Experiences of Post-Diagnostic Support for Children and Young People on the Autism Spectrum

Laurence Hasson

June 2019

Thesis submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctorate in Clinical Psychology

Acknowledgements

Contents Table

List of Figures

List of Tables

Abstract

There is considerable research about individuals' negative experiences of the process of obtaining an autism diagnosis (Crane et al., 2018), however less is known about experiences of post-diagnostic support. A systematic review of the literature showed a gap for research focused on people's experiences of post-diagnostic support for children and young people on the autism spectrum. A qualitative approach was taken, and an inductive thematic analysis was chosen to investigate this topic. Eight parents, eleven school staff, and four young people on the autism spectrum, all from one London borough, were interviewed about their experiences, either individually or in a focus group. Thematic analysis of the data revealed five main themes: a lack of knowledge and understanding about autism, a system overwhelmed by unmet needs, the impact of communication on relationships, negative impacts on quality of life, and hope for the future (developing the system to make it work). The overwhelming finding was of a significant lack of post-diagnostic support, and a system poorly designed to support children on the autism spectrum and their families. Findings are discussed in the context of the ecological systems model (Bronfenbrenner, 1992), and in relation to previous research. Important clinical implications and recommendations are presented with the aim of improving post-diagnostic support for children and young people on the autism spectrum, and their families, in the future.

1. Introduction and Literature Review

1.1. Introduction and Chapter Overview

This research project used thematic analysis to explore people's experiences of post-diagnostic support (PDS) for children and young people on the autism spectrum.[1] This research took place in a London borough, and involved children and young people on the autism spectrum, parents of children on the autism spectrum, and the school staff who worked with them. This research explored people's experiences of all aspects of post-diagnostic support, with a focus on educational support.

The introduction presents the epistemological position of this research, and my relationship to this topic. Key terms and concepts used in this research are defined, and the relevant political, educational and social contexts around support for children and young people on the autism spectrum are discussed. This chapter then presents a systematic literature review on post-diagnostic support for people on the autism spectrum, highlighting the current gap in the research literature and the rationale for the current study. The chapter ends with a statement of the research aims and questions, as derived from the preceding rationale.

Some of my personal reflections are integrated throughout this thesis (in italics), detailing my reflexive and reflective journey through designing, gathering and analysing the data for this research (Mann, 2016). More excerpts from my reflective journal are included in appendix 6.1.

---

[1] There is considerable debate around the terminology used with regard to individuals on the autism spectrum, which is addressed in section 1.4.3.3.

1.2.   Epistemological position

It is important to acknowledge the variety of different epistemological positions, on a broad spectrum from positivism to constructivism, and the potential validity of each position in certain contexts. I approached this project from a critical realist perspective, a post-positivist position which draws on components from both positivist and constructivist epistemological approaches (Denzin & Lincoln, 2011). Critical realism does not deny the existence of a real world which one can endeavour to understand, and seeks theories which help one get closer to reality; theories which help identify potential causal mechanisms underlying social phenomena. Fletcher (2017, p.5) stated that "the ability to engage in explanation and causal analysis… makes critical realism useful for analysing social problems and suggesting solutions for social change" in the form of practical policy recommendations. Fletcher also highlighted the suitability of a qualitative research method to a critical realist perspective, which made it an appropriate choice for this project (this will be discussed in more detail later).

There is some debate in the literature about what critical realism is; while some have stated that it is a philosophy of science (e.g. Brown, Fleetwood, & Roberts, 2003), others have argued that it is a 'meta-theoretical position' (Archer et al., 2016), with a key feature being that it is post-positivist. Whilst there is some variation in the literature regarding critical realism, a fundamental tenet of critical realism is that it deviates from positivism by refuting the problematic reduction of reality to empirical truths (Bhaskar, 1998). Critical realism acknowledges that structures have real causal mechanisms which exist and which impact on events which occur, however our perception of these events is "always mediated through the filter of human experience and interpretation" (Fletcher, 2017, p.5). Willig (2013, p.60) described critical realism as "a perspective that combines the realist ambition

to gain a better understanding of what is 'really' going on in the world with the acknowledgment that the data the researcher gathers may not provide direct access to this reality". As there is some variation in the literature regarding different critical realist positions, I will now describe my interpretation of critical realism and the stance in which I have positioned myself throughout this project.

My interpretation of critical realism is that there is a reality, but our experiences shape our interpretation of this reality; there is not a 'truth' to be found and presented, rather it is shaped by the lenses through which we view it. Our view of reality may be shaped by many things, including our personal experiences, wider societal narratives, and possible contextual expectations (for example, one's hypotheses in a research project). Unlike a social constructionist approach, my critical realist position is that reality is not entirely constructed through our social interactions, but our view of reality is shaped by the lenses through which we interpret it. In this position, therefore, it is very important to acknowledge what we bring to our research and the interpretation of data. When interpreting data collected from participants, I did not present a truth or reality that is inherent in the data, but my own view of that reality, shaped by the various lenses through which I viewed it. This is what separates my approach of critical realism from that of 'naïve realism', where the researcher believes they are simply 'giving voice' to their participants (Braun & Clarke, 2006).

There are many different lenses which may affect the way we view and interpret reality, including social, cultural, political, historical, economic, ethnic, gender, age, ability and many others. As I have reported results and findings based on qualitative data recorded from participants, it is essential that I have remained explicit about the interpretative nature of my account, that is, that I have presented my own interpretation of my participants'

experiences. Remaining reflexive and reflective throughout the process, and including and exploring this throughout this write-up, demonstrates how I adhered to my critical realist position during this project, especially when it came to the interpretation of data.

1.3.   My relationship to the topic

My passion for working with individuals on the autism spectrum began with my first experience of supporting a child with severe autism over twelve years ago. This overwhelmingly positive experience had a profound impact on me, and my desire to work with this client group has never faded. It is difficult to explain why I was so drawn to this type of work, as much of the work within clinical psychology has many of the same positive features as this experience – that of being rewarding, challenging, varied and ultimately fulfilling. However, when the opportunity arose to conduct the biggest piece of research of my life so far, I knew my true passion would be to produce a piece of research that would help improve the lives of children on the autism spectrum. I consider myself lucky that I was able to develop such a piece of research, and I hope that my passion for this topic is evident in the coming pages.

1.4.   Definitions of key concepts

1.4.1.   Children and Young People

The term children and young people refers to anyone under the age of 18. In the UK, 'young people' may be used to refer to 16 and 17 year olds who, like adults, are presumed to have sufficient capacity to make decisions about their own treatment (General Medical Council, 2018; NHS UK, 2016), whilst 'children' may be used to refer to those under the age

of 16, although there are no official or strict definitions around this and clinicians should use

their clinical judgement.

1.4.2. Post-Diagnostic Support

For the purposes of the current study, post-diagnostic support refers to the provision

of support to an individual (and often their family) *after* a diagnosis has been received.

Within this, it is important to consider the definition of 'support', which may encompass a

number of different aspects including: the provision of information (e.g. about one's

diagnosis), direct provision of services (e.g. therapy/counselling) or signposting to services,

financial support or help applying for financial support, additional practical help (e.g.

educational support such as a TA), support for carers and families (e.g. respite), and help

accessing peer support groups.

The following sections explore autism and how people define it, which provides an

important context for thinking about post-diagnostic support for people with this diagnosis.

1.4.3. Autism

1.4.3.1.   History and Definition of Autism

Autism was first written about almost simultaneously by Kanner (1943) in the USA

and by Asperger (1944) in Germany. Both wrote about cases of children they had seen who

presented with similar 'syndromes' of features, including impairment of 'normal' social

interactions, difficulties with interpersonal communication, repetitive and stereotyped

behaviours (including echolalia), fear of loud noises, and an apparent lack of imagination, all in the context of seemingly normal physical development.

Wing and Gould's (1979) seminal 'triad of impairments' paper built on the work of Kanner and Asperger, as well as other previous research (e.g. Lotter, 1966), and classically characterised individuals on the autism spectrum as having 1) difficulties with social interaction, 2) difficulties with communication and imagination, and 3) restricted or repetitive behaviour. It was these three features, along with an absence of schizophrenic features and an onset before 30 months, which formed the definition of 'infantile autism' in the DSM-III in 1980 (American Psychiatric Association (APA), 1980). These criteria remained the fundamental criteria for what was called 'Autistic Disorder' in the DSM-IV (APA, 2000), classified under 'Pervasive Developmental Disorders'. The DSM-IV changed the required age of onset for autism to below 3 years.

The most recent publication, the DSM-5 (APA, 2013) made a number of significant changes to what they now refer to as 'Autism Spectrum Disorder' (ASD). The DSM-5 removed previous diagnoses including Asperger's Disorder and others and replaced them under the umbrella of Autism Spectrum Disorder. The most significant change in the DSM-5 was that difficulties with social interaction and difficulties with communication, two of the three elements of the classic triad of impairments, have been collapsed into one criteria, with the other criteria remaining restricted, repetitive patterns of behaviour. Some have argued that the reduction from the three diagnostic criteria in the DSM-IV to two criteria in the DSM-5 has resulted in a less well defined and more difficult to use system that may deny some individuals appropriate support (Wing, Gould, & Gillberg, 2011). There are concerns about how this will affect the provision of services for children with autism (Heasley, 2014), and others have stated that the new criteria are not appropriately sensitive to diagnosing

more 'high functioning' individuals (McPartland, Reichow, & Volkmar, 2012). Whilst the DSM-IV specified an onset under 3 years of age, the DSM-5 specifies that 'symptoms must be present in the early developmental period'. It is worth noting that the description of ASD in the new ICD-11 (World Health Organisation, 2018) has been similarly updated and is consistent with that of the DSM-5.

1.4.3.2.   Autism: Nature versus Nurture

Kanner (1943, p. 250) wrote "we must…assume that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people". Thus began the nature versus nurture argument within autism, which has been the subject of research for many years. Rimland (1964) continued the argument that autism has an innate organic and genetic basis, and during the 1960s faced opposition from Bettelheim (1967) who argued that autism may have a 'nurture' or environmental basis. Bettelheim wrote that autism was the result of 'emotionally cold parenting', a controversial hypothesis that blamed parents for causing autism in the way they raised their children. The nature-nurture debate continues today, with considerable neurophysiological and genetic research ongoing (e.g. Brandler et al., 2018; Constantino et al., 2017; Gesundheit & Rosenzweig, 2017) alongside conversations about the potential causal contributions of environmental factors (e.g. Hertz-Picciotto, Schmidt, & Krakowiak, 2018; Teague, Gray, Tonge, & Newman, 2017; Zhou & Yi, 2017). Whilst in recent years we have seen more attempts to combine both narratives into a single coherent account of causation, such an understanding seems many years away.

1.4.3.3.   Terminology used to refer to individuals on the autism spectrum

Usage of terminology is highly important, as the dominant language when talking with or about individuals can significantly impact on the identity of individuals, as well as the way society may come to view certain people. It is, therefore, essential to examine the considerable debate regarding the variety of different terminologies available when referring to individuals on the autism spectrum. A common theme within such debates is person-first language (e.g. 'a person with autism') versus identity-first language (e.g. 'an autistic person'). Some people strongly advocate for the use of person-first language (e.g. Blaska, 1993), claiming that it creates more positive identities, and helps to ensure that individuals are not defined by their disability. However, there is a substantial movement within the autism community to use what may be referred to as 'disability-first' or 'identity-first' terminology. Some argue that 'person-first language' may undermine the experiences of people who live with the disability, and furthermore ignore the possibility that someone may take pride in that aspect of their identity, rather than seeing it as a negativity (e.g. Brown, 2011). Sinclair (1999) prefers 'disability-first' language, arguing that an autistic person 'can never, and should never attempt to, be separated from their autism', and that, unlike person-first language, calling oneself 'an autistic person' does not imply that autism is inherently negative.

Kenny et al. (2016), in association with the National Autistic Society (NAS), surveyed 3,470 people in the UK including 502 "autistic adults" about their preferred terminology. Figure 1 (from Kenny et al., 2016, p.445) shows that, whilst professionals preferred the person-first terms "on the autism spectrum" and "person with autism", individuals with autism are divided between those who prefer "on the autism spectrum" and those who prefer the disability-first term "autistic". When asked to choose one term only, the term

"autistic" was the most highly chosen term among people with autism, with "on the autism spectrum" very narrowly behind. The research also showed that parents of people with autism preferred the term "has autism", followed by "on the autism spectrum". Qualitatively, people with autism tended to view autism as intrinsic to themselves, and disagreed with the term 'disorder'. Some people disagreed with the term 'disability' while others described their autism as a disability, and mentioned that, unfortunately, describing autism as a disability can be a necessity for accessing services. Qualitatively, professionals felt strongly that the person should come first, and also disliked the terms 'disorder' and 'disability'.
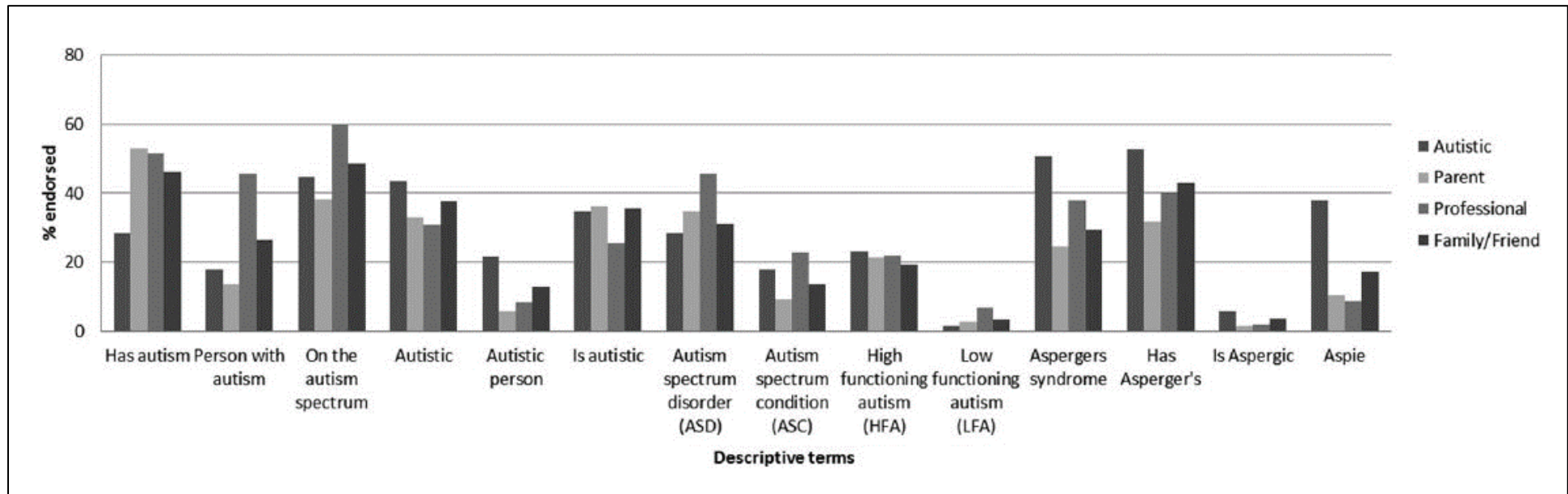
Figure 1: Graph showing the percentage of participants within each stakeholder group endorsing each of the terms used to describe themselves, their child or those they work with (From Kenny et al., 2016, p.445).

Kenny et al. wrote that the results of their survey were inconclusive and there is no 'correct' terminology to use, and there are likely to be a variety of different acceptable terms in use for years to come, a sentiment echoed by the National Autistic Society (2018b). They highlighted that there is disagreement within the autism community about preferred terminology, and between professionals, parents and families. They reported that all groups liked the term "on the autism spectrum", which the NAS stated it would continue to use as a default, while making an effort to gradually increase its use of the term "autistic", especially when talking to autistic adults. This research project attempts to make use of the person-first term "person/individual on the autism spectrum", as this was the most endorsed term by people on the autism spectrum (see Figure 1), as well as being consistently endorsed by all stakeholder groups.

As stated earlier, Kenny et al. highlighted that many individuals on the autism spectrum did not like the term 'disorder'. The term Autism Spectrum Disorder (ASD) is often used in services in the UK, as it is the current terminology used in the DSM-5. However, the neurodiversity movement (e.g. Singer, 1999) has confronted the use of the term 'disorder', instead considering autism as one way of being within the diversity of human minds. Baron-Cohen (2000) highlighted the negative nature of the term 'disorder' and instead offered the term Autism Spectrum Condition (ASC), to highlight the many strengths that individuals on the autism spectrum may have. However, the results of Kenny et al. (2016) found that all stakeholder groups endorsed ASD more than ASC at that time, although we are beginning to see a significant shift in NHS services away from ASD and towards ASC. The current research project hopes to contribute to this by using the term ASC rather than ASD, as this is the term

used across services, parent groups and schools in the local borough where this project took place.

In line with the majority of research on this topic, autism and Asperger's are not differentiated in this research project, in part due to their recent merging in DSM-5 (American Psychiatric Association, 2013) and the variable nature of the diagnostic criteria used to differentiate them. However, it is important to note that for many people diagnosed with Asperger's prior to the DSM-5, their diagnosis may be called into question, potentially leaving them vulnerable as it may be harder for them to access support services.

I spent a very long time reading about and thinking about the issue of terminology, which I believe is very important. I was aware throughout that I had not encountered any research about how children and young people wished to refer to their autism. The best practice when thinking about terminology is, of course, to ask the person you are working with what language they would like to use (Mackelprang & Salsgiver, 2009)*. However, I was aware that this could become a substantial distraction within the current project. As I did not wish to move the focus away from post-diagnostic support, I took the decision to state at the start of each focus group that each participant should feel free to use whatever terminology they were most comfortable with in the focus group. Throughout this project I have tried to use the term "on the autism spectrum" where possible, for the reasons discussed above, but it should be noted that participants brought a wide variety of different terms to the discussions.*

1.5.   Autism in Context

The next section discusses some of the relevant contexts for this research, including the prevalence of autism and comorbidities, relevant governmental policies and guidelines in this area, people's experiences of the diagnostic process, autism in an educational context, and introduces the importance of post-diagnostic support and how this might look in practice. A particular focus is on provision of support for children and young people.

1.5.1.   Prevalence of Autism and Comorbidities

Research suggests that the prevalence of autism in the UK is between 1% and 1.5% (Emerson & Baines, 2010). The most recent large-scale study of the prevalence of ASC in the UK reported approximately 1.1% of individuals are on the autism spectrum – around 700,000 people (NHS Information Centre, Community and Mental Health Team, & Brugha et al., 2012). Autism is typically thought to be approximately 4 times more common in males than females, although a recent increase in research into ASC in females has contributed to a shift in this ratio (e.g. Van Wijngaarden-Cremers et al., 2014), and a more recent study puts the estimate at closer to 3:1 than 4:1 (Loomes, Hull, & Mandy, 2017). Siblings of people on the autism spectrum have a 2-8% increased risk of being on the autism spectrum themselves, which is 25 times more likely than the general population (Abrahams & Geschwind, 2008).

It is estimated that approximately 50% of individuals on the autism spectrum also have a learning disability, although estimates vary widely from around 40%-75% (Emerson & Baines, 2010; Fombonne, Quirke, & Hagen, 2011). It is estimated that one third of people with learning disabilities may be on the autism spectrum (Emerson & Baines, 2010; NHS Information Centre et al., 2012). In the UK, the cost of supporting an individual on the

autism spectrum across their lifespan has been estimated to be £0.92 million, and this rises

to £1.5 million for an individual on the autism spectrum who also has a learning disability

(Buescher, Cidav, Knapp, & Mandell, 2014).

Research suggests that both children and adults on the autism spectrum have

significantly higher rates of mental health difficulties (such as mood or anxiety disorders)

than average (Lugnegård, Hallerbäck, & Gillberg, 2011; Murphy et al., 2016). NICE estimate

that approximately 70% of individuals on the autism spectrum also have at least one other

(often unrecognised) mental health problem, such as anxiety, OCD or depression (NICE,

2013). Mental health difficulties are often overlooked in individuals on the autism spectrum,

and often have significant impacts on the lives of people with autism (Murphy et al., 2016).

1.5.2. Relevant Policies and Guidelines

1.5.2.1.   Government Acts and Strategies

The Autism Act (2009) was a law introduced to meet the needs of adults with ASC –

the first ever disability-specific law in England. The act stated that the government must

publish an 'Adult Autism Strategy' by 2010, as well as statutory guidance for local

authorities on how to implement the new strategy. The first strategy, published in 2010,

was called 'Fulfilling and Rewarding Lives' (Department of Health, 2010). An updated

strategy was published in 2014 called 'Think Autism' (Department of Health, 2014), with a

new set of accompanying guidelines in 2015.

Fulfilling and Rewarding Lives (2010) set out a number of duties and

recommendations, such as improving autism awareness training for all frontline public

service staff, improving transition planning to give people on the autism spectrum the right

start in their adult life, and a set of recommendations around diagnostic pathways and

capacity, including adherence to the NICE guidelines (see section 1.5.2.2). Within this was

guidance around 'providing relevant information to adults with autism and their family or

carers at the point of diagnosis to help them understand the condition and access local

support'. This recommended that there be a person-centred assessment of an individual's

needs, and that an autism diagnosis should be a catalyst for a carer's assessment. Fulfilling

and Rewarding Lives (2010) also highlighted the importance of adults on the autism

spectrum and parents/carers being involved in the development of local services, through

the setting up of local Autism Partnership Boards (APBs).

The 'Think Autism' (2014) strategy built on the previous (2010) strategy and included

a few key new proposals, including setting up local community awareness projects to create

'Autism Aware Communities', and an 'Autism Innovation Fund' for projects that promote

innovative local services and projects. Although the initial strategy did not come with any

additional funding for services, the government did allocate £4.5 million towards the Autism

Innovation Fund and Autism-aware communities programmes. All of the above, in

combination with the Care Act (2014), significantly improved the rights of adults on the

autism spectrum, and carers, and made it easier to access appropriate support.

However, the above acts, strategies and recommendations were for adults on the

autism spectrum. The National Autistic Society (2018a) stated that, while the bill was

initially supposed to cover both adults and children, the government said that they would

help children on the autism spectrum in 'other ways', which the NAS continued campaigning

for.

Although to date there is not yet specific legislation covering children and young

people on the autism spectrum, there are relevant parts of the Children and Families Act

(2014), which improved support for children and young people with special educational needs or a disability. This act replaced the 'statement of special educational needs' with the new 'Education, Health and Care Plan' (EHCP), a single plan to meet children's educational, health and social care needs up to the age of 25 if necessary. However, not all children on the autism spectrum may meet the eligibility criteria for an EHCP, as discussed in more detail later.

In 2017, the National Autistic Society launched a campaign called 'Held Back', alongside a report which highlighted systemic failings in the provision of educational support for children on the autism spectrum (All Party Parliamentary Group on Autism (APPGA), 2017). This report by the APPGA and NAS is discussed in more detail in section 1.5.4.

Finally, in December 2018, the government announced plans to review the 2014 'Think Autism' Strategy and to introduce an updated national autism strategy extending coverage to people of all ages in England for the first time, recognising the need for "a national approach to improve the support that is offered to children and their families" (National Autistic Society, 2018b). In March 2019, the Department of Health and Social Care and the Department for Education begun reviewing the national autism strategy and extending it to cover children as well as adults. The government has now begun collecting evidence from members of the autism community and those who support them about how support can be improved, which highlights the timely nature of the current research.

1.5.2.2.   NICE Guidelines

The National Institute for Health and Care Excellence (NICE) has produced a number

of relevant quality standards and guidelines for diagnosing and supporting individuals on the

autism spectrum. The Autism Quality Standard (NICE, 2014) covers health and social care

services for adults, young people and children on the autism spectrum, and is intended to

be used alongside the governmental autism strategies discussed above. The NICE quality

standard for autism promotes a person-centred, integrated approach to providing high-

quality care to individuals on the autism spectrum, as well as their families and carers. It lists

a number of important quality statements, such as:

- Diagnostic assessments for autism should occur within 3 months of referral

  and include assessment for other possible comorbid mental and/or physical

  health conditions

- Individuals diagnosed with autism should have a collaboratively constructed

  personalised plan and a keyworker to coordinate their care and support

- Individuals diagnosed with autism should primarily be offered age-

  appropriate psychosocial interventions and not medication, for both core

  features of autism or possible behaviour that challenges.

This last point is very important and is in line with NHS England's (2016) 'Stopping

over medication of people with a learning disability, autism or both (STOMP)' campaign, a

national project which identified that individuals on the autism spectrum – including

children and young people – are among those more likely to be prescribed unnecessary

psychotropic medications over long periods of time.

NICE have published one clinical guideline for adults on the autism spectrum (NICE, 2016), and two clinical guidelines for children and young people on the autism spectrum: one for referral and diagnosis (NICE, 2017) and one for support and management (NICE, 2013). NICE guidelines recommend that every autism diagnostic assessment includes a detailed clinical interview with parent(s)/carer and the young person, including taking a developmental history, an assessment of social and communication skills and behaviours (in line with DSM-5 criteria), a medical history and physical examination, consideration of differential diagnoses and coexisting conditions, and the development of a profile of the young person's strengths, skills, needs and impairments so that a needs-based management plan can be created. The NICE guidelines mention using 'autism-specific tools' but do not mention any by name. The ADI-R (Le Couteur, Lord, & Rutter, 2003) or 3Di (Skuse et al., 2004) are often used for structuring autism assessment interviews, while the ADOS-2 (Lord et al., 2012) is a typically used tool involving a set of tasks which assess communication, social interaction and behaviour (e.g. play) in the child or young person. The NICE guidelines crucially point out that information from all sources, together with clinical judgment, should be used to diagnose autism, not the results of any autism-specific diagnostic tool alone.

In terms of post-diagnostic support, NICE guidelines state that the findings of every autism diagnostic assessment should be shared, in person, with parents/carers and if appropriate, the child or young person. This should include sharing with the family what autism is and how it is likely to affect development and function. A written report should be shared with the family, GP, educational professionals (school), and if appropriate, social care. A follow-up appointment should be offered within 6 weeks for further discussion. Families should be signposted to local support services for children and young people on the autism spectrum and for families/carers, for example being given contact details for

organisations who provide courses or facilitate meeting other families with similar experiences, and being given information on welfare benefits.

The NICE guidelines for supporting and managing children and young people on the autism spectrum again highlights:

- patient-centred care

- the importance of access to services

- training in autism awareness for all staff

- making reasonable adjustments and adaptations to help support children and young people on the autism spectrum.

They recommend psychosocial interventions, such as a specific social-communication intervention that includes play-based strategies, including techniques of therapist modelling and video-interaction feedback, to increase joint attention, engagement, interactive play, and reciprocal communication. In terms of behaviour that challenges, NICE guidelines recommend a thorough assessment to identify unmet needs and any factors that may trigger or maintain behaviours that challenge, followed by a systematic psychosocial (not pharmacological) intervention to attempt to address the possible underlying causes, all of which is consistent with a Positive Behavioural Support (PBS) approach (Carr & Horner, 1999; Koegel, Koegel, & Dunlap, 1996).

The following section explores people's experiences of the current process for obtaining a diagnosis of autism, which provides important context for the current project.

1.5.3. People's Experiences of the Diagnostic Process

There is considerable research on individuals' experiences of the process of

obtaining a diagnosis of autism (Crane et al., 2018). A systematic literature review of 28

published research papers on parents' experiences of obtaining a diagnosis of autism for

their child found that, across a number of studies, around 50% of parents were dissatisfied

with the diagnostic process, due to issues such as lengthy delays in the process, poor

communication, disrespectful interactions with professionals, and a lack of information

(Gallagher & Milne, 2013). This is consistent with more recent research which found 52% of

parents were dissatisfied with the overall diagnostic process, and 32% were 'very

dissatisfied' (Crane, Chester, Goddard, Henry, & Hill, 2016). Crane et al. also report that

parents typically had to wait 3.5 years between first contacting a healthcare professional

and receiving a formal diagnosis of autism for their child. Furthermore, 56% of parents rated

the process as 'very stressful', while only 14% did not find it stressful. A survey of adults on

the autism spectrum produced similar findings, although slightly lower levels of

dissatisfaction (Jones, Goddard, Hill, Henry, & Crane, 2014).

There are potential advantages and disadvantages of an autism diagnosis. One of the

positives is that it tends to help people access services and facilitates them receiving

support (Calzada, Pistrang, & Mandy, 2012). For many people, it also provides a sense of

identity and community; many individuals experience a sense of 'relief' as it provides some

explanation of their difficulties, and helps them to see that they are not alone. However, for

many people, one of the negatives of an autism diagnosis is the stigma attached to this

diagnostic label, especially in some cultures, where there can be shame or guilt attached to

having someone in the family with autism (Farrugia, 2009). Whilst a diagnosis is necessary in

the current system to access support, everybody experiences this balance of positives and

negatives differently when a diagnosis is given.

This project largely focuses on the experiences of children and young people on the

autism spectrum, and those around them, in the context of education and schooling. This

context is therefore explored in the following section.

1.5.4.   Autism in an Educational Context

In January 2018, there were approximately 120,000 children with autism as their

primary need in state-funded primary, secondary and special schools in England – about

1.5% of all pupils (Department for Education, 2018b). This appears consistent with estimates

of autism prevalence discussed in section 1.5.1., and does not account for the thousands of

children on the autism spectrum for whom autism is not their primary need.

According to the legal definition, children have 'Special Educational Needs' (SEN) if

they have a significantly greater difficulty in learning than the majority of children of the

same age, or have a disability which prevents or hinders them from making use of typical

educational facilities, and require special educational provision to be made (Department for

Education & Department of Health, 2015). Special educational needs can, therefore, include

intellectual disabilities, physical disabilities, sensory difficulties, mental health difficulties,

and developmental conditions. Approximately 14% of all pupils in England have Special

Educational Needs (SEN), and of those, about 10% have autism as their primary need

(Department for Education, 2018b). Amongst children with SEN, on average 20% have a

statement or Education, Health and Care Plan (EHCP); however, 55% of pupils with autism

as their primary need have a statement or EHCP, and it is by far the most common primary need amongst all pupils with a statement or EHCP, accounting for 28.2%. This is demonstrative of the significant impact that autism can have on a child's ability to learn in a typical educational setting.

Of the 120,000 pupils with autism as their primary need, 72% attend a mainstream school (Department for Education, 2018b). Whilst some parents felt mainstream schooling provided their child on the autism spectrum with beneficial opportunities for social inclusion (Falkmer, Anderson, Joosten, & Falkmer, 2015), other parents were concerned about their child keeping up both academically and socially (Lee, Harrington, Louie, & Newschaffer, 2008). Reid and Ayris (2011) found that 63% of children on the autism spectrum were not in the kind of school their parents believe would best support them. This suggests that, even with SEN support in mainstream schools, children on the autism spectrum may not be receiving sufficient support with their various needs. The most recent data from the Department for Education (2018a) showed that, across England, 14% of children on the autism spectrum had a permanent or fixed period exclusion from school, compared to the national average of 7%, meaning pupils on the autism spectrum were twice as likely to have been excluded from school. This was consistent with the findings of Reid & Ayris (2011), who found 17% of young people on the autism spectrum had been suspended from school – half of whom had been suspended three or more times. Such figures further suggest that schools may be failing to appropriately understand and accommodate the additional needs of children on the autism spectrum. Furthermore, children on the autism spectrum are considerably more likely to be the victim of bullying than other children (Humphrey & Hebron, 2015), with one meta-analysis estimating 44% of children on the autism spectrum to have been victims of bullying (Maïano, Normand, Salvas, Moullec, & Aimé, 2016).

Teaching pupils on the autism spectrum may require specific approaches, so while it is well established that staff training is key to supporting these pupils, many school staff feel they lack the training to appropriately meet the needs of pupils on the autism spectrum (Symes & Humphrey, 2012). Research highlights the extent to which teachers do not feel comfortable teaching children on the autism spectrum: over 70% of mainstream teachers believed that their initial training did not adequately prepare them to teach pupils with special educational needs, and 60% of teachers in England did not believe they have had the adequate training to teach children on the autism spectrum (NASUWT, 2013). Whilst all UK mainstream schools must have a SENCO (Specialist Education Needs Coordinator), there are currently no regulations in place to ensure teachers in mainstream schools have qualifications and experience in teaching autistic children. Other research paints a consistent picture: 77% of parents of children on the autism spectrum felt that a lack of support had impacted negatively on their child's educational progress (National Autistic Society, 2015), and 70% of parents were not satisfied with teachers' level of understanding of autism (All Party Parliamentary Group on Autism (APPGA), 2017). Indeed, the APPGA report highlights that the majority of young people on the autism spectrum and their parents believe that schools do not have adequate understanding of autism and are not able to appropriately meet the needs of pupils on the autism spectrum.

Furthermore, many parents are unaware of what support should be available to them following a diagnosis of autism, or how to go about finding out what support schools are obligated to provide or how to access this. Parents of children on the autism spectrum find it disproportionately difficult to obtain appropriate educational provision for their children compared with families with children with other disabilities (Parsons, Lewis, & Ellins, 2009). The provision of post-diagnostic support is a major challenge for schools, and

has been made worse by the impact of austerity on overall budget cuts, which have had a knock-on impact on the budget for SEN provision. The Key (2016) reported that 82% of mainstream schools did not have sufficient funding to adequately provide for pupils with SEN, and 89% of school leaders reported that the support they received for children with SEN had been negatively impacted by cuts to local authorities' services.

1.5.5.   The Importance of Post-Diagnostic Support

As autism is a lifelong condition, and in line with government policies (see section 1.5.2), post-diagnostic support is crucial in supporting children on the autism spectrum as they transition to become adults on the autism spectrum. Research found that 70% of adults on the autism spectrum felt they were not receiving the necessary support from social services, and that with more support they would have felt less isolated (Bancroft, Batten, Lambert, & Madders, 2012). In addition, research found at least one in three adults on the autism spectrum were experiencing severe mental health difficulties due to a lack of support (Rosenblatt, 2008). These issues have very real impacts on the lives of people on the autism spectrum; only 16% of adults on the autism spectrum in the UK are in full-time paid employment, and only 32% are in some kind of paid work, compared to 80% of the general population (National Autistic Society, 2016). Individuals on the autism spectrum also face considerable challenges accessing higher education in the UK (Lambe et al., 2018).

Historically, there has been poor provision of post-diagnostic support in the UK. A large scale survey by Howlin and Moore (1997) of over 1200 parents of children on the autism spectrum from across the UK found that 25% received **no** offers of help following diagnosis, and 35% were considerably dissatisfied with the post-diagnostic support they

received. They concluded that diagnosis should be accompanied by practical help and support e.g. more direct help for parents in early years to develop skills and strategies. The provision of good-quality post-diagnostic support for people on the autism spectrum can significantly improve quality of life (Renty & Roeyers, 2006a), and could potentially mitigate some of the detrimental impacts of autism on mental health, social isolation and employment and financial difficulties. Post-diagnostic support is also important for families of people on the autism spectrum. Research has found that parents of children on the autism spectrum generally have increased parenting stress, higher levels of anxiety and depression, higher unemployment and financial difficulties, and overall lower quality of life (Dillenburger, Jordan, McKerr, & Keenan, 2015; Ludlow, Skelly, & Rohleder, 2012; Reed & Osborne, 2012; Vasilopoulou & Nisbet, 2016). Early support following a diagnosis of autism is considered essential for improving child outcomes and reducing parental stress (Keen & Rodger, 2012). Unfortunately, recent research still highlights the lack of research into effective interventions for children on the autism spectrum in the UK, particularly when it comes to educational support (Denne, Hastings, & Hughes, 2018).

One current source of post-diagnostic support for parents of children on the autism spectrum is the National Autistic Society's Early Bird and Early Bird Plus courses, which are UK-developed 12-week parent education training programmes delivered by the NHS for parents of children with autism. Dawson-Squibb, Davids & de Vries (2018) conducted a systematic review of thirteen UK-based studies evaluating these programmes. They found studies generally reported an increase in parental knowledge about autism, increase in confidence, decrease in parental stress, and improved communication and behaviour in children. Despite these benefits, they concluded that only 'lower level' support existed for the efficacy of these programs and that more research was needed.

1.6. Systematic Literature Review

1.6.1. Introduction to Literature Review

Until now this thesis has provided a broad overview of autism and the relevant

contexts for this research. This has highlighted the many difficulties which children on the

autism spectrum may experience, and explored in more detail the complex issues often

affecting children on the autism spectrum in educational contexts, such as a frequent lack of

understanding among school staff, difficulties obtaining the necessary support, and specific

issues such as bullying and exclusion from school. It follows from this that post-diagnostic

support, and the people providing it, are crucial elements of helping to support children on

the autism spectrum with such difficulties, notably in an educational context. It is also

important for post-diagnostic support to work with schools to help them support such

pupils, and to support families who (as discussed above) may be finding it difficult to cope

with the additional stresses associated with having a child on the autism spectrum and

trying to obtain appropriate support for that child. Through the process of familiarising

myself with the literature it also became apparent that, whilst there has been much

research in the field of autism, there appeared to be a lack of research on post-diagnostic

support for individuals on the autism spectrum, a feeling also reflected in conversations

with my project supervisors (who have considerable clinical experience in this area).

Systematic literature reviews are high quality, comprehensive and rigorous reviews

which aim to draw unbiased and robust conclusions from the cumulative evidence base for

a particular topic, whilst highlighting gaps and providing implications for practice and

directions for future research (Siddaway, Wood, & Hedges, 2019). A search (including but

not limited to The Cochrane Library and the Centre for Reviews and Dissemination databases) for existing systematic reviews around post-diagnostic support and autism produced no results. The following section therefore provides a systematic review of the literature to address the following question: what are people's experiences of post-diagnostic support following a diagnosis of autism in the UK? The purposes of this were to assess the extent, nature and quality of literature available on this topic, and to present and explore what is known about this topic.

1.6.2. Method

Whilst considerable researching around the topic took place throughout the course of this project, the following describes the specific methodology of this systematic literature review, which follows that of Siddaway, Wood, & Hedges (2019). Given limited available research and to keep the search as comprehensive as possible, the search was not limited to studies concerning children and young people, but included research regarding people of any age. Furthermore, research of a quantitative, qualitative or mixed methods nature was included. It was decided to only include research that took place in the UK as the structures of services can vary widely and it was considered important that the findings provide relevant context for the current study which would take place in the UK. The time period of the search was from 2000 to present in order to broadly capture contextually relevant studies, in part since the DSM-IV was published in 2000, and also due to the fast-changing nature of educational structures and political climates in this country. The inclusion and exclusion criteria for this systematic literature review can be seen in Table 1.

Table 1: Inclusion and Exclusion Criteria for Systematic Literature Review

Inclusion Criteria	Exclusion Criteria
• Research focuses on individuals on the autism spectrum, their families, or professionals who work with individuals on the autism spectrum	• Research on post-diagnostic support following a diagnosis for something other than Autism
• Some part of the research focused on people's experience of support following diagnosis	• Research that does not discuss people's experiences of post-diagnostic support (e.g. research focused entirely on experiences of the diagnostic process)
• Published in a peer-reviewed journal	• Not published in a peer-reviewed journal
• Took place in the UK	• Took place outside the UK
• Published since 2000	• Published before 2000
• Published in English	• Not published in English

As per Siddaway, Wood, & Hedges (2019) methodology, the topic was broken down into individual concepts to create search terms, and alternative terminologies were considered, erring on the side of sensitivity to ensure no relevant articles were missed. Search terms used can be seen in Table 2. Searches were conducted from August to October 2018, using Scopus, PubMed, PsycINFO, CINAHL Plus and Google Scholar. Details of each search can be seen in Table 2. The search terms were used to search for peer-reviewed publications in English published since 2000. Search terms were combined using the Boolean 'AND' operator, and also made use of the 'OR' term within search terms.

Results were extracted and screened using the inclusion and exclusion criteria in Table 1. Titles and abstracts were screened, and duplicates removed, before full-texts were screened. A flow chart displaying the screening process can be seen in Figure 2. Email alerts were set up on Scopus, PubMed and Google Scholar to ensure that any new research was

also considered. All papers which made it to the final stage of screening were checked to

see if there were any relevant papers in their reference lists that had been missed, and

PubMed was used to check whether any paper had been cited by any other relevant paper.

This process produced a number of additional relevant results. It should be noted that,

whilst it appears that PsycINFO and CINAHL Plus did not contribute any papers, they did

both find papers which were included in the review, however these had already been found

either through Scopus or PubMed and were thus removed as duplicates. One systematic

review of some relevance to the topic was found (Legg & Tickle, 2019). This review was

checked for any papers it contained which met the inclusion criteria for this review, and

appropriate individual papers were included.

The systematic literature review was updated in April 2019 with additional relevant

journal articles which the author had been notified about through email alerts (set up as

described earlier).[2]

Table 2: Details of Searches Conducted

Search 1: Scopus	[Title/Abstract/Keywords] autis*[3]
	AND
	[All Fields] "post-diagnosis" OR "post-diagnostic" OR "after diagnosis" OR "following diagnosis" OR "following a diagnosis" OR "having been diagnosed" OR "after being diagnosed" OR "having been given a diagnosis" OR "after receiving a diagnosis"

---

[2] This contributed two new articles to the review.
[3] After considerable experimentation with a number of different terms, I deemed autis* to be the most effective search term as it would retrieve any research relating to autism but not include any other (non-relevant) research, as no other topics use this word stem.

	AND
	[All Fields] "support" OR "help" OR "information" OR "provision" OR "care"
	AND
	PUBYEAR > 1999
Search 2: PubMed	[Title/Abstract] autis*
	AND
	[All Fields] "post-diagnosis" OR "post-diagnostic" OR "after diagnosis" OR "following diagnosis" OR "following a diagnosis" OR "having been diagnosed" OR "after being diagnosed" OR "having been given a diagnosis" OR "after receiving a diagnosis" OR "after having received a diagnosis"
	AND
	[Title/Abstract] "support" OR "help" OR "information" OR "provision" OR "care"
	AND
	[All Fields] "United Kingdom" OR "UK" OR "Great Britain" OR "England" OR "Scotland" OR "Wales" OR "Northern Ireland"
	AND
	Filters: Publication date from 2000/01/01
Search 3: PsycINFO	[Title] autis*
	AND
	[Any Field] diagnos*[4]
	AND
	[Any Field] "support" OR "help" OR "information" OR "provision" OR "care"
	AND
	[Any Field] experienc*
	AND

---

[4] The PsycNET search engine did not respond well to the '-' character as in 'post-diagnostic', returning 0 results, therefore the search used these broader terms which returned a reasonable number of results.

	Year: 2000 To 9999
Search 4: CINAHL Plus	[All Text] autis*
	AND
	[All Text] "support" OR "help" OR "information" OR
	"provision" OR "care"
	AND
	[All Text] "post-diagnosis" OR "post-diagnostic" OR "after
	diagnosis" OR "following diagnosis" OR "following a diagnosis"
	OR "having been diagnosed" OR "after being diagnosed" OR
	"having been given a diagnosis" OR "after receiving a
	diagnosis" OR "after having received a diagnosis"
	AND
	Published Date: 20000101-
Search 5: Google Scholar	autism experiences of post-diagnostic support UK[5]
	Published Since 2000

---

[5] This search was used as Google Scholar automatically searches for related words (e.g. autism will also return autistic) and synonyms of all search terms.

Search conducted	1 Scopus	2 PubMed	3 PsycINFO	4 CINAHL Plus	5 Google Scholar
Titles screened	177	543	390	39	296
Abstracts screened	46	91	36	20	60
Duplicates Removed					
Full texts screened	23	11	0	0	12
Articles for inclusion	8	4	0	0	6

Additional articles added from references, citations & alerts = 7 → **Articles included in review = 25**
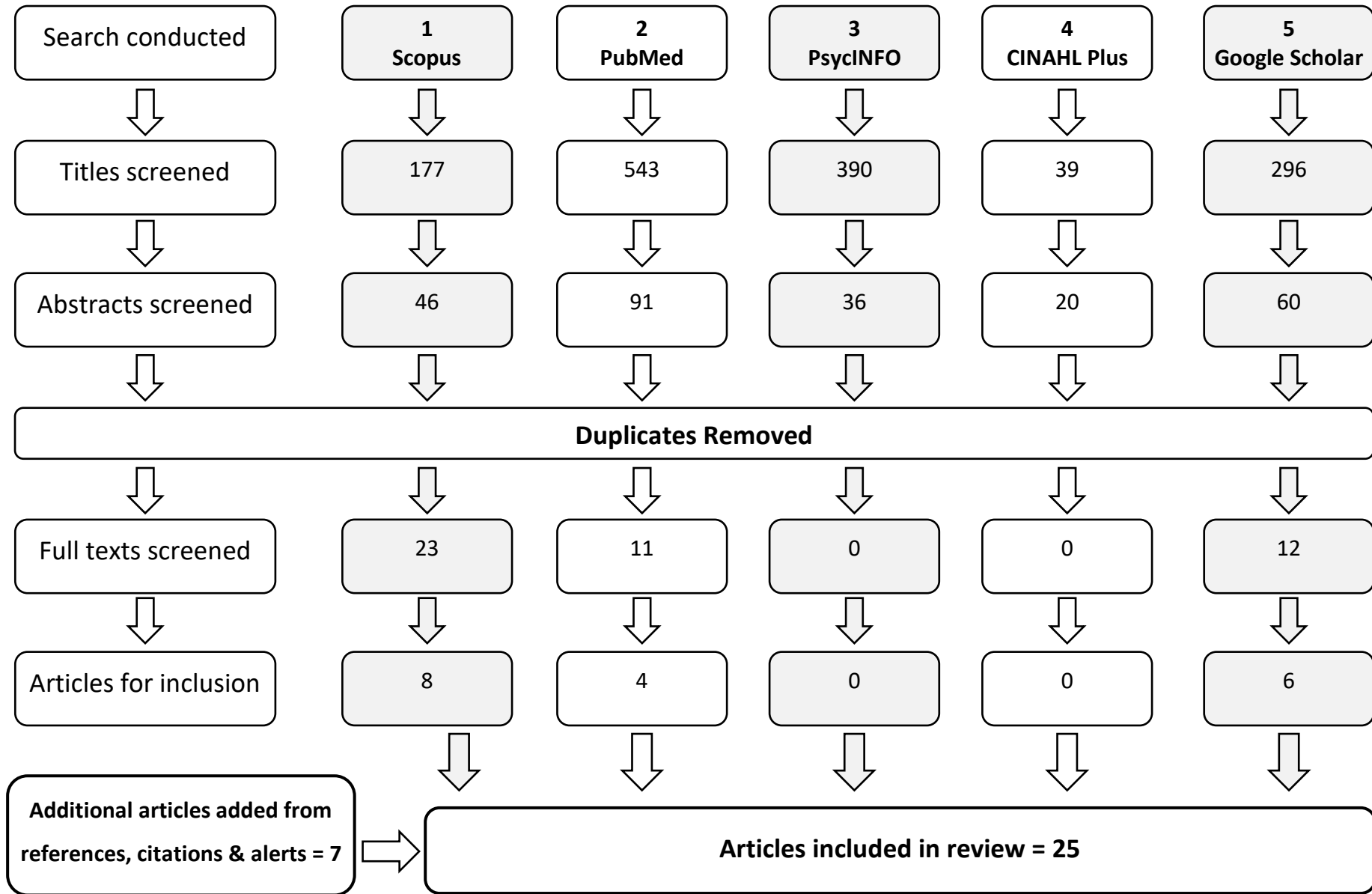
Figure 2: Systematic Literature Review Flowchart detailing search and screening process and results

1.6.2.1.   Assessing study quality

Most systematic reviews tend to focus on either quantitative or qualitative research, and limited work has been done on synthesising quantitative, qualitative and mixed-methods research in systematic reviews (Heyvaert, Maes, & Onghena, 2011), as I have attempted to do in this review (in order to capture as much relevant literature as possible). An essential part of any systematic literature review is to provide a critical evaluation of the nature and quality of the evidence base, and this often makes use of one or more of a huge number of tools designed to assess study quality (Cooper, 2017; Siddaway et al., 2019). Whilst there are a vast number of critical appraisal tools for assessing the quality of quantitative and qualitative research[6], developing quality criteria for mixed methods research has proven more difficult (Bryman, Becker, & Sempik, 2008; Sale & Brazil, 2004). The current systematic literature review contains a mixture of quantitative, qualitative and mixed methods research. Heyvaert, Hannes, Maes, & Onghena (2013) examined thirteen unique Critical Appraisal Frameworks for mixed methods research to compare and contrast the quality criteria proposed for evaluating all types of research. They suggested nine generic criteria which can be applied to qualitative, quantitative and mixed methods research (see Figure 3), which demonstrate their validity (to an extent) in their consistent overlap with many other well-established quality appraisal tools (e.g. Critical Appraisal Skills Programme (CASP), 2018). Whilst these nine criteria may appear quite different from some other examples (e.g. Tracy, 2010), the key concepts at the core of these criteria are very similar (i.e. appropriate sampling and methods, theoretical and practical significance, transparency and ethics, and so on). Heyvaert et al. (2013) state that one advantage of using

---

[6] see http://www.unisa.edu.au/Research/Health-Research/Research/Allied-Health-Evidence/Resources/CAT/ for a comprehensive list of structured Critical Appraisal Tools for different types of studies

a single set of criteria is that it allows for comparability across studies, and they also

highlight the importance that one's quality criteria are "fit for purpose" for the studies to be

included in the review. I therefore decided to utilise these nine robust quality criteria to

assess the quality of all studies included in this systematic literature review. An assessment

of the quality of the current study can be seen in section 2.10.1.

Nine generic quality criteria for appraising research

1) Stating the theoretical framework of the study;

2) Stating the research aims and questions;

3) Using an appropriate design;

4) Applying appropriate sampling and data collection methods;

5) Applying appropriate data analysis methods;

6) Stating the interpretation, conclusions, inferences, and implications of the study;

7) Stating the context of the research;

8) Stating the impact of the researchers;

9) Being transparent in the reporting of the study

Figure 3: Nine criteria for assessing the quality of quantitative, qualitative or mixed methods research, adapted from Heyvaert et al. (2013)*.*

1.6.3. Results

Following the methodology outlined in section 1.6.2, twenty-five papers were

reviewed as part of this systematic literature review. The quality of these papers was

assessed using the criteria in Figure 3, and results of this can be seen in Table 3. A summary

of each paper can be found in Table 4. In total there were eleven qualitative papers, six quantitative papers, and eight mixed methods papers.

Nine papers looked directly at people's experiences of support, including one which looked at mothers', one which looked at fathers', and two which included professionals' views. Ten papers focused primarily on people's experiences of the diagnostic process and also discussed individual's experiences of post-diagnostic support; in these cases, the part of the study focused on post-diagnostic support was included in this systematic review to capture the elements of the research relevant to the current project. A review of people's experiences of the diagnostic process has already been undertaken (see Gallagher & Milne, 2013). One paper was included regarding the evaluation of post-diagnostic support groups. Seven papers were included which focused on experiences of educational provision for people on the autism spectrum.

Four articles were included which were part of a large project exploring the autism diagnostic process in the UK (Crane et al., 2018, 2016; Jones et al., 2014; Rogers, Goddard, Hill, Henry, & Crane, 2016). These are all included as each had a different focus and each made a significant contribution to the topic of post-diagnostic support for individuals on the autism spectrum in the UK. During literature searching, a number of relevant articles were found which addressed post-diagnostic support for people on the autism spectrum in other countries, and these are not included in the systematic literature review but will be discussed later in this thesis. Although one paper (Dawson-Squibb, Davids, & de Vries, 2018) was completed in South Africa, it used data from the UK and so was included.

1.6.3.1.   *Study Quality*

Table 3: Critical Appraisal of the Quality of papers included in the Systematic Literature Review

XX = Criteria not met x = Criteria partly met ? = Unclear ✓= Criteria met ✓✓= Criteria met to high standard	1) Stating the theoretical framework of the study	2) Stating the research aims and questions	3) Using an appropriate design	4) Applying appropriate sampling and data collection methods	5) Applying appropriate data analysis methods	6) Stating the interpretation, conclusions, inferences, and implications of the study	7) Stating the context of the research	8) Stating the impact of the researchers	9) Being transparent in the reporting of the study
Braiden, Bothwell, & Duffy (2010)	x	✓	✓	x	x	✓	✓	✓	✓
Breen & Buckley (2016)	✓	x	✓	x	✓	✓	✓	XX	x
Bromley et al. (2004)	✓	x	✓	✓✓	✓	✓	✓	x	x
Camm-Crosbie et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓
Crane et al. (2018)	✓	✓	✓	✓	✓✓	✓	✓	✓	✓
Crane et al. (2016)	✓	✓	✓	✓✓	✓	✓	✓	x	✓
Dillenburger et al. (2010)	✓	x	✓	✓	✓	✓	✓	XX	x
Emam & Farrell (2009)	✓	✓	✓	✓	✓	✓	✓	XX	XX
Galpin et al. (2017)	✓	✓	✓	✓	✓	✓	✓✓	✓	✓

	1) Stating the theoretical framework of the study	2) Stating the research aims and questions	3) Using an appropriate design	4) Applying appropriate sampling and data collection methods	5) Applying appropriate data analysis methods	6) Stating the interpretation, conclusions, inferences, and implications of the study	7) Stating the context of the research	8) Stating the impact of the researchers	9) Being transparent in the reporting of the study
Griffith et al. (2013)	✓	✓	✓	✓	✓	✓	✓✓	x	x
Hebron & Bond (2017)	✓✓	✓	✓	XX	✓	✓	✓✓	XX	✓
Humphrey & Lewis (2008)	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jones et al. (2014)	✓	✓	✓	✓	✓	✓	✓	?	✓
Ludlow et al. (2012)	x	✓	✓	x	x	x	✓	XX	XX
Mansell & Morris (2004)	✓	✓	✓	✓	✓	✓	✓	✓	✓
McConachie & Robinson (2006)	✓	✓	✓	x	✓	x	✓✓	✓	✓
Osborne & Reed (2008)	✓	✓	✓	✓	x	✓	✓	✓	✓
Parsons et al. (2009)	✓	✓	✓	x	✓	✓	✓✓	✓	✓
Potter (2017)	✓	✓	✓	✓	x	✓	✓	✓	x
Preece (2014)	x	✓	✓	✓	✓	x	x	✓	✓
Rogers et al. (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓✓
Russell & Norwich (2012)	✓	✓	✓	✓	✓	x	✓	x	x

	1) Stating the theoretical framework of the study	2) Stating the research aims and questions	3) Using an appropriate design	4) Applying appropriate sampling and data collection methods	5) Applying appropriate data analysis methods	6) Stating the interpretation, conclusions, inferences, and implications of the study	7) Stating the context of the research	8) Stating the impact of the researchers	9) Being transparent in the reporting of the study
Tissot (2011)	✓	✓	✓	✓	✓	✓	✓	x	x
Unigwe et al. (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓
Whitaker (2007)	✓	✓	✓	✓	✓	✓	✓✓	✓	x

1.6.3.2.   *Summary of findings*

Table 4: Summary and Evaluation of Studies in the Systematic Literature Review

Author (Year) Title	Participants	Research methodology	Summary of key findings and conclusions	Main strengths and limitations
Braiden, Bothwell, & Duffy (2010). Parents' Experience of the Diagnostic Process for Autistic Spectrum Disorders.	Eleven mothers (17% response rate) with children aged 5-11 who received a diagnosis of ASD within 18 months of participating in this study.	Qualitative study. Used face-to-face semi-structured interviews. Employed thematic analysis, verified by interrater discussions.	Ten parents received a verbal explanation of ASD at the time of diagnosis, and 8 also received written info (booklets/ pamphlets), which was 'useful', however they had to rely heavily on relatives/friends/ the internet to gain more information. In terms of PDS, SLT, OT, and support groups were mentioned as valuable supports. 6 parents reported 'a void' of some months between diagnosis and support; 3 parents had had no support at all. Conclusion: parents need to be made more aware of the support available to them.	Strengths: Thoughtful design (e.g. MDT input on interview schedule) and transparency of analysis (e.g. interrater discussions); results well situated in context of previous research. Limitations: Possible self-selecting sample, no demographic information collected, small sample size, "minimal analysis" undertaken, and themes heavily influenced by interview schedule.
Breen & Buckley (2016). Autistic spectrum disorder post-diagnostic support group: Model outline and parental experiences.	25 evaluation forms returned by parents of children with ASD over a block of 6 (weekly) 2-hour PDS groups, typically with 4-7 parents at a group.	Quantitative, non-parametric evaluative study; reports only frequencies/ descriptive statistics.	Parents invited to attend 6 (weekly) 2-hour ASD PDS information groups. MDT provided parents with strategies and resources. 64% of parents felt all their expectations were met, and 72% rated the sessions as 'very helpful'. Conclusion: the model presented enables parents easy access to regular specialist PDS; parents found the ASD PDS group very useful, and other services should adopt similar approaches.	Strengths: relevant clinical implications/practice guidelines for services to enable easy access PDS for parents. Limitations: Did not allow for those who find it difficult to complete forms (due to literacy or language barrier); also did not report response rate. Limited data analysis to back up implications/ recommendations.

Bromley, Hare, Davison, & Emerson (2004). Mothers supporting children with autistic spectrum disorders.	Recruited 68 biological mothers of 71 children (0-18) with ASD (80% male). 76% White British. 31% lone parent. 54% looking after family full-time.	Quantitative study; structured interview including 6 formal measures assessing child's functioning & behaviour, mother's psychological wellbeing, unmet needs, family support and other support services. Descriptive, correlational and multivariate analyses.	Lone mothers reported significantly less support (from all sources) than mothers with a partner. School was top rated source of support (72%), followed by partner (69%) and other children (49%). 29% reported receiving no professional support. 75% had received service from speech therapy in the last 6 months, 31% a social worker, 19% a clinical psychologist. 4% reported no input at all in the previous 6 months. Younger children accessed significantly more support. 74% of mothers said their child was attending their preferred school. Top unmet need was 'help with care during holidays'. Greater family support and lower levels of 'challenging behaviour' were associated with improved psychological wellbeing in mothers. Conclusion: many mothers are receiving inadequate post-diagnostic support and this can significantly affect mental health.	Strengths: Good sample size; use of numerous well-validated measures and appropriate statistical analyses throughout. Relevant clinical implications well-situated in context of previous research. Limitations: does not state specific hypotheses; low response rate, self-selecting participants, likely "unrepresentative of wider population". Study is cross-sectional so can only identify associations, not causality. Does not suggest specific interventions.
Camm-Crosbie et al. (2018). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality.	200 adults (age 18-67; 61% female) with autism but without LD took part. 90% had a mental health diagnosis, of which 83% had received some treatment.	Qualitative; Large online survey, consisting of self-report questionnaire combining open and closed questions. Inductive thematic analysis was used.	Identified three key themes: difficulty finding appropriate treatment and support as autistic adults with mental health difficulties, a lack of understanding and knowledge about autism, and positive and negative experiences of wellbeing. Conclusion: adults with autism are often excluded from mental health services; there is a gap in which services fail to meet needs.	Strengths: good participatory approach used, ensured questions were important, relevant and clear. Online recruitment method more accessible; large sample size. Limitations: Potential self-selection bias. Results not generalisable to those with LD. Lack of distinction between treatment and support.

Crane et al. (2018). Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals.	Stratified sampling to recruit: 10 adults with ASD (age 29-59, all White British, 6 women), 10 mothers (aged 23-56, 9 White British) of children with ASD (aged 3-19, 80% male), and 10 professionals who work with people with ASD (varied roles, 9 White British, 8 women, 7 NHS workers).	Qualitative study; in-depth semi-structured interviews over the phone; Thematic analysis (following Braun & Clarke, 2006), using an inductive approach, by 2 researchers who met to discuss and decide on themes.	One of the 3 key themes identified from the data was inadequate post-diagnostic support provision, which was divided into 'feeling directionless' after receiving the diagnosis (e.g. lack of follow-up appointments, "being dumped after the diagnosis"), general lack of appropriate support (e.g. services not being offered until crisis, "everything's been a fight", services being withdrawn due to financial constraints), lack of family support, and lack of emotional support (e.g. parents feeling their own emotional needs being ignored). Systemic factors (limited funding/resources) restrict professionals' ability to provide PDS, but it might help for them to be more aware of other local support services. Conclusion: parents and professionals both identify inadequate post-diagnostic support provision.	Strengths: in-depth study from perspectives of 3 different groups, including individuals on the autism spectrum. Very clear method, robust analysis. Detailed and important findings leading to clear and realistic implications for both clinical practice and future research. Limitations: telephone interviews may be a barrier to participation for some people, especially those with ASD; lack of ethnic diversity in sample, and sample not representative of gender of ASD population (although this is subject to debate).
Crane et al. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom.	Gathered responses from 1047 parents (93% female, 95% White) of children on the autism spectrum (80% male, mean age 11.8).	Quantitative study. Online survey questionnaire. Used descriptive statistics and multiple regression. Also included some quotes from parents.	85% of parents received written report of child's diagnosis, and 56% a follow-up appointment. Only 21% received a direct offer of support during or following diagnosis; 38% were signposted to advice or help, and 35% received no offers of support during or after diagnosis. 23% were 'quite or very satisfied' with the support offered post-diagnosis, while 61% were 'quite or very dissatisfied' (e.g. "we were left in the dark, we were given no information"). Conclusion:	Strengths: Big sample size (good power), reliable statistics. Well situated in previous research and provides specific clinical implications/recommendations. Limitations: Sample is not representative of gender or ethnic diversity, subject to response bias (self-selecting); paper does not analyse for regional variations so cannot highlight specific areas of

			unsatisfactory post-diagnostic support is an area of particular concern for parents.	need.
Dillenburger et al. (2010). Living with children diagnosed with autistic spectrum disorder: parental and professional views.	Northern Ireland & ROI. 31% response rate. 95 parents/ caregivers (88% mothers; mean age 40) of 100 children with ASD (80% male, age 1-16). 56% of parents unemployed due to being full time caregivers to child with ASD. 67 professionals (88% female; 13 SLT, 10 social workers, 11 psychologists, 11 ABA tutors, 4 OTs)	Questionnaire/ survey study; questionnaire designed for this study; mix of open and closed questions about experiences of provision and needs. Different questionnaires for parents and professionals. Descriptive/ frequency statistics reported, and some qualitative comments given.	75% of parents sought support from family and friends. 66% of the professionals had noted that parents experienced significant distress when seeking funding to support their children's treatment and education. 42% of the parents were not informed by statutory services about multi-disciplinary support available to their family. Professionals thought that nine different support services would be appropriate, yet 71% of families received support from an average of only three different professionals. 29% of the children did not receive any multi-disciplinary support services. Only 38% of parents and 33% of children were in receipt of respite support. 54% of parents felt schools did not always meet their child's needs, although this was much better for ABA schools. Conclusion: parents and professionals agreed that increased support and information should be made available to parents of children with ASD.	Strengths: no exclusion criteria and comprehensive recruitment strategy meant access to participation was not limited; open style of questions allows participants to answer freely; good use of combination of parent and professionals views; qualitative comments highlight personal experiences within statistics. Well situated in theoretical framework. Limitations: possible response bias (may be more likely to obtain responses from those with extreme views), authors do not consider this or their impact on research; they do not report where participants came from (NI vs ROI), limiting usefulness of findings; minimal analysis (e.g. did not undertake statistical tests which would have been informative).
Emam & Farrell (2009). Tensions experienced by teachers and their views of support for	17 case studies: interviewed teachers, TAs and SENCOs of 17 pupils	Qualitative study; combination of case study analytic strategies, thematic	Support for students with ASD varied both in amount (some received none, others 10-20 hours/week) and resource (learning support units/a 'resource room'). TAs viewed	Strengths: well-grounded in theory and context, provides useful conceptualisation of school relationships; provides many

pupils with autism spectrum disorders in mainstream schools.	with ASD in mainstream schools (all of average or above average intelligence; aged 7-16; 88% male; 70% TA supported) from north-west England.	analysis and grounded theory, of semi-structured interviews and direct and indirect observations. Presents key themes in a model and reports many example quotations.	themselves as removing barriers between pupils with ASD and the mainstream learning context. Teachers saw TAs as 'indispensable', providing security to pupils, e.g. pupils able to communicate through TA. However, many noted worse behaviour from pupils when with TA. Teachers feel less responsible for pupils with ASD with a TA. Pupils with ASD without a TA fared better in primary school than secondary. Pupils struggled to effectively make use of 'as needed' TA support. Multidisciplinary 'web of support' highly effective. Some families rejected TAs to avoid stigma. Conclusions: Teachers are highly dependent on TAs for supporting pupils with ASD in mainstream schools.	quotations which highlight people's experiences. Limitations: do not report demographic information of school staff interviewed; average or above average intelligence of pupils limits generalisability to overall ASD population; minimal detail given regarding qualitative analysis – lacks transparency; minimal practical implications given.
Galpin et al. (2017). 'The dots just don't join up': Understanding the support needs of families of children on the autism spectrum.	Inner London. Surveyed 139 parents (78% female) of children on the autism spectrum (aged 4-18, 82% male), all children had SEN statement. 52% Black, 25% White, 10% Asian. Interviewed 17 parents (15 female), 10 who felt	Mixed methods design. Online survey mixing rating scales with open questions. Semi-structured interviews for a subset of participants, conducted face-to-face, analysed using Thematic Analysis (inductive), by two authors who met to	Most common sources of support were partners (40%), relatives (48%) and friends (42%). 23% of parents reported they did not feel they had anyone to turn to for support. When asked what would help, 48% said 'a better understanding of who is working with my child', 37% said 'being in touch with other parents in a similar situation, & 36% said 'more time for myself'. Of those parents who felt they had no support, the top choice was 'increased communication with school staff'. Parents also focused on help understanding their child's behaviour, and increased tolerance and understanding	Strengths: Ethnically and socioeconomically diverse sample, representative of local population. Strong mixed methods design (interviews further contextualised the findings from the survey), results likely generalisable. Clear and practical implications for improving post-diagnostic support, situated within both theoretical frameworks and the context of current policies and acts. Limitations: Researchers recognise that, as the study was carried out

	supported and 7 who felt unsupported.	discuss and decide on themes.	within the community. Themes from the interviews included the need for respite, feeling isolated and alienated (lack of understanding), limited collaboration with school, having to 'battle for everything', existing support does not fit with their lives, lack of whole-family support, the need for tailored post-diagnostic support, the benefits of support from other parents, the need for more information, and more proactive services. Conclusion: existing support is not meeting parents' needs and service provision needs to be improved.	by school staff, parental reports of mental wellbeing & self-efficacy may have been unrepresentatively high due to demand characteristics. Issues raised by parents potentially idiosyncratic.
Griffith et al. (2013). Receiving an assessment and a potential diagnosis on the autism spectrum: a thematic content analysis of parental experiences.	10 biological parents (from 8 families) of children with autism; 7 mothers, 3 fathers. Children were 6 boys, 2 girls (mean age 6.6 at time of referral). Setting: North Wales.	Qualitative. Semi-structured interviews were recorded and transcribed. Thematic content analysis (bottom-up) conducted as per Braun & Clarke (2006).	Of 8 subthemes, 1 was called 'Lack of post-diagnostic support'. Seven parents felt they were abruptly cut off from the service that diagnosed their child and left to cope on their own: "that's when the battles begin". They were given leaflets and not offered a follow-up appointment. Most families expressed a need for a post-diagnostic link service or an assigned keyworker to help them access support. Parents were disappointed to learn that a diagnosis did not automatically lead to support or specific educational placements, and that it was up to them to actively seek support. Many parents found the system complex and thus spent much time and effort gathering information about how to access available	Strengths: well situated in previous research and good service context provided; 'bottom-up' analysis prioritises parents voices over pre-existing theories; good amount of quotations used to illustrate themes. Limitations: authors question the generalisability of their study; data not provided on ages of parents; lack of transparency around thematic analysis (e.g. how many authors were involved, were there any checks); clinical implications are present but lack practical recommendations for improvement.

			support, and described 'fighting' the system rather than having a collaborative relationship with services. Conclusion: parents experienced a significant lack of post-diagnostic support and found it hard to access support while navigating the complex systems.	
Hebron & Bond (2017). Developing mainstream resource provision for pupils with autism spectrum disorder: parent and pupil perceptions.	Purposeful sampling of 5 primary and 3 secondary schools in Manchester: 9 pupils (aged 8-15), 5 with SLI, 4 with ASD; 16 parents (11 of pupils with ASD, 5 of SLI). Included 8 parent-child dyads. Pupils 83% male, 61% in primary school.	Qualitative study. Parents and pupils underwent separate face-to-face semi-structured interviews during first term, at 6 months, and 1 year after admission. Interviews analysed using inductive thematic analysis jointly by 2 authors.	Aim to study how parents and pupils experience additional resource provision in mainstream schools in one local authority in the first year. Relevant findings: positive staff attitudes towards pupils with ASD, staff had better knowledge and understanding of ASD ("autism-aware") and behaviour. Parents described "having to fight on their own to navigate different educational and health care systems"; anxiety around transitions despite parents feeling supported. Outcomes very positive: Improved academic progress. Improved home-school communication. Positive impact on home life. Individualised programs of support including social skills. Pupils more able to participate in wider school life/activities, and make friends. Pupils highly positive about school (e.g. "supportive staff"), less bullying. Conclusion: provides support for benefits of additional resource provision in mainstream schools for pupils on the autism spectrum.	Strengths: study coherently and effectively presented in the context of Bronfenbrenner's (2005) bio-ecosystemic model; findings also presented in this model and in line with previous research findings, clearly highlighting beneficial outcomes, with practical examples, implications & recommendations. Limitations: commented on local social and ethnic diversity but did not report this data in participant demographics. Some participants interviewed at multiple time points, others only once. Some interviews audio recorded, others not (only handwritten notes). Mixture of SLI and ASD limits generalisability. Small sample size. Interview schedules not reported in paper.

Humphrey & Lewis (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools.	20 pupils with high functioning autism from mainstream schools in north-west England (age 11-17).	Qualitative study; semi-structured interviews and pupil diaries (and some drawings). Used interpretive phenomenological analysis (IPA).	Nature and amount of support received varied widely (from no support to support in almost every lesson); most pupils found support helpful, although while some found it protective, others felt they were treated differently (worse) by peers due to the extra attention. Some teachers had minimal interaction with pupils with ASD, and relied heavily on TAs, which pupils did not like. Pupils appreciated 'subtle' support from staff. Some pupils benefited from peer support and found this important, and this should be encouraged. Conclusion: mainstream schools are not fully meeting the needs of pupils on the autism spectrum, and there are a number of issues around support which need to be addressed.	Strengths: promotes voice of individuals on the autism spectrum, involved participants in design of research (e.g. consulted on interview schedules, gave feedback on interpretations), good transparency and awareness of impact of researchers; makes good recommendations for future research. Limitations: do not give details of demographics of pupils involved; authors state the sample size is small and may not be generalisable to the wide population of pupils on the autism spectrum; limited practical implications given.
Jones et al. (2014). Experiences of Receiving a Diagnosis of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom.	128 adults (mean age 39, range 18-76; 55% male) with an ASD diagnosis who were able to remember being diagnosed (at any age); study 'required participants to be high functioning', 84% Aspergers	Online survey questionnaire. Some questions adapted from Howlin & Moore (1997). Mixture of closed and open questions, and Likert scales. Autism Quotient (Baron-Cohen, Wheelwright,	Study of adults' experiences of the diagnostic process, with some focus on PDS. 42% were offered no form of post-diagnostic support. The top 3 sources of support that people would have liked were counselling, social skills training and access to support groups. Only 23% of people were satisfied with the support they received. 22% indicated they would like help with depression and anxiety, however 79% said they did not know how to access such support. Only 3% of respondents were offered a community care assessment.	Strengths: builds on previous research and well situated in context; good sample size (widely advertised online survey makes responding more accessible), space for respondents to give comments (free text), use of formal measures of mental health. Limitations: participants high functioning, limiting generalisability of findings for lower-functioning individuals;

	diagnosis; 90% mainstream schooled; 74% gained GCSEs; 68% living independently; 42% not currently employed or studying.	Skinner, Martin, & Clubley, 2001), depression and anxiety measures. Descriptive statistics, plus bivariate and multivariate statistical analyses.	Many people commented that a follow-up appointment to discuss the implications of the diagnosis would help alleviate some of the distress. Others said there is a need for mental health support geared specifically towards people on the autism spectrum. Conclusion: there is insufficient provision of post-diagnostic support and this can impact mental health.	study largely promoted through support groups so may not have reached people less engaged with such groups; retrospective study may be inaccurate (for some participants many years had passed); measures of depression and anxiety not designed for individuals on the autism spectrum.
Ludlow et al. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder.	20 parents (14 mothers, 6 fathers) of 14 children on the autism spectrum (aged 4-29).	Qualitative study. Individual semi-structured face-to-face interviews (45-60 mins), recorded and transcribed. Analysed using thematic analysis.	Parents expressed a sense of exhaustion and difficulty finding respite due to lack of understanding; general lack of resources, information & support from external organisations ("it's all down to you"); support increases with severity; significant emotional impact on families, isolation; 4 out of 6 fathers felt mothers experience more stress as they spend more time with children. Many parents felt the support of other parents of children with autism was an important and valued source of support, notably sharing coping strategies. 9 parents said professionals had been helpful and supportive; generally mainstream schools were considered unsupportive or lacking in understanding, whereas 'specialist/SEN schools' were an invaluable source of support. Conclusion: parents face daily challenges and need improved support and	Strengths: method allows for a subjective account of parents' experiences, and results are presented as consistent with previous research. Limitations: basic demographic data not collected or presented (e.g. gender of children, time since diagnosis); general lack of transparency throughout, especially in method (e.g. no mention of interrater discussions of themes); limited generalisability of results; no clinical implications or recommendations for future research are given.

			resources.	
Mansell & Morris (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service.	55 responses (55% response rate) from parents of children (50 male, 5 female; aged 2-10) on the autism spectrum. Half responses from mothers, half from mothers & fathers.	Mixed methods. Postal questionnaire. 4-point Likert scales and open questions. Descriptive and frequency statistics, as well as some bivariate statistics. No formal analysis of qualitative data.	51% of parents were happy with how well sources of support had been explained during the diagnosis, and this was 46% for sources of information, 44% for coping strategies, & 31% for future consequences. Most common recommendation was 'both before the diagnosis and during a follow-up session, provide more information about how to access help, support and treatment'. Parents also wanted counselling, more info on dietary interventions, help dealing with schools, and for the parent support group to provide workshops at weekends or in school holidays. Most commonly used **sources of information** were family services worker (89%), SLT (83%) & educational psychologist (77%). Local parents support group (58%) was one of the top rated most useful sources. Most commonly used **sources of support** were SLT (87%), special unit or special school (69%), & support at mainstream school (42%). Special schools and the early years course were rated as highly useful. Some parents expressed dismay with the provisions of the local health and educational authorities, and that schools should be better informed about autism. 71% reported being able to get	Strengths: very well situated in context; good effort to make participation accessible; good use of mixed methods (open questions allow parents to express themselves); thorough presentation of results and implications/recommendations for services. Limitations: possible response bias (parents who responded may have strongest views); ignored ethnicity; results may not generalise to other parts of the country.

			practical help for their child after diagnosis; 14% reported their child had been treated worse after diagnosis. Conclusion: parents have varied experiences but many are frustrated with a lack of service provision.	
McConachie & Robinson (2006). What services do young children with autism spectrum disorder receive?	Families recruited from an evaluation of a training course for parents of children with ASD. 56 children with ASD (mean age 3 years, 80% male; 20 had confirmed ASD diagnosis) and their parents (64% response rate); by the end, 39 families still participating (17 dropped out or 30%).	Longitudinal repeated measures questionnaire study (4 times points over 21 months), asked parents a mixture of descriptive quantitative and closed qualitative questions about services. Presents descriptive/frequency results/graphs, and some bivariate statistics.	Looked at families' access to services over 4 7-month periods. At time 1, almost all families had SLT access, 80% paediatrician, less than 50% educational psychology and less than 20% social worker. At time 4, less than 80% had SLT and less than 50% paediatrician. Ed psych involvement peaked at time 2&3; social worker involvement was inconsistent. At time 1, 39% of parents had a key worker, at time 4 (children aged 4-5) this was 14%. Hours per week of specialist provision increased across all time points, from less than 2 hours/week at time 1, to 10 hours/week at time 4, largely in a specialist setting or with a support assistant in a mainstream setting. Conclusions: significant deficits in the provision of keyworkers and hours per week of specialist provision.	Strengths: very well situated in context of relevant guidelines/ policies at the time; transparency regarding measure/questionnaire used; good links made with previous research. Limitations: Researchers found their research sample was significantly less deprived than those who chose not to participate, and the authors do not address how this may affect results. Similarly, large drop out rate over the course of the research. Data relied on parents' memory over 7 month periods. Only 20/56 had confirmed ASD diagnosis. Limited implications/ recommendations given.
Osborne & Reed (2008). Parents' perceptions of communication with professionals during the diagnosis of	South-east England. 70 parents (80% female) of children with ASD (18 preschool, 29 primary, 23	15 focus groups conducted across 5 LAs. Structured interview. Groups were audio recorded and	53% of parents reported being given very little or no support, advice or information about understanding autism following the diagnosis. 39% wanted more information about services or offers of support/help. Only 26% were offered educational help, 3%	Strengths: well situated in context of previous research; good sample size; good use of quotations to demonstrate experiences; provide good implications and recommendations.

autism.	secondary).	transcribed. Content analysis, with inter-rater reliability on 40% of the data. Descriptive statistics/ frequencies given, with some quotations from the groups.	respite, and 36% report being offered no help at all. 27% of preschool parents were offered an intervention (e.g. EarlyBird) but only 8% of primary/secondary parents. 28% of children were currently receiving educational support, 6% respite, and **37% reported currently receiving no support.** 14% said they would ideally like educational support, 7% a parent support group, 14% practical training for parents, 14% whole family support (e.g. counselling). Preschool and primary parents wanted more information, while secondary school parents wanted training for professionals to increase understanding. Conclusion: most parents want more information and support, and many are receiving no support.	Limitations: minimal demographic information provided (ages of parents, genders of children, diagnoses etc); style of analysis limits each parent to 1 answer (i.e. cannot be counted as wanting both educational support and respite), which may lead to misrepresentation.
Parsons et al. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey.	125 responses from families with a child with a disability. 90% white British. 2 groups: 66 ASD and 59 'non-ASD'. 93% aged 5-16, 74% male; 51% mainstream school, 69% had statement of SEN.	Mixed method. Online survey (part of larger project). 5 point Likert scales, closed questions, open (qualitative) questions. Rating scales and yes/no questions analysed using non-parametric between groups tests. Qualitative	No significant difference between school provision (mainstream, special etc) between ASD and non-ASD groups. ASD group felt significantly less likely to be able to choose the type of school they wanted. Parents in ASD group significantly more likely to say their child had SEN and that they were disabled, but no more likely to have a statement. All parents agreed that, on average, schools were doing well helping their child make good progress and feel settled. Exclusion from school was significantly higher in the ASD group (23%).	Strengths: very well situated in context of current legislation and also previous research; authors demonstrate good awareness and transparency. Limitations: recruitment method only accessed those in contact with/aware of specific support groups/websites; online survey excludes some participants; possible response bias; sample was biased towards middle-class; disability defined by parents not

			comments provided.	Conclusion: generally positive view of educational provision from both groups.	criteria so might limit accuracy, and generalisability is limited.
Potter (2017). "I received a leaflet and that is all": Father experiences of a diagnosis of autism.	306 fathers completed survey. 60% answered the relevant open-ended question: 184 fathers (94% white British, 81% aged 40+, 81% married, 59% employed full-time) of children with autism (82% male, age 0-19).	Qualitative paper. Online survey, 52 closed and 5 open questions, paper reports answers to 1 open question. Mixture of a priori and inductive thematic analysis. Example quotations given.	Several fathers felt 'relief' that a diagnosis/label would help them access support services. 20 fathers (11%) mentioned positive steps they took after diagnosis including information seeking or course attendance. 39 fathers (21%) commented on a significant lack of service support following diagnosis (e.g. "We felt cast adrift by a very poor support structure"); only 1 father described a positive experience of post-diagnostic support. 60% of whole sample (185/306) reported they had not felt adequately supported as the child's father in the period following diagnosis. Conclusion: fathers experience a range of challenges and service provision should be more sensitive to the needs of various genders.	Strengths: identifies and gives voice to fathers as an under-represented demographic in the literature, due to stereotypical gender roles; appropriate thematic analysis; good sample size; well situated in the context of previous research. Limitations: sample potentially not representative of fathers (e.g. sample disproportionately highly educated); lack of transparency in the generation of themes (e.g. no inter-rater discussion).
Preece (2014). A matter of perspective: the experience of daily life and support of mothers, fathers and siblings living with children on the autism spectrum with high	14 English families with at least 1 child on the autism spectrum: 14 mothers, 7 fathers, 4 brothers and 6 sisters, discussing 12 boys and 3 girls	Qualitative study. 32 semi-structured interviews undertaken. Mix of inductive and deductive thematic analysis used (reliability checked	Some families felt supported by extended family, church, or parent support groups, others felt they received limited support from family and friends. Families spoke of feeling guilt when using respite services. Formal social care support was felt to be limited and difficult to access, and some felt stigma attached to needing a social worker.	Strengths: provides and triangulates multiple (lesser-heard) perspectives; inclusion of quotations bring experiences to life; good transparency and reliability of data analysis. Limitations: limited discussion of context of study; does not provide

support needs.	on the autism spectrum (average age 12).	with independent auditor). Example quotations given.	Conclusions: Many felt that poor service exacerbated their difficulties, and that there was little understanding of autism. Schools were generally reported to be a positive source of support.	any clinical implications or recommendations.
Rogers et al. (2016). Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom.	116 professionals actively involved in autism diagnosis; 38 psychologists, 22 SLTs, 21 paediatricians, 15 psychiatrists; 79% NHS; 88% White; 66% had more than 5 years experience; professionals worked with individuals of all ages.	Mixed method online questionnaire combining Likert scales, open and closed questions. Descriptive statistics/ frequencies given. Thematic analysis of responses to open questions, by 2 authors with independent coding, then discussed and merged.	Only 44% of professionals reported they were meeting NICE guidelines and offering a post-diagnostic follow-up session within 6 weeks of the diagnosis. 83% always or frequently offered information leaflets, 82% offered information on support groups, 77% liaison with other services (e.g. school), 47% offered an education or support group for parents. 47% of professionals were satisfied with in-service post-diagnostic provision, while 31% were dissatisfied. Conclusions: Professionals generally felt there should be more provision, and that this should be less fragmented (more streamlined), and offered longer-term, although this was not currently possible in many services.	Strengths: provides much needed perspective/voice of professionals; strong method and analysis, with good transparency; good clinical implications and recommendations. Limitations: authors acknowledge potential sample bias (professionals from 'better' services may have opted to participate), and may have overestimated aspects of their service (responses may be inaccurate); sample was disproportionately White and psychologists were relatively over-represented.
Russell & Norwich (2012). Dilemmas, diagnosis and de-stigmatisation: Parental perspectives on the diagnosis of autism spectrum disorders.	Seventeen parents (88% female) participated, nine parents whose children had already received an ASD diagnosis (age of the diagnosed	Qualitative method; in-depth semi-structured interviews were analysed using thematic and grounded theory approaches. A	Parents described diagnosis as a passport to access services. Parents felt diagnosis was a "weapon" in their "fight" or "battle" to secure resources for their children and themselves. Many resources were accessed after the autism diagnosis, including: Educational resources, specifically one to one support in class; Social resources e.g.	Strengths: two distinct groups provide interesting comparison; well-structured analysis making use of stages identified in previous literature; makes use of participants' own terminology; well-illustrated theoretical implications.

	children at the time of interview ranged from 7 to 16 years old). Recruited via local parent support group or word of mouth.	modified form of constant thematic analysis was used to systematically explore parents' subjective accounts of their experiences.	access to support groups, holiday breaks; Health services e.g. mental health services; Access to information; Financial resources e.g. child benefits. Conclusion: there are many positive forms of support available for people with autism and their families, but it can be a "struggle" to access these without a diagnosis.	Limitations: small sample size; minimal detail provided about nature of analysis; lack of transparency around researcher's impact on analysis and results; no clear practical implications or suggestions for future research.
Tissot (2011). Working together? Parent and local authority views on the process of obtaining appropriate educational provision for children with autism spectrum disorders.	738 surveys returned, 707 from parents of children with ASD (24% aged 5-6; mean age 8-9; 90% had statement; 27% in mainstream school, 19% boarding school, 15% SEN school, 12% independent special school). 5 senior members of local authorities (south England) with responsibility for SEN provision.	Mixed methods. Parental questionnaire had 37 quantitative items and 2 open-ended questions. Semi-structured individual interviews with local authority (LA) personnel. Descriptive statistics/ frequencies; thematic analysis of qualitative data. Many quotations included.	Parents felt a label/diagnosis helps obtain provision, but LA personnel did not agree. Parents felt the problem of financial resourcing was a key barrier to obtaining provision. Process of determining educational setting "time consuming and overly bureaucratic"; parents felt LA focuses on what is 'cheap and available' instead of the child's needs. LA interviewees were well aware of budgetary constraints, but it is not the overriding issue that many parents believe it to be. LA reported issuing fewer statements, which parents said was a big concern. Among both parents and LA, some felt government policies on inclusion in mainstream schools were bad, while some though it was good. Several parents shared positive experiences with the LA. 65% of parents felt the process of obtaining appropriate provision was 'very' or 'extremely' stressful, and 'discussions with LA staff' was identified as the most stressful	Strengths: well situated in context of national policies and guidelines; combines perspectives of parents and local authorities to usefully explore this relationship (e.g. highlighting misperceptions); provides relevant implications of findings for future consideration. Limitations: limited demographic information provided for participants; LAs were in southern England and may not be generalisable to the rest of the UK; 1 of the 5 LA interviews was not recorded (may be less accurate); lack of transparency in thematic analysis procedure; authors do not address the impact of privileging LA voices (5) over parents (707).

			factor. Both parents and LA staff disliked the Tribunal process. 80% of parents had their child in their placement of choice, but only 36% of parents said that reaching an agreement was straightforward. LA staff were proud of their high quality provision, but cited the stressful factor of an increasing number of children with ASD diagnoses. Conclusion: there is a need for more effective communication between parents and local authorities at all stages.	
Unigwe et al. (2017). GPs' confidence in caring for their patients on the autism spectrum: an online self-report study.	304 GPs took part from across the UK; 72% female; age 27-70; 80% White; mean time in practice 11 years.	Mixed method online self-report survey. Combined rating scales, closed and open questions. Includes descriptive statistics, frequencies, correlations and regressions. Qualitative comments analysed using inductive thematic analysis by two authors.	GPs self-rated their confidence as only 4.4/10 for 'Knowing which community resources in my area are available for children and adults with autism'. GPs reported limited resources to provide support post-diagnosis, and said 'support for autistic adults was virtually non-existent'. GPs felt a lack of confidence about what resources were out there, as these services were constantly changing. Some GPs felt their role was to be aware of local support services for ASD, others felt that caring for people with ASD was beyond their scope. Many noted that accessing resources is very difficult and it would be helpful to have more information. Conclusions: GPs are not confident about providing or signposting to post-diagnostic support.	Strengths: large sample size; provides unique professional perspective on post-diagnostic support for people with autism; good transparency of method; well situated in context of recent policies; provides solid implications for both practice and research. Limitations: authors identify potential response bias (almost half of responders had a personal connection to autism), thus may overestimate GPs knowledge and awareness of autism which may be lower amongst non-responders; sample gender and ethnicity may not be representative of all GPs.

| Whitaker (2007). Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say – and what parents want. | 49% response rate. 173 responses from parents of children with ASD in mainstream schools (64% had SEN Statement). | Mixed method postal questionnaire, combining Likert rating scales and open ended questions (after service user pilot); descriptive statistics/ frequencies reported; inductive thematic analysis of qualitative data. Example quotations provided. | 61% of parents were 'satisfied' or 'very satisfied' with their child's educational provision. Dissatisfaction with provision is approximately 4 times higher in mainstream than in special schools/units. Dissatisfaction was higher for those without Statements than those with (around half vs one-third). Dissatisfied parents were most concerned with staff's understanding of their child's difficulties, ability to manage their behaviour, and breaktimes. Satisfied parents reported having a good relationship with the school (80%), being kept informed, and schools being flexible. All parents ranked their child's progress with social skills, staff understanding, and level of structure as top priority issues. 'Staff understanding my child' was the top issue mentioned by both groups in the open ended questions (two-thirds) and has a substantial impact on satisfaction. Only 1 in 5 dissatisfied parents felt their child was accepted by peers, and 70% highlighted problems at breaktimes. Conclusion: the majority of parents are satisfied with their child's educational provision, although all parents still have many concerns which need to be addressed. | Strengths: well situated in local context and in context of current national policies; comprehensive and accessible recruitment procedure; questionnaire went through service user pilot; good transparency of qualitative data analysis method; qualitative quotations exemplify participants' experiences; provides relevant implications and recommendations, again well situated in local and national context. Limitations: potential response bias of parents (views or experiences may not be representative); did not provide demographic information on parents or children (e.g. age, gender, ethnicity). |

1.6.4. Synthesis of Main Findings from Literature Review

The following section synthesises the key themes which emerged from the papers included in this systematic review regarding people's experiences of post-diagnostic support. It discusses three themes: inadequate provision of post-diagnostic support, experiences of educational provision, and gender roles.

1.6.4.1.   Inadequate Provision of Post-Diagnostic Support

Around two-thirds of the papers included were directly in line with a theme that could be described as 'inadequate provision of post-diagnostic support'. The experiences of individuals on the autism spectrum, parents, families, and professionals were consistently that the provision of information and support after diagnosis tends to be limited, difficult to access, and generally insufficient and unsatisfactory. Proportions of people who were not offered or not receiving any post-diagnostic support ranged from 23% to 42%, with approximately one-third of parents reporting that their child was not currently receiving any support. Parents reported a feeling of "just sort of…being dumped after the diagnosis…this is where the system fails" (Crane et al., 2018, p.7) and "we were left in the dark…we were given no information" (Crane et al., 2016, p.159), a feeling mirrored throughout much of the research. It is disappointing to note that this theme of inadequate provision runs throughout the literature from the oldest paper (Mansell & Morris, 2004) to very recent articles (Crane et al., 2018; Galpin et al., 2017), suggesting little improvement in recent years despite the context of recent policies, such as the government's 2014 'Think Autism' strategy. A number of papers addressed the negative impact that inadequate provision can have on mental health (Bromley et al., 2004; Jones et al., 2014), in line with what has been previously well-established in other research about the experiences of families living with

autism (see section 1.5.5). Throughout the review, reports of positive experiences of post-diagnostic support were very rare, and tended to focus around educational provision, which is discussed below (section 1.6.4.2).

Much of the research reports people relying on family and friends for support in the face of inadequate provision from services (Bromley et al., 2004; Dillenburger et al., 2010; Galpin et al., 2017; Preece, 2014). This is concerning as families are often under significant stress and therefore may struggle to support one another, and many people do not have families around them to provide this support (Bromley et al., 2004; Preece, 2014). Many parents turned to other parents for support and this is generally reported as a positive source of support throughout the literature. This applies to both support (e.g. emotional support) and also the provision of information about autism and services, for example: "The best support and advice I have got is from meeting other parents, not the medical profession at all" (Crane et al., 2018, p.8). This theme runs throughout much of the literature, suggesting fellow parents have always been a significant source of information and support for parents of children on the autism spectrum. While parent support groups clearly play a valuable role, this is understandably a serious issue for parents, as one parent highlighted: "that's just hopeless because it's just loads of people helping each other who are…on the verge of a nervous breakdown" (Crane et al., 2018, p.8).

Another theme which emerged within the theme of inadequate post-diagnostic support was 'having to fight' for services, support or resources; no less than seven papers mentioned this. This occurred across numerous situations, from "having to fight on their own to navigate different educational and health care systems" (Hebron & Bond, 2017, p.563), to "embattled with the local authority, fighting for services" (Preece, 2014, p.86), to "parents…needed constantly to fight to obtain the services to which they were entitled"

(Galpin et al., 2017, p.579). These quotations exemplify the persistent difficulties that people experienced trying to access services or obtain support, and it is both disappointing and concerning that parents are having to exert additional energy and endure additional stress simply trying to deal with the services tasked with providing the support designed to help them. As one parent said, "it's an uphill struggle every day battling with the authorities for his rights" (Mansell & Morris, 2004, p.403).

However, it is important to present the other side of this story: the experiences of professionals involved in the provision of support. Four papers took into account professionals' views and experiences (a fifth focused specifically on local authority personnel and will be discussed below in the context of education provision). Overall, professionals were well aware of parents' lack of satisfaction with services, and generally expressed a feeling of frustration that they were not able to provide more support within the restraints of their service. Less than half of professionals were satisfied with the post-diagnostic support their service provided: "Sadly many families are given a diagnosis and that is it…I think there should be more provision as standard" (Rogers et al., 2016, p.828). Whilst professionals agreed that there is a need for increased support and specialist provision (Dillenburger et al., 2010; Unigwe et al., 2017), many cited a number of pressures including lack of funding and limited resources as factors restricting the provision of better post-diagnostic support. Professionals were frank in discussing these pressures: "We would like to provide ongoing treatment and support but we are not commissioned to do this" (Rogers et al., 2016, p.828), and recognised the role that parents and families had in supporting each other: "you'd like to be offering more but the reality is that it's more about helping them help themselves" (Crane et al., 2018, p.8). Whilst many parents may criticise

professionals, these examples highlight the systemic issues and pressures which contribute to people's experiences of inadequate post-diagnostic support.

1.6.4.2.   *Educational Provision*

The second theme which emerged from the review was around experiences of educational provision, and it is interesting to note that, whilst experiences of general post-diagnostic support were overwhelmingly negative, people's experiences of educational provision were consistently more positive across the literature. Around a quarter of the papers in this review reported on education, and the majority of parents were happy with both their child's placement and provision, and generally saw schools as a positive source of support (Bromley et al., 2004; Parsons et al., 2009; Preece, 2014; Whitaker, 2007). This finding is quite surprising; indeed, one author remarked: "the popular media image of children with ASD being disproportionately disenfranchised in the educational system compared with children with other disabilities or difficulties may be inaccurate" (Parsons et al., 2009, p.55). One paper reported on the overwhelmingly positive experiences of pupils and parents of additional resource provision in mainstream schools in one local authority (Hebron & Bond, 2017), including improved autism awareness, and positive impacts on academic outcomes, social skills, school experience and home life/behaviour. However, this was an evaluation of very localised and recent changes in one city in England, and there is limited information about the feasibility of rolling out such changes nationwide. Two papers noted that teachers feel highly dependent on TAs for effectively supporting pupils on the autism spectrum in mainstream schools, and that teachers often take less responsibility for these pupils (Emam & Farrell, 2009; Humphrey & Lewis, 2008).

Despite the general positive regard for education provision across the literature, it was not without its issues; all papers which mentioned education reported some degree of negative experiences. While most parents had the school of their choice, the process of obtaining placements was overall a difficult one. Parents of children on the autism spectrum were less likely than others to have the school of their choice, and often had to battle for placements: "the process itself is a long tortuous affair…to get an educational provision for any autistic child is a nightmare" (Tissot, 2011, p.8). Levels of dissatisfaction were higher in mainstream schools than specialist schools, and the majority of children on the autism spectrum are in mainstream schooling, due to the UK government's policy of inclusion (DCSF, 2009; Tissot, 2011). This often led to tension between parents and local authorities (LAs), with many parents' being of the view that LAs prioritised budgets and costs over their child's needs. As discussed, the literature review generally revealed negative misperceptions in parents' and professionals' views of one another, and nowhere was this more so than with parents and LA personnel. Although funding was raised as an issue, LA staff were more concerned about increasing demand due to increasing numbers of children on the autism spectrum. It may be that the difficulties parents experience battling for the educational provision of their choice are further exacerbated by misunderstandings between parents and professionals.

Another problematic theme within educational provision was experiencing a lack of awareness and understanding about autism; many papers relayed people's experiences of teachers, schools and local authorities not displaying an understanding of their child's autism/needs (Galpin et al., 2017; Ludlow et al., 2012; Preece, 2014; Whitaker, 2007). Whilst this may again be a misperception between parents and professionals, it has significant impacts on the wellbeing of parents and individuals on the autism spectrum, as one mother

wrote: "They seemed to know all about autism, and be clued up…but in actual practice, they're not. So he's always getting told off, and generally he comes home from school in a state. Crying, upset and angry" (Preece, 2014, p.87). Unsurprisingly, this lack of understanding seemed to be worse in mainstream settings (where the largest proportion of pupils on the autism spectrum are placed): "[the school] did not do anything or know anything…they don't seem to understand" (Galpin et al., 2017, p.576). This theme of 'lack of understanding' was prominent across much of the literature, both regarding education but also in people's experiences of post-diagnostic support more generally.

1.6.4.3.   Role of Gender

The final theme to emerge from the literature review was that of gender roles. The vast majority of parental participants across this systematic review were female, and participants on the autism spectrum tended to be male, consistent with existing research (Loomes et al., 2017). Carpenter & Towers (2008) identify that "support services for families focus primarily on the needs of mothers and are predominantly provided by women" (p.118), a fact which has negative consequences for both mothers and fathers of children on the autism spectrum. One paper in the review (Bromley et al., 2004) focused purely on mothers' experiences, as "the vast majority of primary carers of children with ASDs are their mothers" (p.410), and reported that lone mothers experience less family support and less formal support than mothers living with a partner. The expectations placed on mothers to be the primary carers can result in additional psychological distress, and because of this mothers are affected more than fathers by how much support they receive (Boyd, 2002).

This focus on mothers as the primary carer, while causing mothers additional stress, also alienates fathers from the process, an experience addressed by one paper in the review (Potter, 2017). Whilst these fathers mirror the experiences of inadequate provision of post-diagnostic support that was present across the review, the fathers in this study also reported feeling excluded: "I felt unheard – all the focus was on his mum…the assumption is that daddy is either absent or useless" (p.101). The absence of fathers from the autism literature is of concern, as research has shown that mothers and fathers of children on the autism spectrum have significantly different needs and expectations when it comes to support (Papageorgiou & Kalyva, 2010; Preece, 2014). This literature review highlights the importance of considering the role of gender in the provision of post-diagnostic support, and the need for more research in this area.

1.6.5. Evaluation of Overall Quality of Literature

Analysis of the overall quality of the studies included in this literature review shows particular strengths and weaknesses in the quality of the literature. Studies were generally good at having employed an appropriate design for the nature of the study, and many studies went to great lengths to enable access through comprehensive recruitment methods. On the whole, sample sizes were strong, with the majority of the studies including at least 50 participants, and two very large studies with over 500 participants (Crane et al., 2016; Tissot, 2011). Studies covered the majority of regions in the UK, putting together a cohesive picture of the current context in the UK. The balanced mixture of qualitative, quantitative and mixed methods studies also provided a wealth of informative statistics

whilst at the same time providing many example quotations which brought to life people's experiences of post-diagnostic support.

Papers were generally very good at stating the context of the research, with only one paper failing to meet the criteria in this area. This positive quality perhaps reflects the significance of context for this particular area of research. Unfortunately, studies were generally poor at stating the impact of the researchers and being transparent in the reporting of the study, with over half of the papers failing to meet one or both of these criteria. These are important qualities for research as without them it can be unclear how and why certain data was analysed and whether this is representative of all the data collected. These are perhaps the most difficult but important qualities for research to meet; a particularly good example was Rogers et al. (2016). Indeed, the four papers produced as part of a larger project by Crane et al. (2018, 2016), Jones et al. (2014) and Rogers et al. (2016) were exemplary amongst this literature review in adhering to quality criteria, as was Galpin et al. (2017).

1.6.6. Conclusions of the Systematic Literature Review

There are a number of key conclusions from this systematic review. The first is that people overwhelmingly experience inadequate post-diagnostic support following a diagnosis of autism in the UK. The second is that experiences of education provision for children with autism are more positive, although there are still a number of significant issues in this area, especially around process. The final conclusion was that gender is an important factor when considering post-diagnostic support, and traditional gender roles can have negative impacts on both mothers and fathers of children on the autism spectrum.

1.6.7. Gaps in the Literature

There are a number of gaps in the literature identified following this systematic review. Many papers touched on people's experiences of post-diagnostic support as part of research largely focussing on the diagnostic process; few papers focused purely on people's experiences of post-diagnostic support, and none of these were qualitative. While some papers have presented adults' experiences of post-diagnostic support, there is a gap in the literature when it comes to children and young people presenting their experiences. Similarly, while some papers presented the perspectives of NHS staff and local authority personnel, very few papers mentioned the experiences of school staff in providing post-diagnostic support for children with autism. As schools were identified across the literature as one of the key sources of support for families with a child with autism, it seems important to address this gap as well, in pulling together all aspects of post-diagnostic support including schools.

1.7. Rationale for Current Research Project

The systematic literature review above demonstrates that, while there is some existing literature on post-diagnostic support for people on the autism spectrum, there is very little qualitative research focusing on people's experiences of post-diagnostic support for children on the autism spectrum, and none that includes a combined analysis of the perspectives of children and young people on the autism spectrum, their parents, and school staff involved in providing support for children on the autism spectrum. The current project attempts to address this need.

An additional rationale for the current project is that it aims to capture the experiences of people in one specific London borough. This has two purposes, the first being to inform clinicians and professionals in that borough about people's experiences of support to inform and improve practice. The second is to provide information to other geographical areas about parts of the system which are working well (good practice guidelines) and parts which are not working well and need improving. By sharing these types of perspectives, local areas can learn from one another, contributing to upgrades to services on a wider national scale.

1.8.   Research Aims and Question

This project looks at experiences of post-diagnostic support with a focus on education. The primary aim of this project is to allow young people on the autism spectrum, their parents, and school staff to voice their experiences of post-diagnostic support for children on the autism spectrum and their families. The aim is to provide a platform for them to voice what their experiences have been, the potential issues, challenges and barriers, but also examples of good practice and support. The project will aim to generate and facilitate greater understanding of people's experiences in this area, and what could be done to improve this. One emphasis will be on how the system can change to better meet the needs of children on the autism spectrum and their families.

The research therefore aimed to answer the following question:

What are people's experiences of post-diagnostic support for children and young people on the autism spectrum?

This question had three further sub-questions:

1) *What are the experiences of children and young people on the autism spectrum of receiving support after diagnosis?*

2) *What are parents' experiences of post-diagnostic support following their child being diagnosed with autism?*

3) *What are the experiences of school staff of support for children and young people on the autism spectrum and their families?*

2. Method

This chapter details the method used to investigate the research questions. The design of the study is discussed, and a justification of the methodology is situated in the epistemological context. Information is provided about recruitment and participants. Service user consultation is reported, notably in the context of the development of the interview schedules. This chapter also addresses and reflects on ethical issues, before providing an overview of the procedure and data analysis implemented.

2.1. Design

2.1.1. Qualitative Methodology

Qualitative research tends to be interested in how people make sense of the world, how people experience events, and the meanings people attribute to events. It is used by researchers from a variety of different epistemological positions (Willig, 2013). The following outlines why I chose a qualitative methodology, and how this fitted with my epistemological position of critical realism.

The fit between the nature of qualitative research and what I wanted to achieve with this project was overwhelming: the opportunity to give voice to people often drowning in vast and complex healthcare and education systems. I knew I wanted to meet people face to face and hear what they had to say, and to try my best to have an impact by encouraging other people to listen. I knew that this may be more difficult to achieve through quantitative research, as individual voices and experiences may get lost in the numbers. However, I was also aware of the following issue: *If I am claiming to give voice to my participants, how am I*

navigating the power and privilege that come with being in the position of the researcher,

and recognising the role I play in interpreting their voices?

This was where my choice of qualitative methodology fitted with my critical realist

epistemological approach (Fletcher, 2017; Maxwell & Mittapalli, 2011). In Section 1.2 I

described a key feature of critical realism as: 'our interpretation of reality is shaped by the

lenses through which we view it', and I believed a quantitative methodology may struggle to

be consistent with such an approach. A qualitative method, on the other hand, allows one

to study people's experiences of reality whilst acknowledging the various lenses affecting

this interpretation. By acknowledging the impact that I had as the researcher when it came

to interpreting the data, I attempted to create space between myself and the results which

allowed the voices of the participants to be heard. There were a few ways in which I did this,

such as by attempting to minimise the impact of my personal biases/context (e.g. by

involving service users throughout the project), and by demonstrating transparency

throughout the process (e.g. by providing a reflective diary).

2.1.2. Thematic Analysis

Once I had decided to undertake a qualitative project, I set about choosing my

specific method. I considered thematic analysis, narrative analysis, grounded theory, and

interpretative phenomenological analysis. Whilst the majority of qualitative methods would

have fitted with both my epistemological stance and the aims of this project, I settled on

thematic analysis (e.g. Braun & Clarke, 2006; Joffe, 2012) for the following reasons.

Thematic analysis is "a method for recognizing and organizing patterns in content and

meaning in qualitative data" (Willig, 2013, p.178), and it has been described as a generic skill

which forms the basis of much, if not most, qualitative research (Joffe, 2012). Although

some have argued that thematic analysis is a not a specific method in its own right, but a

tool or process used across different methods (e.g. Boyatzis, 1998; Ryan & Bernard, 2000),

others have argued that thematic analysis should be considered a method in its own right

(e.g. Braun & Clarke, 2006; Joffe, 2012). Braun & Clarke (2006, p.15) stated that thematic

analysis "involves the searching across a data set – be that a number of interviews or focus

groups... – to find repeated patterns of meaning". It was clear to me that thematic analysis

would allow me to address the aims of the project – finding meaning in the voices of my

participants.

One of the strengths of thematic analysis is its flexibility: using thematic analysis

does not commit the researcher to any particular theoretical or epistemological approach

(Braun & Clarke, 2006; Willig, 2013). Epistemologically, thematic analysis may be considered

highly congruent with my critical realist approach, as it can be used to try and reflect the

ways individuals make meaning of their experiences whilst acknowledging the wider

contexts impacting on those meanings (Braun & Clarke, 2006). There are two main forms of

thematic analysis. In an inductive or 'bottom up' approach, the themes emerge from the

data and do not reflect pre-existing theoretical codes. By contrast, a deductive or 'top down'

approach to thematic analysis may use a pre-existing coding template, typically informed by

the relevant literature, in order to derive themes from the data. In this project I used an

inductive or 'bottom-up' approach, to allow themes to emerge from the data with minimal

theoretical pre-conceptions. However, it is important to note that, whilst I did not use any

pre-existing template to code the data, it is impossible to entirely free oneself from biases,

so I have done my best to acknowledge the various lenses which I brought to the research

which potentially affected the analysis. Another strength of thematic analysis is its

transparency (Joffe, 2012), which I have attempted to embody throughout this research, not least in my inductive approach to the thematic analysis of my data.

Finally, there was also a good fit between thematic analysis and my main method of data collection: focus groups (as discussed below). There is a considerable amount of literature which states that thematic analysis is one of the most commonly used and appropriate methods for analysing data from focus groups (Wilkinson, 2004), and that doing so is consistent with a realist epistemology (Braun & Clarke, 2006; Willig, 2013).

One of the weaknesses of thematic analysis is that there can be a lack of clarity about how to actually conduct a thematic analysis, which can be paralysing for researchers. However, this was largely remedied, at least in psychology, by Braun & Clarke (2006) who provided detailed guidelines on how to conduct a thematic analysis. Similarly, thematic analysis is sometimes criticised for being overly simplistic, however I would argue that the 'lack of clarity' regarding conducting thematic analysis and its 'simplicity' could both be interpreted as *flexibility*, generally considered one of the strengths of this particular method. Another potential disadvantage of thematic analysis compared to, for example, narrative analysis, is the loss of a sense of continuity through individual accounts, and less focus on language. Braun and Clarke (2006) also stated that thematic analysis can have limited interpretive power if claims are not adequately linked to existing theoretical frameworks. However, many of these potential weaknesses of thematic analysis can be avoided by thoughtfully conducting a rigorous, structured and informed analysis of the data.

2.1.3. Focus Groups

This section details why I chose focus groups as my main method of data collection. Focus groups are a way of collecting qualitative data by engaging a small number of people in an informal group discussion focused around a particular topic or set of issues (Wilkinson, 2004). This is usually based on a series of questions (the schedule) and the researcher typically acts as a 'moderator' for the group. The *interaction between participants* is the 'hallmark' of focus group research (Grønkjær, Curtis, de Crespigny, & Delmar, 2013), and one of its biggest strengths, as it encourages participants to respond to and comment on one another's contributions – thus "statements are challenged, extended, developed or qualified in ways that generate rich data for the researcher" (Willig, 2013, p.122). Another advantage may be that being in a group can be perceived as less threatening for many participants (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009), although this may not be the case for individuals on the autism spectrum due to difficulties with social communication.

Wilkinson (2004) stated that focus groups typically have between two and twelve participants, with the norm being between four and eight, while Willig (2013) wrote that focus groups should consist of no more than six to eight participants. This is to ensure that all participants remain actively involved in the group discussion throughout data collection. It is also noted that it can be difficult to transcribe a group discussion of more than six participants accurately. Focus groups tend to run for one and a half to two hours, although they can often be shorter (Willig, 2013). The group is asked a number of open questions about their experiences, and discusses their experiences with other members of the group and the facilitator, who may ask follow-up questions. In this way, the focus group is semi-structured and will, to some extent, guide the nature of its own conversation.

Willig (2013) stated that focus groups can be:

1) homogenous (where participants share key features) or heterogeneous (where participants are different)

2) pre-existing (e.g. a group of friends or work colleagues) or new (where participants have not met before)

3) concerned (where participants have a stake in the subject matter) or naïve (where participants do not have any particular commitment in relation to the subject matter).

In this study, the focus groups were generally *homogenous* (see section 2.1.4), *new* (although it was reasonable to expect that some parents or school staff may have met before), and *concerned* (where participants have a pre-existing investment in the provision of support for an individual on the autism spectrum).

Whilst I set out to collect my data using focus groups, during the process of service user consultation (see section 2.6) it was suggested that individual interviews might also be necessary, particularly, for example, in the case of children/young people on the autism spectrum, who may find it difficult to participate in a group setting. One young service user noted that she would prefer a one-to-one interview than a group and that this would allow her to talk more freely about her experiences. In the end, all data collected from children/young people on the autism spectrum was obtained through individual interviews.

There was one focus group organised to which only one person attended. Whilst this was quite disheartening (to both the participant and myself), we decided to proceed with the interview. One of the advantages of such an interview, for the participant, was that it

allowed them to talk at length about their experiences, although they potentially missed out

on meeting other people who may have shared their experience. I was very aware that, as

the researcher, I would need to be careful not to unintentionally prioritise some voices over

others when analysing the data. I was also aware that one of the strengths of thematic

analysis is its flexibility, in that it would allow me to integrate and analyse both focus group

and individual interview data.

Additional sections of my reflective diary relating to the focus groups can be seen in Appendix 6.1.

2.1.4.   Designing the study populations

This research project had three study populations: children and young people on the autism spectrum, parents of children on the autism spectrum, and school staff who work with children on the autism spectrum. This design of study populations helped triangulate the experiences of provision of post-diagnostic support, with a focus on education. This was also influenced by the literature review which highlighted that schools are typically a significant source of post-diagnostic provision for a majority of families with a child on the autism spectrum. Separate focus groups were held for parents and school staff, as it was felt that homogenous groups would be the most appropriate setting for discussions and may best facilitate the sharing of individual's experiences and generation of common themes. For example, parents may have found it difficult to express their dissatisfaction with parts of a system in front of teachers or SENCOs, so a safe space was created for them to express

both positive and negative experiences. Children on the autism spectrum may have found it

difficult to speak in groups, so data was collected through individual interviews.

2.2. Setting

This research took place in an inner London borough. The population of this borough

has increased dramatically in recent years to around 230,000 (Office for National Statistics,

2018). Being one of the smallest districts in the entire country, this borough has one of the

highest population densities, at approximately 41,000 per square mile – more than thirty

times the national average. This borough has a diverse population; in 2011 the population of

this borough was 68% white, 13% black, 9% Asian and 6% mixed. Poverty is a significant

problem in the borough, with over a third of people living in poverty (33.7% compared to

27% London average). Child poverty is high, with approximately 40% of children in this

borough living in poverty; over 70% of these live in lone parent households (Trust for

London, 2018). Pay levels are low and income inequality is high; 10% of working-age people

are claiming an out-of-work benefit. There are two main groups that together account for

over 90% of the local population. They are described as "young people renting flats in high

density social housing" (43%) and "young well educated city dwellers" (48%) (The ▮▮▮▮

Fairness Commission, 2016). These diverse groups are representative of the significant

inequality among the population of this area.

This borough has approximately 50 primary schools, 10 large secondary schools, and

about 6 special needs schools, as well as satellite provisions based in mainstream settings.

One of the schools in the borough also provides a specialist school outreach service to

support other schools in the area with pupils with SEN. The local CAMHS service aims to have a CAMHS clinician linked with each school. In collaboration with the local authority, a large national third sector organisation provide Early Help services for families, and SENDIASS (Special Educational Needs and Disabilities Independent Advice and Support Service), a specialist service set up to support parents in navigating the education system when their child has an additional need. The local authority runs the local SEND team which co-ordinates school placements and education health and care plans (EHCPs). The local authority also provide specialist support for Under 5s and their families in children's centres across the borough. The local CAMHS service includes a number of teams, one of which is the Neurodevelopmental team (who perform autism assessments). The specialist Under 5s service for assessment of autism sits separately within children's health services. Another local charity provides the local parent forum which supports parents of children with all types of SEN including autism.

2.3. Participants

2.3.1. Inclusion/exclusion criteria

There were three groups of participants; for inclusion/exclusion criteria, please see Table 5. Participants were recruited from one London borough. Within the scope of the current project, only participants who were able to verbally communicate in English were able to participate. It is recognised that this may have excluded many already marginalised people from taking part who have valuable contributions which need to be heard; unfortunately this was not feasible within this research.

Table 5: Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Young people on the autism spectrum • Have a diagnosis of autism/ASD/ASC • Are of school age • Are attending a school in [London borough] • Have some verbal English language	**Young people on the autism spectrum** • Do not have a diagnosis of autism/ASD/ASC • Are not of school age • Are not attending a school in [London borough] • Have no verbal English language

Parents of children on the autism spectrum
• Are a parent/primary caregiver to a child who:
   o Has a diagnosis of autism/ASD/ASC
   o and is of school age
   o and is attending a school in [London borough]
• Parent must have some verbal English language
	Parents of children on the autism spectrum
	• Is not a parent/primary caregiver to a child who:
	   o Has a diagnosis of autism/ASD/ASC
	   o and is of school age
	   o and is attending a school in [London borough]
	• Parent has no verbal English language

School staff who work with children with autism • Is a member of school staff who supports children with a diagnosis of autism/ASD/ASC • Works in school in [London borough] • Have some verbal English language	**School staff who work with children with autism** • Is not a member of school staff who supports children with a diagnosis of autism/ASD/ASC • Does not work in school in [London borough] • Does not have some verbal English language

2.3.2. Recruitment

Recruitment for this project was an ongoing process from June – December 2018 (alongside data collection). Parents were predominantly recruited through the local parent forum, a local support group in this borough for parents of children with Special Educational Needs or Disability (SEND). This parent forum hosted a monthly meeting for parents of children on the autism spectrum, which was where I began recruiting, and my recruitment was aided significantly by the head of the parent forum. I reflect on the characteristics of my parent sample in section 2.3.3.

School staff were recruited in a few different ways. Recruitment emails were sent to all SENCOs in the London borough, asking them to participate but also to circulate the recruitment information to their staff who work with children on the autism spectrum. Through communication with the SENCO Co-ordinator for this London borough, I was also able to attend the SEN Transitions meeting for this borough (where primary and secondary SENCOs meet to discuss certain pupils who will be transitioning from one school to the other). At this meeting I spoke to many school staff about my project, and many signed up to participate. From the contacts made at this meeting and also through email recruitment, I was able to recruit the majority of school staff for my project. The rest were recruited via school staff who had already participated in my project through snowballing.

Two of the young people in the study were children of parents who also participated in the study. One of these children was recruited via the parent, the other via the school SENCO. The other young people who participated in the study were recruited via school SENCOs who had already participated in the study. Again, it is worth noting that some young

people on the autism spectrum were unable to participate in the study due to difficulties with verbal communication, so their views were not heard. *See Appendix (6.1) for my reflections on these issues.*

2.3.3. Participant demographics

Eight parents took part in the project (see **Table 6**). The eight parents represented ten children on the autism spectrum (two parents had two children with diagnoses), from nine different schools. One of the parents was a grandparent but the main carer for their (grand-)child on the autism spectrum. Of the ten children represented by the parents, eight had additional needs or diagnoses, including speech and language difficulties, learning disabilities, epilepsy, ADHD, anxiety and eating disorders. Data from the eight parents was collected through one focus group of 4 parents, one focus group of 2 parents, and 2 individual interviews. Individual interviews lasted approximately 1 hour and focus groups lasted approximately 90 minutes.

Table 6: Demographics of Parent Participants

PARENT PARTICIPANTS (N=8)	
Age	Mean = 43.4 years Range = 26 – 57
Gender	7 female, 1 male
Ethnicity and First Language	7 = White British; English 1 = Pakistani; Urdu

Number of children	Mean = 2.6
Number of children on the autism spectrum	Total = 10
Children on autism spectrum - gender	6 male, 3 female, 1 f/m*
Children on autism spectrum - age	Mean current age = 10.7 years Mean age at diagnosis = 6.8 years

*participant's own terminology used.

Eleven school staff representing five different schools took part in the study (see **Table 7**). Four were SENCOs (one of whom was also 'Inclusion Manager'), three were teachers, and four were teaching assistants (TAs), one of whom was a 'High Level TA', and one of whom was a TA/Nursery nurse. Eight staff worked with children of primary age, and three worked with children of secondary age. Data from school staff were collected through 3 focus groups (one of 4 SENCOs, one of 3 TAs, and one of 3 teachers and 1 TA). Focus groups lasted between 1 hour and 90 minutes.

Table 7: Demographics of School Staff Participants

SCHOOL STAFF PARTICIPANTS (N=11)	
Age	Mean = 34.6 years Range = 21 – 63
Gender	10 female, 1 male
Ethnicity and First Language	9 = White British; English 1 = White Other; English 1 = Black British Caribbean; English

Time in Role	Mean = 5.0 years
Time in School	Mean = 5.4 years
Time in Borough	Mean = 5.9 years Range = 2 weeks – 26 years

Four children and young people on the autism spectrum participated in the study (see **Table 8**), representing two different schools (one child was from a primary school, the other three from one secondary school). Three children reported having autism, one reported having Asperger's. One child reported additional needs of ADHD and sensory integration needs. Data were collected through four individual interviews, lasting between 30 minutes and 1 hour.

Table 8: Demographics of Children and Young People Participants

CHILDREN AND YOUNG PEOPLE PARTICIPANTS (N=4)	
Age	Mean = 12.25 years Range = 9 – 15
Gender	3 male, 1 female
Ethnicity and First Language	2 = White British; English 1 = Mixed British; English 1 = Bangladeshi; English
Age at diagnosis	Approx. mean = 8.6 years (2 knew, 1 child

	did not know, 1 guessed).

2.3.3.1.   *Sample Characteristics*

The following are a few considerations about how this sample would compare to the broader population. With regards to the ethnicities of the parents who participated, the sample was not representative of the local population of parents of children on the autism spectrum. Less than half of the population of this London borough are White British, which was not reflected in my sample, and some of the reasons for this have been discussed (in terms of recruitment pathways and accessing the study). The genders of parents in this study reflected existing research which tends to be with mothers as the primary caregivers, and mirrored the lack of the male parental perspective in the literature. In terms of school staff, gender reflected that of the broader school staff population, which tends to be female. My school staff were mainly from primary schools, whilst my children and young people who participated were mainly from secondary school, perhaps somewhat reflecting the general ability level needed to participate in the study. The genders of the children and young people who participated (although a very small sample size) did reflect the gender ratio currently in the literature of three males to one female (Loomes et al., 2017). The ethnicities of the children and young people in the study were a more representative reflection of the local population than the parents.

2.3.4. Sample Size

Within qualitative research there is considerable debate around the issue of how much data is required for a particular study. A particularly contentious concept in this area is

that of 'saturation' – the point in the analysis at which all categories are well-developed and additional data adds little new to the conceptualization (Corbin & Strauss, 2008; Glaser & Strauss, 1967). There are a number of issues with saturation; O'Reilly & Parker (2013) note that there is no established consensus in the research community about the meaning or application of saturation, yet it is a common requirement of funders and reviewers of research. Guest, Bunce, & Johnson (2006) state that data saturation is often very poorly defined, and "there are no published guidelines…for estimating the sample size required to reach saturation" (p.60). In one experiment with data saturation, Guest et al. (2006) performed a thematic analysis of 60 transcripts of individual interviews. They found that 73% of codes were identified after the first 6 transcripts, and 92% within the first 12. In terms of high-frequency codes (i.e. commonly expressed themes), 94% had been identified within the first 6 interviews, and 97% after the first twelve. They concluded that, in their analysis, data saturation had for the most part occurred within twelve interviews.

Dey (1999) described saturation as an 'unfortunate metaphor', as it suggests a point beyond which it is not possible to add anything further – a false sense of completeness. Dey instead introduced the idea of data sufficiency, which Nelson (2017) developed into the notion of conceptual depth, meaning the researcher reaches a sufficient depth of understanding of a concept. Nelson produced conceptual depth criteria, which include that a wide range of evidence be drawn from the data to illustrate the concepts, to produce a rich network with complex connections and subtleties, which resonates with existing literature, and stands up to testing for external validity. However, what is important is that researchers are *transparent* about when and why they stopped collecting and analysing data. In the current study, I will not claim to have reached 'saturation'. Thorough data

collection efforts were undertaken to obtain rich data to sufficiently address Nelson's

conceptual depth criteria within the realistic scope of this study. The sample size for this

project was in line with suggestions made by Clarke & Braun (2013) for a 'medium' size

project, and was comparable to other recent published research in this area (e.g. Crane et

al., 2018).

2.4. Development of Interview Schedules

Interview schedules were developed to guide the focus group discussions (and

individual interviews) to generate data that would help answer the research questions.

Interview schedules were flexible to allow participants to discuss their experiences as

openly as possible, and to allow participants to raise any topics, themes or concerns that

they felt relevant and appropriate (Willig, 2013). Three separate interview schedules were

created, one for each participant group. These asked questions about people's experiences

of post-diagnostic support, the positives and negatives of receiving or not receiving support,

and what they would like to change or improve about the system (if anything). The full

interview schedules can be seen in Appendix 6.2.

The process of developing the interview schedules was an iterative process and the

questions evolved through many versions. The initial schedules were created by myself and

my supervisors, and were influenced by my supervisors' experiences, the project aims, and

the consultations with other professionals (see Section 2.5). Subsequent changes were

influenced mainly by service user consultation (see Section 2.6).

The interview schedules were also taken to a peer quality control session in June

2018 (with trainee clinical psychologists and a clinical psychologist). From this session,

changes were made to the order of the questions, and unclear professional jargon was removed to make the questions more accessible.

2.5. Professional Consultation

Consultations were undertaken in November 2017 with an educational psychologist in the borough, and a member of staff from the specialist service supporting children on the autism spectrum in schools throughout the borough. These consultations were for the project as a whole (not just for designing the interview schedules). The information gathered from these consultations helped shape the aims of the project, and provided important context which was thought about when developing the interview schedules (e.g. parental expectations, pressures on school staff, changes to local policies, funding cuts etc.)

2.6. Service user consultation

There are many benefits to both services and service users of involving service users/clients, carers and families in the design, implementation and evaluation of both services and research (Ashcroft, Wykes, Taylor, Crowther, & Szmukler, 2016; Omeni, Barnes, MacDonald, Crawford, & Rose, 2014). This topic is of particular current relevance in the field of autism research, where it is hoped that involving people on the autism spectrum in research more will lead to more relevant research, better translation into practice, and improved outcomes/positive impacts on the lives of people on the autism spectrum and those who support them (Fletcher-Watson et al., 2018). Service users were consulted at various stages of this project, including design (consulting on advertising materials and interview schedules), recruitment, analysis and dissemination.

2.6.1. Involvement of Service Users in Design

Service users were initially consulted on the design of recruitment posters for the project. Children and young people on the autism spectrum and their parents were sent posters with different images and wording, and gave feedback (via email) about which they preferred (e.g. one young person said she liked the brighter colours and hearts), which influenced the final decisions made (see Appendix 6.3 for an example poster used in recruitment).

Interview schedules were also sent via email to children on the autism spectrum, their parents, and school staff (teachers). Four young people on the autism spectrum (aged 9-17) gave feedback on the interview schedule (via their parents' email), having been through the questions with their parents (for the younger children) or by themselves (for the older children). Feedback was typically to do with phrasing of questions. For example, one question had asked children 'what support they dreamed of getting', and young people fed back that this was unclear and could be better phrased as 'ideal kind of help'. Other feedback included: questions were too long, questions were boring, questions did not seem relevant, there were too many questions, words were too hard (e.g. relationship), and some said discussing difficulties at school would be upsetting. Changes were made to the schedule based on this feedback wherever possible within the realistic limitations of the study (e.g. the questions needed to generate sufficient data to answer the research questions), and bearing in mind that much of the feedback collected was contradictory (e.g. young people suggesting phrasing that other young people did not understand), highlighting the often idiosyncratic nature of people on the autism spectrum.

Parents generally gave positive feedback about the interview schedule, although some said they felt some of the questions were repetitive and might generate similar answers, so wording was clarified where possible to ensure questions targeted specific issues. Parents did not mention any issues with phrasing/words used in particular questions.

I also wish to discuss at this point that one of the supervisors for this project is herself the parent of a young person on the autism spectrum, and provided continuous invaluable consultation on every aspect of the project. I feel passionately that her multiple roles as a clinical psychologist, research supervisor, parent and user of services be honoured and acknowledged for 'bridging the divide' – breaking down the barriers between seeing people as either professionals or service users (Keville, 2018). Having someone from one of my research populations on my supervisory team provided me with a constant grounding link to my participants and provided me with unique perspectives throughout, which greatly benefited this research project.

Proposed interview schedules were also looked at by teachers, who gave feedback about phrasing (e.g. which types of support were being asked about?), and also commented that some questions seemed repetitive/similar to others. One teacher pointed out that a question had been phrased negatively ('Have you felt restricted in your role…' as opposed to the positive, 'Have you felt supported in your role…'), which was changed to make the question less leading.

2.6.2. Involvement of Service Users in Recruitment

Service users were crucial to recruiting participants for this project. Whilst my initial contact with parents was facilitated by a third party organisation, all parent recruitment after the first participant was done through other parents of children on the autism spectrum, who were instrumental in helping me recruit other parents.

Similarly, all recruitment of school staff was done through other school staff. Often this involved SENCOs promoting the project to teachers and TAs in their schools and helping set up focus groups for school staff. Recruitment of children on the autism spectrum also generally took place through school staff who had participated in the project.

2.6.3. Involvement of Service Users in Analysis and Dissemination

Following completion of the analysis, a parent service user who had participated in the study was consulted to gain their perspective on whether the resulting themes and narratives made sense and accurately reflected their experiences. This was in an effort to minimise the impact of my interpretation, as the researcher, of the participants' experiences. Some of these additional contributions are included in the Discussion. Only one parent was approached at this time due to time constraints. This parent participant was head of the parent forum, and so was very familiar with the experiences of other parents in the local area. At the time of submission, plans for involvement of service users in the dissemination of findings were ongoing.

2.7. Ethical considerations

Ethical approval for this study was obtained through the University of Hertfordshire

Health Science Engineering and Technology ECDA Protocol number:

aLMS/PGR/UH/03204(1) (see Appendix 6.4). Ethical approval was initially obtained in

February 2018. One ethics amendment/extension was sought and obtained to allow

individual interviews to take place as well as focus groups, and to extend the data collection

date (see Appendix 6.5). All participants were provided with information about the study

(see Appendix 6.6) and an easy-read version of the information sheet was provided along

with the full information sheet (see Appendix 6.7). All participants signed the consent form

to provide informed consent to take part in the study (see Appendix 6.8), and the Consent

by Proxy form was signed by parents where appropriate (see Appendix 6.9). All

demographic data was linked to an anonymous participant number, and all participant

contributions were anonymised in the transcripts. In instances where audio was transcribed

by a third party, a confidentiality agreement was signed (see Appendix 6.10). All data was

stored securely and confidentially in line with the Data Protection Act 2018 (Parliament of

the United Kingdom, 2018), to be destroyed upon completion of the project.

There were a number of ethical issues to be considered in this project. One such

issue was participants' right to withdraw from the project. It was important that research

participants were able to withdraw from research at any stage (including after having

participated) without having to give a reason. However, in this case, participants were

informed that they could withdraw from the study at any time up to one month after having

participated. The reason for this was that once data was analysed as part of the thematic

analysis, it could not be removed from that analysis; although their demographic data

(which was anonymised) could be removed from the study, and their contributions could be deleted from transcripts, their contributions to the development of codes and themes could not be removed.

Another ethical issue in this study was the potentially distressing nature of taking part. Participants were asked questions which had them reflect on a process that, for many of them, was a significantly challenging and distressing experience, and for many was still ongoing and presenting them with difficulties in their daily lives. Focus groups/interviews took place in safe environments familiar to those involved (either in schools or at the local parent forum centre). Participants were informed that they did not have to answer all questions and could stop at any time. All participants were given a debrief sheet (see Appendix 6.11) and the opportunity to follow up on any feelings or issues that had been raised.

2.8. Procedure

The research procedure is outlined in Figure 4. At the focus groups/interviews, participants were again provided with the information sheet, and given the chance to ask questions about the research. Participants then completed the consent form and demographic information sheet. Participants were reminded that the focus of the discussion would be on post-diagnostic support, not the process of obtaining a diagnosis. Participants were also instructed to use whichever terminology they felt comfortable with (e.g. ASD/ASC etc.) Participants were informed that they did not have to answer all questions, and asked to speak loudly and clearly and avoid talking over each other. Participants were told that everything said in the room would be kept confidential but that they may be quoted

anonymously in the final report. Audio recording was then started and participants were asked to begin by introducing themselves. Questions were then asked from the interview schedules. As the researcher, I wrote notes during the interviews about both content and process. At the end of the interviews, audio recording was stopped and participants given debrief sheets (see Appendix 6.11) and the opportunity to comment or ask questions. Demographic information was pseudo-anonymised and added to a secure spreadsheet. Audio files were transcribed to text; the majority of this transcription was carried out by the primary researcher/author, however some was undertaken by a paid third party transcription service who signed a confidentiality agreement (see Appendix 6.10). All transcripts were manually checked thoroughly for accuracy. Transcripts were then imported into NVivo 12 (QSR International Ltd., 2018) and analysed using thematic analysis (See section 2.9).

Recruitment of participants (see Section 2.3.2)

Participants sent Information Sheet

Participants invited to focus group/interview; date, time and location booked and confirmed

Meet – distribute participant information sheets and consent forms (answer any questions)

Participant signs consent form and completes demographic information sheet

Focus group/interview takes place using Interview Schedules (audio recorded)

Debrief sheet issued and participants given opportunity to ask questions

Demographic information pseudo-anonymised; all consent forms, demographic sheets and audio recordings stored securely and confidentially

Audio recordings transcribed to text by author or by professional transcription service who signed confidentiality agreement

Transcripts checked for accuracy and text files imported into NVivo 12

Data analysed using Thematic Analysis (see section 2.9)

Figure 4: Flowchart detailing the research procedure

2.9. Data analysis

An inductive thematic analysis (as discussed in section 2.1.2) was undertaken on the data set. This process followed guidelines by Braun & Clarke (2006), and the specifics of the analysis for this project are outlined below.

2.9.1. Familiarisation with dataset

I immersed myself in my data by re-readings of all transcripts, as recommended by Braun & Clarke as a crucial part of the process. Through this I achieved a thorough familiarisation of myself with the entire dataset, one advantage of which was that it facilitated the efficiency of later stages of the analysis.

2.9.2. Initial line-by-line coding

All transcripts were analysed and initial line-by-line codes were added using NVivo (see Appendix 6.12.1). As per Braun and Clarke's recommendations, segments were coded for as many potential themes as possible, with each segment being coded into as many different nodes as were relevant. Segments were coded along with surrounding data to ensure that the context of segments was not lost. During this initial coding process, notes (or 'memos') of potential patterns and ideas were kept in NVivo. A small section of the dataset was also separately coded by peers (trainee clinical psychologists) to provide an additional check to ensure consistency of coding.

2.9.3. Searching for themes

Once the dataset had undergone initial coding, NVivo was used to begin the process of searching for themes. This involved sorting and grouping codes into potential broad themes, thus collating all relevant segments of data for that theme (see Appendix 6.12.2 & 6.12.3). This was an experimental and iterative process, with some themes being discarded, some being merged, and others being kept on to become subthemes or even superordinate themes. This stage also involved re-examining segments of data and memos to drive this process. Throughout this process, inductive or 'data-driven' coding and theming was undertaken, that is, not allowing myself (as much as possible) to be influenced by pre-existing ideas or themes that I may have expected or read about in existing literature. This stage ended with the creation of tables of 'candidate themes' (in Excel) with the primary project supervisor (see Appendix 6.13).

2.9.4. Reviewing and refining themes

Up until this point, the data had been viewed as three separate participant groups. However, during this next phase, it was noticed that there were many consistent themes and narratives across the groups. It was felt that it would be beneficial to create one coherent set of themes for the entire dataset, presenting a more consistent narrative and emphasising some of the more important issues which had emerged. Candidate subthemes and themes were reviewed and developed with the primary supervisor. This involved re-examining the candidate themes and corresponding data segments to check for coherence, and whether each theme suitably captured the essence of the relevant data segments.

Following this, the dataset was examined more broadly to assess whether the 'thematic map' (all themes and subthemes) accurately represented the data corpus as a whole.

2.9.5.   Defining and finalising themes

The final part of the analysis involved further refinement of the themes and subthemes to detail the 'story' being told by each theme in relation to the research questions, as well as how each theme fitted into the overall 'story' being told by the data. Braun and Clarke highlight the danger of simply paraphrasing a collection of extracts with no coherent analytic narrative, so the consideration of themes within the overall narrative played an important role in ensuring a concise, logical and rich story was presented which captured the vast majority of the data collected.

2.10. Quality, Validity and Self-reflexivity

2.10.1. Assessing the quality of the current research project

This section assesses the quality of the current study using Tracy's (2010) Eight "Big-Tent" Criteria for Excellent Qualitative Research (see Table 9). These criteria were used because, whilst the criteria used in the systematic literature review allowed for the consolidation of a mixture of quantitative, qualitative and mixed methods research, the current project is qualitative, so its quality is best assessed using well-established qualitative quality criteria.

Table 9: Assessment of the Quality of the Current Research Study using Tracy's (2010) Eight "Big Tent" Criteria for Excellent Qualitative Research

Quality Criteria	How the current research meets the criteria
Worthy topic The topic of the research is: • Relevant • Timely • Significant • Interesting	This research is relevant and timely in the context of the government's December 2018 announcement to introduce an updated national autism strategy covering people of all ages in England for the first time. Research is significant and relevant given the lack of research in this area as highlighted by the Literature review (section 1.6).
Rich rigor The study uses sufficient, abundant, appropriate, and complex: • Theoretical constructs • Data and time in the field • Sample(s) • Context(s) • Data collection and analysis processes	This research uses sufficient data (see section 2.3.4) from 3 sample populations from appropriate contexts to achieve 'data sufficiency' (Nelson, 2017). Rigorous recruitment procedures were used to ensure abundant data collection, and complex and appropriate analysis (TA) was adhered to (see section 2.9), with consistency checks (e.g. by supervisors and peer).
Sincerity The study is characterized by: • Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) • Transparency about the methods and challenges	This research includes self-reflexivity throughout (see section 2.10.2), including epistemological reflexivity and reflections on researcher positioning, to minimise researcher bias. Clear audit trail regarding decisions about methods and challenges included throughout (e.g. in reflective diary) to achieve transparency and sincerity.

	Strengths and limitations of study reflected on in discussion (see section 4.5).
Credibility The research is marked by: • Thick description, concrete detail, explication of tacit (nontextual) knowledge, and showing rather than telling • Triangulation or crystallization • Multivocality • Member reflections	Wide range of participant quotations from multiple and varied voices included in results section to thicken description and provide concrete detail. Triangulation of themes by collecting and analysing data from multiple participants from 3 sample populations. Member reflections - Participants given chance to comment on analysis and findings (see section 2.6.3).
Resonance The research influences, affects, or moves particular readers or a variety of audiences through: • Aesthetic, evocative representation • Naturalistic generalizations • Transferable findings	Difficult to objectively comment on whether this research moves people or is evocative. Research has transferability as readers may find it resonates with their own personal experiences. Wider generalisation is potentially limited concerning the extrapolation of findings to other areas.
Significant contribution The research provides a significant contribution: • Conceptually/theoretically • Practically • Morally • Methodologically • Heuristically	Although somewhat limited in its theoretical or methodological contribution, this research makes a significant practical, moral and heuristic contribution in numerous ways, empowering participants, telling a story and providing useful insight which should be acted on, hopefully encouraging engagement and influencing policy to improve lives in the future.
Ethical The research considers: • Procedural ethics (such as human	Ethical issues are reflected on and addressed throughout the report although specifically in section 2.7. Situational and relational ethics

subjects) • Situational and culturally specific ethics • Relational ethics • Exiting ethics (leaving the scene and sharing the research)	were considered throughout to maintain dignity of participants and respect for the autism community. Ethical amendments obtained where necessary.
Meaningful coherence The study: • Achieves what it purports to be about • Uses methods and procedures that fit its stated goals • Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other	Consistently coherent use of critical realist epistemology, focus groups/interviews, and thematic analysis methodology, all of which fit not just each other but the stated goal of the project. Existing literature, findings of this study and interpretations are interconnected (see Discussion), and meaningful implications and recommendations discussed.

2.10.2. Self-reflexivity

As stated early on, I have integrated some of my reflections throughout this project in italics, detailing my reflective and reflexive journey through this research. In addition, I have included excerpts from my reflective diary from various stages of the process in Appendix 6.1. In doing so I have attempted to provide transparency throughout the process, and to minimise the impact of potential biases on the analysis and interpretation of results.

3. Results

Inductive thematic analysis of the data led to the development of five main themes relating to people's experiences of post-diagnostic support. These were: a lack of knowledge and understanding, a system overwhelmed by unmet needs, the impact of communication on relationships, negative impact on quality of life, and hope for the future (developing the system to make it work) (see Figure 5). Each of these contained a number of subthemes which are discussed in more detail below, along with example quotations from the transcripts to illustrate these themes.
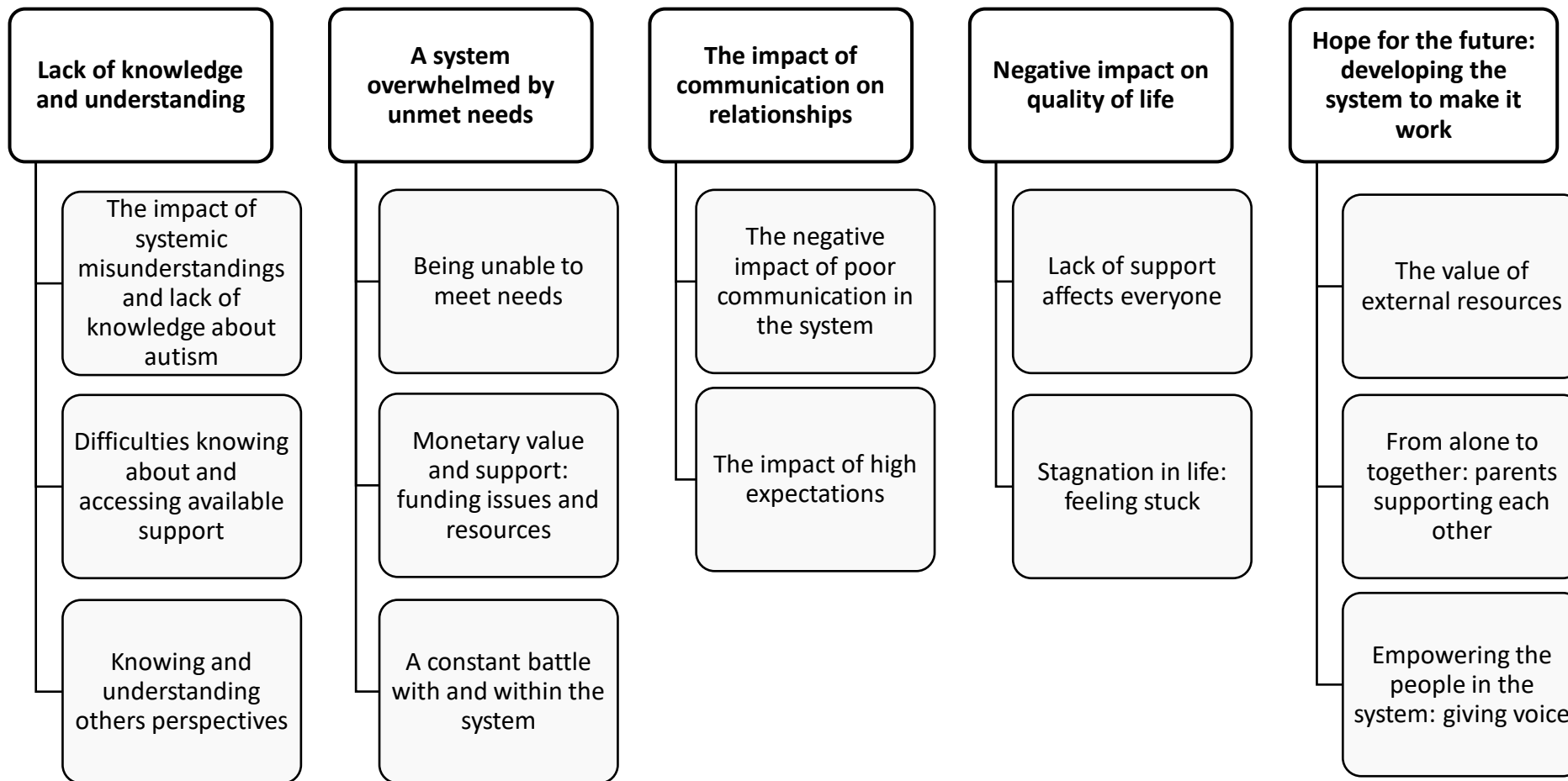
Figure 5: Themes and subthemes for participants' experiences of post-diagnostic support

3.1. Theme 1: Lack of knowledge and understanding

This theme describes people's experiences of an overwhelming lack of knowledge and understanding about autism in the system and the negative impact this had on post-diagnostic support for children with autism. Many participants had witnessed a significant lack of understanding about autism, such as this parent:

> *Interviewer: What do you think was the biggest challenge for you to overcome?*
>
> *Parent8: I would say the people's ignorance. It was the worst thing because I didn't expect my daughter's deputy head to say that her behaviour is because of your leniency.*

Thus, a lack of understanding was a considerable barrier to obtaining appropriate post-diagnostic support. There were numerous other ways in which a lack of knowledge negatively affected people's experiences of support. This theme had three subthemes: the impact of systemic misunderstandings and lack of knowledge about autism, difficulties knowing about and accessing available support, and knowing and understanding others perspectives.

3.1.1. The impact of systemic misunderstandings and lack of knowledge about autism

Many participants' experiences were that a lack of knowledge and understanding of autism had a significant negative impact on the effective delivery of appropriate post-diagnostic support both in schools and in the community. For many parents, this often presented as a lack of understanding about autism from school staff which affected their child's support:

> *Parent2: They [school staff] turned round and said um we all went to this thing where we did autism awareness but they didn't show us how to deal with it… so we know who is autistic but we don't know what to do about them.*

The vast majority of parents expressed such frustrations about a lack of knowledge and understanding from school staff, and for some this had a significant negative impact on their child's experience in school:

> *Parent8: She was just like treated just like other children and if she's naughty, it means she's naughty… They don't even understand that if there is any autistic child what to do with them. If that child is naughty, they are just put in a corner to sit on their own. That's what happened to my child…   So, before that, all the time he was just called naughty. Every school just wanted to get rid of [them].*

The perception of the child as 'naughty' resulted in the school's wish to exclude them, demonstrating how a lack of understanding about autism can result in schools neglecting

pupils with additional needs. For many parents this lack of awareness came down to a lack of training about autism:

> *Parent1: To be honest, schools still are not really aware of what to do… Just the lack of understanding… mainly just for [school staff] to be more aware and for them to be more trained, that is I think one of the biggest issues is that there's not enough training for teachers… And I think even the SENCOs need training on it more... I know the SENCO, it's the SENCOs job but most SENCOs are not specialists in autism.*

Parents' lack of confidence in the knowledge of school staff to appropriately support children on the autism spectrum was very common throughout the interviews. This was also recognised and discussed by school staff themselves:

> *Interviewer: Can anyone think of any other sort of barriers to improving the support for children with autism?*
> *Teacher1: Not necessarily here, but lack of understanding and what an autism, an autistic person is going through, like why are they, or where they're coming from kind of thing. Yeah, not having enough training on autism mainly.*

The verbalisation about the lack of training and knowledge almost seemed like a mantra in the way it was frequently repeated by parents and school staff. For school staff, wanting to understand involved taking the responsibility to do 'my own research', as one teaching assistant highlighted:

> *TA1: I think training on my part to be honest because I've been on some, I've not been on a lot, a lot of it is my own research that I do myself and like being hands on with children and trying something and if it doesn't work trying something else. So for me it's training. I don't go on enough.*

Evidently, some dedicated staff wanted to do more and this is clearly seen in their admission that *'I don't go on enough'* training. The lack of autism-specific training for school staff was also discussed in the context of a lack of funding, as discussed in more detail in section 3.2.2.

> *TA3: And the other thing is like with [specialist school outreach service] as well is like they give free courses. Um but unfortunately that means that I've done Autism Level 1 I think about three times now. You know I want to do Level 2 and I can't because it costs money... TA1: Mmhmm. TA3: And the school's not going to pay for it, so that side of it is what's annoying like you were saying training earlier and stuff.*

The desire was there in staff to understand more, yet the focus was elsewhere such that learning never developed to a higher level. However, while teaching assistants felt that they did not get enough autism-specific training, SENCOs also discussed an important issue about the current education system:

> *SENCO4: you know people that you are expected to work with the .. children with the most significant need are the people who are the least qualified. Fact. SENCO2: Yes. SENCO4: And that's not ok.*

Thus, the staff who typically work most closely with children on the autism spectrum (generally TAs) typically have the least amount of training, and this lack of knowledge and experience can have a significant impact on the support which a child with autism receives, to the frustration of all involved. This may reflect a lack of support and education for teachers regarding how best to differentiate work for and support pupils with additional needs in the classroom.

Parents identified that this lack of understanding was not just in schools, but present in the wider community, often with harmful consequences:

> *Parent8: Another thing that I'd say that there should be more education everywhere. Sometimes I feel so frustrated that I feel like these conditions should be even on the buses and trains that some people are different because they are autistic. So, just give them their space. A couple of weeks ago, I got hit in the bus because my daughter was being naughty… And because she was crying so one lady made a big fuss out of it that like you don't teach any manners to your children… everyone was looking at me like I'm the one who is wrong… So, these things happen and there should be education, a lot of education.*

This parent seemed so worn down by the lack of understanding that they also conceptualised their child's behaviour as '*naughty',* almost as if they had been told this so frequently it was just easier to also label it as this – yet whilst on the bus the parent 'got hit', experiencing not just misunderstanding, but violence. For this parent the solution is clear with their call for '*education'* (repeated 3 times), which would enable to public to respond in

a more supportive and understanding way. School staff expressed a similar concern about

the wider lack of autism awareness in the community, and the impact this had on families:

> *Teacher2: I just think the borough in general just needs to get more out there and*
>
> *say it's the outside community that needs to be more understanding…. But the wider*
>
> *community, the children suffer and the parents suffer in the wider community*
>
> *because when they are in the shops and their child is doing things that other adults*
>
> *don't understand, they are either insulting the parents or being rude to the child so*
>
> *actually there's the bigger and wider community that makes the impact.*

Consequently, there was a real understanding by one teacher of the sense of '*suffer*ing' for

parents and children, with society being '*rude'* and '*insulting'* to both the parents and

children. Another issue which was frequently raised by parents which sits within the sub-

theme of 'the impact of systemic misunderstandings and lack of knowledge about autism' is

parents' experience that there is less awareness about girls and autism (and girls tend to be

diagnosed later) and this negatively impacts the post-diagnostic support which girls receive,

as highlighted in the following dialogue between two parents of girls on the autism

spectrum:

> *Parent 5: Um yeah when [child] was diagnosed we... it was a long gap between*
>
> *having the diagnosis and going on the Cygnet course. Because they were waiting*
>
> *cos she was a girl ...*
>
> *Parent 3: Yeah that's a nightmare.*
>
> *Parent 5: They were waiting to do a course...*

Parent 3 + 5: For girls…

Parent 5: I had no idea what it was or what it would do so we just didn't do.. we had

nothing basically and I felt very very...

Parent 3: and we still girls have nothing.

Parent 5: yeah we have still have no you're right we still...

Parent 3: not for girls… There really is nothing.

This was also echoed in the experiences of school staff:

Teacher3: I think in girls though it's also later. You find it out much later and it's

normally when some sort of catastrophic event has happened. You know they've

completely gone off the wall or shut down.. Teacher1: It's true..   Teacher3: Cos

they just seem to think, 'oh there's a quiet kid in the corner.'   Teacher2:

Yeah.   Teacher1: Girls are more efficient in the sense of they just get on with things

and they cope slightly better… They just skip under the radar..   All: Mmmm.

3.1.2. Difficulties knowing about and accessing available support

This subtheme describes how a lack of knowledge about what support is available and how

to access it often prevents families from obtaining appropriate post-diagnostic support.

For the children and young people interviewed, there was a difficulty knowing and understanding what support they were receiving (or had received). None of the young people were aware of plans (e.g. EHCP, IEP) in place to support them, and often did not know why they were receiving additional help:

> *CYP3: I get given the same work, but... during English I have to go to this one class which is a different English class downstairs.*
>
> *Interviewer: Why do you go to a different class?*
>
> *CYP3: I don't know…*
>
> *Interviewer: And what do you do when you go with him?*
>
> *CYP3: I don't know…*
>
> *Interviewer: Do you know if you have [an EHCP]?*
>
> *CYP3: I don't know. But probably no…*
>
> *Interviewer: do you know what that [transition meeting] was about?*
>
> *CYP3: No.*

For many parents, they did not know what support they were legally entitled to:

> *Interviewer: What things got in the way of you accessing support?*
>
> *Parent4: Knowing what you're legally entitled to. I think that's the issue, you get you've got sort of fobbed off here and there… what am I reasonable in asking what am I not reasonable in asking?….. I think that's missing, I think especially from post-diagnostic support is for someone to go here's all the things that are accessible.*

A common experience was that many parents worry about what is *'reasonable'* for them to even ask for. For the majority of parents, they simply do not know what support exists for them, and some parents are more able to find out than others:

> *Parent4: I think a lot of people just... they don't know what to expect, they don't know what's out there, there is a lot more help if you can access it, if you can find information to access it, it just seems to me that some people are more able to do that than others…… there's still a bit of a struggle with trying to find things.*

This highlights how some parents struggle more than others to find out where to obtain support, and the following demonstrates the impact this can have:

> *Parent2: I think you have to be really pushy, I mean you see some of the parents that come to the groups in tears because they're getting pushed around and don't know where to go. They're getting really bullied by staff….. There were all these useful things by the way like OT and speech and language, but you're not getting any.*

Parents also discussed how, even when parents are aware of support, it can be difficult to know how to access it:

> *Parent5: Yeah. But I've never been able to .. er you know I don't know how to point another parent to it cos I'm not entirely sure how I stumbled into it. Um it's like one of these mystery services like the OT stuff that that lady was talking about, it's at the*

[place] but what does that mean? How do I get there, how do I find it, where's the

telephone number? I don't know how on earth you get to this lovely lady.

In general, parents reported that the system is complicated and confusing, and that

difficulty knowing how to access support services can have a significant negative impact on

them and their family:

Parent8: We called everywhere. No one was there to listen to us. So it's just like if you

don't know the system, you don't know the right vocabulary, right words, you are

being just cornered and pushed into a side that no, you can't get any help. That's

what is happening with my children as well. But I have no idea how to help them and

I'm so overwhelmed and so exhausted during this whole time.

This shows how exhausting and overwhelming this process can be, which is discussed in

further detail later on. Some parents also discussed that finding out what support is

available and how to access can be even more difficult for parents where English is not their

first language:

Parent4: so there is still a big problem with getting the information out there,

especially with... I've noticed with a lot of parents that have not got English as their

first language….. it's not something I could just go here here here, because it's so

much more than that, and also then that person has to be able to take that

information and know how to access it themselves and deal with changes.

3.1.3. Knowing and understanding others' perspectives

Extending subtheme 3.1.1 further, this subtheme explores people knowing and understanding other people's perspectives, and the potential positive or negative impacts this could have.

Children and young people appeared to have some difficulty knowing and understanding the needs of themselves and their parents. All young people reported that they got enough support and did not need any additional help:

Interviewer: Have you ever wished that you had more help?

CYP3: No, I'm fine with my help.

Interviewer: You're happy with the amount of help you get?

CYP3: Yeah…

Interviewer: ok and are you happy with how much the teaching assistant helps you or do you wish they would help you more?

CYP3: Nah I'm fine with it…

Interviewer: Ok cool that's good. So are there any other ways that you need help?

CYP3: No not really…

Interviewer: You're fine with things as they are?

CYP3: Yeah I'm fine.

Interviewer: Have you ever hoped that you could have a bit more help at school?

CYP4: I think the help I got is fine enough.

Interviewer: the help you've got at the moment is enough?

CYP4: Yeah.

Interviewer: so there's nothing that you wish you could have more?

CYP4: No.

Furthermore, all young people interviewed felt that their parents did not need any

additional help or support:

Interviewer: do you think [your parents] want extra help or need it?

CYP4: I don't think they need it now.

Interviewer: do you think they're ok?

CYP4: yeah they're ok with it, and they...even though that I struggle with it they don't

need no help with the autism.

Interviewer: Would you have liked someone to come to your house to help you?

CYP2: No…

Interviewer: Do you think your parents would like any help or are they fine?

CYP2: They're mostly fine.

Interviewer: Can you think of anything that would be helpful for them, for your

parents?

CYP2: No.

Parents generally found it frustrating when other adults were not able to understand their perspective:

> *Parent5: the battle is when you've got children with special needs… you spend half the time battling and trying to explain behaviours of your child… and that's probably one of the most frustrating things, is having to kind of be that middle person all the time when you shouldn't have to.*

Whilst we have noted that some staff do have some understanding, some parents felt that school staff were not able to understand the perspectives of parents of children with autism:

> *Parent1: Teachers and TAs don't really take on board what it's like to have autistic...I know they say they've worked with them and that but there's certain things, you know for instance when they start giving out bad behaviour letters…*

Parents reported that professionals particularly in medical/healthcare services struggled to understand the child's needs through the parent's perspective, which the parent below talked about:

> *Parent5: But I think also for them to have that skill to understand the child through the parent as well… you want them to go 'ok I hear you, this is what you're telling me*

about your child'. And I think that takes a skill and it takes a purpose to have to

really focus on doing, is not focussing on the parent's needs but also listening to the

parent to understand the child's needs. And I don't think we're getting that in

services.

This highlights the importance of listening to parents to understand the child's needs, and how most parents currently perceive this as a shortcoming in many services. Some parents felt that people were not able to understand their perspective as they were not listening to the parent, or were judgmental:

Parent8: I would say that the council and MPs and this sort of things are not helpful

at all because I went to see my MP and they were just judgmental… They were not

listening to me that no [local borough] school was offering him a place, all of them

are so judgmental… I felt being judged and being undermined and no one is there to

listen to me and no one is trying to understand how difficult it is for us.

School staff also found that some parents were unable to understand things from the perspective of the school, which often led to difficulties:

Teacher2: It also depends on the parents… they're not seeing this, they're not seeing

that, they want this, they want that. And then they can come in on us a bit harder

and be like 'put this in place, put that in place'. And you're kind of like… we're

stretched we're doing what we can. They only see five minutes at the beginning of

the day and they watch through the window five minutes at the end of the day,

they're not seeing how we actually get the structure and the work and everything

that's done.

Many parents were able to see and understand the perspective of the school, especially when it came to acknowledging the difficulties that school staff face in relation to the pressures on them:

Parent1: obviously there's teachers there that's got 30 kids and they gotta do this and they gotta do that and they gotta get everything fitted into that… then you start realising things are not getting done, and you know you constantly putting the blame on the teacher and the TA, but actually it's not really their fault… they really want to help these kids and they can't.

Many parents acknowledged that schools are having to support an increasing number of children with additional needs with less funding and resources. Some parents demonstrated an ability to understand how this might affect school staff:

Parent1: they just can't do it, it's just too much now because there's too many children coming in with SEN, there isn't enough resources, there isn't enough teachers and schools are stretched too much to the point where it's just not working, so you know the budget gets cut every year even more, so it's like, what is the answer to that?

Some parents demonstrated a knowledge of the perspectives of school staff who are trying

to provide support but are hindered by the restrictions of the system they work in:

Parent3: I had that at a meeting because during it she [the SENCO] was actually 'we

can put this in place, we can do this'. Headteacher goes 'no you can't, we can't do

everything, we just can't, we can't do all of that'. But [the SENCO] is trying to and I

think and as much as I love her and I think she's fantastic, she's never gonna be able

to reach her potential because she's stuck under the management team.

3.2.　Theme 2: A system overwhelmed by unmet needs

This theme describes how the current system is not meeting the needs of children with

autism when it comes to post-diagnostic support, an overwhelming issue which came out in

all interviews. The subthemes explore how the system is unable to meet the needs of these

children and families, how there is a constant battle to try and obtain appropriate support,

and one of the main features of the overwhelming unmet need: a lack of funding and

resources. For many parents, the awareness of the experience of the system failing to

address unmet needs begins immediately after receiving the diagnosis:

Interviewer: What were your experiences of support following receiving a diagnosis

of autism?

Parent 3: For me I was put on a cygnet course for girls with autism... And that was it.

That literally was it. There was nothing else. And find your own feet. And we were

signposted to [local parent forum]. And that was it. Nothing else.

3.2.1. Being unable to meet needs

This subtheme describes how the current system is failing to meet children's needs, in

particular schools, who are largely unable to meet needs. Part of the context for this is

discussed in the first theme, a lack of knowledge and understanding. All parents and school

staff to some extent discussed how the system is unable to meet the needs of children on

the autism spectrum, with many addressing the fundamental idea that this is because the

system is not set up to do so:

> *Parent5: But you know because the world is set up in a piss poor way for people with*
>
> *autism.*

One parent spoke about how, when it comes to supporting her children, she refuses to

become part of the system that seems to work against people:

> *Parent8: But now when I know that they need help, and they didn't get this help for*
>
> *many years of their life, I can't keep like you know.. the system is pushing them to a*
>
> *corner and I can't - I'm the only person they trust. They know that I'm always going to*

be there with them. And I don't want to be part of this crushing system... I want them

to stop all that but by helping them, not by telling them off and putting them in

detention, no.

This shows how parents feel they are constantly having to work against a '*crushing*' system which is unable to meet needs. One of the main places in which parents felt the system was not meeting the needs of children with autism was in schools. Parents' experiences were overwhelmingly of schools failing to provide appropriate support for children on the autism spectrum:

> *Parent1: I think people are still banging their heads against the wall because schools*
>
> *are just not doing the basic stuff that could be really so helpful for them and the child.*

Many parents felt that the system whereby schools coordinate support is poorly set up and quickly breaks down, leaving them isolated and unsupported:

> *Parent5: they said "we'll hand you over at school" um...an experience which was, as*
>
> *everyone's is with school, basically pretty rubbish where her class teacher didn't even*
>
> *turn up to the handing over meeting… school were disengaged and unorganised and*
>
> *that was it, so I just felt like.. here's a diagnosis, here's a giant boot, off you go.*

This led a large majority of parents to question why the system is set up so that it is the school's responsibility to coordinate support, instead of a service such as CAMHS:

> *Parent5: the structure of it is, well was for us you know, diagnosis from these brilliant excellent people who know lots of stuff and then sent to school who knew nothing... And then school are supposed to be both the providers of support and the conduit for getting other provision in… That's just not the right sort of pathway of support for children with autism. Like you need to keep the brilliant knowledgeable people involved not, not devolve it to the people who know nothing.*

This highlights many people's concern about the *'right sort of pathway'* for support for children with autism, as addressed in the discussion. Many of the issues which parents raised were with mainstream schools failing to meet the needs of pupils with autism and failing to provide appropriate support:

> *Parent1: And I just find mainstream schools generally are just not very helpful… there was nothing put in place to help him deal with that… they never ever really looked at it or thought 'what is the behaviour?', 'what's causing it?', 'how are we going to deal with it?'…. it's very basic stuff, it's very helpful… and it's just no one seems to know how to do it, how to put it into place, and I don't understand why.*

The inability of schools to meet the needs of children with autism can have significant negative impacts on parents as well, as experienced by this parent:

> *Parent8: And even I had one meeting with the head as well after the SENCo meeting because that was so bad that after the meeting, I was shaking and crying… She said, [your] daughter is autistic but I have never seen her as like a disabled person. So, I've*

never like asked for any support for her. Like they own made me feel like I'm guilty

that I'm asking support for her.

A common systemic issue which came up for many parents was EHCPs (Education, Health and Care Plans), and how the lack of an EHCP can make it very difficult for a child's needs to be met:

Parent8: That [EHCP] is the most difficult thing to achieve and our children can get only more support after having this statement and the school resists, like the school come into a war with parents not to have it.

The lack of an EHCP can have significant implications for a child's support, which in turn can have considerable negative impacts for parents:

Parent4: it was like the whole world just shattered because she was just like "well he's not gonna get one"…. Like what? "Oh no he's not going to qualify for one"… that broke me more than the day he got diagnosed because it was just like someone going, you're child has this thing, we spent the whole summer trying to understand it… but he's not going to get any extra support.

The language of *'world just shattered'* and *'broke me'* show how invested parents are in this process and how devastating it can be when they do not get the support they believe they need. Another common systemic problem which parents reported experiencing was schools

and services using the term 'high functioning' to deny additional support, thus typically failing to appropriately meet the needs of children on the autism spectrum:

> *Parent7: So by not having… now having this 'high functioning' has actually made it worse for her and they don't even frigging exist. That's what annoys me, it's a word or a tool they use to create a barrier for you to get something… School was really bad until I stepped in and said get her statemented, get her EHCP sorted. They just let it dwindle because they use this 'high functioning'.*

Other parents found that schools will use terms (such as 'high functioning') from the reports from other services (e.g. CAMHS) to justify not providing support to children with autism:

> *Parent8: Whenever I go to speak to them, I get always this 'but they're high functioning', then it's impossible to speak to the schools because they always put these words on you like stones. No, your children are high functioning, your children are low needs. That's what the report says. You can't contradict the report so they don't need it.*

Many parents felt that one area where the system failed to meet needs was CAMHS not remaining involved after diagnosis to provide ongoing post-diagnostic support:

> *Parent8: And then I was called to give assessment report. After that, nothing. I said, "What's next?" And they said, you need to ask the school to support him more. But they know that schools don't have enough funding to support them.*

Other parents were very surprised that the system is not designed so that children with autism receive regular follow ups to ensure they are receiving appropriate support:

> *Parent5: I still don't understand how you don't get a sort of a clinic basically or the same lovely people that do the diagnosis that spent all that time pouring over the details of what a child is like and what works for her and what doesn't work for her. And then you never see them again.*

Parents also experienced a general inability of the local area to meet needs, and a desire for the local area to be set up to provide more support:

> *Parent1: I think it's just a lot of.... people are looking for more support in general really, I don't know, there's still a bit of a struggle with trying to find things… I just feel that even within this borough and every borough really there should be more.*

Some parents had other experiences of the system not being set up to meet the needs of children on the autism spectrum:

> *Parent 6: it's really strange, seeing as I actually work in a job centre, negotiating the benefits systems are terrible, it's... I work within that situation, I can help other people access it.... trying to access it for yourself or for someone in your family is a nightmare, and I am beginning to think that there are certain barriers that are deliberately put there.*

3.2.2. Monetary value and support: funding issues and resources

A very common theme in all discussions was a lack of funding and resources, and how financial restrictions (i.e. budget cuts) have hindered the provision of appropriate post-diagnostic support for children with autism. Those within the system (school staff) and outside of it (parents) were aware of this issue:

> *Parent1: I understand it's difficult for school as I know there's a lot of kids and I know that everywhere is stretched to everything…. it's just… it's the same its lack of resources, lack of time, all the time…*

The vast majority of parents acknowledged the impact that funding restrictions have on schools' ability to support children on the autism spectrum:

> *Parent1: they just can't do it, it's just too much now because there's too many children coming in with SEN, there isn't enough resources, there isn't enough teachers and schools are stretched too much to the point where it's just not working, so you know the budget gets cut every year even more so it's like what is the answer to that?*

Most parents felt that the lack of funding and resources is a systemic problem which goes beyond schools:

> *Parent1: there so many children with SEN now and there so many more adults being*
>
> *diagnosed now and there's just doesn't seem to be enough. But I'm assuming that*
>
> *just comes down to not enough people not enough resources and not enough money,*
>
> *you know, what do you do?*

Some parents perceived a significant decrease in funding in recent years which has meant a decline in the provision of support compared to previous years:

> *Parent8: the support in the school has reduced significantly. Those parents whose*
>
> *children have diagnosed quite early, many years ago, they say that they see a very*
>
> *significant decline because of the funding cuts. Now, you can't get like additional*
>
> *support for your child so easy.*

School staff also discussed the problem of cuts to funding and lack of resources:

> *TA3: It is just resourcing and funding I think is where it comes down to, it is as much*
>
> *support as our SENCO can give us... she can't just have a money tree and give us*
>
> *everything we want, so it's quite difficult.*

Staff emphasised that they simply are not being given enough funding (and therefore do not have enough staff or resources) to meet pupils' needs:

> *Interviewer: What would it take for you to be able to manage it?*

SENCO4: I think the, you know, the resource... people power or enough money to be able to meet those needs, genuinely that simply.

Some school staff situated the problem in a wider context:

SENCO4: When you talk about setting children up to fail it's really a spot on phrase because it's not necessarily anybody's fault you know, I can be on the phone to [local borough council] saying you know well they're not getting money from anywhere.. maybe it's obviously government level really but it's really hard. The need is getting greater and the money is getting less and the knock-on effect is pretty bad.

SENCOs talked about the significant negative impact of funding cuts and lack of resources on pupils with autism:

SENCO1: And so you've got, you know have a child now who's autism has.. you know he didn't have the resources that he deserved a good couple of years ago and now he's really struggling and behaviour is now coming out. And he you know he's been excluded twice a week. He'll end up in a PRU but genuinely hand on heart that's not where he should be, that's the autism not being resourced well enough and we just can't manage it.

3.2.3. A constant battle with and within the system

Within the theme of a system overwhelmed by unmet needs, many participants discussed battling or fighting with or within the system to try and meet needs. For parents, this took the form of a fight with the system to try and obtain necessary post-diagnostic support for their children:

Parent3: It was very isolating in the beginning… you have to be proactive to fight for your child. You have to fight is the word. To get basic needs…. Since getting that diagnosis you realise well actually you know what I'm fighting a battle that I didn't need to fight in the first place…. you realise that you know what, it is a fighting battle but we all have to fight with it.

Parent1: It is a case of who fights the hardest…. I mean I've spent the last four years battling with the schools and council for three of my children.

Interviewer: And how does that make you feel?
Parent8: So scary. So, like, it means like, you have to fight for everything. That is not enough like…. it's difficult, it's just plain difficult because you have to, like, fight for everything.

Parents described how exhausting this fight can be and the impact this can have on them and their families, but urged other parents to keep fighting:

Parent8: Then kindly after so much of a struggle and hassle it was the biggest struggle for me to get even to that flat that I just had no stamina left to say no and

fight more…. fighting for the right help puts a lot of stress on the family, a lot…. And

if you are like not very exhausted parent like me, so you know, keep fighting on for

your child. Don't give up.

One parent recognised that some services can help them in their fight to obtain support
from other services:

> *Parent7: I must admit, that was good about CAMHS, they backed us up 110% on*
>
> *fighting social services to get them to do something. That was something that when*
>
> *you've got a problem and they believe in it, they're really a powerful body to have*
>
> *behind you… It not only validates your argument but it puts the other professionals*
>
> *with their qualification on the back.*

For school staff, the battle takes place within the system to try and provide post-diagnostic
support and meet needs. The following example demonstrates how children can become
lost in the numbers, or something to be '*haggled over*':

> *SENCO2: I think it's that sort of additional funding for the really complex needs… it*
>
> *becomes a little bit of a battle between you and the local authority… it's not nice if it*
>
> *becomes a bit of like you're sort of haggling over a child… and the child doesn't*
>
> *become a child any more it becomes just like well you need to give us more money*
>
> *and you start throwing numbers at it as opposed to just looking at the child. It*
>
> *becomes quite sort of you versus us.*

3.3.   Theme 3: The impact of communication on relationships

The third theme which emerged regarding people's experiences of post-diagnostic support was the impact of communication on relationships: generally, that poor communication led to poor relationships (between various parts of the system), which had a negative impact on the provision of appropriate post-diagnostic support for children on the autism spectrum. The subthemes within this theme were the negative impact of poor communication in the system, and the impact of high expectations.

3.3.1.   The negative impact of poor communication in the system

This subtheme describes how poor communication throughout the system negatively impacts on the provision of good post-diagnostic support for children with autism. Poor communication appears to be rife in the system, between parents and schools, between parents and other services, between services, and between schools and other services. This poor communication leads to poorer relationships, which further prevents the system from meeting the needs of children on the autism spectrum.

Many parents discussed their experiences of poor communication from schools and how confusing this can be for parents:

> *Parent3: [the report] was really conflicting to what the school were telling me and then what independent and I don't think they realised that the reports would be sent to me. So, I don't think they realised was I'm like ah! You're telling she's doing wonderfully but the reports are telling me you know she's not reaching targets, so what is happening here?*

Other parents found it very difficult to communicate with schools when they wanted to, and the school left them feeling invisible:

> *Parent8: So can you do something about it? She said, no, you have to follow up with the school. It means I am again left to do everything myself with the people who are not listening to the parents. They see parents as invisible people. We don't exist. No matter how many emails I said, no matter how many calls I do, I'm invisible.*

Some parents identified that the poor communication between parents and schools often leads to breakdowns, which need to be avoided in order to best support the child:

> *Parent1: you kind of don't want to always become this big bad person that comes into school going 'well you haven't done this you haven't done that', it's trying to find a way of communicating better with the schools really, without you know, I think a lot of communication breaks down.*

From the other perspective, school staff also discussed their experiences of poor communication from parents, and the impacts this can have on relationships:

> *Teacher3: I'm feeling undermined and let down to be honest. I'm going through a situation at the moment and I am reflecting back to SENCO but there's a lot of lying at the moment going on with the meetings that are happening, what's being said will happen, and not getting back to us to actually implement them… and then we're made to feel like crap because it's oh why haven't you done it, ooh so hang on a minute you didn't come back to us and say you promised this person this this and this so it hasn't happened. So I think sometimes it is let down in communication… they need time to talk to other people for it to then get back to us to make it work, it can't just happen overnight and those parents want it there and then and they make it difficult for us.*

Some parents also talked about their experiences of poor communication between services who are meant to work together:

> *Parent7: They do seem to not be talking to each other, I must admit, given that they are supposed to work together in partnership.*
>
> *Interviewer: Who's not talking to each other?*
>
> *Parent7: Social services and CAMHS… It's really weird, even though they're working in partnership was not there, even in the same building, they were not accessible to each other… Why are you not talking to each other?*

This lack of communication was also recognised by those within the system. School staff frequently talked about their experiences of poor communication from other services:

SENCO4: And all the issues as well, I had a lot of difficulty with the medical side of issues relating to children with autism, toileting....and just the medical profession. Not really being very open or honest or sharing information with us and really having to kind of dig down and try and find out what's happening and who's supporting and er cos all those things matter and it seems so far removed from education sometimes.

Some school staff discussed how poor communication from other services can impact on relationships, setting up a feeling of 'you versus them':

SENCO2: when we have a pupil that's been diagnosed we will receive the report and there's a feedback meeting from the social communication team. These can be quite, they can be quite hit and miss. Sometimes really really helpful, really informative. Sometimes it's like it comes across like as slightly patronising in the way that they're like you know these are some of the difficulties they have and you're like yes I know I've been supporting this child for three years… it's almost like you versus them slightly and that you know they've sort of got a snapshot of this child but you've known this child for three years and you've done a lot of the recommendations.

Many teachers and teaching assistants spoke about the role of the SENCO and how poor communication sometimes hindered their ability to provide support, with this being influenced by the style of the SENCO:

Teacher1: My last SENCO she was very, very just didn't really listen, was kind of always busy doing something, didn't really talk to the children so just different. I think it's the person really. If they care a lot they're gonna put the effort in.

The internal dynamics within the system could thus be a hindrance. Indeed, another way in which poor internal communication affects the system's ability to provide adequate post-diagnostic support is school staff feeling distant or cut-off from understanding other parts of the system, making them unable to think more strategically. For example, both teachers and SENCOs spoke about not understanding the financial situation of their school when it came to budgets:

Teacher1: Even the funding I have no idea how that works, personally I have no idea.

Teacher3: No. No we don't know how the funding's broken down.

Teacher1: Who gives us the funding? I don't know.

SENCO4: so I may well be up there with you know a deputy and a head and we fill out one big... I have not got a clue what money or what budget is going on. It's all as far as I'm concerned completely fictional, means absolutely nothing.

3.3.2. The impact of high expectations

This subtheme explores another dimension of how poor communication can impact relationships in the system. Stemming mainly from the interviews with school staff, this subtheme discusses how parental expectations (sometimes built up by other professionals) can lead to not only disappointed parents, but additional stress and pressure on the staff trying to provide the support within the system.

Some teachers perceived that some parents have unrealistic expectations about what schools can achieve, perhaps due to their own lack of knowledge and understanding about autism:

> *Teaher2: We get a couple of parents, it's typically the ones more who sort of don't engage with us who are almost expecting the cure from us and so that if they are non-verbal and they are in reception they expect that by the end of the reception we will have them talking and there's just this kind of disconnection and what is within that child's capabilities and what we can provide.*

In general, the experiences of school staff are that parents' expectations for post-diagnostic support are higher than schools are able to deliver:

> *TA1: ...immediately and a one-to-one, that is theirs and theirs only and they don't understand the process and the fact of money and everything else that goes with it, they don't…. They want to see differences quite rapidly and they want to see*

differences at home quite quickly as well, but it doesn't work like that and it's a

process.

In addition, staff felt that parents put too much pressure on schools to be the sole source of support, instead of seeking additional support from other services:

> *SENCO2: there's just this assumption that if they've got this need, one-to-one has to be provided by the school and if not providing it then we're failing the child… it just seems to be quite an unrealistic expectation of the support a school actually can provide, and I think they believe that we are the only ones that offer support and that almost it's not beyond them, it's kind of just all back on us now to make sure that their child is getting what they need. Which is hard.*

Many school staff believe that parental expectations are often built up by other professionals, who do not realise that their recommendations may be unrealistic in the current system, and this impacts negatively on school staff:

> *SENCO2: So how do you then say to a parent in that meeting, that child's not going to get one-to-one support and you've got the occupational therapist or whatever saying well he really needs it and you're like I totally agree but when I write this to [local authority] he is not going to get that. Um so there can be this just sort of mismatch of what's realistic, what the professionals think this child's needs and what you can actually provide and you end up being the bad guy because you're the one that is*

going to provide the support or can't provide the support and that's, it's quite a hard

place to sort of sit sometimes.

3.4. Theme 4: Negative impact on quality of life

This theme explores how a lack of post-diagnostic support impacts everyone in the system in numerous ways, including mental health, physical health, and overall quality of life. The subthemes are that a lack of support affects everyone (parents, children, school staff and others), and that a lack of support can cause stagnation in life as people feel stuck.

> *Parent8: Because of the situation, my professional life suffered a lot, my personal life, social life, everything. It was not because of how my children were behaving. It was, I was not having any support.*

3.4.1. Lack of support affects everyone

This subtheme explores how poor provision of post-diagnostic support negatively impacts everyone in the system in a variety of ways. Many parents discussed their experiences of seeing their child's mental health severely impacted by a lack of support in school, illustrated in the following examples:

Parent5: then [daughter] went into kind of school refusal basically she was too scared to go to class. she couldn't get into school without me, because she was so anxious and she couldn't func…, she couldn't sleep, she couldn't eat, they'd driven her to the point of breakdown.

Parent4: they were just at breaking point. And you see your young child having a mental health crisis and it's it's messed up is what it is, it shouldn't ever at five years old. It… how did it get to that point.. it's really really yeah.. distraught. And I had someone sort of go to me, well five year olds can't really have mental health problems, well… watch my child.

Both of the above parents talked about '*breakdowns*' or '*breaking points*', and discussed how difficult it is for parents to watch their child suffering. Other parents talked of their child self-harming and the lack of support for them:

Parent3: I really have an issue with this in nothing for girls. Cos they just they're so different, they really are so different and they need the support. And at that stage, my daughter was self-harming the fact that she was scratching until you know she was bleeding. She wasn't eating, there was no food going on… But the scratching. Oh they phoned me up oh she's got marks… School phoned me up, she's got scratch marks. Well what's triggered it? Oh well nothing, we were just going into assembly.

Parents also talked about the negative impact of a lack of support on siblings of children on the autism spectrum:

> *Parent8: My 9 year old child is sharing a room with my 5 year old child who is autistic and the 9 year old child at that age is getting anxiety now because she's scared of the younger sister…. There should be a lot of support available for the siblings as well, that they suffer a lot. If they are sensitive and if they are nice, they are kind, they suffer a lot inside themselves.*

All parents interviewed discussed the considerable negative impact that a lack of post-diagnostic support has on their health. Many mentioned the significant impact on their mental health:

> *Parent8: some days I'm so like feel so low and so stressed that I don't feel like doing anything like even cooking for them. Once like I was so stressed that I like didn't know and I flipped the cup of tea on my foot and I burnt my foot… But there is no one when I'm just struggling and trying and I'm seeing that I'm really, really getting so much anxious now because there is no help available. No one is there to support me.*

The above illustrates how the sense of isolation and lack of support often leads to stress and low mood. Some parents talked about how they are struggling to cope with the impact of a lack of support for their child:

> *Parent7: Stress levels have gone through the roof. Very much through the roof. Evidence of that is my smoking's increased… I find myself quite annoyed, I feel that annoyance. I've become more aggressive towards people, short fuse, not taking it.*

This shows that, for some parents, the lack of support may result in annoyance, anger and aggression. Some parents also discussed the negative impact of a lack of support on their physical health:

> *Parent3: my physical health went where I couldn't even walk… I thought stuff it but that's life. That's something that I can't.. my physical health my mental health has to suffer because I have to make sure that I'm the primary care for her because there's no-one else to help.*

Some of the parents talked about the importance of trying to look after their own mental health:

> *Parent6: It really is about being kind to yourself, and the thing that I didn't do which is... Making time for yourself because I gave myself 100% over to negotiating this whole thing, and that meant that about 8 years ago I had... I came very close to a breakdown.*

However, lack of emotional support was not just the issue; the majority of parents acknowledged that they were unable to find someone to look after their child and through this were unable to take proper care of their own health:

> *Parent3: My letter came in yesterday for my operation. I can't go to that operation, I can't have that operation. Because there's literally no one to look after her if I have*

that operation. Can't go. I'm gonna have to suffer. That's the reality and people go

well you can't take her health out.. but what can I do? There's nothing there to

support her while I'm in there…

Parent5: I don't go to blood tests, I don't go to the GP.

Parent4: I had the GP sort of having a go at me, well you need to come in for this

blood test… Are you gonna watch my autistic son while I go and do this? …health-

wise it's a huge thing.

School staff also discussed their experiences regarding the impact that a lack of support has

on them:

TA1: I've had quite a few experiences where I've had children lash out at me, I've

walked around with a black eye and it's hard. Cos it affects your life as well, so and I

feel like sometimes you don't feel like you're doing enough because something isn't

working… There's not enough of me to just go around and I'm exhausted by say

lunchtime and I've got nothing to give, I'm empty. Empty vessel.

Many school staff felt the impact of not being able to support children as much as they

would like due to the restrictions in the system, and how this affects them:

TA1: Quite upsetting actually because I feel like I should be doing my job and I can't

do it. So it actually reflects more on yourself cos you feel like you're not doing what

you should be doing. And you feel like you're letting the child down. I feel like I let

them down... So it does, it makes you beat yourself up a bit… It just makes you think

oh well you're not doing your job properly so what's going on… it hits you heavy I think sometimes.

One SENCO commented how this is made worse by the way school staff are treated in the media, due to a lack of understanding:

SENCO2: just a massive thing that's just missing from teaching you know they say the biggest way to change the mental health in your school is to support your staff's mental health and wellbeing. We are just sort of dogs really and... you know like we are bashed about in the press, everyone thinks they can have a shot at education cos everyone's been through it.

3.4.2. Stagnation in life: feeling stuck

This subtheme explores how a systemic lack of support leaves many people feeling stuck, unable to move on in life. One example of this that many parents discussed was how a lack of support impacted their job or career:

Parent5: Like I was a senior civil servant I had you know I used to deal with ministers, I had a proper job. You know and I see people on LinkedIn and off they go with their careers and I am... you know only now lots of years later has that sort of hit me about how kind of personally my life you know… that bit is just sort of erased…

Many parents talked about how the systemic lack of support means they are stuck in this geographical area, unable to relocate:

> *Parent1: I would like to live out of London but it stops me from moving because I know that* ███ *is the best place for them at this present time, and even people that I know that have moved out... it's obviously it's very nice to move out but you won't get the support that's needed… so it does stop people moving around which is a shame really… there's not enough special schools so if I wanted to move I can't because I have to look at where are my children going to school?*

Parents generally agreed that they could not move because the support in their local area is better than other places:

> *Parent3: No matter how much we complain about what [local borough] are doing..*
>
> *Parent5: yeah it's good*
>
> *Parent3: [local borough] are one of the best.*
>
> *Parent4: That's terrifying.*
>
> *Parent3: And that is really worrying.*
>
> *Parent4: I would never leave this borough.*
>
> *Parent3: No, not now. I would love to..*
>
> *Parent4: I will rent a tiny flat for the rest of my life but..*
>
> *Parent3: It's a nightmare.*
>
> *Parent4: but that's what's got to be.*

School staff also experienced feeling stuck, due to a lack of support and systemic misunderstandings about autism in schools, namely performance-related pay not taking into account appropriate progress targets for pupils with autism who are often unable to meet the same standards as other children:

> *SENCO2: I mean with performance-rated pay I mean I've worked in a school where ninety percent of my children had to be at the expected standard at the end of Reception… it's honestly it's not gonna happen, so you don't go up the pay scale the next year. And you're just stuck in this like really unpleasant catch twenty two.*

3.5.   Theme 5: Hope for the future: developing the system to make it work

The final theme which emerged from the data was participants' experiences of when the system worked and was able to meet needs, where this support came from, and what people would like to change about the system to help improve support for children on the autism spectrum and their families in the future. This theme encapsulates the feeling of hope that support can continue to improve:

> *Parent6: things have improved so much in the last 15 years… the information is getting out there… and yes it is kind of baby steps, but you can see it happening, you*

can see it improving as we go along, so even if things aren't quite where I would

ideally like them to be right now, they are getting closer all the time which is really

encouraging.

3.5.1. The value of external resources: some services can meet needs

This subtheme describes people's positive experiences when services were able to meet

needs, and the value of such services. All of the children and young people talked about

positive experiences of support that they had received in school:

Interviewer: Okay. Do you get any help at school?   CYP1: Yes.   Interviewer: What

kind of help do you get?   CYP1: When I'm stuck on my work.   Interviewer: When you

get stuck?   CYP1: Yeah.   Interviewer: How do people help you?   CYP1: They explain it

to me.   Interviewer: Who explains it to you?   CYP1: my teacher, and then my teacher

assistant… They help me figure out what I'm meant to do.

CYP4: I think I recently I had to do a little bit of a thing where like... you had to see if

you had to have like 25% off of your exams put a 25-minute extra I think, so the

recent thing [SENCo] has done.

All parents had experience of attending an autism parent support course (e.g. Early Bird or

Cygnet) provided by the NHS following diagnosis. Overwhelmingly, parents found these

courses to be very helpful in a variety of ways:

Interviewer: What was the most helpful thing?

Parent 6: the Early bird course. The very first one... there were elements where they had to come to your home and see how you interact with your child and guide how you play with them to increase their social skills, and those were the bits that I did, and I found that really useful… and then they'd give you some structured ideas that would help increase their skills. Yeah it's amazing.

Parent3: The cygnet course I can't fault that that was great. There was a lot of wealth of information on that.

Parent4: what I really liked about the early bird course is it didn't dumb it down, like they kind of gave you a lot of respect as a parent to kind of understand the complex information.

All parents interviewed also had positive experiences of receiving support from the local parent forum (which is provided by a charity):

Parent7: This place [local parent forum] has been a godsend… what [they] provided me with is more than what anyone else has provided me with… Meeting other parents, information, knowledge, open... a place where you can come if you've got problem, that is client-centred… they gave me an environment where they can listen to me…

Many of the parents also discussed positive experiences of specific support from CAMHS:

> *Parent3: But I mean they [CAMHS] gave me the support, I was phoning them up in tears literally saying it's not you, it's the school. We know what the school's like. You know but they did give me that support, I'm never gonna fault CAMHS for that.*

> *Parent7: CAMHS has done what they said they would do. They've been a bit clear about what they do and their service has been accessible and accessible by phone as well… They listened to... they had a solution that my daughter said wouldn't work and they listened to her. So yeah, that was good.*

Although parents' narrative around schools largely focused on a lack of post-diagnostic support, it is important to acknowledge that there were some examples where parents had had positive experiences of support from schools:

> *Parent6: school is brilliant, they've got a home school communication book, which can go in both directions… we get reports back in the book about what he did that day… it's all really good because that is their focus... any time I've raised an issue they've dealt with it really quickly.*

Some parents also talked about the support they had received from individual members of school staff:

Parent7: Fortunately for me a SENCO at the school was brilliant. She was fantastic. She is definitely client centred. The first meeting she was at everyone changed their attitude because she wasn't prepared to let people think the way they were thinking, including the school even though she's based in the school. She had done a passport straight away... The SENCO has been brilliant since she's got involved. She's been brilliant.

For school staff themselves, there was one overwhelmingly positive source of support which came up in all interviews – the local specialist school outreach service:

SENCO2: I think ▮▮▮▮▮ are amazing. Absolutely amazing. I know teachers in other boroughs that just they have absolutely no autism outreach and so they're sort of on their own and ▮▮▮▮▮ are just there you know drop of a hat they'll come and help and they've supported us massively with some really high need pupils… They just help us progress that child to get through the class, day to day work… They just give you the confidence to feel like you've made the right decision, they'll come in and be like 'you are doing the right thing' and you feel great… Giving you practical resources, you know?... they are just an absolutely incredible resource um and I think that every local authority should have one.

3.5.2. From alone to together: parents supporting each other

This subtheme explores parent's experiences of having to do everything for themselves, and then of receiving support from/supporting other parents on the same journey. For example:

> *Interviewer: So you kind of had to do that yourself?*
>
> *Parent 1: I've done everything myself…. I'm more proactive myself so everything that I've done I've done myself.*

For some parents, that even meant setting up their own support groups, which they found a helpful source of support:

> *Parent8: And then I made a support group. So, we all are together, we all like put our - our like problems there. And like, you know, listen to it, and help each other, advise each other, no professionals. Interviewer: A group of parents? Parent8: I created it, yeah. You can say my fear helped me to reach this. So, this is the best thing so far because I learned a lot from them. I am still learning.*

For many parents, one of the best sources of support that they had encountered was other parents in a similar situation:

> *Parent2: Meeting other parents is a massive boost… You see the similarities, and you see that it's not just your child being weird and strange it's you know that is part of the diagnosis. So many little things…*

> *Parent3: Definitely. Yeah start getting get all the information out come and see parent's who've gone through it so you know what questions to ask because you're just left in limbo and it's such an isolating feeling.*

All parents felt that sharing information was a good way that parents supported one another:

> *Parent1: I mean for me it was being able to listen to other parents and what they do and how their children behave and how you could do things differently with your children… they're pretty good at finding things out for you, and if there's something in particular that you want to know they can email you stuff so that's been helpful… listen to other people that have got children on the spectrum because their information and their input to you is gonna be quite valuable… they've been through it all before… so listen to people's advice and take on board what other people are saying cos they're only trying to help.*

Most parents felt that the lack of support from the system means parents have to work together to support each other:

> *Parent1: I think parents have to pull together in a big way to make a difference because you just can't leave it now to outside agencies all the time to do things, you have to kind of you know, make your own support group, talk about things together, what could you set up yourself, what is it you want for your children?*

3.5.3. Empowering the people in the system: giving voice

This subtheme addresses a common issue which participants talked about: how the system could change to better meet the needs of children on the autism spectrum. By discussing ideas and recommendations around service development, it is hoped that the voices of the participants will be heard.

One young person on the autism spectrum proposed the following idea about learning in groups:

> *Interviewer: Is there anything you would like to change about school to make it better for people with autism?*
>
> *CYP4: umm...maybe like bring once every two weeks you get a bunch of, you get autistic kids like a couple of autistic kids and a couple of non-autistic kids and do sessions with them and you see how... you see how they see it.*
>
> *Interviewer: what do you think would be good about that?*
>
> *CYP4: so you can see how an autistic kid sees life and you can...and they can know how they feel.*
>
> *Interviewer: so you think it would be good for the people who don't have autism to learn with the people who do have autism to see what it's like?*
>
> *CYP4: yeah and maybe with autism they can see other people with different problems like ADHD and dyslexic.*

Most parents said they would like to see greater awareness and more education around autism, and feel schools should have an important role in this:

> *Parent8: Sometimes some parents are so upset. Most of the time they directly complain to the school, but the thing is, even they don't want to speak to me because they think I'm not stopping my child. So, if there is enough awareness in the school and they do enough assemblies or send like these sort of information in the newsletters; parent should be aware of that, that some children are different. They don't do it on purpose…*

School staff felt that local authorities should do more to increase autism awareness amongst parents to improve understanding:

> *TA1: But I think a lot more of the local authorities need to get more involved and have lots more like workshops you know and for parents to like get involved in and also meet other parents that are going through it as well because you know we have the knowledge in the sense and we've worked with children so we have that understanding behind us. But you know I found with a lot of parents that are in the school are looking at me in a way because they don't have that understanding.*

In terms of recommendations, many school staff advocated for whole school approaches to autism, and felt that this would help all pupils:

SENCO2: things like autism peer awareness - just do it with every class, just try and make it just always a school approach. If you're gonna do autism peer awareness do it with every class. If you're going to do getting back to green as emotional regulation – make that a school policy, every class does it cos it's going to work for everyone… you just run that as whole staff training because it's not just children with autism that are going to benefit from it - make that an absolute standard in your school... I think if you can really do that whole school approach you're laughing… All staff sign, this is our autism awareness policy, you've signed it therefore when I walk into the classroom there is going to be x, y and z up in your classroom.

Parents suggested helping young people with autism to meet other young people with autism so that they do not feel alone (something which CAMHS have recently started facilitating):

Parent2: we pushed the kids to have um sessions together and that's they I think they found that so good well my son did to meet other kids, so he wasn't alone. He loved it and they all really bonded… I think there should be more of that just you know get them together so they don't feel they've been given this diagnosis and they're just alone.

School staff said they would like to have an additional resource for pupils with autism to have 'learning mentors', something they do not currently have:

Teacher2: they need to have someone that's always there… they need to have time with someone to sit with them and to talk through that story of what went wrong, how it could be different and that's ideal cos it seems to make a big impact with the children. Interviewer: And what kind of member of staff might fill that role? Teacher1: The learning mentor? Teacher2: Yeah that would be ideal. That would be an ideal person… They need to hold on to someone they can trust. So if there's that one person for all there will always be someone there for them.

Most school staff believed that teachers need to receive more appropriate training to support pupils on the autism spectrum:

SENCO3: You know I do wonder if we've I'm not being critical but we've lost something having the year out training in and out or two year course. My course was very intense SEN. I learnt so much in that year and I just wonder if you know with the perhaps not preparing our staff enough. We can't learn it from one lecture.

School staff also identified a number of other ways in which they would like to see the system change to better meet the needs of children with autism. Unsurprisingly, the number one change was an increase in funding which could be used to provide sufficient resources for school staff to support pupils with autism:

Teacher3: like the resources you could use in class. They're not readily available for every single person. I think it would be good if everyone had a set of whatever it is you needed. I don't know what it is but whatever it is you needed, if it was wide,

more widely spread. It is just resourcing and funding I think is where it comes down to.

Also along the lines of funding, one parent talked about wanting easier access to personal budgets which they could use to fund support groups:

Parent7: All of these things can be done if you had personal budgets, because if I could find another girl, I could basically pay a female fitness instructor to engage with [child] and engage with another girl who has autism and another girl with autism. Therefore you've got the makings of a self-help group. None of it has to be paid because it all comes out of personal budgets.

With funding, staff said they would like a sensory room for pupils with autism to use when needed:

Interviewer: So if you if you did have more money, what do you think you would spend it on? Teacher1: I think having somewhere safe for them to go if they feel like they need to calm down… I think a sensory room ideally for them to have a break.

One of the children also made a recommendation about how to better support them when they need a break:

CYP2: If the class gets too loud I'd like to have like a minute or so outside… Well just you know make the break and lunchtimes a little bit longer that's all... The more time of... well there's a lot more respite…

Some school staff discussed wanting to see greater transparency about how funding for pupils with EHCPs is being spent:

Teacher3: Just I think we need to know if they get a budget exactly what that budget should be because personally I feel that they've put the budgets together to get other staff in but then other staff aren't necessarily supporting the children that have got them here in the first place, the statement money behind it it's, we need a TA in a class that doesn't have one. So we'll put it there, that's how I feel.

School staff also said they would like a greater presence of educational psychologists in schools than is currently possible given funding:

Teacher2: I think there should be well obviously there's no funding but I personally think there should be Ed Psychs in every school. I know there there's no funding and they can't do that but I think like having a team of ed pychs and just literally just stay in the school cos obviously it's changed now how they have like they go to local authority and go to different schools, they should stay in the school and like help you know be so helpful to help with the SENCO and with the teaching assistants to help those kids, not just autistic kids but also other kids who have learning disabilities as well.

In terms of accessing post-diagnostic support, parents suggested some kind of link/hub service to show them where to obtain support and to point them in the direction of other services:

> *Parent5: There needs to be kind of like a GP or a hub, I don't mean literally a GP, but like someone who knows about it. Because otherwise there's a lot of wasted as you say we're all sort of running around trying to find things, it's super-inefficient.*

Another common issue identified by parents is that children who are diagnosed younger/earlier tend to receive more support and have better outcomes, and changes should be made to the system to try and address this:

> *Parent8: I'm feeling like for younger children, there is some help available afterwards... but for older children there is nothing… if he was provided it at early age, it might be more helpful. Like my older son who is already diagnosed very late, still, he's not receiving any support from CAMHS.... So, like there should be some support from CAMHS for the sort of children who have diagnosed very late in their life.*

Many parents discussed how they would like to see children with autism receiving regular follow ups (like the keyworker role suggested in the NICE guidelines), and that perhaps CAMHS should potentially fulfil this role*:*

Parent5: I'd like you know the people that are involved in the diagnosis to follow your child so that you see them six monthly or even yearly intervals and they come into school and they do this thing of saying how's it going, what could be better, here's our top tips from people who understand autism and know a bit about your child.

Parents would also like to see more local social activities accessible for children with autism:

Interviewer: What about local authority?

Parent6: to have more things available to working parents. To have more things available sort of socially for kids who've been diagnosed, but sort of in the evenings more after school stuff because that's where they kind of need to let the pressure go.

Although all the children and young people who took part did not report that they or their parents needed any additional help or support, two of the young people did report a number of specific school-based supports which they felt might help their learning or ability to cope with school:

Interviewer: how might people help you, as somebody with autism, with your GCSEs?

CYP4: umm maybe put it in a way that I can understand. Interviewer: ok, so we talked about having extra time in exams but you think maybe if the questions in the GCSEs were phrased in a way that was easier for you to understand that would be helpful? CYP4: yeah.

Interviewer: What would have been useful?   CYP2: Just a couple of sample sheets…

The ever-explanatory example sheet... It could be any size paper any size to fill the

example in. And then show the example in general. Like for instance if it's a maths

equation it could show an example of the maths equation.

4. Discussion

"We expect families to hold their hands up from deep inside a black hole of

helplessness. Then, we expect them to have the psychological strength to climb up the thin

rope we throw down" - Paquette & Ryan (2001, p.3)

This discussion section begins by summarising the key findings of the project in

relation to the original aims and research question. The results are discussed in relation to

previous research and theories. A number of important clinical implications and

recommendations emerged from the results, and these are presented. The strengths and

limitations of the project are discussed, as well as directions for future research, before

offering some final conclusions of this project.

4.1. Summary of Findings

This research project set out to provide a platform for young people on the autism

spectrum, their parents, and school staff to voice their experiences of post-diagnostic

support for children on the autism spectrum, with the aim of developing a greater

understanding of people's experiences in this area, and how the system can change to

better meet the needs of children on the autism spectrum. The main research question was:

what are people's experiences of post-diagnostic support for children and young people on

the autism spectrum? This project generated five key themes, each with a number of sub-

themes, around people's experiences of post-diagnostic support for children with autism. These themes highlighted that people's experiences were generally of a lack of understanding about autism, a system unable to meet needs, poor communication impacting on relationships, considerable negative impacts on various aspects of quality of life, and hope for the future in terms of developing the system and increasing resources to improve support.

This study aimed to provide answers to three further research questions:

4.1.1. What are the experiences of children and young people on the autism spectrum of receiving support after diagnosis?

Children and young people were generally happy with the level of support they were receiving, and reported that they did not feel that they or their parents needed any additional support. However, the children and young people interviewed were often unaware of what support they were receiving and why, and were generally unaware of any plans in place to support them. Some young people were able to make suggestions about what they would like to change, and these were mostly around things which school could be doing differently to support them more.

4.1.2. What are parents' experiences of post-diagnostic support for children on the autism spectrum?

Parents' experiences were overwhelmingly of a general lack of post-diagnostic support, not only for their child but for themselves. They often did not know what support

was available or how to access it, and were disappointed with the widespread lack of awareness and understanding about autism, both in the community but also often in schools and services. Parents highlighted the lack of funding and resources as a key barrier to schools and services actually meeting the needs of their child, as well as generally poor communication both from and within schools and services. Parents talked about the significant negative impact that this had on their child's mental health, their own mental and physical health, and their ability to move on with their life. Parents often had to do a lot for themselves, and found support from other parents was highly common and very helpful. Parents shared experiences of services they found helpful, and came up with ideas for developing services to improve support. They had many suggestions about how the system needs to change going forward to better support them and their children, such as increasing funding and resources, and improving awareness and understanding through education and training. When these findings were fed back to a parent participant in this study, they reported that the themes accurately captured and reflected the main experiences and narratives of these parents.

4.1.3.   What are the experiences of school staff of attempting to provide support for pupils on the autism spectrum?

School staff reported many of the same frustrations as parents, such as a difficulty accessing autism-specific training, and a lack of funding and resources. School staff often identified their own lack of expertise when it came to supporting pupils with autism, and the need for them to bring in the local specialist outreach service, which staff experienced very positively. School staff also felt that parents had very high expectations of post-diagnostic support for their child, and that this often negatively impacted on their relationship with

school staff. Furthermore, these high expectations were often contributed to by professionals from other services, whose unrealistic recommendations put excess pressure on school staff. Some school staff discussed how they were hindered from providing better support by poor internal communication and dynamics between school staff, with many staff feeling isolated from knowing about 'higher' features of the system such as finances. Staff reported that the overwhelming barrier to support was funding; all school staff highlighted that recent budget cuts have significantly limited their resources and staffing, making it more difficult to support pupils with autism. School staff talked about how this also impacts on their lives, both by impacting on their mental health and their potential career progression. School staff had many recommendations for how the system should be developed to improve support for children with autism, including more autism-specific training for staff, and more funding and resources for schools going forward.

The following sections explore the results further, both situating them in a theoretical context, and discussing them in relation to previous research.

4.2. Situating the findings in theoretical context

In examining the findings of this study, it was noticed that there was a high level of coherence between the results of this study and Bronfenbrenner's (1992) Ecological Systems Theory. The following sections therefore further develop the key findings by discussing them in the context of the Ecological Systems Theory (see Figure 6), a systemic model which places the child at the centre of the system and identifies various layers with which the child has relationships (Berk, 2000).
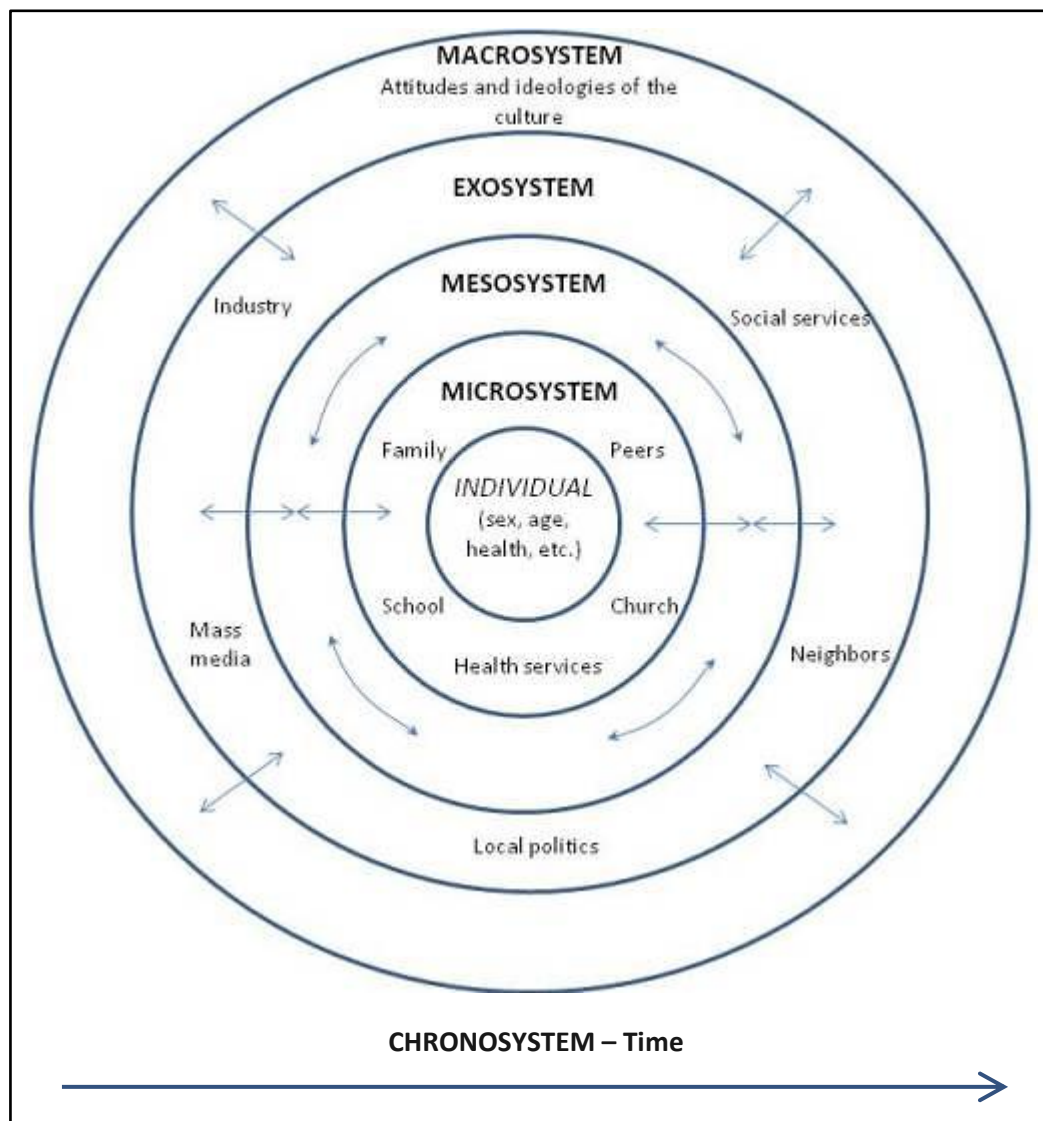
Figure 6: Bronfenbrenner's (1992) Ecological Systems Theory.

Illustration adapted from Hchokr at English Wikipedia (Licensed)

4.2.1. The microsystem

The microsystem is the system closest to the child and includes the direct

interactions and relationships that a child may have with individuals, groups or

organisations in their immediate environment, such as family, peers, school, health services

etc. A key relationship in the microsystem is between the child and their parent(s) or primary carer – their main source of support. While parents often reported that the lack of post-diagnostic support had serious negative impacts on their child, the children interviewed felt that both they and their parents received enough support and did not need any more support. This suggests that young people on the autism spectrum are protected (by their parents) from seeing the negative impact of a lack of support both on their parents and to some extent on themselves. However, parents reported that the persistent lack of support often has severe consequences for the parent's mental and physical health, which can impact on their ability to support their child. This suggests that if this continues then children may no longer be protected from seeing the negative impacts of a perpetual lack of support. It is also important to note that asking children to think about how their parents are feeling and what they might need may be a very difficult task for children on the autism spectrum who may have difficulties with theory of mind (APA, 2013).

Another key relationship in the microsystem is between the child and school, tasked with not only directly supporting the child but coordinating the provision of support. Here the findings were generally that schools are not meeting the needs of pupils with autism, and this is mainly due to the impacts of issues in the exosystem and macrosystem trickling down: most notably, the effects of a lack of funding and resources, and a lack of knowledge and understanding about autism. Schools' inability to appropriately meet the needs of children with autism was another widespread feature of the microsystem which the young people were largely unaware of, although this does not take away from the very real negative impacts on children's mental health, academic progress and social life.

4.2.2. The mesosystem

The mesosystem is the interactions and relationships between the parts of the child's microsystem, such as the connections between the child's parents and school, between parents and other services, and between school and other services. A key finding relating to the mesosystem was poor communication between parents and schools; many parents reported feeling frustrated by a lack of clear communication from schools. Likewise, school staff often reported poor communication from parents, often relating to parents' high expectations of post-diagnostic support. Staff found that unrealistically high expectations put additional pressure on them, and these were often made worse by professionals in other services. This is perhaps due to schools' lack of capacity or confidence in communicating their own limits. Poor communication within schools and between schools and other services complete this circle, emphasising that a considerable barrier to providing appropriate post-diagnostic support is an endemic failure of communication within and between all parts of the mesosystem. This leads to what parents described as a constant fight with the system to try and get needs met: for most parents, the mesosystem is the main battle ground.

4.2.3. The exosystem

The exosystem is the larger system with which the child does not directly interact, such as the local authority, media, and often to some extent the local community (e.g. parent support groups). The structures in this layer can have significant impacts on the child through interactions with their microsystem. For example, the local authority will affect the child's school, and the level of support in the local community will affect the child's parents.

There were three key findings relating to the exosystem: the first was an overwhelming lack of funding and resources. This presented not just as a significant lack of funding from local authorities to schools (reported by both school staff and parents), but also a lack of funding for local activities (e.g. places/activities that parents could take their children to). The lack of local funding is influenced by budget cuts on a wider (national) scale, which many participants felt hopelessly disconnected from. The second finding was a lack of understanding about autism at a community level, relating both to members of the public but also to professionals in services like social care services and the local authority, which impacted significantly on the child's microsystem (parents, school staff etc.) The final result relating to the exosystem was parents supporting each other; many parents found that other parents were one of the main sources of support, be they informal or formal (e.g. parent support groups). Although the child has no direct interaction with this support, it has a positive impact on them through their microsystem (i.e. by supporting their parents).

4.2.4.   The macrosystem

The macrosystem is the outermost layer in the child's environment, and includes societal values, attitudes and laws. These cultural principles impact on all other layers in the system. One theme which relates to the macrosystem is a general lack of awareness and understanding about autism. This reflects society's dominant narrative around neurotypical being 'the norm', and anything that is not 'the norm' being seen as wrong or bad rather than just different. This attitude means that most people receive inadequate education about neurodiversity, including autism. As a result, many of the parent and child participants had experienced bullying or discrimination, and many had been given harmful

or damaging advice about how to care for their child. Furthermore, a lack of awareness and understanding about autism means that it is not a priority for funding, hence why schools have seen their budgets cut, leading to a lack of resources and staff to properly support children with autism. The lack of awareness means that people are less motivated to properly fund support for these children and families. This societal value has impacts which trickle down to every layer of the child's system, and ultimately a lack of sufficient funding and resources will have significant negative impacts on the child and their family. These are issues which need to be addressed at a national level.

4.2.5. The chronosystem

The chronosystem focuses on time as it relates to a child's environments, and the various systems can shift and change over the course of a child's life. One example of this which emerged from the results is that the younger/earlier a child is diagnosed, the more support they tend to receive and the better the outcome. Most parents reported that support dropped off as their child got older, and many said they wished their child had been diagnosed younger, as they felt it would have been helpful for support to be implemented sooner. Another (wider) aspect of the chronosystem is that funding for support appears to have decreased over the years. Many parents reported that there used to be more support, for example it used to be easier to get a statement of special educational needs than it is to get an EHCP now. Both staff and parents believed that recent budget cuts meant that schools and services were now expected to support more children with less funding and resources than before, making providing appropriate support considerably more difficult than it was in the past. Interestingly, this fits with previous research in that the findings of

the current study are (in this particular domain) different from past studies (e.g. Whitaker, 2007; Parsons, Lewis, & Ellins, 2009) which found that schools were a positive source of support and that parents were generally satisfied with the support schools were providing, which was not replicated in the current study. This demonstrates how ten years of budget cuts have impacted on schools' ability to provide appropriate support, and how this impacts on children, parents and staff now. Despite this, some parents did report feeling as though the general level of awareness about autism had increased in recent years, giving some hope for the future.

4.2.6. The Deficit Model

Bronfenbrenner (2005) also highlights the narrative around 'deficits' which affects families' ability to access support, in that society expects parents to label themselves as "deficient" to some extent in order to obtain necessary public support. This is in part due to the Western cultural attitude which values independence; in order for families to obtain more support they must declare themselves to be "failing". Bronfenbrenner emphasises the harmful nature of such a narrative, and instead proposes that support should work alongside families to develop their existing strengths, rather than focusing on deficits. Although this idea comes from America, this model is especially relevant for the current research project, as many parents talked about how the current system waits for their child to fail before providing support, or how support was finally provided just before (or in some cases, after) they reached crisis or breakdown. The need for support should not imply a "deficit" or a "failure", and support should be provided earlier (proactively) rather than reactively to try and prevent further distress and to improve outcomes.

4.2.7. Social Model of Disability

The findings of this study are also consistent to some extent with the social model of disability, the idea that 'disabilities' are not located in the individual but in the interaction with their environment (see Shakespeare, 2006). This notion suggests that 'disability' is something additionally imposed on people in as much as they are isolated and excluded from full participation in society. With regards to the current project, many participants commented on how the current system is not well suited to people on the autism spectrum, and that many of the issues they face are made worse by the fact that their environment is simply not set up for individuals with autism. By increasing awareness and understanding about autism (e.g. autism-friendly whole school approaches), this may help individuals on the autism spectrum to feel less excluded from their environment and may facilitate improved integration in society.

4.3. Links to previous research

In general, the results of this study appear to be consistent with previous research, in that they reflect a general inadequacy of post-diagnostic support as reported in much of the existing literature (e.g. Crane et al., 2018; Galpin et al., 2017; Jones et al., 2014; Legg & Tickle, 2019). For example, Crane et al. (2018) reported that both parents and individuals with autism had experienced a lack of post-diagnostic support and that "everything's been a fight" (p.7). They also reported a lack of appropriate local support that they could access, and noted that voluntary sector organisations had to fill the gaps which should have been filled by services. They also identified a lack of emotional support for families which had

significant negative impacts on quality of life. These findings are very much congruent with the findings of the current study, as discussed above. Experiences of funding cuts by participants in the current study very much echo the findings of the The Key (2016) who reported that insufficient funding had significantly impacted on schools' ability to provide appropriate support.

Other previous research which asked individuals with autism about their experiences of support also identified familiar themes. Camm-Crosbie et al. (2018) reported that an overwhelming lack of knowledge and understanding about autism negatively impacted on many people's experiences of support, and that insufficient support negatively impacted on participants' wellbeing. Whilst these are results from adults with autism, these themes reflect the findings of the current study as pertaining to children on the autism spectrum and their families. The results of the current study also reflect the findings of the APPGA (2017) which reported that the majority of parents were not satisfied with teachers' level of understanding of autism.

Previous research which has focused on parents of children with autism in London found that existing post-diagnostic support (particularly from formal support services) was not meeting parents' needs (Galpin et al., 2017). Many of the findings from this research are mirrored in the current research. For example, parents identified poor communication from schools and other services as a hindrance to good support, as well as 'those who shout loudest gets heard' (p.577), something reflected by many of the participants of the current study. The parents interviewed by Galpin et al. also identified that a big source of support was other parents, a theme which very much came out in this project as well. Another study

by Ludlow et al. (2012) found many similar experiences to those of the parents in this study.

One example is of members of the public not being understanding, and their reactions to

'public tantrums' as naughtiness: "people look at you and think what are doing? What kind

of parent are you?" (p.705). This resonates strongly with the experiences of the parents in

the current study, who identified similar challenges, related to a lack of awareness and

understanding. Ludlow et al. also reported parents' experiences of a lack of information

about what support is available or how to access it, and the sense of exhaustion that

parents often felt trying to obtain support. As in this project, many of these parents talked

about the significant impact of this stress on their psychological wellbeing, and how they

relied on support from other parents. These findings reinforce the results of the current

study.

One of the experiences reported by parents in the current study was that autism

parenting courses (i.e. Early Bird or Cygnet groups) were very useful and parents found

them to be helpful sources of support. Whilst this is reflected in some previous research

(e.g. Cutress & Muncer, 2014), other research suggests that there is still a lack of robust

evidence for such groups (Dawson-Squibb et al., 2018), and further research is needed to

evaluate the efficacy of such parenting courses. Other evidence has shown that formal post-

diagnostic support groups for parents can be highly effective (Breen & Buckley, 2016), a

finding which has been replicated in other countries as well (Banach, Iudice, Conway, &

Couse, 2010).

It is frustrating and disappointing to note that many of the difficulties and issues

regarding post-diagnostic support for individuals with autism which were reported in the

current study are being reported in many other countries, such as Canada (Mulligan,

MacCulloch, Good, & Nicholas, 2012; Woodgate, Ateah, & Secco, 2008), Belgium (Renty &

Roeyers, 2006b), Australia (Anderson, Stephenson, & Carter, 2017; Boshoff, Gibbs, Phillips,

Wiles, & Porter, 2018; Hennel et al., 2016) and Sweden (Carlsson, Miniscalco, Kadesjö, &

Laakso, 2016). Other evidence from outside the UK has highlighted the importance of

support for improving quality of life for individuals with autism (Renty & Roeyers, 2006a).

4.4. Clinical implications and recommendations

There were a number of clinical implications and recommendations which emerged from the results of this project. These are presented using Bronfenbrenner's ecological systems model to structure the recommendations. Whilst this shows that there are changes to be made at all levels in the system, it also highlights how interconnected the layers are, in that changes at any one level would generally necessitate changes throughout the system.

Microsystem

One finding which emerged from the project was that TAs are often supporting pupils with autism while the teacher focuses on the rest of the class, meaning that those individuals supporting the pupils with highest needs are the least qualified. Therefore in terms of implications, it is recommended that teachers should work with the pupils with the highest needs and TAs should be working with those who need less support. One reason we are currently seeing the opposite may be that pupils with SEN have the lowest priority for teachers due to targets; that is, the priority dictated from above is on achieving results instead of accessing learning, so that is where the resource is focused. This will be difficult

to change as it will require a major shift in thinking and it will need to be supported by

headteachers, SENCOs, Ofsted etc, however it seems critical that this begins to change.

Similarly, there is a need for ongoing support for teachers and TAs in terms of autism

training and how to adapt their teaching for pupils with autism. Currently there is minimal

provision for school staff in terms of support around, for example, differentiating work, and

teachers would benefit from additional mentoring around how to work with their TAs.

Furthermore, it is recommended that there should be more training around autism in

teacher training courses, as currently the SEN module is minimal and does not reflect how

big a part of everyday teaching this is, especially as we see increasing numbers of children

being diagnosed with autism. This implication also reflects the findings of the APPGA (2017).

Another important implication is around whole school approaches; it is

recommended that schools consider implementing strategies that benefit pupils with autism

across all classes and years. Therefore if schools are doing movement breaks or teaching

emotion regulation etc, they should do this for all students as it will significantly benefit

everyone, and is also a more efficient way to deliver such interventions. Another clear

implication of the current research is that all boroughs/areas should have a specialist school

outreach service. Participants reported this to be a key source of support, however most

areas outside ███████ do not have a service like this. This will require more funding and

resources which means it needs to be a higher priority (as discussed below).

Mesosystem

One common idea was for CAMHS to remain involved post-diagnosis, to provide

regular follow-ups and to signpost or provide support where necessary. Currently, CAMHS

are not commissioned to perform this role, and therefore parents have to rely on GPs and schools to coordinate support, who often lack the necessary knowledge to do so. Therefore one clinical implication of this project would be for commissioners to consider expanding the role of CAMHS to provide care coordinators who could provide families with ongoing check-ups and help coordinate support as appropriate. This would be closer to what is currently recommended in the NICE guidelines. It is worth noting that those children with SEN should be having regular reviews, however this is again through schools who themselves are struggling with a lack of resources and often a lack of understanding and knowledge about autism. Thus, many of the participants in this study believed that the role of coordination should shift from schools to CAMHS, recognising that this would require additional investment to expand CAMHS services. One initiative which is ongoing is having CAMHS link workers in schools, however these are often under-resourced roles, they do not cover private schools, and many boroughs outside of ███████ do not have this system in place. Additional funding for this initiative would help CAMHS to support schools with coordinating support in the meantime.

Some school staff believed that some of the recommendations from other professionals were unrealistic for them to implement in the classroom. Thus one clinical implication is that school feedback meetings (between CAMHS and school) should be a collaborative meeting to think about how to meet pupils' needs given the resource that the school has and what is realistic for the school to implement. Often this may involve thinking outside the box, and if there is a local specialist school outreach service they should be involved in helping the school to think flexibly about how they could utilise their existing resources. Some staff recommended that schools are given additional funding to employ

learning mentors, and it may be that, while in an ideal world pupils with autism may have an individual learning mentor (if needed), that in reality this is facilitated in a small group, as many schools have lost the funding for learning mentors in recent budget cuts.

Another important implication is the impact that language can have on people's ability to obtain support, with terms such as 'high functioning' and 'low need' affecting the ability to access certain support. There are initiatives by service users to move away from this language, and ████████ CAMHS have moved away from the term 'high functioning' as they acknowledge that it often undermines a person's difficulties and may even limit support. However, the term 'high needs' is still used as it helps many people access support such as EHCPs or special educational provision. One issue highlighted in this research was schools using CAMHS' words such as 'low needs' to deny support, so the recommendation is that CAMHS should add clear and explicit explanations to all their reports so that schools understand what is needed and pupils are more likely to have their needs met appropriately. It should also be indicated clearly that the level of need can change in either direction over time.

Exosystem

One finding of the current research was that there is a lot of confusing information available to parents and as a result parents often do not understand what support they are entitled to, what support is available or what support their child needs. In the past it was easier to obtain a statement of special educational needs (this had 6 bands, from 1 lowest need to 6 highest need), but the new system of EHCPs applies only to children who would have had the highest level of statement in the old system. Furthermore, EHCPs do not

automatically come with additional funding except for the children with the highest needs –

an EHCP means this child's needs are over and above what a school can be expected to

provide using their internal SEN budget and existing resources. Where this is not the case,

the school are still expected to make reasonable adjustments and adaptations, and to

differentiate the curriculum for children with SEN, using their SEN budget where needed.

Much of this information is not known to parents, who believe that support is being

withheld and the only way to obtain it is via an EHCP, which they may well be rejected for.

Indeed many parents believe that if their child does not have an EHCP it means they will not

be receiving any support. Therefore an implication of this project is that parents should be

provided with such information so that they better understand the system and can adjust

their expectations, easing the pressure on schools and services, and potentially saving

parents' energy as they stop fighting for support that they are not entitled to. One issue

here is which service provides this information to parents, and this may fall to SENDIASS or

school SENCOs if possible. Another issue is that the SEN budgets have been cut in recent

years, so some people will continue to see EHCPs as necessary purely for the additional

funding that they might attract and not because they are needed, and this may continue to

be an issue until appropriate funding is provided for SEN pupils.

Another recommendation which emerged was that many parents would like there to

be some kind of central hub/link service where parents can find out what support is around

and how to access it. Currently, there are many services involved and both parents and

professionals often find this confusing. An implication of this study therefore is that a

centralised hub is developed to fill this role. This service could be run by SENDIASS, an

independent service commissioned by the local authority designed to support parents of

children with SEN up to age 25. Again, this may require additional funding for the SENDIASS

service, a common issue which is discussed later in this section.

Macrosystem

One of the most obvious implications across the whole project is underfunding and

the negative impact this has on services. Many parents experienced that each service they

accessed, although helpful, was underfunded and under-resourced; it is not necessarily that

these services need to change drastically, just that they need more funding and resources so

they can provide more of that service. While it is recognised that there is no 'magic money

tree', the implication is that, at a national level, autism is not a priority for funding, and this

needs to change. It is hoped that by increasing autism awareness, it will become a higher

priority for funding which would trickle down and facilitate many of the above

recommendations.

4.5.   Strengths and limitations of the project

4.5.1. Strengths

Although my analysis of participants' experiences is affected by the lenses through

which I view the world, this project has attempted to convey the voices of people often lost

and drowning in vast and complex systems, for their experiences to be heard, and to have

clinical implications to improve support going forward. One way this was achieved was the

use of an inductive thematic analysis to minimise preconceptions and allow themes to

emerge from the data in a bottom-up way. Participants were included and consulted in the

design of the questions asked, recruitment, and analysis of results, to improve robustness

and ensure that experiences were presented as accurately as possible throughout.

Transparency was further achieved through the inclusion of my reflective diary throughout.

One of the unique strengths of this project was the inclusion of three groups of participants (parents, school staff, and children on the autism spectrum), providing three perspectives of the situation, a gap which was previously present in the literature. This design allowed for triangulation of data and the resulting themes, ensuring that robust conclusions could be drawn. It also included staff from various levels within schools to capture different viewpoints. Furthermore, the use of a homogenous geographical sample gives a more accurate picture of the system in this particular borough, allowing the drawing out of clinical implications and also providing generalisable recommendations for other areas in London and the rest of the UK.

4.5.2. Limitations

One limitation of the study relates to the nature of the recruitment of participants. For example, many parents were recruited through the local parent forum, and whilst this helped me to meet more parents and hear about their different experiences, it did mean that the majority of parents in the study were those who had engaged with, or at least had awareness of, the parent forum. This may affect the results, as there may be certain features of such parents, for example they may have turned to the parent forum due to difficulties obtaining support elsewhere. I was also aware of the many parents who may not know about the parent forum or be able to access it for a number of different reasons, and the absence of their views/experiences from the data. With regards to recruitment of young

people through schools, this was quite limiting for the sample, as the young people in the study only represented two schools from the entire borough (and potentially those with the most engaged SENCOs). Furthermore, only staff and pupils from mainstream schools were represented, so the experiences of those in special schools is missing from this study. I also reflected on the pros and cons of having parent-child dyads participate in the study. One of the potential disadvantages might be that one hears a less diverse narrative (fewer different experiences), but this was not the case, as in reality, it provided different perspectives on the same events.

For all participants, it is important to think about participation or response bias – the fact that participation in the study may appeal to certain individuals who do not represent the wider population. For example, in this case, the study might have attracted parents who are particularly dissatisfied with services and want to express this, rather than parents who are happy with the amount of support they have. In terms of school staff, the study might have attracted those who are more passionate about helping support pupils on the autism spectrum, and this may be reflected in the data. For the parents, one limitation of the study was a lack of representation of individuals from minority ethnic backgrounds representative of the local population. Evidence suggests that it can be more difficult for people from minority backgrounds to access post-diagnostic support (National Autistic Society, 2014), an important narrative which is not sufficiently represented in the current project.

The final limitation of the project is the sample size; a larger sample size would have been beneficial, particularly for the children and young people where only four participants were interviewed. This means that the voices of the young people are to some extent

under-represented in the results. Furthermore, some of the focus groups had participants arriving late or leaving early, which may have meant that some participants were unable to talk about particular topics or points that they would have like to contribute to.

4.6.   Recommendations for future research

This project generated a number of ideas for future research projects, to continue improving post-diagnostic support for children with autism and their families. One such idea should focus on providing clarification of what kind of post-diagnostic support parents would ideally like CAMHS to provide. Many parents felt that they were *'booted out'* and wanted more ongoing support, but it remains unclear what such interventions might look like, so future research should examine this. There are also some parents who do not access the support available and it is not always clear why, so future research into the possible barriers for parents not accessing support might help services make themselves more accessible.

There are a number of ideas for future research concerning schools, for example, a study examining the efficacy of autism awareness training being delivered to staff. Some staff felt that they had received training but did not know how to integrate this new knowledge into their practice, so it would be useful to look at the effectiveness of such training and what ongoing support is required for school staff to implement this. Another issue is about EHCPs and funding; many parents felt that school staff dissuaded them from applying for EHCPs, even though these may attract additional funding for the school. Future research may examine this dynamic for parents of children on the autism spectrum and

when school staff believe it is appropriate to apply for an EHCP. It would also be useful for future research to examine whether pupils with EHCPs make significantly more 'progress' or have their needs met more than children on SEN support plans. Such research may help alleviate pressures on school staff by adjusting parents' expectations of what support is needed.

Finally, additional future research is needed with children and young people on the autism spectrum, specifically around what they think would help. Such focused research might help in identifying areas of difficulty and helping young people to generate ideas about what would help meet that need. Such research would require a carefully designed plan to give children and young people the best opportunity to share their ideas.

4.7. Concluding comments

This project set out to explore people's experiences of post-diagnostic support for children on the autism spectrum. In doing so it is hoped that this project has given voice to these individuals, highlighted systemic problems regarding a significant lack of post-diagnostic support, and provided important clinical implications and recommendations to improve post-diagnostic support in the future. Whilst the current situation does not present a particularly positive picture, more widely we have observed some gradual improvements in recent years, such as a general increase in awareness of neurodiversity, the introduction of EHCPs to cover individuals up to age 25, a growing body of research on autism in girls, and the introduction of a new national autism strategy covering children in 2019. Such

initiatives provide hope that the situation is moving slowly in the right direction, and will

continue to do so in the future.

5. References

Abrahams, B. S., & Geschwind, D. H. (2008). Advances in autism genetics: on the threshold of a new

  neurobiology. *Nature Reviews. Genetics*, *9*(5), 341–355. https://doi.org/10.1038/nrg2346

All Party Parliamentary Group on Autism (APPGA). (2017). *Autism and education in England 2017*.

  London, UK.

American Psychiatric Association. (1980). *Diagnostic and Statistical Manual of Mental Disorders (3rd*

  ed.). Washington, DC: Author.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders:*

  DSM-IV-TR. Washington, DC: Author.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (5th*

  Ed.). Washington, DC: Author. https://doi.org/10.1176/appi.books.9780890425596

Anderson, A. H. A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the

  experiences and supports of students with autism spectrum disorder in post-secondary

  education. *Research in Autism Spectrum Disorders*, *39*(April), 33–53.

  https://doi.org/10.1016/j.rasd.2017.04.002

Archer, M., Decoteau, C., Gorski, P., Little, D., Porpora, D., Rutzou, T., Smith, C., Steinmetz, G., &

  Vandenberghe, F. (2016). What is critical realism? Perspectives: A Newsletter of the ASA Theory

  Section, Fall 2017. Retrieved July 4, 2018, from http://www.asatheory.org/current-newsletter-

  online/what-is-critical-realism

Ashcroft, J., Wykes, T., Taylor, J., Crowther, A., & Szmukler, G. (2016). Impact on the individual: what

  do patients and carers gain, lose and expect from being involved in research? *Journal of Mental*

  Health, *25*(1), 28–35. https://doi.org/10.3109/09638237.2015.1101424

Asperger, H. (1944). Die „Autistischen Psychopathen" im Kindesalter. *Archiv Für Psychiatrie Und*

  Nervenkrankheiten, *117*(1), 76–136.

Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post

autism diagnosis support group for parents. *Social Work with Groups*, *33*(1), 69–83.

https://doi.org/10.1080/01609510903437383

Bancroft, K., Batten, A., Lambert, S., & Madders, T. (2012). *The way we are: autism in 2012*. London:

National Autistic Society.

Baron-Cohen, S. (2000). Is asperger syndrome/high-functioning autism necessarily a disability?

Development and Psychopathology, *12*(3), 489–500.

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum

Quotient (AQ): Evidence from Asperger Syndrome/High-Functioning Autism, Males and

Females, Scientists and Mathematicians. *Journal of Autism and Developmental Disorders*, *31*(1),

5–17. https://doi.org/10.1023/A:1005653411471

Berk, L. (2000). *Child Development* (5th ed.). Boston: Allyn & Bacon.

Bettelheim, B. (1967). *The Empty Fortress: Infantile Autism and the Birth of the Self.* New York: Free

Press.

Bhaskar, R. (1998). Philosophy and scientific realism. In Margaret Scotford Archer (Ed.), *Critical

Realism: Essential Readings* (pp. 16–47). London: Routledge.

Blaska, J. (1993). The power of language: Speak and write "person-first." In M. Nagler (Ed.),

Perspectives on disability: Text and readings (pp. 25–32). Palo Alto, CA: Health Markets

Research.

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2018). Parents' voices: "Our process of

advocating for our child with autism." A meta-synthesis of parents' perspectives. *Child: Care,

Health and Development*, *44*(1), 147–160. https://doi.org/10.1111/cch.12504

Boyatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development*.

Thousand Oaks, CA: Sage.

Boyd, B. A. (2002). Examining the Relationship BetWeen Stress and Lack of Social Support in Mothers

of Children With Autism. *Focus on Autism and Other Developmental Disabilities*, *17*(4), 208–

215. https://doi.org/10.1177/10883576020170040301

Braiden, H.J., Bothwell, J., & Duffy, J. (2010). Parents' Experience of the Diagnostic Process for

Autistic Spectrum Disorders. *Child Care in Practice*, *16*(4), 377–389.

https://doi.org/10.1080/13575279.2010.498415

Brandler, W. M., Antaki, D., Gujral, M., Kleiber, M. L., Whitney, J., Maile, M. S., … Sebat, J. (2018).

Paternally inherited cis-regulatory structural variants are associated with autism. *Science*,

360(6386), 327–330.

Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in

Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Breen, J., & Buckley, S. (2016). Autistic spectrum disorder post-diagnostic support group: Model

outline and parental experiences. *Clinical Psychology Forum*, (283), 8–13.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic

spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*,

8(4), 409–423. https://doi.org/10.1177/1362361304047224

Bronfenbrenner, U. (1992). Ecological Systems Theory. In R. Vasta (Ed.), *Six theories of child

development: Revised formulations and current issues* (pp. 187–249). London: Jessica Kingsley

Publishers.

Bronfenbrenner, U. (2005). *Making human beings human : bioecological perspectives on human

development*. London: Sage Publications.

Brown, A., Fleetwood, S., & Roberts, J. (2003). *Critical realism and Marxism*. London: Routledge.

Brown, L. (2011). Identity and Hypocrisy: A Second Argument Against Person-First Language.

Retrieved July 12, 2018, from https://www.autistichoya.com/2011/11/identity-and-hypocrisy-

second-argument.html

Bryman, A., Becker, S., & Sempik, J. (2008). Quality Criteria for Quantitative, Qualitative and Mixed

Methods Research: A View from Social Policy. *International Journal of Social Research

Methodology*, *11*(4), 261–276. https://doi.org/10.1080/13645570701401644

Buescher, A. V. S. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum

disorders in the United Kingdom and the United States. *JAMA Pediatrics*, *168*(8), 721–728. https://doi.org/10.1001/jamapediatrics.2014.210

Calzada, L. R., Pistrang, N., & Mandy, W. P. (2012). High-functioning autism and Asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders, 42(2)*, 230-243

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-cohen, S., & Cassidy, S. (2018). "People like me don't get support": Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, 1–11. https://doi.org/10.1177/1362361318816053

Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016). Negotiating knowledge: Parents' experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language and Communication Disorders*, *51*(3), 328–338. https://doi.org/10.1111/1460-6984.12210

Carpenter, B., & Towers, C. (2008). Recognising fathers: The needs of fathers of children with disabilities. *Support for Learning*, *23*(3), 118–125. https://doi.org/10.1111/j.1467-9604.2008.00382.x

Carr, E., & Horner, R. (1999). *Positive behavior support for people with developmental disabilities: A research synthesis*. Washington DC: AAMR.

Clarke, V., & Braun, V. (2013). *Successful qualitative research: a practical guide for beginners*. London: SAGE.

Constantino, J. N., Kennon-McGill, S., Weichselbaum, C., Marrus, N., Haider, A., Glowinski, A. L., … Jones, W. (2017). Infant viewing of social scenes is under genetic control and is atypical in autism. *Nature*, *547*(7663), 340–344. https://doi.org/10.1038/nature22999

Cooper, H. M. (2017). *Research Synthesis and Meta-Analysis: A Step-by-Step Approach*. London, England: Sage.

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research : techniques and procedures for*

developing grounded theory. Thousand Oaks, CA: Sage Publications.

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism Diagnosis in the

United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *Journal of Autism*

and Developmental Disorders, 1–12. https://doi.org/10.1007/s10803-018-3639-1

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis:

A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153–162.

https://doi.org/10.1177/1362361315573636

Critical Appraisal Skills Programme (CASP). (2018). CASP Checklist: 10 questions to help you make

sense of Qualitative research. Retrieved September 9, 2018, from https://casp-uk.net/casp-

tools-checklists/

Cutress, A. L., & Muncer, S. J. (2014). Parents' views of the national autistic society's earlybird plus

programme. *Autism*, *18*(6), 651–657. https://doi.org/10.1177/1362361313495718

Dawson-Squibb, J. J., Davids, E. L., & de Vries, P. J. (2018). Scoping the evidence for EarlyBird and

EarlyBird Plus, two United Kingdom-developed parent education training programmes for

autism spectrum disorder. *Autism*, 1–14. https://doi.org/10.1177/1362361318760295

DCSF. (2009). *Lamb Inquiry: Special Educational Needs and parental confidence.* UK: Crown

Copyright.

Denne, L. D., Hastings, R. P., & Hughes, C. J. (2018). Common approaches to intervention for the

support and education of children with autism in the UK: an internet-based parent survey.

International Journal of Developmental Disabilities, *64*(2), 105–112.

https://doi.org/10.1080/20473869.2016.1275439

Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research*. London, UK: Sage

Publications.

Department for Education. (2018a). *Permanent and fixed-period exclusions in England: 2016 to 2017*.

London, UK: Author.

Department for Education, & Department of Health. (2015). *Special educational needs and disability*

code of practice: 0 to 25 years. London, UK: Author.

Department for Education, S. E. N. S. T. (2018b). Special educational needs in England: January 2018. Retrieved August 10, 2018, from https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2018

Department of Health. (2010). *Fulfilling and Rewarding Lives: the strategy for adults with autism in England*. London, UK: Author.

Department of Health. (2014). *Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.* London, UK: Author.

Dey, I. (1999). *Grounding grounded theory*. San Francisco, CA: Academic Press.

Dillenburger, K., Jordan, J. A., McKerr, L., & Keenan, M. (2015). The Millennium child with autism: Early childhood trajectories for health, education and economic wellbeing. *Developmental Neurorehabilitation*, *18*(1), 37–46. https://doi.org/10.3109/17518423.2014.964378

Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Living with children diagnosed with Autism Spectrum Disorder: Parental and professional views Living with children diagnosed with autistic spectrum disorder: parental and professional viewsb jsp_455 13..23. *British Journal of Special Education*, *37*, 1–25.

Emam, M. M., & Farrell, P. (2009). Tensions experienced by teachers and their views of support for pupils with autism spectrum disorders in mainstream schools. *European Journal of Special Needs Education*, *24*(4), 407–422. https://doi.org/10.1080/08856250903223070

Emerson, E., & Baines, S. (2010). The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. *Improving Health and Lives: Learning Disability Observatory*. Available from: http://www.wecommunities.org/MyNurChat/archive/LDdownloads/vid_8731_IHAL2010-05Autism.pdf

Falkmer, M., Anderson, K., Joosten, A., & Falkmer, T. (2015). Parents' Perspectives on Inclusive Schools for Children with Autism Spectrum Conditions. *International Journal of Disability, Development and Education*, *62*(1), 1–23. https://doi.org/10.1080/1034912X.2014.984589

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness, 31(7),* 1011-1027.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., … Pellicano, E. (2018). Making the future together: Shaping autism research through meaningful participation. *Autism*, 136236131878672. https://doi.org/10.1177/1362361318786721

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, *20*(2), 181–194. https://doi.org/10.1080/13645579.2016.1144401

Fombonne, E., Quirke, S., & Hagen, A. (2011). Epidemiology of pervasive developmental disorders. In D. Amaral, G. Dawson, & D. Geschwind (Eds.), *Autism Spectrum Disorders* (pp. 90–111). New York: Oxford University Press. https://doi.org/10.1002/aur.239

Gallagher, J., & Milne, E. (2013). *Parents' Experiences of Engaging in the Diagnostic Process for Autism Spectrum Disorder for their Child: a Systematic Review of the Literature*. University of Sheffield.

Galpin, J., Barratt, P., Ashcroft, E., Greathead, S., Kenny, L., & Pellicano, E. (2017). 'The dots just don't join up': Understanding the support needs of families of children on the autism spectrum. *Autism*, *22*(5), 136236131668798. https://doi.org/10.1177/1362361316687989

General Medical Council. (2018). Definitions of children, young people and parents. Retrieved July 5, 2018, from https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/protecting-children-and-young-people/definitions-of-children-young-people-and-parents

Gesundheit, B., & Rosenzweig, J. P. (2017). Editorial: Autism Spectrum Disorders (ASD)-Searching for the Biological Basis for Behavioral Symptoms and New Therapeutic Targets. *Frontiers in Neuroscience*, *10*, 607. https://doi.org/10.3389/fnins.2016.00607

Glaser, B., & Strauss, A. (1967). *Discovery of Grounded Theory*. Chicago: Aldine.

Griffith, G. M., Walker-Jones, E., Fitzpatrick, H., Goodson, L., Pickering, N., Wimpory, D., & Hastings,

R. P. (2013). Receiving an assessment and a potential diagnosis on the autism spectrum: A

thematic content analysis of parental experiences. *Good Autism Practice (GAP), 14*, 59–68.

Grønkjær, M., Curtis, T., de Crespigny, C., & Delmar, C. (2013). Drinking contexts and the legitimacy

of alcohol use: Findings from a focus group study on alcohol use in Denmark. *Scandinavian

Journal of Public Health*, *41*(3), 221–229. https://doi.org/10.1177/1403494812472266

Guest, G., Bunce, A., & Johnson, L. (2006). How Many Interviews Are Enough? *Field Methods*, *18*(1),

59–82. https://doi.org/10.1177/1525822X05279903

Heasley, S. (2014). Federal Autism Panel Raises Concerns Over DSM Changes. Retrieved July 12,

2018, from https://www.disabilityscoop.com/2014/04/07/federal-autism-dsm/19259/

Hebron, J., & Bond, C. (2017). Developing mainstream resource provision for pupils with autism

spectrum disorder: parent and pupil perceptions. *European Journal of Special Needs Education*,

32(4), 556–571. https://doi.org/10.1080/08856257.2017.1297569

Hennel, S., Coates, C., Symeonides, C., Gulenc, A., Smith, L., Price, A. M., & Hiscock, H. (2016).

Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice. *Journal

of Paediatrics and Child Health*, *52*(5), 506–511. https://doi.org/10.1111/jpc.13157

Hertz-Picciotto, I., Schmidt, R. J., & Krakowiak, P. (2018). Understanding environmental contributions

to autism: Causal concepts and the state of science. *Autism Research*, *11*(4), 554–586.

https://doi.org/10.1002/aur.1938

Heyvaert, M., Hannes, K., Maes, B., & Onghena, P. (2013). Critical Appraisal of Mixed Methods

Studies. *Journal of Mixed Methods Research*, *7*(4), 302–327.

https://doi.org/10.1177/1558689813479449

Heyvaert, M., Maes, B., & Onghena, P. (2011). Applying Mixed Methods Research at the Synthesis

Level: An Overview. *Research in the Schools*, *18*(1), 12–24.

Howlin, P., & Moore, A. (1997). Diagnosis in Autism. *Autism*, *1*(2), 135–162.

https://doi.org/10.1177/1362361397012003

Humphrey, N., & Hebron, J. (2015). Bullying of children and adolescents with autism spectrum

conditions: A "state of the field" review. *International Journal of Inclusive Education*, *19*(8),

845–862. https://doi.org/10.1080/13603116.2014.981602

Humphrey, N., & Lewis, S. (2008). "Make me normal": The views and experiences of pupils on the

autistic spectrum in mainstream secondary schools. *Autism*, *12*(1), 23–46.

https://doi.org/10.1177/1362361307085267

Joffe, H. (2012). Thematic Analysis. In D. Harper & A. Thompson (Eds.), *Qualitative Research Methods*

in Mental Health and Psychotherapy: A Guide for Students and Practitioners (pp. 209–223).

Chichester, UK: John Wiley & Sons, Ltd. https://doi.org/10.1002/9781119973249.ch15

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of Receiving a Diagnosis

of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom. *Journal of Autism and*

Developmental Disorders, *44*(12), 3033–3044. https://doi.org/10.1007/s10803-014-2161-3

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, *2*, 217–250.

Keen, D., & Rodger, S. (2012). *Working with Parents of a Newly Diagnosed Child with an Autism*

Spectrum Disorder: a Guide for Professionals. London: Jessica Kingsley Publishers.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should

be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442–

462. https://doi.org/10.1177/1362361315588200

Keville, S. (2018). Across the great divide: reflecting on dual positions in clinical psychology to

enhance equality and inclusion between those working in and those referred to services.

Reflective Practice, 1–15. https://doi.org/10.1080/14623943.2018.1539654

Koegel, L. K., Koegel, R. L., & Dunlap, G. (1996). *Positive behavioral support: Including people with*

difficult behavior in the community. Baltimore, MD: Brookes.

Lambe, S., Russell, A., Butler, C., Fletcher, S., Ashwin, C., & Brosnan, M. (2018). Autism and the

transition to university from the student perspective. *Autism*, 136236131880393.

https://doi.org/10.1177/1362361318803935

Le Couteur, A., Lord, C., & Rutter, M. (2003). *The Autism Diagnostic Interview - Revised (ADI–R)*. Los

Angeles: Western Psychological Services.

Lee, L.C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with Autism: Quality of Life and Parental Concerns. *Journal of Autism and Developmental Disorders*, *38*(6), 1147–1160. https://doi.org/10.1007/s10803-007-0491-0

Legg, H., & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*. https://doi.org/10.1177/1362361319841488

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child and Adolescent Psychiatry*. https://doi.org/10.1016/j.jaac.2017.03.013

Lord, C., DiLavore, P., Gotham, K., Guthrie, W., Luyster, R., Risi, S., … Bishop, S. (2012). *Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)*. Los Angeles, Calif: Western Psychological Services.

Lotter, V. (1966). Epidemiology of autistic conditions in young children: I. Prevalence. *Social Psychiatry*, *1*, 124–137.

Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, *17*(5), 702–711. https://doi.org/10.1177/1359105311422955

Lugnegård, T., Hallerbäck, M. U., & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities*, *32*(5), 1910–1917. https://doi.org/10.1016/j.ridd.2011.03.025

Mackelprang, R., & Salsgiver, R. (2009). *Disability: A Diversity Model Approach in Human Service Practice (Second Edition)*. Chicago, IL: Lyceum Books.

Maïano, C., Normand, C. L., Salvas, M.-C., Moullec, G., & Aimé, A. (2016). Prevalence of School Bullying Among Youth with Autism Spectrum Disorders: A Systematic Review and Meta-Analysis. *Autism Research*, *9*(6), 601–615. https://doi.org/10.1002/aur.1568

Mann, S. (2016). *The Research Interview: Reflective Practice and Reflexivity in Research*. New York: Palgrave Macmillan.

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*, *8*(4), 387–407. https://doi.org/10.1177/1362361304045213

Maxwell, J. A. (2012). *A realist approach for qualitative research*. London: Sage.

McConachie, H., & Robinson, G. (2006). What services do young children with autism spectrum disorder receive? *Child: Care, Health and Development*, *32*(5), 553–557. https://doi.org/10.1111/j.1365-2214.2006.00672.x

McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and Specificity of Proposed DSM-5 Diagnostic Criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(4), 368–383. https://doi.org/10.1016/j.jaac.2012.01.007

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, Hope, and Empowerment: A Model for Partnering With Parents of a Child With Autism Spectrum Disorder at Diagnosis and Beyond. *Social Work in Mental Health*, *10*(4), 311–330. https://doi.org/10.1080/15332985.2012.664487

Murphy, C. M., Wilson, C. E., Robertson, D. M., Ecker, C., Daly, E. M., Hammond, N., … McAlonan, G. M. (2016). Autism spectrum disorder in adults: diagnosis, management, and health services development. *Neuropsychiatric Disease and Treatment*, *12*, 1669–1686. https://doi.org/10.2147/NDT.S65455

NASUWT. (2013). *Support for Children and Young People with Special Educational Needs*. Birmingham: Author.

National Autistic Society. (2014). *Diverse Perspectives*. London, UK: Author.

National Autistic Society. (2015). *School report 2015*. London, UK: Author.

National Autistic Society. (2016). *The autism employment gap: Too Much Information in the workplace*. London: National Autistic Society.

National Autistic Society. (2018a). Autism strategy overview. Retrieved July 20, 2018, from

    https://www.autism.org.uk/about/strategy/overview.aspx

National Autistic Society. (2018b). Big news: national autism strategy to be extended to children (5

    December 2018). Retrieved December 10, 2018, from https://www.autism.org.uk/get-

    involved/media-centre/news/2018-12-05-big-news-national-strategy.aspx

National Autistic Society. (2018c). The language we use to describe autism. Retrieved July 15, 2018,

    from https://www.autism.org.uk/describingautism

National Institute for Health and Care Excellence (NICE). (2013). Autism spectrum disorder in under

    19s: support and management - Clinical Guideline [CG170]. Retrieved July 21, 2018, from

    https://www.nice.org.uk/guidance/cg170

National Institute for Health and Care Excellence (NICE). (2014). Autism - Quality Standard [QS51].

    Retrieved July 21, 2018, from https://www.nice.org.uk/guidance/qs51

National Institute for Health and Care Excellence (NICE). (2016). Autism spectrum disorder in adults:

    diagnosis and management - Clinical Guideline [CG142]. Retrieved July 21, 2018, from

    https://www.nice.org.uk/guidance/CG142

National Institute for Health and Care Excellence (NICE). (2017). Autism spectrum disorder in under

    19s: recognition, referral and diagnosis - Clinical Guideline [CG128]. Retrieved July 21, 2018,

    from https://www.nice.org.uk/guidance/cg128

NCCN. (2018). NCCN Categories of Evidence and Consensus. Retrieved October 15, 2018, from

    https://www.nccn.org/professionals/physician_gls/categories_of_consensus.aspx

Nelson, J. (2017). *Using conceptual depth criteria: addressing the challenge of reaching saturation in*

    qualitative research. *Qualitative Research* (Vol. 17).

    https://doi.org/10.1177/1468794116679873

NHS England. (2016). Stopping over medication of people with a learning disability, autism or both

    (STOMP). Retrieved July 21, 2018, from https://www.england.nhs.uk/learning-

    disabilities/improving-health/stomp/

NHS Information Centre, Community and Mental Health Team, & Brugha, T. et al. (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. *Leeds: NHS Information Centre for Health and Social Care*.

NHS UK. (2016). Consent to treatment - Children and young people. Retrieved July 5, 2018, from https://www.nhs.uk/conditions/consent-to-treatment/children/

O'Reilly, M., & Parker, N. (2013). 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, *13*(2), 190–197. https://doi.org/10.1177/1468794112446106

Office for National Statistics. (2018). Population estimates. Retrieved April 5, 2019, from https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/population estimates

Omeni, E., Barnes, M., MacDonald, D., Crawford, M., & Rose, D. (2014). Service user involvement: impact and participation: a survey of service user and staff perspectives. *BMC Health Services Research*, *14*, 491. https://doi.org/10.1186/s12913-014-0491-7

Onwuegbuzie, A. J., Dickinson, W. B., Leech, N. L., & Zoran, A. G. (2009). A Qualitative Framework for Collecting and Analyzing Data in Focus Group Research. *International Journal of Qualitative Methods*, *8*(3), 1–21. https://doi.org/10.1177/160940690900800301

Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, *12*(3), 309–324. https://doi.org/10.1177/1362361307089517

Papageorgiou, V., & Kalyva, E. (2010). Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders*, *4*(4), 653–660. https://doi.org/10.1016/j.rasd.2010.01.001

Paquette, D., & Ryan, J. (2001). Bronfenbrenner's Ecological Systems Theory. Retrieved May 6, 2019, from http://www.floridahealth.gov/AlternateSites/CMS-Kids/providers/early_steps/training/documents/bronfenbrenners_ecological.pdf

Parliament of the United Kingdom. Autism Act (2009). Queen's Printer of Acts of Parliament.

Parliament of the United Kingdom. Care Act (2014). Queen's Printer of Acts of Parliament.

Parliament of the United Kingdom. Children and Families Act (2014). Queen's Printer of Acts of

Parliament.

Parliament of the United Kingdom. Data Protection Act 2018 (2018). Queen's Printer of Acts of

Parliament.

Parsons, S., Lewis, A., & Ellins, J. (2009). The views and experiences of parents of children with

autistic spectrum disorder about educational provision: Comparisons with parents of children

with other disabilities from an online survey. *European Journal of Special Needs Education*,

24(1), 37–58. https://doi.org/10.1080/08856250802596790

Potter, C. A. (2017). "I received a leaflet and that is all": Father experiences of a diagnosis of autism.

British Journal of Learning Disabilities, *45*(2), 95–105. https://doi.org/10.1111/bld.12179

Preece, D. (2014). A matter of perspective: the experience of daily life and support of mothers,

fathers and siblings living with children on the autism spectrum with high support needs. *Good*

Autism Practice, *15*(1), 81–90.

QSR International Ltd. (2018). NVivo 12. QSR International Ltd.

Reed, P., & Osborne, L. A. (2012). Diagnostic practice and its impacts on parental health and child

behaviour problems in autism spectrum disorders. *Archives of Disease in Childhood*, *97*(10),

927–931. https://doi.org/10.1136/archdischild-2012-301761

Reid, B., & Ayris, L. (2011). *We've got great expectations: the chance of a lifetime for children with*

autism. London: National Autistic Society.

Renty, J., & Roeyers, H. (2006a). Quality of life in high-functioning adults with autism spectrum

disorder: The predictive value of disability and support characteristics. *Autism*, *10*(5), 511–524.

https://doi.org/10.1177/1362361306066604

Renty, J., & Roeyers, H. (2006b). Satisfaction with formal support and education for children with

autism spectrum disorder: the voices of the parents. *Child: Care, Health and Development*,

32(3), 371–385. https://doi.org/10.1111/j.1365-2214.2006.00584.x

Rimland, B. (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior*. East Norwalk, CT, US: Appleton-Century-Crofts.

Rogers, C. L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2016). Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism*, *20*(7), 820–831. https://doi.org/10.1177/1362361315611109

Rosenblatt, M. (2008). *I exist: the message from adults with autism in England*. London: National Autistic Society.

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry, 17*, 229–245.

Ryan, G. W., & Bernard, H. R. (2000). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research, 2nd edn.* London, England: Sage.

Sale, J. E. M., & Brazil, K. (2004). A strategy to identify critical appraisal criteria for primary mixed-method studies. *Quality and Quantity*, *38*(4), 351–365. https://doi.org/10.1023/B:QUQU.0000043126.25329.85

Shakespeare, T. (2006). The social model of disability. *The Disability Studies Reader*, (2), 197–204.

Siddaway, A. P., Wood, A. M., & Hedges, L. V. (2019). How to do a systematic review: A best practice guide for conducting and reporting narrative reviews, meta-analyses, and meta-syntheses. *Annual Review of Psychology*, *70*(1). https://doi.org/10.1146/annurev-psych-010418-102803

Sinclair, J. (1999). Why I dislike "person first" language. Retrieved July 12, 2018, from http://web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm

Singer, J. (1999). "Why Can't You Be Normal for Once in Your Life?": From a "Problem with No Name" to a New Category of Difference'. In M. Corker & S. French (Eds.), *Disability Discourse* (pp. 59–67). Buckingham: Open University Press.

Skuse, D., Warrington, R., Bishop, D., Chowdhury, U., Lau, J., Mandy, W., & Place, M. (2004). The Developmental, Dimensional and Diagnostic Interview (3di): A Novel Computerized Assessment

for Autism Spectrum Disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, *43*(5), 548–558. https://doi.org/10.1097/00004583-200405000-00008

Symes, W., & Humphrey, N. (2012). Including pupils with autistic spectrum disorders in the classroom: The role of teaching assistants. *European Journal of Special Needs Education*, *27*(4), 517–532. https://doi.org/10.1080/08856257.2012.726019

Teague, S. J., Gray, K. M., Tonge, B. J., & Newman, L. K. (2017). Attachment in children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, *35*, 35–50. https://doi.org/10.1016/J.RASD.2016.12.002

The ▉▉▉▉ Fairness Commission. (2016). *Two ▉▉▉▉: Understanding the problem*. London.

The Key. (2016). Children with SEND let down by system-wide failings. Retrieved August 10, 2018, from https://thekeysupport.com/press/children-send-let-system-wide-failings-june-2016/

Tissot, C. (2011). Working together? Parent and local authority views on the process of obtaining appropriate educational provision for children with autism spectrum disorders. *Educational Research*, *53*(1), 1–15. https://doi.org/10.1080/00131881.2011.552228

Tracy, S. J. (2010). Qualitative quality: Eight a"big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837–851. https://doi.org/10.1177/1077800410383121

Trust for London. (2018). *London's Poverty Profile*. London.

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners*, *67*(659), e445–e452. https://doi.org/10.3399/bjgp17X690449

Van Wijngaarden-Cremers, P. J. M., Van Eeten, E., Groen, W. B., Van Deurzen, P. A., Oosterling, I. J., & Van Der Gaag, R. J. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, *44*(3), 627–635. https://doi.org/10.1007/s10803-013-1913-9

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum

disorder: A systematic review. *Research in Autism Spectrum Disorders*, *23*(23), 36–49. https://doi.org/10.1016/j.rasd.2015.11.008

Whitaker, P. (2007). Provision for youngsters with autistic spectrum disorders in mainstream schools: What parents say - And what parents want. *British Journal of Special Education*, *34*(3), 170–178. https://doi.org/10.1111/j.1467-8578.2007.00473.x

Wilkinson, S. (2004). Focus Group Research. In D. Silverman (Ed.), *Qualitative research: theory, method and practice* (pp. 177–199). London: Sage Publications.

Willig, C. (2013). Introducing Qualitative Research in Psychology. UK: McGraw-Hill Education.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, *9*(1), 11–29. https://doi.org/10.1007/BF01531288

Wing, L., Gould, J., & Gillberg, C. (2011). Autism spectrum disorders in the DSM-5: Better or worse than the DSM-IV? *Research in Developmental Disabilities*. https://doi.org/10.1016/j.ridd.2010.11.003

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a World of Our Own: The Experience of Parents Who Have a Child With Autism. *Qualitative Health Research*, *18*(8), 1075–1083. https://doi.org/10.1177/1049732308320112

World Health Organisation. (2018). *International Classification of Diseases 11th Ed. (ICD-11)*. Geneva: Author.

Zhou, T., & Yi, C. (2017). Autism as an Infantile Post-trauma Stress Disorder: A Hypothesis. *Journal of Mental Disorders and Treatment*, *3*(1), 1–5. https://doi.org/10.4172/2471-271X.1000142

6. Appendices

6.1. Excerpts from Reflective Diary

Reflections on method: data collection

My first experience of data collection for this project was a parent focus group where I was expecting around 4 or 5 people to attend but only one turned up. I remember initially feeling disappointed and disheartened. I had been to the same place a few weeks before to recruit and everyone had shown a lot of interest in my project, and had signed up enthusiastically. I was aware of the many stresses on parents of children on the autism spectrum, and I wondered what barriers had got in the way of people attending my group and whether I could make the groups more accessible. The participant who did attend said she also felt disappointed, and was surprised that other parents were not there. She said it was a shame that more parents did not come as they often expressed their frustration at not being listened to, and yet this was there chance to express their views. She put me in touch with another parent who helped significantly with recruitment for the rest of the project!

The focus groups were not always straight forward – in fact they were very messy. In one staff focus group there was one senior member of school leadership present who left half way through, and after they left some of the other staff said it was easier to speak their mind and be honest with that person out of the room. I wish I had been more thoughtful about this dynamic earlier, and it made me glad my other focus groups had staff from same levels within schools, so this problem was largely avoided. Another issue occurred in the SENCO focus group, where one SENCO joined the group half way through (thus missing half

the questions), however she contributed very rich data to the second half, and did address many of the issues raised by the first questions which she had missed. In one parent focus group, one person left half way through as well, and then came back for a second interview to complete the questions.

Following an interview with one parent, in which they were very positive about their experiences of support, I reflected that that parent may have struggled to express herself in the slightly more negative parent focus group I had, so I'm glad she had the opportunity to express her positive view in an individual interview, as she might have felt she could not speak up in a group who had not had positive experiences. This made me consider whether the other parent group had become more negative because they were feeding off each other? Although perhaps more likely, they were all there because they met through the parent forum because they had struggled to obtain support elsewhere or had had problems with school and had sought more parental peer support.

Last bit of data collection today, and it was perhaps the most emotional interview. I think there were a few reasons for this, not just the severe lack of support for this mother with four children two of whom are on the autistic spectrum, but the discrimination that she has faced due to her ethnicity, which has impacted on her ability to obtain support, and consequently her quality of life. She spoke of her hopes that people would read my project and things would change for the better, and I felt pressure for my project to help achieve this, as I feel that too.

Reflection on designing the study population:

When the proposal for this project was first presented, children and young people on the autism spectrum were not an intended study population, and I was asked why I had left out the voices of the individuals at the very heart of this issue. I had initially had several reasons for this, including logistical reasons (e.g. cannot directly recruit, children may find it more difficult to transport themselves around, may require parental supervision) and practical reasons (e.g. some children on the autism spectrum may find it difficult to be in a group, and/or struggle to understand the questions and/or struggle to communicate their answers for a variety of different reasons). Upon reflection, I decided that these were not good reasons to justify not including children and young people in this project, as, whilst it may be more difficult for me to gather data from this population, it was more important that their voices be heard as much as possible in this project.

Reflection on inclusiveness of participants:

I struggled with the idea of only recruiting participants who could verbally communicate, as I knew that many people on the autism spectrum would therefore not be able to express their views and opinions on their experiences of support, and that a vital part of the picture would be missing – what could improve support for those people who are less able to talk about their support? I also found it difficult to exclude those who did not speak English from participating, as I was aware that (especially in this London borough), many people who cannot speak English are already marginalised, and find it more difficult to access support services, and their story needs to be heard. Again I felt as though my project was mirroring services by failing to include the people who needed it the most.

Reflections on analysing the data:

I have just finished coding my first two parent files and I have far too many codes. I have found it difficult to find the balance between being descriptive and being interpretive. I am feeling a little bit overwhelmed by just how much information there is here, and I wonder if this reflects how the parents in my study feel trying to cope with and synthesis all the information out there. I can also start to feel certain themes coming out of the data, and I am conscious not to let my preconceived notions regarding particular themes influence how I code the data, although our interpretations are always influenced by the various lenses through which we view the world. I am trying to think about how the parents would feel if they could see this analysis; whether they feel it is capturing their most important thoughts and feelings and doing justice to it.

Feeling very sad working through the parents' transcripts. The amount of times that other parents in my groups *gasped* at another parent's shocking experience is very telling (e.g. child being turned away from school, parent being threatened with social services, schools not believing parents about diagnosis or accusing parent of causing problems etc). It is making me feel a bit hopeless; I know these are everyday occurrences for these parents, which is concerning, and that this London borough is better than some others, which only makes it worse. Again I hope that my project will be able to help in the way I want it to.

Finished initial line by line coding of all my data today, drowning in so much data and so many codes. Met with Saskia to discuss and think about initial groupings of codes into themes; realised how difficult this is going to be. It is hard to think about abstract/meta themes which capture my data in a meaningful way, and even harder to let go of parts of my data! This is going to take a lot longer than I thought. I hope it still tells the story.

How do I feel about having to discard bits of data because I have so much? There are so many little stories that will not get told because it is important that I tell the big story and present the big picture, but I WANT to tell those little stories as well, I don't want them to get lost. My supervisor encourages me to consider if there are any which I feel particularly strongly about and why? I'm also advised that when it comes to finalising themes and writing up, there is never a good time to stop analysing, one could go back and forth 're-theming' the data forever – there needs to be a point where you move on.

Reflection on clinical implications:

I spoke to Jen today about all the clinical implications emerging from the results. While there are many good ideas about how services can be developed and improved, so many of them depend on there being funding, which rather than increasing keeps being cut. It was interesting to hear Jen's perspective as an active clinician in these services, and the frustration that things which they have been saying for years are still not being acted on. It seems that as long as support for people on the autism spectrum is not a priority issue for those in charge, it will not attract the funding it needs.

6.2.   Interview Schedules

6.2.1.   Parents Interview Schedule

1. What were your experiences of support following receiving a diagnosis of Autism?

2. What was helpful or unhelpful about the post-diagnostic support you received?

    Prompt: helpful/unhelpful (depending on answers)

3. How did the support you received compare to the support you expected you would receive?

4. What, if any, was the biggest challenge to overcome? What things got in the way of you accessing support?

5. What helped you access support?

6. What, if anything, would you like to change about any of the services involved in your child's care after diagnosis?

7. How did you feel going through this process of obtaining support?

8. Did this process impact your relationship with a) your child, b) the school, and if so in what way?

9. What, if anything, would your advice be to someone going through a similar process?

10. How has it felt talking about this today? Is there anything else you would like to add that I have not asked you about?

6.2.2. Children and Young People Interview Schedule

1. Icebreaker: would you/everyone like to say 1 thing you/they like about school and 1 thing they don't like about school?

2. Have you ever had any difficulties at school? When was this? Can you tell me a bit about them? Is this still a problem now?

3. What help did you hope to get to make it better for you?

4. Did people try to help you after you got your diagnosis of autism? If so, how? If not do you think they could have?

5. What was good about the help you received?

6. What was not good about it?

7. How did receiving help or not receiving help make you feel?

8. What was your relationship like with your parents after you got your diagnosis? (Prompt: was it different or similar to your relationship before the diagnosis?) What was it like with your school?

9. Looking back, what do you think people could have done differently to help you and other children? What would you like to change about the way people support you? (Prompt: at school, or in hospitals or at home?)

10. What have you learned from going through this experience?

11. How has it felt talking about this today?

    Is there anything else you would like to add that I have not asked you about?

6.2.3.   School Staff Interview Schedule

1. What support, if any, do young people with ASC in your school typically receive and from whom?

2. What support do parents/carers of young people with ASC typically receive and from who?

3. In your experience, what kinds of support do children and parents typically expect to receive following a diagnosis of ASC?

4. What types of post-diagnostic support have you found are most helpful or unhelpful? Prompt: unhelpful/helpful?

5. Are there any forms of support which are easier or harder to obtain?

6. In your role, do you offer post-diagnostic support and if so what/how? Have you felt restricted in your ability to provide appropriate post-diagnostic support? Why?

7. Do you feel fully supported to provide post-diagnostic support? What helps? Is there any additional support you feel could benefit your practice?

8. What do you think are the barriers to improved provision of post-diagnostic support for children with autism?

9. Is there anything you would like to change about any of the systems involved (schools/LAs/CAMHS/government) and if so what?
    What would need to change to improve provision of PDS?

10. What are your tips for best practice in this area?

11. What have you gained or learned from the experience of supporting a child or young person with ASC?

12. How has it felt talking about this today?

Is there anything else you would like to add that I have not asked you about?

6.3.   Example poster used in recruitment (CYP)

6.4.   **Ethics approval**

University of Hertfordshire UH

HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Laurence Hasson

CC Dr Saskia Keville

FROM Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair

DATE 06/02/2018

Protocol number: **LMS/PGR/UH/03204**

Title of study: The experiences of families and schools of post-diagnostic support for children and young people on the autism spectrum

Your application for ethics approval has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

This approval is valid:

From: 05/03/2018

To: 28/09/2018

Additional workers:
Dr Saskia Keville (supervisor)

Please note:
If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete. You are also required to complete and submit an EC7 Protocol Monitoring Form if you are a member of staff. This form is available via the Ethics Approval StudyNet Site via the 'Application Forms' page
http://www.studynet1.herts.ac.uk/ptl/common/ethics.nsf/Teaching+Documents?Openview&count=9999&restricttocategory=Application+Forms
Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval (if you are a student) and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken. Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct. Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study. Students must include this Approval Notification with their submission.

6.5.   Ethics Amendment

University of Hertfordshire UH

HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Laurence Hasson

CC Dr Saskia Keville

FROM Dr Kim Goode, Health, Science, Engineering & Technology ECDA Vice Chairman

DATE 30/08/18

Protocol number: **aLMS/PGR/UH/03204(1)**

Title of study: The experiences of families and schools of post-diagnostic support for children and young people on the autism spectrum

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Modification: Extend end date, Other modifications as described on the EC2 application

This approval is valid:

From: 30/08/18

To: 07/06/19

Additional workers: no additional workers named

Please note:
If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete. You are also required to complete and submit an EC7 Protocol Monitoring Form if you are a member of staff. This form is available via the Ethics Approval StudyNet Site via the 'Application Forms' page
http://www.studynet1.herts.ac.uk/ptl/common/ethics.nsf/Teaching+Documents?Openview&count=9999&restricttocategory=Application+Forms
Any conditions relating to the original protocol approval remain and must be complied with. Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1/EC1A or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct. Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study. Students must include this Approval Notification with their submission.

6.6. Information sheet for participants

UNIVERSITY OF HERTFORDSHIRE

PARTICIPANT INFORMATION SHEET

Title of study
The experiences of families and schools of post-diagnostic support for children and young people on the autism spectrum

Introduction
You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulations governing the conduct of studies involving human participants can be accessed via this link: http://sitem.herts.ac.uk/secreg/upr/RE01.htm
Thank you for reading this.

What is the purpose of this study?
There is a significant gap in the literature regarding people's experiences of post-diagnostic support (PDS), especially for children on the autism spectrum. The primary aim of this project is to allow young people on the autism spectrum, their parents, and schools to voice their experiences of post-diagnostic support for children on the autism spectrum. The aim is to provide a platform for them to voice what their experiences have been, the issues, challenges and barriers, but also examples of good practice and support. The project will aim to generate and facilitate greater understanding of people's experiences in this area, and what can be done to improve it (how can the system change to better meet the needs of children on the autism spectrum?)

Do I have to take part?
It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw without giving a reason up to one month after you participate. A decision to withdraw, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

Are there any age or other restrictions that may prevent me from participating?
In order to participate we ask that you are either a young person (of school age) with a diagnosis of autism, or a parent of a child with autism, or a member of school staff who works with children with autism.

How long will my part in the study take?

If you decide to take part in this study, you will be involved in a focus group discussion lasting between 1 – 2 hours. You will also be required to provide some information about yourself which should not take longer than 5 minutes.

What will happen to me if I take part?
The first thing to happen will be that you are asked to sign a consent form and provide us with a few details about yourself and your child if applicable. You will then be invited to take part in a group discussion about your experiences with other people like yourself. The group will be asked a number of open questions and you can contribute as much or as little as you like. The group will last 1-2 hours and will be audio recorded. Refreshments will be provided. Following this, you will not have to do anything else. The audio files will be transcribed and the study written up for publication.

What are the possible disadvantages, risks or side effects of taking part?
Some participants may find it emotionally distressing to discuss negative experiences which they have had. If you feel distressed during your participation in this study, please speak to your facilitator.

What are the possible benefits of taking part?
This study may have a number of benefits. Some participants may find it reassuring to meet and talk to other people who have gone through similar experiences to themselves. Some participants may learn new things, e.g. possibly useful advice about managing the system. In a wider context, the benefit of taking part is that you will be given an opportunity to have your opinion heard, and this research will be submitted for publication to be read by professionals and clinicians to improve best practice for other people with autism.

How will my taking part in this study be kept confidential?
Once data is collected, it will be pseudo-anonymised, meaning your name will be replaced with an identifying number. Any and all information recorded digitally will be encrypted and stored securely on password-protected computers at all times. Any hard copies (e.g. consent forms) will be securely stored in a locked drawer to ensure confidentiality.

Audio-visual material
Focus group discussions will be audio recorded and transcribed.

What will happen to the data collected within this study?
Audio data collected in this study will be transcribed and analysed. Some transcription may be undertaken by a third party, but anonymity and confidentiality will be fully preserved at all times. The audio data will not be displayed or presented to anyone else at any time. Excerpts of a transcription of the audio data may be included in publications, however no participant will be identifiable at any time. Transcriptions of focus group conversations will be analysed and written up for publication (this may include anonymized excerpts of the transcriptions). Demographic data collected will be analysed and included in write-ups for publication.

Any and all electronic data collected will be stored in a secure, password-protected environment, until the end of the project, after which time it will be destroyed under secure conditions.
Any and all hard copies of data collected will be stored by the researchers in a secure environment until the end of the project, after which time it will be destroyed under secure conditions.

Will the data be required for use in further studies?
The data will not be used in any further studies.

Who has reviewed this study?
This study has been reviewed by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority
The UH protocol number is LMS/PGR/UH/03204(1)

Factors that might put others at risk
Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities.

Who can I contact if I have any questions?
If you would like further information or would like to discuss any details personally, please get in touch with me by email: Laurence Hasson, lh16acm@herts.ac.uk, or please feel free to contact my supervisor by phone, email or writing: Dr Saskia Keville;

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

6.7. Easy read information sheet for participants

Participant Information Sheet

Title of research: The experiences of families and schools of post-diagnostic support for children and young people on the autism spectrum.

You are being invited to take part in a research study. It is completely up to you whether or not you decide to take part in this study. Please do take your time to decide whether or not you wish to take part. Please read the following information carefully and please ask us if anything is not clear or you would like any more information to help you.

The aim of this project is to allow young people on the autism spectrum, their parents, and school staff to talk about their experiences of post-diagnostic support for children on the autism spectrum. It is hoped that this will help make changes to better meet the needs of children on the autism spectrum.

If you decide to take part in this study, you will take part in a group discussion lasting between 1 and 2 hours. You will also be required to provide some information about yourself which should not take longer than 5 minutes. The group will be asked a number of open questions and you can talk as much or as little as you like. Refreshments will be provided.

All personal details will be kept confidential and stored securely at all times.

More details can be found on the full Participant Information Sheet attached.

If you would like to discuss any details personally, please get in touch with me: Laurence Hasson by phone or email, Phone: XXXXXXXXXXX Email: LH16ACM@HERTS.AC.UK

Thank you very much for reading this information and thinking about taking part in our study.

6.8.   Consent form

UNIVERSITY OF HERTFORDHIRE

CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here*, *in BLOCK CAPITALS]*

…………………………………………………………………………………………………

of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address]*

…..………………………………………………………………………………………………

hereby freely agree to take part in the study entitled

The experiences of families and schools of post-diagnostic support for children and young people on the autism spectrum   (UH Protocol number LMS/PGR/UH/03204(1))

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study without disadvantage or having to give a reason. I understand that I may withdraw from the study anytime up to and including the day of participation and for one month after. I understand that from one month following participation, it may not be possible to withdraw my data from the study as it may have already been included in analyses.

3 In giving my consent to participate in this study, I understand that voice recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to myself. In signing this consent form I accept that medical attention might be sought for me, should circumstances require this.

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that my participation in this study may reveal findings that could indicate that I might require medical advice. In that event, I will be informed and advised to consult my GP. If, during the study, evidence comes to light that I may have a pre-existing medical condition that may put others at risk, I understand that the University will refer me to the appropriate authorities and that I will not be allowed to take any further part in the study.
7 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

8 I have been told that I may at some time in the future be contacted again in connection with this or another study.

Signature of participant……………………………………………………..…

Date……………………………..……

Signature of (principal) investigator……………………..…………..…………

Date…………………………………

Name of (principal) investigator *[in BLOCK CAPITALS please]*

………………………………………………………………………………………

6.9. Consent by Proxy form

UNIVERSITY OF HERTFORDSHIRE

CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS
FOR USE WHERE THE PROPOSED PARTICIPANTS ARE MINORS, OR ARE OTHERWISE UNABLE TO GIVE INFORMED CONSENT ON THEIR OWN BEHALF

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……………………………………………………………………………………………

of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address]*

……………………………………………………………………………………………

hereby freely give approval for *[please give name of participant here, in BLOCK CAPITALS]*

....

to take part in the study entitled

The experiences of families and schools of post-diagnostic support for children and young people on the autism spectrum (UH Protocol number LMS/PGR/UH/03204(1)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of his/her involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent for him/her to participate in it.

2 I have been assured that he/she may withdraw from the study without disadvantage or having to give a reason. I understand that he/she may withdraw from the study anytime up to and including the day of participation and for one month after. I understand that from one month following participation, it may not be possible to withdraw his/her data from the study as it may have already been included in analyses.

3 In giving my consent to participate in this study, I understand that voice recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been given information about the risks of his/her suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to him/her in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to him/her, or to myself. In signing this consent form I accept that medical attention might be sought for him/her, should circumstances require this.

5 I have been told how information relating to him/her (data obtained in the course of the study, and data provided by me, or by him/her, about him/herself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that in the event that his/her participation in this study may reveal findings that could indicate that he/she might require medical advice, I will be informed and advised to consult his/her GP. If, during the study, evidence comes to light that he/she may have a pre-existing medical medical condition that may put others at risk, I understand that the University will refer him/her to the appropriate authorities and that he/she will not be allowed to take any further part in the study.

7 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

8 I have been told that I may at some time in the future be contacted again in connection with this or another study.

9 I declare that I am an appropriate person to give consent on his/her behalf, and that I am aware of my responsibility for protecting his/her interests.

Signature of person giving consent …………………………………………..…………

Date………………………………………………………………

Relationship to participant...

Signature of (principal) investigator...

Date………………………………..…………………………..

Name of (principal) investigator *[in BLOCK CAPITALS please]*

....

6.10. Transcription Confidentiality Agreement

Doctorate in Clinical Psychology

University of Hertfordshire

<u>Transcription confidentiality/ non-disclosure agreement</u>

This non-disclosure agreement is in reference to the following parties:

Insert Name Here **('the discloser')**

And

Insert Transcriber's Name Here **('the recipient')**

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient agrees to stop transcription immediately if they recognise any parties mentioned on the audio recording, and to return the recording to the discloser.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed:...……………………………………

Name:...……………………………………..

Date:...…………………………………….

6.11. Participant Debrief Sheet

<u>**Participant Debrief Sheet**</u>

Thank you for giving your time to take part in this research project. Hopefully this research will help improve processes for providing post-diagnostic support for children and young people on the autism spectrum.

The information that you have provided will be kept confidential and all data will be destroyed after the completion of the research. You can ask to have your contribution removed from the study without giving a reason up to 1 month after participation.

If participation in this research has caused you any distress, discomfort or upsetting feeling, you may wish to contact immediate sources of support such as your family, friends, GP or a therapist.

If you would like further support, please find below the details of some organisations that may be useful. These sources of support will be able to help you regarding any concerns or worries you have regarding your emotional and psychological wellbeing.

Your GP
Please consider contacting your GP if you are feeling low or anxious.

Psychological therapies
If you think that you may benefit from engaging in a talking therapy (such as cognitive behavioural therapy), then you may wish to consider self-referring to your local psychological therapies service, or asking your GP to refer you.
To find your nearest service, you can search on the NHS choices webpage:
https://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008

NHS Choices
If you're worried about an urgent medical concern, call 111 and speak to a fully trained adviser. Website: https://www.nhs.uk/pages/home.aspx   Helpline: 0113 825 0000

Samaritans
This is a 24 hour a day, free and confidential helpline for anyone experiencing any emotional distress.   Freephone: 08457 90 90 90   Website: www.samaritans.org

The National Autistic Society
http://www.autism.org.uk/services/helplines.aspx

If you have any further questions, or would be interested in being informed in the outcome of this study, then please contact the researcher, Laurence Hasson, by email (lh16acm@herts.ac.uk).

If you have any complaints about the study, please contact Dr Saskia Keville by email XXXXXXXXXX

Thank you again for your participation and support.

6.12. Examples of NVivo Process

### 6.12.1. Snapshot example of initial NVivo coding process

6.12.2. Small snapshot example of NVivo nodes residing within larger nodes

Within NVivo, what are known as 'codes' or 'themes' in thematic analysis are called 'nodes', and can be nested. This was a key part of moving the data from initial codes towards potential subthemes and themes.

Parent	Files	Referen
Name		
Parents acknowledging CAMHS are busy and stretched	1	2
Impact on Lives	0	0
Impact on Parent's life	0	0
Impact on parent's mental health	0	0
Impact on parent's physical health	0	0
Impact on parent's job or career	0	0
Parents world seemed to collapse after diagnosis	1	1
Parents feel they talk about their autistic child all the time non stop	1	1
Parents talking to someone when they need help	1	1
Parent having a break from the child	1	1
Parents not wanting children to rely on them forever	1	1
Parents being protective of their autistic children	2	2
Parents experiencing child having eating disorder	2	2
Parents not letting children with autism do things because of worry	1	2
Parents world shattered	1	3
Parents feeling frustrated by children's behaviour	2	3
Parents life changing after diagnosis	2	7
Impact on Child's life	0	0
Impact on child's health	0	0
Impact on child's mental health	0	0

6.12.3. Small snapshot example of NVivo theming (nodes residing within larger nodes)

This is just a visual representation of how nodes sit within larger nodes in NVivo. The broadest layers of nodes would eventually be considered for subthemes or themes. This is only a very small snapshot. This was subject to considerable evolution throughout the analysis.
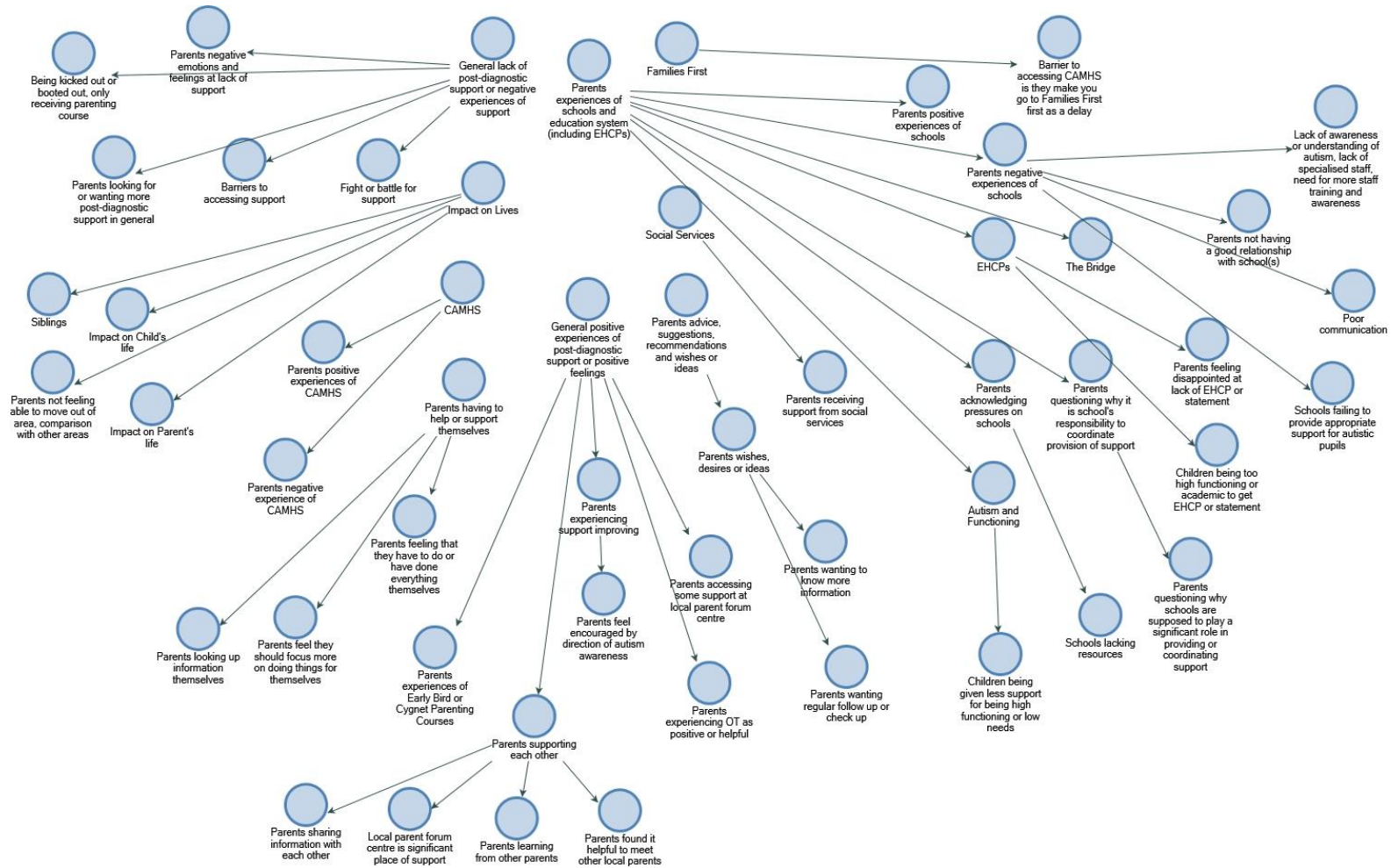
6.13. Early tables of themes and subthemes by participant group

6.13.1. Parents

Systemic failure to meet need/barriers to support	Lack of support has a significant impact on family	Positive sources of support/Improving the situation
Lack of funding and resources (inc schools, EHCPs, local services)	Parents having to fight for support	Parents supporting each other/sharing knowledge
Knowledge - Lack of understanding about autism, lack of training?	Impact on parents (mental and physical health, career)	Parents helping themselves
System not set up for children with autism (systemic/service practical barriers; who you know)	Family not being able to move	Other sources of support (████, Parenting courses, Parent forum, schools)
Parents not knowing what support is available out there or how to access it	Impact on child's mental health	Parents' wishes, advice and recommendations
Other barriers (racism, functioning labels)		

6.13.2. School Staff

Schools not able to meet the needs of pupils on the autism spectrum appropriately	Poor communication and relationships throughout the system, which impacts negatively on everyone	Although there are some areas where the system works well, it needs to change
Fundamentally autistic pupils are not receiving enough support	Parents (and others) have unrealistically high expectations of support	There are some things the school does well
Staff are constrained by financial issues - school restricted by lack of funding and resources	Communication and relationships are generally poor between and within all parties	███████ is a significant source of support and other areas should have one
Support is restricted by a lack of autism training, and general lack of autism awareness	Support is hindered by problems with school staff dynamics	There are many things which should change to improve support
Transitions can be very difficult and secondary schools provide less support than primary	Trying to provide support within the current system has a generally negative impact on staff	School staff feel distant and isolated from systems, don't know how to change them or what to change

6.13.3. Children and Young People

CYPs happy with the support they are receiving	CYPs not knowing or not understanding	CYPs wanting a bit more support
CYP happy with their school/friends	CYPs unsure, unaware, not knowing or not understanding	CYP negative experiences of lack of support or losing support
CYP positive experiences of receiving support	CYP unaware of what support they have received or current support plans	Bullying/fighting with peers
CYP feels they get enough support, don't need more	CYP finds it difficult to think of what would help or what they would change	Things young people would like or think would help
CYP does not think their parent(s) need any additional help or support		