

Parents Caring for a Child with Autistic Spectrum Disorder (ASD) who use English as an Additional Language: Their Experiences of Health and Education, and Societal Responses

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List of initialisms and acronyms

ABA	Applied Behavioural Analysis
ASD	Autism Spectrum Disorder
BAME	Black and minority ethnic
BERA	British Educational Research Association
BESD	Behavioural, Emotional and Social Difficulties
CACHE	Council for Awards in Care, Health and Education
CCG	Clinical Commissioning Group
DCSF	Department for Children, Schools and Families
DfE	Department for Education
DoH	Department of Health
DSM	Diagnostic and Statistical Manual
EAL	English as an Additional Language
EHCP	Education, Health and Care Plan
GNI	Gross National Income
GP	General Practitioner
HICs	High Income Countries
LA	Local Authority
LICs	Low Income Countries
LMICs	Low Middle Income Countries
LUMICs	Low Middle Income and Upper Middle Income Countries
MP	Member of Parliament
NAS	National Autistic Society
NASUWT	National Association of Schoolmasters Union of Women Teachers
NHS	National Health Service
nd	no date
np	no page
OCD	Obsessive Compulsive Disorder

OFSTED	Office for Standards in Education, Children's Services and Skills
SALT	Speech and Language Therapy
SEN	Special Educational Needs
SENCo	Special Educational Needs Co-Ordinator
SEND	Special Educational Needs and Disabilities
TA	Teaching Assistant
UK	United Kingdom
UMICs	Upper Middle Income Countries
WHO	World Health Organisation

Abstract

Introduction

Little is known about the experiences of parents caring for a child with Autistic Spectrum Disorder (ASD), who use English as an additional language (EAL). This study aimed to discover some of the barriers facing these parents who are resident in the UK but who were born in a low income, low middle income, or upper middle income country (LUMIC) in terms of their receiving help and support with their child's condition.

Methods

A qualitative approach was taken with a purposive sample of seven participants born in a LUMIC who were interviewed by telephone or in person. All telephone calls were conducted in private, with the researcher and participants being in their own homes. One face to face interview was conducted in a quiet space within a café, and in two cases, the participant's home (please see Appendix 1 for further details). All parents were asked about their experiences with health and education services in their country of birth and in the UK, and with society more generally. Interviews were recorded, transcribed and coded using thematic analysis to identify and refine major themes in the data.

Findings

Healthcare in LUMICs was limited and professionals tended to have a poor understanding of ASD. In the UK, ASD was better understood, but waiting lists were lengthy for diagnosis and treatment. Educational needs of the children in the UK were not always understood or met by professionals; parents had to battle for their child's rights, but often needed help to do this, which was difficult to access. Parents having EAL was not detrimental to their accessing health or education services, due to participants mostly having a moderately good grasp of English. Issues arose, however, in participants being fully able to understand ASD, as it was commonly unheard of in LUMICs. Parents sometimes felt stigmatised by, or encountered hostility from, wider society owing to their child's ASD.

Conclusion

Both in the UK and LUMICs, greater emphasis should be placed on training health professionals, to improve their diagnosis and understanding of ASD. Public awareness-raising programmes are needed to reduce stigma. Cutting waiting times for assessment and treatment would improve parental satisfaction with services. EAL users would benefit from bilingual information to share with extended family members in LUMICs as this would enhance familial understanding and provision of support around ASD.

Chapter 1 - Introduction

The researcher is a senior practitioner in a private nursery setting working with two to four year olds in a deprived area of West Yorkshire (Kirklees Observatory, 2015), which is home to a wide variety of cultures and communities. The nursery is relatively small, with 29 children attending Monday to Friday for three hours daily. More than three quarters of the children have one or both parents who were born outside the United Kingdom (UK) and live in a household using more than one language. The majority of non-British born parents identify as Kurdish and were born in Iraq. However, there are also parents from Morocco, Poland, Pakistan, Syria, Eritrea, Burundi and Somalia.

A number of children with special educational needs and disabilities (SEND) are registered at the setting. The SEND Code of Practice (Department for Education (DfE) & Department of Health (DoH), 2015) defines a child with SEND as having “*a learning difficulty or disability which calls for special educational provision to be made for him or her*” (p.15). “*Special educational provision*” is defined as “*educational or training provision that is additional to or different from that made generally for other children or young people of the same age*” (DfE & DoH, 2015, p.16). Two of the setting’s four year olds are non-verbal and receive additional provision from external agencies, including speech and language therapy (SALT), and the local early years (EY) SEND team, which provide assistance to children up to the age of seven years, their families and their educational settings. Help is provided regarding children’s learning, and personalised teaching strategies are created and implemented to ensure children reach small targets, aiming to increase their skills. Referrals can be made to this service from nurseries, schools, parents or health and social care professionals (Kirklees, 2017a). Following continued assessment, observation and discussion on the part of various external agencies and the nursery, and their all working together in partnership, both non-verbal children at the nursery were placed on the local authority’s waiting list to undergo an ASD assessment.

In DSM-5, ASD is characterised by “*persistent deficits*” in a person’s social interaction/communication skills and display of restrictive/repetitive behaviour (American Psychiatric Association, 2013). It is estimated that, in the UK, 1 in every 100 children is on the autistic spectrum (Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum & Charman, 2006). Although the causes of ASD are unclear, there is evidence suggesting links to environmental (Bakulski, 2019; Chang, Cole & Costa, 2018) or genetic factors (Bailey, Le Couteur, Gottesman, Bolton, Simonoff & Yuzda et al., 1995; Shomrat & Neshet, 2019) or a combination of both. The theory of genetic influences was validated in research undertaken at the Washington University School of Medicine in St Louis, Missouri, where it was proposed that there could be a link between ASD and a specific gene mutation. Valnegri, Huang, Yamada, Yang, Mejia & Cho et al. (2017) suggest that there is a form of communication error between brain cells, which creates too many synapses; these are the connections that allow neurons to transmit signals to one another. The result of having too many

synapses, is miscommunication in transmitted messages, resulting in learning impairment, but it is not clear how these errors occur.

Although research from Bailey et al. (1995), Shomrat & Nesher (2019) and Valnegri et al. (2017) indicate ASD may be caused by a genetic issue, this view is challenged in other work. Even though ASD is possibly caused by gene impairment, there is, as yet, no way of determining how genes interact with “*other environmental factors*”, such as maternal depression, premature birth or exposure to air pollutants (DeWeerd, 2015), suggesting that a child may develop ASD dependent on their individual situation and circumstances. However, other research suggests ASD may begin during pregnancy. Stoner, Chow, Boyle, Sunkin, Mouton & Roy et al. (2014) discuss how a child’s brain is formed, by creating a multi-layer cortex. Disturbances in the correct development of these layers were discovered within the majority of autistic children. Each layer is responsible for processing certain types of information. If a layer is undeveloped, this may result in learning impairments related to, perhaps, language or social interaction, two major traits of ASD.

Autism is classed as a spectrum condition, meaning all patients will display certain difficulties, such as in social interaction or language delay, but ASD will affect them in different ways. Some people on the autistic spectrum will also have a learning difficulty, such as dyslexia; a mental health issue such as Obsessive Compulsive Disorder (OCD); or another condition, like epilepsy. ASD is a lifelong condition and cannot be cured. However, with support and sometimes medication, patients can live healthy, fulfilling lives whilst working and engaging in everyday tasks (National Autistic Society (NAS), 2017e).

Diagnosis

Obtaining an ASD diagnosis can be a laborious process in the UK. First, concerns surrounding a child’s development must be raised with a general practitioner (GP) or other health professional. Crane, Chester, Goddard, Henry & Hill (2016) showed that in 96% of cases, it is a parent who has first noted “*atypicalities with their child’s development*” (p.156), but concerns also may be observed by one of a range of professionals, such as health visitor or nursery practitioner, and discussed with parents. In the researcher’s professional practice, the two children awaiting ASD assessment were both identified by nursery staff, rather than by their parents or any other professional.

Any health professional must observe a number of characteristics in a child’s behaviour to make a referral to the neurodevelopmental pathway for ASD assessment. In the researcher’s locality of Kirklees, a parent may also make a referral to the neurodevelopmental pathway, which is the new name for the process concerning assessment of Attention Deficit Hyperactivity Disorder (ADHD) and ASD (Thriving Kirklees, 2019). Patients will undergo a series of observations from agencies such as SALT and paediatrics (Karim, Cook & O’Reilly 2014; Rutherford, Burns, Gray, Bremner, Clegg & Russell et al., 2017), enabling professionals to obtain a holistic view of the patient. These views are shared with the lead professional, usually a psychologist, prior to assessment, where the family history is discussed. The patient may

undergo a physical examination, and there may be discussions concerning each family member's strengths and needs. After a full consideration of all aspects of the assessment, a diagnosis is prepared. Families may receive the diagnosis on the same day as the assessment, or within a few days via letter or telephone call (NAS, 2017c).

The waiting list for neurodevelopmental assessment can be very lengthy. Parents in the UK may wait, on average, three and a half years from initial contact with a health professional to an assessment for their child (Crane et al., 2016). A delay in diagnosis can lead to parents losing confidence in health professionals (Harrington, Patrick, Edwards & Brand, 2006) and lower levels of satisfaction in service providers (Howlin & Moore, 1997). These emotions were evident in a 2014 review of services for children with ASD, undertaken across three local Clinical Commissioning Groups [CCGs] (Yorkshire & Humber Commissioning Support, 2014). The review was carried out in response to increased waiting times and complaints from parents and members of parliament (MPs). Service users were questioned about their experiences and how services could be improved. Results indicated that extended waiting times were a source of frustration for many families. Feedback was also received regarding the need for extra ASD training for some professionals, and a lack of support received for families awaiting an assessment.

It is thought that the earlier intensive intervention begins for a child, the better the outcome (Matson, 2007; Warren, McPheeters, Sathe, Foss-Feig, Glasser & Veenstra-VanderWeele, 2011), but it is concerning that the National Health Service (NHS) waiting time for ASD diagnosis is so lengthy. Early intervention is defined as "*making a prompt intervention to support the child and family...if a child receives the right help early on he or she has a better chance of tackling problems, communicating well and making progress*" (Department for Children, Schools and Families (DCSF), 2008, p.8). This is corroborated in research undertaken with children with ASD post-diagnosis, which suggests early intervention could severely reduce developmental delay (McEachin, Smith & Lovaas, 1993; Weintraub, 2013).

Education and ASD

It is usually not possible to access specialist provision, that is, an educational establishment catering wholly for pupils with SEND, without a formal diagnosis of a special need or disability (Autism Education Trust, 2016). A child with suspected ASD and a high level of need could, therefore, attend a mainstream school from the age of four years until diagnosis some years later, bearing in mind lengthy waiting lists. Post-diagnosis, parents may conclude that a special school would have been the most appropriate environment for the past few years, had a diagnosis been received sooner.

Over 70% of children with ASD attend a mainstream school (Ambitious About Autism, 2013; Hebron & Bond, 2017). However, the majority of teachers in England feel they have not had adequate training to teach pupils with ASD (Ambitious About Autism, 2013; Lindsay, Proulx, Thomson & Scott, 2013). Potentially, therefore, the majority of pupils with ASD may not be taught with the most appropriate

pedagogic styles for their individual learning needs, and are unlikely to reach their full potential if their requirements are not holistically met (Allen & Cowdery, 2005; Warnock, 2005).

Following the results of the National Association of Schoolmasters Union of Women Teachers (NASUWT) survey and campaigning by the then Education Secretary, Justine Greening, in 2016, the government agreed that autism would be the focus of more attention in initial teacher training (Espinoza, 2016; NAS, 2016). This is a positive step for future education, considering almost three quarters of children with ASD attend mainstream schools, which means it is likely that every teacher will, at some point, teach a child with ASD (NAS, 2017h). It is essential that every teacher is able to support all of their pupils, as every child has the right to receive an education in an inclusive environment (Lindsay et al., 2013; UNICEF, 2018).

Educational support

It has already been noted that ASD can take years to diagnose from the date when atypicalities are first observed (Crane et al., 2016), so an undiagnosed child may have no option but to begin their education in a mainstream setting. Although considerable support can be provided in mainstream education, it is perhaps not the same as specialist provision, catering wholly for pupils with SEND, where teaching staff may have a greater understanding of SEND and more knowledge of appropriate teaching strategies.

Children presenting with difficulties in preschool can receive additional help through a local authority's "*local offer*". The SEND Code of Practice (2015, 4.1) describes a local authority's duty to "*publish a local offer, setting out in one place information about provision they expect to be available across education, health and social care for children and young people in their area who have SEN or are disabled, including those who do not have Education, Health and Care plans (EHCPs)*".

Within the researcher's locality, under the terms of the "local offer", a "My Support Plan" (excerpt at Appendix 2) may be implemented for any child in receipt of multi-agency help in order for that help to be co-ordinated, but the plan is not a statutory document. In the researcher's own experience, it is a useful tool for the co-ordination of services and information regarding a child's needs and abilities. A well-written My Support Plan that has been reviewed and monitored can be of great value when preparing for an EHCP. A Support Plan is completed with parents and SENCo, together with input from key professionals, such as nursery practitioners or speech therapists. Short-term targets for the child to meet are created as a team effort. The Plan is a working document and can be amended at any time. It is usual for the Plan to be reviewed every six weeks to assess the child's progress. Reviews are opportunities to consider whether (a) targets have been met and new ones are required, or (b) whether targets have not been met and the child needs the unmet target broken down into smaller steps. A good, well-structured Support Plan will often enable a child to meet their targets before the onset of reception "*through delegated funding and coordinated support*" (Yor-ok, 2017).

For those children with more severe impairments or disabilities, the structure of a support plan will not provide enough help when formal education starts (gov.uk, 2017). In these cases, a child will require an EHCP, which is a legally binding document. EHCPs are for any person up to the age of 25 years who needs help additional to that which can be provided through educational intervention and support. EHCPs identify needs across education, health and social care, and list the additional support required to meet those needs (gov.uk, 2017). If an EHCP is deemed necessary, a request must be made to the local authority for a statutory Assessment of Education, Health and Care Needs. At this time, any supporting evidence must be provided, such as reports from professionals involved in the child's life and previously reviewed My Support Plans (Kirklees, 2017b, section 4).

Specialist provision versus mainstream school

A child diagnosed with ASD may access specialist provision or a mainstream setting. The Warnock Report (Department of Education & Science, 1978) considered it would be more appropriate for children with special educational needs to be included in mainstream schools rather than segregated in specialist provision. The recommendations of the Warnock report were implemented into legislation with the Education Act 1981 in an era when reforms for special needs provision and inclusion were high on the political agenda and the term "special educational needs" was first introduced by Warnock. However, it was reported in 2016 that there had been an increase in recent years of children attending specialist provision (DfE, 2016), which is the opposite of what was desired almost forty years previously by Warnock. The DfE reported that 42.9% of pupils with an EHCP or "Statement" attended specialist provision. A "Statement" is outdated terminology used for a document, which is now on par with an EHCP (DfE & DoH, 2015, 1.17).

If parents choose specialist provision, there is much that they have to consider such as location and availability of spaces within the facility. Many such facilities are oversubscribed (Ambitious About Autism, 2017), so a parent must decide whether to wait for a place to become available, or choose another setting, probably mainstream. Ofsted (2006) reported that there was little difference in the quality of provision and children's outcomes between specialist provision and mainstream schools, but were critical of mainstream where students with SEND were supported mainly by teaching assistants rather than teachers. Ofsted's findings are contrary to research undertaken by Reed, Osborne & Waddington (2012), who suggested that specialist provision showed superiority with regard to behavioural and social outcomes in children with ASD. This finding is supported in a study of Irish head teachers (Kelly, Devitt, O'Keeffe & Donovan, 2014). For pupils who had transitioned from mainstream to specialist provision, the main reason given for the move was social, emotional and behavioural needs not being met in mainstream education. However, Reed et al.'s research concentrated solely on specialist provision, and input is needed from mainstream educators to make the findings more realistic, and enable comparison to be made between both types of setting.

A parent needs to be confident that their child will “fit” into any chosen setting and has a host of factors to consider in making this decision. It is possible that specialist provision may seem a more attractive option, as all children will be in a similar position in terms of learning difficulties and an individual will not feel “different” (Hornby, 2011). However, the alternative perspective is that mainstream would be more appropriate as the child is in a “regular” class in a “regular” school without the stigma of attending specialist provision (Stevens, cited in Shaw, 2017), albeit that the school day may be structured differently in mainstream for a pupil with SEND (NAS, 2017d). In a mainstream school it is perhaps more likely for a pupil to feel different to their peers, if their lessons are in a different classroom and if they receive more attention from a teaching assistant or other support network.

There is also the potential struggle with social interaction, which can be an issue for people on the autistic spectrum. Research suggests that problems with social interaction may hinder a child’s ability to form relationships with teachers and peers (Barnard, Harvey, Prior & Potter, 2000). This is an area which may, in turn, cause further problems, as the relationship between teachers and pupils is at the core of education (Pianta, 2006) and if this is strained, it may affect a child’s ability to learn and a teacher’s ability to teach. It is possible that teachers who do not have much experience with ASD pupils, may feel frustrated and worry about how to control the behaviour of ASD pupils in their class (Barnard et al., 2000; Barnard, Broach, Potter & Prior, 2002). Other research suggests that teachers in mainstream schools are overly affected by the pressure of academic league tables and ensuring their class is not disrupted by the behaviour displayed by some children with SEND (Broomhead, 2013). A lesser focus on league tables is cited as one of the reasons parents opt for specialist provision rather than mainstream (Glazzard, 2014; Lloyd, 2008).

Rationale

No relevant studies were found where parents who used EAL and cared for a child with ASD, shared their experiences of education and healthcare provision in the parent’s country of birth and in the UK, and societal attitudes towards ASD in these countries. ASD was a relatively new experience for the researcher, having worked with only two such children (Child A and Child B) in the last twelve months who were awaiting a neurodevelopmental assessment. Both children have parents who had migrated to the UK from Iraq. Considering 1 in 100 children have ASD in the UK (Baird et al., 2006), it was reasonable to believe that the researcher would meet further families living with ASD. It was also reasonable to expect that a number of these families would use EAL, based on the fact that the researcher’s nursery setting is located in a very ethnically mixed area (Kirklees Observatory, 2016).

It was the researcher’s professional experiences that sparked her interest to research issues surrounding ASD and EAL in more depth, due to the early realisation that families using EAL may be disadvantaged in how they acquired and understood information relating to ASD. Child A’s parents were both Iraqi. Child B had one Iraqi-born parent and one British-born parent. Both families spoke Kurdish and English. Both children received additional support in the nursery via the Early Years Access Fund (Kirklees, 2017a),

which allowed children to receive enhanced support to strengthen their weaker areas of development. Both children were non-verbal, so work was focussed on improving their communication in other ways. Strategies to increase their skills were provided by the local EY Service, SALT and the nursery SENCo.

Professionals were helping both families work towards gaining a better understanding of ASD, as it became apparent they had no knowledge of the condition, either from living in the UK or their native Iraq. The British-born parent of Child B had heard of ASD, but knew nothing about its presentation. This lack of knowledge led the researcher to consider the difficulties parents must encounter in learning to understand a very new and real, but alien, concept. Research has shown that people from LUMICs (such as Iraq) are “*less likely to receive an early diagnosis of ASD*” (Sansoti, Lavik & Sansoti, 2012, p.82), if at all, which may be due to geographical access to care or inappropriate screening tools. Hahler & Elsabbagh (2015, p.59) note that “*the majority of people with ASD live in low and middle income countries*”, but research has largely focussed on high-income countries (Hahler & Elsabbagh, 2015; WHO, as cited in Heys, Alexander, Medeiros, Tumbahangphe, Gibbons & Shrestha et al., 2017).

Research has shown that a parent’s need for information is never more than after an ASD diagnosis (Samadi, McConkey & Kelly, 2011) and although the researcher’s nursery parents were not at that stage, the researcher considered that the parents still required a basic understanding of ASD and how it might affect their child. When providing any type of information, thought must be given to the family’s culture, and how this may impact on their understanding of ASD (Lynch & Hanson, 2004; Samadi & McConkey, 2009). The researcher’s experience to date highlighted to her that the Iraqi parents found it difficult to locate comprehensible information relating to ASD in a Kurdish language format. The families of Child A and Child B asked the researcher where to locate such information, and how ASD might potentially affect their children if such a diagnosis was made. It is unusual for a nursery practitioner’s training to have focussed on ASD, so the researcher was unable to answer the families’ questions in detail.

One of the most common qualifications required to practice as a nursery practitioner is awarded by CACHE (Council for Awards in Care, Health & Education). CACHE offer a wide range of courses relating to children and the early years (CACHE, 2017), yet none of them have a specific focus on ASD, even though the reported number of cases is increasing (Staufenberg, 2016). Supporting children with learning difficulties was a requirement of some CACHE courses but was not specified further. Without having a sound understanding of ASD and its complexities, nursery practitioners are unable to assist families in the most informative way, which causes difficulties when a good parent-practitioner relationship has been forged, and one would like to be helpful.

In terms of information available to families from external services, there seem to be limited options. NAS offers a telephone interpretation service in over 150 languages, but callers need to speak English confidently enough to use this service, and to tell the operator which language they require (NAS, 2017g). The problems with this arrangement are that many families may not feel confident enough to ask for help over the telephone, preferring to speak face to face, or may feel their English is not strong enough to

understand the operator and feel too embarrassed to pursue a conversation. The researcher's own experiences are that families using EAL prefer to speak face to face, as gestures and body language assist with conversation, both of which are absent in telephone calls.

Interpreters may be booked to assist parents' understanding of ASD using their first language. However, interpreters are expensive, and families attending the nursery generally have a low income where only one parent may be employed and the other, usually the mother, looks after the children. The nursery is located in one of the most deprived areas of the borough (Kirklees, 2010) and an interpretation service would not be feasible for the majority of families. Opting for the nursery to pay interpreter fees is also not feasible due to the high cost of such a service. Many nurseries are under-funded, and childcare as a whole is known to be a "*low pay sector*" (Office for National Statistics, 2016, item 7). Managers of childcare settings may struggle to pay their staff the national living wage (Crown, 2016) and may not have extra money for services such as an interpreter. This issue has worsened since the implementation of the policy for 30 hours funded childcare since September 2017 (Pacey, 2018). Previously all three and four year olds were entitled to 15 hours of free education per week. This has now doubled for eligible families where both parents work, (or a single parent is employed) and each earns less than £100,000 per year (Pacey, 2018). The hourly rate for a young child paid to nurseries from local authorities can fall short of what it costs to provide care for children, meaning there can be even less money available in the future to provide extra resources (Doward, 2016; Murray, 2017). It is possible that families using EAL are at a disadvantage compared to fluent English speakers, if there is a lack of availability of interpretation services.

The present study was interested in parents from low income countries (LICs), low middle income countries (LMICs) and upper middle income countries (UMICs). According to the World Bank (2017a), a LIC is a country which has a gross national income (GNI) per capita of less than \$1,005. A LMIC has a GNI per capita between \$1,006 and \$3,955. An UMIC has a GNI between \$3,956 and \$12,235. For purposes of transparency within this study, these three groups will be amalgamated into low and upper middle income countries (LUMICs). These classifications were chosen specifically, rather than the criterion being any parent born outside the UK. The rationale for this criterion is linked to the parents the researcher has encountered in her setting. Specifying these three income groups, also allowed for families from a wider range of countries to be explored, and increased the opportunities to recruit participants. It is possible that if the remit had been widened to a parent born anywhere outside the UK, this would invariably have included parents from high income countries (HICs) such as Ireland, Australia and Poland.

Autism is more likely to be recognised and understood in HICs as education is deemed to be of a higher standard (Centre for Global Development, n.d.) and healthcare is more advanced than it is in LUMICs. The three examples of Ireland, Australia and Poland each have a dedicated website for autism in their country (Autism Ireland, 2017; Autism Spectrum Australia, 2017; Help People with Autism in Poland, n.d.). However, even though there is greater awareness of ASD in these countries, this does not mean that the diagnosis rates are higher. According to Charron (2017), the diagnosis of autism in Poland is only 3 per

10,000 people, but this figure may be derived from studies undertaken rather than official data, as many countries do not track the levels of autistic patients.

The rationale for the present study is directly related to the fact that the majority of parents the researcher engages with in her employment identify as Iraqi Kurds, although a minority of parents originate from other LUMICs. Kirklees is only one example of an area in the United Kingdom with an ethnically diverse population, in which many different languages are spoken (Kirklees Observatory, 2016). It is possible that not all children diagnosed with ASD are going to have parents who are fluent English speakers. These parents may need additional support to understand the diagnostic process and ASD itself.

Diagnosis of ASD is increasing (Blair, 2016; WHO, 2018) and in the UK where 1 in every 100 children has autism (Baird et. al., 2006), it is possible that families using EAL may not be fully catered for linguistically. ASD information may need to be available in a wider range of languages to accommodate the potential rise in diagnoses amongst families using EAL. Conversely, however, it is noted that professionals screen for ASD less often in children from minority groups (Mandell, Listerud, Levy & Pinto-Martin, 2002). The reasons for this may be multiple. Cultural beliefs may be a factor whereby parents are too ashamed to seek help, or there may be an obstacle, such as language barrier or distance to a hospital. These issues are explored further within the literature review.

Chapter 2 - Literature Review

All research referred to within the literature review has been obtained from genuine, reliable sources, as can be noted within the references at pages 61-72. This includes, but is not limited to, the online library at the University of Huddersfield. A range of journals and other literature has been consulted to locate the most appropriate and up to date information for the study. Online searches were conducted using key words and phrases relating to the main aims of the study such as ASD in LUMICs, early intervention, and education in LUMICs. More concise information relating to ASD has been located from organisations such as the NAS. The initial date range selected for material was the last ten years but a large amount of literature was written in the last five years. Please see Appendix 3 for a PRISMA detailing the steps undertaken in the literature review. No previous studies have been located that address the aims of this small-scale project or anything similar with regards to ASD and families using EAL in the UK. However, it is interesting to note that a substantial amount of research relates to the diagnosis of ASD in LUMICs, and how health professionals in those countries understand it.

Professional knowledge of ASD in LUMICs

ASD exists throughout the world and affects people from all cultural and religious backgrounds (NAS, 2017e), yet is not understood in LUMICs as much as it is within the UK. There are many countries where ASD is an unidentified condition or is commonly misdiagnosed (Kalra, Seth & Sapra, 2005; Singhi & Malhi, 2001). Many LUMICs are not able to provide statistics for the number of children on the spectrum in their country, meaning it is very difficult to ascertain ASD prevalence internationally (Dababnah, Ghosh, Campion, Hussein & Downton, 2018; Rakhmat & Tarahita, 2018). It can be difficult to gauge the levels of understanding of ASD in LUMICs as there may be barriers to research being undertaken. The taboo of learning difficulties and/or disabilities and the associated stigma, whether real or perceived, can mean that it is difficult for some families and communities to discuss these issues (Brugge, Kole, Lu & Must, 2005; Wilder, Dyches, Obiakor & Algozzine, 2004).

It is estimated that 1-2% of children worldwide have ASD (Elsabbagh, Divan, Koh, Kim, Kauchali & Marcin et al., 2012), although numbers will differ country to country due to variations in knowledge regarding ASD, misdiagnoses and levels of intervention (Desai & Mohite, 2011; Heys et al., 2017). However, ASD recognition is increasing in the developing world and parental views are being explored. Research of this nature has taken place in, amongst other areas, Iran (Samadi et al., 2011) and South East Europe (Daniels, Como, Hergüner, Kostadinova, Stosic, & Shih, 2017). Both of these latter studies report that parents and caregivers are unhappy with the lack of information provided to them and they can struggle with the stigma attached to ASD, which is a common theme outside Western cultures (Gray, 2002; Welterlin & LaRue, 2007). Despite research being undertaken concerning parental views and experiences, this does not extend to immigrant families in the UK.

Rahbar, Ibrahim & Assassi (2011) studied a group of 348 GPs in Pakistan. They discovered that only 45% of the GPs had heard of autism, and many had misconceptions concerning its traits. There is a lack of studies in LUMICs regarding ASD and as such, the statistics for the number of people with ASD in LUMICs are not available (WHO, 2018). However, studies have shown that ASD is frequently undiagnosed or misdiagnosed in LUMICs due to doctors "*lack of knowledge*" (Kalra et al., 2005; Singhi & Malhi, 2001). This finding concurs somewhat with a misplaced idea put forward by Kanner (1943) in which he stated autism was a disorder that could be attributed to childhood neglect. When writing about personal case studies, Kanner reported that one prominent factor in his sample was that "*there are very few really warmhearted fathers and mothers...the question arises as to whether, or to what extent, this fact has contributed to the condition of the children*" (Kanner, 1943, p.250). Kanner's theory was supported by Bettelheim, a child development specialist, and was seen as valid by the medical profession until as recently as the mid-1960s (Autism Independent UK, 2017). This theory is not considered valid currently, but it does go some way to show how one person's misconceptions can have long lasting, detrimental effects upon society whereby parents may feel to blame for their child's condition when they have no other logical explanation.

It appears reasonable for parents to take the word of a health professional, as they would usually have no reason to doubt their honesty and expertise. Families will often take initial concerns to their GP (Dardas & Simmons, 2015; Imran, Chaudry, Azeem, Bhatti, Choudhary, & Cheema, 2011). It is the norm in society to consult a doctor when suffering from an illness, and one would not usually doubt their opinion. There are occasions when second opinions are required, but it would be another doctor that provides that opinion. Previous studies have shown that in many LUMICs, GP's are the only point of contact between a family and the healthcare system. If a child were to receive a GP's diagnosis of ASD, the family would have faith in their professional knowledge (Barbarese, Katusic & Voigt, 2006; Kochanek, 1991; Rauf & Saeed, 2007; WHO, 2009). Conversely, in Pakistan, if a parent was told their young child did not have ASD but was simply "*delayed*", this would also be accepted. Speech delay is a common trait of ASD but "*is not considered atypical in Pakistan at 36 months or beyond, resulting in many children being assessed (for ASD), referred and diagnosed far beyond early childhood*" (Imran et al., 2011, p.3). It appears that a parent is willing to accept any diagnosis from a GP, perhaps over their own instinct and concern.

Children in Pakistan displaying developmental difficulties, such as late onset of self-care habits and other autistic traits, are more likely to be sent to psychiatric facilities for "*treatment*" as doctors are "*far less confident in assessing and managing these children*" (Imran et al., 2011, p.4). Delays in diagnosis, or in a parent first noticing traits of ASD, is also evident in Lebanon. Fombonne (as cited in Chaaya, Saab, Maalouf & Boustany, 2016, p.515) states that "*identification of autism cases occurs at different ages, most commonly...around the age of 8 years*". ASD is also misunderstood in some parts of Kurdistan where disability "*is looked down upon and shamed, and often those who are autistic are locked up*" (Anonymous, 2012, n.p.).

A study of 175 doctors in Nigeria found that although 58 participants had seen a case of ASD, there was an absence of knowledge surrounding autistic traits. Using the Knowledge about Childhood Autism among Health Workers questionnaire, 44 participants did not recognise lack of language development as an autistic trait, and 52 participants could not recognise the onset of ASD (Eseigbe, Nuhu, Sheikh, Eseigbe, Sanni & Olisah, 2015).

In Indonesia, a study of 55 health professionals, mostly psychologists, observed the challenges in diagnosing ASD. 87% of participants requested more training around ASD assessment to update their knowledge and skills (Sidjaja, Newcombe, Sofronoff & Sofronoff, 2017). This need was also highlighted in a Nepalese study by Heys et. al (2017). All health professionals interviewed felt they had insufficient knowledge of, and training on, management of atypical behaviours and/or how to support children with developmental disorders. A further Nepalese study of 54 paediatricians indicated that 22% believed ASD resulted from parental neglect, and 81% believed ASD was treatable (Khatri, Onta, Tiwari & Choulagai, 2011).

The studies above indicate the low levels of ASD awareness amongst professionals in LUMICs. There is substantial work to be done until professionals are confident in their level of knowledge to diagnose and manage ASD effectively.

GPs and other professionals' knowledge of ASD within the UK

It is widely believed that ASD is more understood by doctors in the UK than in LUMICs. This is due in part at least to the fact that medical students in the UK receive training on ASD, which includes its diagnosis and management (Royal College of General Practitioners, 2018).

There has been an increase in the number of children diagnosed with ASD in the UK (Howlin & Moore, 1997). Crane et al., (2016, p.154) believe that the reason for this increase in the UK over the last 20 years, is that ASD has become "*more widely recognised*" by parents and health professionals. However, it was recently proposed in south west London to limit the number of autism diagnoses to only the most "*severe*" cases. The reasoning behind the discussions held by NHS commissioners was that the service provided by five CCGs was facing severe pressure, with patients waiting more than ten months for an ASD diagnosis (Dreaper, 2017). Considering the service received 25 referrals per week, this meant approximately 1,250 referrals per year, when in realistic terms, the service could manage only 750 annually.

For professionals, such as health visitors, who may be in a prime position to detect early atypicalities, it is imperative to have a sound understanding of ASD and its traits. Reynolds (2013, p.286) points out that "*further research and training is needed for front line staff, including health visitors, to ensure earliest detection and subsequent early intervention*". Two recent UK studies aimed to discover self-efficacy amongst professionals in identifying and managing patients with autism. The first surveyed 304 GPs and found that 39.5% had received no formal ASD training in their career. A number of GPs did not see

themselves as specialists in ASD and felt unable to identify/manage ASD as a result (Unigwe, Buckley, Crane, Kenny, Remington & Pellicano, 2017). Many GPs noted that it would be helpful to have “*more information [concerning ASD] to assist patients and their families*” (p.450) yet there was an issue in how much information could or should be provided by a GP with a heavy workload, rather than a specialist. The latter view regarding heavy caseloads was also identified in research undertaken by Crane et al. (2018).

A second study surveyed 172 psychiatrists, researching the same aims as the study undertaken by Unigwe et al. Similarly, 30% of participants had received no ASD training. In terms of ASD screening, diagnosis and management, self-efficacy was higher in those who had received ASD training (Crane, Davidson, Prosser & Pellicano, 2019).

Immigration and cultural beliefs

Families will continue to migrate to the UK and register with local GPs to access health services. It is possible that a child may have received a diagnosis relating to their autistic traits in their country of birth, but a different diagnosis in the UK. At some point, it is possible that deeply rooted values and beliefs may need to make way for ideas that may contravene long-held ideals and principles. “*Families who immigrate....may have specific views of what constitutes a disability, which may be largely based on their unique social and cultural background*” (Welterlin & LaRue, 2007, p.750). However, as much as immigrants need to adapt to “Western medicine”, it can be argued also that GPs need to appreciate immigrants’ views and culture.

It should be noted that culturally appropriate behaviours can vary and account needs to be taken of this. Imran et al., (2011) note that speech delay is not considered unusual in Pakistan for children of three years of age and beyond, yet this would cause concern in the UK. It is also important to consider the language used when questioning a parent. Hoekstra et al., (2018, p.41) found disparity between American and Ethiopian cultures when parents were asked to rate a caregiver’s level of enthusiasm. Options such as “*very enthusiastic*” and “*not enthusiastic*” were offered but meant different things to different people. It is perhaps more meaningful to ask open questions where the parent can state exactly what they mean when providing an answer, rather than being restricted to choosing pre-determined measures on a scale. GPs in the UK should be aware that disabilities in general and more specifically the term “*disability*” can be very taboo in LUMICs and a source of stigma and shame (Daley, Singhal & Krishnamurthy, 2013; Hussein, Pellicano & Crane, 2019). These feelings may be held or displayed by migrant communities long after settling in the UK.

Many Arab Muslims place a strong belief in supernatural forces when attributing causes to mental illness (Dardas & Simmons, 2015). Since there is no single explanation for the cause of autism, immigrants may have their own beliefs, which may be based on religion or culture. Hussein, Pellicano & Crane (2019) found that a number of residents in a UK Somali community believed autism was the result of a ‘*jinn entering the child’s body*’ (p1414). Those participants were a mixture of parents either caring for a child

with ASD or without ASD. Similar opinions were identified amongst parents of children with ASD or an intellectual disability in Ethiopia (Tilahun, Hanlon, Fekadu, Tekola, Baheretibeb & Hoekstra, 2016).

There are many options for the management of ASD in the West, such as medication and sensory therapy, which may contradict with immigrants' beliefs and desires, and which may result in conflicts between patients and doctors (Ravindran & Myers, 2011). Kurds have "*survived an often-challenging journey from the Kurdish regions...they expected the UK to be a rich and safe haven*" (Ravindran & Myers, p.210), and diagnoses of ASD may conflict with this aspiration. Disability can be misunderstood in some areas of Kurdistan. Kashani-Sabet (2010) wrote that biological disabilities, such as ASD or mental illness, are likely to be approached with shame and pity in Iran. This is contrary to the teachings of the Qur'an, which promotes compassion for those who are disabled or mentally incapacitated in some way (Al-Aoufi, Al-Zyoud & Shahminan, 2012). Kashani-Sabet further state that although his research is confined to Iran, the principles and understandings may be applied to other majority Muslim states also.

Religion can be a primary factor in accepting a diagnosis of ASD and it is this reliance upon faith and belief that may enable the disability to be viewed with positivity, rather than shame and pity (Hussein, Pellicano & Crane, 2019). Many Arabs view psychological conditions as a test from God or a punishment for committing sin (Jegaseethan, Miller & Fowler, 2010; Youssef & Deane, 2006). The former study was undertaken in the United States with three South Asian immigrant Muslim families with autistic children. Fathers were of the opinion that having a disabled child was a test from Allah of their spiritual qualities. Parents reported that they believed they had been chosen by Allah to care for the child and protect him from harm. Extra effort was taken to ensure the autistic child was not bullied or mocked at school as parents believed that their child would not be able to disclose any such problems. There was some disagreement with professionals who focussed on what the children could not accomplish, whereas parents were more focussed on the child's abilities and enabling them to have a "normal" life in the community .

Experiences of UK patients who are EAL speakers

For comparative purposes, this section focuses on immigrants suffering with epilepsy, and specifically, their experiences as patients, in the UK.

Ismail, Wright, Rhodes, Small & Jacoby (2005) studied a group of South Asians with epilepsy living in the north of England. They found a common cultural belief that epilepsy was caused by spirit possession. Patients were mostly compliant with UK medicinal practices, but those patients who experienced seizures "*were most likely to turn to traditional South Asian therapies*" (p.500). The most common barriers to patients accessing help were their language and communication difficulties, and a "*lack of appropriate information and advice*" (p.500). One third of participants were not fluent in English, but interpreters were not available. Another common issue was the perceived lack of understanding of epilepsy among health professionals. It was reported by some participants that they felt some South Asian GPs (in the UK) did not have a specific knowledge of epilepsy and were "*unable or unwilling to deal with sensitive issues*" (p.501).

One final problem was referral to support groups. Patients were worried about what language the discussions would be held in and whether the groups would be mixed gender.

A similar study, undertaken by Bartolini, Bell & Sander (2011), reinforced the sense that traditional non-biomedical views are held in relation to epilepsy care by immigrants in the UK. The point was also made that Muslims partaking in Ramadan, the festival of fasting, would not take drugs orally (for epilepsy or other conditions). This is a concern for UK GPs who need to find ways to cater for patients with such religious beliefs. It was also noted that, as with ASD, epilepsy is under-diagnosed in LUMICs. This may be because there is less access to medical provision and diagnostic facilities. Alternatively, the issue could be related to the shame experienced by families in their communities. It is less likely for a person to disclose their epilepsy if they fear being shunned or ostracised, so seeking support becomes a challenging issue.

Both Bartolini et al. (2011) and Ismail et al., (2005) found that: (a) epilepsy and ASD are both under-diagnosed in LUMICs, (b) stigma appears to relate to certain medical/neurological conditions amongst immigrant communities, and (c) an immigrant belief that GPs in the UK do not fully understand certain medical/neurological conditions.

Aims

The aims of the research were to establish what were the experiences of parents of children with ASD, who use EAL, of health and educational services, and societal attitudes in LUMICs and the UK; and to identify ways in which their experiences might be improved.

Objectives

The objectives of the research were to establish:

1. How well ASD is understood in LUMICs.
2. Families' understandings of ASD diagnoses and whether they experience challenges pertaining to, for example, their own cultural beliefs or their language capabilities.
3. What post-diagnostic help is available to speakers of EAL from LUMICs and how accessible this is.

Chapter 3 – Methodology

A piece of educational research is valid if it is “*carried out systematically and critically, (it is) aimed at the improvement of education, (is) relatable, and ... by publication of the findings they extend the boundaries of existing knowledge*” (Bassegy, 1981, p.86). In the present research, data was collected and analysed in such a way that reliable conclusions could be formed. Data was analysed methodically to look for trends in experiences and views that were compared to previous research.

Research strategy

A qualitative approach was utilised, facilitated through face to face and telephone interviews. This approach was selected, against a quantitative one, as the present research was interested in the in-depth experiences and views of participants, which could not be gauged effectively by quantitative measures (Isaacs, 2016; Maher & Dertadian, 2018). Quantitative research is more concerned with numerical aspects of a problem and statistical analysis of the relationship between variables.

Using a qualitative approach allowed for trends in participant’s experiences to be highlighted, thus allowing for issues and situations to be explored in more depth. The research objectives within this study could not be truly assessed through quantitative measures. Qualitative research is concerned with being able to “*maximise the benefits of engaging actively with the participants*” (Yardley, 2008, p.237). Bias could not be removed entirely in that regard as the researcher needed some influence in terms of leading the questions in such a way that suited her study, but did not compromise its integrity.

The researcher was mindful of not exerting any influence on participants stemming from her own experience with, and understanding of ASD. However, bias is almost expected as part of qualitative research due to the fact that the researcher will have knowledge and views about the research topic (Coyle, 2016). The researcher has acknowledged that she holds certain beliefs and understandings from her professional practice. It has been her experience to date that some parents from Iraq may have little or no understanding of ASD and find it difficult to locate information in layperson’s terms relating to the condition. However, the researcher is fully aware that these experiences and accounts may not translate across the experiences of all participants. It is with this, and other experiences in mind, that the researcher believes the disclosure of any such bias, will enhance the transparency of the research process (Coyle, 2016), helping to ensure honesty and integrity.

It is also important to note the discrepancy between the researcher’s position and those of her participants. The “*vastly different lived realities and privileges*” should not be underestimated (Carillo, 2014, p.54). The researcher acknowledges that she is an “*outsider*” in the research process (Rosaldo, 1993; Villenas, 1996) and that there are large differences between her background and understanding of ASD, and that of the participants. This can be described as taking an “*etic*” approach to research (Punnett, Ford, Galperin &

Lituchy, 2017), meaning that opinions are reported and interpreted from the perspective of an outsider. However, it must be recognised that the researcher has been privy to sharing some experiences of ASD, via the families in her practice, so is not a total outsider when it comes to understanding some of their concerns. Having some insider knowledge would warrant using an “*emic*” perspective (Punnett et al.), and being directly involved with the cultures at the root of the research. The researcher contends that her research uses both perspectives. Using both perspectives together is “*better, than when used individually, especially in under-researched areas*” (Punnett et al., p.4). As can be noted from the literature review, the topic at the heart of this study appears to be under-researched, and it therefore seems appropriate to use both emic and etic perspectives.

The research was undertaken with constant reflection and self-critique. This practice is known as “*confirmability*”, which should be one of the main objectives in research, and refers to the practice of not overly allowing personal values to affect the study or its findings (Guba & Lincoln, 1985, as cited in Bryman, 2001, p.274). Reflection should reduce the possibility of the researcher’s personal feelings and attitudes influencing interviews. The researcher’s awareness of bias and how this could be an issue, helped to reduce it as much as possible.

Approach to research

The present research focused on personal life events, and how lives have been shaped by participant experiences. The researcher was interested in the opinions of individuals, which was best viewed with a phenomenological approach. As a whole, phenomenology is concerned with capturing the ‘*subjective experience*’ of participants (Lyons & Coyle, 2016, p.372) but can be broken down into two approaches, descriptive and interpretative (Ellis, 2013). From a researcher’s perspective, descriptive phenomenology is making sense of lived experiences using evidence obtained from the participant and no more. The researcher would not lay any self-interpretation on those views. Interpretative phenomenology relates more to a researcher applying their own interpretation to participant views, taking a more in-depth and psychological approach to research. The researcher would be interested in making sense of how and why a participant viewed their experiences in a particular way.

The researcher used a descriptive phenomenological approach, taking account of parental experiences, in order to understand each participant’s individual situation. Understanding and analysing the participant’s “*personal perception or account of the experience on their own terms*” (Lyons & Coyle, 2016, p.15), allowed the objectives to be answered. The researcher felt that interpretative phenomenology would not fit the remit of the study, as she was solely interested in participant views and not giving her own interpretation of the same.

Phenomenology was selected rather than other qualitative approaches such as ethnography or grounded theory (Denscombe, 2007). An ethnographic approach would have related to the study of cultures and groups, which was not the focus of this study. Although the study was interested in people of different

cultures, it was specifically, their experiences that were the main focus, not their cultural identity. Ethnography would be more focussed on people's lives and how they change over time, linking their experiences to the society or culture in which they lived (Denscombe, 2007). Grounded theory is a methodological approach relating to the discovery or development of theory in an inductive manner. That is to say, themes or patterns, which are derived from data, go on to form new theories, rather than attributing the patterns and theories to past research. This approach was not utilised in the present study, as it would rely too heavily on collected data providing an explanation that is "*waiting to be discovered*" (Denscombe, 2007, p.105). The researcher wished to focus on existing theories, rather than creating new ones.

Sample

Appendix 4 contains socio-demographic data of participants. The researcher acknowledged that the sample size of seven is relatively small, but as Denscombe (2007, p.27) stated "*research in the real world does not take place with infinite time and resources*". On that basis, the researcher chose to allocate her time effectively in selecting a small sample and interviewing each participant at length, to gain rich responses. Detailed transcripts were produced of each interview, which took some time (Smith & Eatough, 2016), but a smaller sample allowed the researcher to be more thorough in analysis.

Another factor in determining the sample size, related to the families in question being typically harder to reach due to the strict inclusion criteria. It is thought there are many more families in the locality that would suit the requirements of the study, but the researcher was not able to access them, due to challenges at the chosen schools. Many schools decided to opt out, as they felt the study would be too time-consuming. There are also many more people who could have been engaged through social media, but who did not put themselves forward. The obstacle of locating participants in studies of ASD was highlighted by Daley et al. (2013): "*although the projection for the number of people on the spectrum in India is 2 million, it is so hard to find 6-10 people/families on the spectrum willing to talk about their experiences*" (p.2009). Braun & Clarke (2016, p.88) wrote that when using interviews, a sample size "*of at least six*" is required, because of "*the emphasis on patterned meaning across cases rather than idiographic meaning*". That is to say, the researcher is more interested in observing patterns in the data rather than explication of individual cases.

Inclusion and exclusion criteria

The three inclusion criteria were:

- At least one parent being an immigrant from a LUMIC
- At least one parent using EAL
- At least one child of the family being diagnosed with ASD, who is currently between the ages of four and 16 years, but older for social media recruits. The study did not discriminate whether the child was diagnosed in the UK or another country.

The researcher received additional offers from potential participants although many were ineligible. Exclusion criteria included:

- Parenting an undiagnosed child
- A child diagnosed with something other than ASD
- Parent being born in a HIC.

The age criteria was chosen as the average age for diagnosis of ASD in the UK is between four and six years of age (Brett, Warnell, McConachie & Parr, 2016; Charman & Baird, 2002; Crane et al., 2016), and also four years is when children start school. Diagnosis can be given earlier than four years, but not usually before the age of two years (Child Autism UK, 2017; NAS, 2017c). The upper age limit for the study was initially chosen as 16 years, to incorporate the ages of pupils at schools utilised in the study, but increased to social media participants as the quality of data received was more important than the child's age. The study focussed on children of parents originating from LUMICs (as defined by World Bank, 2017b&c). Appendix 5 shows a full list of LUMICs broken down into low income, low middle income, and upper middle income countries.

Research instrument

Appendix 6 displays a copy of the interview schedule. Interviews were semi-structured enabling the researcher to obtain data in relation to set areas (Geertz, 1973), yet offering participants an opportunity to raise wider points if they wished. The flexible structure of the study also permitted the researcher to ask further questions linked to a developing line of enquiry. For example, if an important topic arose through a participant's response, which was not part of the broader questions. This gave participants more of a "free reign" to talk about an issue of importance, and may be something that ultimately, was reflected in more than one interview, and became an important issue the researcher had not considered.

The interview was piloted with two parents from two separate families. Both were mothers whom the researcher had an existing relationship with, and both were parents of a child with ASD. The pilot was undertaken to assess the length of interview, and whether there were any flaws in the wording or layout of the questions. No information gathered at either interview was presented as part of this research. One problem the researcher encountered with piloting is that neither parent used EAL. For that reason, it was inappropriate to ask some of the questions in the interview schedule that related to EAL speakers, such as whether information had been provided to the parent in their native language. Therefore, the length of time the pilot interviews took was slightly misleading when it came to interviewing EAL speakers.

Research procedure

Seven schools in Kirklees were contacted as part of a purposive sample, on the basis they catered for children with SEND. Of those seven, five declined to take part in the study. Of the remaining two schools,

headteachers were asked whether or not any of their children with ASD had parents meeting the study's criteria. Families using EAL needed to have a moderate grasp of English to take a full part in the research. Following the identification of potential families, three families were provided with an information sheet (Appendix 7) detailing the study's aims and objectives. There was only one acceptance and the issue of consent was thereafter discussed with this one family. The researcher experienced significant challenges maintaining contact with the schools, and resorted to social media to continue participant recruitment.

Using accounts on Facebook and Twitter set up exclusively for the purposes of this research, the researcher aimed to connect with parents meeting the study's inclusion criteria. The researcher joined "groups" relating to ASD such as Muslim Autism Society, and Autism Pakistan, and groups in the local area, such as Bradford Autism Support, to advertise her study and recruit participants. Social media groups relating to ASD were chosen as the source of the sample, on the basis that people subscribing to these groups are likely to be parents of children with ASD. The researcher was specific in which groups she chose to join, to ensure participants from LUMICs were represented in order to fulfil the requirements of the study. For example, the researcher was aware that Bradford has a large Pakistani community (a LUMIC), so a local ASD support group was joined in the hope that Pakistani participants would express an interest in the study. Participants recruited via social media made contact with the researcher through these channels. Further contact was then made via email to share the information sheet and consent form. These documents can be found at Appendices 8 and 9.

All participants chosen for the study comprised a purposive sample, so some individuals were more likely to be selected than others, based on the study's criteria (Denscombe, 2007), which introduces an element of bias. Although this sampling method did not offer a representative sample of the schools or social media users, it met the requirements of the study. If this bias was to be removed, then the study would have been open to any parent, but this would not have benefitted the terms of the research, nor provided the critical data that was sought (Denscombe, 2007).

Participants were collectively chosen from local schools and social media. The ages of the children ranged from 3 to 22 years. Initially, when recruiting through schools, any diagnosed child would have been between the ages of four and sixteen. However, as recruitment widened to social media platforms, the researcher felt a child's age was irrelevant, as the content provided by participants was the priority. It was beneficial to the study that some of the diagnosed children at least had received some health and/or education services in their country of birth. This acted as an ideal tool for comparing how parental perceptions of services differed between the UK and LUMICs.

Participants five and six were married to each other, but all other participants were unrelated. Overall, parents from six families were interviewed, relating to six children. The sole participant identified through a school was interviewed on school premises, a venue familiar to him, where an interpreter was present as he did not have a moderate understanding of English. The interpreter was asked to sign a confidentiality agreement to ensure the content of the interview remained private. The researcher was having difficulties

recruiting and agreed to fund an interpreter on that basis. There was no option for an interpreter to be provided at every interview due to the high cost of this service. All participants recruited via social media channels were interviewed either by telephone, or face to face if resident in the researcher's local area. All interviews were recorded and transcribed solely by the researcher. Prior to each interview, the researcher discussed the consent form with each participant to ensure good understanding and answered any questions. No participants declined to take part or give consent.

Data analysis

The data was "coded" to prepare it for analysis. A code is a way of labelling data and each label "*captures a key analytic idea in the data that is of potential interest to the research question*" (Braun & Clarke, 2016, p.90). Coding, therefore, is the practice of linking data systematically through patterns that appear within it. These patterns may take the form of repeated phrases or words that occur regularly in the data, and are linked in some way to the research questions (Bryman & Burgess, 1994, as cited in Bryman, 2001; Denscombe, 2007). The present researcher endeavoured to code data systematically and thoroughly to prevent mistakes in analysis. Honesty was crucial in presenting the data to readers (Braun & Clarke, 2013). Any irrelevant data was disregarded and not coded (Braun & Clarke, 2013). Data identified as irrelevant may be that which does not fit the topic, where a participant has strayed away from the subject, or where recorded data was not transcribed due to it being inaudible.

Analysis started with the researcher seeking emerging themes and patterns, or "codes" in the data (Appendix 10). Coding was undertaken manually by working through transcripts and notes, to find patterns or words and phrases that occurred frequently (Braun & Clarke, 2013; Bryman & Burgess, 1994, as cited in Bryman, 2001). When coding was complete, similar codes were combined to form themes. Each theme had a central organising concept, an idea which underpinned it, broken down further into sub-themes. This process formed the basis of thematic analysis, which is described as "*a distinctive method (of data analysis) with a clearly outlined set of procedures*" (Braun & Clarke, 2006, p.178). These procedures are: collecting data, reading the data and noting items of interest, coding, searching for new themes, reviewing themes, naming themes, and finally, performing the analysis. Coding is "*an organic and evolving process*" (Braun & Clarke, 2013, p.210) and it is imperative to read the data more than once, as existing codes may need modification to incorporate new data. Furthermore, it is essential to ensure no information is missed when coding initially (Braun & Clarke, 2013). Appendix 11 shows two anonymised excerpts of transcribed data. Specific elements of the data were highlighted, showing items of interest to the researcher, which would assist the coding process.

Reliability

Denscombe (2007, p.282) made the point that to ensure data is regarded as reliable, the researcher needs to know that if the study were to be conducted again, the same data would be yielded. The present researcher would expect this to be true due to the nature of the study. As the study relates to personal experiences, emotions and possible life-changing news, it is thought likely that a participant's answers might be the same on any given occasion. However, the present researcher appreciates that it is possible answers could vary dependent on the researcher's gender for example.

The idea of reliability offered by Denscombe (2007) is given weight in a study by Brown & Kulik (1977). Their research focussed on participants recalling "*shocking*" life-changing public events from the past, such as the assassination of President Kennedy. It was suggested that events could be remembered years later, with considerable detail. Brown & Kulik called these recollections "*flashbulb memories*", indicating that they were more likely for unexpected events. Their research also suggested that flashbulb memories could relate to more personal events, such as the death of a relative. When important moments in life are committed to memory, it is unusual for these flashbulb memories to become distorted when retold.

The present researcher felt that flashbulb memories were relevant to her study, which focussed on personal events that could possibly be seen as life-changing. It is the present researcher's opinion, drawing on the work of Brown & Kulik (1977), that participant's memories of possibly life-changing ASD diagnosis were committed to memory, and would not be distorted during recall, making the research more reliable. However, the views of Brown & Kulik are challenged by Talarico & Rubin (2007), who alleged that although important life events are well remembered by individuals, accuracy is not always maintained after a period of time. It is fair to say that although these two ideas contradict each other and neither can be proven to be completely accurate, neither study focused on personal life events. In any event, the present researcher has taken all answers provided by participants at face value, as there was no way of determining with absolute certainty whether the data obtained was factually correct. There are no guarantees with the quality of qualitative research, only reassurances that data has been collated and produced according to good practice (Coyle, 2016, p.23). The present data was scrutinised to present honest views of participants, rather than what the data should say to answer the research questions (Denscombe, 2007; Goodman, 2008). This point is also made by Braun & Clarke (2013, p.230) who state that research should not be focused on finding a "*right*" answer, merely the "*best fit*" to answer the research question. Analysing data in detail provided a "*solid foundation for the conclusions based on the data*" (Denscombe, 2007, p.298).

It was imperative for data to be checked for accuracy at the point of interview, limiting the chance for misunderstandings, a concept known as "*validity*" (Denscombe, 2007). The researcher checked regularly with participants that she understood their points, and there were no errors in communication. It was vital

for the researcher to fully understand the views and opinions presented to her, to ensure data was not misrepresented in analysis.

Ethics

Ethical approval for the present research was given by the School Research Ethics Panel (School of Human & Health Sciences, University of Huddersfield). Research was undertaken adhering to strict ethical procedures in accordance with The British Educational Research Association's (BERA) Ethical Guidelines for Educational Research (BERA, 2011a) and guidance from the University of Huddersfield. The researcher ensured participants understood the terms of the research and what was expected of them (BERA, 2011b, pp.5-6). Two of the most important ethical issues procedures were informed consent and confidentiality.

The interview schedule was prepared with participants' interests as its focus, meaning questions were worded tactfully, with the aim of minimising participant distress and intrusion. The researcher stopped if a participant became upset, and allowed time for breaks if required. As much as the researcher wished to collect valuable data, this would be worthless if obtained in a way where the participant felt a lack of compassion from the researcher, and perhaps an element of hostility toward them (Denscombe, 2007).

Questions posed related to personal events in a participant's life that may have caused distress and emotional upset, so the interview needed to be conducted with sympathy and tact. The researcher had experience from employment of discussing upsetting issues, including ASD, with families and was prepared for the possibility that participants may become distressed. There was an option to cancel the interview entirely if the participant did not wish to continue, but this was not necessary at any time.

Informed consent

Information provided to participants meeting the inclusion criteria was in two parts, initially, an information sheet (Appendices 7&8) discussing the terms of the research and later, a consent form (Appendix 9). Information sheets were provided a week before interview to allow participants to truly understand the terms of the research, using the time as a "*cooling off period*" (Bell, 2010, pp.160-161) where participants could ensure they wanted to take part in the study. This period also allowed any queries to be addressed prior to interview, and limited the risk of participants withdrawing midway through the study (Bell, 2010).

The consent form provided a set of statements for participants to agree with. Although participants had sight of this form via email, the document was also read to each participant immediately prior to interview to ensure understanding of the terms therein. It was imperative that participants understood, prior to the study commencing, that their personal information would remain anonymous as per the regulations of the Data Protection Act (1998) and more recent General Data Protection Regulation (2018) guidance. The

researcher also made participants aware of arrangements for data storage, and any breach of confidence that may be required in terms of safeguarding.

Confidentiality and anonymity

It was imperative that the term “confidentiality” meant the same to the researcher and the participants, so there was no confusion at any point in the study. Confidentiality is defined by Sapsford & Abbott (1996, as cited in Bell, 2010) as “*a promise that you will not be identified or presented in identifiable form*” (p.49). The researcher’s promises of confidentiality were not broken, and participants were assured of her good intentions. Responses gathered in the research were presented anonymously. Anonymity is defined by Sapsford & Abbott (1996, as cited in Bell, 2010) as “*a promise that even the researcher will not be able to tell which responses came from which respondent*” (p.49). The researcher is confident that through the procedures adopted in her research, she has adhered to these two definitions. Individual participants were “*humanised*” (Braun & Clarke, 2013, p.251) with pseudonyms rather than numbers.

Disclosure

The information sheet provided to participants, advised them that although all data collected was confidential, there might be situations where confidentiality and anonymity would be breached. “*Safeguarding is everyone’s responsibility*” and the researcher had a duty to follow up on any information she felt may be a safeguarding issue (DfE, 2011, p37; Reid, 2014). Confidentiality would only have been breached where the researcher had concerns that any person was, or might be, at risk of harm. For example, a participant may have disclosed that their child’s condition had caused tension in the home. This could have led to the child being at risk. It is only through the course of discussions that any possible issues would be identified. The researcher’s day to day job role comprised being a Safeguarding Officer within a private nursery, so she was well trained in identifying any potential concerns and following appropriate avenues of referral. Participants signed the consent form to agree to breaches being made, where relevant, and perhaps more importantly, they understood what this meant (Thanh Tam, Tien Huy, Bich Toa, Phuoc Long, Thi Huyen Trang, Hirayama & Karbwang, 2014).

Withdrawal

The information sheet advised participants that they could withdraw from the study without any repercussions, and the researcher would ask no questions concerning their decision. The consent form stated that the last date for withdrawal of data was two weeks after the date of interview. There was one withdrawal from the study, this being the sole participant identified through a local school. No reason was given or requested.

Support

Details were provided in the information sheet regarding specialist advice and support services that might be of use to participants, if they felt this was necessary, post-interview. Suggestions were made to participants to approach the NAS via their website or helpline, or to access any support service offered by their child's school. Measures such as these were put in place to ensure participants felt as comfortable as possible during, and after the interview process. The researcher appreciated that participants may have felt uncomfortable talking to a stranger about personal issues. All participants were made aware that the interview process may be paused or stopped completely at any time upon their request. The researcher was not asked at any time to pause or stop completely.

Chapter 4 - Findings

Table 1 lists the main themes, and sub-themes, identified in the present research. Five main themes were identified with a number of sub-themes emerging.

Table 1 Main and sub-themes identified in the present research

Main theme	Sub-themes
Autism misunderstood	Public perception
	Professional perception
	Family & friends' perception
Health needs unmet	Access
	Acknowledging medical needs
Beliefs shaped by culture	Cultural values
	Religious beliefs
	Stigma and shame
Issues in education	Global differences in ASD provision
	Lack of information
	Lack of support
	EHCPs and funding
	Training
Problems at diagnosis and beyond	Language barrier
	Parental understanding
	Post-diagnostic support

4.1 Autism misunderstood

Some participants expressed dissatisfaction with the way GPs had been unable to diagnose their child, or had labelled ASD traits as a form of slow development, both in the UK and in LUMICs. Conversations with participants also focussed on understanding of ASD amongst the carer's family and friends, and how this understanding, or lack of, impacted on providing support to the carer.

4.1.1 Public perception

Some autistic traits displayed by children are commonly mistaken by the public for "naughtiness", both in a parent's birth country and the UK. Members of the public are perhaps not always aware of ASD and how it can present in children. Participants said they thought that their children were sometimes viewed as "naughty", when they were being loud or disruptive in public, and not conforming to the often expected norms of society, such as obeying instructions or sitting still, "can you ask him to be quiet?" There were also societal perceptions that children were 'just slow' and their development would improve as they got older.

Jamil [pseudonym], from Pakistan, spoke of a trip to Pakistan where he accompanied his autistic 22 year old son to a public bathroom. Upon exiting the bathroom, the father and son were subjected to "seedy remarks" owing to their exiting a bathroom together being perceived as homosexual behaviour. The son did not appear disabled and not in need of physical help, so there seemed to be a misunderstanding of why two men were together.

There were people literally shouting at us so...this is the lack of education. On the other hand, here in the UK, on many occasions, because he [my son] goes into the male toilets, I go along with him and we never have an issue here. In Pakistan, or maybe any other country, that is what it is like, it was quite embarrassing really. (Jamil)

They [members of the public] isolate him [my son]. In my country we don't talk about this [ASD], they say 'smack him, he is a big boy'. Now in my country they still do not know about autism. (Aleena)

Aleena's comment suggested there was a lack of understanding surrounding ASD in Algeria, and how the condition may present in children. Aleena was advised to "smack" her son to make him comply with an instruction. It was suggested that Algerians do not "know" about ASD, but also that it was not talked about, which may link to a stigma around disabilities.

Nina, from Pakistan, took her three year old son to a GP in the UK. Her son was being loud, not sitting still in the waiting room. The receptionist said "can you ask him to be quiet?" Nina felt "anxious" and replied, "how do I do that without him having a meltdown"

Everyone was staring at us...it stresses me out and I wish people would understand, but I know if they don't know what it [ASD] is, they won't understand. It does upset me when people make comments.

Nina's experiences suggest parents with autistic children face struggles with undertaking everyday routine tasks, such as using a GP waiting room. The behaviour of Nina's child fell short of society's expectations. As a result, Nina felt stressed at the way in which she was treated and potentially viewed as a bad parent.

4.1.2 Professional perception

Jamil described the difficult process in trying to obtain an ASD diagnosis for his son in Pakistan. He found that "a number of paediatricians and doctors" could not diagnose ASD correctly. As the doctor was uncertain of his diagnosis, he referred the child for a hearing test to rule out other conditions. The doctor advised Jamil to "pray that your son is deaf, or we have a really big problem". Jamil spoke of how "scary" it was to hear this statement from a health professional.

They just kept telling us that maybe he was 'slow' or you know he would 'come out of it' he is still a young boy. There was a doctor in Pakistan who did sort of diagnose him as autistic only he wasn't completely sure. (Jamil)

Aleena's experiences suggest doctors are aware of ASD in Algeria, a LUMIC, yet little importance is attached to it in terms of education or healthcare provision. A lack of awareness was apparent in society, where ASD appeared misunderstood, and patients were viewed critically. It appeared to be the general assumption that ASD patients will get better in time and traits of ASD are merely a case of delayed development.

The doctor we spoke to know about autism. We lived in the capital where there is everything, hospitals, but...autism is new. No schools, nothing for children. Socially they don't give it [ASD] a lot of importance, there is no funding, no legislation, not recognised. Attitude says he will get better. They [society] think they're stupid, not normal. (Aleena)

Fatima is a Pakistani lady, whose son was diagnosed with ASD and Sensory Processing Disorder (SPD) in the UK at the age of 32 months. Fatima had a basic understanding of ASD through her medical training, and 'suspected' ASD as a diagnosis for her son.

[His] speech and behaviour was alarming from 8-9 months, he was developing traits of autism one by one. We had in fact taken him to the GP earlier to clear our doubts when he was 18 months old, but GP clearly had no knowledge of autism, he put it all on his young age. (Fatima)

Fatima's UK GP seemed evidently unable, or unwilling, to suggest the child may have ASD, even though the parent raised this suspicion with her GP as a result of her own knowledge from her medical background. It may be that the GP was not confident enough to provide an opinion relating to ASD through a lack of knowledge in his own training, or that he viewed the child as still young and developing, and that with time he would "grow out" of those behaviours.

Jamil feared that if he lived in Pakistan, his son would not be cared for appropriately as he was not certain that services existed for adults with ASD. There was a possibility that the son would be living in a mental institution rather than accessing community based services or help within the home.

I don't know if there are any professionals that...specialise in autism, I'm not aware of any...institutions that help...adult autistic people. I would think that if we were there [living in Pakistan], he [my son] would at some point be moved into a mental institution. (Jamil)

Mishti, from India, presented with concerns about her child's speech in the UK, but her GP did not discuss ASD as a possible option for the speech delay. The GP was content to attribute the delay to being bilingual and considered that the child's gender may be an issue in slow development.

Upto two and a half years, his speech was a bit delayed and we were seeing the GP. He [the GP] was saying 'he is just a boy' etc. We thought his language may be delayed as we are bilingual, and the GP said the same, we were not that much concerned. (Mishti)

Chen, from China, was "surprised" by her GP's observation that her son looked "clever". The GP was thought to be "American or Canadian", both HICs where ASD is a well-recognised condition and diagnosis rates are respectively 66 and 65 per 10,000 children (Statista, 2019). As such, it may be suggested that the GP would have a more thorough knowledge of ASD. It seems the GP may have thought ASD was more of a physical disability that was obvious to observe.

4.1.3 Family and friends' perception

Much has been disclosed within the realms of this research, regarding participant's families and friends not understanding a child's ASD, which has sometimes led to a breakdown in relationships. It was also revealed that some participants had not disclosed their child's diagnosis to their close family, because of concerns over their reaction and a lack of understanding from them.

Nina's account indicated that her family's lack of knowledge surrounding ASD was a factor in not disclosing her son's diagnosis to them. She thought her family might simply assume the child was badly behaved and that all children behaved in similar ways, ie. it was nothing out of the ordinary. Nina did not want to spend time explaining her son's behaviour due to an expected lack of understanding and has isolated herself from certain relatives.

I have decided not to tell my family...because culturally, it's...hard for them to accept I think. I think my family will think 'all children are like that, there is nothing wrong with him...he is naughty'. My extended family...do not understand and...it means that if anybody makes a comment, I won't go and see them again. There is no point as you are not going to understand and I won't have anyone saying that about my son. It hasn't isolated me but I have isolated myself because of it. (Nina)

Removing herself from particular situations was a step Aleena decided to take in order to avoid comments from other parents in the school playground. She felt that the majority of negative comments or looks came from Asian parents and she was not keen to engage in conversation with them about her son's behaviour.

I isolate myself from other people. It happens that they are all Asian. (Aleena)

Mishti thought that ASD was more understood in Kerala, the region of India where she had lived, because the people living there are more educated. She made the point though, that some people do not like to discuss ASD, perhaps because of the stigma. Mishti suggested that people with lower levels of education do not understand ASD.

[My family live in] a highly educated place. My family is educated so they can understand [ASD] better, some people cover it up. Lower educated families do not understand it. (Mishti)

Jamil also discussed speaking with his friends in Pakistan, and how they enquired about his son's ASD. It was apparent that although the friends cared and showed concern, they had no understanding of ASD or learning disabilities generally. As a result, the support they tried to offer was not best suited to Jamil's needs.

People ask me 'how is your son?' and I admire their enthusiasm, but the questions they ask, they have absolutely no clue of, not even autism, but not even learning disabilities, they just don't understand the concept of this, and so the questions they ask are irrelevant completely. (Jamil)

Fatima also discussed observations from Pakistan and specifically, her close-knit community of family and friends. Fatima "suspected" her son had ASD, and noticed many other children in the community displayed similar behavioural traits.

There were some kids who were non-verbal until three years, but after that age they were all fine...brilliant academically, there was not a single trace of ASD behaviours. There is a general perception of such behaviours in Pakistan that these kids will eventually grow out of it. (Fatima)

Fatima attributed the change in developmental progression and lack of ASD behaviours displayed in later life to "everybody is interacting with someone or others almost every time". Fatima explained that children are not left alone to be independent, "people will make them [children] pay attention". Fatima indicated that this forced interaction and communication may be a reason why children "learn" to communicate more effectively in later life.

Nina spoke of an apparent lack of ASD diagnosis given by GPs in rural Pakistan. However, she thought ASD was more understood and diagnosed in larger cities. Nina found it hard to explain her son's ASD to her family, due to their lack of ASD awareness. Nina had received comments that her son was naughty and a simple case of discipline was needed to curb his behaviour.

They [GPs] don't diagnose it much. In the bigger cities they think it [autistic behaviour] is their personality, it's how they are. My husband's family have not heard of it...they say he will grow out of it. There is no doctor ever going to explain it to them there [in Pakistan], so I don't explain. In bigger cities there are people who have been diagnosed and there is more understanding. People say 'teach him that you can't do that...discipline him...he is naughty'. (Nina)

4.2 Health needs unmet

4.2.1 Access

It was a common belief amongst participants that to see a “good” doctor or other health professional in a LUMIC, who was aware of ASD, one would need to visit a big city, often some distance from the family home. Consulting a local doctor was not seen as a valid option, as their expertise was viewed as inferior to professionals in metropolitan areas. Improved education of GPs in larger cities was given as the reason for greater expertise.

Doctors are not in shortage there [in Pakistan], especially in cities. There are many child psychiatrists and psychologists both in government and private sector. I am from Lahore so when I tried to find out about child psychiatrist specialised in autism, I was given details of three different doctors near my area. (Fatima)

It is hard to get help in smaller towns [in China]. I know lots of parents who travel for medical or educational help [regarding ASD]. They rent a house in a different city in a metropolitan area where there is better help and autism is understood. You must travel to better areas for diagnosis and intervention, more choices. (Chen)

Families seem to be either recommended to clinics some distance away, or make the choice to travel to other such facilities based on their own research of available services. Families consider relocating temporarily to a new home in a more affluent, metropolitan area, to find the help they are seeking.

Upon returning to the UK and receiving a confirmed ASD diagnosis for her son, Mishti soon realised that the care available for her son was of a different standard to that offered in India.

[In the UK] waiting lists were bad for anything and there was no progress. We tried to find an Occupational Therapist....[but it took] almost two years, too many delays, it's frustrating, you have to fight for everything. We waste so much time waiting, occupational therapy, speech therapy. (Mishti)

Mishti recalls the frequency of speech therapy offered to her son was 30 minutes per week, “no child will make any progress with that”. Frustrated at the lack of support and progress, Mishti returned to India with her son for almost twelve months when he was aged four years. With greater confidence in Indian health services than those in the UK, Mishti had been sure that her son would make more progress.

Mishti pointed out that cost of private therapy for her son was an issue in the UK, one that she need not worry about in India, and she was not prepared to wait for NHS therapy due to lengthy waiting lists. Expectations of a child’s ability levels were also very different in the UK and India. There may also be a discrepancy between the ways in which therapists “push” the child to progress, which may link to the levels of cultural expectations.

If you live in better areas [in India], you get better care. They gave us different options [after diagnosis], like occupational therapy, lots of behaviour training...you would have to pay but not expensive. Everything was cheaper and he had better care and treatment. I could afford two lots of therapy a day. Expectations are very high for children there and he started learning after a few weeks. They [therapists] were pushy but he learnt, I was blessed to have plenty of money. When we came back to the UK he had lots of skills. (Mishti)

4.2.2 Acknowledging medical needs

According to participants, residents in rural areas of LUMICs may have to visit larger cities where medical practice is deemed to be of a higher standard. However, the healthcare accessed in LUMICs may depend on the severity of the health need. There are areas in Pakistan where healthcare is relatively close and accessible to families living in smaller villages or more rural areas. Services might, though, be available only for people with “*proper medical needs*”, those that were conspicuous, such as a broken bone or heavy bleeding. This may indicate a lack of understanding displayed by GPs relating to the seriousness of ASD. The present research stated that it would be pointless to consult a local GP in Pakistan for an issue such as ASD.

No point....this is not what they say is a proper medical need, he is fine, he can walk, he is not hurt. (Nina)

They [doctors] see a child who does not have any physical deformity or obvious disability....they say ‘oh, he is slow, he’ll be fine’. (Jamil)

4.3 Beliefs shaped by culture

4.3.1 Cultural values

Jamil spoke of an incident when his son was being transported on the school bus by an African driver. The driver noticed the behaviour of Jamil’s son and made some comments to the child’s mother regarding his own cultural beliefs.

He asked my wife if she was Muslim and she said yes, and then he said ‘the devil is in your son, do you pray?’ He suggested we should do some sort of ritual...that he would be cured. That I can tell you was really distressing. I read and understand [Islam] well, there are no such things as....it’s more a lack of understanding...why people come up with such things.

Jamil’s wife encountered an African Muslim whose beliefs focussed on the child being “*cured*” if the family undertook a certain ritual. Jamil and his wife were distressed by the comment as this is not a belief they shared. Jamil attributed the incident to “*a lack of understanding*” and stated that these beliefs are not part of his Islamic faith.

Mishti noted that Indian professionals appeared to understand ASD more than the general public, and services were available offering therapies or treatments. The Indian culture of competitiveness may be a factor in ASD services being more widely available across India. Businesses thrive on competition and must provide excellent services to aid a patient's progress in order to secure further clients.

I don't think the general population understand [ASD] but professionals understand it more I would say in India. It is very competitive there. One centre opened for Occupational Therapy, and then soon another opened, so they need to be really competitive and offer the best to show your child is progressing so you don't go to the other centre. It is also cultural, people push their child to the maximum, you do not say 'he cannot do it because he is autistic'. (Mishti)

Competitiveness is also a factor in Chinese culture. It appeared to be important to push the child and show good levels of progression amongst the community. Chen felt her son's nursery in the UK should have understood that his ASD meant he was not developmentally ready for certain things, rather than forcing the issue, which placed families under unnecessary pressure.

My friend asked why he [my son] in nappies. She understand his autism too. He not ready. Nursery told me to try but he is not ready. What is the point?! Even other Chinese parents with ASD children say all their children toilet trained at two years, so I feel pressure. Chinese parents are very pushy. Culture very different. (Chen)

4.3.2 Religious beliefs

Of seven participants, six identified as Muslim. The general consensus amongst this majority, was that any disease or disability affecting a child of the family, such as ASD, is viewed as a test from God. Jamil's wife was "pretty annoyed with God and why did this happen to her...everything happens for a reason, God has destined it to be that way".

Religious beliefs provided the strength Nina needed to carry on with daily life. She felt that she was able to cope as her belief was that she would never be given anything she could not manage. Strength was also gained from believing in the reward of an afterlife, and that her son would be guaranteed the same.

Everything happens for a reason and my religion teaches me that we will never be burdened more than we can handle. We will be rewarded in the next life. My son...[is] guaranteed a place in paradise. It is my religion and my belief that keeps me going really and keeps me strong and helps me. (Nina)

Religion has taught Aleena and Marwan that caring for their "disabled" son meant "rewards" were inevitable. Their firm beliefs enabled positivity, strength and hope, and a shared view of an inevitable afterlife.

We believe we are blessed and will go to paradise. We look after a disabled person and it is a good deed, we will be rewarded. Our religion say nothing about autism, but about disabled child. God doesn't blame him [our son] for anything. We always hope and pray that he will be better, so our religion give us hope. (Aleena & Marwan)

Islamic beliefs underpinned Fatima's hopes to receive "rewards" for her "problems", if she stayed strong and faced her trials with courage. Her religion gave strength in the knowledge she could stay positive and would not face her battles alone.

Islam asks its followers to develop a common strong belief towards every difficult situation in life. That is every misery, problem, deadly disease or such kind of disability is a trial from God just to test who among the humans remains positive. As a result of exhibition of such qualities those humans will be rewarded highest rewards in the life hereafter, if not in this life. (Fatima)

4.3.3 Stigma and shame

Some families do not like the term "disabled", as it could mean different things to different people, especially taking cultural perspectives into account. "Disabled" could imply a physical disability or mental illness, which families may not wish to be associated with. Mishti felt that professionals used the term "disabled" too much, when a different word may be more appropriate to help families understand their child's needs.

They [professionals] talk about Disability Living Allowance, but 'disabled' is not a good word. You need to give them [families] time [to understand and process information]. (Mishti)

Understanding her family's Chinese heritage and desire for "good things" encouraged Chen to make the decision not to tell her parents, for fear of her father expressing "shame". Other family members had already told Chen that she worried "too much" and each child had their own difficulties.

I don't think they [my parents] will understand. My dad likes good things. I don't know if he will feel a bit of shame for having a grandson with autism. My dad always wants to be proud of his children. We told my sister and brother in law. They thought I was taking things too seriously, because every child struggles with something. I worry too much they say. (Chen)

Aleena's mother, resident in Algeria, appeared not to have any understanding of ASD and the reason her grandchild was wearing nappies, reflecting her lack of awareness surrounding his needs. There may have been a degree of shame felt about her grandson's condition by asking Aleena to shield her child from others. This request may reflect the stigma that is felt in Algeria surrounding a child viewed as "different".

My mum says he should not be in nappies, I must teach him. My mum say if neighbours come to my house, don't let people see him. (Aleena)

4.4 Issues in education

4.4.1 Global differences in ASD provision

Participant opinions were that mainstream school was the more widely available option in Pakistan for children with ASD. More specialist provision would only be available to those families living in metropolitan areas. Families could relocate to such areas if they were able to do so, where greater educational choices could be sought that might be more suited to their children's needs.

My child would have been going in mainstream school [in Pakistan] because there are almost rare specialist schools in big cities only. I would have to struggle to find them and then move to some big city to get a residence near them. (Fatima)

For children with ASD in China, education appeared limited to specialist provision only. Chen's account suggested that a child may be accepted into mainstream education but only if the ASD diagnosis was not disclosed. There was a possibility that a child with ASD could be accepted into mainstream education if the family was able to offer some form of one to one support at their own expense.

[In China] schools and nurseries can say, your child has SEND and we are a mainstream school, we can't take him. Lots of parents I know have gone to school interviews and would not tell the Head that their child had autism. If the parent is honest, the schools may say as long as you can supply 1-2-1 it's ok, or we can't cope. (Chen)

4.4.2 Lack of information

Jamil's two year old son received a diagnosis of ASD, but "we were completely unable to understand....whereabouts in the autistic spectrum does our child fit in? No one has actually been able to give us an answer." When it came to making choices regarding his son's education, Jamil experienced frustrations finding the right educational placement. He believed that not receiving sufficient information relating to his son's ASD resulted in the family making the wrong choices. Jamil would have found it useful to be told where on the autistic spectrum his son was situated, in order for improved experiences at school.

He [my son] went to special school...choosing that school...was a bad decision, but that was based on not knowing where on the spectrum [he is]. The school doesn't cater for severely autistic children but from mild to medium, and we thought, well maybe he is mild to medium, whereas now we think he is somewhere between medium and severe, so these things have been a bearing on our decisions. (Jamil)

Nina wanted to know where on the autistic spectrum her son was situated in order to make an informed decision regarding his educational provision. However, professionals advised that her son was too young for that decision to be made, and Nina was advised to take time to observe his development further. It was important for Nina that her son attended a "normal" mainstream school as she felt that this would be in his best interests.

I asked but they said because he is young, it is too hard to say and 'keep an eye on him'. I really want mainstream as I want him to be in a 'normal' place where he is accepted and to do things that everyone else can do. I do not feel he is severe enough for a special school. (Nina)

4.4.3 Lack of support

After leaving secondary school, Jamil's son attended a local college but Jamil was not happy with the placement. It appeared that the college teachers could not manage the child's behaviour and asked the parents for assistance, which the parents felt was inappropriate. Jamil's son was transferred to the college his parents had selected as their first choice (parents initially could not secure a place for their son), but there were still issues. Jamil and his wife had requested that the college try and provide their child with a set of basic life skills, but Jamil was not confident that his son had learnt enough to manage independently.

It was a complete disaster, to the point where the teacher in his class started to ask us if we would come in and, you know, spend the day with him and get him to do things, so that was a complete disaster. I don't know if this college is doing anything [for him], if it's going to help, change him that much, that he can manage himself. The only thing that we have asked of the college is that we want him to learn independent living skills. I think they have taught him a few things like cooking. (Jamil)

Frustration and sadness arose for Chen when she realised strategies in her son's EHCP meant to assist him had not been implemented by nursery staff. Even after raising the issue, she was still unhappy with the way a support package was offered, and the fact that staff had not received additional training to support her son. The consistency of one to one support was unreliable, causing her further frustration.

It was not supportive at all. I felt frustrated and heartbroken. They [nursery staff] told me his behaviour was challenging. I...spoke to the SENCo to see if he is allowed some quiet time...after our request they gave him one to one for an hour each day. All the suggestions given by the SEND team were not in place. They did not do any staff training. It is one staff with him and sometimes they change the staff. (Chen)

Although generally happy with their son's school, Aleena and Marwan were disappointed in the level of communication between school and home. They both felt that more information was needed regarding their son's EHCP, and more specifically, how the EHCP process continued to work whilst their son was at school, in order for them to have a greater understanding of this.

We like the school, but we are not kept well informed about the actual [EHC] plan, reviews etc. (Aleena & Marwan)

Frustrations were felt at the lack of support available to Fatima's son in school. The perceived lack of support related to staff not remembering specifics of the child's needs, and inconsistency with one to one support.

If I don't keep reminding them every day about his needs they easily forget them. He has not been given one to one support until now, because they don't have one [1-2-1 person]. (Fatima)

There were only two choices for Mishti's son in respect of specialist provision in her locality. Alternative provision was provided by the LA, following Mishti's child's bad experiences at his first school. Mishti had high expectations for her son, but felt that his school did not share these thoughts. Mishti felt like a "pushy" parent when she made specific requests to her son's teaching staff, which led to an uneasy relationship between home and school.

First, he was in a school for ASD pupils and he did not make any progress. I complained so they offered me the second school. It is better than the first one, but my expectations are really high for him. They [staff] don't see his potential. Their attitude, I think, is we are looking after your child, you should be happy. If you say do this, they think I am pushy. (Mishti)

4.4.4 EHCPs and funding

Aleena's son attended mainstream nursery provision as he did not have an EHCP. "The Local Authority [LA] did not want him to have an [EHCP] assessment". With support from staff at her son's nursery, the EHCP assessment was undertaken, followed by a full EHCP being granted.

He started three, four hours gradual. He no learn anything. They [school] made an appointment for me with the Educational Psychologist to tell me they couldn't meet his needs. We visit [a special school] and the Council ignore me. I keep asking people for pressure. It is his right, in his [EHC] plan. We went to tribunal [for specialist provision]. Three weeks before the tribunal they said ok, ok, he go to school. (Aleena)

I had to go to tribunal to get everything for him in the EHCP, like therapy. (Mishti)

Four parents described facing issues regarding potential problems surrounding EHCPs and a child's entitlement. Three of those four parents went to tribunals to "battle" for their children's rights. Aleena was told that her son's school could not meet his needs, so specialist provision was sought but refused, leading to a potential tribunal. The LA offered Aleena's son the required place before the tribunal date was due to meet. Mishti knew her son's rights under the terms of his EHCP, and obtained what he was entitled to, but only via a tribunal after being refused additional services, such as therapy, initially. Fatima was aware her son would require an EHCP to obtain specialist provision, but knew she faced a "battle". She was advised to expect a mainstream offer for her son, but intended to persist with her wishes as she knew her son best and would fight on his behalf. "Every year" Jamil faced the same issue regarding a college place for his son. The college always said a place was not available, but once Jamil mentioned a previous tribunal, a place was offered for the year ahead.

4.4.5 Training

Chen was finally happy with her son's nursery placement, but wanted the staff to receive further training around ASD. However, she acknowledged that because all autistic children were different, it would be difficult for any professional to fully understand and be aware of every autistic trait and how these could manifest in a child or young person.

[It is] better than last one but staff not experienced much. SENCo is good. All ASC children are different. The SENCo understand his needs and key person is ok. Need more training.
(Chen)

Mishti felt that her son's teacher and teaching assistant (TA) in the UK did not have the relevant training to understand her son's needs. She felt that further training would be beneficial for education staff to understand a child's individual capabilities, but it would be difficult to understand each individual child. Mishti had also experienced Indian education, which she suggested was superior to that in the UK. Indian education seemed more positive, observing what a child could accomplish given time and opportunity, rather than there being "low expectations" of a child with ASD as in the UK. A negative perceived by Mishti was that her time was not well spent attending school meetings, as there appeared to be an uneasy relationship between herself and the teaching staff. The main issue appeared to be that the parent was aware of her child's capabilities, but her perception was that the school was not.

I don't think the teacher or TA has enough training to know the individual needs of the child. Problem, is lack of training. People have low expectations of ASD children in the UK. [The staff need to] use specific targets for him. I like the Indian way, not he can do everything but there are hundreds of things we can still teach him. The school tells me he can't do things I know he can do. I feel it is a waste of my time going to school meetings, and they don't like me because I question them. (Mishti)

4.5 Problems at diagnosis and beyond

4.5.1 Language barrier

All seven participants interviewed, stated that using English as an additional language was not a barrier in accessing health services, specifically, regarding the diagnosis appointment. However, it is fair to say that the majority of participants had a reasonable grasp of spoken English, which should have given them a greater understanding of health services and the terminology these staff used.

Nina would have liked for her husband to attend the appointment with her, so he could also gain an understanding of the diagnosis. Nina found it difficult to explain her son's ASD to her husband, and to help him understand the terminology used. Although further assistance had been offered to the family by the speech and language team, this had not transpired at the time of the interview. Nina was provided with

some information at diagnosis, but her husband was unable to understand it, as English was his second language.

My husband did not attend as he does not really speak English and understand what is going on. There was no interpreter so he did not go. He has not been able to go to meetings, to understand all of that, so that has made it quite hard, and having to explain it all to him. They [at diagnosis] gave me some leaflets [and] I did give them to my husband, but because he struggles [with English].....he is like, 'oh it is too much, you just deal with it'...but I am doing it on my own. (Nina)

Aleena was offered an interpreter at the diagnosis appointment, but refused as she had a negative experience with a previous interpreter. Aleena spoke Arabic and French.

I would prefer [to use] Arabic, [but] it's easier to understand the medical terminology in French. When we had an Arabic translator, it was not the right Arabic, it was from the east, not north Africa. I couldn't understand her. (Aleena)

An issue arising relating to interpreters was that they might not have enough specialist knowledge. Chen had used an interpreter but was “*disappointed*” with the lack of help he provided. Chen suggested that when interpreting conversations relating to ASD, “*extra skill*” would be an advantage to understand the medical or technical terms used by health professionals.

I don't know if the translators have enough professional knowledge about autism to help a lot. I once used a translator but was disappointed as he didn't supply much help. They need extra skill in autism. They [are] sometimes lost for words, not always a specific word in our language for technical terms. They [are] often freelance people. It is a big problem for people who need translators or help completing forms. (Chen)

4.5.2 Parental understanding

The majority of participants felt they had understood their child's diagnosis, in terms of what the immediate future might hold, and what to expect. Of these, the majority had already anticipated an ASD diagnosis, due to an experience with an older child, or through reading up on presenting behaviours. By the time of the actual diagnosis, some parents had “*lots of information*” from their own research. “*We started reading up on it [ASD]*” as soon as behavioural changes were noticed and attributed to potential ASD, in order to obtain some answers.

4.5.3 Post-diagnostic support

Accounts differed regarding the levels of support offered at UK diagnoses for families. Overall, participants spoke highly of the information received. It appeared that a range of resources were provided in different formats, such as written papers, helplines and online support. Although some participants had already gathered a certain amount of information from their own research, it appeared the resources were still viewed as “*useful*” by the majority.

I was given a lot of information, verbal, pamphlets, booklets, online material, phone numbers, support organisations, brochures. The information was useful to some extent as I had already gained all the knowledge about my child's condition [from own research], so I knew most of it already. (Fatima)

Two participants made telephone contact with NAS, but one of their experiences was reported to be negative. Participant perception was that the service might be overstretched as calls went unanswered a “*few times*”, but there was also one positive review.

I had some leaflets. I have called National Autistic Society once. It is volunteer run, so it is not easy process. [NAS] was not helpful. I was given lots of information...which was useful. They gave me reference books, websites...quite helpful. (Chen)

In terms of diagnosis outside the UK and the subsequent support received, Mishti spoke of how much support would be offered.

In India they tell you how to get therapy and things like that. (Mishti)

Chapter 5 - Discussion

The present research found that parents of children with ASD and who use EAL face many challenges. Two issues relating solely to using EAL were linked to a child's rights concerning additional educational support, and navigating SEND processes, such as applying for EHCPs, which can fall loosely under the remit of post-diagnostic support.

Issues with educational support were more likely to relate to parental perception of a child's needs being understood and/or met. All parents wanted the best for their child, but within the present research it was sometimes difficult to differentiate between what a child was entitled to and what a parent required over and above that entitlement. A school may have provided the best they could but parents sometimes wanted additional services or more time spent with their child. On occasion there really was room for improvement in the services offered by the school in meeting the child's needs.

The overall impression, of the current researcher, was that post-diagnostic support was simply lacking. Participants were either not given information regarding available help, such as how to obtain an EHCP or local support groups for example, or waiting lists for support were lengthy and thus support was delayed. EAL did appear to be a factor in terms of participants knowing their child's rights, and how to progress effectively through various SEND procedures. Those participants who had a greater grasp of English and who described themselves as "educated", showed greater success when fighting for their child's educational rights and understanding the processes involved.

There are three main issues identified as specific to LUMICs, which are explained further throughout Chapter 5:

- Cost of healthcare and/or therapy
- Families and communities being less able to understand ASD and related terminology. This is due to there being no comparable word in their native language as a consequence of lack of awareness and diagnosis
- Less options in educational provision

5.1 Autism misunderstood

Public perception

Challenging behaviour can be commonplace amongst autistic children, and this behaviour is not always well received in public by those who misunderstand ASD or have no awareness. Being overly concerned about their child's behaviour can lead parents to avoid public spaces with their child, and lead to feelings of

isolation between the participant and the community (Byrne, Sarma, Hendler & O'Connell, 2018; Divan et al., 2012; Fox, Aabe, Turner, Redwood & Rai, 2017). Children with ASD can be viewed by the unknowing as disruptive or disobedient (Gray, 1993 & 2002; Ling et al., 2010, as cited in Ka Shing Chan & Bun Lam, 2018), which is echoed in the present research, together with similar feelings of isolation. Some participants had stopped visiting family due to relatives not understanding ASD, or had “*hid*” from other parents at school, so they were not questioned over their child’s behaviour. One participant mother was asked if she could keep her son quiet in a doctor’s waiting room as he was being noisy and disruptive. ASD patients have an “*absence of conspicuous physical markers*” to determine any disability (Ka Shing et al., 2018, p.44), so to an outsider, unfamiliar with ASD, misunderstandings can occur. In the present research, homophobic remarks were uttered when a father was seen accompanying his adult autistic son from a public bathroom in Pakistan. The participant noted that he had never experienced such behaviour in the UK.

Professional perception

Previous studies concerning the extent of ASD diagnoses may present an unrealistic perspective as patients are often diagnosed with something other than ASD (Imran et al., 2011; Kalra et al., 2005; Singhi & Malhi, 2001). Imran et al. conducted a study in Lahore, Pakistan, among 247 health professionals. They found that children presenting with autistic traits were often diagnosed with conditions more related to mental illness and may be referred to a psychiatric facility for help in treating issues such as delayed development. GPs in Pakistan showed “*an unbalanced understanding of autism*” due to “*no formal child psychiatry exposure during their training*” (pp.4-5). These findings were corroborated in the present research. It was noted that some children with ASD were identified as suffering with a mental illness, and referred to an institution to cater for such illnesses. All examples of this were outside the UK. However, misdiagnosis or misunderstanding surrounding ASD is not limited to LUMICs. In the UK, ASD can be misdiagnosed when clinicians attribute typically autistic behaviour to other conditions (NAS, 2017b). One of the most commonly identified barriers to participant satisfaction in the UK, is perceived lack of professional awareness surrounding ASD (Crane, Batty, Adeyinka, Goddard, Henry & Hill, 2018; Royal College of Psychiatrists, 2019), which is corroborated in the present study. Autistic adults in Crane et al.’s study perceived a lack of ASD awareness from GPs, and parents of children with autism shared this view of some education staff. Autism has been, and continues to be, misunderstood in the UK and LUMICs, both amongst the public and professionals.

5.2 Health needs unmet

Families in LUMICs may have restricted access to healthcare for many reasons, two identified as being their distance from the family home and financial cost.

Access

A study undertaken by Dababnah & Bulson (2015) in the West Bank revealed that ASD services were very limited, and those offered might only be available in larger cities. The study indicated that although distance was the main issue in accessing better healthcare, lack of transportation was a related factor. Political issues, such as border control regulations, also increased the difficulty of travelling between cities and accessing services. These findings were corroborated in another West Bank study by Abu-Ras, Saleh & Birani (2018). It should be noted that the studies were limited to 24 and 43 participants respectively and therefore findings cannot be generalised across the West Bank. Within the present research, many participants stated that, in their country of birth, they would have to travel a considerable distance for healthcare deemed as “good”, usually to larger cities. The majority of participants stated that a degree of ASD treatment was available, even if somewhat minimal, just not in the local area and was therefore almost inaccessible.

A Chinese study of 290 families of a child with ASD, reported that in 58.1% of families, annual health care costs “*exceeded the annual family income*” (Wang, Zhou, Xia, Sun, Wu & Wang et al., 2012). The majority of expenditure was for therapies, with money also being needed for transport, accommodation and hospital care. Within the present research, one participant spoke of incidences in China where families had rented second homes at substantial cost to be closer to a facility where ongoing care was being provided to a child.

A study of South African families indicated that when one parent enquired about the cost of therapy, she was asked “*how deep are your pockets?*” by the head of a therapy centre. Applied behavioural analysis (ABA) is offered across South Africa but is extremely expensive and unavailable to the majority of families. 10% of the population is deemed “*affluent*”, and across the study, although the highest paid participant was a chartered accountant, ABA fees would still not be affordable to an employee in that sector (Clasquin-Johnson & Clasquin-Johnson, 2018).

In the present research, financial burden was discussed in India and China. In India there appeared to be different levels of healthcare dependant on income, and no family was excluded from accessing even basic healthcare. However as expected, it was apparent that the more advanced healthcare and therapies were only available to the most affluent families. In China, one participant noted that there was “*no free healthcare, you must pay for diagnosis and intervention*”. No participants indicated that accessing healthcare services in the UK had been problematic in terms of either distance from home or financial

impact on the family. The largest issue regarding accessing healthcare was provision of post-diagnostic support.

5.3 Beliefs shaped by culture

Two pieces of American research (Lovaas, 1987; Orinstein et al., 2014), found that with high levels of early intervention some patients displaying typically autistic traits can develop to such an extent that they “recover” or reach their “*optimal outcome*”, where the patient no longer meets the criteria for ASD diagnosis and has “*normal cognitive function*” (Pollak, 2016, pp.274-275). The earlier these interventions start, the greater the chance of achieving optimal outcomes. This finding was echoed in the present research. One participant spoke of children she had observed in Pakistan who had “*come out of*” their autistic behaviours, and progressed to be “*brilliant academically*”. These children had been subjected to intense interactions in the close-knit community over a sustained period of time, from birth, and it was her opinion that this intense cultural interaction was the reason for the autistic traits “disappearing”. It should be noted, however, that any perceived link between intervention and optimal outcome in this research is speculative and only based on the opinion of one participant. Previous research has focussed on the quantity of intervention rather than quality. Lovaas indicated that greater levels of intervention produced better outcomes, but again, this is correlational and cannot be generalised. Finally, it is noted that the majority of children receiving early intensive intervention do not recover, so that alone cannot be the key to recovery (Helt, Kelley, Kinsbourne, Pandey, Boorstein, Herbert et al., 2008).

Religious beliefs

Faith is identified as a source of comfort and strength for parents, enabling participants to cope with difficulties of a child with additional needs (Dababnah & Bulson, 2015; Fox et al., 2017; Hussein, Pellicano & Crane, 2019). Abu-Ras et al. (2018) studied 43 participants, mostly Muslims, residing in either the West Bank or Israel. Each participant parented a child with physical, mental or other disability including ASD. Abu-Ras et al. concluded that participants felt they had been “*chosen by Allah*” to care for an autistic child and “*my son will be rewarded by Allah in heaven*”. The overall conclusion appeared to be that faith was important in accepting a child’s ASD diagnosis and gave strength to parents. The present research indicated that over three quarters of participants agreed with such ideas. It is important to note, though, that there can be cross-cultural differences between, for example, African Muslims and Arab Muslims, and their beliefs can vary greatly within the same religion (Kpobi & Swartz, 2018).

Previous studies have tried to explain how communities sharing other beliefs understand ASD. A Kenyan study of 103 people, undertaken across different religious groups found that a number of participants believed ASD may be caused by “*witchcraft, evil spirits and curses*” (Gona, Newton, Rimba, Mapenzi, Kihara & Van de Vijwer et al., 2015, p.5). Participants also argued that sins such as infidelity or marrying a relative were also believed to be a cause of ASD. A Canadian study comprising 45 immigrants from a

range of countries showed 11% of participants believed ASD could be attributed to “*spiritual or religious*” causes (Millau, Rivard & Mello, 2018, p.3472). Participants most likely to share these beliefs originated from Western Europe and West Africa. However, the latter study did not detail these beliefs sufficiently to make comparisons with the study undertaken by Gona et al. In the present research, the wife of one participant had been told by an African bus driver that the devil was in her autistic child, which is similar to findings obtained by Zeleke, Hughes & Chitiyo (2018) and Hussein, Pellicano & Crane, (2019) in studies from Ethiopia and Somalia respectively. Stigma and/or shame appear present in many communities across the UK and in LUMICs. However, parents tend to find a lot of comfort and strength in their religion in times of difficulty.

Stigma and shame

Parents and the wider community may struggle to understand a child’s disability as the child may not look disabled (Fox et al., 2017; Hussein, Pellicano & Crane, 2019). The latter study focussed on a group of UK Somali parents, some having a child with ASD and some not. It was noted that a number of parents “*did not want to hide their child...we do not care if we are being judged*” (p.1413). Similar research undertaken by Fox et al. studied a group of UK Somali parents who had children with ASD. These parents found disability a difficult concept to understand, as they had never experienced ASD in their country of birth as “*there isn’t anybody who doesn’t talk in Somalia*” and “*there is no autistic person in Somalia*” (p.308). Negative perceptions of mental illness within the Somali culture encouraged parents not to discuss their child’s condition and to limit the child’s social activities so they were not seen in public. These two pieces of research were limited to small UK Somali communities and may not be representative of other ethnic minority communities in the UK such as Kurds. Fox et al.’s findings reflected the present research. A few participants implied that “*disabled*” was not a term that their community wished to use for a child with ASD, as it had negative connotations. The present researcher also encountered the issue of shame in her professional practice. An Iraqi-Kurdish parent questioned whether his autistic son was viewed as “*disabled*”. It appeared to be the case that “*disabled*” was viewed very negatively by the parent. Kenny, Hattersley, Molins, Buckley, Povey & Pellicano (2016) suggested, and to the contrary, that some UK based parents wish (reluctantly) to use the term “*disabled*” as it allows for greater access to patient services.

Georgas, Berry, Van de Vijwer, Kogitçibasi & Poortinga (2006) undertook a study across thirty nations, and noted it generally appeared harder for a parent to find a bride or groom for a child with ASD. In many LUMICs where arranged marriages are the norm, having a child with a disability or any kind of additional need can make marriage more difficult (Daley et al., 2013). These findings are echoed in the present research. Some participants noted that amongst their close-knit communities in Pakistan, their child’s ASD would be viewed negatively and would inevitably lead to difficulties finding their child a suitable life partner.

Research among Korean-Americans (Kang-Yi, Grinker, Beidas, Agha, Russell & Shah et al., 2018) underlines the issue of shame. One participant in the study stated he might be reluctant to offer assistance to the family of a child with suspected ASD, as doing so might “*damage the family’s image*” (p.631). Kang-Yi et al. suggested families may see the offer of help as an insult or be in denial that their child’s diagnosis was valid.

Research among Hong Kong Chinese families (Tait, Fung, Hu, Sweller & Wang, 2016) indicates that Chinese parents are judged by their child’s “*success when growing up*”. Reference is also made to “*traditional societal pressures*” (p.1165). These cultural pressures were mentioned in the present research. A Chinese participant spoke of the issue of cultural expectations and the importance of being successful. The participant was unsure about informing her parents of her child’s ASD, as she suspected they may have felt a degree of shame.

5.4 Issues in education

Parents of children with ASD can face difficulties across many areas of education. These can include a lack of school choice (Goodall, 2018; McCabe & Deng, 2018), staff not understanding and meeting a child’s needs (Slade, Eisenhower, Carter & Blacher, 2018; Van Herwegen, Ashworth & Palikara, 2018), and staff having limited knowledge surrounding ASD (Wang, 2016). It may not be easy for a parent to decide which school their child should attend (Goodall, 2018), as mainstream education may not suit the child’s special needs, yet specialised provision may not fit their academic profile. The present research found that for a parent, not knowing where their child was on the autistic spectrum, made choosing educational provision more difficult. The majority of participants had moved their child to a new school at least once before being satisfied that the child’s needs were being understood and/or met.

Research has demonstrated that globally, children with ASD are often excluded from education (Daley et al., 2013; Daniels et al., 2017; Divan et al., 2012; McCabe & Deng, 2018). Parents purposefully have not informed schools of a child’s ASD diagnosis, as it was thought likely the child would have been excluded if that information was disclosed. These findings are corroborated in the present research. One participant spoke of occasions in China where she had known friends to withhold this information from schools for fear of a child’s exclusion or non-admittance.

Another vital issue was parental perception of how a child’s needs are met at school. “Needs” may cover legal obligations outlined in an Education, Health and Care Plan (EHCP), or lower level strategies, such as consistent use of visual aids. Pejovic-Milovancevic, Stankowicz, Mitkovic-Voncina, Rudic, Grujicic & Herrera et al., (2018) interviewed 231 parents of children with ASD in Serbia. Over 40% of participants indicated that the most common form of educational support for their child was having access to a “*special classroom*”. 28.6% were “*very satisfied*” with the educational support provided to their child, and only 17.9% “*very dissatisfied*”. Those reporting a “*neutral*” stance amounted to 53.6%. These statistics were not echoed in the present research. Only one participant mentioned there was not enough support in her

child's UK school to allow her child to receive high levels of one to one intervention, and thus the child's education plan was not always followed rigidly. Dissatisfaction levels were higher prior to children being moved between schools, as a prime reason for moving, was that appropriate intervention was not provided frequently enough. However, it is fair to suggest that had a "neutral" option not have been offered in the Serbian study, feelings of satisfaction or dissatisfaction would have been more clearly identified, and perhaps more comparable with the present research.

In a UK study of 82 parents with autistic children, Van Herwegen et al. (2018) noted it was common for parents to feel their child was misunderstood by teaching staff and subsequently that the child's needs were not met. Parents also complained that staff did not have enough training on ASD and that one to one work between the child and staff was inconsistent. This was commonly due to a high turnover of support staff meaning the child was frequently working with a new adult. In the present research, only a minority of parents specifically stated that they felt school staff would benefit from more training and understanding of ASD.

5.5 Problems at diagnosis and beyond

Language barrier

A Californian study of 152 parents of children with ASD suggested that "*those who spoke English as a primary language received significantly more hours of services...than children whose parents primarily spoke a language other than English*" (St. Amant, Schragar, Peña-Ricardo, Williams & Vanderbilt, 2018, pp. 337-338). This may be explained by parents using English as a primary language being more able to access services and knowing where to obtain help compared to parents using EAL. The present research indicated though, that generally, using EAL was not a barrier to accessing ASD services. Participants reported that once they had been provided with information at diagnosis, they were then able to access those services independently without any major issues. A possible reason for this is that participants mostly had a reasonably proficient understanding of English.

A common problem for EAL speakers was that the word "autism" has no equivalent in their first language as found in research among Somalian families (Fox et al., 2017; Hussein, Pellicano & Crane, 2019; NAS, 2014). This issue was highlighted in the present research. Participants stated that interpreters (where available) had not always been able to find comparable words for autism or other medical terms used. This resulted in the parents feeling confused and misunderstanding the diagnosis. A number of participants expressed difficulties in speaking with friends and family about a child's ASD, due to not having appropriate words in their first language. As a consequence, their family and friends did not support them as much as they might have done as they did not have a complete understanding of ASD, and what that diagnosis meant for the child and family.

Post-diagnostic support

Participants might receive a considerable amount of information at diagnosis, or very little (Howlin & Moore, 1997), but the reality may be that post-diagnosis, parents are often left to “*manage the situation alone*” (Crane et al., 2018, p.3761). Research from NAS (2014) indicated parents from black and minority ethnic (BAME) communities found it complicated to find support. Poor experiences led to discouragement in accessing further services, which resulted in isolation. In the present research, the majority of participants seemed generally satisfied with the level of support offered at diagnosis, which included information leaflets and contact details of support groups. Only one participant was provided with bilingual information, but this had not been specifically requested. None of the participants were advised where they could obtain information in their first language, and only one participant stated this would have been useful for passing on to her husband, whose understanding of English was poor.

Previous studies have noted that although post-diagnostic support may be offered to ASD patients, waiting lists can be lengthy and dissatisfaction can occur as a result (Daniels et al., 2017; Siklos & Kerns, 2007). This was echoed in the present research. Private therapy was also an option, but due to high cost, many participants in the present research were not able to take this up. Private therapy would likely have included a greater intensity of the treatment already offered via the NHS, such as multiple sessions per week or even daily. Two participants spoke of ABA being the most common therapy in China and India, but it is only available to the wealthiest families (Pollak, 2016). Clark & Zhou (2005) implied ABA was only used rarely in China, claiming that a mixture of medication and sensory therapies was more common. The financial impact of ABA was echoed in the present research. The sole participant to use ABA was “*blessed to have plenty of money*” or she would not have been able to access this therapy. ABA involves periods of intense interaction between a patient and therapist based on analysing behaviours, eliminating negative traits and encouraging positive signs of skill improvement (Myers & Johnson, 2007; Pollak, 2016).

Previous studies, all undertaken in America, have claimed to show the benefits of ABA (McEachin et al., 1993; Smith, 1999; Weiss, 1999), and have concluded that self-care skills can be learnt quickly and effectively when early intervention is undertaken. Many of these studies though, used small sample sizes and it was unclear whether the skills learnt were maintained in the long term. Of the two participants who spoke of ABA within the present research, only one had experience of accessing this therapy, which was in India. Mishti was of the opinion that her son started learning self-care skills in a few weeks, as he was able to access two sessions of therapy per day. Mishti referred to cultural expectations and the therapists being “*pushy*”, which she thought made her son learn faster.

Limitations

The main limitation in the present study was the small sample. Interviewing only seven participants proved beneficial in terms of the depth of information gathered, but did limit the study's generalisability. However, a lack of generalisability does not mean the present research is irrelevant beyond the present sample (Vasileiou, Barnett, Thorpe & Young, 2018). A qualitative data approach to data gathering was chosen as it was more suited to understanding participant's experiences in depth, rather than being able to generalise to the wider population (Vasileiou et al.).

The researcher acknowledges that it could be considered participants may not have been completely open with their answers, considering the different cultural backgrounds between participant and researcher (Aabe et al., 2019). However, the researcher did not ever feel that any participant was "holding back" information or not answering any question fully for the purposes of this research. Indeed, the majority of participants spoke of themselves as "British" having lived in the UK for a number of years so cultural barriers were somewhat minimised on that basis. Also, the researcher used her own experiences of working with a mix of cultures to ensure her language was appropriate. For example, when discussing the term "disability", the researcher knew this was not a term favourable to many cultures. She was able to use this to her advantage in understanding a participant's concerns and being more sympathetic, resulting in, she felt, honest two-way conversations.

It would have been beneficial to engage with the services of an interpreter in order to reach a wider population, which would have made the sample more representative, rather than being biased towards those with a moderate grasp of English. Using an interpreter may have "opened doors" to making cross-cultural comparisons within a larger sample, and could have broken down any cultural barriers between researcher and participant. Shibre, Alem, Tekle-Haimanot & Medhin (2006) indicated that in HICs the use of a "paper and pen" questionnaire-style interview would be acceptable, but this would not be the case in some LUMICs due to low literacy skills or their preference for speaking rather than writing. However, Shibre et al. felt that using an interpreter to ask questions was an acceptable cultural alternative. An interpreter would also have been advantageous in helping to better answer one of the study's aims, ie. whether language is a barrier in understanding diagnosis. For the purposes of this study, language proved no real barrier, as all participants needed to have a moderate understanding of English to meet the inclusion criteria. As such, they understood the terms of the ASD diagnosis fairly well. However, if those recruited had a poor understanding of English, the findings may have been different.

The present research focussed on participants' experiences only. It could have been enhanced by questioning professionals, and children, where appropriate, to gain a more comprehensive view of services provided. Much has been discussed in previous research around the child's voice and how important it is to take their opinions into account and whether they consent to research concerning them, rather than asking their parent (Huang, O'Connor, Ke & Lee, 2016; Unicef, 2018).

It would also have been advantageous to have sight of the children's medical records to provide an overall perspective of health issues and how many professionals had been involved in the ASD diagnosis, for example. However, the researcher appreciates the potential difficulty in obtaining a child's medical records and that many parents might not have consented to the researcher accessing these, perhaps having concerns surrounding anonymity and confidentiality. It may have been beneficial to have asked more questions relating to the child's diagnosis and whether there was any comorbidity, and the child's level of communication to gain a more holistic view.

Finally, at the start of this process the researcher had a modest understanding of ASD and its multi-faceted components. Following lengthy interviews and after gaining a greater insight into the barriers faced by these parents, the researcher would wish to have worded her interviews more appropriately in order for topics of greater relevance to be explored in more depth. For example, participants provided considerable detail as to how their child's ASD affected the families' daily lives, but although interesting and informative, it was irrelevant in answering the study's aims. If a particular question had focussed more on the benefits of receiving bilingual information relating to ASD, participant responses may have been different and of more use to the researcher. Greater time could have been spent discussing topics such as education and EHCPs, but this was only discovered during analysis and the realisation of how important this issue was for families.

Chapter 6 - Conclusion

Recommendations

This research has identified some common problems arising for UK based parents who care for an autistic child and use EAL. The main issue is how ASD can be misunderstood by the parents' relatives and friends, and by the wider public. In the parent's country of birth, ASD may be a taboo subject or unheard of, so for extended family in those countries, providing emotional support for a condition not understood is difficult. As a result, the child's parents may feel isolated and have a minimal support network (Millau, Rivard & Mello, 2018). It is also not unusual for professionals to display a lack of understanding, especially at school. Parents spoke of teaching staff in the UK not understanding or meeting their child's needs, both in mainstream and specialised provision. Staff did not always implement the terms of a child's EHCP and one to one support was minimal and/or inconsistent. Parents spoke of lengthy waiting lists for ASD diagnoses and further waiting for post-diagnostic treatment. Challenges were faced across many areas in the parent's country of birth and in the UK. These challenges included accessing available services, such as EHCP assessment, without specific signposting and help from professionals; finding a suitable school and ensuring the child's needs were met; and, facing regular stigma and ignorance.

The primary observation from a parent's country of birth is how ASD can be misdiagnosed. Children with ASD traits may be sent to a psychiatric institution or simply left to develop without any intervention, as it is thought the child will "grow out" of such behaviours. It is not uncommon for communities to share this latter view and to believe that a parent is overreacting in seeking medical intervention. The second major observation relates to substandard healthcare and access to the same. Families may have to travel great distances for treatment, which can have a considerable financial impact upon them.

Policy

Changes should be made nationally to the training of health professionals to provide an overview of ASD and where appropriate, tailored to those who diagnose and manage ASD to improve confidence (Crane et al., 2019; Unigwe et al., 2017). The two former studies made recommendations how to improve services for people with ASD within the fields of general practice and psychiatry respectively. Improved accessibility and a greater patient-led focus are two examples. However, recommendations do not encompass the barriers this research has uncovered relating to EAL. It is pleasing to note an ASD training package has been delivered to 350 UK psychiatrists, but nationwide coverage appears sparse (Royal College of Psychiatrists, 2019). The current Secretary of State for Health has detailed a new government initiative for mandatory ASD training for all health and social care professionals with trials due to start in 2020 (BBC News, 2019).

It would be beneficial to place greater emphasis on ASD within medical degrees, internationally, as the number of reported cases is increasing. As the first point of contact for a family in LUMICs, GPs need to know what ASD is and advise on its management. The Department of Health and Social Care recently published a consultation proposing that all health and social care employees should receive training regarding ASD. The Nursing and Midwifery Council (NMC) stated this training should be “*regular...ongoing*” to address a “*fatal gap*” in professional knowledge (Snug, 2019, n.p.).

NICE quality standards state that autism assessments should be undertaken “within three months” of referrals being made (NICE, 2011), which represents a major demand considering that, nationally, services are being cut and budgets reduced. A 2019 report spoke of nationally “*overstretched services and pressure on high needs funding*”, which can only be addressed through greater government spending (BBC News, 2019). However, and more positively, the waiting lists in the researcher’s locality of Kirklees have reduced to “*around eleven months*” (Earnshaw, 2019, n.p.).

NICE standards also state that an interpreter should be available to any family who needs this service (NICE, 2014). Families using EAL need to be made aware that they are entitled to an interpreter and they should be offered this routinely by professionals, rather than having to ask for this basic requirement. It should not be assumed that because families have not asked for an interpreter they do not need the service. They may not know of its availability and do not want to cause a fuss.

In 2016, the Education Secretary stated that there would be a greater emphasis in teacher training on autism and this was successfully implemented for student teachers from September 2018 (DfE, 2016). However, it would be beneficial for teachers to also understand the legal obligations of EHCPs and how these need to be implemented in the classroom. It is important that early years educators are taught about autism as it is often they who first come into contact with autistic children. Developing the content of CACHE courses may be an important future target.

One further important factor is services provided by the NAS. As a major source of information, services need to be more accessible to speakers of EAL. It would be helpful for online information to be available in a range of languages rather than only via telephone interpretation. Families would benefit greatly at diagnosis in receiving information relating to additional help concerning accessing specific benefits such as Disability Living Allowance and completing related forms, and also in terms of applying for an EHCP and what this entails. NAS (2014) research into challenges affecting BAME families discovered the importance of translation and interpretation services. Recommendations to Local Authorities and CCGs focussed on providing these services, as well as advocacy, “*during and following an autism diagnosis*” (p.22), and ensuring information on ASD and relevant services is “*readily available in appropriate languages and is promoted to BAME communities*” (p.22).

Practice

A greater emphasis on ASD is needed in the training of health professionals in LUMICs to ensure there is a greater awareness of autistic traits and to ensure that correct diagnosis is provided. However, it is noted that some behaviours are culturally different and what is considered normal in some cultures appears rude or disrespectful in other cultures (Uono & Hietanen, 2015; NAS, 2014). Diagnosis may be inaccurate unless cultural differences and social norms, such as language ability or eye contact are accounted for. It is too simplistic to suggest that once health professionals in LUMICs receive more structured training that they will be able to diagnose ASD more accurately. Franz, Chambers, von Isenburg & de Vries (2017) note that diagnosis in LUMICs can be difficult when using tools developed in HICs. Previous studies across Africa have utilised DSM/ICD criteria or other autism rating scales as part of their research, but none were “*translated or assessed for cultural appropriateness*” (p.736).

Smaller steps could be implemented to educate all health professionals to ensure they had at least a basic understanding of ASD. This measure would ensure that health professionals in smaller towns or rural areas would be more able to recognise and diagnose ASD. A short training programme for Ethiopian health workers seemed to suggest increased expectations for improved language skills amongst children with ASD, and a reduction in endorsement of negative beliefs across the community (Tilahun et al., 2019). However, the researcher acknowledges that lack of ASD knowledge is not limited to LUMICs or poorer families. Prynne (2018) reported the difficulties faced by millionairess Petra Ecclestone trying to obtain an ASD diagnosis for her child in the UK. Ms Ecclestone stated “*doctors were not helpful, there was very little advice*”.

If bilingual documentation were produced and provided to parents, this would also allow information to be passed to extended family members, allowing them an insight into ASD. This might, in addition, encourage them to provide more support to the family, which the present research has shown is much needed.

Stigma has been and continues to be an issue both in LUMICs and the UK, which could be improved with greater awareness. It would be beneficial for funding to be made available for education programmes to increase knowledge amongst the public and professionals. This could start in its most basic form in secondary schools as part of the curriculum. Health and education professionals would benefit from enhanced training around ASD to identify it earlier, and to be able to offer appropriate advice and treatment. The Global Autism Public Health (GAPH) Initiative is working in more than 70 countries to help reduce stigma surrounding ASD (Autism Speaks, 2019).

The Aga Khan University in Pakistan now has a dedicated faculty with ASD training (Aga Khan University, 2019a). The university has also held public awareness sessions to provide information on ASD to the community (Aga Khan University, 2019b). Steps such as these are an example of a positive progression towards a greater understanding of ASD in LUMICs.

Research

The present research comprised only a small sample of seven participants originating from four countries. Follow-up research with a large sample and a longer timescale would be valuable in obtaining a wider variety of responses. It would be useful to interview families from particular LUMICs in order for generalisations to be made across cultures or countries. Providing interpreter services would greatly enhance the number of available participants, as language would not be a barrier to any person. Using an interpreter service would also allow the researcher to determine whether English usage was a factor in accessing services for EAL speakers. Previous research has shown this to be likely (St. Amant, Schragar, Peña-Ricardo et al., 2018), but the present research was not able to test this, as the majority of participants spoke and understood English moderately well.

To conclude, there are many barriers facing parents of children with ASD, which are increased by using EAL. The challenge begins when atypical behaviour is observed in the child and the family may face stigma and misunderstanding. Typically, there will be a delay in waiting for an assessment without any interim support. Once diagnosed, the family may receive insufficient information about ASD, wait again for therapy and struggle to find an appropriate school. Parents often feel their child's needs are not met and the child is misunderstood by teaching staff leading to potential conflicts between parents and professionals. Challenges also exist around obtaining and implementing EHCPs and fighting for a child's rights. Using EAL often increases the difficulties, as parents do not know what they or the child is entitled to and where to access help.

Barriers are starting to break down with more awareness of ASD, such as in Pakistan and through the GAPH initiative, but there is still much that could be done through new government strategies globally. In the UK, there are initiatives taking shape such as greater ASD training for health professionals and teachers, and reduced waiting times for ASD assessment (DfE, 2016; Snug, 2019; Earnshaw, 2019). Even though these are small steps, societies are moving in the right direction towards a better future for parents who care for a child with ASD and who use EAL.

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APPENDIX 1

Participant name	Location of interview	Other persons present
Fatima	Telephone – both researcher and participant in their own home	One child with ASD in participant's home
Mishti	Telephone – both researcher and participant in their own home	None
Chen	Café midway between homes of the researcher and participant. A secluded area was chosen with no other customers	None
Jamil	Telephone – both researcher and participant in their own home	None
Aleena	Participant's home	Participant's husband (see below) and one child with ASD
Marwan	Participant's home	Participant's wife (see above) and one child with ASD
Nina	Telephone – both researcher and participant in their own home	One child with ASD

APPENDIX 2

My Support Plan

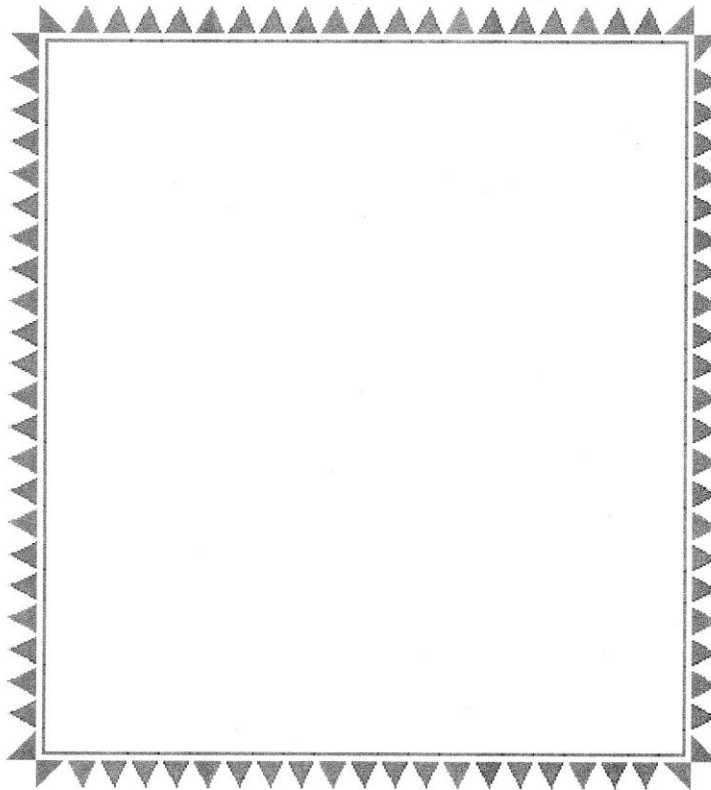
My name is.....

I am known as.....

My date of birth is.....

My school/setting is.....

Current photo of me



My Support Plan: Number Date.....

Date of 1 st review (R1):	
Date of 2 nd review (R2):	
Date of 3 rd review:	

School logo

Introduction to My Support Plan

This is My Support Plan. Included in my plan is information on;

- what is important to me and to my parents, including our goals and aspirations for the future;
- my strengths, my special educational needs (SEN) and my health and social care needs which relate to my SEN;
- the outcomes which will help me to move towards my goals and aspirations;
- the support given to me to help me to make progress towards my outcomes.

My plan should be a useful working plan for those involved in supporting me, and should actively promote co-ordinated support for me and my family so that I can make progress.

I might already have other plans in place such as (please tick as appropriate):-

- Team around the Family (TAF) Plan
- Child in Need Plan
- Child Protection Plan
- Personal Education Plan (PEP)
- Looked After Child Care Plan
- Health Care Plan

Please gain consent of Parent/Carer when using information from plans listed above.

Signed by parent/carers.....

Please see attached 'My Support Plan - Information & Guidance' for further information on aligning My Support Plan with existing plans, and how to act on information which indicates that a child/young person and their family may benefit from further support.

Contents

Section 1: About me

- my profile, my story, my family and my parents/carers views

Section 2: My special educational needs

Section 3: My health needs which relate to my special educational needs

Section 4: My social care needs which relate to my special educational needs

Section 5: Outcomes and provision

Section 6: Reviewing My Support Plan

Section 7: Appendices

Section 1: About me

a) my profile

My profile has been written by:

- Me Me with help from.....

When and how I communicate best, and what help I need

How information and choice need to be presented to me to help me make decisions

What people like and admire about me

-
-
-

What I enjoy doing and what I do well

In school/setting:

-
-
-

Out of school/setting:

-
-
-

What is important to me now

-
-
-

What are the things that aren't working so well for me at the moment

-
-
-

What would make things better for me

-
-
-

What are my goals and aspirations for the future –

Short term - the next 6-12 months

-
-
-

Long term - what I want for my future beyond next year and 'when I am an adult'

-
-
-

Section 1: About me

b) my story (background information)

My story has been written by: My parent My carer Me

with help from.....

Growing up

-
-
-

People involved in helping and supporting me

-
-
-

How do I feel when I am at school/setting and how do I feel and behave when I come home from school/setting

-
-
-

Any other things which are important for you to know about me

-
-
-

Section 1: About me

c) my family

My family has been written by: My parent My carer Me

with help from.....

My family at home / extended family

-
-
-

Wider community connections

-
-
-

Times or days or barriers that make it difficult for me or my family to attend appointments or to meet professionals

-
-
-

Any other things which are important for you to know about my family

Section 1: About me

d) my parents/carers views

Written by: My parent My carer

with help from.....

What is important for my child now

-
-
-

What is not working so well for my child at the moment

-
-
-

What would make things better for my child

-
-
-

What are my goals and aspirations for my child

Short term - the next 6-12 months

-
-
-

Long term - what I want for my child's future beyond next year and 'when they are an adult'

Section 2: My special educational needs

My strengths and my special educational needs are described by my family, education, health and care services. Their assessments are listed at the end of My Support Plan.

A summary of my needs

Cognition and Learning

-
-
-

Communication and Interaction

-
-
-

Social and Emotional

-
-
-

Sensory and/or Physical

-
-
-

Preparing for key transitions and/or preparing for adulthood

-
-
-

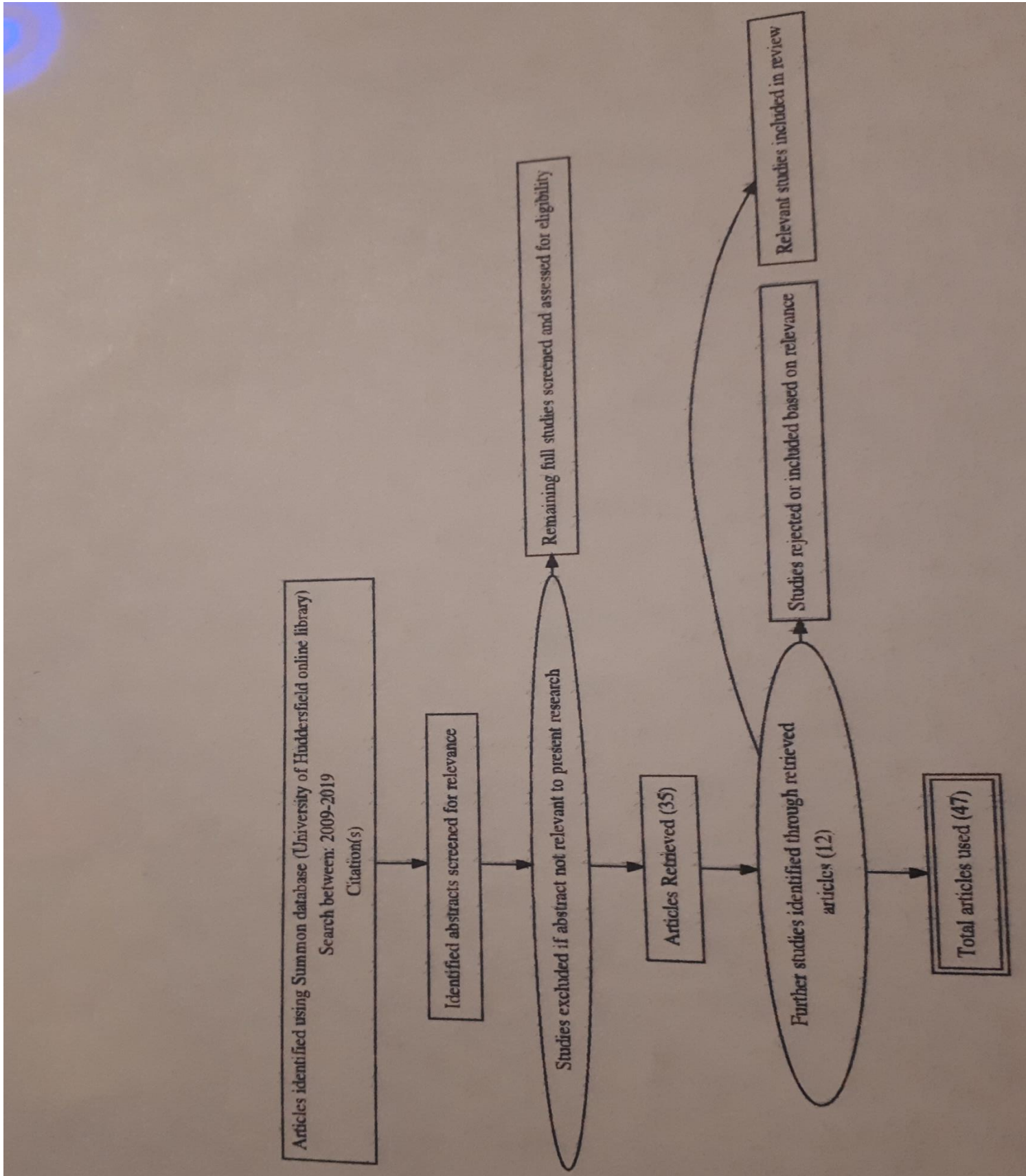
Section 3: My health needs which relate to my special educational needs

Section 4: My social care needs which relate to my special educational needs

Section 5: Outcomes and provision				Supported by		
My Outcomes:-				Education	Health	Social Care
Explanatory note	<p><i>The area(s) of my needs this outcome will address:</i></p> <p><i>(eg: Cognition & Learning, Communication & Interaction, Social and Emotional, Sensory and Physical, Preparing for key transitions/preparing for adulthood, Health needs, Social Care needs or more than one area of need – Cognition and Learning/Communication and Interaction, Sensory and/or Physical/Health needs)</i></p>					
<i>(Add or delete outcome boxes as appropriate)</i>	<p><i>Use wording which allows the outcomes to be measurable (SMART):-</i></p> <p><i>ie. By the end of key stage (Early Years Foundation Stage (EYFS)/KS1/KS2/KS3/KS4) && will be able to.....</i></p>					
Outcome 1	<p><i>The area(s) of my needs this outcome will address.....</i></p> <p><i>By the end of key stage..... will be able to.....</i></p>					
Outcome 2						
Outcome 3						
Outcome 4						
Outcome 5						
Outcome 6						
Outcome 7						

APPENDIX 3

PRISMA detailing work undertaken to compile Literature Review



APPENDIX 4

Participant demographics

Participant number	Participant gender	Child gender	Age of child at diagnosis	Age of child at interview	Parent's first language	Parent's country of birth	Religion
1	M	M	2 yrs 6 mths	22	Urdu	Pakistan	Muslim
2	F	M	3 yrs	3	Urdu	Pakistan	Muslim
3	F	M	3 yrs 9 mths	4	Mandarin Chinese	China	Christian
4	M	M	4 yrs	5	Arabic/ French	Algeria	Muslim
5	F	M	4 yrs	5	Arabic/ French	Algeria	Muslim
6	F	M	3 yrs	12	Malayalam	India	Muslim
7	F	M	2 yrs 8 mths	3	Urdu	Pakistan	Muslim

M - male

F - female

APPENDIX 5

List of low income countries according to World Bank (2017)

Afghanistan	Benin
Burkina Faso	Burundi
Central African Republic	Chad
Comoros	Democratic Republic of Congo
Eritrea	Ethiopia
Gambia	Guinea
Guinea-Bissau	Haiti
Korea	Liberia
Madagascar	Malawi
Mali	Mozambique
Nepal	Niger
Rwanda	Senegal
Sierra Leone	Somalia
South Sudan	Syrian Arab Republic
Tajikistan	Tanzania
Togo	Uganda
Yemen	Zimbabwe

List of low middle income countries according to World Bank (2017)

Angola	Armenia
Bangladesh	Bhutan
Bolivia	Cabo Verde
Cambodia	Cameroon
Congo	Cote D'Ivoire
Djibouti	Egypt
El Salvador	Georgia
Ghana	Guatemala
Honduras	India
Indonesia	Jordan
Kenya	Kiribati
Kosovo	Kyrgyz Republic
Lao Pdr	Lesotho
Mauritania	Micronesia
Moldova	Mongolia
Morocco	Myanmar
Nicaragua	Nigeria
Pakistan	Papua New Guinea
Philippines	Sao Tome and Principe
Solomon Islands	Sri Lanka
Sudan	Swaziland
Syrian Arab Republic	Tajikistan
Timor Leste	Tunisia
Ukraine	Uzbekistan
Vanuatu	Vietnam
West Bank and Gaza	Yemen
Zambia	

List of upper middle income countries according to World Bank (2017)

Albania	Algeria
American Samoa	Argentina
Azerbaijan	Belarus
Belize	Bosnia and Herzegovina
Botswana	Brazil
Bulgaria	China
Colombia	Costa Rica
Croatia	Cuba
Dominica	Dominican Republic
Ecuador	Equatorial Guinea
Fiji	Gabon
Grenada	Guyana
Iran	Iraq
Jamaica	Kazakhstan
Lebanon	Libya
Macedonia	Malaysia
Maldives	Marshall Islands
Mauritius	Mexico
Montenegro	Namibia
Nauru	Panama
Paraguay	Peru
Romania	Russian Federation
Samoa	Serbia
South Africa	St Lucia
St Vincent and the Grenadines	Suriname
Thailand	Tonga
Turkey	Turkmenistan
Tuvalu	Venezuela

APPENDIX 6

Interview Schedule

PART 1 *We will start with a few questions about you and your child's diagnosis*

1. Participant number:
2. Name:
Remind participants that this will NOT be used in the study and it is only for purposes of identifying data if they withdraw.
3. Country of birth:
4. Religion:
5. First language:
6. Age of child:
7. Is your child: M F?
8. How many children do you have?
9. Do any of your other children have ASD or other learning difficulties?

PART 2 *I would like to ask you now to think back to your child's diagnosis*

10. At what age was he/she diagnosed?
11. How long did you wait for a diagnosis?
12. Was diagnosis given in the UK or other (***specify where***)?
12a. If 'other' has there been a different diagnosis in the UK?
13. Who was the diagnosis given by (***doctor, psychologist etc***)?
14. What was the diagnosis given to your child?
15. Did you have an interpreter at the diagnosis?
16. If no, would this have helped?
17. Did you fully understand the information given to you about ASD?
18. What would have helped you understand the diagnosis more?
19. Can you recall your feelings or emotions? What were they?
20. What does your religion say about children with additional needs/disabilities?
21. Has your religion been a factor in accepting ASD and moving forwards? (***giving you strength etc***)
22. How did you feel about the future when you left the appointment? (***scared, confident, reassured, upset etc***)
23. What information was given to you about the condition? ***NAS leaflet (or similar from native country), telephone numbers etc, local organisations/support groups***
- 23a. If any information was received, was it useful? Why was it or why wasn't it?

24. Was any information provided in your first language? If yes, what?

24a. If no, were you told where you could access material in your native language?

PART 3

25. Can you tell me how your child's behaviour is affected by ASD?

26. What help do they need on a daily basis?

27. What services they do they receive to help with their ASD and in what way do these services help?

28. Can you explain how ASD has impacted on your family please?

29. Do you think your child's school understand your child's needs?

PART 4

30. Had you heard of ASD before your child was diagnosed?

31. Does ASD exist in your birth country that you know of? What can you tell me about children with additional needs from your country and how they are treated? **(Stigma, shame, discussed at all?)**

32. Do you think doctors in your native country know enough about ASD?

The National Autistic Society offers a telephone interpretation service to foreign language speakers.

33. Do you know about this service?

34. Have you used this service? **If 'yes' move to number 36**

To use this service you need to call a number and tell the operator which language you require.

35. Would you be confident to use this service? ***Expand***

36. If you need information on ASD, where do you go? ***(Doctor, SENCo, website etc)***

37. Would you prefer to have information in your own language or in English? Why?

38. Do you feel confident that your doctor can answer your questions about ASD? ***Expand***

39. How do you think services could be improved for families like yours, where English is not the first language?

Is there anything you would like to add that you feel is relevant to this topic?

Advise the interview is at an end and ask if there is anything participants would like clarified. If not, thank them for their time and reiterate the last date for withdrawal is in TWO WEEKS. End.

APPENDIX 7

INFORMATION SHEET FOR PARENTS CARING FOR A CHILD WITH AUTISM SPECTRUM DISORDER (ASD) WHO USE ENGLISH AS AN ADDITIONAL LANGUAGE: THEIR EXPERIENCES OF HEALTH AND EDUCATION, AND SOCIETAL RESPONSES

PARTICIPANTS RECRUITED VIA SCHOOLS

You are being invited to take part in a study concerning families who have children diagnosed with Autism Spectrum Disorder (ASD). Before you decide to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

What is the study about?

The purpose of this study is to discover families' experiences of parenting children with ASD. I am interested to find out the information and help you received from your doctor and more specialist agencies such as the National Autistic Society (NAS). My research will consider how well informed you were at each stage of the diagnostic process and if you think you could have been provided with more information at any time. I am interested to find out your views on the services available to you and how services could be improved to make things easier for you. Key areas for consideration are:

- Parental understanding of ASD
- Whether cultural beliefs have an impact on this understanding
- Whether families' linguistic needs are met in the UK in terms of help available
- How well ASD is understood in other countries
- How services providing information on ASD can be improved for users of English as an additional language (EAL)

Why I have been approached?

You have been asked to participate because you are a parent of a child diagnosed with ASD and your first language is not English. However, you must be able to speak and understand English well enough to be interviewed. The requirement will be for you to take part in a spoken interview, with me, for approximately one hour, talking about your experiences of ASD.

Do I have to take part?

It is your decision whether or not you take part. If you decide to take part, you will be asked to sign a consent form. You will be provided with an Amazon gift voucher to the value of £10 as a thank you for taking part. You will be free to withdraw from the study without giving a reason. A decision to withdraw, or a decision not to take part, will not affect you in any way. If you choose to withdraw, any data collected will be destroyed and you will not be at any disadvantage. The last date for withdrawing your consent and leaving the study is **two weeks after the date we meet**.

You should be aware that I will be asking personal questions about your experiences with ASD and you may find some of the questions upsetting. I sincerely hope this will not be the case, as all matters will be dealt with sensitively, but if this should occur you may ask to stop the interview at any time. If you wish to speak to somebody about your interview experience and feel that you need extra support, you should

contact your school support service or the National Autistic Society (NAS) helpline on 0808 800 4104. The Helpline opening hours are: Monday-Thursday 10am-4pm, Friday 9am-3pm (excluding Bank holidays). You may also email the NAS Supporter Team using this email address: supportercare@nas.org.uk.

What will I need to do?

If you agree to take part in the research, you will be asked to attend an informal interview at your child's school at a mutually convenient time. I will ask you questions and make notes of your answers. The interview will be recorded digitally using a machine. I may telephone you in the weeks after your interview for further explanation of any information provided in your interview. The interview should last approximately one hour.

Will my identity be disclosed?

All information disclosed within the interview will be kept confidential, unless you indicate that you or anyone else is at risk of serious harm, in which case I would need to pass this information to my university supervisor. Safeguarding is everyone's concern and if, in the rare event, it is decided that somebody is at risk of harm, the safeguarding team at your child's school may be notified. The names of you and your family will not be used in any research and your identities will be kept anonymous at all times. The name of the school will not be identified in the research.

What will happen to the information?

All information collected from you during this research will be kept secure on the university's own computer systems, which are password protected, in accordance with their data protection regulations. The researcher will not store any information obtained at the interview at her home, once it is saved on the university system. Any identifying material, such as names, will be removed in order to ensure anonymity. It is anticipated that the research may, at some point, be published in a journal or report. However, should this happen, your anonymity will be ensured, although it may be necessary to use your words in the presentation of the findings and your permission for this is included in the consent form.

Who can I contact for further information?

If you require any further information about the research, please contact me on:

Name Jessica Crowther

E-mail ANONYMISED

Alternatively you may contact my supervisor if you are unsure of any points or wish to ask any questions:

Contact name:)

Email:) DETAILS

Telephone:) ANONYMISED

Address:)

APPENDIX 8

INFORMATION SHEET FOR PARENTS CARING FOR A CHILD WITH AUTISM SPECTRUM DISORDER (ASD) WHO USE ENGLISH AS AN ADDITIONAL LANGUAGE: THEIR EXPERIENCES OF HEALTH AND EDUCATION, AND SOCIETAL RESPONSES

PARTICIPANTS RECRUITED VIA ONLINE PLATFORMS

You are being invited to take part in a study concerning families who have children diagnosed with Autism Spectrum Disorder (ASD). Before you decide to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Please do not hesitate to ask if there is anything that is not clear, or if you would like more information.

This research study is being advertised on Facebook and Twitter using the National Autistic Society's research channels. You may contact me via direct message using either of these pages:

Facebook: ANONYMISED

Twitter: ANONYMISED

Both of the above pages are used only for the purposes of this study.

What is the study about?

The purpose of this study is to discover families' experiences of parenting children with ASD and the support they receive from services. I am interested to find out about the information and help you received from your doctor and more specialist agencies such as the National Autistic Society (NAS) or any other groups, either in this country or any other country. My research will consider how well informed you were regarding your child's diagnosis and if you think you could have been provided with more information at any time. I am interested to find out your views on the services available to you and how services could be improved to make things easier for you. Key areas for consideration are:

- Parental understanding of ASD
- Whether cultural beliefs have an impact on this understanding
- Whether families' linguistic needs are met in the UK in terms of help available
- How well ASD is understood in other countries
- How services providing information on ASD can be improved for users of English as an additional language (EAL)

Why me?

You are free to participate in the study if you can say YES to the following:

- I am a parent of a child diagnosed with ASD
- My first language is not English and I am from a developing country.
- You must be able to speak and understand English well enough to be interviewed

The requirement will be for you to take part in a spoken interview, with me, for approximately 60 minutes, talking about your experiences of ASD.

Do I have to take part?

It is your decision whether or not you take part. If you decide to take part, you will be asked to consent to being part of the study and will need to understand what the study involves and how your answers will be used in the study. Before the interview I will firstly ask you which country you were born in. The study is looking for people born in a wide range of countries. If your country of birth is NOT part of the study's requirements, you will not need to take any further part in the research.

If you are interviewed, you will be provided with a £10 Amazon gift voucher as a thank you for taking part. You will be free to withdraw from the study and without giving a reason at any point. A decision to withdraw, or a decision not to take part, will not affect you in any way. If you choose to withdraw, any data collected will be destroyed and you will not be at any disadvantage. The last date for withdrawing your consent and leaving the study is **two weeks after the interview**.

You should be aware that I will be asking personal questions about your experiences with ASD and you may find some of the questions upsetting. I sincerely hope this will not be the case, as all matters will be dealt with sensitively, but if this should occur you may ask to stop the interview at any time. If you wish to speak to somebody about your interview experience and feel that you need extra support, you should contact the National Autistic Society (NAS) helpline on 0808 800 4104.

The helpline opening hours are: Monday-Thursday 10am-4pm, Friday 9am-3pm (excluding Bank holidays). You may also email the NAS Supporter Team using this email address: [**supportercare@nas.org.uk**](mailto:supportercare@nas.org.uk).

What will I need to do?

If you agree to take part in the research, you will be asked to take part in a telephone interview at a mutually convenient time. I will ask you questions and record your answers using a machine. The interview should last approximately one hour. We may hold a face to face interview depending on your location, if you agree to this. All interviews will be recorded.

Will my identity be disclosed?

All information disclosed within the interview will be kept confidential, unless you indicate that you or anyone else is at risk of serious harm, in which case I would need to pass this information to my university supervisor. Safeguarding is everyone's concern and if, in the rare event, it is decided that somebody is at risk of harm, the local safeguarding board may be notified. The names of you and your family will not be used in any research report and your identity will be kept anonymous at all times. Pseudonyms (false names) will be used to refer to you and anyone you mention, such as a child or family member.

What will happen to the information?

All information collected from you during this research will be kept secure on the university's own computer systems, which are password protected, in accordance with their data protection regulations and current GDPR (General Data Protection Regulation) guidelines. The researcher will not store any information obtained from the interview in her home, once it is saved on the university system. Any identifying material, such as names, will be removed or given a pseudonym in order to ensure anonymity. It is anticipated that the research may, at some point, be published in a journal or report. However, should this happen, your anonymity will be ensured, although it may be necessary to use your words in the presentation of the findings and your permission for this is included in the consent form.

Who can I contact for further information?

If you require any further information about the research, please contact me on:

E-mail ANONYMISED

Or use direct messaging on Twitter or Facebook.

Alternatively you may contact my supervisor if you wish to ask any questions or to verify who I am:

Contact name:)

Email:) ANONYMISED

Telephone:) FOR THIS PAPER

Address:)

APPENDIX 9

Title of Research Project: Parents caring for a child with Autism Spectrum Disorder (ASD) who use English as an additional language: their experiences of health and education, and societal responses.

It is important that you understand and sign the consent form. Your contribution to this research is entirely voluntary and you are not obliged in any way to participate.

- I have been fully informed of the nature and aims of this research as outlined in the information sheet.
- I consent to taking part in this study.
- I understand that I have the right to withdraw from the research without giving any reason. I understand the last date for withdrawal is two weeks from the date of my interview.
- I give permission for my words to be quoted anonymously.
- I understand that the information collected will be kept in secure conditions for a period of ten years at the University of Huddersfield.
- I understand that no person other than the researcher will have access to the answers I provide in interviews and that all answers are anonymous.
- I understand that a breach of confidence may occur if the researcher feels she receives information that means me or another person may be at risk of harm. In this case she will discuss the matter with her university supervisor. If the supervisor agrees that a breach is required, details may be passed to a safeguarding team for further action.
- I understand that my identity will be protected by the use of pseudonym and that no written information that could lead to my being identified will be used in any report.
- I understand that the interview will be recorded digitally and I consent to this taking place. This data will be deleted once it is transcribed and uploaded to the university server.

I understand that all information provided by me at interview will be stored on password protected university computer systems, in accordance with the university's data protection regulations. This includes any digitally recorded data. No information gained at interview will be stored at the researcher's home once it is uploaded onto the university's systems.

If you are satisfied that you understand the information and are happy to take part in this project, please put a tick in the box next to each sentence and print and sign below.

Signature of participant

Print name

Date

Signature of researcher

Print name

Date

APPENDIX 10

Coding relating to questions posed at interview. These are the most common occurrences across all transcripts.

1. Nobody can really diagnose ASD in my native country and/or maybe in bigger cities only
2. My child is (seen as) slow
3. I was happy to receive a diagnosis for my child
4. I did not know where to go after the diagnosis
5. Post-diagnosis we still did not understand ASD
6. We felt confused by the diagnosis
7. Our family/friends do not understand ASD/we receive little or no support from them
8. I do not know where on the spectrum my child fits
9. At diagnosis I felt a huge amount of emotions and/or distress
10. I feel there is a lack of understanding in public
11. My religion helps provide strength/gives me answers
12. The UK is better for help than my native country
13. ASD has caused stress in my marriage
14. My diagnosed child has little or no sibling relationship
15. I have little or zero verbal communications with my child diagnosed with ASD
16. I have had to change my work commitments to care for my child
17. I have kept information from my partner to not distress them
18. My child's school does not understand his needs
19. In my native country my child would probably be institutionalised
20. I have received unpleasant comments from the public about my child's behaviour
21. I do not trust my GP for answers relating to ASD, the condition is too vast for the GP to know everything
22. There is no obvious disability presented to others so they think my child is ok
23. I waited 6months or more for an ASD assessment for my child
24. I was not offered an interpreter for our diagnosis appointment. We should have asked for one
25. I was in denial at the diagnosis
26. I would have preferred in hindsight to have the diagnosis, let it sink in then have an opportunity to ask questions maybe a week or so later
27. I have isolated myself from family/others as a result of my child's ASD
28. I feel my child's school/nursery understands and 'gets it'
29. I ask Google for help in the first instance if I have questions about ASD
30. It would help to have received written bilingual information at the diagnosis

List of occurrences.

Place a ✓ each time the code is mentioned in transcript.

(numbers refer to participants)

1	✓ ¹	✓ ³	✓ ⁵	✓ ⁴					
2	✓ ¹	✓ ⁵	✓ ⁷	✓ ⁸					
3	✓ ¹	✓ ³	✓ ⁴	✓ ⁹					
4	✓ ¹	✓ ³	✓ ⁵	✓ ⁶	✓ ⁷				
5	✓ ¹	✓ ³	✓ ⁷	✓ ⁸					
6	✓ ¹	✓ ³	✓ ⁵	✓ ⁷					
7	✓ ¹	✓ ³	✓ ⁵	✓ ⁴	✓ ⁷	✓ ⁹			
8	✓ ¹	✓ ³							
9	✓ ¹	✓ ³	✓ ⁵	✓ ⁷	✓ ⁸	✓ ¹⁰			
10	✓ ¹	✓ ³	✓ ⁵	✓ ⁸					
11	✓ ¹	✓ ³	✓ ⁵	✓ ⁶	✓ ⁴	✓ ⁷	✓ ⁸	✓ ¹⁰	
12	✓ ¹	✓ ⁴	✓ ⁷						
13	✓ ¹	✓ ³	✓ ⁵	✓ ⁶	✓ ⁴				
14	✓ ¹	✓ ⁸							
15	✓ ¹	✓ ⁵	✓ ⁶						
16	✓ ¹	✓ ⁴	✓ ⁸	✓ ¹⁰					
17	✓ ¹								
18	✓ ¹	✓ ⁴	✓ ⁸						
19	✓ ¹	✓ ⁷							
20	✓ ¹	✓ ³	✓ ⁵	✓ ⁷	✓ ¹⁰				
21	✓ ¹	✓ ⁷	✓ ⁴	✓ ⁸	✓ ⁹	✓ ¹⁰			
22	✓ ¹	✓ ³	✓ ⁹						
23	✓ ³	✓ ¹⁰							
24	✓ ³								
25	✓ ¹	✓ ³	✓ ⁵	✓ ⁴	✓ ⁷	✓ ⁸	✓ ¹⁰		
26	✓ ³								
27	✓ ³	✓ ⁵	✓ ¹⁰						
28	✓ ³	✓ ⁵	✓ ⁶	✓ ⁴	✓ ⁷	✓ ¹⁰			
29	✓ ¹	✓ ³	✓ ⁷	✓ ⁴	✓ ⁵				
30	✓ ³	✓ ⁷							

APPENDIX 11

EXAMPLE 1

N: Yeah because he has to take care of my son as well and most of the time I feel like, I mean I do leave my son with him, but I feel sometimes he doesn't understand things, like he has not been able to go to meetings, to understand all of that, so that has made it quite hard and having to explain it all to him, but you see when I am explaining it all to him it is different to when the doctor would explain things.

Me: Does your husband have a good understanding now of things and where your son is at?

N: Not really, I have asked if somebody could maybe meet him and speak to him and explain things to him because, you know, he says he understands but I think really he is not ready to accept it as he has not had a professional explaining it and I think that they (SALT) said a while ago they would try and arrange an interpreter for him, but nobody has got back to me. She said she was going to speak to his HV to arrange all this, but it has been a while and my husband was happy to do that, but we have not heard anything so I am hoping to give them a call and see what has happened.

19: I think it was hard even though I think I knew, but, let me go back a bit, I was the one who brought it up when he was younger and I am the one who said I think he is on the spectrum. I mentioned it to his neurologist and his doctor and the paediatrician but it took a while for things to start going, but I knew a long time ago, so I think, why was I not ok when they told me because I should have been as I already knew. It was really hard, even though I already knew in my heart, it was just when somebody says it, the confirmation was really hard. Because he has other needs as well, he has a heart condition, the tracheotomy, 9 or 10 surgeries, he has had quite a lot going on. It was really hard and because I was on my own as well. I think that is why I said give him more time because, you know, I want what is right for him and what if later on, now he has had his tracheotomy removed, what if he can go to nursery more, but I think they were all just excuses because I didn't really want to accept it. It wasn't until I got home.

Me: Did you have any thoughts at that time about the future re: education etc?

N: Yeah definitely, I thought is he going to get worse, is he going to be able to go to mainstream school, how is he going to cope with making friends, you know, I think you start thinking everything, is he going to be ok when he is older, is he going to be able to get a job, I mean he is only 3 but, just all these thoughts because before I had thought, is he going to be able to breathe properly, and now that that is ok I am thinking is he ever going to talk, I have had all these thoughts. I think that is why, I rang them a couple of days before this meeting and I said, have you got a diagnosis for him, because.. can you tell me beforehand so I can prepare myself? I think that would have been helpful if they had told me before and then I had gone into the meeting with questions rather than just a shock.

20: For me it is not anything to do with religion, it is more cultural. It depends which country you come from I think. For me, as a Muslim, there is no stigma attached, it is because of the culture that we come from, the kind of thinking that people have.

EXAMPLE 2

Me: Ok so you mentioned that you had an appointment with your GP so was the GP the first person you raised your concerns with?

J: Uh, no we um, initially um we had um, ok, at 2 and a half years he came to Pakistan and that was just about the time when the diagnosis happened, however, um, we did have some um inclination that there was something not right and uh in Pakistan we tried to contact a number of paediatricians and doctors and apart from one of them, um none could actually diagnose him as autistic, they just kept telling us that uh maybe he was just slow or um you know he would come out of it, he is still a young baby boy and yep. There was a doctor in Pakistan who did sort of diagnose him as autistic only he wasn't completely sure. This was at the same time as he moved to the UK and um then I contacted my GP for an appointment with the paediatrician and we had an hour and a half appt with the paediatrician at the end of which she told us the diagnosis.

Me: So the official diagnosis was received in the UK, only you did speak to a doctor in Pakistan who said that autism was a possibility is that correct, just to clarify?

J: That is correct yes.

Me: Ok, so, question 13, the diagnosis was given by a doctor or a paediatrician, can you remember which in particular?

J: I don't exactly remember, I would probably have some documents on that. It was at the local hospital.

Me: So what was the actual diagnosis for question 14, given to him? Was it just autism, did they say there were any other difficulties presenting or was it just solely autism?

J: I think it was solely autism.

Me: Q15, did you have an interpreter at the appt? Did you want one, did you ask if you could have one?

J: We were asked if we wanted one but we didn't need one.

Me: Number 17, did you fully understand the info given to you at the apt about your son's condition?

J: Um, I think yes we um, ok we weren't really clear on what autism was at that point so it was a bit of a learning curve then um but we, we were happy that there was a diagnosis and having gone through what we had gone through in Pakistan, um we were happy there was a diagnosis and I think at that point once we did receive the diagnosis, we weren't exactly sure how things, um, would pan out going forward, so about you know special schools or medication or treatment or what would exactly happen, although the, I remember the doctor did tell us that she would, someone would prepare a report and then she would get an OT to come in.