principles of informed consent and debriefing.

### 3.11.2 Anonymity and confidentiality

The principle of anonymity in research refers to the protection for participants’ identity in research (Wiles et al., 2008). Thus, in ensuring anonymity, names of the participants or any means of personal identification is not used or revealed (Cohen, Manion and Morrison, 2011). The importance of protecting the anonymity of research participants and of keeping research data confidential at all costs is highlighted by Frankfort-Nachmias and Nachmias (1996) and Denscombe (2007).

Within this study, all BME parents were given culturally appropriate pseudonyms which were used on all interview transcripts and throughout the research process. These parents were referred to by the use of culturally appropriate pseudonyms and any features of the transcript which could identify the individual participant were also made anonymous. It was also important to ensure that all selected participants would not be identified in the published analysis. I removed information that might have otherwise made it possible to identify individuals who had participated in this study and therefore ensuring their anonymity.

Similarly, all participants within the stakeholder group were promised anonymity through
suitable abbreviated pseudonyms that were used to refer to them throughout the research process. Additionally, other identifying details were removed such as in this case, the name of the selected area in which the study took place or where the participants reside. The ethical safeguards were also explained to these participants via a consent form (see Appendix 3) that was emailed to them prior to their acceptance of participation. The participants’ rights to privacy were also protected through confidentiality which was outlined in the consent form.

In addition, all audio recordings and the electronically saved interview transcripts that were obtained from the interviews were subsequently protected within my personal web space within the university. Moreover, all printed transcripts were also safely locked away in the premises within the university and electronically protected by a password, not known to others.

3.11.3 Informed consent and debriefing

The principle of informed consent arises from the participants’ right to freedom and choice (Frankfort-Nachmias and Nachmias, 1996; Cohen, Manion and Morrison, 2007, 2011; May, 2010). All participants who participate in research should be aware of their rights in taking part (BERA, 2011). In view of the need for informed consent to be obtained from parents in this study, I sent letters to all parents who were considered to have met the inclusion criteria for participant selection. This was done by hand delivering these letters personally to a member of staff at the selected schools for distribution to the selected parents.

In addition, relevant stakeholders were also sent separate covering letters together with an information sheet and a consent form to explain the purpose of the research and to seek their consent. Prior to the start of the interview, I explained the relevant aspects of ethical consent to both parents and relevant stakeholders in order to assure them of their right to take part in the interview. Within the consent form, the boundaries of confidentiality and anonymity were explained to all participants and they were also reminded of their right to withdraw their consent at any time. This included informing the participants that the findings from the interview would be written up in my thesis. It was also explained orally and in writing to each participant that data would be stored securely and anonymously.
In addition, the process of debriefing was an important consideration within this research. For example, some participants may have had particular feelings raised during or after the interview as a result of talking about their experiences of having a child with autism and this could have caused them significant stress in their lives. I remained sensitive to this during the interview and once the interview had been completed, I asked how the participant had found the experience though they were not directed to any counselling or support services by me.

The timeline showing the sequence of events that took place from the start till the end of this study is shown in Appendix 10.

### 3.12 Conclusion

The research design had to take into account the objectives of the study and therefore influenced the selection and subsequent adoption of the research design and the methodology in this study. A qualitative interpretive case study approach using in-depth interviews for data collection was then made possible for thematic analysis. Within the idea of reflexivity, I had to take into account my BME background since the study also involved parents from BME background which could reflect my bias.

The choice of both case study method and the qualitative method was reinforced by the review of the literature in this field where particular consideration was given to the approaches that were adopted in similar studies in the past (Tams, 1998; Beale, 2007; O’Sullivan, 2009; Perepa, 2008; Lee, 2010). The analysis of the gathered data was based on TA and since the interviews were expected to generate a mass of data, its analysis was facilitated by the use of NVivo software. The interviews with stakeholders had to take into account the nature of their professional background within the education system and therefore required the use of both elite and non-elite interviews.

Prior to the start of the study, it was necessary to ensure that the instruments that were applied were effective in capturing data and to carry out the analysis for the study and which would address the research questions in the study. In order to achieve this, the interview schedule that was administered for both BME and stakeholder participants was subject to a pilot. In order to manage the sensitivity of the data, all required processes and procedures with regard to ethical rules of British Educational Research Association and the
University were strictly adhered to, including being a data controller while the research was being carried out.

The analysis of data will be presented in the next chapter.
Chapter Four

Analysis of data
4.0 Introduction

This chapter presents the analysis of data from the interviews carried out in this study. The analysis relates to two categories of participants, who took part in this study. The categories included, firstly, the Black and Minority Ethnic (BME) parents of a child with autism and, secondly, the stakeholder group comprising key personnel in education and relevant support organisations which provide services for these children and their families. The term ‘stakeholder’ refers to both key personnel in education and relevant support organisations when referring to them as a whole group. For this study, BME parents and their children were given suitable pseudonyms in keeping with their ethnicity so as to give an appropriate identity during the course of the research and the write up.

The data derived from both groups of participants are presented according to the research questions. Based on the research questions, key themes which were derived from the interviews were identified using Thematic Analysis as explained in Chapter three. The chapter will firstly identify and present the analysis from the interviews with parents and then do the same for the stakeholder group and, finally, through the perspectives of both the parent and stakeholder groups, identifying key principles that are relevant for future support of BME pupils with autism and their parents.

Part One

4.1 Research question one

In this study, the first research question which begins with the experiences and perceptions of BME parents is as follows:

What are the experiences and perceptions of BME parents of the support they and their children with autism have received via the education system, relevant support organisations and their families and wider BME community?

Following the interview phase, I obtained the views of BME parents of the educational support that they received from the relevant stakeholders as well as from their families and their communities.
The data analysed in this section refers to interviews with eleven parents who replied to the letter of introduction and who agreed to participate in the study. The sample comprised ten mothers and one father. In two instances, both the mother and father were present during the interview and were, consequently, interviewed together as shown in Figure 1 in the methodology chapter. In addition, the viewpoint of one stakeholder who is also a parent of a child with autism from a White background was included. The voice of this parent participant was captured by default and therefore is given the pseudonym PPD (Parent-Participant by Default). This participant was interviewed as a stakeholder but was also able to provide valuable information as a parent herself. An explanation of this participant is provided in the methodology chapter (explained in page 98).

As explained in the methodology chapter, during the initial selection phase before the interviews were carried out, some parents were reluctant to participate in a formal interview. Therefore, the transcripts examined in this study include only the views of those parents who were willing to participate. Their responses were categorised according to their identification within their ethnicities.

As can be seen from the table, the parental sample represented a range of socio-economic backgrounds and this is seen in reference to their occupations. The analysis explores similarities and differences in the views of BME parents on similar questions. A number of themes which emerged from the interviews with parents were identified, based on the research questions in this study. Since this is a case study, the analysis of the data has been based on a thematic approach. The themes are as follows:

- Pre- and early school experiences’ relates to parents
- Available services from staff in special and mainstream schools
- Support from health services and relevant support organisations outside of education
- Support from their families and wider BME community

The analysis of these themes which include sub-themes within them, are discussed next.
4.2 Pre- and early school experiences’ relates to parents

The first theme relates to parents’ understanding and concerns about autism through a cultural context. In this section, parents’ perceptions of their young children’s initial behavioural indicators of autism were explored. This is followed by parents finding out about their child’s diagnosis of autism and their reactions before their child entered the education system. The analysis of data within this theme reveals parents’ expression of a range of reactions during the early years of their child’s development. It is about parents finding out about the condition of autism before their child entered the education system as well as their experience in schools and their child’s diagnosis of the condition. As part of the interview questions, the parents were invited by me to tell their stories. These stories follow chronologically from the moment they realised that something was not right with their child’s development and everything else which followed in time, not just pre-school.

4.2.1 Expressions of early suspicions

A range of behaviours which led to early suspicions about their child’s developmental progress were referred to by nine parents. These included, among others, speech delay as well as repetitive and ritualistic kinds of behaviour. These parents suspected that something was not right during the early months of their child’s development. For example, Tammy’s daughter, Nina who is of an English-Pakistani mixed heritage, at nine months had “episodes of screaming around about four-thirty in the morning every day … she would scream for several hours” (Tammy, 5/1). Further, in describing her daughter’s mannerisms during playtime, Tammy said,

She didn’t so mix with other children. She would play and they would be around but she never complained if they took something of hers, she just waits, you know. That’s not normal isn’t it? Usually a baby would scream if somebody takes something off them (Tammy, 5/1).

Similarly, three parents, Mina, Nazia, and Bibi, all of whom were from Pakistani backgrounds suspected that something was not right with the behaviour of their children at around thirteen to eighteen months. For example, Nazia described her son, Ali, as being obsessed with the spinning of objects like wheels.

However, it was different for one parent, Amin, who was also from a Pakistani background since when his son Yusuf went to nursery, “the teachers noticed that he was parallel
playing which is their term for kids not playing with anybody else” (Amin, 8/1). Another parent Riza however recollected moments in the past when she came to terms with her son’s autism following his diagnosis. At this point, it is necessary to note that the spouses of Nazia and Riza are doctors and therefore they may have more understanding about the condition and about providing for their child at home.

4.2.2 Reactions to diagnosis

After realising that something was different, the most common reactions expressed by seven parents in this study was that of denial or the refusal to believe and accept their child’s condition. An example of one parent who went through a difficult phase was Shara, who is from Sudan, a country in north Africa. She said,

I took him (her child) to the doctor there (in Sudan) but the doctor said it is normal. He also said that some children talk early and some don’t. He was only two years old then (Shara, 6/1).

According to Shara, the doctor in Sudan was not helpful since he was not aware of autism and therefore she decided to return home to the UK. Shara also said that, on her return to Wales, she phoned and let her Health Visitor (HV) know that something was not right with her child. However she said that her HV did not believe her. She subsequently met her regular General Practitioner (GP) who, she said, gave her advice on her child’s condition.

In addition, Shara’s spouse, Adeo, said “I don’t want to know” (Adeo, 6/46) which means that he did not want or could not face up to his child’s condition and therefore was in denial on his part. This view of Adeo was similar to another parent, Anne, who felt the same way. Nazia spoke about the lack of physical signs in autism. Like Adeo, Nazia also believed that their children would get better with age. There were others who found it difficult to accept the initial diagnosis that was given to their children, although they later accepted it.

In this study, eight parents stated that diagnosis was made by the paediatrician or consultant, except for two who stated that it was through the local GP. In one instance the staff at school recognised the condition of the child and advised the parent on how to proceed to the diagnosis process through other professionals. In relation to the time it took to make the diagnosis, while eight parents stated that it took six months to a year, one said
that it took only six weeks. Further, it took four years for Riza and eight years for Mina to obtain a diagnosis for their children. It is useful to note that the ages of the children of these two parents, at the time of the study was fourteen and eighteen and as such these parents were recounting their memories of the diagnosis, at a time which was further away from the event and experiences than the others.

4.2.3 Isolation

The denial and refusal to accept their child’s condition initially led to ten parents feeling isolated since they believed that they were the only parents of a child with autism. The couple as parents, Adeo and Shara, who were mentioned earlier said that the delay in obtaining a diagnosis for their child could have been due to the low level of awareness of autism by professionals. This in turn led them to feel isolated. The couple also stated that they experienced delay in waiting for professional assistance after diagnosis in Wales, which, on average, was at least six months to a year. In addition, although all parents stated that diagnosis was explained in English, Adeo and Shara said that they were not offered interpreters. These parents said that if they had the presence of interpreters during the diagnosis, they would have better understood their child’s condition.

Similarly, Lim who is from a Chinese background, stated that the diagnosis of their son’s condition was given in English and that she and her spouse were not offered interpreters. Lim stated that she could speak English while her spouse did not and therefore the diagnosis was clear only to her. She went on to state that it would have been better if an interpreter had been present to explain the diagnosis process to her spouse who did not speak the language. In addition, eight parents stated that the diagnosis process was not seen as helpful since they did not fully understand the condition of autism. However, four parents, Nazia, Mina, Tammy and Anne said that they felt relieved after their children were given a diagnosis for their condition because these parents knew that there would be some support available for them. For example, Tammy, said,

Relief, I was relieved because there was some help there (Tammy, 5/11).
4.2.4 Grief, acceptance, worry and hope about the future

Linked to thoughts about denial, some parents expressed feelings of sadness and anxiety and not knowing which way to turn. Nine parents, when interviewed, expressed feelings of grief after their child was diagnosed with autism, while the other two felt that they were in denial. Expressing her sadness, Jamilla said,

> At the end of the first day at the nursery, the nursery teacher said to me if she could have a word with me. I knew ... but I was hoping that they would say something like he’s got hearing difficulty. He wasn’t stringing sentences at 3. He had a lot of single words. It was a sort of a pattern you would see in deaf children … for me it was like something had died. That was badly wrong and it wasn’t going to be right (Jamilla, 11/1).

Jamilla was visibly emotional during the interview and this could be detected through her voice. Jamilla also mentioned that her father had died two days after her son was diagnosed with autism and that instead of grieving her father’s death, she was grieving for her son, hence, her sadness.

There is a natural tendency for any parent of a child with autism to be worried about what would happen to their child when they are no longer there to care for them (Evans, 2011). Ten parents in the study stated that they were worried about their child’s future. Mina’s worry was about her eighteen year old son, Mahmud, who also had the condition of autism and what would happen to him when they were no longer there to care for them. It was noted that Mina’s spouse had experienced a heart attack while caring for their son at home. Similarly, in the cases of Tammy and Riza, concerns and worry about their children’s future affected their own health.

Amin’s worry was in relation to whether his other children would take care of their brother with the condition. Amin was also concerned about whether his son would be able to live independently and who would be there for his son when he and his spouse were no longer there to care for their son. He said,

> … they don’t look after him, they don’t have the maternal feeling towards him. I realise that Yusuf may have to stay with me slightly longer. Well I hope that he will become independent … away and independent (Amin, 8/46).
Amin suggested that he looked after his own health since “I want to be there for him” (Amin, 8/46). Similarly, concerns of worry were raised by Anne who is from an English background. Her concerns were in relation to her own age and how her child was going to cope in adulthood without her.

However, in the case of Shara’s spouse Adeo, his thoughts about his young son’s behaviour was that “he was just naughty” (Adeo, 6/5) and due to this held thought, Adeo said, “I never worry because … I think he will get better (Adeo, 6/46). But his wife Shara’s main concern was about how her own community would react to the disability.

In Tammy’s case, she felt that she needed to focus on her child’s ability to live independently, rather than think about her child’s educational qualifications. She said that she wanted her daughter to be able to use “public transport, look after herself, wash herself and prepare food for herself” (Tammy, 5/46). Tammy’s spouse, on the other hand, felt that since there was good provision of service from professionals, they had not been hindered due to the fact that their child was from a mixed heritage. In response to her spouse’s comment, Tammy added that their positive experience may be due to their education and their ability to speak English.

There were also difficulties in getting appropriate support for their child. Although there was assistance from professionals and carers, one parent, Mina, felt that this assistance did not help her son. She said,

I feel that he’s eighteen now and he hasn’t developed the skills he needed for his teenage years. I feel that all agencies who work around it have benefitted and Mahmud is the only one who has not benefitted (Mina, 3/46).

Mina felt that all the professionals who worked with her son Mahmud benefitted since they had an insight into autism through their experience with Mahmud. According to Mina, the experience for her son was not the same since she felt that all services provided by professionals such as GPs and Health Visitors did not help her son.

From the interviews it became evident that most of these parents went through many difficult phases in their lives and tried to make sense of their child’s condition. One parent, Amin, in reflecting on his experiences said,
You have your own intuitive understanding of what’s happened to him. … you go through phases of anger, pain, denial and then acceptance or whatever it is, we went through all that … and look for the miracle cures (Amin, 8/21).

Amin’s perception was that the experiences of parents appear to be cyclic in nature. Amin also pointed out that he was aware that there are individuals with autism who have developed ways of coping with their condition throughout their lives.

In order to highlight the lived experiences of parents, it is also useful to refer to the perceptions of some parents who expressed positive aspects as well as taking into account less favourable instances regarding their child. Within the sample, six out of eleven parents gave examples of their child’s strengths such as those in relation to the child’s ability to remember and recollect past events, a talent in painting, in music and in their ability to use computers. However, there were five parents who mentioned less favourable behaviours saying that their children liked to roam around, spin everything that they come into contact with and often enjoyed only speaking to themselves. These examples as cited by the parents show that they were very familiar with the characteristics of their child’s condition.

4.3 Available services from staff in special and mainstream schools

The second theme reveals the perceptions of parents about what support they receive for their child from staff at various schools. The data that is presented shows parents’ perceptions of staff at various schools, some of who were seen as inexperienced in supporting pupils with autism. The theme, relates to the available support and resources in education for parents and their child with autism which also includes parents’ concern about transition and their relationship with the school and the local authority. These parents also felt that there was better support in special schools and although they initially wanted their children to go to mainstream schools, they were quite critical of the support there.
4.3.1 Parents’ perception about the support they receive from staff at school

On the whole, parents were generally positive about the help that their children received in the school environment. One parent said that the support that she received for her son in the early stages of his education was,

… quite fab, he has had support ever since play group (Bibi, 9/14, 15).

However, there were mixed views regarding the role of professionals in mainstream nursery school. In this case, Tammy said,

The lady who used to support her, the one-to-one support that they employed had no experience at that time but she was brilliant (Tammy, 5/1).

It appears that Tammy had someone supporting her child whom she felt was doing a good job, even though in her view the person lacked experience and specialist training.

In another instance, a parent in a mainstream primary school said that although “her child was different there was no support teacher for her there” (Anne, 7/6). This parent stated that she wanted to meet other parents because she felt “pretty isolated” (Anne, 7/10) and because of this, started the first support group for parents of a child with autism, at the school.

In Riza’s case, staff at her son’s school told her that “she should just be a mum to her son” (Riza, 10/6) which in her view was not helpful. Similarly, Adeo stated that the earlier mainstream nursery school that his son attended,

… don’t have facilities and don’t have qualified teachers who can do that job (Adeo, 6/1).

The use of the term “qualified” may be associated with teachers who may be inexperienced in supporting pupils with autism within the classroom.

There was evidence from Amin who felt anger in the way staff at a Welsh medium primary school cared for his son in the reception class. He said,
They couldn’t cope with him and from what I learnt was they had legally to keep him there unless we ask for him to be removed. I got the distinct impression that they didn’t want him there and because they were overwhelmed or didn’t know what to do. And the thing that the teacher said to me is that, “I’m happy to leave him in the corner, playing with water all day” but I’m not sure how beneficial it is to him (Amin, 8/1).

Since he felt so strongly about his experience with staff, Amin decided to find another school which was equipped with resources for his son. He said that he took his child out of one Welsh medium school within the selected Local Authority (LA) into another Welsh medium school within the same LA in Wales and that he was pleased with the staff at the chosen school.

It was different for Mina as she was expecting the head teacher of the mainstream primary school that her son attended, to go further to explain and educate her family about her son’s condition. Mina felt that an explanation was needed for her family, since it was they who were involved in providing care for her son, Mahmud, at home. Therefore she wanted her family to be aware of his condition so that they could better support his condition.

Further, in reflecting on an earlier experience when her son was in another primary mainstream school, Mina said that her son was quiet and did not speak much in school, and this ‘quiet’ (Mina, 3/1) trait was interpreted by staff at the school as being related to his culture. She further said,

Mahmud needs to go to a special school because the school (a mainstream primary school) did not have the resource and funding. So they (staff) said that he needs to get one-to-one in XXX (special school) and … teachers there are a lot more experienced and they are special educational needs teachers and that Mahmud would gain more there (Mina, 3/23).

Another parent was of the opinion that the demanding behaviour of her child appeared to have created difficulties at school. She said that she did not like the teacher’s attitude since the teacher made her feel that her child had been a “nuisance” (Fante, 4/6). According to this parent, the teacher said,
Oh, Bini has been screaming and she has been upsetting the other kids (Fante, 4/6).

Fante said that she felt uncertain about whether the teacher was aware of her child’s unique behaviour as a special need. She further added that teachers should be able to understand how children may behave, given that they may have special needs. Similar feelings about the quality of support from staff at school were also expressed by Anne, when she said,

I would like more help … and get staff that were not trained in autism to understand what it may feel like to be autistic so that they may appreciate the anxiety (Anne, 7/31).

Anne in stating her view said that it is likely that a child with autism will be looked after with care only where there are staff who are able and experienced.

With regard to support in special schools, there was one parent who felt that there was more resource and support in these schools. Evidence for this came from Lim who said,

I can see the other people in mainstream, they don’t get much support like resources, I still think my boy is better in special school (Lim, 1/23)

While eight parents were of the view that staff at various mainstream schools are not experienced in supporting pupils with autism within the classroom. There were three parents who said otherwise. Evidence for this came from Anne who said,

… she’s (her daughter) in mainstream in XXX (name of primary school) and I think that it has been okay (Anne, 7/1).

Another parent referred to the support in a mainstream primary school as, “quite fab” (Bibi, 9/14).

Similarly, Amin whose child attended a Welsh medium school, said,

I’m very happy with his teachers … the level of the teaching is very good (Amin, 8/2).
Although Amin did not initially receive good support for his son in a Welsh medium mainstream school, his experience was different when he moved his son from this school to another Welsh medium mainstream school within the same LA.

### 4.3.2 Choice of educational setting

A question on the choice of school was asked during the interviews which included choice of mainstream, special school or a specialised unit within mainstream (the latter was not always available). Five parents stated that they just accepted the school that was offered to their child since they felt that they did not know any better. Another three parents whose children were much older than the rest of the children, said that earlier in time when their children were younger, there was not much information about autism and therefore no available support for autism. Of the three, when referring to the choice of school, one parent, whose son went to a special school, in the interview, blamed the education system for not giving her a choice of school for her son. She said,

> Even though Mahmud had a bit of behaviour ..., I think he would still be able to cope in a special unit in mainstream and this choice wasn’t actually given to us (Mina, 3/29).

Mina’s view was that due to her son’s behavioural difficulties, his health deteriorated and he stopped going to the special school. She added that Mahmud’s self-hygiene was worrying and he did not want or was not responding to any carers who were “coming to our house” (Mina, 3/30). Mina also said that her son’s carers were not able to cope with his condition since they did not have much understanding of autism. She believed that if her son had been given the choice of a special unit in mainstream school, he would have coped better.

There were three parents who said that there was choice of support for their child, although they indicated that they had to “fight” for the support that they wanted for their child (Lim, 1/22; Tammy, 5/12; Amin, 8/22). One parent even went on to say that she had to “fight” the system which in her view was very demanding (Lim, 1/22). In saying this, the parent appears to be aware of the legal process in education where appeals could be made to the SEN Tribunals if they are not happy with the choice of support that is offered to their child by the LA.
Similarly, Tammy whose daughter transferred from a special primary school to a resource base unit in a mainstream secondary school, said,

XXX (unit in mainstream secondary school) was a better environment but they didn’t have support in the classroom and Nina would have had to walk from the resource unit to a classroom on her own (Tammy, 5/1).

Tammy was unhappy that her daughter did not get adequate support while she was at the resource base unit and therefore felt that the school did not meet her daughter’s needs.

One parent’s concern was about finding a place in a special school for her two children when they moved from England to Wales. Nazia said that her two children with autism, had difficulties in gaining placements in a special school in the selected LA in Wales. She stated that her three year old daughter, Ani was already attending a special school in England and after moving to Wales, she was told by professionals in education that Ani had to be assessed for a second time. Nazia said that she was advised by professionals in Wales that after the assessment procedures, she would be able to send her child to any special school of her choice. However, according to this parent, the procedures took about three to four months and during this time, her daughter lost almost half a year and a placement in a mainstream school was given to her when she was five.

With regard to choice of provision of support services, seven out of eleven parents stated that they simply accepted what was provided for their child after they were diagnosed and statemented with autism. The seven parents stated that they did not have much choice and that they did not know what was available then for their child. There were four parents, namely, Tammy, Mina, Lim and Amin who said that they were ready to make the effort to try to improve the support given to their children. For example, Lim, in ‘fighting’ the system to get the preferred choice of school for her son, said,

… if you don’t agree we have to fight and say that I’m not happy. I have to pick up the phone to the local authority …. We have to take the information and phone the people and ask (Lim, 1/22).

Lim uses the term “fight” to mean that she had to express her opinion to those who provide services for autism. She also said that if a parent is unable to voice their concerns then
they may not be able to obtain the relevant support for their child. She also added that she found this “fight” very stressful.

Shara and her spouse Adeo spoke of their frequent requests for a special school placement for their child of which they were refused by professionals in education. Shara referred to the responses by the professionals as “bad times” (Shara, 6/1). There were also some parents who highlighted certain aspects of support that they had received over a decade ago. According to them, there were not many services to support their children at that time, compared to the present when more support is available.

Reflecting upon her past experiences, Mina felt that her son with the condition would have acquired more skills “if I’d have received help for Mahmud” (Mina, 3/31) earlier in time. In view of her son’s experience, she said, “I think help from the residential care should be there from the age of 8 and 10” (Mina, 3/31). She felt that residential care should be made available in good time for those who may need it. Similar feelings were shared by Amin, Tammy and Jamilla who hoped that their children would, in the future, be able to go to residential schools where they would be taught life skills to lead an independent life.

4.3.3 Specific additional support

There were six parents who spoke about the specific additional support that is available for their child in and out of school. In one case, Lim stated that she had visits by the Health Visitor (HV), the Speech and Language Therapist, an Educational Psychologist (EP) and from carers. However, she mentioned that when her son got a placement in a special school these visits by professionals became less with time. This may be because special schools have their own provision of specialist support within its own system. Riza, on the other hand, had a team of tutors to assist her son in using the Applied Behavioural Analysis (ABA) approach to teach social and behavioural skills since she could afford to pay for the private service herself. Three other parents relied on the HV to get answers related to questions on professional services.

Majority of the parents were appreciative of the school transport that was provided and paid by the LA for their children and of the support that they received from the social workers. According to these parents, the service by LA allowed some relief for them as carers of their child. However, Tammy’s experience of transport provided for her daughter
was different. While she spoke about her daughter’s good experiences, she also referred to
the difficult times that her daughter experienced with drivers from Asian-Muslim
backgrounds who were assigned for her daughter by the LA to take her to and from school
for a year. Tammy said, “most of the drivers have built good relationships with her
(Tammy’s daughter Nina) and she’d tell them where to go” (Tammy, 5/28). She said,

… we had this group of, Muslim men who ... had no experience
and used to tell her to be quiet because she tend to talk too much.
And they were always late and this really caused Nina a lot of
problems. Urh … (pause) the lateness had become a real issue
because the school had started before she got there (Tammy, 5/28).

Tammy particularly felt that the drivers, who were from an ethnic background similar to
Nina, did not understand the special need of her child.

Additionally, Lim said that she initially experienced some difficulty in arranging for the
transport due to her difficulties in communicating with the LA. She said that she
experienced stress due to her son’s anxiety that was caused, for example in one instance,
when she decided to take a detour so that her son would not be late for school. With regard
to specific additional support, five parents mentioned that they were assisted by
professionals such as the Paediatrician, Educational Psychologist, Occupational Therapist,
Child Psychologist and Speech and Language Therapist (SaLT). However, there were
three parents who said that they would have liked more support from the SaLT since they
felt that these professionals would have helped their children with their speech and
communication.

4.3.4 Concerns about transition
The experience of parents of their concerns in relation to transition, which happens when
the child moves from various phases in education, are presented in this section. For pupils
with autism, the term transition could involve a number of instances, such as, leaving home
to go to school, when moving from one classroom to another or when moving from one
school to another. The move may cover a period of time when a pupil may be transferred
from one place to another. For example, the transfer could be from home to nursery,
nursery to primary school or primary to secondary school.
In the case of Jamilla, she said that her son was anxious, confused and unsure of what was going on in relation to the changes that were taking place. She said that he initially attended a mainstream nursery school where he was statemented with autism and then went on to be transferred to a special school. She further added that the special school that her son attended specifically catered for children with autism and therefore had appropriate resources for its pupils. In comparison, she said that although the mainstream school catered for pupils with various disabilities, it did not cater for pupils with autism and this therefore was unsettling for her child.

When referring to transition from home to school for the first time, Tammy said,

That was a tremendous ordeal, to get her to school because she was kicking, screaming, grabbing … didn’t want to be left there but again it was a really good thing when we did because eventually it went from fifteen minutes … I would leave her … then half an hour and we built it up to the full session over the period of the year so that when she went to the primary school nursery, they were able to take her (Tammy, 5.1).

Tammy experienced difficulties earlier in settling her daughter at nursery school but succeeded in this early transition from home to school, through her perseverance. Here the parent appeared to differentiate between different educational settings as her child went through nursery, primary and then to special school and then to a unit for children with autism that is based in a secondary school. Another more difficult phase of transition was with regard to growing up. Tammy said that there were concerns when her daughter went through puberty since behaviours may often become increasingly difficult to cope or handle for parents at those times. She said,

I mean, Nina had recently some increasing behaviours. Obviously, she’s going through transition, she’s going through puberty. So, I obviously don’t want to have issues over her behaviours (Tammy, 5.29).

Transition takes on another meaning here and it is not about moving school but rather the concerns about the child growing up and entering the phase of puberty. Tammy’s view was that she was not ready to face the typical changes around puberty. This may be for the reason that parents of a child with autism may find it difficult to explain to their child about the typical developmental changes that their child may go through during puberty.
Tammy gave another view of transition, this time linking it to the attitudes of professionals in education. She felt that there were difficulties in communicating with people about transition, for example those in the LA. In revealing that it was not easy to talk to LA personnel, Tammy said,

The people who I struggle with are the education authorities, to get them to communicate with you. I feel that the school had felt that Nina should have come out of XXX (special school) years before she did. She was ready for transfer into mainstream, in support units like, two or three years before she left and because they (the LA) didn’t allow that, I think that it affected Nina’s development (Tammy, 5/1).

Tammy stated that there was initial support for her daughter’s transfer to mainstream school from staff at the special school that her daughter attended. She also stated that when the LA did not approve of this transfer, the staff at the special school were found to be supporting the LA in their decision.

For Mina, the transfer from one educational setting to another became more difficult for her son when he moved from nursery to reception in the same mainstream primary school. She said,

I think things started to get a bit difficult because he went with 32 other kids. It was a big class and I think that the teacher identified that Mahmud was not coping in a big class. And it was not working for him and an instruction was not enough for him to make him understand things. I mean, at that time there was no concept of picture instructions or pictorial kind of instructions so Mahmud was finding it difficult (Mina, 3/1).

In explaining the above quote, Mina in saying that “an instruction was not enough” meant that her son needed visual instructions which were not available in mainstream school when he was younger.

The Parent Participant by Default (PD), a parent within the stakeholder category and from a non-BME background, who was also interviewed, confirmed feelings of anxiety or difficulty for children with autism during transition. This parent was selected by default because she came forward willingly to speak in an additional role of her experiences as a parents herself. I have also acknowledged in this study that she is not from a BME
background but she has valuable insight as a parent. She gave an example of when her son with autism, experienced delay in transfer from a special school at primary level to a resource-based unit within a mainstream secondary school. She said,

So the children who were meant to be going to XXX (name of secondary school) had a melt-down when we told them that they had to stay at XXX (name of special school) for another year. The children really struggle with change and when I asked my son if he was worried about September, he said, “yes” (PPD, 16/5).

The anxiety during times of transition is evident among children with autism as well as for their parents. In this case, the parent is herself a carer and also experienced in supporting other parents in similar situations.

4.4 Support from health services and relevant charitable organisations outside of education

The third theme incorporates the available support provided by charities including parent support groups for BME pupils with autism and their families and professional awareness of autism. It highlights BME parents’ perceptions of the role of charitable organisations, the support that the health service and social workers provide for their child with the condition. The key personnel from charitable organisations in this study include those from the national charity and society, the parent support groups, Charity A which is self-funded with some support from the government and Charity B, which receives part of its funding from the LA.

4.4.1 Sources of information on support

It is noteworthy that all parents in this study, including those who had comparatively little English, began to search for information when they first became suspicious that something was not right with their child’s development. Parents’ search for information included scanning the internet for information, seeking those who provided respite care, as well as reading up information that was available through books and flyers. It is also noted that medical professionals gave guidance on financial matters related to their child’s care needs.

When referring to health service in the UK, the practice is usually for GPs to refer the family to a Health Visitor (HV). There were four parents who phoned their HV and told
them that something was wrong with their child but they said that their HV did not believe them initially. However, these parents said that their HV later directed them towards available resources. Additionally, eight of the eleven parents found out about support that was available through a national society, from their HV, through the internet or from parent support groups.

In Amin’s case, it was also mentioned that it was the HV who gave him information on available benefits such as Disability Living Allowance (DLA) and family tax credits which he found helpful. As for Anne, she said that she received this information from her HV. However, with regard to family tax credit, she said, “I found this help accidently about this money support. It comes in dribs and drabs and I got better in asking for help” (Anne, 7/16).

When parents were asked from where they obtained information about autism, one parent said,

Yes, I do use the internet for information about autism and other disabilities. I’ve got a load of experience now (Nazia, 2/40).

With regard to receiving support, Anne stated that she received help from her HV who she regarded as the ‘real key’ (Anne, 7/15) since it was from the advice of the HV that she was able to get substantial help for her child. According to her, the help included a carer to take her child out for a couple of hours and thus giving her some time for herself.

However, Tammy said that her visits to her GP did get her somewhere. She said,

I kept going back and pestering my GP and then one day I broke down and cried (Tammy, 5/1).

As a result of this, the parent stated that she received a range of support for her child.

In terms of understanding the needs of children with autism among medical practitioners, some parents suggested that their responses are often not appropriate. In one case, the parent’s view was that when she went to see the GP who was their family friend about her son’s condition, the GP told her, “I was the mad one and not my child, and not to pursue it anymore” (Jamilla, 11/6). Similar experiences were revealed by Riza when she told her
GP that her son “keeps grinding his teeth when he’s sleeping” (Riza, 10/7). Riza then said that the GP told her to take him to the dentist and this upset her because he didn’t think that it was a sensory issue. Riza added, “So the medical field to me was completely oblivious as far as I’m concerned” (Riza, 10/7). This particular instance is a negative view of the medical professionals.

4.4.2 Specific information and support provided by charity organisations

Sources of information are available for parents of children with autism in Wales by various organisations which include charitable organisations such as the national society and parent support groups such as Charities A and B (as shown in Table 5). In all, ten parents said that they benefitted from the information that they gathered from the national society except for one participant who said she knew that the national society existed but did not seek any information from them.

There were four parents, namely Lim, Tammy, Amin and Jamilla, who attended and found the Early Bird training programme which was provided by the national society, very helpful and beneficial. According to these parents, the training programme provided them with information about autism and helped them understand how to deal with their child’s specific difficulties. For example, Tammy, found the Early Bird programme helpful since it gave her the confidence in supporting her daughter’s social communication as well as her difficult behaviours. She pointed out that her daughter is also being supported by her carer who is engaging her in various activities and life skills and that her daughter is “learning to catch the bus now with the carer” (Tammy, 5/25).

Lim, when stating her concern about the language in which the information was shared, mentioned that, although there is help from the national society in the form of information materials in English and in the Welsh language, it did not mean much to her. According to Lim, her spouse did not speak English or Welsh and therefore was unable to read material in these languages concerning the condition.

A different experience was expressed by Mina who said that the national society did not provide her with any other support except for some leaflets which the society produced and which were passed to her by her social worker. She said,
I think the XXX (national society) haven’t got the funding and resources to help us. They say a lot but nothing happens … but they have good information and are a good organisation” (Mina, 3/42).

With regard to the support from the national society, Jamila said, “I got a lot of information from the society’s website right in the beginning” (Jamilla, 11/41). She has a lot of information leaflets from them which she thought were really good, but apart from these leaflets, nothing else was accessed. Her spouse is a medical doctor and therefore she said that she was aware of the needs of their child and would have gone to other sources for more information had she needed to.

Tammy said that in the past, she had been involved with a parent support group (Charity A) which offered parents support but she did not find it useful. In contrast, Amin and Bibi found ‘Charity A’ useful. Amin said,

> My son goes every week and we meet parents, it’s a mixture of parents. We see a lot of kids with autistic spectrum disorder. His sisters and brother come along too (Amin, 8/14).

Bibi was also appreciative of ‘Charity A’ since she felt that she was able to share her feelings with other parents with similar experiences. According to her, the charity arrange activities for parents and children with autism and other special needs and this was seen as helpful to her. Similarly, Fante who also had a positive experience about the charity, said,

> I think XXX (Charity A), the parent support group, they are wonderful. I don’t think they have any office but they have a range of activities and they do have programmes with mother and child and sometimes with just the mother (Fante, 4/34).

Fante suggested that the support that was provided by the charity had a variety of activities for the family and this, in her view, was seen as helpful.

The experience of the PPD from a charitable support organisation who is also a parent of a child with autism and who is from a non-BME background appears to confirm feelings of isolation expressed by parents. This participant, in referring to meetings in the organisation said,
I know how it feels, I’ve been there and I felt alone, scared, isolated and especially with the summer holiday coming now, it’s actually a lifeline. It helps you to survive those summer holidays without feeling alone and scared because to go out with your child, especially when they are like this really. You end up meeting people who become your friends and would be your friends for life because they understand how it feels (PPD, 16/1).

The above view shows that experiences of parents of children with autism are often similar regardless of ethnicity.

Tammy in speaking about another parent group (Charity B) said,

    Obviously, I had to get involved with XXX (Charity B) and push for her to be statemented (Tammy, 5/1).

According to Tammy, she found the parent support group (Charity B) helpful since it was this charity that led to the child being given a statement for autism. It is evident in her case that she was aware of this support group and knew how to get in touch with them when they first suspected the condition in their child. While three parents found support group meetings helpful there were eight parents who did not. These parents were generally aware of meetings but they had their reservations about taking part in such gatherings. The concerns of these parents were with regard to venue and time. For example, one parent said,

    At XXX (a special school) they don’t have a parent group or a child group that I can access because it’s always in a pub, quite late on whereas in XXX (another special school), we did it on Tuesday mornings in school and I can’t do that for various reasons. Firstly, I don’t really want to be in a pub and secondly, the timing of it (Jamilla, 11/21).

Jamilla explained that according to her religion, it would not be appropriate for a Muslim woman to be in an environment such as a pub or to be seen out of her home in the later hours of the evening. It should be noted that majority of these parents were from a Muslim background and that places such as the pub are not accepted venues, particularly for the women within this community.
4.4.3 Concerns specific to language and ethnicity

A specific concern that emerged from the interviews with one parent was their search for information about autism in a language that they could understand. It is interesting to note that when Lim and her spouse decided to quit their jobs and look after their son with autism, they found that there was no literature about autism in her Cantonese Chinese dialect. Lim said that her spouse found it difficult since he could not speak English. She said,

For me it is easier but for my husband who doesn’t speak English, he is in the dark (Lim, 1/42).

Lim explained that since she could speak and understand English, she was able to obtain some information for herself, unlike her spouse who found the language a barrier. Lim in stating her concern mentioned that although there is help from the national society in the form of information materials in English and the Welsh language, it did not affect her since she spoke English. Further, Lim’s perception was that there appears to be no information on autism in her native language at the Chinese Church that she and her family attended and she regarded this as rather unfortunate.

On the other hand, one parent who could speak and understand English, Punjabi and Welsh, chose to send his son who had autism to the same Welsh school that his other children attended. With regard to his family’s ability to speak several languages, he said,

It’s a major topic of conversation that comes up every year when at the end of the year and we always think, shall we take him to an English medium? (Amin, 8/24)

In their experience, Amin and his spouse had found that the Welsh medium schools had better facilities to offer to his son than the English medium schools.

When parents were asked if they had the opportunity to talk with other parents and teachers about the support that their child received at school, all eleven parents mentioned that there was some provision of services such as ‘coffee mornings’ at school and ‘parents’ evening’ which took place after school. Although these services were available, not all parents took up these opportunities. For example Tammy commented,
I haven’t made good use of the coffee mornings. … because I work full-time, I tend not to go to all the coffee mornings (Tammy, 5/33).

Tammy’s reason for not taking up these opportunities was because she worked in full-time employment and therefore found it difficult to attend.

There were two parents, Lim and Nazia, who attended the coffee mornings but found it difficult to socialise at these meetings. In the case of Lim, she felt that she had difficulty in making friends within the local Welsh community. She said,

I don’t know … (pause) if I’m a Chinese or because there was other reasons. But … uh … it is very difficult to make friends. … I know some of the White parents, they go out together and they arrange to have meetings. … but it is not easy for us to try to adapt in what they are doing (Lim, 1/33).

Additionally, when referring to the opportunity to meet other parents, Nazia indicated that,

… there’s a parents’ coffee morning every fortnight. We could go there if we want to meet other parents and ask any questions about our children. But it’s not the same, our culture and what we talk about is different from the English. We are more quiet in that sense (Nazia, 2/33).

Further, Lim had the impression that ‘White’ parents of children with autism at school meetings have the view that if there was another person sharing the available resources then there would be fewer resources for themselves. Evidence for this comes from Lim when she suggested why a few of the parents who were her friends at the special school that her son attends, “tried to withdraw” from her (Lim, 1/34).

4.5 Support from their families and the wider BME community

The final theme explore features within a cultural context, such as, cultural and religious beliefs, the education system, relevant support organisations, and their families and the wider BME community. It examines BME parents’ involvement with their families and communities within a cultural context. The views of parents in relation to the support that they receive from their family and the wider BME community are also discussed here. The participants in this study were families who were living on their own with their partners or spouses in small nuclear families.
4.5.1 BME communities’ understanding of autism and ethnicity

In exploring the relationship of parents with their communities, it is evident that most parents were of the view that their ethnic community to which they belonged did not understand autism. However one Chinese parent felt that this was more the case with the older generation. An interesting point made by this parent was,

I think the older generation nobody understood it … now I think more people understand it better …especially now when I take my boy out I don’t hide (Lim, 1/35).

Lim went on to say that, “there is no help from the Chinese community and I think they don’t understand autism” (Lim, 1/43) and this she referred to earlier in time.

In referring to his Pakistani Muslim community’s attitude towards disability, one parent said,

They have this attitude of this disability which is unfortunate. It is not mired in the last century, it is mired in centuries ago attitudes ... mysticism, witchcraft, and ridiculous notions which has got nothing to do with either their religion. It’s all cultural mambo-jumbo. And these xxx (derogatory term), the religious ... are the worst because they said that you have done something against God. I have a deep understanding about science and biology and I can tell you that, that is not the case (Amin, 8/43).

Amin regarded his community as unhelpful and backward in their thoughts about the condition. Similarly, Lim felt strongly that the Chinese church that she attended was not taking her child’s condition seriously and for this reason looked to the Salvation Army for support. Lim felt that the Salvation Army which is part of the Christian church was warm and understanding of her plight. Evidence for this comes from Lim’s comment that,

Some doctors and teachers are members there (Salvation Army) and so they would say that so and so has got an autistic child. So my boy is not the only one. People there try to understand more (Lim, 1/38).
Lim then said,

I think the Welsh community people generally know about autism
(Lim, 1/38).

It is interesting to note that only one participant believed that there is a greater understanding of the condition of autism within the Welsh community rather than within their own ethnic communities and that. According to one Pakistani parent, BME parents did not engage with their local Welsh community because the venue selected for meetings are “always in a pub, quite late on” (Jamilla, 11/21), which would be inappropriate particularly for those from Muslim background.

There were four parents who said that there was no support from their own BME communities in relation to autism. Even within the family, one parent said that, her older son who did not have autism described his brother with the condition as, “somebody who is retarded” (Lim, 1/36). Lim, in referring to some families where there may be a member in the family with SEN, went on to add that within these families “many parents may have hidden their children at home” (Lim, 1/36). She was also aware that statistics have shown that “twenty per cent of the population have got special needs” (Lim, 1/38). As such, in her view, there are people within the Chinese community who are bound to know about autism too.

The views of these parents appear to restate and confirms widely across the different BME groups that their own communities are not helpful and therefore they need to obtain support from the Welsh community who are the providers of services in Wales.

In developing a different argument, Nazia, a Pakistani mother of two children with autism, said that people in her community are more aware and getting better in understanding SEN but “not for autism” (Nazia, 2/1). In reflecting about the past, Nazia said that a child’s disability would have been blamed as “a punishment from God” (Nazia, 2/46) due to past sins of the family. She further said that things are improving and that people from her community recognise that people with SEN are now being accepted as “part of society” (Nazia, 2/36). She cited herself as an example of an individual who has become more aware of her children’s disability due to her day-to-day experience of caring for them.
However, by comparison, Nazia believed that “the English people understand autism more than ethnic people” (Nazia, 2/36) and that this was due to their acceptance of the condition. Similar views to those of Lim and Nazia were shared by five other parents who also stated that there was no acceptance of autism in their communities.

The view of Adeo was that, he found it difficult to speak about autism to people from his community (the African community) who have settled in the UK. According to him, once the community know that you have a child with a disability, they will “push you off and that’s really destroying” (Adeo, 6/36).

Similarly, another parent blamed the attitudes towards disability as a, “cultural and religious baggage that is carried over” (Amin, 8/36). Amin believed that his community (the Pakistani Muslim community) have not changed in their thinking about disability. However, Amin also said that he felt that individuals from younger generation seem to understand and accept disability better due to them being educated. However, he felt that those from the older generation were still of the view that parents “have done something wrong to the child” (Amin, 8/36). He further added,

As you know, being Asian it’s something that’s frowned upon (Amin, 8/6).

In this case, Amin is relating to the negative and undesirable attitudes of the Asian community in the way they look down on individuals with a disability and their family. Amin further posed a negative picture of his community by saying that,

It’s just an Asian thing … urh … If a child is disabled, they (the community) will blame it on you, they will blame it on anything but what that actually is (Amin, 8/35).

Amin’s disappointment was evident to the interviewer as he paused when he spoke about his community’s lack of awareness of autism and how they perceive disability in the twenty-first century.

In speaking about reactions towards disability by the Pakistani community, Jamilla said,
They just think that my child is “paagal” ... that’s what they think. I’d say a good seventy per cent of them still have the same attitude. You know, ‘to be looked down and frowned upon’ (Jamilla, 11/37).

According to Jamilla, many people from Pakistani community relate negatively to a disability and they think that anyone with a disability is “paagal”, a Pakistani word which means ‘mad’. Her perception of the Pakistani community was similar to that of Amin since both their perceptions were related to the negative attitudes by their community towards a disability.

With regards to how people within their communities viewed special needs (which includes autism), some of the parents were of the view that members of their communities did not understand the meaning of such conditions. In one case, Mina said that some people in the Muslim community are not aware of not only special needs but also autism in particular and still think that the condition of autism is caused by bad parenting.

Additionally, in another case, Fante who is from an African background said,

I come from a society where disability is ... you know ... looked at differently. They tend to spiritualise everything and it’s not only the child who is looked at differently. It’s the mother too, I mean, the father is always innocent. It’s always the mother (Fante, 4/13).

Fante, in referring to the African community in Wales, said that they tend to blame the mothers for their child’s disability. She said that she refused to make an effort to explain about her child’s disability to people in her community because of their attitudes.

Another thought-provoking comment made by Fante was,

I’ve seen people with disabled children who rather hide them. … but someone from the minority ethnic community will not talk about it. When we are able to talk about our child’s condition, and all those things, it will really help us emotionally and it will take some of the burden off and even psychologically help us move forward. But when we are not able to express ourselves … like everything is inhibited within us, we are like silent sufferers and it is even more dangerous (Fante, 4/47).

With regard to the above quote, when referring to perceptions of the African community regarding a disability, they were most likely to hold back their feelings and not express
their experiences with others for fear of being looked down upon. Fante felt that it was important to talk about one’s difficulties and not suffer in silence, which according to her is more dangerous since it can lead to health concerns. The comment by Fante vividly illustrates the lifetime suffering that a parent of a child with autism may experience.

In another instance, Shara stated that her Chinese friend who had a son with autism was afraid to mention about her child’s disability to members of her community. According to Shara, her friend said,

I can’t say to others in my community that my child has SEN ... it’s a secret. If I say that everyone will put me down (Shara, 6/35).

Shara explained that the use of words “will put me down” by her friend can be associated with her fears that she would be shamed and blamed for her child’s disability. Shara went on to say that this behaviour within the Chinese community was similar to that of the African community. In speaking about the African community in his native country and in Wales, Shara’s spouse, Adeo, further added,

It just happened, it is not something I did and somebody will make you feel it is your mistake or God wanted to punish you. God won’t punish a kid because ... (paused). They will be all heart than help. That is why half of them, I don’t talk to them. Even the family in Sudan, I don’t talk openly to them. They will only worry me (Adeo, 6/13).

Adeo further stated that the BME community is not able to accept a disability and “That’s why we are so behind” (Adeo, 6/38).

There were also comments about the general public’s poor perception of autism. One parent said,

The public may often see the behaviour of a child with autism as similar to bad behaviour, being mainstream children and they just think that tantrums or the hesitance to do things is just due to nervous, shyness, anxiety or tantrum (Anne, 7/1).

While the view overall is that there is very little understanding of the condition within the BME community, another three parents commented that presently there is better
understanding among BME communities in the UK due to changing attitudes. One parent, Fante, referring to the mainly White community within which she lived, said,

We go to the community library (local library) about five to six times a week on Mondays to Saturdays. It’s like when we are there, they do understand Bini and her needs. They make sure that she is settled and help her with her colouring and they are very supportive (Fante, 4/39).

Fante’s perception is that the White community was more supportive to her child’s needs than the BME community. Additionally, Fante in making a different point compared the society in the UK to that of her native country, Ghana, which is in Africa, where all concerns are shared by others within the community. She said,

This society [in Wales] is different from what I’m used to back home where your problem is everybody’s problem (Fante, 4/12).

Another three parents felt that it was a waste of time explaining their child’s condition to their own ethnic communities since they were themselves confused about autism and found it difficult to explain the condition. However, Tammy said,

My approach to Nina (daughter) ... is she got to live in this world somehow ... their world is the same as everybody else’s and people are meant to deal with it (Tammy, 5/13).

Tammy gave a reflective statement expressing a wish that society should accept the condition so that these individuals may be able to be included and live within the local community here in Wales.

4.5.2 Support and understanding of family

This section describes the support from the families of the informants which included all members within the family such as mother, father, siblings, grand-parents uncles and aunt. In relation to the support given by their families, seven parents stated that their families did not understand the disability. For example, one parent from a Pakistani background, said,

They (family) didn’t say anything because they did not understand it ( Nazia, 2/13).
Nazia’s view was also shared by three parents who said that it was a waste of time explaining their child’s autism to the family. Nazia stated that, although her family did not understand her children’s condition, she did ask her parents who reside in Pakistan to come to the UK to help take care of her children when she and her spouse decided to make the pilgrimage to the holy city of Mecca.

However, one parent stated that her family “have started to understand and are coping” with her son’s difficulty (Mina, 3/6), although, this parent’s son was eighteen and attending a residential independent school at the time when she was interviewed.

There was also help given by some of the grandparents who turned to other people in their communities for advice. Amin stated that those from the older generation still seek assistance from “Fakirs” or religious doctors and “Pirs” or living saints (Amin, 8/36). He also said, “I didn’t realise that they are allowed in the Muslim religion but they are” (Amin, 8/36). The evidence given by him was,

My mother would occasionally go through a ‘Pirs’ and drop in money after the advice. I think the older generation is still like that (Amin, 8/36).

Amin said that some people in the Pakistani community pay the “Pirs” for their advice. The ‘advice’ as suggested by Amin may in turn be related back to something that the parent’s family had done in the past which was against God and therefore the child’s condition seen as a punishment from God.

A parent from an English background who depended on her family for support for her child described the education and guidance that was given to her child by the late sister of her spouse, who was from a Mauritian background. The parent, Tammy, explained that her sister in law would teach her child mathematics by breaking biscuits in half and saying, “this is half and this is quarter” (Tammy, 5/13). Tammy’s spouse, Tariq, who was also interviewed for the study, further added,

My sister was a big part of Nina’s life and unfortunately she passed away in 2007. That’s been a big hole for Nina … She was looking after Nina most days when we were working … Tariq, 5/25).
The support provided by Tariq’s late sister as evidenced by him was acknowledged as crucial since it allowed the couple some relief in terms of sharing the pressures of caring for their child.

For another parent, Anne, it was different since as parents, she and her partner helped each other but were, “pretty isolated” (Anne, 7/44). She said that she moved away from her family because, “they don’t really recognise autism” (Anne, 7/44). It is noted that Anne’s parents are from an English background so the lack of understanding of autism was not entirely restricted to families of interviewees from BME communities.

Lim felt that teachers in school were more helpful than families. In expressing how she felt about help from her family, Lim said,

I think they don’t know how. My brother ‘don’t’ know how to help and sometimes I feel that they isolate from us. Like my husband’s brothers, especially, they try to withdraw from us. They told their children to go away from us. (Lim, 1/43).

Lim stated that her family are not aware of autism and therefore do not know how to encourage and assist a child with the condition. In this case, Lim’s family appears to be treating autism as a contagious disease rather than a developmental disability and therefore are not aware of the nature of the condition. Most of the parents who were interviewed were of the view that they received very little support from their own extended family except for Tammy whose child did get a great deal of support from her late sister-in-law.

4.5.3 Parents’ view about religion

There were several examples in the data relating to religion in the previous section based on the views of eleven parents who participated in the study. Of the eleven, eight were Muslims and three of whom were Christians. Of the Muslim parents, six were from the Pakistani community, one from the African community and one English parent whose spouse is from the Pakistani community. The parents from Christian background included a Chinese, an African and an English parent whose spouse is from an Afro-Caribbean community. In the interviews, the Chinese parent and eight parents from Muslim backgrounds stated that there was no religious-based support provided for parents and children with any disability within their communities.
However, one parent, Tammy, said that,

> The fact that we have not been given [help] is our own fault. It’s not that, it’s not there but we haven’t taken up the opportunity (Tammy, 5/44).

Here Tammy’s reasoning for “not been given” implies that she may not have searched for religious-based support from her spouse’s Pakistani community. In Tammy’s case, the reason for not looking to religious-based support may be explained by the fact that Tammy comes from a Christian background while her spouse is from a Muslim background.

One response to diagnosis was to have recourse to religious belief. For example, Nazia believed that God gave her a child with autism for a reason. She said,

> We should not complain and we should not think that it’s a punishment. God must have thought this for them. I wish that they will not be dependent on people .... It might not sound good for the English people because they don’t have that sort of belief (Nazia, 2/46).

Nazia’s thoughts were inclined towards acceptance from God. However, most importantly, she made a crucial statement with regard to her ethnicity. She did this by stating that “English people” may not have similar beliefs to that of BME communities. She suggested that unlike Western beliefs, the beliefs and thoughts of the Pakistani community revolve around their religion.

Like Nazia, Jamilla described the way her family thinks about a disability. She said, “The classic one is, “pray for your forgiveness” and “I’m thinking, oh what have I done wrong to deserve this” (Jamilla, 11/35). She added, “I have strong belief in God and I just think that he is going to be the way that God makes him” (Jamilla, 11/1a).

One interesting finding within the data revealed a married couple’s conflicting views about what their child could or could not do within her religious boundaries. For example, Tammy, who is from a Christian background, related to the way the school often, asked parents if it was acceptable for their children to take part in Christian school play. Tammy’s husband, Tariq, who is from a Muslim background, said,
I wouldn’t like her to sort of participate in acts of worship outside our religion really …. The school has always taken this on board. 
(Tariq, 5/46).

Although Tariq had a firm view that reflected his religion, the view of his spouse was different. She said,

But then again, we are flexible; we are not very rigid about it. We are quite happy for Nina to take part in school plays … Christmas plays” (Tammy, 5/46).

Moreover, Tammy may have looked at the difficulty of her daughter through a western perspective, in that she took a step further by searching to improve the quality of life of her daughter.

These views of BME parents will be further explored in the discussion chapter.
Part Two

4.6 Research question two

The second research question in this study is as follows:

What are the perceptions of key personnel in education and relevant support organisations of the support provided for BME children with autism and their parents?

The data which was obtained in the interviews to explore this question are analysed in relation to interviews with sixteen participants within the stakeholder group comprising eleven key personnel in education and six personnel from relevant support organisations. The key personnel in education refer to those who were working in mainstream and special schools. They include the Special Educational Needs Co-ordinator (SENCo) who was based in a mainstream primary school and the Deputy Head (DH) of a special school. The sample also included two Specialist Support Teachers (SST1 and SST2) who, respectively, were based in a resource-based unit in a mainstream secondary school and in a special school. Other key personnel in education included a teacher who supports pupils in a special school and two Teaching Assistants (TA1 and TA2) who were based in a resource-based unit in mainstream secondary school and in a special school.

However, the sample within the key personnel in education group also included those personnel in education who were not actually based in the schools but those who may often come into schools to assess pupils and advice staff in supporting pupils with a Special Educational Need (SEN). These personnel also included the Speech and Language Therapist (SaLT) who works in health and education, two Ethnic Minority Achievement Service advisors (EMAS1 and EMAS2) and a Local Authority Officer (LAO) in Wales.

The participants from relevant charities and other support organisations comprised five representatives. These included an Executive Officer (EO) of a national autism charity that provides services for individuals with Autism Spectrum Disorder (ASD) and which is funded by the Welsh government, as well as through other grants. Another representative was a Project Manager (PM) of another national society that provides information and
support for individuals with ASD and their families. The society is funded through voluntary and charity events, with some projects funded by the Government.

The participants from the relevant support organisations also included the chairperson of a parent support group (Charity A), that enables individuals with a disability to improve the quality of their lives through the use of gardening as a therapy; and the Developmental Manager (DM) of a parent partnership service (Charity B), which provides training for families of a child with a disability. Finally, the Transitional Co-ordinator (TC) of a national society who is based in England was also included as a participant in this study. A detailed profile of these participants within the stakeholder group is shown in Table 5 in chapter 3 and these participants were interviewed individually.

The interviews yielded data relating to the research questions which are presented here under the following theme headings, namely:

- Support provided for BME pupils with autism in schools
- Support provided for BME parents of pupils with autism
- Specialist services provided by stakeholders
- Stakeholders’ role in the provision of additional support for BME parents

The analysis of these themes which include sub-themes within them, are discussed next.

**4.7 Support provided for BME pupils with autism in schools**

The first theme relates to the needs of BME pupils with autism in education and the challenges faced by teachers and others in meeting the needs of these children. Although the focus in this section is specifically on the support provided for pupils from BME backgrounds, many of the comments made by participants in interviews were also relevant to non-BME pupils with autism. In analysing the responses, an attempt has been made to differentiate between specific services that are available for minority ethnic pupils and the services that would be provided in mainstream, special school and in resource-based unit in mainstream school.
4.7.1 Available support and resources in mainstream schools

The question that was raised to one key member of staff in education who is a Specialist Support Teacher (SST1) in a resource-based unit within a mainstream secondary school concerned the level of support for pupils with learning disability. The SST1 when making it clear that there is not one straightforward answer to the level of support provided, said,

It’s a complex question because each pupil requires different amount of support. ... most of the boys also have a TA with them. Some have one to one … we’ve got 2 TAs mixed between 4 boys and we’ve also got some pupils who are not statemented to have 1 to 1 support but do end up receiving one, for example, the boy in question in this one, he is not actually statemented to have 1 to 1 support but he needs 1 to 1 support (SST1, 7/4).

According to SST1, there is strong evidence of one-to-one support in the mainstream school. However, evidence also emerged that mainstream schools are not always able fully to meet the needs of pupils with a disability. This teacher, referring to a pupil from a BME background, said,

He has massive communication difficulty. If I say to him, “What did you do in your last lesson?” He could come out with a random answer like ‘Red Balloon’. He has no concept of putting sentence together and understanding sentences. That’s the same if you spoke in Malay or if you spoke in English, for example, when I last spoke to his father, he was saying stuff like, his son doesn’t know what his dad’s name is. He knows his dad but every time he explains that his name is Muhammad, his son doesn’t seem to understand. We are trying to think whether this is the best place for him. We were trying to put him in a special school. Whether that happens or not, is another matter (SST1, 7/5).

From the perspective of meeting the pupils’ needs, the SST1 suggests that the present unit may not be suitable for the pupil with autism due to its lack of provision. This view of SST1 was shared by SST2, a specialist support teacher at a resource-based unit in another mainstream secondary school, who stated that there is a tendency for pupils with autism to get overwhelmed in noisy and crowded environment such as in a mainstream school and where there may not be sufficient resources available.
A different point was expressed by a teacher in a special school when she was asked about specific needs when supporting pupils with autism from BME backgrounds. The teacher said that she could not tell what these parents were thinking and what they really wanted since their ethnic and cultural needs were different. The teacher said,

The parents were not in agreement with what’s going to happen and I think that might have had a cultural origin … but then all our job is to allow the families the opportunities. ... they have to be informed and be aware of the opportunities but the decision that is being placed in front of them, it’s for them to decide together and that’s the hard bit. It’s all about parents’ choice (Teacher, 3/19).

The teacher indicated that since she did not understand the cultural needs of the BME parents, the obligation is with the parent to make the decision on the nature of support that is appropriate for their child.

Further, the SST1 described the difficulties in supporting one BME pupil. He said that there were differences in views between the parent and himself that could be explained by cultural differences. The SST1 said,

His dad wants him to wear a badge saying that he’s got these difficulties but obviously you can’t go around wearing a badge saying that you’ve got difficulties. It’s a stigma. But the parents are absolutely lovely and I don’t know what’s going on at home with these difficulties (SST1, 7/20).

In addition, the SST2 stated that, it was difficult for some of her pupils, without referring to BME pupils in particular, to go into a crowded classroom. In stating that many pupils with autism may have many challenges in their daily encounters in mainstream classrooms, the same person said,

There are lots of challenges. The pupils that we have got, a lot of them still have a big problem with their commitment. Some of the pupils we’ve got are echolalic, they repeat the things that they hear, what their peers say. Some have difficulty understanding verbal instructions and language (SST2, 6/5).

Further, when discussing the difficulties in communication skills of these pupils, the SST2 suggested that since these pupils have difficulty in communicating with staff and peers, visual aids, such visual timetables and instructions, are put in place within the school
environment. This comment by the specialist teacher in turn suggests that there is some support provided in mainstream schools for these children although not sufficient, in her view.

The participants from mainstream primary schools also stated that it was challenging to try to meet the needs of pupils with autism. For example, one Special Educational Needs Coordinator (SENCo) in a mainstream primary school suggested that one way of getting around the difficulties faced by pupils with autism in the classroom is through an “anxiety box”. Referring to a girl in the class, the SENCo stated,

We have what’s called ‘her box’ and she’s allowed to put in the box any of her anxieties that may occur and she writes it and puts it in the box. We try and find what works for our children and it is a bit of an experiment (SENCo, 5/11).

The SENCO stated that the “anxiety box” is used to give relief to the child at a time of difficulty or distress. While there appears to be some support for pupils with autism, it is acknowledged that only one mainstream primary school participated in this study, resulting in limited data for BME pupils with autism from this sector.

With reference to BME communities specifically, one Ethnic Minority Achievement Service (EMAS) advisor (EMAS1) stated that due to the lack of relevant information about the cultural aspect of autism, schools often have to cope on their own when the need arises to support a pupil with autism from a BME background. However, another EMAS advisor (EMAS2), who was of the view that the present support should be left the way it is, said,

… generally parents are very appreciative and grateful, ME parents in particular, about any aspect of care that their children get. I don’t think just throwing money at particular community for a particular thing is going to actually solve any more problems (EMAS2, 4/16).

In stating the above, EMAS2, believes that the current assistance for the management of difficult behaviours for all, including BME pupils within classroom settings, is adequate. In addition, she also clarified that EMAS’ role was to provide support for pupils with English as an Additional Language needs and not SEN needs and thus suggesting that it is not about supporting BME pupils with autism.
4.7.2 Available support and resources in special school

From interviews with staff in a special school, it emerged that there are differences in the extent of facilities and related resources that are provided to pupils with autism in mainstream schools and special schools. In the context of a special school, when a teacher was asked about this provision, she said,

The whole day is geared around their (pupils) communication. You do all the structured TEACCH stuff which is embedded in all of the school. You have got schedules wherever you go, you have got the visual timetable, visual structure within their work baskets too where there are mini schedules within task schedules as well. You’ve got support from the health authority like the SaLT and OT (Teacher, 3/12).

The suggestion here is that there is a variety of support that is provided specifically for pupils with autism in the special school. For example, the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) programme which is an approach that uses structured teaching methods via the use of visual learning.

On the point about difficulties of meeting with parents from minority ethnic backgrounds to discuss their child’s learning, the Deputy Head (DH) at the same special school stated that,

Most of the children come by provided transport. We have home books and we have an IEP (Individualised Education Plan) meeting coming up, so parents will be coming up but to actually have that one on one in-depth is very difficult. So I think it’s very difficult to do that with parents whose children don’t have English as first language (DH, 4/19).

The DH states that while there is support available for most children with autism, there is concern about communicating with parents from BME backgrounds. Although, the above data shows a difference in the extent of support provided in schools, SST1 stated that “at the end of the day, it’s the parent’s choice” (SST1, 7/20) in choosing the preferred school for their child.

A Teaching Assistant (TA) in a special school described her experiences on how she supported pupils with autism. She explained,
They have a lot of behaviour problems these autistic children like some of the children do self-harm like bite themselves. Well, basically you would just stop them all the time and you’d intervene (TA2, 2/5).

According to TA2, the school caters for all pupils with the condition and all staff are aware of the behaviours of these pupils through their own experiences in supporting them. When asked the question of how BME pupils are supported, TA2 said that except for their religion and culture acknowledgements in terms of Diwali and Ramadan celebrations and dietary needs, the support that is provided is “all the same for every child” (TA2, 2/20).

Further, from the point of view of a support teacher, there are also resources provided to help the staff learn about autism in special school on which the TA2 said,

I get my info from books, specialist teachers. We’ve done a lot of courses on autism. Books are available to any of us from the outreach department. Speech and language therapist for speech and language and the OT work along … motor skills (TA2, 2/19).

The TA2 also highlighted the nature of support provided in special school and the training that the staff receive to support all pupils with autism.

4.8 Support provided for BME parents of pupils with autism
The second theme discusses the role of stakeholders in assisting BME parents to help them in seeking support for their child’s autism. This theme also explores the extent to which stakeholders aim to meet the cultural and linguistic needs of these parents.

4.8.1 Involvement of key personnel in education
An important issue within this theme is the role and involvement of the parent when it relates to the placement of the child in either a mainstream or a special school. The key personnel in education however, state that this right of the parent should be weighed against the need of the child.

In recognising that one aspect of autism is about how the child behaves in an educational setting, one lead professional in education, namely, the DH of the special school stated that she has confidence in the knowledge of parents regarding their child’s behaviour.
According to the DH, the parents provide valuable information regarding the child’s behaviour that these professionals may find useful. The DH stated,

Parents always give you key pieces of information that other people don’t see or don’t have (DH, 4/14).

The comment by the DH acknowledges that parents have useful knowledge to share with teachers who do not have as much access to the pupils all the time. However, they made no reference to BME parents in their response.

Referring to parental involvement, the SENCo in a mainstream primary school stated that English Language classes are provided for BME children and their parents. The interviewer did not request information on the timing of these classes. The SENCo further explained that,

We also have a fantastic resource by the Ethnic Minority Service in the computer called “EMAS UK” So that has allowed us to communicate with some of our parents and children. So we type in what we want to tell the parent whether it be, it’s PE on Monday and it speaks to the parents in their home language. It’s a fantastic resource. (SENCo, 5/8).

Further, in referring to support for all parents, she (SENCo) said,

We have a special needs support group in this school which came about because I approached the mum to help support another family whose child has been given a diagnosis of autism and who found it quite tough to come to terms with (SENCo, 3/13).

The SENCo also stated that it was only as a result of the need of one parent of a child with autism that a special needs support group was formed within the school by the parent, Anne, and a group of pro-active mothers experiencing similar situations. Anne, a parent from an English background who was also interviewed in this study, confirmed that she started the first support group for parents of a child with autism at her child’s primary school since, “there was no support teacher for her (her child) there” (Anne, 7/6). This parent explained that she wanted to meet other parents because she felt “pretty isolated” (Anne, 7/10). She further added,

I wanted it (the support group) to be there and if somebody wanted to talk about it (autism) they could come there (Anne, 7/11)
In describing the support group, the SENCo said that it involved, for example, among other things, discussions on how all parents could support each other when they needed to fill out forms. It also included other support which involved inviting professionals such as clinical and educational psychologists to talk about support and management of special needs including autism behaviours. The SENCo further added,

> We did a special needs fair in the hall where lots of people came along. That’s the first time we’d done anything like that. The parents that did come found it very useful because they got to know a bit more about what’s out there to help them (SENCo, 3/13).

There is an attempt by this school to create a special needs exhibition fair to enable and encourage all parents of children with SEN to participate and to find out about various forms of support that may be available for their child or for themselves as carers. I attended the fair and noted that both BME and non-BME parents were present.

### 4.8.2 Involvement of relevant support organisations

There are support organisations, which include, among others, the national society and various parent support groups. One parent support group also felt that the siblings of pupils with autism also needed supporting. According to the representative of this parent support group, the siblings share the family’s experience of the child with the condition. In relation to the role of siblings, the chairperson of the support group said,

> We think that it is really important to give them (siblings) a break because they do miss out a bit and we recognise that … they (siblings) just see them (individuals with autism) for who they are and they don’t see the disability (Chairperson, 16/4).

The Transition Co-ordinator (TC) of a national society added that there are awareness programmes for a couple of hours weekly for individuals with the condition and their family, including siblings. The TC stated,

> We have specific topics on supporting new siblings, one on managing anger in young people …. We have toileting, so there are topical seminars (TC, 17/7).
With regard to the way stakeholders reach out to parents, the Project Manager (PM) of a national society in Wales stated that it all depends on whether BME children with the condition are able to benefit from what is provided for them. According to the PM, when you talk to the BME parent,

… they will often talk about the ‘fight’ they’ve had to get the support and the ‘battle’ they’ve had to get the right kind of schooling for their child” (PM, 14/8).

It can be seen from Part 1 of this chapter that similar language was used by an interviewee in this study, when telling the story of their child’s disability.

4.8.3 Continuous Professional Development training in autism for school staff

In referring to Continuous Professional Development (CPD) training for staff in schools, a majority of the participants within the stakeholder group stated that there had not been any training for staff with regard to providing for cultural needs and ethnic differences of BME children.

Further, a teacher at a special school said,

I’m not aware of having attended anything that has made a particular point of providing extra information on that (Teacher, 3/23).

However, the TA2 at the same special school stated that the school provided her with CPD training in autism and even sent her to do courses on the condition.

Two key personnel, the SaLT and the DH of the special school had specific qualifications and experience in working with pupils within autism, but were not specifically provided with CPD training to support BME pupils with the condition.

In highlighting the need for specific support, the SST2 in a resource unit based in a mainstream school, said,
We could employ staff who are of ME and obviously we haven’t been able to in fact we’ve never had anyone apply to our job and I think that would be quite important because then we could have from the staff point of view an additional perspective on a different religion or a different culture but at the moment we can’t do that if someone applies for our job (SST2, 6/22).

Although both the DH and SST2 recognised that resources and specifically trained staff are limited, they hoped that there was more that they could do to meet the needs of these pupils and their families.

Another member of staff in a special school, TA2, stated that the school had provided her with the training that was needed to support pupils with autism. However, when she was asked if the training enabled her to support BME pupils, she said that the training was “not specifically for the purpose of that (TA2, 6/23).

4.8.4 Provision of specific support for BME parents

When referring to the support for BME parents, the Transitional Co-ordinator (TC) of a national society commented on the diversity within the BME community. The TC said,

Our family support worker clearly understands the need to tailor information to different ME groups because not all ME groups are the same. … If she sends out a piece of information that she’s planning to look at, the key languages that she put that information in and how she phrases things is important because the understanding of autism across ME groups is very variable across the different community groups” (TC, 17/5).

The TC went on to say that information on autism is vital to the BME community, to make them aware of the support that is available. Such information when provided to these communities would raise their awareness and understanding of the condition. However, when referring to such information, the TC also stated that,

… all our information isn’t tailored to different cultures (TC, 17/5).

In acknowledging that the BME community is not a homogenous group, the TC stated that it is necessary to be sensitive to the different communities’ understanding about autism when providing them with information on autism. When referring to the situation in Wales, data collected in this study shows that support is provided for all pupils on the same basis.
In reflecting on provision of support for a BME child with a disability, the Project Manager (PM) stated that he had been talking to the carers at the parent support group meetings in view of finding out whether they are being “completely missed out” (PM, 14/5). He also mentioned that he had been exploring the possibility of producing a DVD about autism which may be dubbed in other languages, though he was uncertain about its effectiveness.

According to the PM, other possibilities of providing further support included the need to take into account the issue of both BME parents and others’ particular needs to manage their child’s needs. The PM said,

… we gave trouble-shooting workshops throughout the region on anxiety, sleep, toileting and diet. I organised that (PM, 14/4).

Further, the PM referred to a meeting that he attended with the Social Services Committee that is responsible for monitoring and influencing the regulation of services in Wales (Community and Adult Service Scrutiny Committee, 2012). The PM stated that at this meeting, a question was raised about whether awareness raising booklets for parents of children with autism were available for BME communities. According to PM, a Welsh Government (WG) spokesperson responded by saying, “oops” (PM, 14/5) which may appear as being a reflection of policy that is ‘culturally-blind’ (Castro, 2005) in its provision of services. However, the response by the spokesperson, as narrated by the stakeholder, in my opinion, could also imply that the spokesperson may not have been aware of anything that is specific for BME needs.

In referring to the response of the spokesperson, the PM said,

Can you let me know, if not, that’s not a problem, I’ll ask the Minister this afternoon at the meeting.” And they said, “Don’t do that” (interviewee laughs). I got an answer but it took 10 minutes for that. This was when Welsh Government was launching the awareness raising booklets at the Pier, just before the three-year ASC review meeting at the Welsh Assembly (PM, 14/5).

Further, in stating the obligations of the WG, the PM pointed out that,

… their only legal obligation is to produce in English and Welsh and they don’t do anything else which is a bit sad but it’s not even
on demand. Talking to the Carers in XXX (name of place within selected LA), they were saying that leaflets are not effective (PM, 14/5).

Further, in relation to BME communities, the EMAS2 advisor, said that compared to twenty years ago, the social stigma was “lesser now, actually parents are aware that we are a supportive sort of society and so does the school system here and that we are not going to exclude the kid” (EMAS2, 11/12). According to the EMAS advisor, although the stigma may remain within some families, these communities are not going to be shut in isolation because according to her, the school and the non-BME community are there to offer support. On this subject of social stigma, there was a similar view expressed by the PM who said that,

There’s a certain amount of shame in some communities and it’s kind of hidden away and they don’t want to talk or isolate it and the families look after it and they don’t seek support and help outside because that brings attention to this and they don’t want to (PM, 14/5).

Similar views to these were expressed by two BME parents were that they could not relate to others in their own community about their child’s disability. For example, one parent from the African community felt that “everyone will put me down” (Shara, 6/35) which relates to her fears of being shamed and blamed for her child’s disability. Further, another parent from the Pakistani community in speaking about his community’s attitude towards a disability said that they “will blame it on you, they will blame it on anything but what that actually is (Amin, 8/35).

It is interesting to note that the PM, although he mentioned earlier in the interview that he was aware of the shame and isolation faced by certain groups within the BME community, was not fully informed of the cultural aspects of the BME community. The PM said that,

We’ve clearly not reached them. I don’t think we’re reaching them (PM, 14/10).

As such, he believed that there was still much to be done in terms of providing for the possible diverse needs of BME parents.
The PM then went on to acknowledge that,

If you don’t have the stomach for that fight or if you don’t understand the system or communication skills in terms of how to contact education, social services, health or whatever it may be. Logically you would think that the child has less chance of accessing the services (PM, 14/8).

When referring to the ‘fight’ by parents, another view with regard to cultural needs was given by an EMAS advisor who also spoke about the difficulties that BME parents might have with understanding the education system. According to the PM, if parents are unable to voice their concerns then they may not be able to obtain the relevant support for their child. He also explained that there may be difficulties for the BME parents to engage in obtaining services if they do not understand how the system works within the country that they live in.

Additionally, when referring to cultural needs, EMAS1 also talked about difficulties BME parents might have in understanding the education system. EMAS1 stated that, when parents come into the UK as migrants, they would often not know about the procedures or regulations of schools or the expectations of schools. According to this key advisor, her job role is to “familiarize” BME parents about the appropriate support provided by teachers for their children within the classroom (EMAS 1, 10/10). In relating to addressing cultural needs, the SaLT said that,

Sometimes we would need an interpreter and then you’d have to go through the process of that. It is important what a parent understands about who I am, and what I do to support their child and themselves (SaLT, 12/11).

In acknowledging different customs of behaviour within different communities, the teacher at a special school said,

Sometimes you feel as if you’re asking a question and mum might hesitate and not come up with a response because she’s waiting to discuss that with her partner. Sometimes you feel that, that’s different in some people’s culture and that dads might have the major say, in a decision and yet not always available to come to meetings (Teacher, 3/21).
The teacher said that the role of parents in different communities may not always be similar and that one may have to recognise that the final say may rest with the male spouse particularly within the BME community. As such, this implies that they (teachers) may be reaching out to the wrong spouse.

Further, the SaLT said that it is necessary to recognise that parents of BME pupils may have particular needs relating to their ethnicity that those in education should be aware. She said,

I have to be aware. I think there are certain cultural backgrounds like, for example, I try and be aware of where a particular family is coming from. There is a number of multi-cultural clients that I have on my case load (SaLT, 12/5).

The majority of stakeholders who appeared to be aware of the multicultural nature of the families also emphasised that there were more similarities than differences between the way in which BME and non-BME pupils were given assistance.

4.8.5 Differentiation of support and provision

When referring to support provided to pupils, there were views given by TA1 and TA2 who stated that services for BME pupils are “all the same” (TA1, 1/13) for every child in any community within the whole school population in terms of autism specific needs.

The evidence from one key person in mainstream education was that the support that is provided for BME pupil is,

... all the same for every child (TA2, 2/20)

A similar response about the difference in support for BME pupils was given by the Local Authority Officer (LAO), who said,

It doesn’t differ from those who are not from ME backgrounds (LAO, 9/15).
However, one BME parent emphasised that,

… it’s not the same, our culture and what we talk about is different from the English (Nazia, 2/33).

The comments of this participant highlights the view that there is a need to recognise the cultural diversity of the BME community (Lloyd and Rafferty, 2006; Fryberg, 2010) and therefore the parent’s view appears to be explained by the ‘culturally-blind’ theoretical framework (Castro, 2005).

Yet, there were some key personnel from the support organisation who acknowledged that “not all ME groups are the same” (TC, 17/5), further recognising that the BME community is diverse. The same person said “Obviously, all our information isn’t tailored to different cultures, we know that there is a lot of issues” (TC, 17/5).

Finally, it is worth quoting from the interview with the EO at length since he spoke strongly about the issue of addressing cultural differences in services in Wales. The EO said,

… we have to take into account the needs of families based upon their religious, their cultural sort of differences and those cultural differences, there are many of them and not just the usual way of which we approach things in Wales. It’s a big challenge for all of us. It’s one that is not lost, I can assure you. I genuinely do feel that we do need to move in Wales. I just feel and I have now for some time, in terms of the ME side, we need a sort of champion as it were. I think there is an issue here … we had lots of dealings in terms of significantly higher population of ME families and so on. Some of it is about the cultural difference and some of it is about language differences. We got to make every attempt to make our services accessible and understandable (EO, 13/13).

The EO therefore felt that there is a major question surrounding the issue of recognizing language and cultural difference: there was a need to acknowledging this as a big issue and to lead on and publicise it.

4.9 Specialist services provided by stakeholders

The third theme relates to resources provided by stakeholders to the parents and training needs specifically for those supporting pupils with autism. This includes the ability of
stakeholders to advise parents in order to assist them in supporting their child to enable continuity when the child comes home from school.

4.9.1 Support provided by professionals in education and relevant charities

In describing the range of support provided to meet the educational needs of a child with autism, the Local Authority Officer (LAO) said that staff includes specialist professionals, such as, Education Psychologists, Occupational Therapists (OTs) and SaLTs. The LAO further stated,

Every child with a statement with ASD in mainstream will have on it what provision is needed. We have a team of specialist teachers and we have got an effective model … we have some mainstream bases attached to mainstream schools. So we have specialist bases in our mainstream sites (LAO, 9/6).

According to the LAO, there were sufficient support provided by a team of LA specialist teachers working together to meet the needs of pupils. However, I was not successful in getting a response from another LA official who had responsibility in this area, as noted in the previous chapter.

The SENCo of a mainstream primary school acknowledged that there were different stakeholders working together and these included the TAs working very closely with the OT, SaLT and other specialist professionals when implementing a programme in school. In describing how these multi-agencies work, the SENCo explained,

… they will take time out of class to work with that child for twenty minutes, maybe on a handwriting programme or within a social skills group for a period of six weeks. And then they review and reflect and see whether we need to continue (SENCo, 5/5).

In emphasising that there is specific support for BME families, at her school, the same SENCo said,

We also have XXX (name of person) who is our Governor and she is of ethnic minority background. She speaks regularly with myself as inclusion and team leader and she attends my team meetings and helps with anything going on in the community that I could do with a bit of a hand with (SENCo, 5/15).
On another point when referring to the services provided by SaLTs, the Executive Officer (EO) of a national autism charity said,

There is a paucity of Speech and Language Therapists within Wales. There’s not enough of them (EO, 13/12).

Similarly, when asked the reason for this lack of expertise, the SaLT when interviewed, responded by saying,

I think there has been … [participant pauses] in the past … a lot of it is linked into finance. … and not service expansion. (SaLT, 12/16).

Both the EO and the SaLT confirmed the shortage of such skilled people in south Wales.

When a question was asked about staff training, the Teaching Assistant (TA2) of a special school said,

I’ve done a lot of courses: Picture Exchange Communication System (PECS) with in-house training. We do a lot of positive handling courses as well which is basically safe ways of handling children and moving them from one place to another (TA2, 2/3).

The comment by TA2 is that staff at special school are equipped through training, to care for children with autism.

The provision of training and cost of paying for support services was also raised by EMAS1, who said,

Everything is about money. It’s the need to keep providing quality training and continuing professional development for teachers. It is to have enough interpreters so that when parents actually come into school, you could actually have a good conversation with them but most schools can’t afford to buy in interpreters on a regular basis (EMAS1, 10/13).

Although the needs of BME parents were recognised, funding was perceived to be insufficient, and this, rather than a reluctance to provide services was one of the main reasons given for the lack of provision.
Similarly, the TA in mainstream school whose role is to assist pupils with SEN including autism said,

We really don’t have the money at the moment (TA1, 1/22).

Conversely, the Developmental Manager (DM) from a parent support group stated that free advice was provided to parents. Further, if any professionals in education requested it then the training would be provided for a fee. However, the DM said,

… if somebody wanted a special training in something through the training unit then that would have to be paid for (DM, 15/6).

However, the DH of the special school and SST2 who is the Head of autism for a resource-based centre located within a secondary mainstream school, when asked about support given by other charitable organisations, said that the Early Bird programme had been useful. Both these key personnel in education also acknowledged that the programme which advises parents and that is provided by the national society had been useful for most parents except for those who appeared to be,

… struggling with the language (DH, 4/8).

Both DH and SST2 stated that the booklets, as mentioned earlier, that were produced for the society’s programme were not in any of the main BME languages. They said that it would make a lot of difference if the society could provide translated material for minority ethnic parents who were having difficulty in English.

Although, some of the parents who were interviewed stated that the Early Bird programme is useful to them, the DH stated that the booklet that the society produced,

… is not in any of the main languages” (DH, 4/8).

The SST2 said that she had requested information about the structure, content and application of social stories and had bought a lot of books on autism from the NAS and these were found to be useful for her and her staff. Then again, she said,
nothing that they have said is being massively new in terms of information … we don’t rely on their advice” (SST2, 6/16).

The perception of both the DH and SST2, of services in education, was that they did not rely on the national society for information but rather, of that provided by the LA.

4.9.2 Available services in special and mainstream schools

When referring to specific support, key personnel in education who were interviewed stated that most BME parents of pupils with autism were aware that the support and facilities in special schools are provided to cope with the needs of their children. They said that this was especially the case for children who had severe behavioural difficulties and therefore needed to access specialised resources in these schools.

It was noted that staff in a special school are able to recognise the particular need of the child which may be complex. For example, the Teacher in the special school said,

… the co-morbidity thing that the child with autism may have other or commonly, quite a lot of children have dyspraxia … they are sort of a little bit clumsy in their movements and whether the autism prevents them from picking up phonics or whether there is some element that some children with autism have dyslexia (Teacher, 3/11).

The same teacher then went on to list a host of facilities that are provided in the school. She said,

… you have got the visual timetable, visual structure within their work baskets … from the health authority the SaLT and OT. We have music therapy … education psychologist … and provide the school with some additional ideas to support, if there is difficult behaviour (Teacher, 3/12).

Additionally, a TA stated that the special school that she worked in recognised and provided for the needs of BME pupils with autism by looking into “all aspects of religion and multicultural diversity” (TA2, 2/12) of their pupils.

It is also noted that when relating to the subject of ethnicity, the DH of the special school said,
We don’t have any staff who are ME, but we do have, when we have annual reviews or parental meetings. I did an annual review the other day and we did have an interpreter in, so we do make special arrangements (DH, 4/12).

Further, the TA in a resource-based unit in a mainstream school stated that if a particular pupil with the condition gets upset with another pupil who does not have autism, then the provision of support is designed accordingly. According to the TA, when the pupil with autism becomes aggressive with other pupils who do not have the condition, then,

… we sit down with the other pupils and we will write a story with him. And this will give the boy a chance to understand how his mate will feel during that time he’s being upset (TA1, 1/9).

These are examples of how staff works in engaging children with the disability within the mainstream schools.

A key person in education, the SENCo in a mainstream primary school, stated that the school is doing all they think is necessary to support pupils with autism. She expressed that,

…we meet at least half a term to discuss the progress of the children we monitor, where they’ve been, where they go, any problem that might have occurred that we need to deal with (SENCo, 5/3).

The SENCo also said that in doing her work, she interacts with other staff in the school, for example she said, “I also work with a lady, who is the SALT for the autistic children. I work closely with her for one of my children” (SENCo, 5/3). As for additional support, she added that, “visual timetables are something we have tried to develop in all our classes with children who have autism” (SENCo, 5/5).

4.10 Stakeholders’ role in the provision of additional support for BME parents
The final theme relates to additional services concerned with language and religious issues of BME parents and also the matter of dealing with difficulties related to children with autism moving from one school setting to another. It is recognised that it may sometimes
be necessary for stakeholders to provide for additional services for BME parents and their children from outside the school's resources. Such resources may include the recruitment of more BME support staff in schools and translators to meet their specific cultural, linguistic and religious needs, although literature states that they are not always available (Jones et al., 2009).

4.10.1 Provision for the language needs for BME parents

Several stakeholders commented on the difficulty of providing support for parents and pupils whose first language was not English. Both the TA2 in a special school and the chairperson of Charity A stated that language has been a barrier when relating to BME parents and their children with autism.

With regard to the language needs of the BME community, while stating that there was evidence of support, the TC of the national society raised the possibility that there could be difficulties for the BME parents in accessing it. She highlighted the evidence by stating that,

> It’s there, whether they can access it, is a different thing in terms of our information. Obviously all our information isn’t tailored to different cultures and we know that there are a lot of issues. Well, if money was no object we’d love to have information flyers in all languages that we know unfortunately we’re relying on donations, fundraising and government funding. So there is no specific support group (TC, 17/6).

Additionally, EMAS2 emphasised that the role of translators, although expensive, were beneficial to parents. She said that translators were,

> … most important in meeting the needs of parents. I think it’s a resource that’s expensive but can do so much good (EMAS2, 11/20).

Additionally, the Chairperson and the DM of the parent support groups stated that some of the families who join their parents’ groups did not speak English. In this case, a member from these families who may speak the native language as well as English would be asked to act as a translator.
Another piece of significant data that is important in the study was revealed by the Deputy Head (DH) with regard to the Early Bird training programme which is provided to all parents of a child with autism. In so far as this programme is concerned, the DH said,

… we don’t actually get much take-up by parents from ME groups (DH, 4/7).

The DH suggested that the low up-take of services by the BME community was due to difficulties in obtaining material in their languages. As such, she said,

… if the literature that we could provide was translated, it would make a lot of difference and might get over that initial sort of sensitivity to coming along (DH, 4/7).

In explaining the ability of staff at the special school, the DH stated that staff at the school were trained in the TEACCH programme and the PECS and positive behaviour strategies. The DH went on to state that training was provided by external agencies and took place outside the school and through in-house training. In relation to meeting needs of parents, a teacher in a special school said that there is generally assistance for those parents who have English as an additional language. Here, the stakeholder appears to be suggesting that their concern is about providing material in the BME native languages rather than about providing services that are inclusive and taking BME communities’ diverse needs into account.

4.10.2 Provision for the language needs of BME pupils with autism

While the earlier part of this section refers to parents of a child with autism, it is also important to note that the data shows that the support is also provided for pupils with the condition. This includes specifically the provision of visual material for the pupils to take home, such as printed information about autism. However, the view expressed by the DH of the special school is that, this is not the case at all times. The DH went on to say,

… it would make a lot of difference if the literature that is provided by the school to ME parents could be translated (DH, 4/8).

The above comment by the DH shows that language can be a barrier to children who have English as their second language. Moreover, when TA2 was asked about language support, she said,
Language barriers, sometimes you can get problems with. Occasionally, you find children with English as their second language. We have had translators especially if there is a review or something and if you got parents and ... it’s always available. ... it comes to down to Picture Exchange Communication System (PECS), it’s used for so much because you can identify things by using it and there’s no barriers, you know. It’s available to every child because the picture tells a story as well (TA2, 2/16).

Although, language may often be seen as a barrier to obtaining services by the BME community, both lead professionals in education and in relevant organisations do suggest that they have various ways of meeting the needs of the different BME communities, to overcome barriers, such as providing information materials, using visual strategies, the use of PECS and through the use of translators.

Another aspect of support was in relation to providing for appropriate language needs of pupils. When this question of support was put to the DH of a special school, she replied,

There is always this argument with children on the spectrum, if they do have 2 languages, which language do you sort of plump for or does it make a difference, can they cope with the 2 languages? (DH, 4/8).

The view of the DH is that there are children who can effectively communicate in English, Welsh and in their native language, thus emphasising that they can cope with lots of languages. While there is the question about which language may be suitable for the child with autism, there are some pupils who show the ability to learn and speak different languages. In describing his son’s language skills, Amin said, 

He had acquired a certain amount of language, when he basically spoke he could understand English, Punjabi and Welsh (Amin, 8/24).

However, the DH further stated that it may be difficult to provide outreach to BME pupils who have a language other than English as their first language. While continuing on the subject of language, the SST2 of a Resource Unit for pupils with autism that is based in a mainstream secondary school stated that even though her pupils spoke different languages at home, she did not provide anything in their own language. According to the SST2, there are twelve pupils in two classes with two teachers in her school, of whom three are from
BME backgrounds. She stated that the educational provision at the Resource Unit does not differ for BME pupils and therefore is exactly the same as for all pupils. It was interesting to note that the English language was not considered a barrier with these pupils since all of them spoke English. For this reason, there was not a concern for purposes of communication and on the service that was provided by the staff at the Resource Unit.

4.10.3 Recognising religious aspects of pupils’ lives

There were various stakeholders who stated that they took into consideration the religious needs of BME pupils with autism when providing them with support in education although there were a few who found it difficult to provide specifically for their needs. For example, the SENCo in a mainstream primary school stated that her school had,

… a bilingual assistant, Mrs XXX, a Pakistani who speaks Urdu, Punjabi and Bengali and who supports and provides for the religious aspects of BME pupils’ lives (SENCo, 5/8).

One very clear adaptation by the resource based unit for pupils with autism at the mainstream secondary school was to recognise that the BME pupils at this particular school were all Muslims and were being educated in a Christian school setting. In giving an example of the adaptation, the Specialist School Teacher, SST2 said,

… the three pupils who are all Muslims and the fact that we being a Church of Wales School, we had to address it in a different way because a lot of our focus is more Christian focus. The parents have all agreed that they don’t mind their children being involved in Christian basics but they have all had one request that none of them pray with their hands closed but with their hands open according to the Islamic practice. So that’s our one adaptation (SST2, 6/11).

The comment by SST2 shows that being in a Christian based school, minority ethnic parents were consulted about their wishes for their child within their religious practices.

In addition, the DH of a special school stated that the school catered for the religious aspects of different BME pupils within their communities. The DH said,

We recently had Chinese New Year. We actually had two parents who provided Chinese food. We had an Indian week … and in a
couple of weeks we’re going to do Ghana. Actually it is a good vehicle to teach children because you sort of try to immerse them in that week and the whole thing, in terms of their learning needs (DH, 4/8).

Moreover, when the same question on religious needs was raised with the TA1 at a mainstream secondary school, he said,

Obviously, some children are off for Diwali and some are off for Ramadhan and they are all supported. It’s never ever a problem and if parents don’t want their children to be in a Christmas concert for any reason but you don’t get that (TA1, 1/19).

Similarly, the nutritional needs of BME pupils which are linked to cultural and religious beliefs, was explained by TA2 of a special school, who said,

The cultural and religious needs is always taken into account, the vegetarian option we know exactly what, when they come in, we have a book of the children of exactly what their dietary needs are (TA2, 2/17).

The Speech and Language therapist (SaLT) who is a health professional and who works with children in education, was also asked about how she provides for religious aspects of BME pupils’ lives during her assessments of speech and development of these children. She said,

The thing that I have to be aware of is … if there is any behavioural type feeding difficulties. I try to find out if somebody is vegetarian … or whether or not there is a cultural aspect that I need to be aware of (SaLT, 12/8).

While there is recognition of cultural and religious aspects of pupils’ lives by professionals, there are in some cases where support in dietary needs is not easily provided. Evidence for this comes from SST1 who said that the EMAS advisor who provides for a particular BME pupil at the resource based unit in the school “struggles to meet his need” (SST1, 7/7).

In relation to what was stated about religious based support by the relevant support organisations, the Project Manager (PM) of a national society also said that the aspect of religion was “fairly handled” (PM, 14/7). His view was no different to the view of the
Executive Officer (EO) of a national charity, who also said that,

We have to take into account the needs of families based upon their religious and their cultural differences. Perhaps it’s differences between ... those cultural differences, there are many of them and not just the usual way of which we approach things in Wales. It’s a big big challenge for all of us. It’s one that is not lost, I can assure you. I genuinely do feel that we do need to move in Wales (EO, 13/11).

The Local Authority Officer (LAO) in the selected LA also went on to say,

So we are very clear that actually your additional needs relate to your language acquisition or your being particularly vulnerable because you’re in a group who are likely to go under a change. So we would always expect our schools to take account of the whole child and so they would of course consider what their language acquisition was, what their, you know, special needs in some cultures is not as, is much more content in the family. It will take longer to be confirmed that, they actually have a special needs as well (LAO, 9/8).

It is evident that both the EO and LAO, state that they are aware of the cultural and religious differences of BME needs. These stakeholders also recognise that although it may be a challenge for them, they will be able to meet the needs of the different BME communities in Wales over time.

4.10.4 Support for BME pupils with autism during transition

Transition is the time when a pupil transfers from one education setting to another, one classroom setting to another or from home to school and back (DfES, 2004; Wilkinson and Twist, 2010). As the interviews with parents demonstrated, times of transition are particularly worrying for pupils with autism. The role of the outreach team in the phase of transition was explained by the Deputy Head (DH) who is a specialist teacher and who has also a role as Head of outreach. The DH explained that the aim of the outreach team is to offer advice and training to schools supporting pupils with autism. In giving a brief explanation of about how outreach is carried out in schools, the DH said,

So a lot of children that we do in outreach might be attending XXX (name of a special school) for their first placement. So we are able then to liaise with the school staff, parents, they come and visit (DH, 4/10).
The process of outreach as explained by the DH is to make the transition from one setting to another as comfortable as possible for pupils, parents and staff who are involved.

With regard to supporting pupils’ concerns around transition, the DH said,

…we make booklets, before they come in transition and when they leave. We do have some children who have split placements, so they attend mainstream school for maybe a day a week some of them do and some of them don’t, we have very good links with XXX and YYY (names of resource units based in mainstream schools) if they do go there (DH, 4/10).

Further, when questioned on key issues during the phase of transition for pupils with autism, the teacher at a special school responded by saying,

There is a well-established process in that when we find out where the child’s going, then the receiving school and ourselves will discuss how we are going to set the transition up. The person from the school will visit with the child here and then the child will be taken over to the new centre (Teacher, 3/15).

There appears to be a good liaison between key personnel in education during the transition phase in the special school.

When discussing the transitional phase at a mainstream primary school, the SENCo stated,

We have a girl who came from the unit at a primary school … I liaised very closely with the SENCo of her previous school. Next year, when she goes to high school, we will … invite the SENCo from the high school that she will be attending … to discuss what her needs and supports are. I have very close relationship with the SENCo at the high school (SENCo, 5/9).

In recognising that the provision of resources and support for pupils with special needs including autism may vary between LAs in Wales, the comments by the SENCo paint a picture of efficiency and care in the transition process in the present education system in the selected LA. Similar to special schools, there appears to be a close liaison within mainstream schools in the study when supporting pupils in their previous and future placements, between primary and secondary schools. This includes weekly discussions
between the two schools and an annual review discussion involving key personnel in education, to follow the progress of the child.

While the need to cope with transition is not unique to the BME community (Jones et al., 2009), it is noted from the interviews with EMAS advisors that they are not required to work in special schools. In one case, when an EMAS advisor was asked to support and advise teachers on aspects of cultural diversity of pupils with autism, she found it difficult. Evidence for this was revealed by EMAS2 when she said,

I was called out to various schools, where they had a concern over pupils and so I was asked to go to XXX, an autistic school in xxx Wales, to advise on aspects of cultural diversity, to the teachers. I wouldn’t have the faintest idea on how to begin with autistic children really (EMAS2, 11/7).

The above comments made by EMAS2 show that she was able to advise teachers in relation to cultural needs of pupils whose first language is not English, but not about the needs of children with autism.

Part Three

4.11 Research question three

In what way do BME parents and stakeholders identify improvements for the future?

This section focuses on providing an overview of the key principles for future support of BME parents and their children with autism. The responses from the interviews show that in several instances both groups of participants, namely parents and stakeholders refer to common issues which can be used to inform a discussion of what kind of support should be available in future. These common issues which give rise to key principles may be useful to be taken into account when addressing in particular, the needs of BME communities in education. However, it should be noted that, as illustrated by the data, that these concerns may not be unique to the BME community but are across the wider population.

In this study and as mentioned in Chapter 2, the term good practice refers to the extent of awareness of autism, good relationships and knowledge understanding by lead providers in education who support parents and their children with autism (NAfW, 2002; Jones et al.,
The good practices that are highlighted here are taken from the data that were given by parents and relevant stakeholders during the interviews. These interview data are then broken down to highlight the main quotations to indicate the main ideas that are relevant to good practice. It is these main highlights from the interviews that are elaborated and discussed upon next.

4.11.1 BME parents are being ‘pushed off’ by their own communities

One of the significant issues that have emerged from the data is that parents from the African, Pakistani and Chinese communities have stated that they received support from the non-BME community rather than from their own communities whom, they felt, appear to ‘push’ them away. For example, in stating his experience, one parent from an African background said,

… once they (BME community) know that you have a child with a disability, they push you off and that’s really destroying” (Adeo, 6/36).

Similarly, another parent from a Pakistani background blamed the attitude of his community, particularly of the older generation, towards disability. This parent said that the attitude of his community towards disability is,

… mired in centuries ago attitudes of mysticism, witchcraft, … which has got nothing to do with their religion (Amin, 8/43).

In comparison, Amin said that the younger generation seems to understand and accept the disability due to them being better educated.

These cultural and religious aspects of the perception of their child’s disability from their own communities result in these parents looking towards the non-BME education system for support, which is the source of support anyway.

The data also showed that one key advisor in education was also aware that BME parents feel that they are being ‘pushed off’ by their own community. However, this key advisor said that, compared to 20 years ago, the social stigma was, “lesser now” and that BME parents are “aware that we are a supportive sort of society” (EMAS2, 11/12). A similar view was also expressed by the PM of a national society, when he said,
There’s a certain amount of shame in some communities and it’s kind of hidden away and they don’t want to talk (PM, 14/5).

This key person was of the view that some BME parents do not seek help because they do not want others knowing about the ‘shame’ of having a child with a disability.

The need for support in the religious aspects of BME parents of pupils with autism are also acknowledged and reflected in the perception of stakeholders. This need is highlighted by a key person (SST2) within a resource based unit within a mainstream secondary school, when she stated that there are special facilities laid out for BME pupils, such as, a prayer room for Muslim children. According to the key person, the school appears to take into account the special needs of BME pupils by providing additional care where they deem it to be necessary, such as, in observing special diet for these pupils in relation to their cultural needs.

This study which refers to the changing demography in Wales raises the need to address the cultural, religious and the different languages of BME parents of children with autism within education, thus giving rise to the next key issue.

4.11.2 BME communities are not homogenous

It was emphasised by participants and it became clear when analysing the data that it is too simplistic to talk of the ‘BME community’ as though it was a homogenous entity. What emerged from the data is that there is a diverse range of backgrounds and various groups within the community. In highlighting this diversity, the role and involvement of BME parents in the education of their child should be taken into account, particularly recognising that the community is not homogenous within and between themselves. With this change in population comprising migrants coming into the UK from different parts of the world, there is also diversity of languages within this community. The following examples by parents show that the BME community comprises of different communities within itself.

In one instance, when a parent was asked if she had the opportunity to talk to other parents about the support for her child at school, she said,
Not many, I don’t know … if I’m a Chinese or because there was other reasons (Lim, 1/11).

A different parent, when asked about how her community viewed autism, said,

We are Africans and we have a different mindset when it comes to autism. … we tend to spiritualise things (Fante, 4/13).

From the perspectives of stakeholders, a key person in education, when referring to the diversity within the BME communities and the nature of the changing society through new migration into the UK, stated that there was the need to recognise that the BME community is not homogenous. The key person said,

I know there’s been a new challenge recently … like with people from the Eastern Block moving here and also the Somali migrants. That’s been an increase … that’s something that you have to be aware of and you have to respect (SaLT, 12/22).

The same key person stated that there should be services within schools to cater for the diverse cultural mix of pupils in schools. This person added that in order to understand the different cultural aspects of these pupils, it would be necessary to provide them with translators.

Further, a key person from the national society who was also aware of the diversity of the BME groups, said,

Our family support worker clearly understands the need to tailor information to different ME groups (TC, 17/5).

Additionally, another key person from the support organisation (Charity B), said,

More from different ME could be volunteers now, they could be brought in and they could help with the language barrier (DM, 15/17).

There were also examples of the type of specific activities that could be provided to improve the way cultural needs of the BME are addressed. This is evidenced by the Deputy Head of a special school, who said,
I would like to translate some of that literature … and some training for staff about cultural differences. I don’t think we really realise that there are different cultural perspectives on that and beliefs (DH, 4/21).

Other ideas that emerged from the perspectives of the stakeholders referred to what more could be done so that these children and their parents could have better support. Evidence for this comes from a key person of a national charity, who said,

I think the task has to be primarily to increase the awareness of the practitioners about the needs of the ME groups and the challenges and the cultural differences … there is for ME people and their families (EO, 13/12).

The comments that are made by both parents and stakeholders reflect the diversity of the BME community and the need to take this into account when planning to support the needs of pupils with autism from BME families.

The next section will therefore present data relating to policy making in relation to diversity.

4.11.3 Delivery of educational services is not culturally appropriate

The perceptions of parents and stakeholders in this study highlight that the approach to the provision of services are similar for all families of pupils with autism without differentiating that the needs of BME communities may be unique. In highlighting this point, data shows that BME parents regard support groups that are provided by relevant support organisations as being inaccessible to them because of the location and timings of their meetings. This is evidenced by one parent from the Pakistani community, who found it difficult to seek support from the non-BME community, when she said,

… they don’t have a parent group or a child group that I can access because it’s always in a pub, quite late on” (Jamilla, 11/21).

This is because in her view, the chosen venue may not be acceptable for Muslim women within her community.

When referring to culturally appropriate services provided by the Welsh Government, a key person from the national society said,
… their only legal obligation is to produce in English and Welsh and they don’t do anything else (PM, 14/5).

Further, there is the view from a key person in a mainstream school that support provided for pupils with autism is “the same for all” (TA2, 2/20). This view was similar to that of a key person from a special school who also stated that, “everyone is treated the same (TA1, 1/27).

A number of other key concerns regarding the delivery of services were also pointed out by the PM, who said,

I think the needs of the pupils, once they have accessed the system, are being met. I think the system will be blind to where they come from or what their ethnic background is … Whether the ME pupils are able to access the system as easily as others, that is another question (PM, 14/8).

Finally, in reflecting upon his own non-BME ethnicity and the way avenues for meetings and information materials are selected and delivered in Wales, the PM, in his view, stated that,

I think the trouble is the material produced and the way we deliver the materials … because of who we are, tending down the White Anglo-Saxon route … that’s what we are familiar with and that’s the kind of things we do (PM, 14/5).

When referring to good practice, the Local Authority Office (LAO) within the selected LA, said,

Schools need to be autistic friendly then you would probably be good at dealing with … with behaviour needs (LAO, 9/35).

The next key principle refers to the principles of inclusion and the choice of school.

**4.11.4 BME parents have a choice of school that they want for their child**

Another key issue referred in the interviews was the question of choice of school that parents are recognised to have within the principle of inclusion and how this could impact on the support provided to pupils in either mainstream or special schools. The right of parents to express their choice of school was raised by one parent when recalling her son’s
position early in time. It is noted that the age of the son of this parent was nineteen at the
time of the interview in this study. On this point, the parent said,

I wanted a choice actually from the local authority … although I think he (son) would still be able to cope in a special unit in
mainstream and this choice wasn’t actually given to us (Mina, 2/7).

In terms of relating to the choice of support that would be useful for them, there were
some (Lim, Nazia and Fante) who expressed a preference for after-school clubs and
summer schemes for their children so that they could get respite for themselves. The
evidence in the data shows a parent’s exhausting need for support when she said, “I’m
tired because … it is mentally draining” (Fante, 4/7).

However, Tammy’s preference was for her daughter at the resource base unit to be
allowed to participate or get involved within the mainstream classrooms. In Tammy’s
view, this could only be achieved by the school if the needs of autism are incorporated
within its policies and procedures. She also said that it would be helpful if schools had
visual timetables and photographs of all teachers and peers on the door of each classroom.
According to her, this would instil clear ideas for a pupil with autism of what happens
within an education setting.

In referring to the nature of the parents’ choice, a key person in education, SST1, stated
that in one case a BME parent chose a mainstream resource-based school for his son
despite the fact that his child had severe autism. In the view of SST1, this was an incorrect
choice. According to SST1, parents are invited to come up to the school where they are
couraged to spend their day at the school before they select a school for their child. The
SST1 went on to say that, “at the end of the day, it’s the parents’ choice (SST1, 7/21).

When referring to good practice in the provision of facilities in schools, one parent said,

The school should be very clear to all the children what the routines
and plans and the timetables of everything was so that children had
very clear notions of what is happening, their peers, the staff and
everything (Anne, 2/7).
Apart from the views of parents on the choice of schools, there are other key issues which have been raised. These include how support might be provided in future especially during the transition phase of education.

4.11.5 Apportioning blame and shifting responsibility

The data in this study shows that there is blame placed by both the parents and the stakeholders on each other for what they see as the best way to support the child with autism. There is evidence from one parent from an African background who stated that she did not like the teacher’s attitude since the teacher made her feel that her child had been a “nuisance” (Fante, 4/6). According to Fante, the teacher said,

Bini (Fante’s daughter) has been screaming and she has been upsetting the other kids (Fante, 4/6).

There was also evidence from a parent who felt angry in the way staff at a Welsh primary school cared for his son in the reception class. He said,

They couldn’t cope with him and from what I learnt was they had legally to keep him there unless we ask for him to be removed (Amin, 8/1).

From the stakeholders’ perspective, the evidence also shows that they are also considering where the fault or weakness lies. It is interesting to note that, in one case, a key person from a national society, the Project Manager (PM), in commenting on the way services are currently being accessed by BME parents, said,

… because of the way they push and the way they access … I think that there may be an issue. I think it’s all down to not being aware of the condition. I hesitate to say that the ME children are being let down by their parents. But who knows? I’m aware of these issues but I don’t have answers to the issues (PM, 14/8).

The PM was not willing to say that BME parents are to blame because they are unable to ‘push’ as hard as the White parents, and is also suggesting that the blame or lack of services may lie with the stakeholders. Here the PM is stating that the non-BME parents are better able to push to access to services to meet their child’s needs. A key person in education, SST2, blamed her own lack of knowledge of BME needs, as a specialist teacher on the provision of training that was provided for her and her staff at the resource-based
unit within mainstream school. The SST2 gives the impression that there is something different about the BME communities when comparing to the non-BME community, which is evident when she said,

I don’t necessarily know a lot about the ME and where they are coming from. … there’s not been a lot of training on this (SST2, 6/16).

On the other hand, another key person in education, SST1, in relating to a BME pupil with autism whose parent wanted him to wear a badge stating his difficulties, felt that it was the parents who lacked understanding of their child’s condition.

In highlighting that schools have a major role to play in education, EMAS2 said,

Schools are the gatekeepers of education. You drop the child off, then it’s up to the teacher to do everything and you don’t interfere (EMAS2, 11/19).

The next section examines the data which highlights the principle that parents have valuable insights due to their lived experiences.

4.11.6 Parents have valuable insights since they have close knowledge of autism

Data in this study show that parents consider themselves valuable since they feel that they have close knowledge concerning the condition of their child through their lived experiences. They felt that these are strengths which were not being appreciated by the schools, for example, half of the selected parents in this study spoke about their children’s strengths.

One parent, Lim, stated that her son is, “good at remembering different country’s flags (Lim, 1/2). Another parent, Mina, said that her son’s, “concentration is very good. If he sees a portrait, he will actually draw it exactly like the same. It’s part of his talent” (Mina, 3/3).
There were also other parents who mentioned less favourable behaviours saying that their children “liked running and playing outdoors” (Amin, 8/3) and “very obsessed with spinning things” (Nazia, 2/3).

There is also confirmation of this view by some professional stakeholders grounded in the data. For example, in recognising that one aspect of autism is about how the child behaves in an educational setting, the DH of a special school stated that she has confidence in the knowledge of parents regarding their child’s behaviour. According to her,

> Parents always give you key pieces of information that other people don’t see or don’t have (DH, 4/14).

The EMAS advisors within education then said,

> The school is the expert so they get on with it (EMAS1, 10/19).

When highlighting the idea that parents are the ‘experts’, the Local Authority Officer (LAO) also stated that,

> Sometimes, schools do not listen enough to parents and sometimes parents have a very unrealistic expectation of what is good progress (LAO, 9/35).

The comments so far show that professionals in schools need to take into account that there are strengths in the views of parents concerning their child. Professionals in education should then address pupils’ strengths in order to achieve a balance when providing services in education that reflects their strengths.

4.11.7 Continuous Professional Development (CPD) training for staff in mainstream and special schools

Literature shows that pupils with autism, who may have individual needs, may require specific support by professionals in education (Jordan, 2006; Wing and Gould, 2011). Thus, indicating that teachers should be provided with CPD to enhance their understanding on how best to support these pupils in education.
In two cases, the parents of children in mainstream schools mentioned that “there was no support teacher” (Anne, 7/6) and that the school “don’t have facilities and don’t have qualified teachers who can do that job (Adeo, 6/1). In their views, these parents appear not to have had a good experience in relation to their children’s time at school. The comments by these parents indicate that there was a lack of facilities and teachers who are not experienced to support pupils with autism. Additionally, Fante said that she felt uncertain about whether the teacher was trained to be aware of her child’s unique behaviour as a special need. She added that teachers should be able to understand how children may behave given that they may have special needs.

The majority of parents were of the view that staff at various mainstream schools are not experienced in supporting pupils with autism within the classroom. There were three parents who said that they were satisfied with the level of teaching provided by staff in these schools. There was also one parent who said that the special school that her daughter attended made a difference to her daughter’s behaviour. She said that she could “see that she (her daughter) was improving there” and that she was “calm and controlled” (Nazia, 2/1). The mixed feeling of parents’ views may refer to the level of support which depends on the severity of the child’s condition.

The perspectives of the stakeholders have also been useful in understanding the way resources and training needs are met for those supporting pupils with autism. When referring to the services provided by SaLT in Wales, the Executive Officer (EO) of a national autism charity said, “There’s not enough of them” (EO, 13/12). Similarly, when asked the reason for this lack of expertise, the SaLT responded by saying,

I think there has been in the past … a lot of it is linked into finance. (SaLT, 12/16).

Both the EO and the SaLT confirmed the shortage of such skilled people in south Wales and therefore felt that more people should be trained specifically to fill this shortage.

When a question was asked about the Continuous Professional Development (CPD) training for staff, a Teaching Assistant (TA2) in a special school said,

I’ve done a lot of courses: PECS with in-house training (TA2, 2/3).
The comment by TA2 is that staff at special school are equipped through CPD training, to care for children with autism. The TA2 then added,

We have had translators especially if there is a review or something and if you got parents ... it’s always available (TA2, 2/16).

The Specialist Support Teacher (SST1) in a resource-based unit in a mainstream secondary school appeared to show a lack of understanding of the support that should be offered to BME parents or carers of pupils with autism. He said,

If they have a problem, all the parents have our emails, phone number and direct lines (SST1, 7/16).

With regard to the role of charitable organisations, the SST1 and the TA1 at a secondary mainstream school stated that they did not rely on charity for help with staff development. In contrast, five other stakeholders stated that although they had not relied on any information from these organisations, they did have a look at the charity websites in their need to understand or self-educate themselves in autism. Instead, they said that they relied on the LA for information and material.

Additionally, the SST2, when referring to the need to have more resources and what that would be able to achieve said,

We could employ staff who are of ME and obviously we have been able to because ... in fact we’ve never had anyone apply to our job and I think that would be quite important because then we could have from the staff point of view an additional perspective on a different religion or a different culture (SST2, 6/17).

The comment seen to suggest that just by employing one of ME staff would make a difference in the provision of support to BME communities.

When referring to good practice the PM said,

What we can use are the leaflets, emails, websites … which have been developed over many years (PM, 14/10).

Moreover, when the PM was asked the question about what happens to a child with autism from a minority ethnic background, after school hours, he said,
I haven’t got an answer and what it needs I don’t know. But I think something is missing. Like a jigsaw puzzle. Yes, I need to find the missing piece (PM, 14/10).

In view of engaging with the BME community, the Development Manager of a parent support group (Charity B), said,

More from different BME could be volunteers now, they could be brought in and they could help with the language barrier (DM, 15/11).

Finally, the EO of a national charity pointed out that teachers within Wales are professionally qualified in the field of autism and “there has been a big attempt to, over the last 20 years to improve the awareness of teachers” EO, 13/9). The EO also added that new modules in Additional Learning Needs had been created and were available through web-based learning resources for teachers in Wales and that this includes a unit on autism.

The next chapter will present the discussion on the first and second research questions in this study. The third research question which refers to good practice in education, which has emerged from the analysis of the interviews however is found to be more appropriate to be presented in Chapter six.
Chapter Five

Discussion of findings
5.0 Introduction
This chapter discusses and highlights the findings in relation to research questions one and two and addresses within each of these questions, relevant explanations that emerged from the interviews. The sequence will be firstly, of the experiences and perceptions of Black and Minority Ethnic (BME) parents and secondly, the perceptions of key personnel in education and relevant support organisations, which are together referred to in this study as the stakeholders. The third question which identifies improvements for future support is discussed in chapter six.

5.1 Research question one
What are the experiences and perceptions of BME parents of the support they and their children with autism have received through the education system, relevant support organisations and, their families and wider BME community?

The aim of the first question was to examine BME parents' experiences and perceptions of the educational support that they and their child with autism receive. These perspectives are addressed in the following sections, firstly, to their experiences and perceptions of support within the education system. Secondly, in relating to the services provided for them by relevant stakeholders comprising key personnel in education and relevant support organisations and thirdly, in view of the support they receive from their families and their community.

5.1.1 Pre - and early school experiences
The involvement of parents of children with autism, with support agencies, often begins in time with pre-school experiences of their child when they start to have early suspicions that something is not right with their child’s behaviour. There were seven parents in this study who indicated that they experienced feelings of denial or refusal to accept their child’s condition which led them feeling isolated. In addition, nine of the parents expressed feelings of grief after the diagnosis of their child and they described their feelings as being similar to a kind of bereavement phase. However, there were three who felt relieved on receiving a diagnosis, since they knew that they would be able to receive some support for their child. These feelings were also confirmed in the findings of a study by Midence and O'Neil’ s (1999) that was based on a sample of parents from a British White background. Additionally, these authors stated that a diagnosis for autism may also provide parents with
an explanation of their child's behaviour. However, it was different in Perepa’s study, where the common response after diagnosis by most parents from BME backgrounds was that they had never heard of the condition and with some parents “trying to find a medicine that would cure” their child’s condition (Perepa, 2008, p. 143).

There is also the perception of BME parents that they are able to express valuable insight through their lived experiences about their child’s behaviour, which is also confirmed in the literature (Tam, 1998; Willig, 2005; Perepa, 2008). These parents feel that their own lived experiences in turn could assist professionals in providing educational support services for their child. While many parents feel that they are able to offer close knowledge, there were others who felt that their knowledge was not seen as such by some key personnel in education. Although best practice suggests that parents should be involved in the process of making decisions with staff in schools about their child’s learning (NAfW, 2002), the response by parents in this study suggest that it is rare that they are involved.

It is important to ensure that when communicating with children and their parents from BME communities, they should be provided with translated materials on support provided in their own language. It is noted that in this study, only one parent within the sample stated that translated material in her own native languages would have made a difference. Literature also confirms the need for translated information materials to be made available for BME communities (Jones et al., 2009). There is also confirmation by key stakeholders that they recognise that language concerns communishould be addressed, for example, through the use of relevant translated material for BME parents and their children.

It is noted that parents who participated in this study were from different socio-economic backgrounds. Some of the parents were found to be fluent in the English language and this was recorded in the interview transcripts. Further, they were living in affluent areas within the selected Local Authority (LA) and through their social networking, were better exposed to the support that was available. For example, there was a participant in this study who is an academic in a local university and another, a radiographer at a local hospital and these parents were seen to be more pro-active in their search for information and support that they received. However, there were others who were not as informed. For example, one couple from an African background, who was not in employment and who lived in a poorer area within the selected LA, believed that their child would get better
with age and continue to develop. This belief differs to what is stated within the triad of impairment that autism is a lifelong developmental disability (Wing and Gould, 2011).

There were also four parents who were seen to be “fighting” the education system for the preferred choice of schooling for their child. They stated that they had to ‘fight’ to obtain support for their children and this ‘fight’ could be a way of getting their voices heard and “who may otherwise remain silent” as confirmed in the literature (Bogdan and Biklen, 1998, p. 204). The findings in this study on the need to ‘fight’ for services is also similar to that evidenced in the literature of other studies (Corbett and Perepa, 2007; Perepa, 2008; Jones et al., 2009).

The particular difficulties of caring for their child were continuously highlighted by parents when they expressed their views on the services that they expected from staff at schools. The data in this study shows that BME parents were of the view that Speech and Language Therapy (SaLT) and the provision of school clubs were regarded as valuable for their child. From a resource perspective, it is useful to be aware that research has shown that while SaLT services are seen as useful specifically for pupils with autism, such services are not provided adequately in many areas of England and Wales (Lindsay et al., 2002; NAfW, 2002; Jones et al., 2009). Evidence for this is from the Executive Officer (EO), who when questioned about the lack of SaLT services, said, “There’s not enough of them” (EO, 13/12). This was also confirmed by the SaLT who when interviewed in this study, said, “a lot of it is linked into finance” (SaLT, 12/16) and thus highlighting the concerns of parents in this study.

There were two parents whose children attended mainstream schools who commented that the teachers in these schools were not ‘qualified’ to work with pupils (Adeo, 6/1; Amin, 8/1). It is important to note that I as the researcher did not probe into the meaning of the term ‘qualified’. Therefore, my inference is that the use of the term by BME parents could refer to their views of teachers who may not be experienced in supporting pupils with autism. It is also relevant to note that, the use of the term “qualified” was also used by one mother in Lee’s study (2010, p. 164) to refer to the experience of staff in education.

It is also relevant to refer to Willig (2005) who suggests that the interpretive approach recognises that the phenomenon that is explored could be influenced by the researcher’s own view of that phenomenon. Since I am also from a BME background, it is likely that
those participating in my study may view the questions that are posed to them in the interviews, as reflecting similarities of our ethnicities. Here it is useful to refer to the view by one parent who said to me that stakeholders should recognise and relate to the ethnicity of their children in education. The parent in this case may be stating this view because we come from similar backgrounds. Evidence for this is from the parent who used the phrase, “As you know …” (Amin, 8/6) during the interview which implied that the parent thought that I would understand the parent better.

The issue of transition has also been raised in the data as being of importance and one which has to be taken into account within the education system, since it is a difficult time for both parents and their child with autism. Literature confirms that the phase of transition is particularly worrying time for parents of children with autism particularly when they have to cope with difficult behaviours of their child such as kicking and screaming (Jones et al., 2009). Other difficulties include when their child has to travel from home to school and back, when moving from one school environment to another, or from one classroom setting to another. There were also issues that focused around pupils’ physiological development which parents felt that professionals should take into account. This refers to the child’s growing up phase when the child goes through puberty and which may lead to behaviours that may often become increasingly difficult to cope with for parents.

While parents in this study stated that they experienced difficulties during the phase of transition, one participant from a non-BME background and from within the stakeholder category, was able to give valuable information as a parent of a child with autism herself. This parent, referred to as ‘PPD’ confirmed that difficulties such as moving from one educational setting to another or feelings of anxiety were experienced by all parents of pupils with the condition. This parent referred to the transition as a “melt-down” phase (PPD, 16/5), where children with autism experience anxieties and have to struggle with change resulting in times of difficulties in their lives. Therefore, in my view, it may be that these difficulties by parents during transition may not be particularly related to those from BME communities.

Parents also stated that they were aware of the differences in the provision of support in mainstream and special schools (Lim, 1/23; Mina, 3/23). According to them, there are fewer resources in mainstream schools compared to special schools and this is confirmed
in the literature (Jordan, 2006). The data in this study show that there were two parents who preferred mainstream school for their child, although, they were aware that there were not sufficient resources within these schools (Tammy, 5/1; Mina, 3/29). The reason for their preference was that they felt that the setting within mainstream schools would instil clear ideas of routine within mainstream classroom settings for their child. It is also noted that policy emphasises the need to adopt an inclusive approach by increasing the participation of pupils with SEN in mainstream schools (UNESCO, 1994; NAfW, 2002) and to provide these pupils with a fair opportunity to be educated with their peers (Booth and Ainscow, 2002).

The understanding of parents’ views on what they expect as support for their needs may be explained by the affirmative approach. The approach states that there should be a more supportive society and that a disability is not to be viewed as a ‘tragedy’ (Swain and French, 2000; Wall, 2006; Cole, 2008) or negative experience. Some parents in this study were of the view that resources that are provided for their children should address their child’s disability and acknowledge their ethnic, cultural and linguistic diversity (Lim, 1/23; Jamilla, 11/21). Cameron (2011) argues that those who provide care for individuals with disabilities have a duty to be sensitive and appreciate the situations of the individuals in their lives.

5.1.2 Role of relevant support organisations outside of education

When referring to the view of personnel in relevant support organisations, there were four parents who said that the provision of respite care or short breaks and parent support group meetings were found to be helpful. They highlighted that provision of respite care enabled them to have some time with their other children who did not have the condition. There was one parent who said that there was no help of this kind earlier in time. Another said that her life had been “mentally draining” (Fante, 4/7), suggesting that respite care that she subsequently received had made a difference to her life. Further, another parent who got involved with relevant parent support group himself became aware of respite care and stated that his spouse was considering this support. In addition, there were also four parents who attended and found the Early Bird programme, which was provided by the national society, helpful and beneficial. According to these parents, the programme provided them with skills to support their child’s social communication and to manage appropriate behaviours as they start school.
Parents also confirmed that the support organisations such as Charities A and B were helpful, particularly for gaining information, providing legal advice and support, and in assisting parents during meetings with professionals in education. As confirmed in the literature, these meetings provided opportunities for social networking that were seen as helpful in terms of reducing feelings of isolation that some parents experienced (Huws, Jones and Ingledew, 2001; Benford, 2008). However, these networking or interactions are inevitably not the same for all since it may be effective for some and not for others.

The evidence in this study shows that eight out of eleven BME parents stated that they do not get support from their families or their communities, unlike three who said that they had some support from their own parents and siblings. When referring to the parents’ reliance on support groups, one parent stated that she felt that she was able to access local support groups run by people from the non-BME community rather than from the BME community. This parent indicated that she was looking for support from the local community, since she was unable to relate to her own community for support. Although, this aspect of her view concerns the way that she relates to her community, it also highlights that there are charitable organisations that provide support for those in need. For example, in this parent’s view, the local non-BME community understood autism better and this led her to seek support from the Salvation Army, a religious and charitable organisation. The importance of the contribution of support groups is also acknowledged in the literature (Bitsika and Sharpley, 2000; Mandell and Salzer, 2007; Osborne and Reed, 2008).

5.1.3 Support from family and the wider BME community

There is also evidence in the study which has shown that parents of a child with autism relate to their families and their wider communities in various ways. An idea that emerged from the voices of these parents was that only a few members within their family and their community seemed to understand their child’s condition. Literature indicates that accepting a child being born with special needs may be difficult within some cultures since attitudes towards special needs can be rooted deep within their cultural beliefs (Dyches et al, 2004). There is also the view in line with both Chamba et al.’s (1999) and Dyches et al.’s (2004) study that parents believe that their children would outgrow the disability and lead a normal life. There is evidence grounded in data within this study showing that some
parents were of the view that their child would outgrow the disability (Nazia, 2/1.1; Adeo, 6/46).

There is also the view among the parents in this study who stated that their communities regard autism as due to bad parenting and that they tended to blame the mother rather than the father for the disabling condition of the child. This view was earlier criticised by Rimland (1964) who suggested that the idea of bad parenting was derived only from anecdotal evidence from Kanner’s study of children with severe behavioural difficulties. In addition, Eisenberg (1957) explained that autism is a biological condition and not the result of unloving parent-child relationships. Regardless of the findings of earlier research, many of the parents in this study continue to state that some members of their communities still regard autism as due to bad parenting, which is regarded as “unfortunate” (Amin, 8/43).

In line with this view, one parent stated that she did not want to make an effort to explain about her child’s condition to people in her community. Instead, this parent said that she would rather remain a “silent sufferer”, which as specified by her as “even more dangerous” (Fante, 4/47). This statement by the parent is a thought-provoking comment that could be taken into account and explored in future research.

When a child is diagnosed with a disability, it is usually the case that the parent may want to reach out to their immediate family members or even their community for support (Hatton et al., 2004). In some cases, on account of the stigma associated with the child’s condition, the parents state that they isolate themselves from their families. This was because they believe that their families’ lacked understanding of the condition as well as the fear of how they may respond to them and their child.

In one case, a parent from a Chinese background said that members of her family believed that her son’s condition was contagious and isolated themselves from her family. Similar findings within Asian communities were also reported in a clinical study by Dobson and Upadhyaya (2002). However, in some cases, parents may not have a close relationship with their families and may not expect any kind of support from them.

Parents also acknowledged that the role of family is important and one parent in this study recalled and described the “education and training” that was given to her child by the late
sister of her spouse, who was from a Mauritian Pakistani background. Therefore, assistance from the family was crucial since it allowed the parents to ‘unload’ and share some of the burden of caring for their child with other family members. Literature also state that the emotional stress and anxiety of parents were largely due to the lack of attachment and emotional comfort from their families (Pisula, 2003). While family members may be seen as important in helping to take care of children with disabilities, the views given by BME parents were that they were not able to rely upon family members particularly those beyond siblings and grandparents.

The view by parents when looking towards family and community for support are also related to beliefs that surrounded their religion. Some parents who were from an Islamic background were of the view that religious beliefs within their community to some extent determined perceptions of disability among children, for example relating the disability as a punishment from God. Earlier studies also confirm that in much of the Asian cultures, having a child with a disability is perceived as a punishment from God (Chamba et al., 1999; Dyches et al. (2004). One view was that “It’s always the mother” (Fante, 4.13) who is then stigmatised by their own community for the child’s disability. This blame on mothers is also reported in research by Jegatheesan, Miller and Fowler (2010). Literature acknowledges that the idea of disability as a punishment is not uniquely an Islamic belief (Begum, 1995) and that there are similar beliefs and attitudes found amongst many other religious believers, including Christians (Katbamna, Bhakta and Parker, 2000). Research also suggests that ethnic communities may relate to their religion and beliefs when interpreting the support that they receive from professionals for their child with a disability (Lindsay, Pather and Strand, 2006).

Another parent of an African background was of the view that her community “tend to spiritualise everything” (Fante, 4/13) and that the blame for the child’s disability was often on the mother. This parent’s view about her community’s view of disability was similar to that found in earlier studies by Fatimilehin and Nadirshaw (1994) and Bywaters et al. (2003) who explored views of Asian parents. These authors found that parents from Asian backgrounds also tended to turn towards a spiritual explanation when there is or when they do not have access to information about a disability. These authors also found that Asian parents often felt isolated and as a result withdrew from their family, religious or social events.
There was also a view by a Pakistani parent that his community is backward in their thoughts about disability, since such views are “mired in centuries ago attitudes” (Amin, 8/43). According to Amin, their thoughts about disability have not changed from the past. Another parent also stated that the older generation were more likely to not understand autism and therefore be inconsiderate towards those with a disability. The view of one parent was that the older generation appear to be still seeking relief from “religious doctors” and “witchcraft” (Amin, 8/43) and this is seen by this parent as negative and unhelpful. In comparison, there was also the view that the present younger generations within the BME communities are regarded as more educated and appear to be better informed and caring.

Further, there was one Pakistani parent who spoke about how her community considered the condition of her child as “paagal” (Jamilla, 11/37) which she translated to me into English as ‘mad’. The parent in using the term ‘mad’ could be translating from the Pakistani word “paagal” by choosing a word that she recognises in English. Thus, this parent’s language and thoughts may be linked to her cultural understanding of autism when explaining her experiences in another language.

The experiences of BME parents, who have settled in the selected LA, also provide comparison to their lived experiences in their native countries, which they perceived as not the same. In relating to situations in their native country, one parent stated that “your problem is everybody’s problem” (Fante, 4/12) and therefore suggesting that there is more community support in their native countries than in Wales, where they presently resided. Although the responses in this study are provided by one or a few parents, it is recognised that their voices are important in highlighting the individual difficulties that their communities may experience.

5.2 Research question two
What are the perceptions of key personnel in education and relevant support organisations of the support provided for BME children with autism and their parents?

The second research question addresses the perceptions of key personnel in education and of relevant support organisations that together represent the stakeholder group (see Table
5, Chapter 4). This question explores the perceptions of stakeholders who are involved in supporting BME children with autism and their parents in education.

5.2.1 Support provided for BME pupils with autism in schools

There are interesting ideas that have emerged that show perceptions of stakeholders on the level of support provided for pupils with autism in mainstream, resource-based unit within mainstream and special schools. These perceptions include reference to the parents’ choice of school for their child, as well as on the perceptions of relevant support organisations of the support provided for BME pupils and their parents in these schools.

In reference to mainstream schools, there were staff at different resource-based units within the schools who acknowledged that they were aware of the complex needs of support needed for pupils and revealed that there might not be sufficient services for these pupils in the unit. When referring to one BME pupil with autism within a resource-based unit, a key specialist staff stated that the pupil whose condition was severe, would have been better supported in a special school with better facilities and resources, rather than in a mainstream school where there might be fewer resources. There is also evidence of one-to-one support in the mainstream school offered to pupils without a statement, although data also showed that such schools were not always able to meet the needs of these pupils. Literature acknowledges that the needs of some pupils with autism can be met in mainstream schools (Reid, 2012; Jones et al., 2009) with the help of the school, professionals and parents working together in order to better support these children.

Further, a key specialist staff of another resource-based unit stated that due to the lack of resources, pupils with autism can experience sensory difficulties and feel overwhelmed within a noisy and crowded environment in mainstream schools and this perception supports the views of Schopler (1995) and Jones et al., (2009). There were also seven parents who had different views on the support in mainstream schools and generally preferred that their child be placed in such schools rather than in special schools so that their children would learn social skills from their peers. There is also evidence from literature expressing that parents hope that their children may engage with their peers within mainstream school environment (Booth and Ainscow, 2002).
While there is reference to policy of inclusion and the right of parents to choose the school that they think is appropriate for their child with a disability (UNESCO, 1994; NAfW, 2002), there were parents in this study when faced with a choice, preferred their child to attend a special school. This is based on their perception that there are more resources available in the specials schools. There are also differences in the views regarding parents’ right to exercise this choice, where key personnel in education believe that in specific instances, this choice by parents should only be exercised after taking advice from professionals. For example, in one case, a BME parent chose a mainstream resource-based unit for his son, although his son had severe autism and in the key person’s view, this was an incorrect choice. According to this key person, parents are invited to come up to the school where they are encouraged to spend their day at the school before they select their choice of school for their child. However, the key person acknowledged the right of the parent and concluded by saying that, “at the end of the day, it’s the parent’s choice” (SST1, 7/20).

Another key person (teacher) in a special school stated that there was a process put in places for staff in schools and parents when making decisions about the choice of school for particular pupils. There was also a comment by a staff at a mainstream school who said that he did not believe that “parents make the right choice” (SST1, 7/5). This highlights the difficulties that staff at school may experience following the parents’ preference for a mainstream school, since they suggest that there are fewer resources available to support pupils with autism within this environment. In comparison, other key personnel (Teacher, TA2) within special school explained that there was a range of support provided for pupils within the classrooms. These support included ways in managing pupils’ anxieties and difficult behaviours such as biting, punching or pulling hair. These staff at the special school also spoke about special resources that were made available for BME pupils such as, a prayer room for Muslim pupils and observing special diet in relation to their cultural needs.

Interestingly, another key advisor in education said that, while she was aware of the diversity within the BME community, she did not have an answer as to how to address BME issues in education. In this case, the view of the key advisor was that BME parents were pleased with the services that they presently receive and added that “throwing money at particular community … is not going to actually solve any more problems” (EMAS2, 4/16). The impression here is that while there is support provided for all pupils regardless
of ethnicity, it is also seen that some staff are not familiar of the cultural needs of BME pupils in schools. The reference to the unfamiliarity of needs may be linked with the notion of the colour-blind services which refer to services that are “offered on the same basis to all families” (Raghavan and Waseem, 2007, p. 30).

The idea of policy being colour-blind has also been referred to in this study by both BME parents and stakeholders who have stated that it was not easy to address such services that would reflect diversity within BME communities and this view is also confirmed in the literature by Mir, Nocon and Ahmad (2001) and Lall and Gillborn (2004). These authors state that it is necessary to acknowledge cultural understanding and beliefs about disability of individuals within a multi-ethnic society. They also perceived that in a non-BME society, services are seen to be provided to their needs and therefore seen to be not aware of the needs of those from the minority community. This approach to delivery of services could be also regarded as being colour-blind without taking into account the diverse ethnicity within a society (Mir, Nocon and Ahmad, 2001; Lall and Gillborn, 2004; Raghavan and Waseem, 2007).

With regard to special schools, the views of key personnel in education were that there is a range of educational provisions in special schools for pupils with autism. These provisions included the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) which is a structured and organised programme used in the schools in the form of schedules which is embedded within the classrooms. According the Deputy Head (DH) of a special school, staff at the school are taught positive techniques to manage the difficult behaviours of children with autism and to be aware of the cultural and religious needs of BME pupils. Earlier research also point to evidence of a host of other related resources and services that are provided in the special school (Gray and Garand, 1993; Gray, 2000). These included visual timetable and various therapies provided by specialist professionals such the speech and language therapist (Jones et al., 2009; WAG, 2010b) and occupational therapist (WAG, 2008).

The need for specific support for BME pupils were raised around their language needs (Jones et al., 2009). In this study, the view of one key person in the special school was in relation to parents’ difficulties in obtaining outreach services for their child especially where there may not be sufficient staff to teach in their mother tongue. Earlier research by Modood, Berthoud and Lakey (1997) shows that BME pupils, whose families have settled
in Britain, may face cultural difficulties which will affect their educational prospects. There is also concern in some BME households where English is not the first language and therefore it may be necessary to acknowledge that there may be difficulties faced by pupils to cope with two languages rather than necessarily an indicator of disability (NAfW, 2002). Apart from language needs, there was a variety of other support in special schools such as, individualised education plan for every child in the school, dietary needs, transport facilities (TA2, 2/17; SaLT, 12/8). Additionally, there was the acknowledgement in this school by stakeholders, of the need to address religion (PM, 14/7; EO, 13/11) and of parents’ involvement with their children in schools, particularly during times of religious festivities (TA1, 1/19; TA2, 2/17).

5.2.2 Support provided for BME parents of pupils with autism

The relevance of the role and involvement of the parents in the education of their child in either a mainstream or a special school has also emerged in this study. This would include aspects concerning their decisions about their child’s placements that have to be taken into account within the policy of inclusion (UNESCO, 1994; NAfW, 2002). This involvement of parents is seen from the perspective of the views of stakeholders surrounding the policy of inclusion.

When referring to the involvement of parents, one key stakeholder, the DH in a special school spoke about a programme provided in the education of their child which is referred to as the Early Bird programme. This programme provides all parents with information and advice to support pupils’ difficult behaviours (Shields, 2000; Birkin et al., 2008). This key person revealed that there was not much participation by BME parents in the programme and stated that it may make a difference if the literature about the programme was translated into BME languages. This lack of participation is also confirmed by Anderson et al. (2006) in their review of the Early Bird programme, when they indicated that cultural values and needs of minority ethnic caregivers were not accommodated within the programme. In their argument, the authors affirmed that the programme may not be seen as useful by BME parents. Therefore, in addition to the programme, it may be useful to provide these parents with translated materials in the different BME languages so that it becomes relevant to them.
Since the sample in this study comprised parents who could speak English, they did not criticise the programme with regard to the need for translated materials. However, one parent in this study whose spouse did not speak English or Welsh said that her spouse was unable to read the available material (Lim, 1/42). Following the view of this parent and Anderson et al.’s criticism, it may be necessary to consider evaluating the Early Bird programme for BME parents in Wales to include material in community languages, due to its present diverse mix in population and therefore to achieve more involvement by BME parents. This need for language support within the programme may be relevant in the context of this study which explored the experiences of migrant BME communities of a child with a disability in the UK.

However, there was no mention from any of the participants in this study about the weakness of the programme, similar to that in Anderson et al.’s (2006) study. Instead, the parents who took part in this study and who were able to access the programme highlighted its positive aspects. The findings in Anderson et al.’s study therefore may be relevant when considering the present diverse multi-cultural society in Wales, particularly where language would be considered a relevant aspect.

A further view by key personnel in education was that parents have valuable information regarding their child’s behaviour that professionals may find useful. However, they also stated that while there is this valuable knowledge, in certain cases, the relevance of this knowledge should be balanced against the expertise of professionals. For example, where it concerns the choice of school for pupils whose autism is severe and where the provision of support for their needs would often not be met in a mainstream school, this choice by parents should give way to the advice of professionals, who may advise that children in these cases would be better placed in special schools. In such situations, the extent to which parents’ right to choose placement may be balanced against the needs of the child as seen by professionals in education.

When referring to support for BME pupils with the condition in education, the view of a key person in mainstream education was that there is a diverse range of support which includes firstly, English language classes provided for BME children and their parents in mainstream primary schools. This has resulted in better communication between parents and staff, particularly when discussing activities in schools. Secondly, they said that they have support groups to assist mothers to enable them to meet other parents in similar
situations, who would otherwise “feel isolated” (Anne, 7/10). The effectiveness of parent support groups during and after the diagnosis of a child with a disability in the UK has also been confirmed in the literature (Bitsika and Sharpley, 2000; Mandell and Salzer, 2007; Osborne and Reed, 2008). This is in terms of parents’ need to share experiences with other parents and the knowledge that they are not alone. There are also support groups in and outside schools which recognise the need of family and siblings of children with the condition. The parent support group, Charity A, provides support such as anger management and awareness of autism so that parents are better able to cope within the family environment. Interestingly, the support organisations are also aware that in order for parents to be able to obtain the right kind of support for their child, parents have to “fight” and “battle” (PM, 14/8) for services.

The use of the term ‘fight’ and ‘battle’ by BME parents in this study could be referred to parents’ socio-economic background as stated by researchers (Perepa, 2008; Jones et al., 2009). In this study, there were three parents who said that they were aware that they had a choice of support for their child, reflecting their ability to seek out information from various support services. These parents were more educated, lived in a more affluent area and spoke well in the English language during the interviews. It is interesting to note that, given their socio-economic background, they also indicated that they had to “fight” for the support that they wanted for their child (Lim, 1/22; Tammy, 5/12; Amin, 8/22). One parent even went on to say that she had to “fight” the system which in her view was very demanding (Lim, 1/22). In saying this, the parent appears to be aware of the legal process in education where appeals could be made to the SEN Tribunals if they are not happy with the choice of support that is offered to their child by the LA.

In referring to how staff relate to pupils with autism in schools, a majority of them stated that there had not been any support for staff in terms of Continuous Professional Development (CPD) with regard to providing for cultural needs and ethnic differences of BME parents and their children. It was also noted that the SaLT and the DH of a special school had qualifications and experience in working with all pupils within autism and not specifically to support BME pupils. Literature shows that teachers’ training in autism was inadequate in England (Batten et al., 2006; Jones et al., 2009) and in Wales (NAS Cymru, 2006, Evans, 2011). However, in Wales, there is evidence for CPD to maintain general levels of skills that are needed for dealing with autism in schools (Withers, 2009; WG, 2010). In this study, the view of one key person in a special school was that there were
sufficient skills provided for staff within the school on “safe ways of handling children and moving them from one place to another” (TA2, 2/3). However, this key person in the special school went on to explain that the level of services often depended upon the available funding and this was also confirmed by other staff in the special school.

When referring to language needs of the BME community, the Transitional Co-ordinator (TC) of a national society in England, which is a charitable support organisation, was aware that support materials are not tailored to meet the needs of these communities and further that they were also of the view that there are shortage of funds for such purposes. The TC also held the view that information on autism is vital to the BME community in order that they are made aware of the support that is available to them. This is because such information, when provided to these communities would raise their awareness and understanding of the condition. However, although the support organisation was positive about what should be made available for BME communities, they pointed out that, “all our information isn’t tailored to different cultures” (TC, 17/5). Further, the support organisation also acknowledged that they were aware that the BME community is not a homogenous group and that it was necessary to be sensitive to the different BME communities’ understanding about autism when providing them with information. Although there were some stakeholders who suggested that there was the need to take into account the diversity in the BME community, the data in this study shows that the perceptions of stakeholders was that support was provided for all pupils on the same basis (TA1, 1/27; TA2, 2/20; LAO, 9/15; TC, 17/5) and this was also confirmed in the literature (Raghavan and Waseem, 2007).

While referring to information on autism in other languages, it is useful to note that relevant support organisations have played a role in directing parents towards obtaining translated materials on autism from English to Welsh and also from English to a few main BME languages. One Chinese parent in this study stated that there was no translated information in her native language to support her spouse who “was in the dark” (Lim, 1/42). Except for the spouse of this parent, the need for translated material in BME languages was not considered an issue in this study since all participants spoke English. However, it is useful to note that, while translated material was not a concern in this study, the need for translated material was raised in several other studies (Shah, 2001; Perepa, 2008; Jones et al., 2009).
There is also the perception from a key person (SaLT) whose work is based in both the health and education service, that services are similar for all children with autism. This perception, in the view of some parents was that the needs of pupils from BME communities should be differentiated from the needs of pupils from the non-BME community. This was also reinforced by the view of a key person of a national charity organisation who acknowledged that the BME communities are different although this person stated that it was “a big challenge” (EO, 13/13) to provide services that take into account these differences. The challenge according to the EO’s view was to ensure that services that are provided for the BME communities are understandable, accessible and sensitive to their needs so that they are able to work the system, within the country that they live in.

This idea of the challenge can be seen from the perception by another person within another support organisation (national society) that the present service delivered by the government is perceived through a “White Anglo-Saxon route” (PM, 14/5). Similarly, an earlier study by Mockett, Hackett and Theodosiou (2009) also stated that the provision of services for Asian parents was provided in English and from a Western perspective. This could be regarded as some education service providers and charities being culturally-blind, where they see everybody as being ‘White’.

According to literature, it is stated that an effective way to deal with different cultural attitudes may be to recognise that there is cultural diversity within BME communities rather than assuming that they are homogenous and leading to ignoring their diverse cultures (Lall and Gillborn, 2004; Raghavan and Waseem, 2007). Similarly, other researchers have also proposed the need to address these differences within these communities (Mir, Nocon and Ahmad, 2001; Lall and Gillborn, 2004). These authors argued that the ‘colour-blind’ theory failed to acknowledge these differences within a multi ethnic society.

Azmi et al. (1996) refer to the lack of minority ethnic staff to help children with language and the perceptions of parents as carers that policies do not recognise their own cultural and religious differences. According to Azmi et al., the lack of minority ethnic staff may result in parents having to care for their children with learning disabilities in their own homes. These authors also stated that the lack of appropriate staff was linked to policy that is ‘culturally-blind’ (Castro, 2005) in its approach since it did not recognise that the needs
of the minority ethnic communities which are different from that of the dominant White community (Azmi et al., 1996).

The national society stated that they explored the possibility of awareness raising booklets for parents of children with autism that would also be made available for BME parents. For example, one person from this support organisation stated that the Welsh Government (WG), at the time of this study, did not have any awareness booklets specifically for the BME communities (PM, 14/5). The PM also stated that the legal obligation of WG is only to produce material in English and Welsh which is also confirmed in policy (Welsh Language Board, 2001; NAFW, 2002).

When referring to the BME community, key advisors in education stated that although they are aware that there is a social stigma attached to disability, they felt that it is lesser now compared to 20 years ago. One key advisor stated that although the social stigma may remain within some BME families, they are not going to be shut away and left in isolation. According to another advisor, the school and the non-BME community are there to offer them support (EMAS2, 11/12). However, data in the study shows that the Pakistani and African parents perceived that they are being 'pushed off’ by their communities and blamed for their child’s condition. These BME parents were of the view that the non-BME-based community is more supportive than their own communities and therefore look to the non-BME-based community to access educational support for their child. Evidence from the literature supports the view that BME communities’ perception of disability as a social stigma influences the way that they view their child’s disability (Corbett and Perepa, 2007; Perepa, 2008).

5.2.3 Services provided by stakeholders

With regard to the provision of services, literature states that staff at both special and mainstream schools need to have knowledge and understanding of a pupils’ disability (Powell and Jordan, 1993; Jordan and Powell, 1995; Jordan, Jones and Murray, 1998). These key personnel in education recognise that following a diagnosis by professionals, the child who is statemented with a disability will be offered a range of services in education (Midence and O’Neill, 1999; Jones et al., 2009).

Literature suggests that the process of diagnosis for children with autism usually begins later in children from BME backgrounds and takes longer to diagnose (Dobson and
Upadhyaya, 2002; Corbett and Perepa, 2007). This may be due to cultural differences and language difficulties experienced by BME parents when explaining their children’s difficulties to professionals during diagnosis. However, the majority of the parents in this study said that their children were diagnosed reasonably quickly except for two parents whose children were much older at diagnosis. In these two cases, the delay in the views of two parents was that there may have not been awareness of autism earlier in time.

Additionally, while one parent felt that BME parents may not be approaching the right people for the appropriate support for their child, another said that there were parents who may “hide them” from others due to the “shame” (Fante, 4/47) of their child’s condition. Literature also confirms that the understanding about disability by ethnic parents is based on their own communities’ cultural understanding and superstitious beliefs and with some parents actually ‘hiding’ their children and therefore not seen accessing the available services (Dobson and Upadhyaya, 2002; Perepa, 2008). However, it is noted from the sample in this study that majority of the parents have accessed the available services that are provided within the selected LA in Wales, which is different from the findings in the literature. The BME parents in this study say that they were seeking support from the local non-BME community since there was little support from their own communities.

There was the view expressed by key personnel in mainstream education that different professionals work closely together to support a child with autism and this included frequent review on how to provide support for these children. There were also views that support in mainstream education made a useful contribution, although this was from a Governor who was from a minority ethnic background. There were other instances of support that were directed to the BME communities such as the “anxiety box” (SENCo, 5/11) to relieve the difficulties that are experienced by pupils with autism. This included also the “EMAS UK” (SENCo, 5/8) which is a computer-based resource used for translating a BME language into English or from English to a BME language, in view of enabling communication between staff and parents. These examples of support show that stakeholders are not only aware of the necessary support but are also seen to be providing specific support for these communities.

There was an emphasis on support for BME families where there were meetings and discussions to engage and reach out to these communities. A theme referred to often by stakeholders was the need for funding, whether within schools or to pay for additional
support from outside the school such as Speech and Language Therapists (SaLT). With regard to services provided by SaLT, the view of one SaLT was that there is a shortage of a key service provided by them and this was due to the “lack of funding” within Wales (SaLT, 12/10). She gave an example of a case where a translation service had to be paid for when there was a need to communicate with BME pupils and their parents. Similar views by key personnel in education (EMAS1 and TA1) were that they did not have the funding for translator services.

There was one participant (TC) from a support organization, who said they relied on donations, fundraising and government funding. Similarly, there were other stakeholders in the study who made their views known on the importance of having fundings to support activities that were carried out in schools. For example, when referring to the provision of training and cost of paying for support services, EMAS1 had made the comment that, “most schools can’t afford to buy in interpreters on a regular basis” (EMAS1, 10/13). Further, the TA in mainstream school, who also stated that, “We really don’t have the money at the moment (TA1, 1/22). Another strong argument was given by the SaLT who stated in the interview that there was a shortage of their services due to the “lack of funding” within Wales (SaLT, 12/10). This therefore raises an important element relevant to the provision of support in education where there is a fairly consistent view that any support that is needed to be provided may need to be looked from the view of available resources. Therefore, while BME parents may be asking for more support to be extended to them which takes into account their unique multicultural diversity and recognising that they are not homogenous, the stakeholders are arguing that their ability to deliver support beyond what they are providing is constrained by what they refer to as the ‘lack of funding’.

However, as far as the stakeholders are concerned, while the lack of funding was stated to be creating constrains, it was not the only difficulty experienced by them. There were also other issues which are discussed in this study such as, among others, the idea of inclusion (UNESCO, 1994) and integration (Warnock, 1978) and in relation to various aspects of ethnicity such as culture, language and religion.

When referring to the ability of staff, in a special school, the perception of a key person was that, staff were provided with sufficient in-house skills training on positive and “safe ways of handling children” (TA2, 2/3). While there is this help for staff, the extent of this
support depended upon the available funding. There was also the perception by a few key personnel in education, that there were some parents who benefitted from the advice of social workers who pointed them towards claiming Disability Living Allowance (DLA) and family tax credits. Similarly, the perceptions of some key personnel of relevant support organisations were that there is advice available specifically for children with autism and for their parents.

When referring to support in schools, there were some key personnel who stated that they were aware of the support and facilities that were provided in special schools, which are crucial to care for children with severe behavioural difficulties. There is evidence from literature that staff at special and mainstream schools have been provided with skills to be able to recognise needs of pupils with autism, when the condition co-occurs with other learning difficulties, such as Dyslexia or Dyspraxia (Frith, 2008; Heap, 2010).

The data in this study showed that there are also available facilities such as visual timetable and support from the health authorities, such as from the Speech and Language Therapist and Occupational Therapist in special school which are embedded within the school system. However, there were other key personnel who said that they were not aware of anything specific for BME pupils. There was also the view by a few of them who perceived that when providing support in special school, they took into account “all aspects of religion and multicultural diversity” of all pupils (TA2, 2/12). The data in this study also revealed that the provision of support services in special school differed from that of mainstream school setting. Unlike the mainstream school, staff at special school were seen to be more engaging and supportive towards pupils with a disability within the classroom setting.

The language needs of BME pupils with autism and their parents has been an area of concern when providing them with support in education (Dobson and Upadhyaya, 2002; Lee, 2010). A key advisor in education stated that it is not easy for some BME parents in Wales who have English as a second language, to “familiarise” themselves (EMAS1, 9/11) about what to expect in schools, since these parents and their children could experience difficulties in language. The key advisor recommended the use of translators to overcome language difficulties, although they stated that there is a lack of funding for this service.
Another perspective on the use of translators was given by the Speech and Language Therapist (SaLT) who stated that “time is the main factor” (SaLT, 12/19). The SaLT added that to obtain translator services she had to go through a long process of application which in her view was “frustrating for everybody” (SaLT, 12/9). It was also noted that, it is not always about the competence of language of BME parents and their children but also includes the assessment and engagement of the expertise of relevant professionals who are able to provide for particular children from these communities (DfES, 2004).

Key advisors in education, EMAS1 and EMAS2, acknowledged that they must reach out by engaging with BME parents in order to find out their needs. It was noted that these key advisors do not always have an answer and appeared not to be clear in their response to questions on the needs of the BME parents. Their inability to answer, as explained in the literature could relate to them not recognising the uniqueness of BME communities (Raghavan and Waseem, 2007).

However, from the viewpoint of stakeholders both key personnel in education and relevant support organisations, the need for language support becomes relevant since they have to support all parents who reside in Wales, some of whom may not speak the English language. The perception of a key person of Charity A was that language is a barrier when relating to BME parents of children with autism. A different view was stated by a key person of a national society who was based in England. She said that the national society had several translators if there was a need to communicate with BME parents in different BME languages. This key person also explained that in cases where a BME parent did not speak English at a support group, then in such cases, the support group would rely on one of the family members who may speak the native language as well as English, to act as a translator. This reliance on family members as translators for BME parents who are unable to speak out due to their lack of language is also confirmed in the literature by Perepa (2008) and Jones et al. (2009); although this may also be viewed as unethical due to the possible biases within the family (Shah, 2001). However, it felt like the stakeholders may be just offering one step solutions rather than really thinking about the inclusion of BME parents and their children with autism, in an wholly inclusive way.

There is also the observation that language could be difficult for children who have English as their second language (Bhugra, 2002). The view by stakeholders is that there are translators and also visual material and instructions to support these children in education.
Further, in the case of BME pupils who have their native language as their first language, the use of English as a main language may not be enough. This is because there may not be sufficient staff to teach in their native language. It was also noted that mainstream schools, there were no information materials that were provided in the various BME languages and that the provision that was provided was the same for all pupils in education.

An area of concern is the experiences faced by BME parents and their children during the phase of transition in education (DfES, 2004; Wilkinson and Twist, 2010). In this study, key personnel in education were aware of the difficulties that parents of children with autism experience during their child’s transition or move from one setting to another. A key person in special school stated that a “well-established” (Teacher, 3/15) system was put in place to ensure that the pupils experience a smooth transition or transfer from one school setting to another. According to this person, the transition included consultations between staff of the sending and receiving schools. There also appeared to be a close liaison within mainstream school when supporting pupils in their previous and future placements, between primary and secondary schools and this included weekly discussions between these two schools to follow the progress of the children. Further, literature suggests that the need to cope with transition in schools is not unique to BME communities (Jones et al., 2009; O’Sullivan, 2009).

5.2.4 Recognising religious aspects of pupils’ lives

The religious needs of BME pupils appears to be an aspect that was taken into account by most stakeholders when providing support in education, although there were some who found it difficult to identify and manage aspects of pupils’ religion. Key personnel in education addressed religious aspects of pupils in mainstream primary school by proposing that schools could recruit “bilingual assistant who speaks the native language and … understand the religious aspects of BME pupils’ lives” (SENCo, 5/8). There is also a provision within the SEN Code of Practice which states that “bilingual support staff … should be enlisted from the outset” (NAfW, 2002, p. 35, paragraph 4:25) for the purpose of better communication in education.

Another illustration of general adaptation that took into account cultural and religious differences within a school setting was given by a key person in a resource-based unit in a
mainstream secondary school. In this school the BME pupils were all Muslims and were
being educated in a Christian school setting. Since the focus of the school was on
Christianity, the consent of the Muslim parents was given that during prayer none of their
children would “pray with their hands closed” (SST2, 6/11) rather than open as in Islamic
practice. According to the stakeholder, this response by the school is an effort by the staff
to meet the religious needs of pupils from the BME community. Additionally these pupils
within the mainstream school were allowed to take days off to be away from school during
the fasting month of Ramadan and also not to take part in any Christmas concert. There
was also an emphasis on the cultural aspects of the diets of these pupils in the special
school, where special effort was made; for example, to provide vegetarian options for these
pupils.

There was also evidence provided by a key person in mainstream school who revealed how
Ethnic Minority Achievement Service (EMAS) advisors at the school “struggled to meet”
the needs of a particular BME pupil at the resource-based unit in the school (SST1, 7/7).
The reason could have been because the primary role of these advisors is to assist children
with English as a Second Language, and they do not have specific training in autism and in
cultural and religious needs of the BME communities. However, the views of key
personnel from support organisations were that the religious aspects of BME pupils are
encouraged and fairly well handled within the selected Local Authority (LA), although the
data showed that participants did not elaborate on this aspect. While these views are
interesting to provide an understanding of the cultural and religious support that are
provided to BME pupils and their parents, this support does not specifically relate to
autism.

It is appropriate here to state that the next chapter will present the third research question
which explores the views of both the BME parents and the stakeholders, in the way they
perceived improvements in educational support services in Wales.
Chapter Six

Conclusion
6.0 Introduction
This chapter begins with a discussion of the third research question, entitled, ‘In what way do BME parents and stakeholders identify improvements for the future?’, in order to identify what participants consider to be best practice. This will be followed by highlights of findings in the study, a discussion of the limitations and recommendations for future research. The chapter will then conclude with some personal reflections and an evaluation of the research as whole.

6.1 Research question three
In what way do BME parents and stakeholders identify improvements for the future?

The third question in this study explores and identifies the main areas that are considered relevant for improving the future support that are provided for BME parents and their children with autism. The areas identified in this study are based on various themes that emerged in the discussions from the perspectives of both parents and stakeholders.

6.1.1 The need for the host community to recognise that BME parents of children with autism cannot depend on their own BME communities for support

In this study, the parents who were from BME backgrounds, namely, Pakistani, African and Chinese, expressed similar views that they were being ‘pushed off’ by their own communities and as a result looked to the Welsh community which is the host community for support. The reference made to the Welsh community may refer to support services within health, education and charitable organisations, which are generally provided to all people in Wales by local Welsh stakeholders. There was also confirmation on this perception from stakeholders who were aware that parents from BME backgrounds were not supported by their own communities.

In this study, the spouse of a parent from an African background stated that when his community became aware of a child’s disability, they would “actually push you off” and this according to him was “really destroying” (Adeo, 6/36). There was one parent from a Pakistani background who blamed the attitudes of his community which regarded
disability as “cultural and religious baggage” (Amin, 8/36) and therefore suggesting that the attitude had still not changed over time. There was also the perception by the same parent that things could be different for the future since the younger generation who were being educated do not regard disability in a similar way. An inference that may be made from the voice of this parent could be that the younger generation who were born in Wales, and had been educated within an education system where perhaps attitudes towards disability are explored, would be better able to communicate their thoughts compared to their parents who may have come as migrants into Wales. The same parent’s view was also that the education system may need to recognise the deep-rooted cultural attitudes of his community which was “mired in centuries ago attitudes” (Amin, 8/43).

Moreover, the view of two stakeholders confirmed that BME parents look for support outside their communities and not within, where disability was regarded as a “stigma” and a “shame” (PM, 14/5; SST1, 7/20; EMAS2, 11/12). This sense of shame was also confirmed in the literature by Fazil et al., (2002) when referring to Pakistani and Bangladeshi communities in the UK. However, the view of the stakeholders in education was that they would not let these parents be “shut in isolation” (EMAS1, 10/12; EMAS2, 11/12) since according to them, the school and the non-BME community are there to offer support.

The context of the changing demography in Wales raised the need to address the cultural, religious and linguistic needs of BME parents of children with autism within education. This is in relation to the idea that the BME community is diverse and not homogenous.

6.1.2 BME community is diverse not homogenous
The idea of homogeneity as expressed by BME parents and explained by stakeholders was relevant to understand the diversity within these communities and how they explained and related to support services. One finding that emerged was the need to recognise that the BME community was not homogenous. While the population demography is changing following migrants coming into the UK from different parts of the world, the diversity of the population is also changing. In this study, it is noted that parents refer to themselves as being Chinese, Pakistani or African and not BME as a whole. For example, while one parent said, “We are Africans and we have a different mind-set” (Fante, 4/13), another related her difficulty in making friends within the local Welsh community, to her ethnicity, when she said, “I don’t know if … I’m a Chinese” (Lim, 1/33).
In explaining the diversity that exists within the BME community it is important to focus on the voices of participants in this study. It is interesting to note that a parent from a Pakistani background, when relating to a term used in her language said, “They just think that my child is “paagal” (mad) (Jamilla, 11/37). This highlighted a negative perspective as stated by the parent who then went on to say that it was how she was seen by her community, thus inferring that this perspective may not be the same within other communities. In the case of the Chinese parent, her older son who did not have autism, described his brother’s condition as, “somebody who is retarded” (Lim, 1/36). The Chinese parent also said that members of her family isolated themselves from her family for fear that autism could be caught by ‘touching’ the person with the condition. Similar expressions by Asian parents are confirmed in a clinical study by Dobson and Upadhyaya (2002). The data in the present study show BME parents explaining the way their families and others in their community relate to their experiences which is unique within their own communities.

In referring to the approach of policies, there is the perspective of one BME parent that key personnel in education were not aware of her child’s autism. She said that the staff at her child’s nursery believed that her child’s quietness was “part of our culture” (Mina, 3/1) rather than relating the behaviour to the child’s difficulty of communicating with others. Based on this parent’s view, it could be inferred that BME parents in general expect stakeholders to understand their specific needs which reflect their culture. These voices of parents and stakeholders reveal an emerging idea that the BME community is not a homogenous whole but is within itself diverse. The perception by parents relating to their different cultures in explaining the condition of their child is also confirmed by Lloyd and Rafferty (2006: 36) who argued that “diversity both within and between ethnic and cultural groups should not be overlooked”. Therefore, when considering support for the BME parents, their context within a diverse community, need to be recognised.

There were also key personnel in a special school who suggested that there was a need to translate information on disability and to provide “some training for staff about cultural differences” and of “BME’s perception of disability” (DH, 4/21). According to the staff at this special school, they were not aware about different cultural perspectives and beliefs about disability. Another perception of staff in this school was the idea to link “families who shared the first language so that they could support one another” (Teacher, 3/28).
There were common ideas by staff at mainstream schools that also pointed out the need for additional services such as “to have enough translators” (EMAS2, 11/18) to support BME parents and their children.

Further, the view of the support organisation was that there was the need to provide better services to parents and children from BME communities. These include the need to increase “the awareness of the practitioners about the needs of the ME groups”, their “cultural differences” and to recruit “specific workers employed from ME who work with ME groups” (EO, 13/12) and thus acknowledging the diversity of the BME communities.

6.1.3 The need for culturally appropriate educational services

Another finding relates to support services that are provided to BME parents of a child with autism within education. There was a view from some stakeholders in this study which suggested that the support services that were delivered in education did not take into account the cultural aspects of BME parents and in their need to support their children in education (DH, 4/21; EO, 13/12). When discussing parents’ needs, it is useful to begin with the perceptions of stakeholders, who in this study were of the view that service provision in education are generally similar for all pupils without differentiating for the different needs of pupils from BME communities. This explanation offered by the stakeholders relates to the ‘culturally-blind’ concept (Castro, 2006), which refers to the need for policies in education to take into account the BME parents’ cultural diversity.

While this is the case, the BME parents have stated that their cultural and religious beliefs about disabilities are different from those of the non-BME communities and therefore consider the services that are provided to them by stakeholders as not culturally appropriate. These parents stated that parent support meetings arranged by support organisations, were found to be unsuitable within their culture due to the location and timings of these meetings. This view of the BME parents is confirmed in the literature which states that the BME communities may have needs that are not similar to dominant White community in the UK (Mir, Nocon and Ahmad, 2001) and therefore there would be a need for services to take into account the cultural and religious sensitivities of these communities.
Another point that was raised was timed to the Welsh Government’s (WG) launching of the awareness raising booklets. It was interesting to note that during the launch, which included a question and answer session, the representative of the WG was not able to point to any specific reference to the translation of the booklets in different BME languages, thus not recognising the diversity of these communities in general. It is interesting to note that even within policy; the emphasis by the WG is on the legal obligation of public services which is to produce information materials only in English and Welsh, as stated in the official literature (Welsh Language Board, 2001; NAfW, 2006).

There was evidence by one parent who stated that she would have preferred translated material in Chinese for her spouse since he was “unable to read the available material” (Lim, 1/42) that was provided only in English and Welsh. However, there was also the view by stakeholders that due to limits of funding, the information available is not tailored to different cultures although they recognise that there are differences. These stakeholders have also stated that translated materials, if provided, “would make a lot of difference” (DH, 4/7; TC, 17/6) to the understanding of these parents’ needs.

From the stakeholders’ point of view, they acknowledge the need to recognise the diversity within the BME communities and that the society is constantly changing as people from other countries migrate into the UK. Within the support organisation category, although they recognise that there is this diversity, they state that when referring to the support for all individuals with autism, all their information “is not tailored” to support those from “different cultures” (TC, 17/5). Further, there were also key personnel in education who seemed unaware of BME parents’ needs and stated that support that is provided is “all the same for every child” (TA2, 2/20) and that “there is no difference” (TA1, 1/27). There is the perception by these stakeholders who felt that by treating everybody the same, they were being inclusive of BME pupils. This view of the stakeholders confirms the explanation offered by the culturally-blind concept (Castro, 2005), where there is no distinction to highlight the diversity and differences within the BME communities.

Further, when exploring support for BME parents, it is recognised that there is provision that information for those with special needs should also be provided to meet the needs of those from BME backgrounds (Equality and Human Rights Commission (EHRC), 2010). It is also noted that within Wales an initiative of good practice was developed within policy entitled, The Equality Improvement Framework for Wales, to assist those who
deliver support services, such as the local authorities (WLGA, 2011). The initiative refers to those listed as ‘protected characteristics’ under the Equality Act and these include, among others, age, disability, gender, race, religion or belief (p. 8), thus recognising that those from BME backgrounds may have unique needs. However, in this study, the stakeholders did not make any references on the outcome of this framework which could identify improvements in Wales.

There were also some examples of stakeholders in this study who highlighted that they provided an individualised approach to BME pupils in terms of their religious and dietary needs and this was a common finding across the participant sample. A means of moving away from the cultural blind policy would be for all key stakeholders, in addition to support that is generally available, to include translated material for parents in various languages for the purpose of communication and education and, thus, be able to provide adequate support for pupils from BME communities. However, the view here was that it may involve more resource in terms of funding, which was often an issue highlighted by stakeholders. The evidence from one stakeholder was that “if money was no object we’d love to have information flyers in all languages” (TC, 17/6).

When exploring support for children with autism in this study, the EO of a national charity highlighted that the awareness should be “within the curriculum of the training of the new teachers” (EO, 13/9). There is also reference in earlier research in England which has shown that teachers’ professional support in autism is inadequate (Batten et al., 2006; Jones et al., 2009). However, in Wales, although there is no requirement in Initial Teacher Education Training (ITET) to incorporate aspects of managing pupils with autism, there is some evidence of Continuous Professional Development (CPD) services (NAS Cymru, 2006; Evans, 2011). In reviewing teachers’ professionalism, the Welsh Government included measures to improve schools by ensuring that the provision of CPD for teachers in schools would include modules within the CPD for supporting vulnerable children (WG, 2012), which would include pupils with autism. The literature states that teachers have to be aware of Special Educational Needs (SEN) within their training (NAfW, 2002), although, there is no requirement to undertake any training in autism in Wales (Evans, 2011). However, teachers are trained to be aware that they are required by law to make ‘reasonable adjustments’ within their classroom setting to enable pupils with autism to learn (NAfW, 2002, p. xiii).
In addition, there was the perception of the need to provide support for those with a disability which included taking into account parents’ particular concerns about their child’s requirements. These included support for issues concerning anxiety, sleep, toileting and diet which are offered to them as workshops by a national society in Wales. Further, the PM pointed out a key concern regarding the delivery of services, which was to ensure that BME pupils were getting the support as easily as others. Regardless of the similarities of the condition of all children, there could be reasons to be sensitive to parents from some BME cultures who associate disability with “a sense of shame (Fazil et al., 2002), “a punishment from God” (Chamba et al., 1999; Dyches et al., 2004) and as “blamed or stigmatised” towards parents (Gabel, 2004; Jegatheesan, Miller and Fowler, 2010). Other researchers have also argued that service providers should take into account cultural perspectives when providing support services for those in need from BME communities.

There is also a misconception among stakeholders that there is social networking among the BME communities such as communications with families and relatives and that religious meetings would provide them with some support for themselves and their children. Stakeholders were of the view that there should be translated materials and access to information on the provision of services to create a better awareness of the disability in these communities.

It is also noted that the majority of parents in this study were able to access information material on support provided for them by the non-BME community; only one parent was not able to access it for her spouse because of his difficulty in the English language. However, some key personnel in education (DH and SST2) highlighted that, for the BME population as a whole, translated resources should be made available as a way to bridge the gap created by the culturally ‘blind’ approach. This was also acknowledged by the Transitional Co-ordinator (TC) of a charity who was aware of BME cultural needs and who was supportive in providing material for the needs of these parents.

There is also an interesting observation made by BME parents that they have often the need to “fight” and “battle” to get the right kind of support for their child (Lim, 1/22; Tammy, 5/12; Amin, 8/22). There is the view by parents that they have to be strong or put in more effort on their part to be able to access the support and also the need to understand the system in contacting services in education and related health services. A key person in a support organisation acknowledged that if parents “don’t have the stomach for that fight” or “don’t understand the system” or don’t have the “communication skills” (PM, 14/8),
they would have less chance of accessing services. The idea to take note is that
stakeholders may want to acknowledge the views of parents since the experiences of their
‘fight’ could reflect the strain in their lives as they go through the stages of shock, sadness,
despair and disbelief about the condition of their child and their thoughts in terms of how
best to support them (Perepa, 2008; Lee, 2010).

Further, literature suggests that parents may benefit from participating in technology based
online discussion support group and sharing similar experiences with each other to reduce
feelings of isolation among themselves (Huws, Jones and Ingledew, 2001; Fleischmann,
2004). In this study, although the majority of the parents used the internet to search for
information about autism, there was not one BME parent who accessed the online
discussions or blogs for support. This question on online discussions was not asked during
the interview with the parents. However, if it was asked, it is likely that I would have had
additional information from these parents. This is an issue that could be explored in
further research.

There was also the perception by BME parents who regarded their needs as different from
that of the wider non-BME community. Similar findings in earlier research have
confirmed that services that are provided for BME parents should take into account their
“cultural and ethnic differences” (Raghavan and Waseem, 2007: 30). In view of these
findings, there could be improvements in teaching practice to include awareness of autism
so that teachers can become familiar with the issues of pupils and their parents from the
non-BME as well as BME backgrounds.

Finally, the explanation offered on the basis of support for BME parents could be seen
through the affirmative model, which suggests that the support for their needs should go
beyond just taking care of their disability (Swain and French, 2000; Cameron, 2008,
2011). Their diversity as a group from within the BME community and their cultural and
religious differences should be acknowledged to include positive ways to provide support
within education. This is also confirmed in the literature where, according to Swain and
French (2000), the affirmative model takes into account the differences within the
community that is provided with support. This view is also expressed by Cameron (2008)
who argued that society should go further by accommodating and providing individuals
with disabilities with more support. Cameron (2011), in explaining the affirmative model,
proposed that society had a duty to be sensitive and appreciate individuals’ situations.
Additionally, the ‘culturally-blind’ concept (Castro, 2005) is relevant when referring to the need to provide support to BME parents. This concept would therefore require that there is the need to be aware of the cultural diversity not only within the BME communities but also in relation to the non-BME community. The need therefore, when providing support is to acknowledge and not to ignore or ‘be blind’ to this cultural diversity of the BME communities, as expressed by the parents in this study.

Following upon the idea that services should be culturally sensitive, another finding concerned the role of parents of a child with autism, in exercising their choice of school for their child.

**6.1.4 BME parents have a choice of school that they want for their child**

When referring to the role of parents in this study, an area of interest is the right of parents to exercise the choice of schooling, when it concerns the placement of the child with autism in mainstream or special schools. This exercise of choice of school relates to the policy of inclusion which recognises the development of strong educational, social and moral grounds for educating children with SEN in mainstream schools (UNESCO, 1994; 2009). The choice of parents within the policy of inclusion which refers to the right of the parent in choosing a placement for their child in either a mainstream or special school is also recognised and provided in the SEN Code of Practice (CoP) (NAfW, 2002; Jones et al., 2009).

Although both these policies provide the framework within which parents exercise their choice, there is a need to take into account that professionals in education also have a specific role to play. While professionals recognise that parents have lived experiences of caring for their child, to support their preference for the choice of school, this choice should be weighed against the assessments provided by professionals based on the severity of the condition of the child. Therefore, it is likely, as evidenced in this study that there could be possible conflicting outcomes where the parents may prefer a mainstream school for their child and the professional may advise on a special school. Further, when referring to the same question of choice, parents in this study stated that they would prefer if the choice of school had been left to them rather than to the professionals who may not understand the needs of their child as well as they do.
Additionally, there is also the SEN tribunal that provides possibilities of resolving conflicts
between the parent and the LA (DDA, 1995; NAfW, 2002; WG, 2011a), for example with
regard to parents’ preferred choice of school or the level of support provided. When the
choice of school by parents was raised with stakeholders in this study, one key person in
education at a resource-based unit within a mainstream secondary school stated that within
the unit, a particular BME pupil with a statement for autism, showed difficulties in
learning. The key person (SST1) stated that it would have been better to place this pupil in
a special school where there are more resources for support instead of a mainstream school
where there is a lack of resources for pupils with autism. Moreover, a teacher in a special
school commented that although parents have the right to make the choice of schooling for
their children and according to the earlier key person, in this case, the parents may have
made the “wrong choice” for their child (SST1, 7/21).

There is also literature which states that the decision to place the child with a disability in
either special or mainstream school should depend not only on the choice of parents but on
the individual child’s needs (Jones et al., 2009; Reid, 2012). Jones et al. (2009) and Reid
(2012) also propose that there should be a joint decision made by both parents and
professionals’ expertise to determine the nature of support that should be provided for the
need and level of support for a particular child. There is also reference in the literature put
forward by Barnard et al. (2002) and Jones et al. (2009) about conflicting opinions between
professionals and parents as to what is appropriate for a particular child with a disability.
These authors propose that inclusion is about the choice of being better supported rather
than just being included in a mainstream school (Barnard et al, 2002).

6.1.5 The need for parents and stakeholders to work together

The next theme that emerged from the data referred to the need to work together by both
the parents and the stakeholders, for what they see as the best way to support the child’s
condition. This idea emerged from the culture of ‘blame’ that was evident from the views
that were expressed by both parents and stakeholders on each other in several instances
within this study. These participants in ‘blaming’ each other may have pointed towards
areas of differences, as a way forward to explore the need to work together for the best
interest of the parents and their child. Therefore, this section highlights the possibilities of
these participants to engage and work together.
One aspect of the ‘blame’ was in relation to the lack of choice of school by one parent from a Pakistani background. The view of this parent was that professionals at a mainstream school that her son attended did not recognise that he would have been better supported in a special school. According to this parent, due to this lack of choice, her son was affected with health issues. Further, another parent from an African background stated that the teacher had made her feel that her child had been a “nuisance” (Fante, 4/6), when referring to instances of screaming of her child in the classroom. The perception of this parent was that the teacher did not seem to understand the disability of her child.

There is also the view by some parents that nursery schools do not have appropriate facilities including a lack of qualified staff who are able to cope with a child with autism. Evidence for this blame came from a parent who said that the teacher told him, “I’m happy to leave him in the corner, playing with water all day” (Amin, 8/1) but the parent was not sure how the action would help his son. There was the assertion by the same parent that he was aware that schools have a “legal obligation” (Amin, 14/5) to keep their children in the school, although they seemed unable to support the child at school. However, this legal obligation, as shown in literature, includes also a requirement within the SEN CoP which states that “Parents, schools, including nursery schools, and early years education settings … can make a request to the LEA for a statutory assessment” (NAfW, 2002, paragraph 4:34) of the child’s condition. Further, children with SEN who have attended nursery school “should have had their needs identified” (paragraph 5:1) and these schools “should therefore be aware that any child admitted to the reception class might have unidentified special educational needs” (paragraph 4:34). It is acknowledged that this parent is highly educated and showed awareness of his ‘rights’ to access support for his child in education. However, other parents (Adeo, 6/46 ; Bibi, 9/14) who did not have much education, appeared to accept whatever was offered to them and for their child.

From the perspective of the stakeholders, the study also shows that they may blame the BME parents on grounds that those who ‘fight’ for support may not understand the system that they are settled in. The stakeholders go on to say that these parents may often give up and end up not taking up the services that are available for them and that it is the parents who “let down” (PM, 14/8) their children. These stakeholders are also aware that parents feel stigmatised by their own families and communities due to their child’s disability which is also similar to the findings in other studies (Chamba et al., 1999; Dyches et al., 2004). Literature shows that teachers’ training is adequate in both England and Wales,
and that Continuous Professional Development (CPD) is provided to maintain and ensure that there are skills that are needed for supporting pupils with autism (NAS Cymru, 2006, 2011; Withers, 2009; WG, 2010). However, there were other stakeholders who blamed the inadequacy of the CPD training that was provided to them which may not have incorporated elements of knowledge about autism or culturally related issues.

The WG policy acknowledges that within education, the LA and other agencies have a duty to work together to provide support for children with a disability (WAG, 2008). There is evidence in the study that there is the perception that stakeholders are working independently of each other and although there is some communication with each other, there may be a need for a more cohesive approach to working as a team. Literature also states that stakeholders should ensure that the care that is provided to support these children is of an appropriate standard and that those professionals in education need to share their experiences in practice among other professionals, as well as with parents and carers (WG, 2011).

The evidence in this study also shows that BME parents tend not to access provision of services that are provided in schools such as coffee mornings and parents’ evenings which take place during and after school. The data shows that parents do not attend these services due to their own personal reasons such as difficulty in taking time off from their work or they may have difficulty in interacting with parents from cultures other than their own.

There is the recognition by stakeholders that schools have a major role to play in educating children. One stakeholder made a strong point concerning the role of parents by saying that once the child is dropped off at school by the parents, “it’s up to the teacher to do everything” and that parents should not “interfere” (EMAS2, 11.19), although not a typical view. According to this stakeholder, staff at school are “the gatekeepers of education” (EMAS2, 11/19). However, there could be difference in interpretation of these views since literature on policy acknowledges that parents have a vital role in their child’s education (NAfW, 2002, paragraph 2:2).

There is also evidence of parents ‘blaming’ the school by highlighting specific instances that they regard as inappropriate when referring to how staff in schools relate to their child. For example, one parent said, “the school didn’t want her (the child) there because she was
going to be difficult (Tammy, 5/1), another also held the view that the school, “didn’t want him (the child) there because they were overwhelmed or didn’t know what to do” (Amin, 8/1). However, the observation was also made by stakeholders that parents relied on their own experiences and made unrealistic expectations on what progress means to them for their child. The message that emerged from these conflicting views could also be regarded as apportioning blame. Therefore, the view of parents and stakeholders’ professional knowledge needs to be taken into account so that a balanced view can be achieved within the education system.

Following the analysis of the data on the need to work together by both parents and stakeholders, the next section highlights the importance of acknowledging the insights of parents.

6.1.6 The importance of acknowledging the insights of parents

An idea that emerged from the study was that parents, through their lived experiences, consider themselves as having valuable insights of their child through their lived experiences and this is confirmed in the literature (Modood et al., 1997; Tams, 1998; Fombonne, 2005). These parents have expressed the view that they have close knowledge concerning their child which includes both the child’s strengths and less favourable behaviours. The evidence was from parents who said that their child was “good at remembering different country’s flags” (Lim, 1/2), “concentration is very good” (Mina, 3/3) and “very obsessed with spinning things” (Nazia, 2/3). This is also confirmed by a key person in education who stated that, “parents always give you key pieces of information” (DH, 4/14) that others may not be aware of or have.

There were also stakeholders who acknowledged that parents have useful information regarding their children’s disability that professionals may not have. Thus, there is the view of stakeholders that parents hold “key pieces of information” (DH, 4/14) that other professionals may not have, which plays a vital role in their child’s education (SEN CoP, 2002, paragraph 2:2). There is also the impression from the data that stakeholders feel that parents’ close knowledge is not adequate and their decisions concerning support for their child in school should not be left entirely to these parents.
In addition, stakeholders feel that decisions about pupils’ support should rely upon the advice by professionals in education who are trained to assess and consider the needs of these children. These decisions relate to situations such as support within education, within a school setting or choice of schools which stakeholders acknowledge, usually relied upon the knowledge of the parents regarding the condition of the child. The lived experiences of parents in the context of best practice suggests that parents should be involved with schools about their child’s learning (NAfW, 2002) although parents in this study suggest that they are rarely involved.

Thus, while the parents feel that their lived experiences should be taken into account, they also feel that their views are not seen as valuable enough by professionals in education. Therefore, the competence of professionals in relation to the support provided for the child that is expressed in the context of the lived experience of the parent is a point that continues to be argued by both stakeholders and parents. There appears to be a conflict between these two groups of participants as to who had the final say, when considering the need for inclusive education for children.

The next section highlights policy responses that are appropriate in making sure that teachers are able adequately to provide their professional service within the classrooms in education.

6.1.7 The need for Continuous Professional Development (CPD) training for staff in mainstream and special schools

One of the challenges in education is to ensure that teachers and teaching assistants are knowledgeable about autism and also understand and support pupils from culturally diverse backgrounds in mainstream and special schools. The section here explores what is required in terms of professional competence by those who provide educational support for BME parents of pupils with autism. It is noted that there is no requirement for either trainee teachers or practising teachers to undertake any training or professional development in autism (NAS Cymru, 2006, Evans, 2011) even though they are required by law to make ‘reasonable adjustments’ to their lessons to enable children with autism to learn (NAfW, 2002, p. xiii).
From the perspective of BME parents, they were generally positive about the support in teaching and care that their child received at school. For example, there was one parent in this study who was satisfied and referred to the support in a mainstream primary school as, “quite fab” (Bibi, 9/14). However, there are also mixed views regarding the role of staff in other instances such as in a mainstream nursery school. There were parents who referred to the lack of support by teachers and who said that schools did not have “facilities” or “qualified teachers” (Adeo, 6/1) to do the job. It is also evident in the literature that practising teachers have avenues for CPD training in SEN as well as in subjects relating to meeting the needs of SEN pupils (WG, 2011b). Further, the Qualified Teacher Status (QTS) standards also enable teachers to understand the diverse learning needs of all learners’ to include “cultural, linguistic, religious and ethnic backgrounds” (WG, 2009, S1.1).

One parent’s view was that teachers were not able to recognise the special needs of her child and that there should be staff who are able and experienced to look after children with autism within the school setting. Further, the majority of parents were of the view that staff at various mainstream schools were not experienced in supporting pupils with autism within the classroom. There were also two parents who felt that their children fared well in a mainstream school and specifically said that the level of teaching was very good.

There were also staff at a special school who were trained to provide, for example, positive handling or physical intervention to manage the difficult behaviours of children with autism and in the way these children are safely moved from one setting in the school to another. Another view by stakeholders was that there is a lack of funding in mainstream schools and with resources placed largely in special schools. They also mentioned that there was a lack of CPD training among the staff in education although it is better in the special school compared to mainstream schools. When referring specifically to the training of teachers within Wales, the perception of a key person of a national charity was that “there has been a big attempt to, over the last 20 years, to improve the awareness (of autism) among teachers” (EO, 13/9). When referring to staff who are able to support BME children, there was the suggestion by a key person in a resource-based unit within a mainstream, to recruit those who are from BME background. According to this key person, staff from these backgrounds would be able to better understand BME religion and cultures.
When examining the question of CPD training from the perspectives of key personnel in education, the view that emerged was that different categories of stakeholders have different perspectives on the nature of the issue in education. For example, a key person in education namely the Special Educational Needs Co-ordinator (SENCo), pointed out that there were different stakeholders working together and these included the TAs working very closely with the Occupational Therapist, Speech and Language Therapist (SaLT) and other specialist professionals when implementing a programme in school.

It is noted that the sample in this study includes parents who are in contact with teachers who are already professionally trained. However, their argument is about how staff at school relate to their child within an education setting. It is about teachers’ competence and how they acquire skill and knowledge through CPD training, particularly in their ability to support pupils with a disability from culturally diverse backgrounds. The discussion shows that there are different views of how professionals relate to these pupils from the perspective of both BME parents and relevant stakeholders in education.

6.2 Highlights of findings

It is useful to note that several ideas of relevance have emerged from the views and perception of both parents and stakeholders. These ideas that are presented could be regarded as the main highlights of the findings in this study.

Firstly, there was the view of BME parents that they are not homogenous themselves and that their own ethnicity and religion influenced their experiences differently. The parents in this study felt strongly that support services that are provided by stakeholders in education need to be culturally appropriate. There was also the perception of parents that they were ‘pushed off’ by their own communities and as a result, looked towards the non-BME community for support. The study also found that parents who were from higher socio-economic backgrounds were better able to network and search for suitable resources compared to others who were not from similar backgrounds. From the perspectives of stakeholders, the approach to provision of support was generally similar for all pupils without differentiating the needs of BME communities. These stakeholders were concerned that any widening of support in services that had to take into account cultural diversities, would be limited by resources.
Secondly, another view by parents was that they want more than the basic support that is provided to all pupils with disability in education. The view by parents could be explained by the affirmative model which suggests that those within society need to understand that people with a disability do not want to be treated with pity but to be fully and positively accepted in society (Swain and French, 2000).

Thirdly, parents considered themselves as having valuable insights of their child through their lived experiences and this view was confirmed by the stakeholders. However, stakeholders felt that when decisions about pupils’ support are taken in education, such decisions should not be guided only by reference to parents’ lived experiences. Instead, the decisions should be based upon information, advice and decisions that are also provided by specialist professionals who are trained to assess and consider the needs of these children. These decisions could relate to choice of schooling for their child where it may be more appropriate to rely on their professional competence rather than relying just on the judgement of parents’ lived experiences.

Fourthly, in Wales, public policies acknowledge that within education, the local authority and other agencies have a duty to work together to provide support for all children with a disability (WAG, 2008). Literature also states that professionals in education need to share their experiences in practice among other professionals, as well as with parents and carers (WG, 2011). It was also noted that, although policy makers acknowledged that stakeholders in education have a duty to support all children with a disability, it appeared that there was no awareness of the specific cultural needs of these communities.

Finally, there was evidence from support organisations that it would be useful that material on awareness of disabilities, which include autism, should be provided within the curriculum for Initial Teacher Education Training. It was also recognised that all teachers in Wales have to be aware of special educational needs within their training (NAfW, 2002). However, there is no requirement for either trainee teachers or practising teachers to undertake any training in autism in Wales (Evans, 2011), even though they are required by law to make ‘reasonable adjustments’ to their lessons to enable children with autism to learn (NAfW, 2002, p. xiii).

Arising from these highlights, I am of the opinion that the study has provided an insight into the experiences of BME parents of pupils with autism in education. The unique
stories told by parents in this study were captured using the interpretive approach, which also enabled an explanation of the stakeholders’ perception about these parents’ experiences. The similarities and differences of the findings which emerged from the data gave insights into the experiences of the different backgrounds within the BME community, which is not a homogenous group. Moreover, the affirmative model provides an explanation as to why BME parents of children with autism should be provided with relevant culturally appropriate educational support and be included as part of the society in Wales.

On the whole, the study gave an explanation of the experiences of BME parents in terms of their understanding of autism and how their own cultural and religious understanding of disability influenced them in accessing support that was provided for them and their child by the education system. This study has raised a number of questions that relates to our knowledge about the BME communities, in terms of the need to be sensitive by providing them with culturally appropriate services. It is hoped that this study will contribute to further research in supporting parents of children with autism from different BME communities in Wales and elsewhere.

In summary, parents’ perceptions are that the support provided to them was in no way different to that which was provided to everyone else facing the same disability in education. A view similar to this expressed by stakeholders was that the system was being fair by providing support to those with a disability in education on the same basis. According to parents, although stakeholders may mean well, in the way they interpret support that is similar to all, the parents, however, may regard such support to all, as not considering their cultural diversity and thus being blind to their specific cultural needs. In raising this concern, it is my inference that the parents are suggesting that they want tailored support that should focus on their cultural diversity. This perception by parents points towards the need to take into account the cultural diversity of BME communities, when providing support for a disability such as autism. They were clear in not finding faults in the basic support that they received in education, however, what they wanted was more support that acknowledged their cultural needs. They stated that they do not get support within their own communities and that they were relying on the education system in Wales, to support them.
6.3 Limitations of the study

One of the main limitations of the study was the selection of the BME parent sample that was derived through the use of purposive sampling. The purposive sampling technique was preferred since the snow-balling technique, which is often recommended as a useful strategy when reaching out to segregated groups of people, was not successful. It was found that some BME parents were seen to be so isolated that they did not know of any other parent of a child with autism within their own community. Future researchers who plan to use the snow-balling technique should be aware that this technique may not necessarily provide the required sample.

Although purposive sampling was used in this study, it did not include or capture parents who may have had difficulty in the English language. This point was highlighted when analysing the views of key stakeholders whose opinions reflected that they faced a more diverse population which included parents with language difficulties. While the interviews with BME parents were from a range of different cultures and in terms of levels of knowledge of English, it is acknowledged that it did not include parents who could not speak English at all and therefore their voice is missing in this study. At this stage, I would have been ready to translate but it was not needed. However, there may also be certain voices that I have not been able to capture. For example, one key person in the LA who had earlier agreed to take part in the study later withdrew herself prior to the agreed time of the day of the interview and there was no reason as to why she withdrew.

It is noted that the parents who participated in this study were all mothers with the exception of one father. Although there were also fathers present with the mothers in two cases, the voices that were provided here were mainly from the mothers and with the fathers joining in the conversation but not leading it. As such, the voices that were recorded digitally were largely from mothers and the reason may be due to the cultural roles of parents’ responsibilities within certain communities.

Moreover, I believed that in the early phase of the research, that it would be straightforward to reach out to these communities since I myself was from a BME background. However, this belief turned out to be incorrect. I also found that some of the parents, although they spoke English, were thinking in their first language which was not English and in some cases appeared to be translating what they wanted to say. Therefore,
in future it may be useful to conduct research with BME parents in a language in which researchers may also be competent in.

6.4 **Recommendations for future research**

The findings and limitations identified in this study have pointed towards a number of areas that could be explored for future research. One suggestion for future research would be to look at other LAs in different types of areas, compared to the selection of the LA in this study which explored the phenomena within a large urban LA. It may therefore be useful to replicate the method used in this study to other LAs, which is different from this selected urban LA, compared to the different composition of BME groups in other LAs in Wales. This would be useful to determine whether the outcome is similar to the selected LA in this study.

Since BME parents may not receive support from their extended families (Corbett and Perepa, 2007; Perepa, 2008), the influence of such support could be an area of research that could be explored in future. Other studies in England have recommended that future studies could explore the experiences of extended families within BME communities, such as grandparents, aunties and uncles (Jones et al., 2009; Lee, 2010), on questions that are similar to this study. Jones et al. (2009) and Lee (2010) have both emphasised that the extended families can be valuable in terms of how children with autism may be better supported in future.

Another area of research could be to explore the way parents understand their child’s condition. In this study BME parents have shown that they preferred to remain as “silent sufferers” and as such it is suggested that an in-depth case study of individual BME parents should be explored in future research. This could include taking into account their lived experiences of their child with the condition. In this study, when BME parents were interviewed, they not only related to their views about the support that their child received in education but also about their personal life history. This included their personal grief, their relationship with their own community and their fears for their child’s future when they were no longer alive. It was found that during the interviews with BME parents, they went on to talk about their personal lives which were beyond the objective of this study.
Presently in Wales, the Cross Party Autism Group (CPAG), a forum in the National Assembly for Wales has been effective in raising awareness and promoting the interest of people with Autism Spectrum Disorders (ASD), their families and carers (CPAG, 2011). The extent to which the ASD plan has made a difference has been monitored and evaluated by various local and national stakeholder monitoring groups since 2010. This includes exploring the impact in the first four years of improved diagnostic facilities for children and adults. A useful research in future could explore the extent to which the monitoring and evaluation of the ASD plan for Wales has been able to determine whether the objectives of the plan have been achieved. It is anticipated that the findings in this study would contribute to further research within other LAs in Wales and in the UK, particularly in supporting parents of pupils with autism from BME communities.

6.5 Reflections and evaluation on the research as a whole

This research has been an experiential journey for me as the researcher and I will present here my reflections now that I have reached the final phase of my research. My initial thoughts were that it would be straightforward to actually design the research and carry it out. However, I found out that this was not the way that the study would move forward and that there are useful points on both design and findings that I want to share from this experience.

An early impression for me was that I was aware of the difference that is often seen as being present in the researcher-participant relationship. There appeared to be an advantage to me being an Asian female and living within the selected LA. This was because I come from similar background as the majority of the BME participants who were also females and in my opinion, they tended to trust and relate their experiences more openly to me. This is evidenced in the comments by parents in this study, for example, one parent said, “As you know ...” (Amin, 8/6) and another used familiar terms such as “paagal” (Jamilla, 11/37) which is also native to me. However, it is important to acknowledge potential bias within the researcher-participant relationship based on these very factors (Gunaratnam, 2003).

I also experienced some of the sensitive stories that the parents chose to share with me. In view of the parents’ openness, I had regular discussions about my interview experiences with my supervisors. These discussions were important to reflect upon the sensitive nature
of the topics raised and to make sense of the experiences that these parents had shared with me.

It is useful also to note that within the context of Wales, there is the legal obligation to deal with two languages by law and that because of this pressure, policy makers may have neglected or had little time to think about other languages that are present (WAG, 2010). In view of the increasing and changing demography of BME population in this part of the UK, it is hoped that the findings in this study such as the need for materials in different community languages, might influence research on policies relating to these communities who may have an additional need.

When I was developing the design of this research, I recognised from the literature that relatively little is known about the experiences and perceptions of BME parents of a child with autism in education. I had to think about how I could carry out the study, given that the focus in the questions to be explored was appropriately addressed. The design of the research, which is qualitative in nature, had to adopt an approach to capture the voices of BME parents in which they related their experiences through interviews which then formed the basis of the study. I had to build relationships with the parents at their homes and with the relevant stakeholders from whom I collected the data.

Furthermore, gaining access to the sample was a difficult process, although I thought at first that I would be able to gain contacts easily. The process involved writing a number of letters and sending out uncountable numbers of emails to schools and to the relevant people in education, and also relied on the university mentors for assistance. On the positive side, I was able to get some information and contacts from the LA who provided me with the names of schools to be included within the sampling frame of the study and this enabled me to begin the research process.

The literature on autism was extensive and it sometimes became overwhelming due to the fact that it draws on different approaches and research paradigms. The methodology in this study is similar to that adopted in earlier research by Corbett and Perepa (2007) and Perepa (2008) who explored individuals with autism using interviews as the main method of enquiry. The intention in this study was to provide a voice for BME parents.
Further, it is acknowledged from the analysis and findings that an important part of the research design was the interviews with stakeholders which allowed different perspectives to be seen on the questions that were raised. Thus, the views of parents were seen against stakeholders who had a role to play in delivering services within and outside the school setting. It was interesting to take note of the perceptions of stakeholders in their role as providers of support on how they viewed BME parents’ perceptions on the similar questions that were raised in education.

In designing the research in this study, the importance of a pilot became relevant since it was only after a pilot that I found the need to be sensitive about the interview times and locations. For example, in the light of the research questions that were explored in this study, the pilot revealed that when interviewing parents of children with autism, the choice of location and timing for the interviews and the presence of others during interviews with these parents were important aspects in deciding the design of the interview. These are explained in the methodology chapter and are important to revisit here since when the actual study took place, all eleven interviews with parents took place when their children were not at home.

Another aspect that emerges is my perception that BME parents were comfortable in taking part in the study due to my Indian ethnicity which was similar to that of some of them. There is evidence by parents using their own ethnic languages when greeting me before the interview commenced and in using familiar terms such as “paagal” (translated as ‘mad’), which is also native to me. The main idea in this research was to provide these parents with a voice. Further, literature states that the experience of the researchers also enables them to examine themselves in relation to those being researched (Bolton, 2009).

Finally, during the course of my research, I was also aware that there were a number of stakeholders who were also parents of a child with autism. I am of the view that these parents could have been convinced of the need to take part in relevant charitable organisations to find an explanation for their child’s condition so that they are able to cope and relate to others in society.

I believe that this study has managed to reach the aims it set out to explore and to contribute to an understanding of the questions raised. This study has also provided me with insights into how support services for BME parents of children with autism might be
improved in the future in order to provide better support for them. It has clearly contributed to an area within education in Wales where there has been very little research until now. Even though the services offered in education often have constraints on resources and funding, it is hoped that the findings in this study will raise the awareness of the concerns of BME parents of children with autism that are relevant to further developing policies and good practice in education.
List of references


Welsh Assembly Government (WAG) (May 2010a) *Open Letter Regarding the Term Changes to ‘Local Education Authority’ and ‘Children’s Services Authority’*. Cardiff: WAG.


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Appendices
Appendix 1: Covering letter and information sheet for parents

Dear Parents / Carers,

I am interested in your personal life experiences of having a child with autism. I am particularly interested to find out the concerns that you have in your child’s education. Currently, there is some information on autism and support for those from the Black and Minority Ethnic (BME) groups.

Taking care and coping with an autistic child can be challenging and exhausting. This can be even more so when it concerns the BME groups, in terms of language barriers and cultural needs. Some parents suffer in silence because firstly, they are not aware of autism and secondly, as they are not aware of the existing education support services that are made available by the state.

By taking part in this study, you will have an opportunity to voice out your needs. This in turn may help others, for example, the education authorities and policy makers, to understand better, your needs and take into account, your feelings and cultural needs in the society that you live in.

I am inviting you to take part in this study. Please find below some facts of the study. If you need any translation help, we can set that up for you.

If you wish to take part in this study, please complete the return slip using the self-addressed envelope provided.

Title of Research Project:
The experiences and perceptions of parents of BME pupils statemented with autism in relation to the educational support provided for their children and for themselves as carers.

The aim of the study
The aim of the study will be to explore the experiences and perceptions of parents or carers of BME pupils statemented with autism in special and mainstream schools and investigate the educational provision and support provided by schools and the Local Authority (LA). In the study, the reference to autism will not include those with Asperger’s syndrome.

What are the benefits of taking part in this study?
It is anticipated that the findings from this study will contribute to a better understanding among teachers, support staff and the LA of the needs of parents and carers with regard to educational support services for those pupils with autism among the BME groups. This improved understanding will benefit pupils and their parents or carers. Furthermore, through participating in the study, parents and carers may become more aware of the educational support available to them and their children, thus encouraging autistic pupils to move forward positively in their learning environment. It is hoped that a more informed understanding of the educational and cultural needs of BME groups in the context of autism will help promote inclusion and help develop educational provision for these groups.

Why have I been invited to take part?
You have been invited to take part because you are the parent of a child from a BME group who has autism.
Do I have a choice in taking part?
It is entirely voluntary to take part in the study. If you wish to withdraw from the study at any time or decline to answer any questions at any point in time, you may do so. Should you decide to do this, be assured that no negative consequences follows.

The interview
In order to meet the aims of the research, I shall be interviewing parents or carers of pupils from the BME groups. If you choose to be interviewed, you may decide to be interviewed individually or with your partner. The interview will take place at a time and place convenient to you and I will do all I can to ensure that you are not inconvenienced during the interview. Each interview is likely to last up to one hour and will be audio recorded using a digital recorder. If you choose to answer interview questions in a language other than English, a translator will be present and will translate questions and answers, so this may take a little longer. I have a good understanding of autism and will also be very sensitive to any cultural issues or language issues which may arise during the interview.

What happens to the information from the interview?
The recorded interview will be written up as a transcript and will be kept by the interviewer for the duration of the project. All interviewees will be given a pseudonym instead of their real names, and any mention of schools or names of staff made in the interviews will be anonymised. The interview transcripts will be shared with my two supervisors at Cardiff Metropolitan University. For interviews in a language other than English, the translator who will assist me in my research will also see the interview transcript. The recordings and the transcribed interviews will be stored securely and no one other than the researcher will have access to them. The information will be used to write my doctoral thesis and any quotations selected will be anonymised.
Contact for further information

If you wish to contact me or have any query regarding my research, my e-mail address is XXX. My department telephone number is XXX. My mobile number is XXX.

My director of studies is Dr Sian R Williams XXX and my supervisor is Dr Cheryl Ellis XXX

Please tear here
..............................................................................................................................................

Return Slip

I am happy for you to contact me.

Name:______________________________

Tel. No: __________________________

Signature: ________________________

In which language do you prefer to be interviewed: ______________________
Appendix 2: Information Sheet for Stakeholder group

Title of Research Project
The experiences and perceptions of parents of BME pupils statemented with autism in relation to the educational support provided for their children and for themselves as carers.

You are invited to take part in a study which is part of my doctoral research for a Ph. D. in Education. Your participation is entirely voluntary and you will be able to withdraw from the study at any time should you wish to do so.

The aim of the Study
The aim of the study will be to explore the experiences and perceptions of parents or carers of BME pupils statemented with autism in special and mainstream schools and the educational provision and support provided by schools and the LA.

Why have I been invited to take part?
You have been invited to take part because you contribute to the support of BME pupils with autism within education.

The Interview
The research will be undertaken through a series of interviews with parents or carers of pupils from BME groups, teachers including special educational needs co-ordinators and learning support assistants in schools and with staff from the LA who have particular responsibility for policy and/or support autistic pupils from BME groups in education. The interview will take place at your convenience and you can be assured that you may decline to answer any questions or prompts should you feel uncomfortable at any time. Each interview is likely to last up to 30 minutes and will be audio recorded and transcribed.

What happens to the data from the Interviews?
The researcher will be very sensitive to the cultural concerns of BME groups. All the interviews will ensure anonymity of participants by using pseudonyms in place of participants’ and schools’ names. Data will be shared with my supervisory team, and in the case of the interview being undertaken in a language other than English, the translators who will assist me in my research. On completion of the study the data will be stored securely.

Do I have a choice in taking part?
It is entirely voluntary to take part in the study. If you wish to withdraw from the study at any time or decline to answer any questions at any point in time, you may do so. However, you will be assured that in doing this, you will not have any negative consequences.

What are the benefits of taking part in this study?
The findings from this study will contribute towards a better understanding of the experiences and needs of parents with regard to educational support and services for those pupils with autism among BME groups. This, in turn, will help improve the awareness of teachers and other relevant staff in education of the needs of this particular group. Also, as a result of the study, parents are likely to become more aware of the role of educational support staff and of other services in education.
It is anticipated that an improved understanding of the cultural concerns of BME groups by the education research community and the relevant personnel in education, will help promote inclusion and help support a positive learning environment for minority ethnic pupils with autism in Wales.

Contact for further information
If you wish to contact me on any query regarding my research, my email address is XXX. My department telephone number is XXX. My mobile number is XXX.

My director of studies is Dr Sian R Williams XXX and my supervisor is Dr Cheryl Ellis XXX.
Appendix 3: Consent Form

(Please tick the boxes)

(1) I confirm that I have read and understood the information sheet for this study and have been given the opportunity to have any questions explained to me.

☐

(2) I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

☐

(3) I have been informed that what I say in the interview will be recorded. I give my consent to this recording being made.

☐

(4) I understand that all information that I provide will be treated as confidential and will be anonymised.

☐

(5) I agree to anonymised quotations from the interview being used in the research thesis and in future academic publications which may derive from the study.

☐

(6) I agree to take part in this study.

☐

Signature of participant:__________________________  Date:_______________

Print Name: _________________________________

Signature of Researcher: _________________________  Date:________________
Appendix 4: Revised parents interview schedule

Title: The Experiences and Perceptions of Parents of Black and Minority Ethnic (BME) Pupils Statemented with Autism in Relation to the Educational Support Provided for their Children and for Themselves as Carers.

Aims of the Research
To examine the experiences of parents or carers of BME pupils statemented with autism within special and mainstream schools and the education support services that are available to them in Wales.

In view of the above, the objectives of this research are:

1. to explore the experiences and perceptions of parents or carers of BME pupils of educational provision in special and mainstream schools;
2. to examine parental or carers’ experiences and perceptions of community based support organisation for the support of BME pupils with autism; and
3. to investigate the educational provision and support available in special and mainstream schools for BME pupils with autism.

Information Sheet

Part One- Personal details of parent
(Tick or circle answer where appropriate)

(a) Your name: ..........................................................
(b) Address :.....................................................................................................
(c) Phone number:............................................
(d) How many children do you have?..........................................................
(e) How many of them have SEN?............................................................... *
   *If more than one please complete one information sheet for each.
(f) Relationship to SEN child/ children: mother / father / parents/ carer

Information on your Child

1.1 What special needs does your child have?
   Autism / other (if other please give details)

..........................................................................................................................

1.2 Age of the child: .............................................

1.3 Gender of child: Male / Female

1.4 Statemented for SEN: Yes / No

1.5 At what age, did your child start attending school?

..........................................................................................................................
1.6 Which school does your child attend? Please name the school.
................................................................................................................................................

1.7 Type of school your child attends:

- (a) Mainstream school ( )
- (b) Special school ( )
- (c) Unit specific to autism in mainstream school ( )

1.8 Does your child receive specialist help for autism/ Aspergers at school?
Yes / No

If yes, who provides this help?
................................................................................................................................................

1.9 Who lives with you and your child?
................................................................................................................................................

1.10 When not in school, who takes main care of your child?
................................................................................................................................................

Parent /Carer and Ethnicity

1.11 How long have you been living in the UK?

- (a) 6 months - 1 year ( )
- (b) 1 - 3 years ( )
- (c) 3 – 5 years ( )
- (d) More than 5 years ( )
- (e) More than 10 years ( )

1.12 How many languages do you speak?
................................................................................................................................................

1.13 What language do you speak to your child?
................................................................................................................................................

1.14 What language do you mainly use in the community / socially?
................................................................................................................................................

1.15 What is your child’s first language?
................................................................................................................................................

1.16 How would you describe you and your child's ethnicity?

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(a) Indians ( )
(b) Pakistani ( )
(c) Bangladeshi ( )
(d) African ( )
(e) Caribbean ( )
(f) Somali ( )
(g) Chinese ( )
h) other ethnic backgrounds (please specify).................................

1.17 How would you describe your friends?
(a) only from your ethnic background
(b) mostly from your background
(c) from your background as well as other groups
(d) mostly with different ethnic groups
(e) only with a different ethnic groups

Part two
Section One: Support in education
(8/1) Can you tell me your story about your child?
(8/2) What does your child enjoy doing?
(8/3) What is her strength?
(8/4) When did you first realize that something was different with your child?
(8/5) How worried were you about this?
(8/6) Who did you go to for advice or to speak to about your concerns?
(8/7) Who made the diagnosis? (Was it your GP? Was it other health professional?)
(8/8) How long did it take to make this diagnosis?
(8/9) In what language was it explained?
(8/10) How was the diagnosis explained to you?
(8/11) How did you feel when diagnosis was given?
(8/12) Do you think it was made clear to you?
(8/13) How did your family and friends react to the diagnosis?
(8/14) Tell me about the help that was given to you after the diagnosis?
(8/15) Who gave this help?
(8/16) What kind of help did you get?
(8/17) When did you get this help?
(8/18) When was statement of SEN made?
(8/19) Was the statement made at first diagnosis or later?
(8/20) Did the school arrange for you to meet with them after the statement was made?
(8/21) After diagnosis, did you think that it helped you understand autism better?
(8/22) Did you have a choice in the support that was offered to your child?
(8/23) Why did you choose mainstream or special school for your child?
(8/24) Who has helped your child up until now and what kind of help have they been given?
(8/25) Who is helping you now and how often?
(8/26) How is this help given?

(8/27) When did this help start for your child?
Prompts: Was the help from the Education Psychologist?
What about the SaLT?
What about the SENCo, teaching assistant?
What about school transport?)

(8/28) Have you had any problems with the support given for your child?

**Prompts** - frequency, type or individual

(8/29) What kind of help would you like from the school if it is possible?
(8/30) Why do you want the help?
(8/31) How often would you like it?
(8/32) Do you have contact with parents of other children with autism?

(8/33) Is there an opportunity to talk to other parents and teachers about the challenges of helping your child in school?

**Prompts** - What about teachers?

Section Two: Support from relevant charitable organisations
(8/34) Has the school told you about any other help outside the school?

(8/35) Have you heard of National Autistic Society (NAS) Cymru or any other organisation and how did you hear about it?

(8/36) What support are you having from them?

Section Three: Support from family and the wider BME Community
(8/37) How do you think others in your community view autism?
(8/38) How do you think your community view Special Education Needs?

(8/39) Are they aware of autism and what do they think about autism?
(8/40) What help is available to you from your community and how did you find out about this help?
(8/41) Can you tell me about any social/group meetings that you attend and if so how often do you attend them?
(8/42) What do you talk about when you are there? Do you talk to other families with children with autism within your own community?
(8/43) Does your family/community support you in any way in terms of information about autism and assistance?
(8/44) Are there religious based support groups for parents within your communities?
(8/45) How do they guide you when you need help for your child?
(8/46) How worried are you about your child’s future and what are your worries?
(8/47) Is there anything else that you wish to say?

Thank you.
Appendix 5: Interview schedule for the elite stakeholder group

Part 1: Personal Details
(a) Your name:
(b) Name of School:
(c) Job title:
(d) Phone number:
(e) E-mail address:

Professional background
1. Can you tell me about your current job role?
2. What was your previous role?
3. Can you tell me about your background in relation to working with children with autism (in terms of courses followed and qualifications etc.)?

Part 2
1. Can you tell me about the support that is offered to pupils with autism? (Can you please describe briefly the support by giving an example) If so, how it has impacted on your normal day to day work?
2. Is there any support provided for pupils with autism from BME backgrounds? (e. g. within the triad of impairment: social communication, social interaction and in relation to their way of thinking or thought process)
3. Can you tell me about the specific factors which you take into account while providing support to BME pupils with autism in schools? (e. g. cultural, religious and linguistic). Please elaborate by giving details or examples.
4. Can you tell me if there is training provided for you/ your colleagues, to help to support and meet the needs of BME pupils with autism and their parents? (Please explain and specify)
5. Do you have any links with other outside agencies or community groups?
6. Is there any published literature produced by you to support parents of a child with autism and is this available in a range of languages? (Could you please elaborate)
7. From your experience, can you think of any examples of good practice for meeting the needs of BME pupils?
8. If you had available time, money or resources, how would you provide to meet the needs of BME pupils with autism and why?
Appendix 6: Interview Schedule for Non-elite Stakeholder Group

Part 1

Personal Details
(a) Your name:
(b) Name of School:
(c) Job title:
(d) Phone number:
(e) E-mail address:

(For staff at school)
(f) How many years have you been a specialist teacher?
(g) How many years have you been supporting pupils with special needs?
(h) How many years have you been supporting pupils with autism?

Professional background
1. Can you tell me about your current job role?
2. What was your previous role?
3. Can you tell me about your background in relation to working with children with autism (in terms of courses followed and qualifications etc.)?

Part 2

Section One: Support at school (mainstream primary or secondary/ resource unit in mainstream school/ special school).
4. Can you tell me about the support you provide for [primary/special/secondary school] pupils who have been statemented with autism and how does this differ throughout the stages in mainstream school?
5. Are there any specific challenges that you face in meeting the needs of pupils with autism? (for example, social interaction, social communication and rigidity of thought)
So how is his learning?
6. How does the provision differ for pupils with autism from BME backgrounds in [primary/ special/ secondary] school? 
[Is he verbal? 
At what age did he come to this unit?
If this is a mainstream secondary school, how does he manage to cope? 
Why did the parent send him here?]
7. Are there any specific needs for pupils from BME backgrounds?
8. How does this impact on the support that you provide?
9. What are the issues around transition from primary to secondary schooling, from the secondary school point of view? 
Are there any from special schools coming here?
10. Is the transition from primary (mainstream or special) to secondary or into full-time residence different for BME pupils with autism?
**Section Two: Training Needs**

Findings from the Literature: Would you mind giving me your thoughts on some things that I have read about:

I’ve read that parents/carers from BME backgrounds may view things in a different way and struggle due to language, religion, culture, customs, family support or their way of life.

11. Are you aware of these problems faced by them? If so, what is being done within your service in relation to this?

12. Do you do anything to address, in response to this? If so, how?

13. Do you explore the above factors with your teachers? (Prompt: How do you do it and why is it important?)

14. Can you tell me if there is training provided to you/ your colleagues, to be able to meet the needs of pupils with autism from BME background?

15. In relation to your work with pupils with autism, do you rely on any charity organisations for any advice? If so, can you elaborate further on this.

**Section Three: Range of Support and Good Practice**

16. Can you tell me about any support that is offered to the parents as carers of pupils with autism?

17. Is there any other additional support offered to BME parents or carers?

18. What links are there with BME parents and agencies such as Local Authorities and Ethnic Minority Achievement Services?

19. From your experience, can you think of any examples of good practice for meeting the needs of BME pupils?

20. From your perspective, do you think the needs of BME pupils with autism are currently being met?

21. If you had available time, money or resources, what ideally would you like to introduce to meet the needs of BME pupils with autism and why?

22. Finally, is there anything else that you would like to say that we may not have covered in this interview?

Thank you for your assistance.
Appendix 7: A description of the participants (BME parents)

Participant 1

Lim is from a Chinese background. She and her husband live in a middle class neighbourhood within the selected Local Authority (LA) in Wales. They have two sons. The older son, aged eleven, attends mainstream school while the younger, Lee, aged ten, who is statemented with autism, attends a special school which is about five kilometres from their home. Both Lim and her husband are presently not in employment. Lim’s husband is the primary carer for Lee. They have lived in the UK for more than ten years. Lim speaks Chinese and English but her husband speaks only Chinese. Lee’s first language is English. They speak Chinese with their community.

Participant 2

Nazia is from a Pakistani background. She and her husband live in an affluent neighbourhood within the selected LA in Wales. They have two children, a daughter and a son who are both statemented with autism. Their daughter, Ani, aged eight is non-verbal while their son, Ali, aged five is verbal. Nazia is the primary carer for her children when they are not in school. Her husband, who is a doctor, helps her when he is not working. Both the children attend a special school. They have lived in the UK for more than five years. They speak two languages, Urdu and English and speak both these languages at home with their children as well as in their community. Their children’s first language is Urdu.

Participant 3

Mina, a Pakistani is a retired teacher but currently works part-time in a family business. Her husband is a retired Dental Technician. They live in a middle class neighbourhood within the selected LA in Wales. They have four children and their third child, Mahmud who is eighteen has autism and is currently in residence. He used to attend a special school previously. They have lived in the UK for just over twenty-five years. The family speak four languages: Urdu, Punjabi, Arabic and English. They speak English to their son who is diagnosed with autism when he was young but now speak Urdu and English to all their children and the language that is spoken within their community is Urdu. Mahmud’s first language is Urdu.
Participant 4

Fante is from an African background. She and her partner have two children. Their older daughter aged six has speech problems and attends a mainstream school. Their younger child, Bini, aged four, has autism and attends a special school. Fante is a qualified lawyer but due to the circumstances is presently the main carer for Bini when she is not in school. Fante’s partner is in part-time employment. They presently live in a poorer part of the selected LA in Wales and have lived here for more than five years. The family speaks English and use it within their community and their friends are mostly from different background.

Participant 5

The father, Tariq, is of a Mauritian origin while the mother, Tammy is English. Tariq is a business man and Tammy does part-time care work. They have two daughters, one of whom has autism. The older daughter aged fourteen attends a mainstream school while the younger daughter, Nina, aged twelve attends a unit specific to autism at a mainstream secondary school, which is situated near their home. Nina’s first language is English but understands Creole. Tammy is the main carer for Nina. They live in an affluent area within the selected LA in Wales and therefore from a higher socio-economic background. They have friends from both White and Asian backgrounds. They have lived in the UK for more than ten years and have been living in Wales for about eight years. The father speaks four languages, namely English, Arabic, French and Creole while the mother speaks English and understands Creole. Therefore, English and Creole are the languages used socially within their community.

Participant 6

Shara and Adeo are married and from Sudanese background. They have two children, an older daughter aged seven, who is in a mainstream school and a son, Adi, aged five, who attends a special school. Both of them are not in employment. Shara attends English classes at a local centre and is the main carer for Adi. Adeo assists Shara in caring for their son. They live in the poorer part of the selected LA in Wales and have lived there for more than ten years. They speak Arabic and English most of the time. Since Adi is non-verbal, the parents communicate with him through Arabic. Their friends are mostly from their backgrounds.
Participant 7

Anne is from an English background while her partner is from a Caribbean background. They live in a middle class neighbourhood within the selected LA in Wales. They have two children of dual heritage, an older son, aged ten and a daughter, Canna aged nine who has autism. Both the children attend a mainstream primary school which is situated not far from their home. Both Anne and her partner are in employment however, Anne, an artist and painter by profession works on a part-time basis. The main care for their daughter is shared between them. They have lived in the UK all their lives and speak only one language, English and therefore English is their children’s first language. Their friends are mostly from mixed backgrounds.

Participant 8

Amin is from a Punjabi Muslim background. He works in a local University while his wife, who is also from the same background, is a home-maker. They live in a middle class neighbourhood within the selected LA in Wales. They have four children, two boys and two girls. Yusuf who is seven and the third child in their family has autism and attends a unit specific to autism in a Welsh medium mainstream school. The main carer for their son is the mother. The parents have lived in the UK all their lives identify themselves as Pakistani-Welsh. They speak English and Welsh at home and also with their children. The first language of their children is Welsh, which is given priority over English. So the parent’s communicate to their child with autism in Welsh. They speak English, Welsh and some Punjabi within a social environment.

Participant 9

Bibi is from a Pakistani-Punjabi background. She lives with her partner in a poorer area within the selected LA in Wales. Her only son, Din aged nine is going through the process of statementing for autism. Din attends a mainstream school which is situated near Bibi’s mother’s home which is in a middle class area within the selected LA. Bibi is not in full time employment however she helps out in a corner sundry shop that is managed by her family. Her partner works in the family run shop as well. Bibi is the main carer for Din. This care is also shared by her family. Bibi and her family live in a poorer part of the selected LA in Wales and have lived in the UK for more than ten years. The language that is spoken by them is Punjabi, Hingko, Urdu, Hindi and English. Din’s first language is Hingko and English. Their friends are mostly from mixed backgrounds.
Participant 10

Riza is from a Pakistani background but describes her ethnicity as British. She lives with her spouse in an affluent area in Wales. She has three children who are all boys. Her second son, Zul aged fourteen has autism and attends a special school. Riza is the primary carer for Zul. Her spouse, a doctor and her eldest son help out when they can. They have lived in UK all their lives. The family speak two languages, Urdu and English and spoke these languages at home with their children. However, Zul’s first language is English. The main language used socially and within their community is English. Their friends are mostly from their background.

Participant 11

Jamilla is from a Punjabi Pakistani background. She and her spouse live in an affluent area in the selected LA in Wales. Jamilla, works part-time as a radiographer at a hospital in Wales. She has three children, two boys and a girl. Her eldest son, Irwan is fourteen years and eight months old and has autism. Irwan attends a special school in the selected LA in Wales. He started attending special school at the age of three. Jamilla is the main carer for Irwan when he’s not at school. Her spouse, who is a doctor, helps her out whenever he can. They have lived in Wales all their lives. They speak three languages, Punjabi, Urdu and English but speak English and Punjabi with their two other children. However, they speak only English to Irwan. The main language used socially and within their community is English and Punjabi. They describe their ethnicity as Pakistani and their friends are mostly from their background.
Appendix 8: Original interview schedule for parents used in pilot study

Title: The Experiences and Perceptions of Parents of Black and Minority Ethnic (BME) Pupils Statemented with Autism in Relation to the Educational Support Provided for their Children and for Themselves as Carers.

Aims of the Research
To examine the experiences of parents or carers of BME pupils statemented with autism within special and mainstream schools and the education support services that are available to them in Wales.

In view of the above, the objectives of this research are:

1. to explore the experiences and perceptions of parents or carers of BME pupils of educational provision in special and mainstream schools;
2. to examine parental or carers’ experiences and perceptions of community based support organisation for the support of BME pupils with autism; and
3. to investigate the educational provision and support available in special and mainstream schools for BME pupils with autism.

Information Sheet

Part One - Personal details of parent
(Tick or circle answer where appropriate)

(a) Your name: ..........................................................
(b) Address :..................................................................................................
(c) Phone number:............................................
(d) How many children do you have?..........................................................
(e) How many of them have SEN?...............................................................*If more than one please complete one information sheet for each.
(f) Relationship to SEN child/ children: mother / father / parents/ carer

Information on your Child

1.1 What special needs does your child have?  
Autism / other (if other please give details)

.......................................................... ..........................................................

1.2 Age of the child: .............................................

1.3 Gender of child:  Male / Female

1.4 Statemented for SEN:  Yes / No

1.5 At what age, did your child start attending school?

.......................................................................................................................
1.6 Which school does your child attend? Please name the school.
.........................................................................................................

1.7 Type of school your child attends:

(a) Mainstream school (    )
(b) Special school (    )
(c) Unit specific to autism in mainstream school (    )

1.8 Does your child receive specialist help for autism/ Aspergers at school?
Yes / No
If yes, who provides this help?
.............................................................................................................................

1.9 Who lives with you and your child?
......................................................................................................................

1.10 When not in school, who takes main care of your child?
.............................................................................................................................

Parent /Carer and Ethnicity

1.11 How long have you been living in the UK?

(a) 6months -1 year (    )
(b) 1 - 3 years (    )
(c) 3 – 5 years (    )
(d) More than 5 years (    )
(e) More than 10 years (    )

1.12 How many languages do you speak?
.............................................................................................................................

1.13 What language do you speak to your child?
.............................................................................................................................

1.14 What language do you mainly use in the community / socially?
.............................................................................................................................

1.15 What is your child’s first language?
.............................................................................................................................

1.16 How would you describe you and your child's ethnicity?

(a) Indians (    )
(b) Pakistani (       )
(c) Bangladeshi (       )
(d) African (       )
(e) Caribbean (       )
(f) Somali (       )
(g) Chinese (       )
(h) other ethnic backgrounds (please specify).........................................................

1.17 How would you describe your friends?
(a) only from your ethnic background
(b) mostly from your background
(c) from your background as well as other groups
(d) mostly with different ethnic groups
(e) only with a different ethnic groups

Part two

Section One: Awareness of autism
1.1 Can you tell me your story about your child?
1.2 What does your child enjoy doing?
1.3 Can you tell me about your child’s strengths?
1.4 When did you first realize that something was different with your child?
1.5 How worried were you about this?
1.6 Who did you go to for advice or to speak to about your concerns?
1.7 Who made the diagnosis?
1.8 How long did it take to make this diagnosis?
1.9 In what language was it explained?
1.10 How was the diagnosis explained to you?
1.11 How did you feel when diagnosis was given?
1.12 Do you think it was made clear to you?
1.13 How did your family and friends react to the diagnosis?
1.14 Tell me about the help that was given to you after the diagnosis?
1.15 Who gave this help?
1.16 What kind of help did you get?
1.17 When did you get this help?
1.18 When was statement of SEN made?
1.19 Was the statement made at first diagnosis or later?
1.20 Did the school arrange for you to meet with them after the statement was made?
1.21 After diagnosis, did you think that it helped you understand autism better?
1.22 Did you have a choice in the support that was offered to your child?

Section Two: Support at School
1.23 Why did you choose mainstream or special school for your child?
1.24 Who has helped your child up until now?
1.25 What kind of help have they been given?
1.26 Who is helping your child now and how often?
1.27 How was the help given to your child?
1.28 When did this help start for your child?
1.29 Have you had any problems with the support given for your child?
1.30 What kind of help would you like from the school if it is possible?
1.31 Why do you want the help?
1.32 How often would you like it?
1.33 Do you have contact with parents of other children with autism?
1.34 Is there an opportunity to talk to other parents and teachers about the challenges of helping your child in school?
1.35 Has the school told you about any other help?
1.36 What help is available outside the school?

Section Three: Support within the Community
1.37 How do you think others in your community view autism?
1.38 How do you think your community view Special education needs?
1.39 Are they aware of autism and what do you think about autism?
1.40 What help is available to you?
1.41 How did you find out about this help?
1.42 Tell me about the help?
1.43 How often do you go?
1.44 What do they talk about when you are there?
1.45 Do you talk about your child’s needs to members of your community when you feel that you need help?
1.46 Did you search for information on the internet or did you find it from other sources?

1.47 Have you heard of National Autistic Society (NAS) Cymru and how did you hear about it?
1.48 What support are you having from NAS Cymru?
1.49 Does your family/community support you in any way in terms of information about autism and assistance?
1.50 Are there religious based support groups for parents within your communities? N/A
1.51 How do they guide you when you need help for your child N/A
1.52 How is special education needs viewed in your community? N/A
1.53 Is there anything else that you would like to say?

Thank you for your time.
Appendix 9: A Sample Interview Transcript of One BME Parent

(Amin (father) and Yusuf (7) are culture appropriate names given to the parent and his son in the study.)
Date of interview: 2012.
(view 8, para 1 = 8/1)

**Section One: Support in education**

(8/1) 1 Can you tell me your story about your child?
Amin (A): So he was quiet child, very compliant child and he did speak. He would say words like milk although he was young as a child. So we didn’t think anything was wrong. But we noticed that as he was around two years old, he stopped speaking at all and he would repetitively do certain things like he would watch a certain video like Toy Story. He could watch that all day and he could watch it day after day after day and he wouldn’t play with other children. Although we didn’t think much of this, and then ... preschool. I taught my daughters to read so I did the same with him but he refused. I didn’t think that there was anything wrong in that specifically. But then when he went to nursery, the teachers noticed that he was parallel playing which is their term for kids not playing with anybody else. And they noticed that he wasn’t learning in the same way and that he was withdrawn and then at that moment then he was at the start of the process of him being diagnosed with autism. He would have been about four or five. Urh … probably four, yes.

He then stayed in the nursery still at that school which is XXX (Welsh medium school) and then he moved into the reception year. The reception year was a lot more difficult for us and him. Urh ... he’s always happy anyway, he wants to play with water but obviously he wasn’t a normal child in terms of doing what the teacher asked him to do. They couldn’t cope with him and from what I learnt was they had legally to keep him there unless we ask for him to be removed. So they were under constraints and their constraints were, ‘okay, we have to have another teacher to look after him and then would the teacher be qualified to look after him and meet his needs’ but I’ve learnt this, they have legally to keep him. Given the attitude of the school, given the attitude of the head-mistress, I got the distinct impression that they didn’t want him there and because they were overwhelmed or didn’t know what to do. And the thing that the teacher said to me is that, “I’m happy to leave him in the corner, playing with water all day” but I’m not sure how beneficial it is to him. Then we tried to sort out another ... This is a Welsh medium school, that’s why my son is there with his older sisters. So then we decided to find another Welsh medium school which had some sort of special needs for ... and which was equipped for special needs for autistic. Then we found XXX (Welsh school) which is in XXX (place) and that’s where he is now, currently and I’m very happy with his teachers, yes.

(8/2) 2 What does your child enjoy doing?
A: He enjoys ... particularly likes the ‘wiggles’ and particularly enjoys going on the computer and playing games.

(8/3) 3 What is her strength?
A: Strength is probably running and playing outdoors.

(8/4) 4 When did you first realize that something was different with your child?
A: That would be it ... I tried to teach him the concept of red. We didn’t do the alphabets. He could learn the alphabets off rote. It’s not a problem for him. But you could see that he was not learning like my other daughters. I taught my daughters phonetically, the
alphabets “ah, bah, cah, dah”. We do this and we’d do words, we’d do reading and then with lists of words. It took about two or three months and the children could read after that. We tried the same with him, but that failed completely. Then I tried to understand ...
Does he understand the concept of things ... or more basically than that? I went around the house one day and we tried to learn the concept of red: what red is; things that are red; the word red, you know. But he just refused and burst into tears. He would have been about three.

(8/5) 5 How worried were you about this?
A: Yeh, extremely worried (he sighs). You hear anecdotal stories of children who don’t speak, you know and then do speak. Because he was three years old, I thought okay, maybe that’s the reason why and maybe when he goes to nursery things will even out and he’ll be fine. But that clearly wasn’t the case. So, obviously when he went to nursery, the teachers noticed and from that point.

(8/6) 6 Who did you go to for advice or to speak to about your concerns?
A: I got it all from the internet. He was referred to ... the school did the referral and then it went to (name of hosp.)Hospital and we were allocated to Consultant Paeditrician.
I: Did you go to the class teacher?
A: We did, ya, I mean, she told us that he was playing parallel.
I: Did you go to the SENCo?
A: No
I: Did you see a speech and language therapist (SALT)?
A: No
I: Did you talk to anyone to anyone from you community?
A: No, as you know, being Asian it’s something that’s frowned upon. Children who are disabled are kept in the background. And people interact, not the parents, they obviously love the child ... we love our child obviously, but relatives around you, they don’t have the attitude. It’s quite stern.

(8/7) 7 Who made the diagnosis? (Was it your GP? Was it other health professional?)
A: The Consultant Paeditrician.
(8/8) 8 How long did it take to make this diagnosis?
A: It takes 6-8 months. It takes a long time.

(8/9) 9 In what language was it explained?
A: It was in English.

(8/10) 10 How was the diagnosis explained to you?
A: Yes, I was told that he was on the autistic spectrum and because of the nature of the spectrum, every child's diagnosis is different. I know it’s obviously the case because I’ve never seen two children with the same diagnosis. I mean, they get the same diagnosis but they are not the same. They are always different.

(8/11) 11 How did you feel when diagnosis was given?
A: Well, you know, we knew beforehand (laughs) anyway it’s just that he required the diagnosis for certain things to happen to him. But we knew he was autistic, it was obvious.

(8/12) 12 Do you think it was made clear to you?
A: It was. Yes, our experience fitted well to what diagnosis was given. So, it was plain to see that was the case.
A: I think they knew anyway, that he was but what you or they would term a normal child. He was different. They were of an opinion, even my parents, now, they have an element of denial. Such that they think, when he goes to bigger school, he’ll just get better. He’ll be just like a normal boy but we’re trying to like … make them understand, that this is who he is. He may be able to devise strategies to make it appear that he’s normal but he will never be that person.

A: Okay, the best help we received was from the HV (health visitor) and it was fantastic like benefits, that was important because it would help him more, pretty much that was it. The only other help we’ve had is that we’ve gone out and found parent groups. It’s called “Thrive”. So we go away every week. My son goes every week and we meet parents, it’s a mixture of parents. We see a lot of kids with autistic spectrum disorder. So we get to meet them and talk about what’s going on. His sisters and brother come along too and they have been on a sibling course by NAS although I don’t know whether it benefitted them. They play together there. I’ve been on a couple of courses by the NAS.

A: When he got the diagnosis, we got help from the HV but the real help from the school came from the NAS who basically said that you have to empower yourself.

A: He was six and was in a Welsh school and doing fine. He is now seven, he’s progressing, it’s slow. The only thing he really needs at the moment is speech therapy and he doesn’t get that often enough. He gets it once a month and the teachers act on that advice. He occasionally has an Education Psychologist, if his behaviour is abnormal and then the Education Psychologist will be called in and monitor his … for a week or two, ya.

A: And during his SEN statement, which is only about two weeks ago, the Education Psychologist was in that meeting as well. The statement, that would have been when he was five. It was made when he was five, 2 years ago.

A: later

A: urh no … so he transferred school, by then, from XXX to XXX (one Welsh school to another Welsh school). It has an English part which is XXX (English medium) and a Y part (Welsh medium) and it has a special resource base which my son attends and which also means that he can attend mainstream classes as well as get specialised help. He does attend mainstream school.

A: No … you have your own intuitive understanding of what’s happened to him. You have to read books and there’s a lot of contradictory advice … you go through the anger … that phases of anger, pain, denial and then acceptance or whatever it is we went through all
that. We have anger then we have the pain, you go through the denial and look for the miracle cures. And you have to go back and agree that this is the way he is. The way you learn is that you find out that other people have devised strategies to make it appear that they’re normal and they use the strategies all through their lives.

(8/22) 22 Did you have a choice in the support that was offered to your child?
A: You have a choice whether you want it or not and that’s about it.

(8/23) 23 Why did you choose mainstream or special school for your child?
A: Special school, XXX because he was basically abandoned in his previous school. We went to look at the school and they had ... they were teaching autistic children in that school. So obviously they had experience of being able to teach autistic children. It was a special resource based and everything was geared towards autism. And as soon as we went into the class we knew that this is where he needs to be. And now, they had a new head in the unit, it has got even better. The teachers have made the area, more friendly for autistic children and you know he is making progress and it’s good.

(8/24) 24 Who has helped your child up until now and what kind of help have they been given?
A: So he forms very close bond with the TAs, and they had TAs in the class. He works very well with the teacher that is there, whose name is XXX and I like the atmosphere in the school. So all the teachers, every teacher knows Yusuf. My daughters went to Welsh medium school, so he went to a Welsh medium school. We thought ... urh, okay, and he was there for one and a half years and we thought let’s not rock the boat in terms of what he has learnt so far. He does take in, he does learn words. He can communicate when he wants. He had acquired a certain amount of language, when he basically spoke he could understand English, Punjabi and Welsh. So I mean, you know, whether sending him to Welsh school or English school, either you know, I think it was a viable option at that time. It just so happened that we looked at Welsh schools and we thought that’s the one. We were advised at that time, whether it is wise to send him to a Welsh school ... and we did think about that and we are ... That’s one of our many concerns, should he still be in Welsh medium school education but because the level of the teaching is very good. We are happy at the moment but this is revised every year by ourselves, by me and my wife. We always talk about ... it’s a major topic of conversation that comes up every year when at the end of the year and we always think, shall we take him to English medium. And we are looking, occasionally we all will go in to school and have a look. But we will only ever move him if the school was much better than what is for the moment.

(8/25) 25: Who is helping you now and how often?
A: The TA is there in the resource base.

(8/26) 26 How is this help given?
A: And so, the TA formed very close bonds. They are there always. Occasionally, he will go to ... he will spend most of the time in a resource base. Once a week he would go to the main lesson. It might be a key lesson, it might be a craft lesson. It will be about an hour, which is about as much as his attention span can last.

(8/27) 27 When did this help start for your child? (prompt: Was the help from the Education Psychologist? What about the SaLT? What about the SENCo, teaching assistant? What about school transport?)
A: It started straight away and he would have been 4 or 5, ya.
I: Was there help from the SaLT?
A: Ya, there was a SaLT in XXX and she goes over to XXX (Welsh special school) and once a month she’ll advise XXX (teacher) what his progress is. And you know, they will sit down with Yusuf and try and understand how far he has got compared with other children and she will give her recommendation of the work that needs to be done in the next couple of months.

I: What about school transport?
A: Yes, it’s a real problem at the present but hopefully that’s been sorted out. And he builds a very good relationship with people and trusting relationships. So his first driver was fantastic but there are these stupid and horrible rules where after the one year, the same driver is not used. I don’t know what that’s about. He’s built a fantastic relationship with his previous driver whose name is Ali and he took him there for a whole year. And Ali wanted to see Yusof and take him to school ‘cause they had built up a good trusting relationship and you know what, Ali came back the next year even though he was not meant to do it but they put someone else in. That really hasn’t worked out. My son gets quite violent in the taxi and quite agitated and be quite disruptive sometimes. But now he’s changed drivers and things have calmed down now. He was travelling with another child and that’s when it all started. The other child started becoming disruptive by kicking and taking his shoes off. And then Yusof copied him. Because the assistant who is in there couldn’t control both of them, they tried to get harnesses for them and then …I think the person who’s with them is very old and has no training at all and had no clue how to do it.

(8/28) 28 Have you had any problems with the support given for your child? (prompt: frequency, type or individual)
A: No, I mean I think he needs more speech therapy. That’s his real deficit and if he gets his speech going he’ll be okay. His previous teacher, who’s retired now, Mrs. XXX, she’s been at XXX (name of Welsh school) for 20 or 30 years. And when she left we saw her previous pupils come in and they were all chatting. So she has had long experience with teaching pupils with learning difficulties. So when she looked at Yusof, she said, “Oh don’t worry, I can tell that he’s going to be a speaker”. So just from her instinct and her sixth sense which is … been held over 30 years. We became a bit more relaxed, you know. He can speak sentences. He’s been in the school play now first time ever. You know, when he needs something, when he’s desperate for something, the word ice-cream or chips will come out from nowhere. It’s all there it’s just that he has no need to bring it out at the moment.

(8/29) 29 What kind of help would you like from the school if it is possible?
A: More speech and language.

(8/30) 30 Why do you want the help?
If they had more teaching materials, helpful materials that’s specific for autistic children, hmm (pause). It’s very poor. In the school, they have all these things. So they have the stick, the PECS and his time things. He hates PECS by the way. He despises PECS. So, that didn’t go very far. If he is given PECS, he will dispose of it very quickly or in a nearest crack anywhere. When he wants something he’ll make his own intonation that he wants something. I’ll ask him in Welsh, what he wants and he’ll answer in Welsh if he wants a drink or whatever he wants or biscuits.

(8/31) 31 How often would you like it?
A: All the time.
(8/32) 32 Do you have contact with parents of other children with autism?
A: Yes, through THRIVE (parent support) meetings.

(8/33) 33 Is there an opportunity to talk to other parents and teachers about the challenges of helping your child in school?
A: They help … So they do special activities. Yusuf likes outdoor activities, for example, he did cycling with the “Go Paddle Power” or something in (name of place) and you know, they asked us if he wanted to join. So we sent the money off, So he’s going to become a member. So he can go back again, you know. Urh … my wife, she’s a housewife and is seriously considering respite at the moment. Now I think during term time it’s not too bad because he’s in the school and in the weekend, I usually take a lot of my time in taking care of him because he needs to go out and he’s an outdoor kid. He’s very big and very strong. So he needs to go out, you know, I take him out every weekend.
I: What about teachers?
A: Yes I suppose … Mrs XXX (school teacher) was helpful. The early nursery was not. We did it ourselves and contacted Thrive, it’s a parent organization that help you with answers about queries on learning disabilities. So there they were very helpful.

Section Two: support organisation
(8/34) 34 Has the school told you about any other help outside the school?
A: No

(8/35) 35 Have you heard of National Autistic Society (NAS) Cymru or any other organisation and how did you hear about it?
A: huh … NAS, My wife has and she … from HV yes for certain things, they were helpful

(8/36) 36 What support are you having from them?
A: I think occasionally sees somebody there. We get leaflets so we know what is available. I haven’t been on their website, maybe I should. The Early Bird, that is the first thing they (NAS) tell you to do. It is useful and beneficial. It was about 3 to 4 weeks and you have to attend one afternoon for 2 weeks. Me and my wife attend this.

Section Three: Support within the Community
(8/37) 37 How do you think others in your community view autism?
A: Very badly, with, urh … it’s just an Asian thing. “If a child is disabled, they will blame it on you, they will blame it on God, they will blame it on anything but what that actually is.”

(8/38) 38 How do you think your community view Special Education Needs?
A: Urh, It is cultural and religious and baggage that is carried over. But the younger generation, they are a lot more understanding. They understand better because they are lot more educated. It’s education. I think, most younger people realise that, that is what a child requires and that’s the way it should be done. They (older generation of ME groups) still think that you’ve done something wrong to the child. So you can take them to a ‘Hakim’ (doctors) or ‘Fakir’ (doctors) or a ‘Pirs’ (saints).
I: Can you explain what a Hakim, Fakir and Pirs is?
A: Oh, ‘Hakim’ and ‘Fakir’ are like doctors and ‘Pirs’, it’s like a living saint. I didn’t realise that they are allowed in the Muslim religion but they are. My mother would occasionally go through a ‘Pirs’ and drop in money after the advice. I think the older generation is still like that but the younger generation, they understand and they are fine with that, I think.
(8/39) 39 Are they aware of autism and what do they think about autism?
A: Clearly not, I mean, clearly they think that it’s ... transitory phenomenon or ... I won’t say disease, it is a developmental defect or difference that pervades you from the rest of your life. It doesn’t go away and there’s no miracle cure for it.

(8/40) 40 What help is available to you from your community and how did you find out about this help?
A: Absolutely nothing, (he laughs)

(8/41) 41 Can you tell me about any social/group meetings that you attend and if so how often do you attend them?
A: Absolutely nothing. My heritage says I should be Muslim but I’m not. I don’t believe in a God. There’s nothing ... Well, I attend these things, it’s part of cultural life. It’s not that I don’t talk about it but they don’t talk about it either. Children with autism, we have cousins ... I have an uncle and my cousin is autistic. Well, we think she has a developmental disorder which may be autism but I’m not sure ... talk to parents ... it’s my uncle and my cousin and I treat them normally. I did that before anyway. I think most people did because that’s the way they treat them. She comes over to us. We don’t mind, we give respite to her sisters.

(8/42) 42 What do you talk about when you are there? Do you talk to other families with children with autism within your own community?
A: If someone asks me about my son, they’ll ask how he is doing in school or if he is enjoying himself. He’s a kid who loves life. He’ll be always finding something to do. So when people see him because he isn’t talking, they assume that he is fine. No, I don’t talk to families; however Yusuf will want to, to particular cousins. He likes particular aspects of persons. One of my cousins, he has a beard and Yusuf will stroke his beard. I think when he was young, we’ve been overly loving, he now expects that sort of treatment from everybody. So he will hug everybody you know. I don’t think that’s bad now, he’s so young. When he was young he was very weary about others coming to our house. He would be weary and cling to us ... he would be extremely agitated and cry for example, one of the first words he learnt was ‘bye-bye’, because he wants people to go out of the house.
I: Did you search for information on the internet or did you find it from other sources?
A: Yes, that’s how we found the parent groups and they’ve been really important. We have seen other parents who are Muslims or Pakistanis there as well. Even, they don’t meet or contact much, in Thrive. The ones we go to, is towards XXX then it was in XXX, and now it is in XXX.

(8/43) 43 Does your family/community support you in any way in terms of information about autism and assistance?
A: Nothing, I won’t expect it...they have this attitude of this disability which is unfortunate. It is not mired in the last century, its mired in centuries ago attitudes...mysticism, witchcraft, and ridiculous notions which has got nothing to do with either their religion. It’s all cultural mambo jumbo. And these idiots, the religious... are the worst because they said that you have done something against God. I have a deep understanding about science and biology and I can tell you that that is not the case.

(8/44) 44 Are there religious based support groups for parents within your communities?
A: Absolutely nothing and again I would never expect there to be any unless there is an outbreak.
(8/45) 45 How do they guide you when you need help for your child?
A: No guidance absolutely not.

(8/46) 46 How worried are you about your child’s future and what are your worries?
I am very worried you know. We have to plan ahead, we have to look after ourselves because ... and the reason we had another child who was younger, was specifically because my son was autistic. Ya, we would never have had a fourth child, we were happy with three, you know. And ... I...I think maybe if it was a girl and she was autistic, I think ...we wouldn’t have had another child because my daughters may have been a lot more sisterly and looked after the little one. However, they are not, ... don’t look after him, they don’t have the maternalist feeling towards him. I know that they are sisters and they should have sisterly feelings towards their brother but I don’t see that at all. They are 11 and 10 and they have other interests in the world, their school, their friends and everything else. And their brother doesn’t come high in their list of priorities. They ... they look after him, but ...you know, they won’t go out of their way to help him or they know that we will do that anyway. You know we try and change them. The main reason we had child no. 4 was that as we grow older ... I realise that Yusuf may have to stay with me slightly longer. Well I hope that he will become independent. That is my dream, obviously and we work to ensure that will happen and then he would have a fruitful life. You know away and independent. And then he can hopefully make his own decision of what he wants in life but ... being realistic, if it was my daughters and they went off and did this I would be happy. I am OK with that. If I passed away or I was on my death bed, I know they will be alright ... hmm ... my son is a different thing. I look after myself a little bit better. I want to be there for him. We have to think about his future eventually. It is finding the right school and then I think intuitively we will realise that he has had enough of us. Generally, he is ... we understand him enough when to know when he is fed up with something. There may come a time, just like my daughters, when they will get fed up with me and my wife and just say, “Look, get out of our lives”. And I truly hope and wish that will happen one day with him as well and then he will say, “Look, I don’t want to do this with you, I want to do it on my own”. We will be the first ones to push him out of the door or send him to a residence so that he can get that independence that he needs to get away and lead an independent life.

(8/47) 47 Is there anything else that you wish to say?
A: No

Thank you.
## Appendix 10: Timeline of the sequence of events in the study

<table>
<thead>
<tr>
<th>Activities</th>
<th>Times</th>
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<tbody>
<tr>
<td>Enrolment and development of proposal</td>
<td>October 2009</td>
</tr>
<tr>
<td><strong>Literature search &amp; reading</strong></td>
<td>Oct. 2009 to January 2014</td>
</tr>
<tr>
<td><strong>Selection of Research Methods</strong></td>
<td>April 2010 to November 2012</td>
</tr>
<tr>
<td><strong>Research Design &amp; gaining sample for study</strong></td>
<td>April 2011- November 2012</td>
</tr>
<tr>
<td>Work on research design in relation to the case study</td>
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<tr>
<td>Literature search and reading</td>
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<tr>
<td>Devise schedules for interviews with parents, staff at schools and relevant support organisations</td>
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<tr>
<td>Prepare interview questions</td>
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<tr>
<td>Prepare sampling frame for this study</td>
<td></td>
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<tr>
<td>Select samples from education settings and from charitable organisations in relation to study</td>
<td></td>
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<tr>
<td><strong>April 2011-December 2011</strong></td>
<td>Gain consent from parents and relevant stakeholders</td>
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<tr>
<td><strong>Permission</strong></td>
<td>April 2010 to Dec.2010</td>
</tr>
<tr>
<td>Piloting and revising the interview schedules</td>
<td>August 2010 to February 2011</td>
</tr>
<tr>
<td>Identification of staff in education and charitable organisations</td>
<td>April 2010 to August 2010</td>
</tr>
<tr>
<td>Interviews took place with parents at their homes</td>
<td>June 2010 to April 2011</td>
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<tr>
<td>Completion of the interview schedules for both categories. Parents and stakeholders were contacted to arrange for interviews</td>
<td>Sept. 2010 to Oct. 2011</td>
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<tr>
<td><strong>Data collection</strong></td>
<td>April 2010 to Oct. 2011</td>
</tr>
<tr>
<td>Carry out interview with selected sample</td>
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<tr>
<td>Continue literature search and reading</td>
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<tr>
<td><strong>Autumn11/Spring12</strong></td>
<td>Data entry and preparing for data analysis facilitated by NVivo</td>
</tr>
<tr>
<td>1. Qualitative data analysis</td>
<td></td>
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<td>2. Interview method</td>
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<td>3. Records and document</td>
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<td>4. Review progress with supervisor</td>
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<tr>
<td>5. Analyse qualitative data gathered from interviews</td>
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<tr>
<td><strong>Data Analysis</strong></td>
<td>Spring12/Summer12</td>
</tr>
<tr>
<td>Collate and analyse data</td>
<td>Verification of data including clarifying upon unclear data</td>
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<tr>
<td>Begin writing up the analysis</td>
<td>Begin discussion on completed written work</td>
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<tr>
<td>Continue literature search and reading</td>
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<tr>
<td><strong>Autumn12/Spring13</strong></td>
<td>Carry out data analysis and continue to devise further activities based on findings of the study</td>
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<tr>
<td><strong>Spring13/Summer13</strong></td>
<td>Collate and complete analysis and first draft of written work</td>
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<tr>
<td>Discusssion with supervisor</td>
<td>Continue updating literature and reading</td>
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<tr>
<td><strong>Writing up</strong></td>
<td>Feb. 2010 to November 2014</td>
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<tr>
<td>Spring 2014/Summer 2014</td>
<td></td>
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<tr>
<td><strong>Completion of writing whole thesis</strong></td>
<td>Spring 2015</td>
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