HOW ARE CHILDREN AND YOUNG PEOPLE (CYP) WITH AN AUTISM SPECTRUM DIAGNOSIS SUPPORTED TO UNDERSTAND AUTISM AND THEIR DIAGNOSIS?

VOLUME 1: THESIS

by

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ABSTRACT

Literature suggests that an autism diagnosis can have positive and negative psychological ramifications, which range from improvements in self-esteem (Jones, 2001) through to significant negative impacts on mental health (MacLeod and Johnston, 2007). This study aimed to understand the impact of an autism diagnosis for children and young people (CYP), through the perspectives of those most closely involved, to identify factors most likely to influence positive outcomes. This thesis presents two key strands related to this aim, a systematic exploration of the literature and a mixed-methods research study.

A systematic review was undertaken following the preferred reporting items of systematic reviews and meta-analyses (PRISMA) protocol (Moher *et al*., 2009). The number of papers meeting the search criteria for each of the key stakeholders were: CYP with an autism diagnosis (n = 11); parents of children with an autism diagnosis (n = 7); professionals involved in diagnosis and post diagnostic support (n = 11). Findings were synthesised using thematic analyses. A common theme identified across the papers was the impact of autism diagnosis on CYP's self-identity, which was especially influenced by their social experiences and the communication they heard about autism. Parents were identified to be more likely to support children's understanding of the diagnosis than professionals and the importance of a strengths-based approach was highlighted.

For strand two, a mixed-methods approach was utilised to enable CYP's experiences of learning about their autism diagnosis to be understood, and to explore the conversations and interactions that parents and professionals had with them. Views of the three key stakeholders were collected through online surveys and interviews. Twelve CYP with an autism diagnosis participated (survey n=11; interview n=1); thirty-six parents (survey n=30; interview n=6); fourteen professionals (survey n=9; interview n=5). Participants provided rich accounts related to young people's experiences. Although there was variation in the views shared, most CYP with autism, and parents of CYP with autism, identified that post-diagnostic experiences were more positive than experiences before the diagnosis. Furthermore, knowing about the diagnosis appeared to be a resilience boosting experience for some young people, as the new knowledge about their diagnosis enabled them to make connections with strategies suggested by others, or with strategies they identified for themselves. Parents' and professionals' views about disclosure were aligned, suggesting that discussion of diagnosis should be developmentally tailored for the individual, it should focus on strengths related to autism, which are contextualised to the individual's experiences. Positive role models with autism were also highlighted to support positive perceptions. The findings highlight that, in addition to learning about autism through the positive conversations about the diagnosis, processing and coming to understand what an autism diagnosis means for the CYP is a process that takes time, which is best supported by ensuring that the social contexts that CYP experience, at the point of diagnosis and beyond it, reflect a positive understanding of the differences that are experienced in relation to autism.

DEDICATION

Thank you

Dad, my funny, eccentric, and irrepressible hero, for your resolute faith in me.

My husband, for being my rock, as well as chief cook and bottlewasher while I completed this study.

My son, for always making me proud; you are my inspiration.

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CHAPTER 1: INTRODUCTION

1.1 Background to the research

Prior to undertaking this research, I worked as an advisory teacher, providing support for children and young people (CYP) with autism and advice for their parents and educators. I observed that many CYP with autism had difficulty understanding and accessing appropriate information about their autism diagnosis. Parents and the children's teachers regularly told me that they did not know how to discuss autism with CYP. Furthermore, parents often asked for advice about whether they should tell their child about their diagnosis and how they should do this. The anxieties that were regularly expressed included lack of confidence related to knowledge of autism, being unable to find appropriate information to support discussion of autism with CYP, and uncertainty about how to explain autism. Educators and parents were also worried that, if they did not explain autism appropriately, learning about their autism diagnosis might be detrimental for CYP's wellbeing. As a result, I was often called upon to provide support for CYP to aid their understanding. Exploration of the research literature highlighted that parental and teacher concerns were well-founded, learning about an autism diagnosis might be detrimental for some young people, yet it could be beneficial for others (e.g. Humphrey and Lewis, 2008; Huws and Jones, 2008). However, there was little literature to inform best practice for informing CYP about their autism diagnosis, or about what might influence a positive or negative impact when CYP were informed about the diagnosis. Therefore, this study aimed to investigate how CYP have been supported to understand autism and their diagnosis, and to consider a range of perspectives to explore factors that might influence outcomes.

1.2 A rationale: understandings about impact of diagnosis

When I first set out to investigate this topic, research commissioned by the National Institute of Health and Care Excellence (NICE, 2011a) and undertaken by the Guideline Development Group [GDG] for the National Collaborating Centre for Women's and Children's Health (NCC-WCH) (2011), had just been published. However, their report highlighted there was insufficient evidence about effective approaches to support CYP's understanding of an autism diagnosis and they were unable to make recommendations for practice. Despite the lack of evidence-based guidance for professionals, I was aware from my practice-based experience, and the existing literature, that an autism diagnosis can have psychological ramifications (Ruberman, 2002). Attwood (2006) suggested that reactions experienced include denial, depression, and masking through imitation of typical peers. Personal accounts from people with autism revealed a broad range of psychological impact ranging from improvements in self-esteem (Jones, 2001) to extreme depression and even suicidal feelings (MacLeod and Johnston, 2007).

This range of reactions resonated with my observations when working with CYP in the weeks, months and years following their diagnosis. Given this range of possible impacts, I felt that it was vital to understand the views and experiences of the CYP, who have been through this process, as this would enable identification of aspects of their experiences that they viewed both positively and negatively. By understanding these experiences, I felt that the strategies that were more likely to impact positively on CYP's understanding of autism diagnosis might be identified. This information could then be used to inform my professional practice and the advice I offered to parents and professionals. At this time, I often delivered parent training that aimed to help parents to understand their child's autism diagnosis. Within these sessions, parents revealed feelings such as relief, confusion, anger, and distress, as they shared their thoughts and concerns during sessions. Through this range of interactions with CYP with autism and their parents, it was clear to me that they were negotiating their understanding of the autism diagnosis together.

I also worked with professionals involved in diagnosing autism and supporting CYP and their parents following an autism diagnosis. As I was regularly present at multi-professional meetings when the diagnosis was shared with parents and young people, I was aware of different approaches to disclosure taken by professionals, and of the differences in the support provided post diagnosis. I felt that the way in which CYP and their parents learnt about the diagnosis, influenced how they came to understand and conceptualise autism. Therefore, my broad aims for the research were to explore CYP's, parents' and professionals' views, as the three key stakeholders in disclosure of an autism diagnosis, to identify factors that might influence positive understandings of an autism diagnosis.

1.3 Brief overview of the approach to the research

Robson (2002, p. 4) identifies the complex nature of ‘real world’ research, which can be difficult to control and frequently ‘messy’. This is perhaps why, much of the literature about the processes and impact of an autism diagnosis on CYP has focussed on exploring the views of one of the key stakeholders at a time. However, this does not allow the system to be considered as a whole, or the way that different stakeholders might influence each other. Therefore, I felt it was essential to explore the views of all the key stakeholders and I was drawn to the work of Bhaskar (2011), whose critical realist approach focusses upon the systems in which humans interact with each other. As processes and systems that influence perceptions of autism were the focus for the research, critical realism was adopted as the philosophical basis for the research. Furthermore, I was also drawn to the pragmatic rationale for the critical realist approach, which does not ignore the scientific method, rather it aims to employ the approach that best meet the aims of the study.

The overall aim of the study was to explore the perspectives of key stakeholders who have been involved in sharing an autism diagnosis with CYP, and of those who have received an autism diagnosis as a child, to identify how CYP were informed about the diagnosis and the factors that influenced CYP’s views about autism and self. To explore both the range of experiences and to facilitate depth of understanding, a mixed methods approach was employed. A range of views were collected through online surveys, and interviews were undertaken to explore experiences in greater depth. This enabled CYP’s views about autism and the autism diagnosis to be understood in relation to the conversations and interactions that parents and professionals had with them about autism.

1.4 A brief rationale for the autism related terminology employed

Through my interactions with CYP on the autism spectrum, I have become aware of the negative language that they sometimes applied when discussing themselves, especially when their mood was low, and when they were experiencing difficulties with peers or academic demands. I had observed that the language they used was sometimes linked to the medically based language of diagnosis. I remember, for example, one young person who was struggling to establish and maintain friendships, who explained that:

> They all know I have a '***disorder***', so they don't want anything to do with me.

Although I had heard CYP discuss similar ideas previously, on this occasion, his emphasis on the term disorder particularly struck me. It is the reason that within my professional practice when interacting with CYP and their parents, I avoid such language. I was therefore relieved to discover that the Autism Education Trust (Wittemeyer *et al.,* 2012) National Competencies and Standards for educators also advocated this approach, using the concept of difference and the term autism, rather than autism spectrum disorder. Therefore, throughout this thesis, this is the term that I employ, unless quoting from the work or views of others, where it is important to provide the idea as it was shared or written. However, I am aware of the range of views in relation to autism terminology, therefore, this is discussed more fully in the chapter that follows.

1.5 Structure of the thesis: Overview of chapters

The thesis is arranged in nine chapters, including this introduction. Chapter Two (Definitions and Conceptual Frameworks) begins by exploring the diagnostic criteria for autism, before presenting the summary findings from an initial scoping review of the literature. The review provided the context and rationale for the development of the research in 2012, including perceptions of autism, theories and conceptions that were important to understand when designing the study. After exploring and defining the terms and conceptual frameworks identified, the chapter concludes by detailing the research questions this study sought to address.

Chapter Three presents a systematic literature review, which was undertaken after the empirical study in 2019, as further relevant research has been published. As highlighted by Gough, Oliver and Thomas (2018, p. 3), this systematic review aimed to ensure that a comprehensive context was provided for interpreting the results of the empirical study. Chapter Three comprises three sections, which are organised to focus on each of the key stakeholders' views: CYP with autism, parents of CYP with autism, and professionals. This systematic literature review was undertaken in 2019, after the empirical phases of the study had been completed, as more research related to the research focus had been published. However, it is presented before the empirical study in this thesis to provide the reader with a summary of previous knowledge and research related to this topic, how the topic has been explored, and how views vary across studies (Gough, Oliver and Thomas, 2019, p. 3). The 2019 systematic review aimed to draw together the existing evidence base about CYP's experiences prior to diagnosis, during the process of diagnosis, and after the diagnosis from a range of perspectives. How CYP found out about their diagnosis, and were supported to understand it, was also a key focus. Literature related to parental and professional experiences of disclosing an autism diagnosis to children, and the impact, was also reviewed.

Chapter Four (Methods) explains the research design, the research methods, the recruitment, and the sampling methods. The chapter outlines several phases of research, including a brief overview of the first study that explored a post-diagnosis information programme for CYP and parents about autism, and how the perspectives of the programme's participants were collected, which were valuable in informing the survey development for the main study. Next the trialling and focus group evaluation that was undertaken during the development of the online survey for the main study is explained. The procedures for the main study are described next, including the online survey for CYP, parents and professionals; this is followed by the procedures for the interviews with the same stakeholder groups. The chapter concludes by outlining the ethical considerations for the study.

The results are presented in Chapter Five (Results-Children), Chapter Six (Results-Parents) and Chapter Seven (Results-Professionals); within each of the results chapters, the survey findings are considered first, followed by the interviews. The results' chapters conclude with a discussion of the findings, to draw out the implications in relation to each of the key stakeholders and to consider how the results inform the research questions. Chapter Eight synthesises the findings across the three stakeholders.

Chapter Nine (Discussion and Conclusion) discusses the findings across the key stakeholders to summarise the way in which the study has addressed the research aims: to understand how children come to understand an autism diagnosis, and how this might be influenced and supported by others. After considering the study’s limitations, the thesis concludes by identifying the implications for those supporting CYPs’ understanding of an autism diagnosis in the future, and for future research.

CHAPTER 2: DEFINITIONS, EXPLORATION OF THE EVIDENCE BASE AND CONCEPTUAL FRAMEWORKS

2.1 Purpose of the research

As this research aimed to explore how children and young people (CYP) come to understand an autism diagnosis, this section considers how understanding of autism has been conceptualised and developed by professionals within the field. This includes key definitions and diagnostic criteria for autism, which provide the context for the diagnosis, and how it has been discussed clinically, academically and within society. The key findings from the initial review of literature, which was undertaken in 2012, are presented. The 2012 review aimed to provide the context and rationale for the development of the research and identified relevant topics that warranted further exploration. After briefly summarising the review findings, this chapter explores these key topics, exploring the perceptions of autism, relevant theories and concepts that were identified. The potential impact of these conceptualisations of autism are considered by exploring related research and readings, including those which considered the views of people with an autism diagnosis, to explore what was understood and why it was relevant to this research.

2.2 The diagnostic context: conceptualising autism and the autism spectrum

For the purposes of this research, the conceptualisations of autism within the diagnostic criterion are important because they are likely to have influenced the way in which autism has been explained and discussed with CYP. Due to the age range of the CYP considered and the data collection period (2014-2017), the participants will have experienced the diagnosis under different criteria, including: Diagnostic and Statistical Manual, Forth-Text-Revision (DSM-IV-TR) (American Psychiatric Association [APA], 2000); DSM-5 (APA,2013); and the International Classification of Diseases, Tenth Edition [ICD-10] (World Health Organization [WHO], 1992).

As most data collection took place before 2018, and the NICE (2011b) diagnostic guidelines have not yet been updated to reflect ICD-11 (WHO, 2018), most participants will have been diagnosed with reference to ICD-10 (WHO, 1992); DSM-IV-TR (APA,2000); or DSM-5 (APA,2013). The revision to the criteria has been discussed academically (e.g., Volkmar, State and Klin, 2009; Rutter, 2013; Baird and Norbury, 2016) and in the general media (e.g., Daily Mail, 2012; The Guardian, 2012; Zeldovich, 2017) during the years leading up to the change. Therefore, at least some of the participants who have taken part in this research are likely to have been aware of the criteria changes, which could have impacted perceptions.

Before 2013, the APA (2000) criteria defined ‘autistic disorder’ as a pervasive developmental disorder. This criterion identified a triad of difficulties underlying autism, which included impaired social interaction and communication, alongside circumscribed behaviours (APA, 2000). Wing (1996) and others have advanced the view of autism as a spectrum disorder, due the way in which autism can impact people to a lesser or greater degree. The latest version of the APA (2013) criteria recognises autism as a spectrum and uses the diagnostic term Autism Spectrum Disorder. It also combines impaired social interaction and communication as a conjoined diagnostic symptom, alongside a second diagnostic aspect: restricted behaviour. While the DSM is influential, especially in academic writing and research, the United Kingdom's, National Health Service advocates use of WHO's International Classification of Diseases (ICD) for diagnostic purposes. However, clinicians are also able to use other diagnostic criteria, such as the DSM, if it is preferred for clinical reasons (NICE, 2011b, p. 14). As NICE allows the use of DSM and ICD, both will be discussed. ICD-10 employs the diagnostic name 'Childhood Autism', describing autism as a:

> …type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. (WHO, 2010, F84.0).

While DSM-5 (APA, 2013) and ICD-11 (WHO, 2018) now agree on the name for autism as "Autism Spectrum Disorder", there remain differences within the descriptions. For example, DSM-5 explicitly identifies difficulties in processing sensory information, however, there is no specific reference to sensory processing issues within ICD-11. Although the term spectrum was not use previously within the criteria, ICD-10 (WHO,

1992) identified a range of autism spectrum traits and corresponding differential diagnosis, including autism with and without intellectual impairment, and ‘Asperger syndrome’, which it identified as being primarily different from autism due to there being:

> … no general delay or retardation in language or in cognitive development… (WHO, 2010, F84.5).

While a spectrum of needs and abilities is recognised, neither DSM-5 (APA, 2013) or ICD-11 (WHO, 2018) include Asperger syndrome diagnosis. ICD-11 (WHO, 2018) defines autism as:

> … persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests. (WHO, 2018, 6A02)

ICD-11 identifies the full spectrum of intellectual functioning and language skills and highlights that while the onset is typically in early childhood, it might not be recognised until later in childhood (WHO, 2018).

Asperger syndrome (AS) is an autism spectrum diagnosis, which describes people with average, or above, intellectual ability, who also have social difficulties (Wing, 1981; Attwood, 1998). When discussing AS, Ghaziuddin (2010) highlighted that few disorders have generated as much controversy. ICD-10 indicates that individuals with AS have the triad of impairments found in autism, but they differ in presentation from those with autism, as a delay in cognitive development and language is not identified, but marked clumsiness is displayed (WHO, 1992). Several studies have attempted to differentiate the underlying presentation of autism and Asperger syndrome at the base of these descriptions. Ozonoff *et al.* (2010), for example, found early history to be the most useful differentiating factor; with language and behaviour being more significantly impacted in children on the autism spectrum in their preschool development, but these differences had largely disappeared by adolescence. Ylisaukko-oja *et al.* (2004) were able to identify a potential common genetic pathway for AS in their genome study. Despite the calls to maintain the diagnostic category of AS, as a useful differential diagnosis that also aids research (e.g., Ghaziuddin, 2010; Giambattista *et al.*, 2019), it has not been included within the DSM-V (APA, 2013), or ICD-11 (WHO, 2018). Removal of Asperger syndrome from the diagnostic criteria has been both controversial and widely publicised (e.g., Ghaziuddin, 2010; Patterson-Peppers, 2010; The Guardian, 2012; Linton *et al*., 2014; National Autistic Society, 2016; Howley, 2019). Therefore, as differences of opinion about AS continue to be discussed in the scientific literature, and the general media (e.g. Browne, 2017; Limberg, 2019; Pesce, 2019), this may prove confusing to CYP with an autism spectrum diagnosis, and their parents, in terms of the precision of the diagnosis. Such concerns could lead to rejection of diagnosis, as demonstrated by Armstrong (2011), an adult with autism, in his post diagnostic exploration of the clinical basis of the diagnosis.

2.3 Impact of changes within the autism spectrum diagnostic criteria

The impact on individuals with an AS diagnosis, of the removal of AS from DSM-5 and ICD-11, is a pertinent illustration of the possible impact changes to diagnostic criteria can have on the identity of people with autism. Giles (2013), for example, explored online social media discussions of participants with AS, which focussed on the proposed changes to be brought in by the DSM-5 (APA, 2013); findings identified a strong ‘Aspie identity’ within online communities. The views shared included both positive views and concerns regarding the proposed changes. Nevertheless, Giles (2013, p. 179) also identified that, even before the final draft and implementation of DSM-5, members of the online communities were already beginning to shape a new identity, that of the ‘spectrumite’.

Due to the potential psychological impact of an autism diagnosis, being able to give a precise and definitive diagnosis has been considered important to some people with an autism spectrum diagnosis, for example Armstrong (2011). However, as suggested by use of the term ‘spectrum’ within the diagnostic criteria, the diagnostic validity of autism and the previously used AS diagnosis, as single constructs, have been questioned (Happé, Ronald and Plomin, 2006). After critiquing claims of a sound continuity and historical progression in developing understanding of autism, Verhoeff (2013, p. 455) questions the impact of such changes:

> … in describing the reshaping of the concept of autism, the historicity, provisionality and plurality of knowledge and truth about autism become apparent. As a consequence, […] it destabilizes the present ‘truth’ [and] it creates space for other possible perspectives and conceptualizations of autism…

It is how these changes impact CYP with an autism diagnosis that concerns this research. Consistent with the critical realist philosophy underpinning this study, diagnostic criteria changes are of interest as they concern both the system and the language within which CYP with autism, their parents, and the professionals who work with them will interact and discuss ideas in relation to the diagnosis. An example of this is preferences for specific diagnostic terms. Although there is little literature about the impact and potential stigma associated with both autism and AS diagnoses, research has found that AS is a more positively perceived diagnosis than autism (Kite, Gullifer and Tyson, 2013). Given the changing diagnostic criteria, and the controversy relating to autism spectrum diagnostic categories, it is perhaps understandable that an autism diagnosis has proved problematic for some people to accept (e.g., Armstrong, 2011; Davide-Rivera, 2012; Robison, 2012; Case, 2013, Giles, 2013).

Through exploration of posts from the Aspies Central online community, and interviewing regular contributors to the community, Parsole (2015) identified varied views within the community, including identification with a biomedical view of autism, alongside changing views that demonstrated agency, and a move towards a cultural perspective. Brown (1995, p. 34), in discussing diagnosis related to physical health, is credited as being the first to articulate the phrase ‘a sociality of diagnosis’. More recently, Jutel and Nettleton (2011, p. 794) described diagnosis as a ‘starting point’ and ‘the foundation from which sense-making and experiences are crafted’. However, while some positive viewpoints related to the autism spectrum and identity are emerging (e.g., Giles, 2013; Parsole, 2015), it might be that many more share concerns and confusion about diagnosis, and even the basis of the condition, but are less confident, or less able, to articulate and share their concerns.

Diagnosis of autism is often delayed, as there is no medical or biological test currently available that can enable accurate early identification. If such a test did exist, there would be no guarantee of early diagnosis because differences in development must be observed before the need for assessment is recognised. This is especially so for those with average, or above, communication and intellectual abilities, who might not be diagnosed until later in childhood, by which time their sense of self and identity is likely to be established (Howlin and Asgharian, 1999; Coo *et al.,* 2012). As a result of late diagnosis, Rhodes *et al*. (2008, p. 385) suggest that individuals are left with the stark choice of accepting that others now view them as disabled, or of refusing to accept the diagnosis as part of their identity. In terms of an autism diagnosis, it is therefore the lack of biological evidence and the ephemeral nature of an autism diagnosis which have been identified to be problematic in terms of acceptance (e.g. Armstrong, 2011; Timimi, Gardner and McCabe, 2011).

2.4 Views about terminology related to autism within systems in which the key stakeholders interact

Wittemeyer *et al.* (2012, p. 58) highlighted differing opinions about the medical criteria and the related terminology within the Autism Education Trust (AET) Standards and Competencies, which they created for educators. They explain that some people value the term ‘autism spectrum disorder’ because they feel it describes the range of difficulties experienced, while others feel that terms such as disorder can be stigmatising. After considering a range of views from literature and people on the autism spectrum, Wittemeyer *et al*. (2012, p. 58) made the decision to refer to ‘autism’ or the ‘autism spectrum’ to respect the range of views across the spectrum. However, more recently, Guldberg *et al.* (2019, p.16) undertook a large review for the AET about what is considered good educational practice related to autism. After acknowledging differences in opinion about language related to autism, they decide to use both the terms autism and autistic across their report. However, the rationale for this decision does not explore the views of the CYP with autism diagnosis, despite CYP being the focus of many educators. The guidance is written for educators working with CYP in early years’ settings, mainstream schools, and special provision, in addition to those in the post-16 sector. In explaining their decision, Guldberg *et al.* (2019) identify the research by Kenny *et al.* (2016) that explored views of parents, professionals, and adults with autism diagnosis, but not CYP, which found differences of opinion across groups. A point of agreement across the participant groups in the research was the avoidance of the language of deficit. Kenny *et al.* (2016, p. 444) also highlighted that those with autism diagnosis who contributed to the research were articulate adults and should therefore not be considered as the voice of all with autism, as they cannot understand or represent the experiences of ‘severely disabled’ people with autism. What is not considered by Guldberg *et al.* (2019) in explaining their decision is that there is not yet an evidence base about CYP’s preference for the terminology in relation to autism.

Another important consideration within the literature about the terminology of autism is how to apply diagnostic terms, such as autism, when discussing people identified with the diagnosis. A specific concern highlighted in the literature is whether the diagnostic term should come after the person (person-first) or before the person (identity-first), as demonstrated by Sinclair (1999, p. 1):

> I am not a ‘person with autism’. I am an autistic person.

Gernsbacher (2017, p. 859) explains that the person-first approach uses the person-based noun before the term that refers to a specific diagnosis (e.g., child with autism), while an identity-first approach utilises the diagnostic name before the person-based noun (e.g., autistic children), or fully encompasses the identity in ascribing the diagnostic term as the person-based noun, such as Lupin (2018, para. 1) who explains:

> I am 21, an aspiring actor from Brighton and I am autistic.

Some people on the autism spectrum are strong advocates of the identity first approach. Sinclair (1999), for example, explains that the identity-first approach is his preference because autism cannot be separated from the person. Sinclair (1999) further suggests that person-first language heightens the perception of autism as a negative entity, which unlike other characteristics, such as generous and athletic, are accepted and used before the person-based noun (e.g. athletic child). Therefore, he suggests, the person-first approach reinforces the difference and implies negative connotations.

Views such as Sinclair’s (1999) run counter to those of many equality advocates and academics who have, for approximately thirty years, emphasised the importance of person first language (See for example: Gernsbacher, 2016; 2017; Crocker and Smith, 2019). The advocacy of the person-first approach arose due to the frustration that disability was increasingly being conceptualised within society as a medical condition, and perpetuated by the use of overly medicalised and deficit-based language (e.g. Oliver, 1990; Shapiro, 1993; Charlton, 1998; Barnes, Mercer and Shakespeare 1999). Person-first phrasing was therefore advocated to influence more positive attitudes. As a result, professional training often advocates person-first language (Crocker and Smith, 2019), and there has been a move towards person-first language in academic writing (Gernsbacher, 2016; 2017). However, whether person-first language is used in practice situations, when conversing with, or about, people with specific diagnoses, has been called into doubt (Crocker and Smith, 2019). Furthermore, as discussed above, some people with autism rejected person-first language (e.g. Sinclair, 1999; Silberman, 2015), as do others with different conditions, for example, the 'Deaf community' (e.g. Ladd, 2003). Therefore, a specific approach to language related to people with specific diagnoses, such as autism, has not been universally agreed and applied. The large-scale study by Kenny *et al.* (2016) did, however, identify that across groups, the most highly endorsed term was 'on the autism spectrum' and the second most accepted being 'autism'. Therefore, while views about 'autistic' and 'person with autism' were more varied, 'autistic' was more popular with adults with autism, and 'person with autism' by parents and professionals.

Therefore, when considering the most appropriate terminology and phrasing for this study, as suggested by Kenny *et al.'s* (2016) research, I wanted to employ an ethical approach that reflects the people that the research considers. This is problematic, as the terminology preferences of CYP with an autism diagnosis have not yet been identified. Nevertheless, I was conscious of the power of language, and terminology, and the impact it can have upon society's perceptions, as well as upon individual identities (Bedell *et al.,* 2018). I was also aware that research about the views of people on the autism spectrum tends to be self-selecting and can therefore be dominated by adults with autism who have average, or above, language and learning ability; such limitations are identified within the work of Kenny *et al*. (2016) and Crane *et al.* (2019). While there is evidence that some adults with autism prefer use of the term autistic, as they feel it is a central element of their identity, these views might not be representative, except of those with strong views on the topic and terminology. Furthermore, this research study is specifically focussed on the views and experiences of CYP on the autism spectrum, and there is not yet enough evidence about CYP's preferences about the term used to name autism. Due to their phase of development, the views of CYP might be very different to those of adults on the autism spectrum, they might not be ready to accept an 'autistic' identity. As for adults with autism, CYP's views might differ and while some might prefer identity–based language, it might be perceived as stigmatising to others. Therefore, as the views of CYP are not yet known, I will use person-first language and have aligned the language of this study (using 'autism' or 'on the autism spectrum') to the evidence about the most popular terms, as identified across the participant groups in the research by Kenny *et al.* (2016), while also acknowledging known differences of opinion.

2.5 Age at diagnosis

There is little evidence about the relationship between age of diagnosis and the impact on the identity of CYP with autism. However, age of diagnosis will influence when CYP are likely to learn about the diagnosis. A Swedish study by Wilkner-Svanfeldt *et al.* (2000, cited in Jones, 2001) identified that children with autism began to ask questions that suggested desire for a better understanding of differences from peers at approximately nine-years-old. It might therefore be that the age of diagnosis is also a factor that impacts the reaction to diagnosis.

As early diagnosis has been identified with better outcomes (e.g. Harris and Handleman 2000; Oono, McConachie and Honey, 2012; Magiati *et al*., 2014), initiatives often focus on ensuring early diagnosis. Towards the end of the twentieth century, Howlin and Ashharian (1999) found 5.5 years to be the average age of diagnosis for autism and 11 years for AS. More recently, Crane *et al*. (2016) identified the that the mean age of autism diagnosis was 5.6 years, while for AS it was 9.9 years. The evidence relating to the UK points to a level of consistency in the age of autism diagnosis and a lowering age for AS.

Literature also shows that age of diagnosis is related to a range of factors such as awareness of autism, access to services and professional training, which have changed both across and within countries (Daniels and Mandell, 2014; Crane *et al*., 2016). Therefore, across the literature, as suggested by Daniels and Mandell (2014), it is the children with autism, but **without** language delay or intellectual impairment, who are identified to be diagnosed later. Therefore, these children will learn about their diagnosis later, even though they might have been aware of being different at an early age, which could impact their acceptance of the diagnostic label. As Jones (2001) suggested, regardless of age related to diagnosis, the right time for discussing the diagnosis is likely to vary and the experience will be individual to each person.

2.6 The 2012 review of the literature

An exploratory literature review was undertaken, prior to initiating the research in 2012, to inform the development of the research plan and the application for ethical approval for the study. A lack of evidence related to the views of CYP about their autism diagnosis, and good practice for supporting CYP with autism to understand their diagnosis, had already been identified (NCC-WCH, 2011). As the review revealed that only a few research papers specifically relevant to children's experiences of autism and an autism diagnosis were available, the review search framework was widened to include the perceptions of other participant groups that might also provide useful information about relevant experiences and approaches in relation to diagnosis. The aim was to inform the development of the research study by identifying relevant topics and concepts. Therefore, in addition to the experiences of key stakeholders in the process: CYP with autism, parents of CYP with autism, and professionals involved in supporting CYP with autism in relation to their diagnosis, the review was widened to explore the views of CYP with a diagnosis other than autism, and the views of adults with an autism diagnosis.

2.6.1 The approach undertaken for the initial literature review

Higgins and Green (2011) emphasised that systematic reviews use methodical approaches to identify and synthesise research in order to reduce bias and to provide more reliable findings. However, Munn *et al.* (2018, p.3) have highlighted that scoping reviews differ, as they aim to 'provide an overview or map' of the relevant evidence relating to the review subject matter, rather than a 'critically appraised and synthesised' understanding of a specific issue. Munn *et al*. (2018) also emphasise that while systematic reviews began to emerge in the 1970's and 1980s, scoping reviews are a more recent approach. When the 2012 review was undertaken, the first guidance for conducting a scoping review (Peters *et al*., 2015) had not been published; therefore, little guidance was available for researchers about scoping reviews. However, in retrospect, the aims for the 2012 review of the literature, met the rationale for a scoping review, which was later outlined by Munn *et al.* (2018), as shown below in Table 1.

The approach taken aimed to be as rigorous as possible but broad enough to identify the research evidence and other literature that might inform the topic. As identified to be the general aims for scoping reviews (Peters *et al.*, 2015, p. 142), the aims of the 2012 review were to bring together the emerging evidence, to identify key concepts, and to explore how the topic had been researched by others. As two of the papers identified had already explored perspectives of people with autism through autobiographies written by people with autism, these peer reviewed research papers were included rather than individual autobiographies. However, some individual autobiographical accounts have been drawn on in the general discussion of literature within this chapter. The date range for the review was from March 1979 to 28th December 2012, however, the earliest paper identified that met search criteria was Howlin and Moore's (1997) paper.

Table 1 The rationale for scoping and systematic reviews identified by Munn *et al*. (2018)

Scoping reviews aim to:	Systematic reviews are undertaken to:
• Find the existing evidence for a specific field/topic • Identify relevant concepts and definitions • Discover how similar research has been conducted • Identify specific characteristics related to concepts • Identify gaps in the knowledge • Provide a foundation for a systematic review	• Discover the evidence (usually internationally) • Identify current practices, variation and developing practice • Inform future research • Identify and explore conflicting results • Generate statements to research planning

The focus of the search was to identify stakeholder perspectives of the autism diagnostic process, the support provided and the impact of the diagnosis. The key stakeholders were children and young people with an autism diagnosis, parents of children and young people with an autism diagnosis, adults with an autism diagnosis and professionals involved in the diagnostic process or post diagnosis support (See Appendix 1 for the full details of the search parameters and search terms, the list of papers identified and summary tables of findings from papers for each of the participant groups). This approach enabled a broad range of perspectives to be explored, while the inclusion and exclusion criteria facilitated a rigorous approach to screening for relevant papers. Figure 1 below, gives an overview of the papers identified at each stage of the review process.

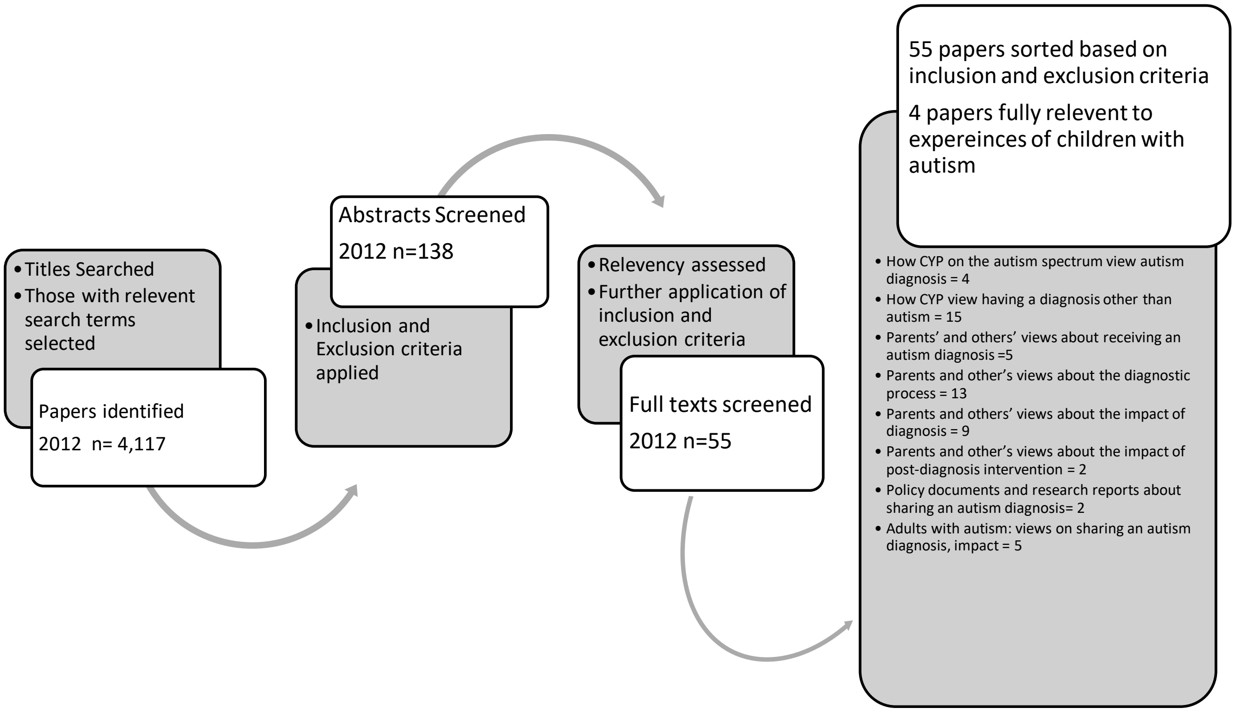


Figure 1 Processes applied for the literature search

2.6.2 Overall findings from the review of the literature

During the final screening process, the papers reviewed were organised into sections, based upon the population whose views were being considered. The focus of the papers, details of the participants and methods employed within each paper are summarised in Table 2 below. Appendix 1.1 provides a detailed summary of the procedures for the review, including the search criteria and search parameters. Appendix 1.2 provides a summary of the references, aims, participants, methods and findings for each of the individual papers identified for the review. Appendices 1.3

through to Appendix 1.7 give details of the process used to identify themes and the comparison across the papers identified.

Table 2 Overview of the research participants and methods employed within the papers identified by the 2012 review

Participants	Number of papers	Number of participants within the studies	Methods (*Note paper number refer to papers listed in Appendix 1.2)
CYP with autism	4	Min: 1 CYP Max: 9 CYP within individual papers Total 18 across papers	2 papers reported interview methods (*Papers 3;4) 1 paper reported observation and interviews methods (*Paper 1) 1 paper reported on case study method (*Paper 2)
CYP with diagnosis other than autism (e.g. epilepsy, diabetes, human immunodeficiency virus, cystic fibrosis, Huntington disease, physical disability, attention deficit hyperactivity disorder & mental health needs)	15	Min: 2 CYP to Max: 2802 CYP within individual papers Total: 3,545 CYP across papers	11 papers reported interview methods (*Papers 6; 7;8;10; 11; 13; 14; 15; 16; 17; 18) 2 papers reported questionnaire methods (*Papers 5 & 17) 1 paper reported case study method (*Paper 12) 1 paper reported survey method (*Paper 19)
Parents of CYP with autism	29	Min: 3 parents to Max: 14,000 within papers Total 18,140 across papers	11 papers reported interview methods (*Papers 20; 22; 24; 25; 27; 30; 32; 34; 36; 39; 44) 16 papers reported questionnaire and standardised scale methods (*Papers 21; 22; 23; 28; 29; 31; 33; 37; 38; 40; 41; 42; 44; 44; 45; 46; 47; 48) 3 papers reported focus group method (*Papers 22; 33; 35) 1 paper reported observation method (*Paper 24) 1 paper reported analysis of online blogs (*Paper 26) 2 papers used mixed methods (*Papers 22; 24-these are also listed above with the specific method)
Professionals involved in diagnosis and post diagnostic support	6	Min-5 to Max-1588 professionals within papers Total 1667 across papers	2 studies used interviews (*Papers 34 & 50) 2 papers were mixed methods, employing focus groups and questionnaires (*Papers 22 &33) 1 paper used 2 focus groups (*Paper 20) 1 paper used scaled questionnaires and standardised measures (*Paper 40)
Adults with autism	7	Min-1 to Max 45 adults with autism within papers Total 104 adults with autism across papers	3 papers reported interview methods (*Paper 50, 52 & 55) 2 papers reported on analysis of autobiographies and personal narratives (*Paper 53 & 54) 1 paper reported on a case study based on observation and interviews (*Paper 51) 1 paper reported analysis of online blogs (*Paper 26)

The review showed that a range of approaches had been used to explore this topic by other researchers, the methodologies were most varied within papers that explored the views of parents and professionals, for which, questionnaires and interviews were the most commonly used. The research papers that presented the views of CYP with autism, and CYP with diagnosis other than autism, used qualitative approaches, the most common being interviews. The papers exploring the views of adults with autism were also all qualitative, three generated data through interview and three analysed written information drawn from autobiographies and blogs. The review was useful to inform understanding of the successful methods that previous research related to being told about and coming to understand a diagnosis had employed, which informed planning of the research study. A mixed method approach using a survey and interviews seemed to be the most appropriate to provide both an overview of experiences and depth of understanding, which Cresswell (2009) highlighted was a key benefit of mixed-methods studies. Furthermore, the previous research exploring the views of people with autism through autobiographical writings and blogs also highlighted the potential of gaining in-depth qualitative written information; therefore, it was decided to design the research so that participants could contribute their views either in written form via open survey questions, or in spoken form through interviews.

2.6.3 Key topics explored to understand diagnostic experiences

To understand diagnostic experiences, across the research papers identified for the review, a consistent set of topics have been explored by previous researchers (See Appendix 1, which highlights the occurrence of the key topics across the full list of papers). As shown in figure 2, the main topics explored by researchers included the experience of having a specific diagnosis, being told about a diagnosis, or telling someone about a diagnosis. The impact of receiving diagnosis was also explored, the papers that focussed on children's views, and the views of adults with autism, mostly explored the impact of receiving a diagnosis on the identity and self-views of participants. However, the practical impact was also explored across the papers from different participant groups, for example, access to services and support, and changes in the understanding of others (family, peers and educators).

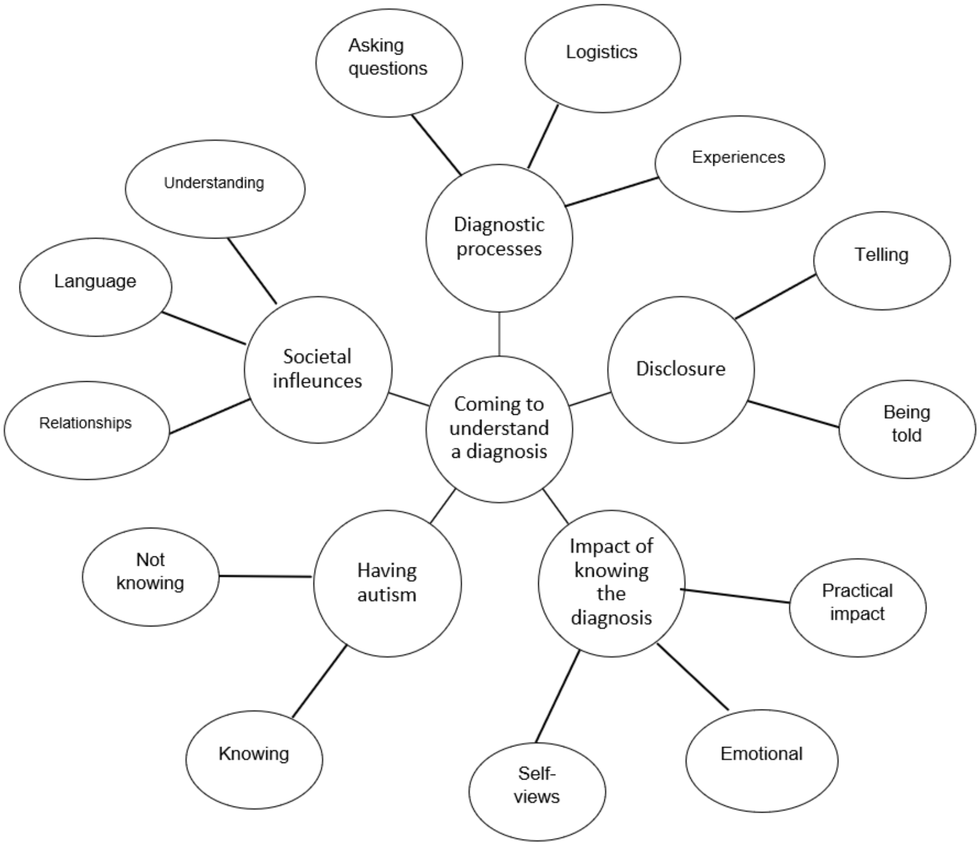


Figure 2 Topics explored in previous research

2.6.4 Key themes identified through the review of the literature

The topics explored by the researchers and their research aims influenced the themes that the research participants discussed. Although there were differences in the research aims across the papers, there were also some consistent overarching key themes shared by the participants across the studies identified by the search.

2.6.5 Key findings from papers exploring views of CYP with autism

As participants' ages within the studies exploring the views of CYP with autism mostly fell within adolescent stage of developmental, it is perhaps understandable that perceptions of self and self-identity was a common theme. Factors that could impact self-identity were highlighted when CYP discussed social experiences and the impact of having an autism diagnosis. Challenge and change in relation to identity is known to be a significant and common phase experienced by young people within the age ranges considered (e.g. Kroger, Martinussen and Marcia, 2010; Tanti, Stukas, Halloran and Foddy, 2011). However, as highlighted by Molloy and Vasil (2004), there is a danger of focussing upon explaining all behaviour in relation to an identified diagnosis, rather than considering the individual and their phase of development. The views shared in three papers also demonstrate the potential impact of social experiences and of experiences related to autism diagnosis upon young people's self-esteem and identity (Molloy and Vasil, 2004; Huws and Jones, 2008; Baines, 2012). Only one study (Huws and Jones, 2008), specifically reported on CYP's experiences of learning about diagnosis. To facilitate participant agency in terms of the focus of the interview, the information reported in this study was in response to three general questions about what autism is, what it meant to the young people, and how they would explain it to others. Some of the participants chose to discuss their diagnostic experiences. Facing delay between the diagnosis and disclosure was a concern for some of the participants. While Huws and Jones (2008) participants discussed disclosure delay and the impact of the disclosure, they did not go on to discuss how they were told. Therefore, as the four papers that explored the views of CYP with autism did not specifically explore children's disclosure experiences, the experiences of diagnostic processes that were shared by CYP with a diagnosis other than autism were identified to be crucial to explore.

2.6.6 Key themes from papers exploring views of CYP with diagnoses other than autism

Across the literature about understanding and disclosing diagnosis other that autism, while some views did differ, most agreed that disclosure should be immediate, or close to diagnosis. CYP mostly felt that the diagnosis should be explained during the medical consultation between the specialist and the young person to explain the assessment outcome, even from an early age (e.g., Forrest-Keenan *et al*., 2009; Taylor *et al.*, 2010). Negative emotional reactions to diagnosis were also discussed by children with diagnosis other that autism (e.g., Forrest-Keenan *et al*., 2009) but, as in the study by Huws and Jones (2008), negative emotional responses were transitory, as CYP processed what the diagnosis meant them. The research from CYP with diagnosis other than autism highlights several important factors during disclosure that would be useful for professionals to consider; for example, an approach that avoids 'overloading' with information by ensuring it meets the child's pace and level of maturity was suggested, along with supportive ongoing care to maintain psychosocial well-being. Furthermore, coming to understand other diagnoses was identified to be a process, in which CYP showed agency, for example, by accessing online general health information and post-intervention, internet-based peer support (Gray *et al*., 2005; Forrest-Keenan *et al*., 2009; Stewart *et al.,* 2011).

2.6.7 Key findings from papers exploring views of adults with autism

As for children with autism, adults with autism discussed links between their experiences, their self-views and self-identity (Bagatell, 2007; Punshon, Skirrow and Murphey, 2009). Other people's perceptions of autism were also identified to have impacted their self-views (Cousins, 2001). It is therefore understandable that whether to tell others about the diagnosis was a concern for adults with autism (Davidson and Henderson, 2010). Where diagnosis was late, adults often discussed how, before the diagnosis, they were struggling to understand their experiences, of feeling different and struggling to fit in (Cousins, 2001; Bagatell, 2007). Given these feelings of confusion and difference, it is understandable that the diagnosis was described as a sense making experience (Cousins, 2001; Jones, 2001; Punshon, Skirrow and Murphey, 2009). While participants discussed varied emotional responses, knowing about the diagnosis was important to help participants put their experiences into perspective and therefore important to their self-identity and their approach to dealing with difficulties when moving forward from the diagnosis (Cousins, 2001; Bagatell, 2007; Davidson and Henderson, 2010; Punshon, Skirrow and Murphey, 2009). Across papers, the reports from people with autism strongly suggest that knowing about the diagnosis is important. However, timing was important to consider; for example, Jones (2001) suggested that there might be individual circumstances when giving the diagnosis might not be advisable. Further guidance for the process was also identified to be needed. Participants also shared their views about how the diagnosis was explained to them, emphasizing the importance of a positive focus. Language and societal perceptions in relation to diagnosis was also a common theme, stigma related to the diagnosis of autism was discussed, this was linked with negative experiences of labelling and notions of disability (Jones, 2001; Punshon, Skirrow, and Murphey, 2009; Davidson and Henderson, 2010). Participants discussed their actions to avoid labelling (Davidson and Henderson, 2010) and some participants discussed the way that the discourse and negative language related to autism becomes internalized, thus, impacting their self-views (Bagatell, 2007).

2.6.8 Key findings from papers exploring views of parents of CYP with autism

The papers exploring the views of parents have focussed on parents' experiences of learning about a diagnosis of autism for their child, diagnostic processes, the impact of the diagnosis on them and their child, and about the impact of post-diagnosis intervention. As identified by adults with autism, parents were consistent in highlighting the importance of positive, hopeful messages when explaining a diagnosis (Bartolo, 2002; Brogan and Knussen, 2003). The professional's manner and quality of information was also identified to be important (Brogan and Knussen, 2003; Harnett and Tierney, 2009). There was also evidence that views might differ over time (Landsman, 2003).

Across the papers within the review, parents' views of the diagnostic process were mixed, however, dissatisfaction was commonly reported (e.g. Howlin and Moore, 1997; Howlin and Asgharian, 1999; Moore *et al*., 1999; Gray, 2002; Siklos and Kerns, 2007; Clarke and van Amerom, 2008; Mansell and Morris 2008). Parents often suggested concerns about lack of professional expertise in discussing the diagnosis with parents (Moore *et al*., 1999; Siklos and Kerns, 2007) and also lack of empathy (Kerrell, 2001, Nissenbaum, Tollefson and Reese, 2002; Osborne and Reed, 2008).

In terms of the impact on parents, of a diagnosis for their child, communication during the diagnostic process was identified by parents as central to the process of coming to terms with a diagnosis. For example, research by Nissenbaum, Tollefson and Reese (2002) highlighted the central place of the 'interpretive conference' in helping parents to understand a diagnosis. However, many parents reported that professionals did not clearly state the diagnosis of autism. Parents also reported mixed views about whether their child should have been present at the meeting about diagnosis. Some parents reported needing time to 'grieve' without having to worry about their child. While Clarke and van Amerom (2008) found that parents usually accept the medical diagnosis, but that seeking support and/or a 'cure' for their child was a common response. Valentine (2010) highlighted that the responsibility that parents can feel might drive their desire to improve their child's life experiences, which can mean they become consumers by seeking out treatments. This differs from the perspective of some adults with autism, who have argued against a medicalising perspective of autism (Smart, 2006). Parents also reported experiencing both felt and enacted stigma (Russell and Norwich, 2012, Gray, 2002), such as: '…avoidance, hostile staring and rude comments from others' (Gray, 2002, p. 734).

Research related to parents' experiences has shown that they often go through a period of adjustment and adaptation following their child's diagnosis; this process has been likened to the process of bereavement (Dale, 1996; Hornby, 1995). Parents have also highlighted that once they could name the condition, they were able to research, understand and manage their child's behaviour more effectively, which supported them to come to terms with the diagnosis (Russell and Norwich, 2012). Parents have also indicated the need for simple general information about autism, but after a period of adjustment and consolidation, they suggest that more information regarding the range of interventions available for their children would have been beneficial (Osborne and Reed, 2008).

It has been recognised that the earlier effective intervention begins, the better the possible long-term outcomes are for the child with autism and their family (Woods and Wetherby, 2003). Delays in obtaining an autism diagnosis were found to contribute to parental distress and difficulties for the family in coping with the disorder (e.g. Quine and Pahl, 1987; Goddard et al., 2000; Goin and Myers, 2004). However, parent-focussed interventions following a child's autism diagnosis were shown to reduce child-related parenting stress and to increase parenting self-efficacy (Keen *et al.*, 2010). Furthermore, high levels of parental stress were also found to negatively impact upon the success of early interventions (Osborne et al., 2007; Robbins et al., 1991). Therefore, providing appropriate support and services was identified by parents as crucial. Unfortunately, research also showed that such support is not always provided appropriately (e.g. Osborne and Reed, 2008). The timing in terms of post diagnosis support was also highlighted to be important. Mansell and Morris (2004) found that while parents felt that providing support too soon after diagnosis was problematic, they did value support at the right time, especially the opportunity to engage with other families.

2.6.9 Key findings from professionals' perspectives

Finke, Drager and Ash (2010) explored paediatrician's views about diagnostic processes. Good communication with families was felt to be crucial and central to the diagnostic process, this was identified to be easier when they got to know the child and their family well. Important elements that supported relationships included listening to, valuing and following up parental concerns. However, paediatricians highlighted insufficient training and difficulty in talking with parents about what the diagnosis of autism meant for their child. Paediatricians used the internet as a resource to compensate for lack of training. They also suggested this to parents but cautioned them about being informed consumers of such information.

The National Collaborating Centre for Women's and Children's Health (NCC-WCH) (2011) research report explored the evidence-base that might inform guidance about autism referral and diagnosis of children and young people, and also explored how the results of the diagnosis should be communicated. Although the report identified that there was insufficient evidence to inform recommendations related to disclosure of the diagnosis to young people, on the balance of the evidence, it was identified to be important to discuss the outcome of the assessment sensitively, in person and without delay with the child's parents and, if appropriate, the child or young person. Professionals were advised to consider the child's developmental profile to inform such decisions (NCC-WCH, 2011, p.125: Recommendation 60). Furthermore, it was recommended that CYP should be offered a follow-up appointment within six weeks, to enable further discussion about the assessment outcome and diagnosis (NCC-WCH, 2011, p.125: Recommendation 67). The recommendations also highlighted that diagnostic team should provide reports and written information for parents and, if appropriate consent is given, to other key professionals involved in the child's or young person's care to inform a needs-based management plan (NCC-WCH, 2011, p.194: Recommendation 65).

2.6.10 Summary of learning from across the papers exploring views about autism diagnosis

Across the different participant groups, several similar themes were identified. However, as shown in Table 3 below, although there was similarity in themes, there were also some differences. Professionals' views tended to centre around their role in making and giving the diagnosis and the difference this made in terms of service provision. Parents of children with autism also focussed on how the diagnosis is explained to them and upon access to services for diagnosis and support. Across papers, adults with autism and CYP discussed the relationship between the diagnosis and themes related to their social experiences, as well as learning about the diagnosis and the emotional and practical impact. However, there were also differences in focus, CYP tended to focus their discussion on social interaction with peers, and comparisons of themselves to peers, when discussing themes related to diagnosis. While adults with autism discussed the way that they negotiated the diagnosis and their decision making about disclosure to others. CYP discussed the impact of the diagnosis in terms of access to support and factors related to their identity. CYP also discussed processing the diagnosis, and how knowing about the diagnosis influenced their understanding of their previous experiences.

Table 3 Summary themes from each participant group

Themes from CYP	Themes from adults with autism	Parent Themes	Professional Themes
Identity: self-views-comparison to peers	Negotiating identity and self-views		
Social experiences/influences	Social experiences/influences on self-views	Social experiences/influences on self-views	
Disclosure – how they learnt about diagnosis	Disclosure – how they learnt about diagnosis	Disclosure – how they learnt about diagnosis	Giving the diagnosis
Impact of diagnosis	Autism: knowing/not knowing - comparing before and after diagnosis	Impact of diagnosis	
Intervention/support	Mental health	Accessing services & factors impacting diagnosis	Service provision
	Language, disability & stigma	Disability, labelling & stigma	

Themes discussed by adults with autism tended to focus on differences between experiences and self-perceptions before diagnosis compared to after diagnosis. In addition, while CYP discussed access to general educational support related to the diagnosis, adults discussed experiences related to support for their mental health. Themes from parents of children with autism, and adults with autism, had a greater focus on disability and stigma than the themes from CYP. Language related to autism, and the impact they felt negative language had, was also a theme discussed by adults.

The guidance for professionals about protocols for autism diagnosis has highlighted the importance of empathy and clarity when communicating diagnosis to CYP and their parents (NCC-WCH, 2011). Furthermore, evidence from parents (Moore *et al*., 1999; Siklos and Kerns, 2007) and CYP (Forrest-Keenan *et al*., 2009; Taylor *et al.*, 2010) suggests that while this is important, it is also an element of practice about which professionals lack skills and confidence (Nissenbaum, Tollefson and Reese, 2002). Across the evidence from CYP with diagnoses other than autism, adults with autism, parents of CYP with autism and professionals, the perspectives shared were consistent in highlighting the importance of a positive focus when explaining a diagnosis (Bartolo, 2002; Nissenbaum, Tollefson and Reese, 2002; Brogan and Knussen, 2003). The professional's manner and quality of information was also identified to be important (Nissenbaum, Tollefson and Reese, 2002; Brogan and Knussen, 2003; Harnett and Tierney, 2009). There was also evidence that views about a diagnosis might differ over time, and that the information that participants felt was useful to support their understanding might also need to differ; therefore, providing information in greater depth, as individuals move forward beyond the point of disclosure, was advocated.

Previous researchers have explored perspectives related to learning about a diagnosis using a range of methods, however, qualitative methodologies, especially interviews, have been used most frequently across participant groups. The largest studies had gained views from parents using postal questionnaires. Although four small-scale qualitative studies have explored CYP's views about autism and identity, only one of the studies reported on children's perspectives on how they learnt about their autism diagnosis, the participants explanations were focussed on when this happened, some identifying a delay, rather than how it was explained (Huws and Jones, 2008). Therefore, a lack of research information relating to the views of CYP about how they learnt about their diagnosis was identified (NCC-WCH, 2011). Furthermore, while the views of adults with autism are useful to aid understanding of the experience of being given an autism diagnosis, there are differences in the focus of the perceptions shared by CYP with autism in the small number of existing papers. Therefore, further evidence specifically exploring children's experiences of receiving an autism diagnosis was identified to be an especially important focus for research.

In summary, the 2012 'scoping review' highlighted the importance of exploring the perspectives of CYP about learning about an autism diagnosis. It also pointed to parents and professionals as key stakeholders who would also be able to inform this topic. As parents and professionals were the key people identified to be involved in telling children about the diagnosis, parents were also most likely to experience the disclosure of an autism diagnosis alongside CYP. Evidence from adults with autism also indicated that they could be eloquent in sharing their perspectives through written methods such as autobiographies and online methods such as blogs.

The review also highlighted that across previous research from other participant groups, researchers explored topics related to participants' experiences before their diagnosis, when finding out about the diagnosis, and upon the changes that participants experienced following diagnosis. The impact that the diagnosis had on the individual and the support they received was also a topic that was found to be useful to explore. Furthermore, across the papers identified by the review, a range of theoretical concepts were discussed, including self-views relating to self-efficacy and the impact this had on identity; perceptions of autism within society and how these are constructed were also popular topics of discussion, including who has the power to influence and construct them. The papers also explored how societal views influence the self-perceptions of people with autism, and the agency they experience in relation to issues related to their diagnosis. Therefore, these concepts will be explored next, before presenting the research questions.

2.7 Concepts of importance: understanding the impact of diagnosis

The language of health, psychology and psychiatry has dominated research related to autism. However, despite progress in understanding the biology of autism, there is currently no biologically based medical test which can support diagnosis. Identification of autism therefore involves psychiatric diagnosis based on agreed diagnostic criteria, general observations, and specific observations of individual performance on psychological assessments (Jacob *et al*., 2019). As a result, research related to diagnosis often incorporates terminology related to human development and abstract concepts related to psychological constructs (such as intelligence and self-efficacy), which are based on shared understanding of developmental norms and human psychological traits that can be measured (Oravecz *et al*., 2015). Key concepts, which occur in several studies, are considered next to clarify their meaning in preparation for the literature review; these include identity and self-efficacy.

2.7.1 Self-efficacy

Bandura (1977) identified self-efficacy as a concept that describes an individual's belief that they can achieve specific goals or attainments. Self-efficacy is not a global trait, as each person has areas of comparative strengths and weaknesses, but a belief system that is linked to different areas of functioning (Bandura, 2007). While self-esteem is concerned with self-worth, self-efficacy is a view about one's capability. Self-efficacy therefore has a central role in human functioning, as it influences people to align goals and aspirations with relevant outcome expectations, based upon their perceived abilities and limitations (Bandura, 1997). Efficacy also influences whether we think optimistically or pessimistically, as such, self-efficacy as a belief system will be intrinsically linked to self-identify.

Individuals with higher levels of self-efficacy are more likely to take the initiative, while those with lower levels of perceived efficacy can lack the confidence required to initiate action (Flamer, 2001). Therefore, Bandura (1977) applied the term self-efficacy to the inter-relationship between an individual's perceived efficacy and their level of agency. Sen (1985) highlighted individual agency as being the combined result of the level of personal liberty afforded to individuals, alongside their intrinsic motivation. This notion of agency, however, recognises that it is not possible to separate these concepts, they are intertwined and inseparable. Personal liberty will therefore influence levels of self-determination and motivation. Research has shown that there is also a link between higher levels of self-efficacy and high levels of self-esteem and general wellbeing (Bandura, 1997; Flammer, 2001). As a result, Flammer (2001) emphasises the importance of protecting children from feelings of hopelessness by encouraging them to recall successes, to influence a positive self-efficacy.

Bandura (2001) also highlighted that self-efficacy has an influencing role on habits that can enhance or impair wellbeing. Higher levels of self-efficacy were shown to increase resilience against depression in research by Maciejewski *et al*. (2000). Bandura (2006) has emphasised that self-efficacy is so important because the impact is wide-ranging, for example, influencing emotional tendencies, ambitions, and hopes. However, of greatest pertinence to this study, is the impact that self-efficacy can have on individuals' 'perceptions of impediments' and social opportunities (Bandura, 2006, p.309). Although studies exploring self-efficacy in autism are few, research by Shattuck *et al.* (2014, p.4) found that almost one-third of college students with autism perceived themselves to have neither a special need nor a disability. Lorenz and Heinitz (2014) compared working adults with AS to a group with no diagnosis, they found the AS group had lower self-efficacy in relation to both their views about their occupation and their self-efficacy overall. An association has therefore been shown between identity, self-efficacy and the resulting opportunities for success (e.g., Erikson, 1968; Bandura,1997; Zarrett. and Eccles, 2006; Shattuck *et al.*, 2014).

Holland *et al.* (1998) suggested that identity is formed by both the individual's view of self and the perceptions of others. The construction of individual identity has been identified as both a highly complex and highly social process, in which self-efficacy and other self-views, shape identity through their definite relationships to others' views (Mishler, 1999). Therefore, as suggested by Davidson and Orsini (2013) discourses that construct autism can disable the self-view by focussing on negative perceptions or enable by constructing a positive view of autism. Therefore, regardless of the direction of the narrative, it is the dominant construct that has the potential to influence the self-efficacy of CYP with autism.

2.7.2 Identity

Erikson's (1963) identity theory is a model of life-long, typical human development, which identifies sameness and continuity as key elements in the formation of identity (Friedman, 1999). Erikson (1968) recognised that the identity crisis, which many of his patients experienced, occurred when they no longer felt they belonged or had a sense of what the future held for them. Erikson (1968) suggested the sense of identity is amassed gradually through interaction with others, from feedback related to these interactions and the thought processes that take place in response to social experiences. Despite the recognised differences in social understanding, people with autism are also impacted by social experiences. Baines' (2012, p. 547) research, for example, explored the views of people with autism, it highlighted that those who participated felt that being viewed as ‘autistic’ had a negative impact on others’ perceptions, which resulted in acts of social positioning to distance themselves from the autistic label.

2.7.3 Autism, disability and identity

Within relevant legislation, autism is recognised as a disability, as such, it is a protected characteristic in both international agreements and national legislation (*Human Rights Act 1998;* United Nations 2006, *Conventions on the rights of people with disabilities*; *Equality Act 2010*). When considering the ‘disablement process’, Verbrugge and Jutte (1994, p. 3) described disablement as the impact of ‘acute conditions’ on the ability to act within society in ‘personally desired ways’. Kapp *et al*. (2013), however, highlighted that disability is a culturally created concept, and also emphasised that disability is a concept that does not exist in all cultures. Navajo people, they explained, do not have a word for disability. Such concepts relate to the medical and social models of disability, which have been debated in disability studies for some time. Scullion (2010, p. 699), for example, explained that the medical model identifies the cause to be within the individual, due to impairments of bodily systems, in a way that is like illness. However, he also highlights that despite being a model that has persisted; the medical model has few advocates. When considering the inclusion of children with identified disabilities within mainstream education, Cooper and Jacobs (2011, p. 6) described the actuality of the practice as being so misleading, due to lack of training and preparation for inclusion, that it was actually an “*…insidious form of exclusion*”. Terzi

(2010) also highlighted similar tensions and incoherence between policy and the practices in place.

2.8 Theories of knowledge and conceptualising autism

Knowing how current understandings of autism have developed, and how they are experienced in practice, is important when exploring what might influence young people's understanding of the diagnosis. Theories of knowledge are embedded within a theoretical perspective and are informed by three key elements: the knower, the known and the processes of knowing (Genova, 1983). The concept of reality has been central to philosophical thinking; Descartes famously wrote 'I think therefore I am' (Voorhoeve *et al*., 2011, p.134). It is how children with autism can be supported to understand autism that is central to this study, therefore the way that knowledge of autism is constructed will influence what each child with autism thinks an autism diagnosis means for themselves.

2.8.1 Constructing and knowing self

Foucault's writings on human perception and the social world suggests that many things do not actually exist unless we discuss and describe them (Pitsoe and Letseka, 2013). This process of knowing the self, Foucault (1977) believed, was shaped through discourse-based knowledge, which is influenced socially through our insouciant acceptance of the reality that is presented through discourse (Pitsoe and Letseka, 2013). Foucault (1977) identified discourse as that which is said and thought, but also that which is shaped by power relationships related to who can speak, when they can speak, and with what authority. As such, discourse has a central role in the social construction of knowledge, and thus in the development of knowledge about autism (First *et al*., 2004; Verhoeff, 2013).

However, Foucault (1982, p.778) also highlighted that power relationships operate in highly complex ways. Foucault (1982) argued that the political rationality for actions was important, as sometimes what can seem to be merely banal ideas can be used with the power that authority brings to significant effect. Foucault (1982, p.779) also warned that we should not wait for bureaucracy or for significant examples, such as concentration camps, but should continually strive to identify the existence and impact of such relations. Furthermore, Foucault (1982, p.779) highlights that analysing forms of resistance can help to highlight the locus of power and how that power is applied. Disability rights and autism advocacy activists have highlighted such issues in relation to disability of all forms (e.g. Oliver, 1990; 1996; Shakespeare, 1996; 2002) and autism specifically (e.g. Bagatell, 2003; 2007).

Foucault (1982) considered the influence and power of the medical profession to be important, highlighting that it can exercise great control over people's lives, their health and death. The involvement of organising bodies such as the medical profession, he argueed, acknowledge the right to be different, yet they highlight and seek to normalise that which marks out the individual, thus compromising individuality and constraining identity. Tremain (2015, p.19) highlighted that a crucial element of Foucault's view of power is that it is most productive when it enables subjects to act in order to constrain them. Bio-power, Tremain (2015, pp. 40-41) argues, is significant in relation to disability, as it is concerned especially with human health, through new technologies that enabled measurement, identification (or diagnosis) and tracking of health-related issues from birth through to death. These measurements, Foucault (1974, p.144) argued, enabled the norm to be established. Foucault's (2008, pp. 304-308) concept of bio-power, is useful in describing the way that policy and practices have created, coded and controlled differences, which it is argued has resulted in the objectification of a range of differences (Rogers *et al*., 2003). This idea was extended by Hacking (1999) to include psychological concepts including autism.

In relation to autism, Mullen (2015, p.4) has argued that paying attention to discourse, as advocated by Foucault, is important to understand the cultural and institutional context in which autism is influenced. Maynard and Turowetz (2019, p.94) suggested that there is a narrative inherent in the way that an autism diagnosis is explored and given by physicians. The diagnosis is based on the criteria designed by powerful bodies within the medical profession, such as the ICD and DSM (WHO, 1992; 2018; APA, 2000, 2013). However, Maynard and Turowetz (2019) also highlighted that autism diagnosis is interactive, involving others as part of the assessment process, through the stories that they share to inform the assessed. The success of a diagnosis is therefore dependent on the success of this interactional process, in which factors related to the diagnostic criteria are discussed. Professionals and parents who are involved in the assessment share knowledge about the individual in relation to social expectations beyond the assessment process. Maynard and Turowetz (2019) highlighted that narrative is the tool that physicians use to present the assessment outcome, weaving the stories that parents and others have shared, with the requirements of the diagnostic criteria. Therefore, they emphasised that autism becomes characterised through these symptomatic narratives, as well as through the diagnostic criteria (Maynard and Turowetz, 2019, p.93). Fisher and Goodley (2007) and Farrugia (2009, p.1013) have also highlighted that parents employ medically-based discourse to reduce the stigma associated with having a child with autism, which emphasises that although the child is 'not normal', their individuality is valued rather than inferior. The discourse that parents and professionals engage in, related to a CYP's assessment and diagnosis of autism, therefore relates to Foucault's (1990, p.144) concept of 'bio-power'. Foucault (1990, p. 141) highlights that these psychological technologies are "…methods of bio-power capable of optimizing forces, aptitudes, and life in general." Bio-power therefore describes the mechanisms by which a subject is created, through discourse linked with the technologies that identify or objectify individuals (Foucault 1982, p. 792); in relation to autism these technologies might include diagnostic criteria such as ICD and DSM (WHO, 1992; 2018; APA, 2000, 2013). Butler (1993), however, suggested that agency can also be actualised through these discursive acts, in resistance to the power dynamics that create a subject. Such resistance has been identified above, for example, by the agency related to the autism diagnosis and the 'Aspie identity' that individuals in the study by Giles (2013, p.179) advocated, or the identity-first resistance suggested by Sinclair (1999). Bio-power and discourse can therefore be recognised as powerful mechanisms through which understanding of diagnoses, such as autism, are developed.

Coming to understand an autism diagnosis is therefore identified to be a complex process involving other people; it is social and will involve discourses that are shaped by culture, state and science, especially medical science. The terminology related to autism influences the discourse that individuals encounter in their social encounters, which can become internalised and impact self-views (Bagatell, 2007). As Foucault (1977) emphasised, identity is impacted by powerful organisations and individuals, such as national and international organisations that make decisions about what constitutes a medical condition and by those clinicians with the power to give a diagnosis. The scoping review, identified the impact that decisions about the diagnostic criteria had on individuals with autism (e.g. Nissenbaum, Tollefson and Reese, 2002; Armstrong, 2011; Davide-Rivera, 2012; Robison, 2012; Case, 2013), as well as the impact of those who make the diagnosis (for example, a lack of professional expertise and empathy in discussing the diagnosis with parents was identified in the studies by Moore *et al*. (1999); Kerrell (2001); Nissenbaum, Tollefson and Reese (2002); Siklos and Kerns (2007); Osborne and Reed (2008). However, other social interactions were also of influence in the construction of identity, including those within the family and with peers (as discussed, for example, in the studies by Cousins, 2001; Molloy and Vasil, 2004; Huws and Jones, 2008; Baines, 2012). Through social experiences and institutional cultures, dominant views are imposed, which can be considered as political and cultural constructions rather than personal ones (Holland et al., 1998), as has been suggested in relation to the medically influenced construct of autism (e.g., Armstrong, 2011; Davide-Rivera, 2012; Robison, 2012; Case, 2013).

Bourdieu (1993) also identified the influences at both the institutional level and the societal level that have the potential to influence self-views. Bourdieu (1993), however, employs concepts drawn from his interest in rugby, through concepts such as fields, games, as well as habitus, and capital, to explain how social experiences and institutional pressures interact to shape the discourses and everyday practices that influence and shape thinking. The ‘game’, he suggests, involves a struggle for powerful positions in the field, which are reinforced through participation. ‘Fields’ in which these games are played are not fixed but responsive to the game and to the other fields that interact with it. ‘Habitus’ describes beliefs, values, tastes, and predispositions; therefore, each player and field will generate its own habitus. Finally, ‘capital’ refers to interrelated forms of power, including financial, social, and cultural capital (symbolic, educational, scientific, and linguistic), an individual’s capital is not fixed but is related to the field in which they are taking part. Bourdieu’s (1993) concepts recognised that an individual’s views will be framed by gender, class, age, culture, social and institutional experiences, which frame personal expectations of what is possible, thus shaping self-efficacy. Therefore, habitus is a central concept shaping human actions, which is similar to grammatical structures within language (Bourdieu 1984). Like Bandura’s (1997) self-efficacy, at the individual level, Bourdieu’s habitus is the internalised remains of every encounter experienced within the social world. Shakespeare (1996) suggested that a social constructivist view of disability as a negative identity, is influenced through socialisation and inscribed by institutional structures. However, Shakespeare (1996) also highlights that because identity is constructed through the complex connections between personal, cultural, and political experiences, a more positive identity can be forged by positioning within the larger disability community, and by coming together to resist the dominant discourse.

2.8.2 Autism, disability and concepts of influence

As suggested above, CYP’s perception of their autism diagnosis will be influenced by language related to autism, and by the way in which language is used to portray the views and attitudes of the society in which they live. Understanding of autism has developed through psychological and medical research, which has informed the list of human traits understood to identify an autism diagnosis (Tantam, 2013). Medical science has therefore had a significant influence on the development of concepts related to autism and disability (Ryan and Thomas, 1987; Wilson and Beresford, 2002). Although there is variation in presentation of autism, many people with autism in England and Wales meet the legal definition and are recognised to have a disability (*Equality Act, 2010*; National Autistic Society, 2019). The National Autistic Society (2016), an influential source of information about autism in the UK, has described it as a ‘developmental disability’ (National Autistic Society, 2016). Rioux (1994), however, highlighted that society views disability as a deficit, and disabled people as individuals in needs of fixing. Furthermore, Becker (1997) suggested that this view is embedded in society and related to an ideology of the norm. Thompson (1997) also highlighted the role of media and charity campaigns that make disabled people appear pitiable, as important influencing factors. While Scheff (1974) stressed that the impact of disability can be twofold, in creating a negative self-fulfilling prophecy, which in turn influences the perceptions of others. In addition, Lindemann-Nelson (2002) emphasised that it is both bodily representations and how other people react to them that play a part in the formation and maintenance of personhood. Therefore, inability to meet society's expectations for functioning can have a negative impact. If individuals with disabilities are influenced to focus on inabilities, low self-efficacy and lower levels of agency can diminish their future plans (Gray, 2001).

Darling (2003) highlighted that due to societal agents that devalue disability in society, disabled people have tried to hide their disabilities and pass as normal. A similar phenomenon has been described by parents of CYP with disabilities, who have highlighted that they employ a range of strategies to maintain normality, or the appearance of it (Birenbaum, 1970; Voysey, 1975). Research exploring the views of parents of children with autism has emphasised the psychological tensions that parents described experiencing, prior to their child's autism diagnosis, as they simultaneously wish for vindication of their concerns about their child, while also hoping that an impairment will not be identified (Russell and Norwich, 2012).

Due to social influences on views of disability, Siebers (2008) suggested that disability is not a biological or natural phenomenon, but a cultural and minority identity, which is both subject to social control and able to influence social change. Bagatell (2010, p. 33) has also highlighted that a combination of factors, such as increased use of social media and the broadening of autism to a spectrum, have facilitated the growth of an autism self-advocacy movement, which has challenged the established medicalised view of autism. In addition, Davidson and Orsini (2013) suggested that movement towards an enabling narrative is possible by valuing theory informed by those with autism, and by recognising the highly individual presentation of autism, alongside the emergence of autism culture. Such change, it is suggested, could improve the self-view of individuals with autism and enable more positive identities to develop. This would suggest benefit from including individuals with autism within activities linked with the methods of bio-power identified by Foucault (1990), and the fields and games discussed by Bourdieu (1993), such as decisions related to evaluation and change within diagnostic criterion like the ICD and DSM (WHO, 2018; APA, 2013), or with the development of guidelines, such as those about the diagnosis of CYP with autism (NICE, 2011b), as well as within the research that explores the impact of these policies, which might then be drawn on to inform change.

2.8.3 Autism, narratives, and impact of discourse

Early experiences have been shown to significantly impact upon self-identify, therefore the way in which children learn about disability and autism will be impacted by the conversations that they hear. Research by Fivush and Fromhoff (1988) explored mother-child conversations and identified that autobiographical memory influences the way in which individuals define themselves, which has both personal and social value. Nelson (1993) suggested the importance of autographical memory to the views we form of our own history, emphasising the potential influence of others, as we hear about our experiences from them. Research by Hudson (1990), for example, found that when parents discuss events with their child, the details they add influence the self-narratives that children develop. This links with the model of internalisation, which Vygotsky (1934) identified occurs after recounting has taken place. Thus, parents have a crucial role in the development of children's self-efficacy through their recounting of events, which influences the self-narratives that children develop

The NICE (2011b) clinical guidance for autism also identifies a key role for professionals in disclosing the diagnosis to CYP, through discussion of the results of assessment. The guidance states they should explain the outcome "…*sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person*" (NICE, 2011b, p.20). Professionals therefore hold key information about the approach they take when they give the diagnosis, and they also observe the immediate impact on CYP and their parents. Therefore, professionals will also be able to inform research about how children are supported to understand an autism diagnosis and the impact it has upon them.

2.8.4 Autism diagnosis and outcomes

Although research has suggested that early diagnosis and intervention leads to better outcomes (Estes *et al*., 2015), Russell *et al*. (2012) found that the impact of diagnosis was varied, as the diagnosis for one individual might be positive, while for another it is negative. Russell *et al*. (2012) suggested that obtaining a diagnosis might not actually impact positively upon outcomes. Given that this is the main benefit usually suggested for diagnosis, they highlight the need for more research upon the impact of a diagnosis upon functioning.

However, Whitaker (2006) highlighted a key benefit of sharing a diagnosis with a child was that it helps them to make sense of their experiences. Whitaker (2006) also acknowledged potential issues, such as the continuing debate about the diagnostic criterion and terminology. The ‘autistic way of thinking’ was also identified as a significant challenge (Whitaker, 2006, p. 127). However, many of the topics highlighted to be important in the academic and research literature are mirrored in the perceptions revealed by the experts in the lived experience of autism (e.g., Mukhopadhay, 2000; Barron and Barron, 2002; Armstrong, 2011), which emphasises the potential benefit of exploring views of those for whom the diagnosis has greatest significance, the CYP who have undergone the experience and their parents.

Narrative research has already been used successfully to explore experiences of autism diagnosis and has highlighted some common themes in the accounts explored (e.g., Jones, 2001; Huws and Jones, 2008; Ashby and Causton-Theoharis, 2009). Prentice (2014) used narrative analysis to explore a small number of published personal accounts (Armstrong, 2011; Autism Education Trust, 2012), finding similar themes to those identified by Ashby and Causton-Theoharis (2009). When first exploring the accounts, they seemed to be positive accounts by confident young people with autism (Prentice, 2014). However, further in-depth analysis identified negative elements in the participants’ descriptions of themselves and their experiences, which appear to have been influenced by the medical view of disability (Oliver, 1996). Like the findings of Whitaker (2006), the analysis highlighted the influence of medically focussed language, which the young people employed to describe autism and their related traits (Prentice, 2014). As suggested by Thompson (1997), such diagnostic experiences can shake the developing view of self and have the potential to negatively influence self-efficacy. The accounts, however, also described positive experiences that suggest the possibility of good outcomes, as greater resilience was fostered when discussion of the diagnosis focussed on CYP's abilities and achievements. Furthermore, the participants highlighted that a diagnosis can bring benefits, such as access to services and specific forms of intervention. The most significant positive impact appeared to stem from others understanding of the autism diagnosis, which led to adjustments being made (Prentice, 2014). As identified by Fernell, Ericksson and Gillberg (2013), once families, educators and other relevant people in the young people's lives knew about the autism diagnosis, they were able to draw upon this understanding to create autism-friendly environments to support them (Prentice, 2014).

2.9 Disability: perception and influences

Stark theoretical contrasts have been drawn about the influences upon an individual's view of disability, including the potential for normalisation through recognition of an alternative, affirmative disability culture (Darling, 2003). The philosophy of 'normalisation' has influenced the development of services, which have strived to do this by overcoming segregation and institutionalisation within education and care. Darling (2003) highlights that this has been pursued with a crusade like commitment, which has led to a reluctance to question or criticise, and therefore enabled it to significantly impact upon education and care throughout Europe and the USA. Therefore, this institutionally driven aim for total inclusion, with a philosophy underpinned by acceptance of the social model, could be considered to have been a significant influence upon the maintenance of negative perceptions of disability through the strive for normalisation. The social model has also been criticised for not considering the differences of the wide range of people labelled as disabled (Morris, 1996; Corker and Shakespeare, 2002). It has been argued that by focussing on socially imposed disability, the range of disabled people's experiences are not considered (Thomas, 2007). Crow (1996, p.209) highlighted, for example, that impairment might cause pain which can disrupt an individual's ability to engage with the world, however, even if the barriers erected by society were removed, the underlying issues relating to the impairment would remain.

WHO (2002) highlighted that the *International Classification of Functioning, Disability and Health* (ICF) aimed to reconceptualise health and disability by recognising that anyone can experience health problems, and potentially a degree of disability. It also changed the focus from the cause to the impact of health and disability, acknowledged social influences and emphasised the importance of moving beyond disability as a medical or biological dysfunction, and towards contextualised understandings. In so doing, disability is described as a 'bio-psychosocial model' of functioning (WHO, 2002, p.9). While this model has been viewed positively (Shakespeare, 2004), it has not proved satisfactory for all and could be considered as another concept imposed upon people with impairments by the 'experts' (Goodhall, 1995, p. 324). Swain and French (2000) proposed that an affirmative view of disability is developing because the individual and collective experiences of disabled people were being increasingly heard. Such a model, they suggested, confronts the personal tragedy models of disability and impairment, and could be further developed, influenced, and owned by disabled people.

Bourdieu (1987, p.170) described habitus as a social agent, comprising a ‘structuring structure’ that is influenced by one’s past and present experiences, which in turn influence present and future practices. Bourdieu’s (1987) sociologically founded philosophical perspective upon inequality has been criticised for being both obtuse and complex. However, it has also been considered to be very practical in making sense of the relationships between institutional ideologies and the potential impact of their practices (Webb, Schirato, and Danaher, 2002). Bourdieu (1988, p. 64), for example, summarised the diagnostic process while graphically identifying the power imbalance that exists as the expert within the:

> … dissymmetrical social relationship […] is able to impose his own cognitive presuppositions on the indices delivered by the patient, without having to worry about any discrepancy between the tacit assumptions of the patient and his own explicit or implicit assumptions about clinical signs which might generate misunderstandings.

Foucault (1977; 1990) conceptualised this power dynamic as bio-power, which is also linked with who holds the authority within such situations and in relation to the discourses that take place in relation to it. However, it is Sen, the economist, who argued that inequality is not just about capital. Power, Sen (2003) suggested, is related to capability, freedom, agency and individual vulnerability, and to the ‘actual lives’ people can live (Sen, 2009, p. 27). Inequalities of gender, race and disability are fundamental to Sen’s functioning and capabilities. Sen (2009) further argued that it is capability failures that hinder the ability to act freely, because of the power of others, which should be warranted special urgency in the cause of social justice. Therefore, the power of the medical specialist to ‘impose’ an autism diagnosis upon their patient could be considered as one of Sen’s (2009) causes for social justice. Power struggles in relation to autism diagnosis are evident in the narratives of parents, who discussed their experiences of the diagnostic process as they attempt to have their child’s needs recognised and met (e.g., Avdi, Griffin and Brough, 2000; Slator, 2012). Although professionals hold the power to diagnose autism, their lack of understanding of autism, which is identified by both parents (e.g., Midence and O’Neill, 1999; Avdi, Griffin and Brough, 2000) and by professionals (e.g. Nissenbaum, Tollefson and Reese, 2000; Bartolo, 2002; Finke, Drager & Ash, 2010), could lead to both the misunderstandings described by Bourdieu (1988), and to the feelings of social injustice discussed by Sen (2010). Furthermore, a similar power imbalance has been identified by CYP, for example, in a study by Mogensen and Mason (2015), CYP described the diagnosis as oppressive. Yet CYP in the study by Huws and Jones (2008) revealed distress when their parents withheld the diagnosis from them. Therefore, as suggested by Baines (2012), CYP are not isolated from the sociocultural influences in relation to autism diagnosis and these social dynamics hold the potential to impact on their self-views and identity.

2.9.1 Understanding, disability and autism: implications for researchers

Due to the complexities involved in understanding the processes and experiences involved in coming to understand an autism diagnosis, an approach that recognises these complexities is crucial (Guba and Lincoln, 1989; Pease, 2010). As evidenced above, much of the research that has aimed to understand these complex social, cultural and policy driven processes, has been qualitative narrative research. However, while it is recognised that such studies can be useful, the review of evidence by the National Collaborating Council for Women's and Children's health (NCC-WCH, 2011) suggests a key limitation is that the quality of evidence is low because such studies are uncontrolled. Furthermore, as evidence is often related to specific contexts and approaches, it can be difficult to apply findings more broadly, as these contexts might not be reproduced widely (NCC-WCH, 2011). Empiricist researchers hold the view that knowledge should be generated by observable experience and scientific experiments rather than theory. However, Darlaston-Jones (2007) has suggested that these empiricist assumptions fail to take account of the human drive to understand and make sense of the world. The drive to interpret and to make sense of an autism diagnosis is evident in the accounts of parents who have experienced the diagnosis of a child (Beatson and Prelock, 2002; Nissenbaum, Tollefson and Reese, 2002; Russell and Norwich, 2012). Furthermore, it is increasingly being argued that both quantitative and qualitative approaches are equally important research methodologies (Creswell and Tashakkori, 2007). McEvoy and Richards (2006), for example, suggested that critical realism offers an alternative perspective that can underpin both qualitative and quantitative approaches. As emphasised by Bhaskar (1975), critical realists believe that scientifically observable knowledge about the world can provide a point of reference, against which theory can be tested. However, a critical realist perspective also recognises that because perceptions of reality are shaped by the discourses experienced, it is impossible to fully understand this reality. Nevertheless, it is possible to gain empirical feedback from concepts that are definable (Sayer, 2004), such as self-efficacy (Bandura, 2007).

Therefore, critical realism recognises there are many potential influences on individuals' perceptions, such as factors related to bio-power, as identified by Foucault (1990), or habitus as a structuring structure described by Bourdieu (1987), which can influence freedoms, vulnerabilities, and the actual lives that people can live (Sen, 2009). The critical realist perspective, however, recognises it is not possible to control and measure all variables empirically. Due to the wide range of factors that influence experiences of autism diagnosis, such as: the range of the spectrum (Ghaziuddin, 2010; Ozonoff *et al*., 2010); the changing diagnostic criteria (APA 2000; 2013; WHO 2010; 2013); and the different ways in which diagnostic criteria and descriptions are applied (Toth and King, 2008), controlling all variables is especially difficult. Furthermore, individual differences such as levels of agency, which are the result of intertwined experiences of self-determination alongside intrinsic motivation (Sen, 1985), can influence self-efficacy. This, in turn, shapes outlooks and behaviours that can both enhance health or impair development (Bandura, 2001). Although earlier diagnosis is possible, most children are still diagnosed after 3 years of age (Goin-Kochel, Mackintosh and Meyers, 2006; Valicenti-McDermott *et al*., 2012). Therefore, by the time an autism diagnosis is made, levels of self-efficacy will already have been shaped through the developmental sequence of stages and experiences (Flammer, 2001). Even if it were possible to control for such factors, as well as being ethically inappropriate, by the time autism is suspected, it would be too late to control potential variables. Therefore, while it might be possible to empirically measure factors such as self-efficacy, to explore the impact of diagnosis, it is only when combined with qualitative information, such as narrative accounts, that it will be possible to understand the richer details of the meaningful experiences, influencing perspectives and processes (Denzin, 2012).

2.9.2 Perceptions of autism: power and agency

The United Nations (1989) *Convention on the rights of the child (UNCRC) (Article 12: Views of the child*) emphasised that children have a right to be heard and to have their views considered seriously. As a result, recent decades have witnessed a growing imperative to listen to CYP, including children with disabilities. Although the UNCRC has not been incorporated into national law within the United Kingdom, in current statutory guidance, a commitment has been made to pay due regard to the Convention, by emphasising the importance of listening to children (Department for Education and Department of Health, 2015, p.1).

Advocates of the social model suggest disability is caused through restrictions imposed by a society, which does not consider the needs of people who have impairments, thereby excluding individuals from social activities (Union of Physically Impaired Against Segregation, 1976). Bagatell (2003, pp. 9-10) has emphasised that the identities of people with autism are not inherent elements awaiting recognition, they are constructed through their interactions within society. Shakespeare (1996) suggested that rather than allowing the traditional medical narrative, involving concepts such as intervention, rehabilitation, decline and disability, to shape the identity of people with impairments, by exerting agency and taking part within these processes, a more positive self-identity could be constructed. While the language of disability and impairment can have a negative impact, Baines (2012) highlighted that CYP with autism are not isolated from social and cultural experiences that influence identity, therefore, they can shape their own identity and advance a positive perception of themselves, especially when it is their needs that are being explored (Cromby, Harper and Reavey, 2013).

2.10 Conclusion

Acknowledging the views of people with autism, and ensuring they are at the centre of the research process, has been suggested to be essential to understand diagnostic experiences (e.g., Whitaker, 2006; Waltz, 2014; Woods *et al*., 2018). This will enable the impact of diagnostic experiences related to bio-power (Foucault, 1990), such as the measurement and identification of autism, and the structuring structure (Bourdieu, 1987) of the diagnostic pathways to be understood, to highlight whether diagnosis has a positive impact, or as Sen (2009) suggested, this creates vulnerabilities and constrains the freedoms of CYP with autism and their parents. The critical realist perspective adopted does, however, recognise that although it is not possible to understand, control and measure all variables (Bhaskar, 1975), by paying greater attention to the perspectives of CYP with autism, to their parents, and professionals involved in autism diagnosis, it will be possible to begin to understand the complexities of experience within the diagnostic system, and to understand what might influence CYP’s views positively and negatively (NICE, 2011b). Such information could be used to inform future practices related to support offered during the diagnostic procedures and after diagnosis, to maximise the positive aspects and to minimise the negative, so improving outcomes. Therefore, a critical realist approach was chosen to underpin the study, as it recognises both the existence of reality and the importance of discourses, such as those highlighted by Foucault (1982, 1990), and the structures and processes that create them, as identified by Bourdieu (1993). Critical realism recognises that experiences of this reality will be shaped through discourse and interactions within the social context in which it was experienced. Therefore, as suggested by Waltz (2014, p. 1337) in addition to exploring the perceptions of those involved in the research, the criticality will come from considering these views against the 'power dynamics' that influence discussion and definition of autism, and by exploring the way in which this might produce, or reduce, the potentially disabling impact of diagnosis.

2.11 Research questions

After considering the gaps in the knowledge base and key concepts identified through the initial scoping review, the research questions that this study sought to explore when commencing the research in 2012 were:

1. What are young people's experiences and views of an autism diagnosis?
2. How do parents and professionals discuss the diagnosis with young people on the autism spectrum?
3. What factors influence young people's understanding of an autism diagnosis and how does this impact their view of self?

4. How do experiences prior to diagnosis, and when finding out about the diagnosis, impact children and young people’s views after they are told about an autism diagnosis?

Chapter Three presents the systematic review undertaken in 2019, as during the period between the initial review in 2012 and 2019, the amount of literature increased to enable a more thorough review to be undertaken.

CHAPTER 3 SYSTEMATIC LITERATURE REVIEW

3.1 Introduction

The main aim of this systematic review is to explore existing evidence about the experiences of children and young people (CYP) on the autism spectrum in relation to their autism diagnosis. A lack of evidence has previously been identified about good practice to support CYP with autism to understand their diagnosis (NCC-WCH, 2011), especially evidence drawn from the views of CYP about both the diagnosis and the support they have received to understand autism. This literature review explores, systematically, the existing research related to experiences of autism diagnosis, and coming to know about the diagnosis from the perspective of the key stakeholders: CYP with autism, their parents, and the professionals who work these CYP in capacities related to the diagnosis. As highlighted by Meerpohl *et al*. (2012, p.1), approaches that synthesise research have a long history and are recognised within evidence-based research, as they can provide a comprehensive overview, while also identifying gaps that require additional exploration. This systematic review of the literature was undertaken in October 2019 and focussed on the three key stakeholders involved in childhood diagnosis, whose views have also been explored within the empirical part of the research study: CYP with an autism diagnosis, parents of CYP with and autism diagnosis, and professionals involved in the diagnostic process and the support that follows it.

3.2 The approach for the systematic review

The review was conducted in accordance the preferred reporting items of systematic reviews and meta-analyses (PRISMA) protocol (Moher *et al*., 2009). The aim was to ensure that all recent and relevant research, which might support understanding of children's experiences, had been incorporated into the final draft of the literature review. Gough, Oliver and Thomas (2018, p.3) have highlighted several reasons why reviews are so important. However, the main reason they identified is that any study may be fallible, due to the design or procedures used, studies may also have only limited relevance due to the focus of the research aims. Therefore, it is highlighted that systematic reviews provide a more thorough and critical overview of a topic than any single study can provide. However, it is also emphasised that as reviews might inform decisions that impact people's lives, they should be conducted with care. Therefore, Gough, Oliver and Thomas (2018, p.5) suggested the aims of a systematic review should be explicit and rigorous, and that the methods used for the synthesis of findings should also be clear. The 2012 broad scoping type of review discussed in Chapter 2 aimed to broadly explore the literature and topics that might inform understanding of receiving an autism diagnosis at that time. However, as suggested by Gough, Oliver and Thomas (2018, p.47), in this late stage of the research process, the focus of the systematic review was narrowed to tightly focus on the research questions. Gough, Oliver and Thomas (2018) also highlight that it can be useful if several syntheses are undertaken of findings before they are combined, this approach was undertaken for this review by synthesising the views across papers for each of the key stakeholders, before synthesising the findings across the key stakeholders.

The approach taken for this systematic literature review was a thematic synthesis, which, Gough, Oliver and Thomas (2018) suggested can enable any type of methodology to be included within the review, meaning the researcher is not required to make a judgement about the type of knowledge that the review will explore. As a critical realist and mixed methods approach had been undertaken for the research study, a thematic synthesis was most closely aligned to the research paradigm employed within the empirical element of the research. Critical realism is a theory of science that accepts that there is a real world that is independent of the researcher's view of it, but that our understanding of this world is influenced by discourses related to it, and to experiences of it (Sayer, 2004, p. 6). The critical realist and mixed methods approach to the empirical study is explored more fully in the next chapter. However, as Gough, Oliver and Thomas (2018, p.190) have explained, a review that employs thematic synthesis will develop theory from open questions and may also identify a few initial concepts of importance to explore. The theoretical framework, they emphasised, will emerge from the analysis, however, no statistical claims are made as the aim of a thematic synthesis is to develop understanding of a phenomenon, which might lead to theory being developed and to further research. As suggested by the name, within thematic syntheses, themes are identified, explored and applied across studies; these themes might have been identified within the research papers being explored, or from the analysis of them. This approach was identified as the most appropriate, as it complements the critical realist approach adopted across the research and provided a stronger evidence basis against which the findings from the empirical study could be considered.

3.2.1 Rationale for the systematic review

The scoping review, undertaken in 2012, identified only a small number of studies specifically focussed on how CYP learn about and come to understand an autism diagnosis. While there was a body of evidence exploring parents’ views, there were no studies that had explored their experiences of discussing autism with their child. However, between 2012 and 2019, it was apparent that interest in these two topics was increasing, as further research had been published that discussed these specific themes from the perspective of CYP with autism, parents of CYP with autism and the professionals involved in both the diagnostic process and the support that might follow it. Therefore, to ensure that the thesis was fully informed by previous research, it was felt important to undertake a further systematic review to ensure that all the previous research, related specifically to the research questions, had been considered. Gough, Oliver and Thomas (2018, p.3) have highlighted the usefulness of systematic reviews when ‘interpreting the results of a new primary study’, particularly as any one study might be fallible, or have limited relevance due to limitations related to the context or scope. Furthermore, as difficulties with recruitment of survey participants, especially of CYP, was a factor within the empirical study, it was crucial to draw together all the existing data, to learn as much as possible and to facilitate analysis of the study findings against the synthesis of the existing evidence base. As Gough, Oliver and

Thomas (2018, p.3) have also highlighted, this provides a stronger and more comprehensive understanding, based on many studies and contexts, than can be provided by any individual study.

Systematic reviews also have limitations, for example, current systematic review protocols (e.g. Gough, Oliver and Thomas, 2018) do not guide upon inclusion of potentially useful information from grey literature (Mahood, Van Eerd and Irvin, 2014). Furthermore, it has been highlighted that the very nature of grey literature makes it more difficult to search for, alongside peer reviewed commercially available literature (Tillett and Newbold, 2006). To understand why grey literature searches can be difficult to carry out systematically, Tillett and Newbold (2006, p. 70) suggested that grey literature is better understood in terms of characteristics, for example, literature that is not peer reviewed and not produced by commercial publishers, such as that produced by governments, think tanks, universities, and charitable organisations. When considering autism diagnosis, this might include policy documents, PhD theses, surveys produce by autism charities, and the autobiographical writings of individuals with autism. It has been highlighted that inclusion of the grey literature can enrich a review by reducing publication bias and addressing stakeholder concerns (Mahood, Van Eerd and Irvin, 2014, p. 230). However, Mahood, Van Eerd and Irvin (2014, p. 229) also identified several significant challenges, such as the great number of potential sources of grey literature, with different interfaces and features, which mean searches can be difficult to replicate systematically. Furthermore, a challenge identified that was specifically pertinent to this study, was that the high number of potential grey literature sources, which such searches produce, can make grey literature searches so complex to undertake systematically, that they require a review team to make it possible. For example, Mahood, Van Eerd and Irvin (2014, pp. 229) found that even with a review team, the time required was considerable and that it was problematic for the team in judging relevancy. Therefore, due to limitations in time and resources available in undertaking the 2019 literature search, it was decided that it was most appropriate to undertake a systematic review. However, as universities' repositories and data bases such as EThOS have made PhD and other doctoral studies easier to access, it was possible to include doctoral theses, which have previously been counted within the grey literature (Tillett and Newbold, 2006, p. 71).

However, more important than the pragmatic decision that it was not possible to undertake a scoping review and synthesis that include all relevant grey literature, due to the time and resources identified to be required, the most important factor that informed the decision about the approach to the 2019 literature review was the purpose. Peterson *et al.* (2017, p.12) have highlighted that scoping reviews are traditionally undertaken to explore the emerging evidence related to broad questions and to identify relevant approaches and concepts, therefore they are most useful within the early phase of research. This systematic review was undertaken after the empirical part of the study had been completed, as further research had been published since undertaking the 2012 scoping review. Therefore, a systematic review was identified to be more appropriate at this stage because, as suggested by Gough, Oliver and Thomas (2018, p.3), a systematic review provides understanding of the existing research evidence, which is especially useful when interpreting the results of an empirical study. However, it is acknowledged that the systematic approach reduced the capacity to understand the emergence of broader conceptual factors relevant to the general topic, which might have emerged since 2012, that a scoping review might have revealed (Arksey & O'Malley, 2005). Furthermore, the search was limited to papers written in English, as this is the only language that I can read fluently. This is also a recognised limitation, as relevant and valuable studies written in other languages might have been omitted from the review.

3.2.2 The search protocol and search terms

Following the PRISMA protocol, to ensure a systematic approach, a set of relevant search criteria were identified from the initial exploratory review. The search criteria related to four key elements: autism, diagnostic processes, experiences of diagnosis and the views of the key stakeholders identified. Within each topic, specific criteria were included, for **autism diagnosis**: autism, Asperger syndrome (AS)/Asperger, Autism Spectrum Disorder (ASD), Autism Spectrum Disorder/Condition (ASD/ASC), and High Functioning Autism (HFA). For **autism diagnostic processes**: diagnostic interview, consultation, assessment, and pathway. For **experiences relating to diagnosis**: experiences, views, perceptions and narratives; and **views of the key stakeholders**: child(ren) and young person/people, youth and adolescent, parents-mother/father/carer, professionals-paediatrician, speech and language specialist, teacher, specialist/advisory teacher. The key terms were combined in a systematic way to inform each search (See Appendix 2 for further details of the approach to the systematic review, search terms, inclusion and exclusion criteria and a full list of literature).

3.2.3 Search procedure

The search was undertaken using a comprehensive higher education data base (LibrarySearch), which can search and retrieve documents from all databases relevant to experiences relating to autism diagnosis. The search terms were systematically combined within the electronic database using a combination of keywords and Boolean operators (AND; OR; NOT; *); for example, for the search: autis* AND diagnosis AND child* AND views', a total of 784 articles were identified. The ten databases with most articles included: MEDLINE (156); Academic Search Index (114); Social Sciences Index (99); Complementary Index (92); CINAHL Complete (64); Science Citation Index (56); Education Abstracts (H.W. Wilson) (32); ERIC (29); ScienceDirect (29); Directory of Open Access Journals (21).

3.2.4 Selection procedure

The article titles and abstracts were screened first, those that did not meet the search criteria, as shown in Table 4 below, were discarded.

Table 4 Systematic review: inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Texts were included if they: • were written in English (therefore accessible to the researcher) • were within the date range 1979 to October 2019 • explored the perspectives of children, young people, parents or professionals • explored the following topics ○ CYP's experiences of the autism diagnostic process ○ CYP's experiences of being told about an autism diagnosis or learning about autism ○ CYP's views/perceptions of having autism ○ disclosure of an autism diagnosis ○ approaches to support CYP's understanding their autism diagnosis ○ the impact of an autism diagnosis on CYP	Texts were excluded if they: • were not in English language • were outside of date range 1979 to October 2019 • views/perceptions were not related to the impact upon the child/young person • topic **did not** relate to: ○ CYP's experiences of the autism diagnostic process ○ CYP's experiences of being told about an autism diagnosis or learning about autism ○ CYP's views/perceptions of having autism ○ disclosure of an autism diagnosis ○ approaches to support CYP's understanding their autism diagnosis ○ the impact of an autism diagnosis on CYP

During in-depth reading of the papers for eligibility, papers that met the criteria, identified in Table 4, were retained (See Appendix 2.2 for summary details of all the papers included the systematic searches). Figure 3 below, summarises application of the PRISMA protocol, as applied to the search process employed for review of the literature in 2019.

As shown in Figure 3 below, after removing duplicate studies 159 full text articles were screened, 130 were excluded as they did not meet the criteria, leaving 29 studies that met the criteria across the three key stakeholders.

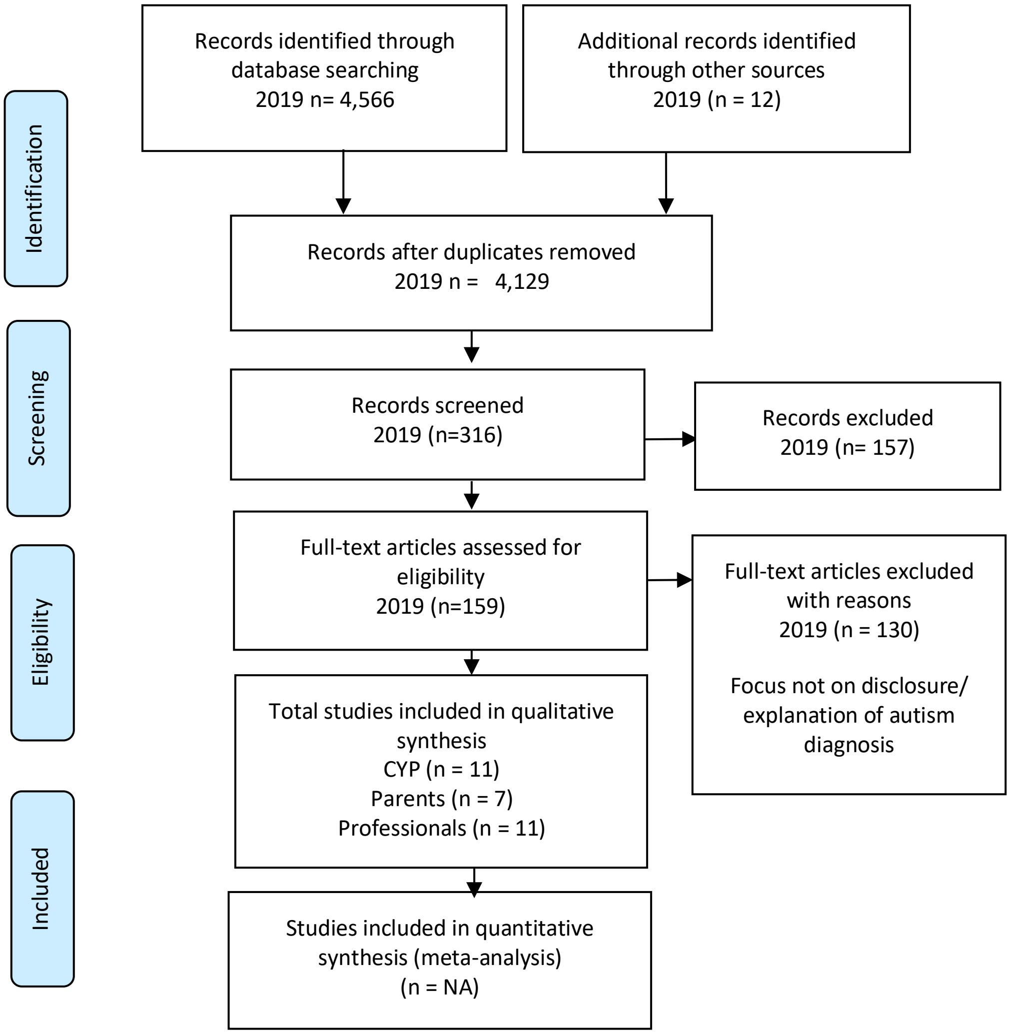


Figure 3 PRISMA diagram showing the processes applied for the systematic literature search as advised by Moher et al. (2009)

3.2.5 The review analysis and synthesis

Gough, Oliver and Thomas (2018, p.191-194) summarised an approach undertaken for thematic syntheses that has been successfully employed in several previous studies. The approach that they identified has three stages, but they also emphasised that there might be overlap between stages one and two. Within stage one, themes are identified across studies, which Gough, Oliver and Thomas (2018, p.19) highlight involves '*translating*' the ideas across the papers into a '*shared language'*. At stage two, a framework is established that demonstrates overlap. While at stage three, the synthesis of the findings is undertaken to explore how the descriptive themes can be drawn upon to address the research questions.

Within this systematic review, the thematic synthesis was undertaken in three stages. Following the approach for a thematic synthesis, during stage one, themes were identified within and across studies. In line with the approach suggested by Gough, Oliver and Thomas (2018), each theme was given a label that described it and examples of the themes were collated, within each theme, both negative and positive examples were identified for when relevant. This approach was applied systematically and, as advised by Gough, Oliver and Thomas (2018), with the text highlighted and the label annotated. For example, one of the themes identified within the review was self-efficacy, which might be discussed either positively or negatively. Within discussion of the theme of 'degrees of ability', identified in the paper by Huws and Jones (2015, p.88), the research participant Clare discussed being told of traits related to positive self-efficacy as she explained she had been told she was '[…] *really good with cooking sometimes and helping out* […]*'* (Paragraph 8, Lines 7-8), but also later discussed traits that might be linked with negative self-efficacy as she described herself to have *'*[…] *communication and just socialising problems* […]*'* (Paragraph 10, Line 2).

Gough, Oliver and Thomas (2018) indicate that stage two of a thematic synthesis involves translating and developing descriptive themes. As suggested by Gough, Oliver and Thomas (2018), within this study, themes that were identified within the first study, were applied to the second study, and this process continued across the analysis of all of the papers. Table 5 below demonstrates how examples of themes were tracked across papers for autism narratives related to self-views and is followed by examples from the papers.

Table 5 Examples of occurrences of overlapping themes across papers about children's views from my study

Subthemes	Baines. (2012)	Billington (2006)	Gaffney (2017)	Gordon, *et al.* (2015)	Huws & Jones (2008)	Huws & Jones (2015)	Jones *et al.* (2015)	Jones, Huws &Beck (2013)	Molloy & Vasil (2004)	Mogensen & Mason (2015)	Rossello (2015)
Autism narrative & self/identity	Pg:550 Para: 3 Lines: 1-3				Pg:105, Para:3, Lines: 8-16	Pg:88, Para:10 & 17, Lines: 1-3 &1-8	Pg:1495 Para:3 Lines: 1-3 Pg:1496 Para:3 Lines: 1-3		Pg:664 Para:5 Lines: 7-9 Pg:666 Para:1 Lines: 2-4	Pg: 261 Para 1 Lines: 3-4	Pg: 95 Para:2 Lines:2-6

Within Baines' (2012) paper, the autism narrative related to self-identity theme was discussed within discussion of positioning theory, which is explored in relation to the narratives. Baines (2012) discusses this in relation to participant Mark, for example:

> "…he thought of himself as a 'recovering' autistic. This identity shift came in eighth grade, when he decided he did not belong in a special education class…" (Baines, 2012, p. 550, para: 3; Lines: 1-3).

> “When I was two, I couldn’t really talk. My parents were really worried I was going to become really autistic and stuff, but thanks to a lot of circumstances that sort of really helped me and I sort of overcame my autism.” (Baines, 2012, p.551, para 4, Lines 1-4)

Baines (2012) identified this theme within the other participant’s account, for example, Anthony explained he was:

> “[…] worried whether people would perceive him as disabled, but he had a different relationship with his disability due to being diagnosed with Asperger’s syndrome at 13. […] Anthony was accustomed to being told there was something ‘wrong’ with him. …Anthony identified as ‘the guy who gets thrown out of class’, ‘water boy’, or ‘retard’ […] (Baines, 2012, p.552, para 4, lines 1-8)

Huws and Jones (2008, p. 105, para 3, lines 8-19) discussed how their analysis revealed that within children’s autism narratives, their self-views were impacted as the diagnosis caused ‘biographical disruption’ as children’s ‘taken-for-granted assumptions and behaviours’ caused ‘rethinking of biography and self-concept’, whereby ‘[…] uncertainty about the future that calls for a re-evaluation of biography and a reconstruction of self-identity’. For example, they highlighted this in Darren’s account:

> “Um, I think it’s because I got told so late and I already had my hopes up about going to another college before […]. Uh things like I didn’t get to go to college when I left school, what I wanted to go to, college back at home. […] and things

> like can't do the job you exactly want to do like because of it." (Huws and Jones, 2008 p.103, para. 17, lines 1-5; 12-13)

Huws' and Jones' (2015) paper discussed how CYP made comparisons in their narratives about themselves. These comparisons appeared central to their constructions of their identity. When explaining their views, they compared their present self with their past self, as well as comparing themselves with others with autism. The participants presented views of themselves that were more positive in the present than the past. They also viewed themselves to be less impacted by autism than the peers they compared themselves too, as explained by Clare, for example:

> "I'm not really disabled-disabled, I've just got like communication and just socialising problems and that. I'm just a bit disabled, not all, not loads disabled". (Huws and Jones, 2015, p.88 para.10, lines 1-3)

Within the systematic review, this process was continued for each theme, across the papers, for each participant group: CYP with autism, parents of CYP with autism and professionals who work with them in relation to an autism diagnosis. As well as explaining how the themes were identified, the review highlighted how frequently they occurred across papers. The final stage followed the approach identified by Gough, Oliver and Thomas (2018) to generate analytical themes that aimed to develop a synthesis that offered new conceptualisations and explanations. In the final stage of the review, which synthesised the themes across the papers from the three different stakeholder groups, the process described above was also employed to synthesise the findings across the three participant groups.

The review presents the findings from the systematic search in four sections: how CYP on the autism spectrum experience and view autism diagnosis; parents' views about explaining an autism diagnosis to their child; professionals' views about sharing and explaining an autism diagnosis. The final section presents the synthesis of findings from the review across the papers from the three key stakeholders. The next section presents the findings from the papers that have explored the views of children and young people.

3.3 How CYP on the autism spectrum experience and view autism diagnosis

The literature search identified eleven papers, which have explored the views of CYP about their autism diagnosis. Table 6 below presents a summary of the papers identified. Ten papers followed a qualitative methodology to gain CYP's views of their experiences of autism diagnosis and having autism. One paper reports a randomised control trial (RCT) to evaluate an intervention aimed at developing understanding of autism.

Table 6 How children and young people view autism diagnosis and learning about the diagnosis

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
1	Baines, A. D. (2012) 'Positioning, strategizing, and charming: how students with autism construct identities in relation to disability', *Disability and Society*, 27 (4), pp. 547-561.	USA	To explore how young people with autism construct identities through social interactions at school and home	2 male high school (11th & 12th grade) pupils with autism	Multi-sited ethnography comprising two years data including interviews and participant observation	Young people with autism can: -partake in socially governed practices. - construct their identity socially to support participation, competition and belonging -distance themselves from the 'autistic' label Their social interactions were observed to exert power that helps to shape youth identity Young people with autism were not disengaged from sociocultural process related to identity Participants strove to encourage other people to view them positively. Being identified as 'autistic' negatively impacted others' perceptions	Not identified by author Author does identify the need for longitudinal, cross-context research to explore how young people with autism construct identity in and out of school.
2	Billington, T. (2006) 'Working with autistic children and young people: sense, experience and the challenges for services, policies and practices', Disability and Society, 21 (1), pp. 1-13.	UK	To encourage narratives of autistic experience that are focussed on assets rather than impairments or deficits	1 male young person with autism across a number of years	Observation and analysis of one case with interpretation based on published autistic 'insider' accounts	The author highlights the intense impact of senses on emotion and social construction of meaning demonstrated the young person with autism Author suggests practitioners should - develop practices and discourses concentrate on strengths - establish provision that facilitates difficult feelings/distress to be shared - be aware of interactionist influences and avoid assigning responsibility for behaviour change only on the child, parents and professionals also have a role - need for more research to elicit views of CYP with autism about how they manage their 'worlds'	Not identified by author Author does identify the need to search for effective ways to gain the views of children with autism about heir perceptions of social interactions and other experiences.
3	Gaffney, J.G. (2017) 'It's autism, it's just a name': Exploring the impact of autism spectrum diagnosis with adolescent females using Interpretative Phenomenological Analysis.	England, UK.	To find out how girls/young women who have an autism diagnosis view diagnosis and what can be learned from hearing their voices	Six females aged between 14 and 20. 5x mainstream education 1x young adult attending university	Interpretative Phenomenological Analysis (IPA)	Three themes were identified-each with sub-themes **Understanding Autism:** Diagnosis in a problem context; What is autism; Communication; It's my autism; Siblings with autism. **Acceptance or rejection:** Acceptance; Dissonance; Rejection. **Self and autism**: Struggling with sense of self; Stronger sense of self It is concluded that diagnosis useful, perhaps at certain times, but for some the diagnosis is unwanted and sometimes harmful to personal identity	The author acknowledges experiencing the difficulty identified by Watts (2014) of ignoring theoretical and personal views and tendencies before commencing data analysis' The author appropriately acknowledges potential for bias through the questioning activities in the interview and during analysis A limitation in meeting the recommended IPA approach for member checking (feedback on analysis and interpretation, as described by Birt *et al*., 2016) was also identified. Therefore, participants' views about researcher interpretation were omitted as a quality check.

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
4	Gordon, K., Murin, M., Baykaner, O., Roughan, L., Livermore-Hardy, V., Skuse, D., & Mandy, W. P. L. (2015) A randomised controlled trial of PEGASUS, a psychoeducational programme for young people with high-functioning autism spectrum disorder. *Journal of Child Psychology and Psychiatry*, 56, 468–476.	England, UK	To design and evaluate a psychoeducation group for young people with autism [PEGUSUS], which aimed to enhance the self-awareness by teaching them about their diagnosis.	48 young people (9–14 years) high-functioning ASD 40 males (PEG18/Con 22) 8 females (PEG6/ Con 2) Aware of diagnosis; English speakers IQ over 65 Able to function in a small group	Randomised control trial	Young people with ASD reported good levels of satisfaction with PEGUSUS: quite enjoyable' (n = 4, 18.2%); extremely enjoyable' (n = 17, 77.2%). Over half (n = 12, 54.5%) found PEGASUS 'extremely helpful'; seven (31.8%) found it quite helpful. Most (n = 21, 95.5%) reported that PEGASUS increased their knowledge about ASD and supported understanding of themselves. There was no reduction in self-esteem from learning about the diagnosis Authors suggest this may reflect the focus on strengths as well as difficulties Compared to the control group, the participants' results showed greater positive change for knowledge of ASD and self-knowledge.	Authors identify that the ASD awareness measure demonstrated good reliability but cautioned that its psychometric properties had not been fully established. The management as usual (MAU) control group employed as part of the RCT methodology meant that interpretation of the findings was limited as it was not possible to identify which aspects of the programme were implicated in change in ASD self-awareness and knowledge Although some children engaged in the programme showed positive impact after taking part, the authors highlight that almost 60% of the PEGUSUS participants' scores did not show statistically reliable change. Therefore, impact was variable and the design did not support identification of possible cause in the variable outcomes.
5	Huws, J. C. and Jones, R. S. P. (2008) 'Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism', *Journal of Intellectual and Developmental Disability*, 33 (2), pp. 99–107.	Wales, UK	To explore the retrospective accounts of young people with high functioning autism of their experience of autism from the perspective of an ''insider'' in order to highlight topics for future research.	9 young people with high functioning autism 3 females 6 males	Qualitative, Interpretative phenomenological analysis, Semi-structured interviews	Participants perceptions of having autism were identified to be embedded with their diagnosis and their experiences of diagnostic disclosure. The study identified 5 themes within the accounts: - disclosure delay - providing explanations - potential effects of labelling - disruptions and opportunities - acceptance and avoidance	Authors identify that only seeking perspectives of children and young people limited possible interpretations and understanding. The researchers identify that triangulation would have facilitated broader understanding of the research themes identified. For example, by exploring reasons related to the logistics of diagnosis: when and how to disclose an autism diagnosis.
6	Huws, J. C. and Jones, R. S. P. (2015) 'I'm really glad this is developmental': Autism and social comparisons – an interpretative phenomenological analysis', *Autism,* 19 (1), pp. 84–90.	Wales, UK	To explore young people's perceptions of autism	9 students 16-21 yrs with autism attending a specialist college 3 females 6 males	qualitative methodology interpretative phenomenological analysis	Making comparisons was a significant concept. Three related themes were identified: (a) Changes over time: 'I'm really glad this is developmental' (b) Degrees of autism: 'They've got it really bad' (c) Degrees of ability: 'I'm not really disabled-disabled.	A limitation in meeting the recommended IPA approach was also identified as member checking (feedback on analysis and interpretation) was not undertaken. Therefore, participants were not able to inform or challenge the authors' interpretations. However, during data collection, the interviewer's initial interpretations were checked with participants.

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
7	Jones, J.L., Gallus, K.L., Viering, K.L. and Oseland, L.M (2015) 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses', *Disability and Society*, 30 (10), pp. 1490-1504.	USA	To provide a better understanding of how adolescents with autism identify with and make meaning of their diagnosis by examining how they construct narratives regarding their diagnosis	10 adolescents with autism 8 males 2 females Aged 13 to 20 years mean=16.24, 2 had lower verbal mental age than chronological	Phenomenological-qualitative interviews using data from a larger mixed-methods study	Themes: 1. Formation of an ASD narrative • Acknowledgment of the label • Recognition of unique behaviours and characteristics • Self-awareness and reflection 2. Social construction of the label • Distinction within the label • Pride and belonging 3. confusion regarding whether autism spectrum disorder is a disability Participants beliefs were influenced during social interactions with peers, family, and others. Language used to describe autism, as well as social stigma influences young people's views of self and their diagnosis	Sample bias was discussed by the researchers, including: • A small but fairly heterogeneous sample of participants with a broad range of diagnoses across the spectrum • geographical bias, all participants were from one area, therefore experiences that are different in other areas are not represented- e.g. adolescents in the study might have had greater or lesser access to services compared to other areas • parents of participants were involved in support groups, therefore the sample might have been biased toward those with greater knowledge of autism. Member checking (feedback on analysis and interpretation) was also identified as a limitation. Therefore participants' views about researcher interpretation was omitted as a quality check. Methodological concerns about the interview process and whether it was appropriate were also identified as depth of responses were limited.
8	Jones, R.S.P., Huws, J.C. and Beck, G. (2013) 'I'm not the only person out there': insider and outsider understandings of autism', *International Journal of Developmental Disabilities*, 59 (2), pp. 134-144.	Wales, UK	To gain an insight into how people with autism spectrum disorder (ASD) view the concept of autism and how they view society's reactions to people with this diagnosis	9 students 16-21 yrs with autism- attending a specialist college 3 females 6 males Also an expert author: a person with autism completing the analysis	Qualitative interviews followed by interpretative phenomenological narrative analysis by and expert author (a person with autism)	Themes: insider and outsider experience of autism. Results suggest that the participants had an awareness that interpersonal relationship were complex. They also demonstrated feelings of difference and a desire to fit into their peer group. a desire The authors highlighted that employing an expert author helped to reduce diagnostic overshadowing. Finding were interpreted as an interaction between age, developmental phase as well as in relation to diagnosis of autism.	Limitations were not identified by the authors. However, although an 'expert author' (an adult with autism) view was sought the interpretations was not subject to member checking (feedback on analysis and interpretation). Therefore, participants' views about the 'expert author's' interpretation were omitted as a quality check.

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
9	Molloy, H. and Vasil, L. (2004) *Asperger syndrome, Adolescence and Identify: Looking Beyond the Label. London*: Jessica Kingsley Publications	England & Singapore multi-national	Aim to provide 'an inside-out view' of the experiences of young people with an Asperger diagnosis.	6 cases-aged 12-18 yrs 3 in England; 2 ex-pats in Singapore; 1 from Australia living in Singapore; 4 male 2 female	Narrative interviews and analysis	The authors highlight that while the 'quirks' that young people without autism display are likely to be considered as part of their unique and complex personalities, 'quirks' of young people with Asperger's are likely to be viewed as symptoms. - Participants were accepting of the diagnosis - 2/6 viewed themselves as disabled and perceived this to impact socially - Views varied about the significance of AS to identity - authors suggest that individuals that discussed more life successes were less dominated by the diagnosis - Most participants choose not to disclose their AS - 3 participants discussed misconceptions of autism being influenced by either the savant or medicalised severe disability view. - Scrutiny and linking all traits to diagnosis was also discussed - The authors highlight how trying to meet social expectations can influence low self-esteem. - The authors suggest a relationship exists between self-esteem and the extent AS was viewed as a disability	Bias in narrative happens due to errors by tellers, is influenced by the accounts of others and information from other sources Life stories are only as good as the teller, the can be changed by the teller over time. As some people might not be able to 'tell their story', their voices might not be heard. Researchers might seek &/or encourage telling of stories that link with research aims Relying on stories might miss other influences that impact tellers' stories, such as social; economic; political and/or related policy decisions
10	Mogensen, L. & Mason, J. (2015) 'The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder', *Sociology of Health and Illness*, 37, pp. 255–269. doi:10.1111/1467-9566.12208	Australia	To learn about the lived experience of having an autism diagnosis and to facilitate direct participation in the research by people with autism	5 x teenagers 13 and 19 years with autism spectrum diagnosis 3 males 2 females	Collaborative, participatory research approach Involving photos, drawings, interviews, e-mail and communication cards	Key themes include diagnosis as - Oppressive, - liberating - facilitating control; - a positive identity; Themes also include: - Dilemma of disclosure, social identity: stereotypes and negative attitudes; - Impairment and losing control - Impairment and taking control Authors suggested that the diagnosis facilitated understanding of self; impacted individual feelings of control and agency, and impacted whether it was perceived to an advantage or disadvantage.	Limitations were not identified by the authors. Member checking (feedback on analysis and interpretation) was undertaken but only 2 out of 5 participants provided feedback. Neither the nature of the feedback nor how it informed the findings was discussed. Therefore the impact of participants' views on interpretation is unclear.
11	Rossello, E. (2015) *'I have what?' A phenomenological inquiry into disclosing a diagnosis of Asperger's disorder to adolescents* Doctoral dissertation: Chicago School of Professional Psychology.	USA	To explore the most common ways a diagnosis of autism is disclosed and positive and negative outcomes following disclosure	12 participants 4x parent sets & 4x adolescents aged13-17 who had Asperger diagnosis at least 12 months 3 females 1 male	Qualitative, semi-structured interviews	Disclosure of Asperger syndrome adolescents was identified to have a more positive than negative impact on their mental health. Three quarters of the adolescent participants wished they had known sooner. The author concludes that the more positive the adolescents' reaction to being told about their diagnosis, the more optimistic they were about their future and they were also more likely to tell others about their diagnosis.	Limitations included small sample size, which was identified to mean that the findings were not generalisable to the general population. Selection bias was also identified due to purposive recruitment from a small number of sources, described as 'good subjects' who had greater knowledge of autism as they were involved in autism spectrum groups.

3.4 Summary of participation methods within the studies identified

The randomised control trial (RCT) undertaken by Gordon *et al*. (2015) explored young people's views through scaled questionnaires. The ten qualitative papers mostly reported on participant views that were collected through interviews. However, the paper by Baines (2012) employed interviews and observations. Billington (2006) employed observation and analysis of one case, with interpretation based on published autistic 'insider' accounts. Mogensen and Mason (2015) employed interviews as well as photographs, communication cards and drawings to collect their participants' views. All participants within the studies had an autism spectrum diagnosis and were able to communicate their views about the diagnosis and the processes related to learning about the diagnosis. Most papers collected views at one point in time. However, the two young people in Baines (2012) study provided information through a series of interviews over time.

3.5 Synthesis of findings

Table 7 below shows the key themes identified across the eleven papers about children and young peoples' views of an autism diagnosis and finding out about the diagnosis. Analysis of the qualitative findings followed the approach described by Boshoff *et al.* (2016). This involved three sequential stages: first summarising themes identified in the findings (As shown in Appendix 3: Analysis of papers and synthesis of findings); next, similar findings were connected; finally, the syntheses were organised into overarching broad topics. Each one of these broad topics were drawn from the themes and sub-themes in the eleven papers, which are discussed below. After presenting the key findings from the synthesis, the limitations are also discussed.

As identified within the four papers identified within the 2012 scoping review, across the eleven papers identified in 2019, it was evident from the research aims that the way in which young people viewed the diagnosis, and the corresponding impact on their view of self, was of interest to the researchers. Kelly (1955) is credited as one of the first psychologists to apply rigorous methods in relation to personal construct theory, in which human traits were organised hierarchically. A key element identified by Kelly (1955) was the way in which past social experiences influence interpretation of new experiences and information in relation to self. Kelly (1955) also highlighted that personal constructs were malleable and subject to change, but that this change would still be channelled by past experiences. All the papers considered how the participants discussed autism in relation to self, as underlined in the aims in Table 6 above. This links with the notion of personal identity constructs. This is shown in the following examples of phrases from the research aims, which explored, for example: ‘how young people with autism construct identities’ (Baines, 2012); ‘narratives of autistic experience’ (Billington, 2006); and ‘how adolescents with autism identify with and make meaning of their diagnosis’ (Jones *et al*., 2015). Similarly, the programme trial undertaken by Gordon *et al*. (2015) aimed to enhance their participants’ self-awareness.

3.6 Main themes from the perspective of CYP with autism

As shown in Table 7 below, the most discussed themes related to the way in which young people discussed topics that connected the diagnosis with their view of self. Discussion of this nature was grouped together across the papers and appears to reflect the participants' '**personal construction of identity'**. Across eight papers, nineteen topics were identified that linked with this theme, there were a further thirteen related subthemes.

The second most discussed topic related to the '**impact of knowing about the diagnosis**', discussion related to impact was discussed within five papers, six main themes and eight subthemes were identified. Young people also discussed other people's views of autism, which appeared to impact their own view of self. These themes were drawn together under the topic: '**social construction shaping identity'**, this was discussed in four papers, which contained six themes and two subthemes.

CYP participants' views also demonstrated understanding of autism alongside awareness of how other people might misunderstand it. These themes were brought together in the topics: '**understandings and misunderstandings**' of autism. This theme was identified in four papers, and one of the four papers also had a related subtheme. In three papers, CYP discussed the dilemma of disclosure to others and revealed uncertainty about whether '**to disclose or not'**. No subthemes were identified. In one paper, '**traits related to autism**' were discussed, three topics related to this were identified but there were no subthemes.

Table 7 Synthesis of findings from the identified studies about CYP views about autism diagnosis

To disclose or not Themes=3 • Sub-themes =0 Papers=3	Understandings & Misunderstandings Themes=4 • Sub-themes=1 Papers=4	Social construction shaping identity Themes=6 • Sub-themes=2 Papers=4	Personal construction of identity Themes=19 • Sub-themes=13 Papers=8	Impact of knowing about diagnosis Themes=6 • Sub-themes=8 Papers=5	Traits related to autism Themes=3 • Sub-themes=0 Papers=1
Perceived negative social impact of being ‘autistic’ To disclose AS or not The dilemma of disclosure and social identity	awareness of the complexity of interpersonal relationships Recognition of unique behaviours and characteristics Misconceptions of autism influenced by either the savant or medicalised view of disability. Scrutiny and linking all traits to diagnosis Stereotypes and negative attitudes	Autism and collective cultural practices Social construction of identify Professional misunderstandings of autism Social construction of meaning related to autism • social construction of the label • Distinction within the label Interactions with peers, family members, and others influence beliefs about the diagnosis and themselves Insider and outsider experience of autism	Distancing from the ‘autistic’ label Social promotion of positive self Symbolic importance of friendships/own interests to identity Understanding Autism Diagnosis in a problem context • What is autism • Communication • It’s my autism • Siblings with autism Acceptance or rejection & dissonance Changes over time Degrees of autism Degrees of ability Formation of an autism narrative • Acknowledgment of the label • Self-awareness and reflection Confusion regarding whether autism is a disability Desire to ‘fit in’ to a wider group Experience of being regarded as ‘different’ Impairment and losing or taking control Varied reactions & feelings: • scared and a little bit angry; • confusion-wishing not to know but also glad to know • weird and upset, then mad, now don’t really care • relieved! • Things made a lot more sense”	Self and autism • Struggling with sense of self • Stronger sense of self • Improved understanding of autism strengths and difficulties =better understanding of self Perceptions of “having’’ autism • disclosure delay • providing explanations • potential effects of labelling • disruptions and opportunities • acceptance and avoidance • Pride and belonging Acceptance of the diagnosis Identity- self as disabled linked to social difficulties Identity- not dominated by the diagnosis when successes were the focus	Different communicative style Passive processing of information about self Emotion response and sensory defences

The themes identified are discussed next, the most commonly occurring themes are considered first. The subthemes are also considered within the overarching main theme to which they relate. Table 8 below provides an overview of the themes and subthemes identified across the papers to illustrate the level of overlap. Some subthemes were very similar across the papers, Table 8 below therefore identifies the occurrence and discussion of the key topics across the papers identified by the search. As each theme and the related sub-themes are discussed, a small number of excerpts are provided to exemplify the way in which CYP discussed the topics identified.

Table 8 Subthemes and overlap across papers, as identified through the thematic synthesis

Subthemes	Baines. (2012)	Billington (2006)	Gaffney (2017)	Gordon, *et al.* (2015)	Huws & Jones (2008)	Huws & Jones (2015)	Jones *et al.* (2015)	Jones, Huws &Beck (2013)	Molloy & Vasil (2004)	Mogensen & Mason (2015)	Rossello (2015)	Total number of papers per sub-theme
Autism narrative & self/identity	✓				✓	✓	✓		✓	✓	✓	7
Distancing from autism /degrees of autism	✓		✓		✓	✓	✓		✓	✓		7
Degrees of autism	✓					✓	✓					3
Emotional reactions to diagnosis			✓		✓	✓					✓	4
Diagnosis in a problem context	✓	✓	✓						✓			4
Delay/desire to have known sooner					✓						✓	2
Importance of social standing/Social promotion of positive self	✓	✓			✓	✓	✓		✓	✓		7
To tell or not to tell others	✓								✓		✓	3
Accepting/rejecting the diagnosis	✓		✓		✓	✓	✓		✓	✓		7
Social expectations, communication & self-esteem	✓	✓	✓			✓	✓					5
Labelling/disability/stigma /stereotyping					✓		✓	✓	✓	✓		5
Autism a challenge to identify	✓	✓			✓	✓	✓					5
Self-awareness			✓	✓			✓				✓	3
Levels of autism & comparisons	✓		✓		✓	✓	✓		✓			6
Understanding autism			✓	✓	✓		✓				✓	5
Diagnostic disclosure and understanding self	✓		✓		✓		✓				✓	5
Strengths/successes reduce impact of diagnosis	✓		✓	✓	✓	✓	✓		✓	✓		7
Impairment & losing control vs taking control	✓	✓	✓							✓		4
Belonging							✓	✓				2
Feeling different/desire to fit in	✓					✓		✓				3
Understanding autism as an insider							✓	✓		✓		3
Autism misconceptions							✓		✓	✓		3

3.6.1 Personal construction of identity

Molloy and Vasil (2004) were the first researchers identified by the literature search to have explored young people's views of an autism diagnosis. They adopted a narrative approach, conducting interviews with young people and their parents to collaboratively construct the life stories of six teenagers with Asperger Syndrome (AS). Molloy and Vasil (2004) suggested that a relationship existed between self-esteem and the extent to which their participants held the view that AS is a disability. They highlighted two accounts to demonstrate this, firstly Lee who demonstrated scepticism about the notion that AS was a disability:

> I wouldn't term Asperger Syndrome a disability. One way of looking at Asperger syndrome verses neuro-typical-ness is that everyone else (NTs) has a gift for emotional or social understanding but they've got this disability in abstract concepts. It all depends on your viewpoint. (Molloy and Vasil, 2004, p. 119)

This is contrasted with their interview with Chee Kiong, who considered the diagnosis as a lifelong disability with no benefits:

> You can't take it away. If I could change myself and get rid of the Asperger Syndrome then I definitely would. (Molloy and Vasil, 2004, p. 119)

Although Chee Kiong did not see any correspondence between his strengths and AS, he did link his difficulties with social interaction to AS. Molloy's and Vasil's (2004) research highlighted the influence of society's perceptions on young people's views of self. They emphasised that while none of the young people they interviewed described themselves as being disabled, they all regarded themselves as different, and it was their interactions with others that helped to shape the views that young people developed of themselves.

Mongensen and Mason (2015) interviewed young people to explore their lived experience of having an autism diagnosis. Their five teenage participants held a range of views about their diagnosis, for some it was oppressive, for some a liberation, and for others it facilitated feelings of greater control. A commonality in the young people's explanations was the impact of the diagnosis in re-framing their sense of self. The extract from Ian demonstrates this reframing, although he acknowledges negative perceptions of diagnosis, learning about the diagnosis enabled him to reframe difficulties as surmountable:

> … it just put everything into perspective for me because [...] 'Oh, it's a label' … but…a secure sort of thing for me. I wanted to be labelled because I suddenly knew what I could do and I knew there was a way I could cope with that problem once it had been identified. (Mogensen and Mason, 2015, p. 259).

To understand perceptions of autism and experiences of diagnosis, Huws and Jones (2008) employed Interpretive Phenomenological Analysis (IPA) (Smith, 1996; Smith, Jarman and Osborn, 1999) to explore views of nine young people (aged 16 to 21 years) with autism. Their aim was to understand the process from an insider perspective. Their participants identified concerns about the potential effects of labelling and their worries about the diagnosis disrupting their future ambitions. Huws and Jones (2008) likened this to 'biographical disruption', which was described by Bury (1982, p. 169), within the context of physical health, when the diagnosis caused a re-appraisal of self. The views of participants in the study by Huws and Jones (2008) varied, some participants did not welcome their diagnosis and avoided information related to it. However, despite the challenge of being told about the diagnosis, over time, most eventually adjusted their personal construct to acknowledge having an autism diagnosis. Huws and Jones' (2015) analysis identified ongoing change in their participants' personal construct of self, as it was influenced by the comparisons that they made between themselves and others.

Jones *et al*. (2015) identified similar changes in participants' self-narratives, which also changed over time. They identified how their participants began to make sense of the diagnosis in relation to self in three key phases: firstly, acknowledging the label, then making links between their unique characteristics and autism, which led to greater self-awareness and to reflection on the implications. This process was also identified to be influenced by others through perceived social stigma and terminology used to describe autism, which was found to influence how the participants viewed themselves, and how they made meaning out of their diagnosis. Where the language and social context was discussed in negative terms, participants were more likely to distance themselves from the diagnosis. Therefore, suggesting that the context in which young people come to understand the diagnosis will be crucial.

3.6.2 Understanding autism diagnosis in a problem context

Understanding the diagnosis in a problem context was a main theme identified by Gaffney's (2017) doctoral study. However, participants' views varied, the six female participants discussed times when knowledge of the diagnosis was useful and times when it was unwanted. When they discussed the diagnosis as unwanted, Gaffney

(2017) highlighted that this negatively impacted participants' discussion of their personal identity. All the participants discussed their diagnosis in relation to a problem context, and rejection of diagnosis was identified. Micha's perspective is illustrative of the negative context in which information about the diagnosis can be experienced, which can lead some young people to associate the diagnosis with problems:

> When I was in nursery they said that I was acting a bit different and I wasn't fitting in with the other kids … So my mum took me to the doctor…, we found out that I had autism. My mum got upset, she started crying 'cause she felt bad for me. (Gaffney, 2017: 60)

Gaffney (2017) later contrasts this with Ellie's experience. Ellie was diagnosed at university and actively sought out the explanation, as she was aware of differences to peers. Ellie described feeling like she was 'going mad' and her consequential 'relief' in learning about the diagnosis (Gaffney, 2017, p. 72). Gaffney (2017) linked such experiences with participants' struggles with their sense of self, but also highlighted that despite the difficulties, four of her participants' narratives revealed that through learning about the diagnosis, they have a stronger sense of self.

3.6.3 The impact of knowing about the diagnosis

The impact of the diagnosis was identified to vary across participants and across the studies, both negative and positive impacts were discussed in five papers. Rossello's (2015) doctoral research explored the diagnostic experiences of four adolescents with an Asperger diagnosis, through semi-structured interviews with both the young people and their parents. All the participants revealed that, at some level, they were glad to have been told about their diagnosis. Rossello (2015) highlighted that there was no evidence that being told about the diagnosis negatively impacted their hopes for their futures, and three of the participants wished they had known sooner. The findings highlighted that learning about their Asperger syndrome diagnosis was more beneficial than detrimental for the participants' mental wellbeing. Rossello (2015) also highlighted that those participants who had a more positive reaction to the diagnosis, were more positive about their futures and more likely to tell other people about the diagnosis.

The impact on individuals varied across studies, Huws and Jones' (2008) adolescent participants related 'having autism' to problems such as disclosure delay and the potential effects of discrimination. Mark, for example, revealed anger because he did not want to be 'labelled'. He felt people without autism might make assumptions about him (Huws and Jones, 2008, p. 103). However, Huws and Jones (2008) also highlighted that by learning about the autism diagnosis, participants were also able to reflect on previous life events and make sense of experiences. Jemma, for example, explained that through learning about the diagnosis, she had been able to understand the different treatment she had experienced previously (Huws and Jones, 2008, p. 102).

The PEGASUS psychoeducational group programme developed by Gordon *et al.* (2015) was designed specifically to enhance the self-awareness of CYP with autism by teaching them about their diagnosis. Most of their participants reported increased knowledge about autism, identifying that the programme had helped them to understand themselves better. As the participants' post programme assessment did not show any reduction in self-esteem, Gordon *et al*. (2015) concluded this was a result of the programme’s focus on both strengths and difficulties, which lead to participants’ better understanding of self.

Jones *et al.* (2015) reported a more mixed impact from learning about diagnosis. In addition to discussing the negative themes such as disability, stigma and confusion, their participants revealed a positive impact from learning of their diagnosis. Some participants revealed feelings of pride due to unique attributes, which influenced a feeling of belonging. James, for example, explains:

> I’m not alone; I’m not the only jellybean. There are jellybeans just like me… (Jones et al., 2015, p. 1499)

Jones *et al.* (2015) explained that this ability to link their own experiences with others, enabled their participants to feel they belonged with others who shared similar traits, and with whom they identified. Thus, for some, the impact of learning about the diagnosis was the re-shaping of their identity in a positive way.

3.6.4 The Social construction of autism shaping identity

Huws and Jones (2015) employed interpretative phenomenological analysis (IPA) in their study involving nine participants with autism (aged 16–21 years), to explore their views about autism. Three key underlying themes were identified: making comparisons; changes over time; and degrees of autism and disability. Huws and Jones (2015) highlight that because participants’ juxtaposed views about being both different and the same, when compared to those without autism, this signifies that they viewed autism within a spectrum of human variability. Huws and Jones (2015, p. 89), therefore, suggest autism is an identity which is ‘socially constructed, situated and negotiable’.

A similar IPA study from the USA, by Jones *et al.* (2015), also used qualitative interviews to explore how ten adolescents with autism identified with, and made meaning of, their autism diagnosis. Jones *et al.* (2015) highlighted that it was their participants’ interactions with their peers, families and wider community, which shaped their perceptions of the diagnosis and themselves. While there are cultural differences, which can impact experiences when phenomena are explored in different countries, the participants in the study of Jones *et al.* (2015), reflected the suggestion by Huws and Jones (2015) that autism is a social construct. Jones *et al.* (2015) also highlighted that some participants shared conflicting views about their diagnosis, liking some of the characteristics related to autism, despite the difficulties they experienced with peer relationships. This was particularly highlighted by Chris’ views:

> I would try to get rid of my autism. It can be a burden [...] but that’s what makes up […] most of my intelligence. (Jones *et al*. 2015, p. 1498)

Jones *et al.* (2015) suggested that the stories their participants told themselves, in relation to the diagnosis, also influenced their self-perceptions. They also identified negative language and social stigma related to autism in their participants’ stories, and suggested that this influenced how their participants subsequently coped and adapted, as demonstrated by Kelly:

> I feel like I am just marked […], some people just …treat me different, and I don’t want to be treated different, I just wanted to be treated how I was [before receiving a diagnosis]. (Jones *et al*., 2015, p.1498)

3.6.5 How social influences impact on the acceptance/rejection of diagnosis

Huws and Jones (2008, p. 102) suggested that their participants’ perceptions of ‘having autism’ were influenced by how they were told about the diagnosis and concepts related to it. They identified five themes relating to: delays in diagnosis, explanations of autism, the impact of labelling, the way that diagnosis provides both opportunities and disruptions, as well as participants acceptance and rejection of the diagnosis. While some participants suggested the diagnosis enabled them to understand prior experiences, others felt anger and viewed autism was a discriminatory label. Participants who were distressed by the diagnosis, felt engulfed by it and worried that it would negatively impact their future, as explained by Darren when discussing the disclosure of autism:

> … because I got told so late and I already had my hopes up about going to another college […] I didn’t get to go to college when I left school, what I wanted to go to, college back at home. (Huws and Jones, 2008, p. 103)

Although diagnosis was a negative experience for some participants, Huws and Jones (2008) highlighted that the young people in their study were eventually able to accommodate the diagnosis and adjust their perceptions.

3.6.6 How social experiences related to autism can challenge identity

Social influences were also found to be significant in influencing the views of the two adolescent participants with autism by Baines (2012), who used interviews and participant observations across a range of contexts over two years. Baines (2012) observed that the participants made conscious attempts to demonstrate socially acceptable behaviours that would be viewed positively. Baines (2012, p. 548) suggested that the participants were trying to distance themselves from the label through ‘nuanced efforts to position’ and to ‘pass’ as ‘normal’, as Mark explains in one of his interviews:

> … it’s the impression that you want kids to have. And I know that having this impression of arrogance is really bad, because then people are going to be kinda distasted by you… (Baines, 2012, p. 555).

Mark’s self-reflections, like Kelly’s above, revealed awareness of stigma, and the struggle between being ‘true to themselves’ and achieving acceptance from peers. Baines (2012) suggested that this highlighted how young people on the spectrum are likely to be aware of, and actively involved in, the sociocultural process related to identity. It also highlights the important role that parents’, peers’ and professionals’ views of autism can have, as these will be communicated during interaction, including both general interactions and those specifically related to discussion of an autism spectrum diagnosis.

3.6.7 Understanding and misunderstandings of autism

Methodological good practice within interpretative phenomenological analysis, emphasises that the views of participants should be included at all stages of the research (Smith, 1996; Smith, Jarman and Osbourn, 1999). Therefore, Huws and Jones employed an ‘expert author’ (Beck, an adult on the autism spectrum), to aid further interpretation of the data from their 2008 study (Jones, Huws, and Beck, 2013). Transcripts and analysis were re-analysed by Beck to provide the additional interpretation of a person with autism and to avoid diagnostic overshadowing when interpreting young people's perceptions of autism. The authors suggested this helped to locate the views of the participants within the appropriate context, by considering their participant's age, life stage and diagnosis. Two key themes emerged from the analysis: insider and outsider experiences of autism. Insider views were identified to suggest that only people with autism '…can truly know and understand what autism is' (Jones, Huws, and Beck, 2013, p. 138). The participants also recognised that insider insights could only highlight individual experiences of autism. Nevertheless, the participants' felt their appreciation of autism, while unique, is an understanding that individuals on the spectrum can share in a mutually supportive way. Jones, Huws and Beck (2013) emphasised a benefit of Beck's secondary interpretation was recognition that their participant's views also reflected their developmental stage. Some responses were reflective of responses that would also be expected of adolescents without an autism diagnosis. Jones, Huws and Beck (2013, p. 138) suggested that while participants felt 'true understanding' of autism is only possible for people with autism, any such insider understanding is also unique to that person. Jones, Huws, and Beck (2013, p.139) further highlighted that views about autism, as expressed by people without autism, are often based on either a stereotypical highly able person with autism, or a person lacking ability. Such understandings are important considerations for anyone without autism, who seeks to explore the views of those that do have autism, therefore, this was recognised as an important factor for the methods employed and the interpretations made for this study.

Molloy's and Vasil's (2004) participants with Asperger syndrome (AS) also identified others' misconceptions of autism, which they suggested were influenced by perceptions of the extreme ends of the autism spectrum, linked to either the savant level ability, or to autism with co-occurring intellectual impairment. Molloy and Vasil (2002) have previously argued that there should be a move away from a deficit model, which understands Asperger syndrome as a disorder, suggesting that instead AS should be viewed as a difference. They highlighted that through diagnosis, when autism is conceptualised as a disorder, children are labelled due to the diagnosis and their individuality is compromised, therefore, the expectations of others can be diminished. Molloy and Vasil (2004) also highlighted that their participants felt these socially constructed views impacted them post diagnosis, as scrutiny meant that individual traits were conceptualised in relation to the diagnosis. Luke, for example, contrasts the recognition of young people without autism as individual, with the identity uniformly attributed to people with AS:

> It's like every symptom has to be ticked off. But it isn't really like that – people can't be labelled as easily as that. We're not clones. (Molloy and Vasil, 2004, p. 92).

Luke then moves on to identify the things he does well, such as public speaking, computing, and making films. Accounts such as Luke's, highlight the importance of recognising positive aspects of the individual, in addition to identifying and supporting their needs. Luke's account points to the important role others might have when conversing with, and about, people with autism, to support the social construction of a more positive and balanced identity. The importance of social construction of identity relating to autism is highlighted by the regular occurrence across studies (e.g. Baines, 2012; Huws and Jones, 2015; Jones *et al*., 2015).

Participants in Mogensen's and Masons' (2015) participatory research also raised concerns about general understanding of autism within society, which was identified to be influenced by a stereotypical understanding of autism. These concerns were shown in Lucas' criticism of peers' understanding of the:

> … stereotype of an autistic or borderline autistic, and of Aspergers, as people who are anti-social, can't handle relationships (sexual and otherwise) and know a lot about trains. (Mogensen and Mason, 2015, p. 261)

Despite the social difficulties attributed to autism, young people such as Lucas are clearly aware of social perceptions related to autism. As a result, some CYP are reluctant to tell others about the diagnosis, to prevent negative connotations being applied to them.

3.6.8 To tell or not to tell others?

Participants in three studies that discussed disclosure of the diagnosis to others, revealed varied views (Molloy and Vasil, 2004; Baines, 2012; Mogensen and Mason, 2015). Some participants did not want others to know about their diagnosis. For example, five out of the six young people interviewed by Molloy and Vasil (2004) had chosen not to disclose information about AS to peers, suggesting an expectation that to reveal the diagnosis would impact upon their relationships with their peers. Chee

Kiong, for example, had not told peers due to their lack of understanding of autism, as he felt this might impact on peer relationships:

> They think that autistic people are hopeless cases, that they are mentally abnormal people who can't be changed or saved, which is just not true… People will think that you are slower in learning and that you are not a very friendly person to mix with. That is why I haven't told anybody. (Molloy and Vasil, 2004, p. 76-77)

Baines (2012) discussed his participants' nuanced efforts to distance themselves from autism, as they felt it impacted how others perceived them. Mogensen and Mason (2015) also identified participants' concerns about disclosure and the potential impact on social identity. Participants identified fears about being treated differently if peers found out about their diagnosis. When discussing whether peers knew of her diagnosis, Kim revealed that she:

> *…*didn't want to tell them at first because I wanted them to have their own opinion before they find out something that could… you know, let them treat me differently… I didn't want to be perceived as different. (Mogensen and Mason, 2015, p. 262)

Mogensen and Mason (2015) contrasted Kim's concerns with the views of other participants, such as Lucas, who has known about the diagnosis since early childhood and who did not share the same struggle to make sense of autism in relation to self. Although he was unsure if peers knew about the diagnosis, he revealed that it did not concern him:

> … my friends have some idea about me being unusual, but I’m not sure that they know a complete diagnosis, and I don’t think it really matters. (Mogensen and Mason, 2015, p. 262)

This resonates with the Rossello’s (2015) interpretation of her participants’ experiences, the adolescents who were more positive about autism, were identified to be more likely to be open to their peers knowing about the diagnosis in the future.

3.6.9 Linking autism traits with the view of self

Although participants in other papers sometimes discussed the way society viewed traits linked with autism, only Billington’s (2006) paper specifically identified these as main themes of the study. It is important to highlight that this paper differs from the other papers identified through the search, it uses only observation, and it is the only single case report (James). In this study, James’s ‘voice’ is interpreted through observations of behaviours that are supported by published ‘insider’ accounts of autism by verbal adults with autism. It is therefore understandable that the author, who is an educational specialist, makes links between the diagnostic features of autism and the observations made. The emotional responses observed in James, are linked with the evidence base for linking emotional and sensory processing in autism (Damasio, 2004) and ‘insider accounts’, such as Williams (1992). Billington (2006) also drew on his observations and insider accounts to evidence some professional misunderstandings and resulting problematic responses. For example, lack of eye-contact and social response, which had previously been understood as ‘rigid’ or socially ‘disconnected’ behaviours, were reinterpreted as defensive after considering the following insider account:

> The blackness I had to get to was the jump between 'my world' and 'the world', though I had never been able to make it in one piece… Too many well-meaning people would have tried mercilessly to drag me through the darkness unprepared, and killed my emotional self in the process. (Williams, 1992, p. 91).

Billington (2006) suggested that when interpreting behaviours, practitioners should focus on autism strengths and an awareness of the interaction between individuals with autism and their environment. Parents and professionals were also advised to avoid placing the responsibility for change onto the young person, but instead to consider their own actions and practices.

3.7 Limitations within the literature: CYP views about autism diagnosis

Due to the qualitative methods used by all except one of the studies that explored the views of CYP with autism, they were limited in having a small number of participants. However, as emphasised by Jones *et al*. (2015, p. 1501), such approaches do not aim to achieve 'power through numbers' but by establishing common themes and by achieving saturation within the analysis. As found by the systematic review about methods for gaining the views of CYP with autism within research (Fayette and Bond, 2018), most of the studies did not include information about how the methods used were appropriate for CYP on the autism spectrum. Milton (2014) has also identified this as a limitation which could impact the quality of the knowledge produced. Another limitation identified in five of the papers, which followed an IPA approach, is that member checking was not undertaken to seek the participants' feedback on interpretation of their views by the researchers (Birt *et al*., 2016). Such issues have been identified to produce a 'power imbalance' between the researchers and participants (e.g. Birt *et al*., 2016; Hadi and Closs, 2016).

Although the studies largely defined their participants' diagnoses as autism or Asperger syndrome, they provide less detail about their participants' language and learning skills. However, the information provided indicates that all the participants were able to discuss their diagnosis and were able to assent to participation in research. One study indicates that the participants were members of the debating society, suggesting good communication skills within a formal format. Only the study by Jones *et al.* (2015) identified a specific assessment to identify the verbal mental age of their participants; using the Peabody Picture Vocabulary Test (Dunn and Dunn 2007), they identified that only two of their participants' verbal mental age was lower than their chronological age. However, their communication skills were also at a reasonable level for participation, being over 10 years. Therefore, the studies do not represent views from the range of ability and impairment seen across the autism spectrum.

Bornstein, Jager and Putnick (2013) highlighted that the approach to sampling can introduce biases. Indeed, there are several limitations to consider that occur across the studies, which therefore also apply to the synthesis of the findings. The number of included studies is small, and the authors of several studies did not fully discuss the limitations. Therefore, as methodological transparency is not consistently demonstrated, it is not possible to fully understand potential confounding factors. In addition, while the male gender dominance reflects the evidence base about gender differences in autism, this does not preclude sampling bias. As suggested by Lai *et al.* (2015), the autism screening tools used in many population studies are more likely to identify features of autism recognised in able males on the autism spectrum. This means that, although a male bias remains evident in the literature, the suggested ratio of approximately 3:1 is likely to be lower than the existing evidence base identifies. Furthermore, it is evident that across the papers, the samples were drawn from CYP with autism diagnosis whose communication and intellectual skills were within the broad average, or above, level of ability (e.g. Kenny *et al*., 2015; Jones *et al*., 2015). Thus, the heterogeneity identified to exist across the autism spectrum (Paulais *et al*., 2019), were not represented in the evidence-base focussed on CYPs' views about coming to understand autism and an autism diagnosis. Most of the studies also did not identify the cultural or socioeconomic background of participants. However, information about ethnicity and socioeconomic status was provided by Rossello (2015), whose participants were from families with higher socioeconomic backgrounds, three identified themselves to be Caucasian and one participant Asian. Molloy and Vasil (2004) also identified the nationality of the participants. Three of the six participants were living in England, but ethnicity was not identified. Three were living in Singapore (one identified as Australian American, one Australian and one Chinese). The other papers did not provide information about these demographic aspects of their participants' backgrounds. Therefore, there is insufficient information about how representative the research studies were in terms of sociocultural background of the participants.

Despite the limitations, the views that CYP on the autism spectrum shared demonstrated the potential impact that experiences related to autism diagnosis can have upon young people's self-esteem and identity (Huws and Jones, 2008). The existing research has also highlighted the potential impact of the terminology, and communication experienced in relation to self and autism diagnosis, alongside the social experiences of individuals, to shape the self-perceptions and identity of young people with autism (e.g. Baines, 2012; Huws and Jones, 2015; Jones *et al*., 2015). While the research evidence about young people's views related to autism diagnosis and being on the autism spectrum is increasing slowly, understanding is limited in relation to views specifically focussed upon the diagnostic processes and the support related to receiving and understanding the diagnosis.

3.8 Conclusion from synthesis of the literature about CYPs views

Despite the limitations identified, this synthesis of the literature demonstrated the potential impact that experiences of autism diagnosis can have upon CYP's self-esteem and identity (Huws and Jones, 2008). In particular, the synthesis highlighted the potential impact that the social experiences of CYP with autism can have upon their views of self. Social experiences were common points of discussion across papers, including feelings of stigma, inclusion/exclusion, and concerns relating to social self-efficacy. CYP also linked their discussion and views of the autism diagnosis with the context that they learnt about it. Where discussion of autism and the social context was negative, it was highlighted that CYP were more likely to distance themselves from the diagnosis (Jones *et al*., 2015); whereas the more positively CYP discussed their social experiences and their autism diagnosis, the more positive they were about their future (Jones, *et al.,* 2015; Rossello, 2015), and the more confident they were about disclosing the diagnosis to others (Rossello, 2015). Therefore, the socially influenced construction of autism appears to shape CYP's self-narratives, their self-perceptions and social self-efficacy, consequently, this is likely to impact their perceptions of autism and their identity development (e.g., Baines, 2012; Huws and Jones, 2015; Jones and colleagues, 2015). Bias is highlighted in the evidence base, however, as the participants across the papers appear to only represent the views of people with autism who do not have significant learning needs and who are able to communicate their ideas in ways that enable them to participate via commonly used methods. Furthermore, as discussed by Luke in the research of Molloy and Vasil (2004), CYP on the autism spectrum do caution against focussing explanations of autism only on the behaviours related to an identified diagnosis, rather than considering the individual, and their phase of development; as also suggested in the research of Jones, Huws, and Beck (2013).

While the research evidence about young people's views related to autism diagnosis and being on the autism spectrum is increasing slowly, understanding is limited in relation to views specifically focussed upon the diagnostic processes, and the support received to aid understanding of the diagnosis.

3.9 Parental views

Parental views are important to the way in which children might come to understand the diagnosis for several reasons. Recently, a large survey which sought parental views about discussing an autism diagnosis with their child by Crane *et al*. (2019) identified that parents were the key providers of information about the diagnosis for their children. The survey results also highlighted that only just over twenty percent of parents received any support with the disclosure processes. Parents are therefore the group who hold the most useful information about the strategies used to explain the diagnosis and about the impact of the diagnosis on their child. Research has shown that parent-child relationships are significantly associated with learning, social competence, peer relationships, and children's own views of themselves (Utting, 2007, p. 3-4), and to their educational outcomes (Department for Education (DfE), 2010; Campbell, 2011). Parental involvement is also identified as being crucial to a child's mental health and well-being (e.g., Cripps and Zyromski, 2009; Thomas et al., 2020). The research exploring the views of CYP with autism, as discussed above, suggested that their understanding of autism is socially constructed through interactions with peers, families, and the wider community (e.g. Huws and Jones, 2015; Jones *et al.,* 2015). It is therefore also likely that parental experiences during the autism diagnosis processes will shape the development of their own views about autism. Furthermore, parents are identified as the key advocate for CYP within the current governmental policy of England and Wales, as part of a person-centred approach, when decisions relating to an individual's education, health and care needs are being considered (DfE and Department of Health (DoH), 2015). Parents are therefore the key advocates for their child in relation to the diagnosis and the approaches utilised to support them. They are also key figures who will impact the way their child constructs their understanding of autism, and subsequently incorporates this understanding, as they build their view of self.

3.9.1 Results of the literature search: parents' views about explaining an autism diagnosis

As no papers were identified in the 2012 scoping review that specifically explored parents' experiences of explaining an autism diagnosis to their child, the scoping review explored broader topics related to parents' experiences of their children's autism diagnosis, such as the impact of the diagnosis on parents, their experiences of the diagnostic process and its impact, and the impact of post diagnosis interventions. However, as further research has been undertaken since 2012 on this topic, the 2019 systematic literature review identified seven studies specifically focussed on gaining parental views and knowledge about explaining an autism diagnosis to children. The research that has been undertaken is mostly qualitative, but does include a large mixed-methods survey, one large qualitative study, and four smaller qualitative studies that employed semi-structured interviews. In total, the papers represent the views of 675 parents. The parents who took part were mostly mothers (n=606), representing almost 90 per cent (89.78) of participants. However, a smaller number of fathers also contributed (n=69), just over 10 percent (10.22%). The search was limited to papers written in English. Two studies are from Canada and two from the UK, including the large mixed methods study, which collected the views of parents from across the UK, one study collected views from one area in England. One study collected views from Ireland, and another from parents in the USA. The final paper identified is a literature review, which synthesises views from more than one country.

The systematic review by Smith *et al.* (2018), which focussed on parental disclosure of autism, has not been included within the thematical analysis of qualitative information as three of the five studies identified by their review have been individually analysed for this review. The other two papers identified by Smith *et al*., (2018) focussed on children's perspectives rather than parents and were considered in the review of literature about children's views above. However, the Smith *et al*. (2018) review does provide a useful summary of some of the evidence base and an introduction to this review and analysis. The review highlighted the importance of the parental role in supporting children's understanding of the diagnosis, as they are most likely to be involved in both initial and subsequent explanation about autism to CYP. However, the review also revealed the lack of literature focussed specifically on the way that parents disclose diagnosis to their child. Smith *et al*. (2018) identified the key themes that occurred across the three parent focussed papers to include: explanation, processing, stigma, delay, and child self-disclosure. While these themes are evident across many of the papers, they do not capture all the themes or the relationship with the process that many parents describe. Parents in all three studies in Smith *et al.'s* (2018) review, identified that professionals' explanation of the diagnosis to them was significant, as it provided information about autism traits, which gave them confidence in the accuracy of their child’s diagnosis. A delay between finding out about the diagnosis and the subsequent disclosure to their child was also reported in all three studies. Parents discussed needing time to process the diagnosis in two studies (Rossello, 2015; Cadogan, 2015). Worry about the impact of the stigma that a diagnosis might bring was discussed in all three studies.

Smith *et al.’s* (2018) review highlighted that parents’ learning about the diagnosis is the first step, before explaining autism to their child, and observing and describing the subsequent impact on the child. A similar sequential process was also evident through the analysis of the papers identified below in this review. This sequential process involved: suspecting differential development; diagnostic experiences; the diagnosis being confirmed and the impact; preparing to tell the child about an autism diagnosis; communication about autism with the child; the child’s perceptions and actions upon learning about autism; and the longer-term impact of the diagnosis upon the child. Furthermore, the analysis of the themes across the papers pointed to the sequential location of the themes as crucial to ensure contextualisation. The themes in this review are therefore considered in terms of their relationship to the point of autism disclosure, their pertinence in terms of the most discussed themes is also highlighted.

3.9.2 Focus of the papers presenting parental views

While all the papers identified by this review explored parents’ views about sharing a diagnosis with their child, as shown in Table 9 below, the specific focus of the studies did vary. Cadogan’s (2015) study focussed on the impact of the disclosure on the child, while the study by Finnegan, Trimble and Egan (2014) explored Irish parents’ lived experiences of learning about and adapting to their child’s autism diagnosis, before considering the way that parents tell their child about their autism diagnosis. The studies of Ward (2014), Rossello (2015), Smith-Demers (2018), and Crane *et al.* (2019) all focussed specifically on the way that parents discuss autism with their children.

Table 9 below, summarises the papers identified by the search. It is followed by discussion of the review findings and the themes identified across the papers.

Table 9 Results of the literature review: parents' views about explaining an autism diagnosis to their child

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Cadogan, S. (2015) *Parent reported impacts of their disclosure of their child's ASD diagnosis to their children*. MA Thesis. University of Calgary.	Canada	To explore parent-reported impacts of disclosing a child's autism spectrum disorder (ASD) identify practical implications for parents and professionals.	15 interviews with parents of children with ASD 13 x mothers only 2 x mothers and fathers	Semi-structured interviews and thematic analysis	Parental disclosure of autism to their child was identified to have discernible positive impact. Six overarching themes were identified -telling children about their diagnosis facilitated discussions about autism related differences between children and parents. - difficulties associated with autism, explanations of autism and strategies overcoming problems and problem-solving strategies were discussed -understanding autism and autism awareness - reactions and impact of autism disclosure - views and feelings associated with autism disclosure - the impact, magnitude and valiance good"-ness vs "bad"-ness of an event).	Small study size, which the author highlights might not be generalisable to or representative of all families who tell their child about an autism diagnosis. Sample bias was also discussed by the researchers, including: • The small sample, the author identified the participants as a fairly homogeneous sample which comprised ○ more mothers than fathers ○ only parents who had disclosed were interviewed ○ children discussed by parents who were mostly without cognitive impairment The researcher also acknowledged that the methodological aspects might impact the findings: • Retelling of stories might miss other influences that impact • The methodologies and interpretation of data might have been influenced by researcher bias • Qualitative approaches do not identify cause in relation to disclosure and impact
Crane, L.,Jones, L., Prosser, R., Taghrizi, M. and Pellica'no, E. (2019) Parents' views and experiences of talking about autism with their children', *The International Journal of Research & Practice*. 23 (8), pp. 1969-1981.	UK	To understand parent experiences of talking about autism with their autistic and non-autistic children	558 Parents Fathers 24 (4.3%) Mothers 533 (95.5%)	Mixed methods Survey Descriptive presentation of quantitative data and thematic analysis	Of the parent participants most had told their child about the diagnosis (n = 379, 67.9%) Just over 20% had had support or advice about disclosure to their child (n = 163, 20.4%) Parents felt satisfied with the approach they adopted (n = 319, 84.2%) Most parent who had not yet disclosed, planned to in future (n = 339, 92.4%) and confident about disclosure (n = 100, 73.5%) Qualitative themes included openness, tailoring explanations of autism and understanding the challenge of diagnosis	Authors highlighted the potential for sample bias despite the large sample, parents were mostly: • Parents of children able to talk about autism • mothers • from white ethnic background, • educated to university level (more than half) Participants were likely to be those who accepted the diagnosis Parental perspectives might not mirror those of their children
Finnegan, R., Trimble, T, and Egan, J. (2014) 'Irish parents' lived experience of learning about and adapting to their child's autistic spectrum disorder diagnosis and their	Ireland	To understand parents' experiences of receiving the diagnosis and how parents communicated the diagnosis to their child	Parents of 7 children with autism diagnosis aged 8 to 12 years 6 mothers 1 father	Qualitative Semi-structured interviews and interpretative phenomenological analysis	Age of the disclosure to the varied from 8 to 12 years. Qualitative these identified in parent views were: • -problems in accessing diagnosis and then adjusting to it • challenges accessing support • balancing protection of the child with disclosure to support understanding and access to provision	As a small study, author identified it was not designed to representative of and generalizable to all parent child diagnostic disclosure experiences Potential sample related bias was discussed by the researcher including: • factors not considered such as gender, socio-economic status age, ethnicity or the nature of the diagnosis on parental experiences during diagnosis

Reference	Country	Aims	Sample	Methods	Findings	Limitations
process of telling their child about their diagnosis', *The Irish Journal of Psychology*, 35 (2-3), pp. 78-90.					• the need to adjust communication aid children's understanding	• Participants were mostly mothers, had more fathers participated, differing views might have been identified
Rossello, E. (2015) '*I have what?' A phenomenological inquiry into disclosing a diagnosis of Asperger's disorder to adolescent*s. PHD Thesis. University of Chicago.	Multi-national	To explore the most common ways a diagnosis of autism is disclosed and positive and negative outcomes following disclosure	8 parents (4x parent sets Mothers and fathers) 4x adolescents aged13-17 who had diagnosis at least 12 month	Qualitative, semi-structured interviews	Telling an adolescent about their AS diagnosis was identified to have greater beneficial than negative impact on their mental health. -No correlation was identified between the age that adolescents were told of their diagnosis and changes in mental wellbeing or behaviours - The desire to have known about the diagnosis and to have disclosed it earlier to their child was greater for fathers. Mothers' responses varied. Mothers were more likely to desire social group/online support with the process of disclosure. -There was no indication that location of disclosure (home/clinic) impacted adolescents emotional or behavioural responses. -There was no evidence that either the mother or father disclosing had a lesser or greater benefit that when both paren ts disclosed. -Parents who sought advice from professionals or conducted their own research led to a higher confidence level in making the disclosure	The author identified a number of limitations: • Generalisation to a larger population is restricted by the small number of participants as responses might or might not be coincidence • As the study was located in one area, their experiences might be different to those experienced by participants in other locations; • Researcher bias in topic choice and question design might have influenced results • Parental involvement in a community group that supports parents with similar needs may have skewed their experiences and the results of the study • Participants were selected from the agency where the researcher was employed, the researcher identified a strong commitment to the organization, which might have influenced both participant responses and researcher interpretation.
Smith-Demers, A.D. (2018*) The Elephant in the Room: The Lived Experience of Talking to Children with ASD about their Diagnosis*, PhD Thesis. University of Calgary.	Canada	To explore the decision-making process about whether to, and if so how and when to inform children about an ASD diagnosis	20 parent dyads (mother and father) who had disclosed & 20 parent dyads who had not disclosed	Qualitative, semi-structured interviews	Parents in the study identified: - Disclosure as gradual process that changes and develops over time - Unique approaches to disclosure that is situational for each child and family - Disclosure as important and has benefits - Discussing difficulties without naming autism prior to disclosure - Disclosure reasons: process/never thought not to disclose; part of who they are; child asking questions/aware of their differences; parents afraid they would find out - the experience of fear and deliberation throughout the decision-making process - disclosure—for some it just happened; some prepared narratives; letting the child lead was felt important; focussing on positive aspects gained attention to the discussion **Parental advice to others re disclosure:** - Parents know their child best and should personalize approach and resources based on their knowledge of their child's interests and development;	Potential sample related bias was discussed by the researcher, who identified that the sample was more homogeneous than planned, despite the recruitment of both disclosed and non-disclosed participants. The author identified; • No non-disclosing parents were fundamentally opposed to diagnostic disclosure, • There was limited diversity in age, cultural background, and family constellation • Participants required online access to contribute • Participation may have been limited by interest in the topic and being able to articulate and express in the English language • The study was limited to one geographical area Therefore, the views of parents who participated might differ to other and are not generalizable in different areas in this study may hold differing perspectives based on their access to resources and geographic location. parental report of a formal diagnosis was not verified; such verification could have improved the rigour of the study design. limited the number of participants who could participate and share

Reference	Country	Aims	Sample	Methods	Findings	Limitations
					- Normalise the process by making it a shared-decisions to disclosure and how to do it; - Process and understand the diagnosis prior to disclosure - Access resources to support to disclosure process.	their narrative around the concept of diagnosis disclosure
Smith, I. C., Edelstein, J. A., Cox, J. E. and White, S. W. (2018) 'Parental Disclosure of ASD Diagnosis to the Child: A Systematic Review', *Evidence-Based Practice in Child and Adolescent Mental Health*, 3(2), pp. 98-105.	USA	To identify articles describing the process of disclosing a diagnosis of ASD from the perspective of children, parents, or both.	5 qualitative papers identified 2x papers reported 30 Parental views included but parent gender not specified 2x papers reported Youth views 1x paper reported Youth and parent views	Systematic review	Across studies, findings suggest: - parents mostly tell their child before adolescence - varied responses to disclosure were identified - previous behaviours/symptoms were made sense of by the diagnosis Concerns reported: - delay between parents being told of the diagnoses and telling their child - processing the emotions related to diagnosis takes time. - the autism label would lead to stigma for the child Primary Themes: Delay-in 5 papers Explanation- in 4 papers Processing- in 4 papers Stigma- in 4 papers Child self-disclosure-in 3 papers Author suggested - best practice guidelines are needed to support parents with disclosure of autism - further research as it is an understudied element of the diagnostic process	Small number of studies identified. Not all studies were peer reviewed, therefore authors identify lack of sufficient evidence to enable provision of concrete, empirically supported recommendations
Ward, E. (2014) *Parental accounts of sharing an autism spectrum diagnosis with their child: a thematic analysis*. DClinPsy Thesis. University of Nottingham.	England, UK	To explore how parents share an autism spectrum diagnosis with their child	10 parents of children with autism diagnosis 2x fathers 8x mothers	Qualitative Semi-structured interviews and thematic analysis	Three main connected themes & related sub-themes: - Process of sharing: naming autism; exploring; meaning-making; acceptance and integration - Motivation to share: providing an explanation; protection - Management of sharing: preparedness (parent/child); approach and strategies; sharing as a process	- Self-selected sample of participants positive about sharing diagnosis is unlikely to reflect wider views. - Retrospective accounts were collected, parents have had time to reflect on the process, they might differ than the views of parents at other points of time in relation to explaining the diagnosis to a child. - Sample bias due to over-representation of mothers.

3.9.3 An overview of findings from a large survey

The large qualitative survey undertaken by Crane *et al*. (2019) reported the views of over five hundred parents, most of whom were mothers (95.5%). The parents were asked demographic questions about themselves, their family, and their children, in addition to questions about how they talked about autism. Parents who reported they had already told their child about the diagnosis, indicated that the mean age that children found out about the autism diagnosis was 8.59 years. Parents were more likely to inform, or be planning to inform, children about the diagnosis (87.6%) than professionals (13.2%). Although only just over a quarter of parents (28.8%) had been offered support by professionals, most (84.4%) who had received support were satisfied with the support provided. There was greatest variation in how well parents felt their child understood the diagnosis, just over a quarter (26.4%) felt their child fully understood what the diagnosis meant. Nevertheless, the survey highlighted that most parents (90.8%) were satisfied with their decision to make the disclosure.

3.9.4 Themes identified from the qualitative data across the studies

Across the papers, the main topics discussed by parents were parental experiences of diagnosis, parental preparation for disclosure to the child, parental views on disclosing and/or communicating about autism with their child, parental views about children's initial reaction to the diagnosis, children's perceptions and actions after disclosure, and the broader impact of the diagnosis on their child's experiences. The three most discussed topics across the papers were children's reactions immediately on being told of the diagnosis, their perceptions after diagnosis, and parental preparations for discussing the diagnosis with their child.

Analysis of the qualitative findings from the studies followed the same approach as that utilised for the papers about child views, as described by Boshoff *et al*. (2016). This involved three sequential stages: summarising, analysing and connecting themes. After summarising the themes identified in the findings (as shown in Table 9 above), detailed analysis of the papers and synthesis of findings involved connecting similar themes into overarching broad topics and sub-themes. Table 10 below summarises the main themes, sub-themes, and the number of times they occurred across the papers.

After Table 10, the themes are discussed sequentially in relation to the diagnosis. Themes relating to the period before disclosure are discussed first, followed by views relating to the disclosure and the immediate impact upon the child, and finally, the longer-term impact is considered. Within each section, the most commonly occurring themes are considered first, followed by the lesser occurring topics of discussion.

Table 10 Synthesis of findings from the identified studies about parent views of sharing a diagnosis

Parental experiences of diagnosis= 7 sub-themes identified 18 times across 5 papers	Theme: Parental preparation for disclosure to the child=16 sub-themes identified 43 times across 6 papers	Disclosing and/or communicating about autism to their child=11 sub-themes identified 38 times across 6 papers	Children's initial reaction to the diagnosis =11 sub-themes identified 28 times across 6 papers	Child perceptions and actions moving forward after disclosure 16 sub-themes identifies 38 times across 6 papers	The wider impact of diagnosis-7 sub-themes identified 11 times across 6 papers
Noticing differential development Diagnostic delay/diagnosis took a long time Frustration with the process Professionals not empathic Shock/surprise/negative emotional impact Confirmation/relief/hope Supported familial understanding	Pre/non-disclosure-Child/others don't notice Pre/Non-disclosure – child will not understand Pre/Non-disclosure – might impact child's self-esteem mental wellbeing Disclosure when-the child asks questions Disclosure when-child can understand Researching to prepare for disclosure Pre disclosure discussion with child about differences Parents feeling emotionally ready to disclose Parent's need/seek professional support Support from others useful or perceived to be useful Recognise the need to be open about diagnosis/ Never though not to disclose Disclosure needed/decided upon as a problem-solving tool Approached as 'everyday' neutral informative discussion/situational vs specific event Delay/desire to have known/disclosed sooner Concerns that disclosure that might have detrimental impact Worries about stigma, labelling or stereotyping	Tailoring discussion of diagnosis to individual Diagnosis in a problem or problem-solving context Disclosure to child challenges parents A learning opportunity for the child Discussion of difficulties/differences Role models with autism identified Tailored discussion to child needs/child led Focussing on positive aspects Disclosure should be as soon as possible Explanation a gradual process over time Disclosure is stressful for parents	Time to process Asking questions Accessing resources/researching Positive emotional reactions to diagnosis Accepting the diagnosis Improved understanding of self Strengths/successes reduce impact of diagnosis Relief Indifference Negative emotional reactions to diagnosis Rejecting the diagnosis	Importance of social standing/Social promotion of positive self Autism narrative & self/identity Autism a challenge to identify Acceptance of diagnosis Levels of autism, comparisons and distancing Understanding autism specific traits Impairment & losing control vs taking control negotiating autism and association with labels and stigma Understanding autism as an insider/owning the diagnosis Autism misconceptions/lack of understanding Feeling different/desire to fit in Belonging Improved self-awareness/empowering Social expectations, communication & self-esteem Disclosure to peers/associates Reluctance to disclose to peers	Negative impact Improved self-awareness More support in education following diagnosis Insufficient support Improved peer understanding Improved family understanding Experiencing stigma, labelling or stereotyping Used as an excuse

3.9.5 Parents’ views on their own experiences of the diagnostic process

Parental participants shared their views on their own experiences of the diagnostic process within some studies, this is useful as parents’ experiences could influence the way in which they feel about the diagnosis, thus potentially influencing their interactions with their child in relation to it. As shown in Table 11 below, parents’ experiences of the diagnostic process were discussed in five of the identified studies. In four studies, parents discussed their observations of their child’s differential development compared to peers or siblings. The diagnostic process was also identified to be problematic, for example, in three papers, parents identified lack of empathy from professionals to be problematic for them during the diagnostic process.

Table 11 Parental views about the autism diagnosis process

Theme: **Parental experiences of diagnosis= 7 sub-themes identified 18 times across 5 papers**	**Cadogan (2015)**	**Crane *et al.* (2019)**	**Finnegan, Trimble, & Egan (2014)**	**Rossello (2015)**	**Smith-Demers (2018)**	**Ward (2014)**	**Total number of papers in which theme identified**
Noticing differential development		✓	✓		✓		3
Diagnostic delay/diagnosis took a long time		✓	✓	✓	✓		4
Frustration with the process			✓		✓		2
Professionals not empathic		✓	✓	✓			3
Shock/surprise/negative emotional impact		✓			✓		2
Confirmation/relief/hope			✓		✓		2
Supported familial understanding		✓			✓		2

Parents' views across the studies suggest mixed experiences in finding out about the diagnosis. As shown in Table 11 above, although parents in two studies discussed experiencing negative emotions when learning about the diagnosis, parents in two studies also indicated more positive impact, some indicating the diagnosis was a relief and it was also reported to support familial understanding.

Smith-Demers' (2018) qualitative interviews explored the views of two groups of parents/parent dyads, twenty parents/parent dyads who had disclosed to their child and twenty who had not. Across the groups, parents discussed differences in their child's development as a reason for initiating the diagnostic processes, many parents identified that they noticed differences from a very early age. Parents also discussed feeling there was lack of clarity when the diagnosis was disclosed and frustration that the meeting was so short. Parents highlighted a range of feelings including shock and disbelief when the diagnosis was confirmed, but some also spoke of confirmation and relief. Reactions in relation to the confirmation of autism diagnosis also varied between those had and those who had not told their child. Parents in the study who had not disclosed the diagnosis to their children discussed problematic issues in the diagnostic process and the impact this had on themselves. Smith-Demers (2018) interpreted this to be an influencing factor for many parents. Worries about the potential negative impact on their child was also considered both in terms of disclosure and non-disclosure. Parents in Cadogan's (2015) study also identified fear that their child would disclose their diagnosis to others, as a reason for non-disclosure or delay. The parents in Smith-Demers (2018) study who had not yet disclosed the diagnosis to their child were, however, having conversations with their children about issues related to the diagnosis, even if they were not naming autism. This was also a theme identified in interviews with parents who had disclosed.

Finnegan, Trimble and Egan (2014) analysis of semi-structured interviews with parents of seven CYP with autism revealed very similar findings to those in the research of Smith-Demers (2018). Despite parents observing differences that led them to suspect that their child was not developing typically, upon reporting this to professionals, some parents reported feeling that their concerns were ‘brushed-off’. These experiences led parents to feel exasperated by the process, especially when they were certain that the diagnosis would be made once investigated. Parents also discussed professionals’ lack of empathy and lack of recognition of the impact of the experience of the diagnosis for parents. Although some parents reported feeling that their concerns were vindicated once the diagnosis was made, parents spoke of what might have been and a sense of loss.

The impact on parents, of a diagnosis for their child, highlights that communication during the diagnostic process has also been identified by parents as central to the process of coming to terms with a diagnosis. For example, research by Nissenbaum, Tollefson and Reese (2002) highlighted the central place of the ‘interpretive conference’ in helping parents to understand a diagnosis. Features that professionals felt supported this were preparation of information for parents about autism, provision of completed essential paperwork and reports including recommendations and the use of visual aids. Within the conference, effective communication skills were felt to be important, including non-verbal skills such as smiling. They also highlighted the importance of being honest about the diagnosis, but without providing too much information that might overwhelm parents. The professionals also identified that providing precise information related to the diagnostic criteria was important, as was emphasising the child's strengths, especially at the end of the meeting, in order that the family were left with a positive perception fresh in their minds. However, Nissenbaum, Tollefson and Reese (2002) also found that many parents reported that professionals did not clearly state the diagnosis of autism. Parents also reported mixed views about whether their child should have been present at the meeting about diagnosis. Most parents recalled their child being in the room when the diagnosis was given. However, parents who were certain that their child had been present, generally felt that their child was too young to understand. Furthermore, some parents who would have preferred them not to be present suggested this was because the child might understand the discussion. These parents reported needing time to 'grieve' without having to worry about their child (Nissenbaum, Tollefson and Reese, 2002, p. 35). The existing evidence base would therefore suggest the importance of considering the disclosure meeting with parents as a crucial moment, which can shape their views moving forward and, therefore, their interactions with their child in relation to autism disclosure.

3.9.6 Parents' preparations for sharing the diagnosis with their child

Preparation for disclosure to a child varied for the four parent dyads who took part in Rossello's (2015) study, approaches included seeking professional advice and attending conferences. As shown in Table 12 below, the most discussed preparation was use of books and internet research, which was identified by parents in four studies.

Crane *et al.'s* (2019) participants shared their views through open survey questions, about the advice they would give to other parents to prepare them for discussing autism with their children. Thematic analysis revealed the importance of being open about the diagnosis, sharing the diagnosis as early as possible, but at a point when they felt their child was ready. Parents also described coming to understand the diagnosis as a gradual process for children. They also emphasised children's right to know about the diagnosis and, despite worrying that disclosure might have a detrimental impact, they suggested it helped children's understanding of themselves, which could be empowering.

Table 12 Parental feelings, decision making and preparation for disclosing autism diagnosis to their child

Theme: **Parental feelings, decision making and preparation for disclosure to the child=16 sub-themes identified 43 times across 6 papers**	**Cadogan (2015)**	**Crane *et al.* (2019)**	**Finnegan, Trimble, & Egan (2014)**	**Rossello (2015)**	**Smith-Demers (2018)**	**Ward (2014)**	**Total number of papers in which theme identified**
Pre/non-disclosure-Child/others don't notice		✓			✓		2
Pre/Non-disclosure –child will not understand			✓		✓		2
Pre/Non-disclosure –might impact child's self-esteem mental wellbeing			✓		✓		2
Disclosure when-the child asks questions					✓	✓	2
Disclosure when-child can understand					✓	✓	2
Researching to prepare for disclosure (Internet & Books)	✓			✓	✓	✓	4
Pre-disclosure discussion with child about differences					✓	✓	2
Parents feeling emotionally ready to disclose		✓			✓		2
Parent's need/seek professional support		✓	✓	✓	✓		4
Support from others useful or perceived to be useful		✓	✓	✓	✓		4
Recognise the need to be open about diagnosis/ Never though not to disclose	✓	✓		✓	✓		4
Disclosure needed/decided upon as a problem-solving tool	✓	✓			✓		3
Approached as 'everyday' neutral informative discussion/situational vs specific event	✓	✓			✓		3
Delay/desire to have known/disclosed sooner		✓	✓	✓	✓		4
Concerns that disclosure that might have detrimental impact		✓	✓			✓	3
Worries about stigma, labelling or stereotyping		✓	✓				2

3.9.7 Parental approaches to sharing an autism diagnosis with their child

As shown in Table 13 below, parents in one paper felt their children should be told about the diagnosis immediately after the diagnosis was made. In three papers, parents indicated feeling that disclosing a diagnosis should be a gradual process that takes place over time. Parents who contributed to the study by Finnegan, Trimble and Egan (2014) reported that disclosure happened when they felt their child was developmentally and emotionally ready, to ensure knowledge of the autism diagnosis supported understanding, rather than being perceived as stigmatising. Finnegan, Trimble and Egan (2014) suggested that while parents were wary of the potential for negative impact, they also felt that understanding the diagnosis might be of comfort to their child. All parents in the study discussed wanting to protect their child's own self-image. They highlighted that they did this by focussing the disclosure on the uniqueness of the diagnostic features.

Ward's (2014) research employed semi-structured interviews with ten parents, and explored three main topics: sharing the diagnosis with their child, motivators for disclosure, and the process of sharing. Parents explained that their main motivation for sharing the diagnosis was to protect their child from negative self-perceptions, by providing an explanation for them. To manage the disclosure process, parents highlighted that they ensured that they and their child were ready. They also tailored the approach and resources that they used when explaining the diagnosis.

Table 13 Parental approaches to telling their child about their autism diagnosis

Theme: Disclosing and/or communicating about autism to their child=11 sub-themes identified 38 times across 6 papers	**Cadogan (2015)**	**Crane *et al.* (2019)**	**Finnegan, Trimble, & Egan (2014)**	**Rossello (2015)**	**Smith-Demers (2018)**	**Ward (2014)**	**Total number of papers in which theme identified**
Tailoring discussion of diagnosis to individual	✓	✓	✓	✓	✓	✓	6
Diagnosis in a problem or problem-solving context	✓	✓	✓	✓			4
Disclosure to child is an emotional challenge for parents		✓	✓		✓	✓	4
A learning opportunity for the child	✓	✓					2
Discussion of difficulties/differences	✓	✓	✓		✓	✓	5
Role models with autism identified		✓	✓		✓		3
Tailored discussion to child needs/child led		✓			✓	✓	3
Focussing on positive aspects	✓	✓	✓		✓		4
Disclosure should be as soon as possible		✓					1
Explanation a gradual process over time		✓			✓	✓	3
Disclosure is stressful for parents		✓			✓	✓	3

Some of Ward's (2014) participants explained that autism was always discussed within the home, while for others, there was a specific event when it was revealed to the child. As identified by Crane *et al*. (2019), parents in Ward's (2014) study identified that for their children, negotiating understanding of autism was a process rather than a single event. Parents described it as a process during which children made sense of the diagnosis, as they moved towards acceptance, before integrating autism into their view of self. Ward (2014) highlighted an important strategy that parents used successfully was to use their own understanding of autism, as it related to their child, alongside 'day-to-day' events, which provided specific examples that helped their child to understand the diagnosis in relation to their own experiences.

As shown in Table 13 above, participants in all the studies discussed tailoring the discussion of autism to their child. In five papers, parents indicated they explained their child's differences and difficulties when discussing the diagnosis with their child. In four studies, parents discussed focussing on strengths.

Parents who were interviewed for Cadogan's (2015) study, which explored how parents explained an autism diagnosis to their children, indicated the importance of open communication and highlighted that the disclosure can be used as an opportunity for problem solving. Parents explained that they discussed their child's differences and difficulties, and that such discussion provided opportunities for their child to learn about and understand the diagnosis. As in Ward's (2014) study, discussion of autism as it related to the individual was highlighted to be important. Rossello (2015) also explored parents' ideas about what would have been helpful to them in sharing the diagnosis, all identified that further professional support would have been useful. They also highlighted other useful factors, including undertaking more research themselves, discussion with other parents/online communities with experience of disclosing a diagnosis and access to a 'how to guide' (Rossello, 2015, p. 65).

3.9.8 Parents views about the impact of the diagnosis on their child

As shown in Table 14 below, children's reaction to the diagnosis was mixed. All papers identified themes related to accepting and rejecting the diagnosis, although within papers, rejection of the diagnosis was less commonly discussed by parents. In five papers, parents highlighted that knowing about the diagnosis led to an improved understanding of self. Parents identified both positive and negative reactions to the diagnosis in four papers.

When discussing the impact on their child, parents in Cadogan's (2015) study identified five themes: thinking and processing, seeking information, accessing resources, autism as an excuse and developing self-regulation skills. In four out of the fifteen interviews, parents discussed their child needing some time, after the initial disclosure, to think about and process the disclosure information. Some parent interviews highlighted that the disclosure was associated with their child actively seeking out more information, by either asking questions, or carrying out their own research using books or websites about autism. As reported by children themselves (e.g., Molloy and Vasil, 2004; Huws and Jones, 2008; Mogensen and Mason, 2015), parents also reported varied reactions to the diagnosis by their children. The most common reaction was relief, other reactions were specific to individuals, including anxiety, and worry about stigma if others found out (Cadogan, 2015; Rossello, 2015; Smith *et al.* 2018).

Table 14 Children’s reactions when first learning about their diagnosis

Theme: **Children’s initial reaction to the diagnosis =11 sub-themes identified 28 times across 6 papers**	**Cadogan (2015)**	**Crane *et al.* (2019)**	**Finnegan, Trimble, & Egan (2014)**	**Rossello (2015)**	**Smith-Demers (2018)**	**Ward (2014)**	**Total number of papers in which theme identified**
Time to process	✓			✓			2
Asking questions	✓					✓	2
Accessing resources/researching	✓						1
Positive emotional reactions to diagnosis		✓	✓	✓	✓		4
Accepting the diagnosis	✓	✓	✓	✓	✓	✓	6
Improved understanding of self	✓	✓	✓		✓	✓	5
Strengths/successes reduce impact of diagnosis			✓	✓	✓	✓	4
Relief	✓	✓	✓		✓	✓	5
Indifference	✓						1
Negative emotional reactions to diagnosis		✓	✓	✓	✓		4
Rejecting the diagnosis	✓	✓	✓	✓	✓	✓	6

Rossello’s four parent dyads (2015) reported varied responses from their child upon being told of the diagnosis. Two sets of parents reported very little change in their child before and after the diagnosis, other than asking questions related to the diagnosis. One parent reported that their child seemed sad about having a syndrome and being more hesitant in social interactions for a time, before returning to their usual interaction style. Only one child was reported by their parent to display a significant emotional response, which included screaming, refusing to accept the possibility that she might have autism and accusing her parent of lying. However, this reaction did not continue, behaviour soon improved, and she eventually seemed more relaxed than before being told of the diagnosis. Her parents also explained, that undertaking her own research about the diagnosis appeared to be the factor that helped her to understand the diagnosis, as she was able to reconceptualise it in light of this knowledge and her own experiences. A similar approach has been reported to be taken by adolescents when seeking information related to their health (Gray *et al.,* 2005), and by parents following their child's diagnosis (e.g. Cadogan, 2015; Rossello, 2015; Smith-Demers, 2018).

Parents in Ward's (2014) study described interactions with their child in relation to the diagnosis, which were interwoven with their acceptance of the diagnosis. Ward (2014) linked parents' acceptance of autism holistically, as part of their child's personality, to the way in which they were able to promote this positively to their child to facilitate their acceptance.

3.9.9 Parents views about their child's perceptions and actions following diagnosis

Across the papers, sixteen sub-themes were identified in parental discussion of their children's perceptions and actions moving forward after disclosure. As shown in Table 15 below, parents in five papers explained that following the diagnosis, children became more self-aware. Many parents in these papers also highlighted that knowing about the diagnosis had an empowering impact on their child.

Table 15 Children's perceptions and actions following their diagnosis

Theme: **Child perceptions and actions moving forward after disclosure 16 sub-themes identifies 38 times across 6 papers**	**Cadogan (2015)**	**Crane *et al.* (2019)**	**Finnegan, Trimble, & Egan (2014)**	**Rossello (2015)**	**Smith-Demers (2018)**	**Ward (2014)**	**Total number of papers in which theme identified**
Importance of social standing/Social promotion of positive self		✓			✓	✓	3
Autism narrative & self/identity	✓	✓			✓	✓	4
Autism a challenge to identify		✓			✓	✓	3
Acceptance of diagnosis	✓			✓			2
Levels of autism, comparisons and distancing			✓		✓	✓	3
Understanding autism specific traits	✓						1
Impairment & losing control vs taking control		✓	✓				2
Negotiating autism and association with labels and stigma	✓						1
Understanding autism as an insider/owning the diagnosis	✓	✓				✓	3
Autism misconceptions/lack of understanding	✓	✓				✓	3
Feeling different/desire to fit in	✓						1
Belonging		✓				✓	2
Improved self-awareness/empowering	✓	✓	✓	✓		✓	5
Social expectations, communication & self-esteem			✓			✓	2
Disclosure/reluctance to disclose to peers/associates	✓	✓					2

Parents in four papers discussed their children developing a narrative about autism as part of their identity, in three papers parents discussed the theme of owning the diagnosis. However, in three papers, parents identified that the diagnosis could challenge identity. Misconceptions and lack of understandings were also themes discussed in three papers.

Parents in Cadogan's (2015) study identified themes which suggested that the disclosure had discernible positive impacts on their children. Parents also identified that their children felt 'relief' on learning about the diagnosis (Cadogan, 2015, p. 44), which mirrors the views shared by children, (e.g. Gaffney, 2017, p. 72). Three parents suggested that their child accepted that autism was merely part of them, four parents suggested it was accepted in a matter of fact' way. Time to think and to process the information was also highlighted to be important, this was supported by children seeking out information and asking their parents questions. Cadogan's (2015) participants also identified that children's understanding of self was an important development following discussion of the diagnosis, which parents identified led to improvements in self-regulation, as discussions facilitated exploration of associated difficulties and related problem-solving strategies.

Some negative impacts were highlighted by parents in Cadogan's (2015) paper. For example, one parent described their child's worry about "stigma". Two parents suggested that their children were reluctant to disclose to others, which might also relate to anxiety about stigma associated with autism. Cadogan's (2015) findings also highlighted that knowing about the autism diagnosis could be empowering for CYP, as they then had the choice about whether to disclose to others. Parents discussed a range of responses that children encountered when others learnt about the diagnosis, some reported positive, supportive responses, while others described teasing. Cadogan's (2015) analysis suggested that, overall, the positive impact exceeded the negative.

Views of parents in the study of Finnegan, Trimble and Egan (2014) also varied about their child's perceptions moving forward from the diagnosis. However, they all hoped that their child would feel relief and that it would enable them to recognise that there were other people with autism. One parent explained how their child enjoyed hearing about other people with autism, especially '…the really intelligent people like Einstein' (Finnegan, Trimble and Egan, 2014, p.85). Parents who had disclosed the diagnosis felt there were mixed implications for their children. The 'label' was discussed as a source of comfort, but also to have potentially limiting impact. One parent, for example, explained the diagnosis would be of no benefit to their child, if it became an excuse, reasoning that '…life would not be so forgiving' (Finnegan, Trimble and Egan, 2014, p.85).

3.9.10 Parents views about broader impact of diagnosis on their child

Broader impacts from the diagnosis were identified in seven sub-themes, as shown below in Table 16. Parents in three papers discussed the way that their child's improved self-awareness led to improved wellbeing more broadly. In two papers, experiences of stigma, labelling and stereotyping were discussed, and some parents also discussed their worries about their child using the diagnosis as an excuse. Other sub-themes relating to this overarching theme were varied across the papers, these included, understanding of others and levels of support.

Table 16 Parents views about the broader impact of diagnosis

Theme: **Broader impact of diagnosis-7 sub-themes identified 11 times across 6 papers**	**Cadogan (2015)**	**Crane *et al.* (2019)**	**Finnegan, Trimble, & Egan (2014)**	**Rossello (2015)**	**Smith-Demers (2018)**	**Ward (2014)**	**Total number of papers in which theme identified**
Improved self-awareness			✓	✓		✓	3
More support in education following diagnosis			✓				1
Insufficient support		✓					1
Improved peer understanding		✓					1
Improved family understanding		✓					1
Experiencing stigma, labelling or stereotyping					✓	✓	2
Used as an excuse	✓	✓					2

Rossello's (2015) study reported ongoing positive impact on wellbeing after learning about the diagnosis, for example, one parent described their child as 'more relaxed' and to be 'less sensitive' about things.

Cadogan's (2015) study identified variation in terms of self-awareness related to autism traits. For some CYP, awareness of traits facilitated development of problem-solving strategies, such as advance planning for events and finding alternative access methods. However, some parents remained unsure how well their child understood the autism diagnosis. Regardless of how well the child understood the diagnosis, Cadogan's (2015) analysis suggested it could still facilitate access to resources as

CYP understood that specific strategies, resources, and organisations were available to them for support.

However, Finnegan, Trimble and Egan (2014), found that further to the difficulties experienced in obtaining the diagnosis, some parents reported they continued to experience difficulties accessing services for their child. Discussion in Cadogan's (2015) study focussed on children's ability to engage with resources that were already available, of which they were previously unaware, rather than on new resources being made available to them. Therefore, this different focus might be a factor that has influenced the different findings about post diagnostic access to resources.

Parents in Ward's (2014) study highlighted that children were able to access beneficial support from peers with autism once they knew of their own diagnosis. For example, one parent explained that by observing peers with autism, they were able to see positive role models, who were able and amusing. When this experience is linked with a new understanding of their own autism diagnosis, it was identified to instil a sense of belonging. Ward (2014) suggested that interacting with peers on the autism spectrum is therefore likely to support acceptance and integration of the diagnosis and a positive sense of self, as children experience acceptance from others.

3.9.11 Limitations in the research about parents' views of sharing an autism diagnosis with their child

The largest study by Crane *et al*. (2019) identified many of the limitations that were also evident in other studies. Despite the study being relatively large, the sample was highlighted to demonstrate bias towards certain characteristics; the participants were mostly white (97%) female parents (95.5%). Fathers were under-represented, as were parents from minority ethnic groups. More than half of the participants had also been educated to higher education levels. The children represented were mostly male (74.7%), less than a quarter were female (24.2%). Parents indicated a range of autism diagnostic labels, but less than twenty per cent reported that their child had intellectual difficulties (19.7%), and less than ten per cent (7.9%) reported that their child had little spoken language. As the survey was focussed on ‘talking to a child about autism’, it could be that fewer parents of children with learning and communication needs opted to participate, as they had not discussed diagnosis with their child. This has been identified in relation to children with different diagnoses, for example, many parents of children with intellectual disability have reported that they do not discuss a diagnosis with their child in order to protect them (e.g. McEnhill, 2008; Bernal and Tuffrey-Wijne, 2008; Tuffrey-Wijne *et al*., 2013). While seventy percent of parents reported not disclosing to CYP with Down syndrome (Goodwin *et al*., 2015). Crane *et al*. (2019) also highlighted that participants in their research were more likely to have been accepting of their child’s diagnosis. Therefore, the study might not reflect those who find the diagnosis difficult to accept. Perhaps of greatest importance is that the views are those of parents, not children, and parent’s views might differ to the views of their children.

Cadogan’s (2015) small study, also reported a fairly homogeneous sample from one geographical area, which comprised mostly mothers who had disclosed to children without intellectual impairment. Furthermore, as parents were only asked about communicating the diagnosis, other influences that impact understanding of autism diagnosis might have been missed. Finnegan, Trimble and Egan (2014), Ward (2014), Rossello (2015) and Smith-Demers (2018) were also relatively small studies that reported sharing similar sample limitations. However, as small qualitative studies, they were not designed to representative and generalisable, but to understand the richer, contextualised experiences of discussing an autism diagnosis with a child. As Finnegan, Trimble and Egan (2014) suggest, this might provide a better understanding compared to those studies that rely on standardised measures, which might provide little useful information about the actual process.

3.9.12 Implications from the wider literature about the impact of the diagnosis on parents

In the studies identified within this literature review, there were clear parallels between parental views about the impact of their child's autism diagnosis on themselves, and the way in which they discussed the impact on their child (e.g., Ward, 2014; Rossello, 2015). Wider research about parents' experiences of the diagnosis has identified that they experience a period of adjustment and adaptation following their child's diagnosis. Hornaby (1995) and Dale (1995) likened this to the process of bereavement. However, a study by Russell and Norwich (2012) highlighted a more practical process; their parent participants explained that one they had a name for their child's needs, they could research the condition, and understand and manage their child's behaviour more effectively. This process also facilitated the process of coming to terms with the diagnosis. In the papers identified for this review, parents describe a similar process when discussing their own diagnostic experiences (e.g., Finnegan, Trimble and Egan, 2014; Smith-Demers, 2018; Crane *et al.*, 2019) and those of their child (Cadogan, 2015).

3.9.13 Parents' views about impact of post-diagnostic intervention

Wider literature about parental experiences of support in relation to their understanding of the diagnosis might also point to strategies of benefit for children. For example, Osborne and Reed's (2008) research about group interventions for parents, investigated how parents might be supported to understand autism and their child's diagnosis. Parents in their study indicated that their needs changed over time. Parents reported needing simple general information about autism immediately after being told about the diagnosis. After a period of adjustment, however, they felt that information about the range of interventions that were available would be useful. Abbott, Bernard and Forge (2013) undertook narrative research with parents who had experienced the diagnostic process. Parents in their study reported that the autism assessment feedback meeting was both a significant and stressful event. They indicated that the emotional impact was greatest when they were told, and for some time afterwards. The emotional impact sometimes resulted in parents being unable to focus upon the other information provided during the session. Abbott, Bernard and Forge (2013) therefore suggest that information overload is a risk at this crucial point in the diagnostic process.

Kerrell's (2001) analysis of parental views found that they wanted an explanation of the clinical processes during assessment, and written information about services following the diagnosis. Individualised advice related to their child, including their current development and projected progress, was also highlighted to be important. Mansell and Morris (2004) found that parents wanted information throughout the assessment and at the time of diagnosis. Parents in their study also identified the need for professionals to provide reassurance and to show empathy. Therefore, the evidence from parents suggested that the provision of timely and appropriate information is crucial following the diagnosis.

Providing appropriate support services has also been identified by parents to be crucial, unfortunately, research shows that such support is not always provided appropriately. Research by Mansell and Morris (2004) found that while parents felt that providing support too soon after diagnosis to be problematic, they did value the opportunity to engage with other families. Research by Beatson and Prelock (2002) identified other elements that were viewed as good support by parents, these include the involvement of the child's school, alongside parents, within the assessment process; this was especially useful in helping parents with the cognitive process of understanding the diagnosis, which also supported them to accommodate their child's behaviours.

3.9.14 Conclusions from the studies identified: parental views on disclosing an autism diagnosis to their child

Recommendations from the National Collaborating Centre for Women's and Children's Health (2011) review of research suggested that, following diagnosis, parents wanted information that included simple definitions of all relevant terminology, as well as signposting to useful reading and the support available. Engaging with this type of information had been identified to support parents to develop their understanding of the diagnosis and the narratives they develop in relation to it. Russell and Norwich (2012) highlighted that parents benefit from developing positive narratives to de-stigmatise the concept of autism. These narratives, they suggest, were employed by parents in their study as a medium to influence the views of others; however, employing the narratives in this way was also a process that supported parents to come to view the diagnosis more positively. Parents who contributed to the papers in this review, suggested that their children experienced a similar process. For example, parents in Cadogan's (2015) research identified thinking and processing, seeking information, and accessing resources as processes that children went through upon finding out about the diagnosis.

The Clinical Guidance relating to autism diagnosis (National Institute of Health and Care Excellence (NICE), 2011b) suggests there are both benefits, and potential harms associated with the way that information is provided to CYP following diagnosis. The guidance therefore recommended that, to maximise benefits, good communication between professionals, parents and children was essential. However, the literature identified for this review identified it is parents who are the main providers of information about autism to children following an autism diagnosis (Crane *et al*., 2019). The NICE (2011b) guidance also highlighted that communication should be supported with accessible, specially tailored, evidence-based written information, which is appropriate to the child or young person. In the studies identified by this review, parents indicate that they do tailor their information when explaining the diagnosis to their child, by making it specific to their child's development level, and also to their experiences, thus ensuring that their understanding is contextualised (e.g., Crane *et al.*, 2018; Finnegan, Trimble and Egan, 2014; Ward, 2014). Furthermore, as identified by Ward (2014), parents used both their own understanding of their child, and about autism, to shape this discussion with their child. This highlights the potential importance of the professional role in providing information about autism to support parental understanding, as this will increase the likelihood of accurate information being shared with children. In addition, as parents identified that CYP often sought out information themselves following diagnosis, provision of, or signposting to, good quality written information, as suggested by NICE (2011b), could also provide essential support for CYP, as well as parents, following disclosure of an autism diagnosis. The NCC-WCH (2011) review of research suggested there was insufficient robust evidence to provide advice about how to disclose an autism diagnosis to CYP. A large study and several small qualitative studies now add to the evidence base, all of which highlight the importance of the parent role. Moreover, a number of consistent themes were evident across the research studies from parents, which suggest the need for: parental and child readiness for disclosure; provision of information in developmentally appropriate ways; and the focussing of information for CYP on strengths, as well as on child specific experiences, differences and difficulties. It is also highlighted that disclosure of diagnosis, when contextualised and individualised, can support CYP's problem solving skills. Children were also identified to need time to process the diagnostic information, as well as being interested in searching out information for themselves following the disclosure. While some consistent themes are emerging through research, also evident are the limitations in the evidence base, especially in relation to sample characteristics, which means that the evidence cannot be generalised across all parents of children with autism who wish to share the diagnosis with their child. There remain gaps in the evidence, especially related to the way disclosure is impacted by ethnic culture, and about disclosure to children with autism who also have additional learning needs.

3.10 Professionals' views

In the UK, NICE (2011b) clinical guidance for autism diagnosis relating to CYP, identified that autism diagnosis should be made by a multi-agency autism team. The guidance also highlighted that, in addition to skills for diagnostic assessment, professionals should have the competencies required to '… communicate with children and young people with suspected or known autism, and with their parents and carers, so they can sensitively share the diagnosis with them' (NICE, 2011b, p. 6; s: 1.1.6). Therefore, as professionals are identified to have a role in both making the diagnosis and communicating the diagnosis to children and their parents, their views and experiences of sharing an autism diagnosis are useful to understand.

3.10.1 Summary of the papers giving professionals' views about disclosing autism diagnosis

There is a significant body of literature focussed on professional's general views about issues such as changes in diagnostic criteria, applying criteria when making diagnosis, and accuracy within diagnosis. However, the search identified only eleven studies that explored the ways in which professionals explain the diagnosis to children, or to their parents, which is seven more than in 2012. However, most focussed on the disclosure to parents and only two specifically focussed on explain an autism diagnosis to children. As shown in Table 17 below, the papers identified all employed qualitative methodologies. The most common data collection method used in the studies was interviews; six studies used interviews; four of the studies employed only face to face interviews (Nissenbaum, Tollefson and Reese, 2002; Finke, Drager and Ash, 2010; Jacobs *et al*., 2018; 2019) and one study employed telephone interviews (Crane *et al*., 2018). Bartolo (2002) considered how two multi-disciplinary teams approached autism diagnosis, utilising interviews and discussions with their case teams to generate the data for the study. Two studies employed a child focussed case-based approach (Fletcher, 2013; Miller, 2015). Fletcher (2013) undertook a general literature review and described how the strategies identified by the literature were utilised with one child. Miller (2015) provided a qualitative case–based study outlining the implementation of a programme to support understanding of an autism diagnosis, drawing on four illustrative cases. Gray, Msall and Msall (2008) presented a general literature review and Rogers *et al*. (2016) employed a large online survey. The final study by Braun, Dunn and Tomchek (2017) used retrospective analysis to explore how the diagnosis was presented by professionals in their diagnostic reports.

Table 17 Professionals’ views about giving the autism diagnosis, interventions and impact

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Bartolo, P.A. (2002) ‘Communicating a diagnosis of developmental disability to parents: multi-professional negotiation frameworks’, *Child: Care, Health & Development*, 28(1), pp. 65–71	England, UK	To explore how disclosure of autism was negotiated with parents by multi-professional groups	2 tertiary, multi-professional groups in London: G1: paediatrician, clinical psychologist, speech therapist, G2: educational psychologists, psychotherapist, special needs advisor and colleagues	Case study approach Professional discussions & interviews following assessment	3 social-interaction frameworks for discussions with parents were identified: • parent-friendly frame • hopeful-diagnostic-formulation frame • defocussing-of-bad-news	Not identified by authors A small number of cases and professional groups, limits the the generalisability of the findings. A focus on giving assessment results should be included in training for practitioners
Braun, M.J., Dunn, W. and Tomchek, S.D. (2017)’ A pilot study on professional documentation: Do we write from a strengths perspective?’ *American Journal of Speech-Language Pathology*, 26, pp. 972–981.	USA	To analyse diagnostic reports for strengths-based writing	psychologists, speech & language pathologists, occupational therapists 20 patient reports (299 phrases)	Descriptive study using retrospective analysis of existing patient reports	Diagnosticians tend to write more from a deficit perspective that a strengths-based perspective Diagnostic criteria that influence diagnostic reports are based on deficits and might influence report writing	Sample of reports was from variety of interdisciplinary clinicians but only from one clinic and may not be generalisable to all diagnosticians The focus on autism diagnosticians also limits the generalisability to other interdisciplinary clinicians
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*, 48, pp. 3761–3772.	UK	To identify aspects of the diagnostic process that are working well, and areas in which improvements are needed.	10 parents 10 adults with autism diagnosis 10 professionals 8 Female;2 Male 3 clinical psychologists, 2 paediatricians; 2educators 1 educational psychologist; 1 psychiatrist; 1 speech and language therapist; 1 specialist	Qualitative research -telephone interviews and thematic analysis	Three key themes were identified by professionals that related to: • communication about diagnosis • barriers within the diagnostic processes impacted satisfaction • support after diagnosis being inadequate	Generalisation of findings is limited due to the small study size, Sample bias was highlighted due to lack of ethnic diversity, participants were mostly white females. Rosenthal and Rosnow (1975) highlighted that women are more likely volunteer for research than men

Reference	Country	Aims	Sample	Methods	Findings	Limitations
			early years practitioner			
Finke, E. H., Drager, K.D.R. and Ash, S. (2010) 'Pediatricians' perspectives on identification and diagnosis of autism spectrum disorders', *Journal of Early Childhood Research*, 8(3), pp. 254–268	USA	To describe paediatricians' experiences of autism diagnosis	5 general paediatricians	Qualitative interview	Themes identified related to: **Knowledge/training**: Characteristics and signs of autism; rate of incidence; causes; professionals' personal experiences of autism; what they wished to know and advice for junior doctors. **Diagnosis** Assessment; initial signs and concerns; a wait and see approach, referral, giving a diagnosis and related time factors. **Communication** Relationships with the family; asking questions of the family, addressing questions and concerns and families' reactions to diagnosis **Conclusions:** Insufficient number of paediatricians challenges the process. Insufficient training may cause professionals to feel unqualified to make a diagnosis	Participants' demographics and roles were varied A small study, which limits the the generalisability of the findings
Fletcher, I. (2013) 'Exploring the diagnosis of Asperger syndrome with a primary-aged pupil: resources, issues and strategies', *Good Autism Practice*, 14(2), pp. 8-22.	England, UK	To review the literature on what is known about sharing the diagnosis with children with Asperger syndrome and to identify a framework to define how this might be done	Literature Review and experience of using the approach with 1 primary child	Literature review and case study to develop framework	Author synthesis of findings suggests: text resources need to be tailored for individuals -vocabulary should be unambiguous and images appropriate to support understanding - materials should be age appropriate and should include interests or characters children can identify -an interactive element is also suggested to encourage engagement and to empower the individual	None identified by the author General rather than systematic review, important factors could have been overlooked
Gray, L.A., Msall, E.R. and Msall, M.E. (2008) 'Communicating about autism: decreasing fears and	USA	To provide information about developmental and behavioural perspective to guide professionals to	No participants	General literature review	Review identified importance of: Listening to families concerns; comprehensive early intervention and education; considering developmental needs relating to autism; support improve social communication,	None identified by the author General rather than systematic review but papers discussed are peer reviewed,

Reference	Country	Aims	Sample	Methods	Findings	Limitations
stresses through parent-professional partnerships', *Infants & Young Children* 21(4), pp. 256–271.		support families throughout the diagnostic process of autism			promotion of adaptive skills building on strengths; ensuring parents understand autism cannot be cured. Physicians do not need to be experts but should be able to signpost parents to appropriate information and support.	nevertheless, important factors could have been overlooked
Jacobs, D., Steyaert., J., Dierickx, K. and Hens, K. (2018) 'Implications of an Autism Spectrum Disorder diagnosis: An interview study of how physicians experience the diagnosis in a young child', *Clinical Medicine*, 7, pp. 348-364.	Flanders Belgium	To explore the way clinicians experience ASD and an ASD diagnosis in their clinical practice.	16 physicians working children under 6 years without a diagnosis of intellectual (or other) disability but with autism (or presumed autism) diagnosis	Qualitative, semi-structured interviews & interpretative phenomenological analysis	Physicians perceive certain risks and benefits associated with autism, but felt diagnosis should be made to facilitate more effective approaches for the child Parent impact is mixed, e.g., relief, devastation but the benefits of diagnosis outweigh negative implications. Professionals mostly (5/16) relied on parents to disclose to the child. Four functions identified for diagnosis: (1) giving clear plausible explanation for parents, child, and others (2) confirming parental concerns (3) support realistic expectations (4) lifting blame from parents and child	Sample identified to be homogeneous group;, however, selection bias was identified as participants were volunteers and might therefore hold particular views of diagnosis.
Jacobs.D., Steyaert.J., Dierickx,K. and Hens,K. (2019) 'Physician view and experience of the diagnosis of Autism Spectrum Disorder in young children. *Frontiers in Psychiatry*, 10, pp. 372-383.	Flanders Belgium	To gain an insight into the conceptualizations of autism of physicians working with children presumed to be on the autism spectrum but without intellectual disability	16 physicians working with preschool children without a diagnosis of (intellectual or other) disability with a (presumed) diagnosis of autism	Qualitative, semi-structured interviews	Physicians' multi-faceted and sometimes ambiguous perceptions of autism impacts autism diagnosis. 1) physicians' views link personal clinical styles and professional knowledge 2) Diagnosis of autism is seen as a descriptive element of the clinical trajectory; 3) treatment suggestions are a mix of personalised with standard approaches Physicians were found to experience difficulty defining, diagnosing, and explaining diagnosis clearly to parents.	Self-selection bias: participants volunteered and were interested in sharing views Sampling issues-focus on autism without intellectual impairment and assumed diagnosis No attempt to quantify the findings or suggest generalisability as the authors identified it would require contextual translation to facilitate clinical use in other settings/cultures.
Miller, A. (2015) 'The All About Me Programme: a framework for sharing the autism diagnosis with children and young people', *Good Autism*	England, UK	To summarise the author's experiences of using the *All About Me Programme* to support children and young people with autism to	Views of 1 specialist advisory teacher who had utilized the programme with over 200 children	Qualitative explanation of programme inclusion and exclusion criteria and presentation of 4 case studies	Most children reacted positively to being told about autism via the programme. Important to emphasise child's strengths and talents to support difficulties to be overcome. Time to process is important, more than 3 programme sessions are likely to be needed	Programme limitations: Availability of professionals with sufficient skills Parents must also be ready for the diagnosis to support the

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Practice, 16 (1), pp. 79-92.		understand their diagnosis			Teaching children about autism: - is hard and never routine -is a unique emotionally charged event - requires a positive focussed, outwardly calm, confident, reassuring, and matter of fact manner - demands a good understanding of individuals and appropriate pedagogy	CYP processing of information during and after sessions Not generalisable, no control group, a small number of cases presented, but discussion also informed by work with over 200 children.
Nissenbaum, M.S., Tollefson, N. and Reese, M.R. (2002) 'The Interpretative Conference: Sharing a Diagnosis of Autism with Families', *Focus on Autism and other Developmental Disorders*, 17(1), pp. 30-43.	USA	To examine professionals' and parents' perceptions of giving and receiving a diagnosis of autism,	11 nonmedical professionals 17 parents of children (2-5 yrs) with autism/AS diagnosis 15 mothers 2 fathers	Qualitative interviews	Professionals mostly described autism using negative terms Themes included: • Presentation to families ○ nonverbal communication skills ○ Being honest ○ avoiding too much information ○ highlighting the child's strengths, ○ Discussing the criteria & scores • Who gives the diagnosis? • When the diagnosis is given • Whether to include the child • Interventions • Positive and negative reactions to giving and receiving diagnosis	Selection bias is possible as most participants were white mothers from affluent families in one county. Does not provide balance of views. Views from others such as fathers, other parent relationships, cultures, and socioeconomic might view professional diagnosis differently
Rogers, C., 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: The International Journal of Research and Practice*, 20(7), pp. 820–831.	UK	To explore professionals' experiences and opinions of three key areas of service: accessibility, the diagnostic process and post-diagnostic support	116 multidisciplinary professionals heterogeneous sample: psychologists, speech and language therapists, paediatricians, psychiatrists, nurses, teachers and occupational therapists	Online questionnaire Descriptive presentation of results & thematic analysis for open question responses	Most professionals were satisfied with service access but 40% indicated their service missed timescale expectations. Standardised diagnostic tools were identified helpful and used consistently Uncertain complex cases were reported to be upgraded to autism diagnosis. Concerns were highlighted about tool validity for detecting atypical autism. Professionals found disclosure of autism challenging, especially ensuring caregiver understanding, pitching information correctly, and managing distress. There was dissatisfaction with post-diagnostic provision and improvement in service provision identified as needed.	Anonymity of the online survey did not facilitate - Accuracy of responses to be checked - Provision of in-depth responses. - Sampling limitations: - Lack of ethnic (90% White). - Geographically skewed, e.g. 35% London and the South East, - Psychologists over-represented relative - to other professions

3.10.2 Overview of participants within the papers exploring professionals' views

The eleven papers presented the views of one-hundred and eighty-eight professionals. Although not all papers were specific about the professional roles, taken together they represented views from a range of disciplines. Twelve roles were explicitly named, including: paediatricians; clinical psychologists; speech and language therapists; occupational therapists; educational psychologists; psychotherapist; special educational needs advisors; psychologists; psychiatrists; nurses; teachers; and early years practitioners. The roles identified in the papers were all linked with either education or health. No social care professional roles were identified. However, some papers use vague terms such as 'nonmedical professionals' (e.g., Nissenbaum, Tollefson and Reese, 2002), therefore, it might be that a small number of social care professionals' views were included, even though these roles were not specifically named.

As shown in Table 17 above, although eleven papers were identified that explored the way in which professionals disclosed an autism diagnosis, most of the papers explored the disclosure of the diagnosis to parents, with occasional brief references to the child during assessment, or to the child being in the room at disclosure. The two papers that were identified to have explored the disclosure of diagnosis of autism specifically to children are Fletcher (2013) and Miller (2015).

3.10.3 Overview of themes across the papers: professionals views and disclosing to parent

Themes that were apparent across the professional papers were focussed under five overarching topics: professional views about autism, service delivery, professional training and competence, framing autism (for parents), establishing relationships, disclosure logistics (who, when and how), and the impact of diagnosis. Table 18 below presents an overview of the key themes and sub-themes; this is followed by discussion of the key themes and sub-themes, including their occurrence across the papers identified by the search.

Table 18 Identification of professional views across the papers

Professional views about autism, training and service delivery	Disclosure logistics (who, when & what)	Communication, Attributes & Relationships	Framing autism	Impact
Views about autism: • neurological reality • heterogeneous in nature • characteristics • Genetic cause • Hole in knowledge • Developmental milestones • Checklists • Parent insight as a trigger for professional concern • ASD-difficult to define, diagnose and explain clearly to parents • diagnostic descriptive profile **Dealing with uncertain diagnosis**: • Wait and see/hedging • Avoiding cause of alarm with • Emotions of family • Fear of giving incorrect diagnosis **Service delivery** • External demands vs quality of care • Lack of autism training • Lack of CPD • Shortage of trained staff • Shortage of services to refer to **Referral pathways** • A clear process • Open referral processes • Service access improvements	**Who is there** • Child • Involve individual & parents **When to parents** • hinting to diagnostic pointers • Only when certain • Diagnostic conference **Reducing time** • wait times • time taken to access service & • complete diagnostic process **What** Professional advice: • Highlight strengths • Discussing the criteria linked to the child's behaviours, • avoiding misconception • Avoiding too much information that might overwhelm • communicate the realities (positive and negative) • Advances in understanding of autism • Using an enablement framework • strength-based developmental history • Preschool presentation • expert clinical judgment • Intervention • individual child • Multiple sources of information • next developmental challenge • Caution about non-traditional therapies • Appropriate referrals • Support understanding of funding realities	**Good communication** • Open • Effective • Nonverbal skills • Reflective listening • Simple language • Humour, smiles • Honesty • Aligning parents/ professionals' views • Giving parents time to express concerns • Clarifying communications • providing valuable information • Addressing concerns • Addressing reactions to the diagnosis **Professional attributes:** • Outwardly calm • Confident • Reassuring • Matter of fact • Positive **Relationships** • Rapport building • Establishing a bond • Colluding • Comfort level/ familiarity with family • building alliances/ relationship with parents • Fostering respectful communication	**Parent-friendly frame** • Relate-to-child • getting the story straight • focussing on progress • Defocussing bad news • non-labelling frame • improvement frame **A hopeful-formulation frame** • child progress • entwining problems with appreciation of achievements • hedging the prognosis • ability perspective • empathic **Interpretive Neutral** • quantification & qualitative interpretation • neither positive nor negative **Interpretive Positive** • ability perspective strength or • positive attribute **Interpretive Negative** • behaviour is a deficit • disability rather than ability • deficit, a problem • Descriptive	**On professionals** Feelings • emotionally challenging for professional • Professionals emotional and physiological changes • sad, • Tearful, • Empathy for families, • Nervousness • Diagnostic doubts • Uncertain of parents' reactions. Physical changes: • Nausea • Body temperature increase • Heart rate raised • Thirst • Headache • Tiredness • Heavy breathing • Changing speech • Stuttering, or word retrieval difficulties **On parents** Psychological & Emotional Impact • Explanation • Legitimisation • Reduced expectations • Exculpation • Dual emotions- devastation and relief • Diagnosis sometimes actively pursued Positive-relief Negative • denial, • emotionality, misperception of the diagnosis, • no longer listening

3.10.4 Professional views about autism diagnosis

As shown in Table 19 below, when sharing their views about autism, professionals identified it to be a dynamic condition that changed over time (e.g., Rogers *et al*., 2016; Jacobs *et al.,* 2018; 2019). However, professionals also indicated that although autism is a neurological reality, the notion of a spectrum is problematic (e.g., Jacobs *et al*., 2019). Professionals also discussed autism having a genetic cause and being a condition for which the knowledge base is expanding (e.g., Gray, Msall and Msall, 2008; Finke, Drager and Ash, 2010; Rogers *et al*., 2016). Professionals also reported the importance of parental insight to support diagnosis and highlighted this as a trigger for professional concern (e.g., Finke, Drager and Ash, 2010; Jacobs *et al*., 2018; 2019).

As a result of the heterogeneous nature of autism, when making diagnosis, the professionals indicated that it can be difficult to diagnose, to define, and to explain clearly to parents. Therefore, many reported using a descriptive profile and checklists to support diagnosis (e.g., Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008; Finkle, Dragger, Ash, 2010; Jacobs *et al*, 2019). Autism diagnosis was identified to require expert clinical judgment (e.g., Gray, Msall and Msall, 2008; Finke, Drager and Ash, 2010), but where there were professional uncertainties, therefore, professionals reported using a wait and see approach (Finke, Drager and Ash, 2010; Rogers *et al.,* 2016; Jacobs *et al*. 2019).

Table 19 Professionals' views on autism diagnosis

Professional views on autism diagnosis (6 papers, 12 themes occurring 31 times)	**Bartolo (2002)**	**Braun, Dunn & Tomchek,**	**Crane *et al.* (2018)**	**Finke, Drager & Ash (2010)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Jacobs et al., (2018)**	**Jacobs et al., (2019)**	**Miller (2015)**	**Nissenbaum, Tollefson &**	**Rogers, *et al.*, (2016)**
Genetic cause & neurological reality				✓		✓					
Dynamic condition that changes over time							✓	✓			
Advances in understanding & hole in knowledge				✓		✓					✓
Developmental, behavioural milestones, IQ checklists				✓		✓		✓		✓	
Early identification and intervention				✓		✓	✓				
Diagnosis as a process							✓	✓			✓
Importance of parental understanding of child				✓			✓	✓			
ASD difficult to diagnose arbitrary cut-offs								✓			✓
Expert clinical judgment				✓		✓					
Dealing with uncertain diagnosis wait and see				✓				✓		✓	✓
Diagnostic delay or not given when full criteria not met				✓							✓
Devastated if given to own child										✓	

Professionals across the papers clearly recognised the significance of an autism diagnosis, while discussion was focussed on the diagnostic criteria, many revealed feeling that the diagnosis would be problematic for both the young person and their family (Gray, Msall and Msall, 2008; Finke, Drager and Ash, 2010; Jacobs *et al*., 2018; 2019). This view of autism as a problematic condition was exemplified best by professionals in the Nissenbaum, Tollefson and Reese (2002, p.33) study, many of whom reported they would be 'devastated' if their child received an autism diagnosis.

3.10.5 Professional views about professional training, competence and service delivery

The complexities around making the diagnosis are perhaps the reason that professionals raised concerns about lack of autism training (Nissenbaum, Tollefson and Reese, 2002; Finke *et al.,* 2010; Rogers *et al*., 2016; Crane *et al*., 2018).

Table 20 Professionals' views: training, competence and service delivery

Professionals: training & competence (5 papers, 4 themes occurring 10 times)	**Bartolo (2002)**	**Braun, Dunn & Tomchek, (2017)**	**Crane *et al.* (2018)**	**Finke, Drager & Ash (2010)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Jacobs *et al.*, (2018)**	**Jacobs *et al.*, (2019)**	**Miller (2015)**	**Nissenbaum, Tollefson & Reese (2002)**	**Rogers, *et al.*, (2016)**
Lack of autism training & CPD			✓	✓						✓	✓
Improved understanding of autism needed				✓							✓
Shortage of trained staff and services to refer to				✓							✓
Improvement needed in service access								✓			✓

As shown in Table 20 above, professionals also revealed concerns about balancing external demands while ensuring provision of quality care (Rogers *et al*., 2016; Jacobs *et al*., 2019). Other professionals reported that care was compromised by shortage of trained staff and of services to refer to (Finke, Drager and Ash, 2010; Rogers *et al*., 2016; Jacobs *et al*. 2019).

3.10.6 Professional views on disclosure logistics: who discloses, when and what

Across papers, professionals discussed aspects of disclosure of autism to parents, five papers discussed this explicitly (Nissenbaum, Tollefson and Reese, 2002; Finke, Drager and Ash, 2010; Rogers, Goddard, Hill, 2016; Crane *et al.*, 2018; Jacobs *et al*., 2019). As shown in Table 21 below, the topic of the child being involved in the diagnostic conference was discussed by five papers. Nissenbaum, Tollefson and Reese (2002) found that professionals had mixed views about whether the child should be included. Professionals in three studies discussed the parent and child being together during disclosure, but the child's needs were not explicitly considered in the views shared (Bartolo, 2002; Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008).

When to disclose was also a consideration by professionals. Nissenbaum, Tollefson and Reese (2002) suggested that professionals highlighted diagnostic markers during assessment to prepare parents. Participants in three papers emphasised that the diagnostic conference should take place only when the diagnosis is certain (Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008; Crane *et al.*, 2018). Professionals in the study by Rogers, Goddard, and Hill (2016) emphasised that the diagnosis should be made as early as possible. They also discussed concerns about the time taken to both access to the diagnostic service and to complete the diagnostic process.

Table 21 Professionals' views on the logistics of disclosure: who, when and what

Disclosure logistics (who, when & what) (8 papers, 15 themes occurring 25 times)	**Bartolo (2002)**	**Braun, Dunn & Tomchek, (2017)**	**Crane *et al.* (2018)**	**Finke, Drager & Ash (2010)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Jacobs *et al.*, (2018)**	**Jacobs *et al.*, (2019)**	**Miller (2015)**	**Nissenbaum, Tollefson & Reese (2002)**	**Rogers, *et al.*, (2016)**
Expect parents to disclose to child							✓				
Professional to parent				✓						✓	
Mixed views of whether child should be present										✓	
Professional to parent and child together but child not focus of discussion	✓					✓				✓	
Professional to parent and child together									✓	✓	✓
Reducing time for early diagnosis											✓
Only when certain at diagnostic conference			✓			✓				✓	
Enablement framework strength-based developmental history						✓				✓	
Discussing the criteria linked to child						✓				✓	
communicate the realities (positive and negative)						✓				✓	
Avoiding too much information						✓					
Advances in understanding of autism						✓					
Caution about non-traditional therapies						✓					
Intervention & school-based special education										✓	
Appropriate referrals						✓					

Professionals in the Nissenbaum, Tollefson and Reese (2002) study were asked what advice they would offer to other professionals about giving diagnosis, they emphasised the importance of highlighting the child's strengths but also of communicating the realities to parents, both positive and negative. They highlighted the usefulness of discussing the criteria, the scores and graphical range linked to the child's behaviours. However, they also emphasised the importance of avoiding too much information that might overwhelm.

Professionals in the study of Gray, Msall and Msall (2008) also shared views about what should be discussed with parents, highlighting the importance of using an enablement framework, based on a strengths-based developmental history. This, they emphasised, requires multiple sources of information about a child's strengths and weaknesses, as well as expert clinical judgment, which was suggested to be more reliable than algorithm-based diagnosis. To maintain a positive frame for parents, professionals highlighted advances in understanding of autism to parents. They also emphasised the importance of clarifying myths, such as those about vaccinations, which they highlighted can lead to 'family uncertainty' (Gray, Msall and Msall, 2008, p.258). To support the parent and child to move forward from the diagnosis, professionals suggested they followed a functional model of child development, which focussed on the individual child to inform advice about the next developmental challenge, potential interventions, and school-based special education. The importance of cautioning parents about non-traditional therapies, and supporting understanding of funding realities, was tempered with an emphasis on making appropriate referrals to provide support following the diagnosis. However, professionals also recognised that in addition to the correct information about an autism diagnosis, as it is an emotional event for parents, good communication skills and relationship building were also crucial.

3.10.7 Professional views: Communication, attributes and relationships

Relationships and communication were identified to be crucial across studies and were also recognised to rely on positive professional attributes and good communication skills. As shown in Table 22 below, professionals discussed the need for open communication, good nonverbal skills and reflective listening.

Table 22 Professionals' communication and attributes: establishing relationships

Attributes, Communication & Relationships (11 papers, 8 themes occurring 33 times)	**Bartolo (2002)**	**Braun, Dunn & Tomchek, (2017)**	**Crane *et al.* (2018)**	**Finke, Drager & Ash (2010)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Jacobs *et al.*, (2018)**	**Jacobs *et al.*, (2019)**	**Miller (2015)**	**Nissenbaum, Tollefson & Reese (2002)**	**Rogers, *et al.*, (2016)**
Getting the communication right	✓	✓	✓	✓	✓	✓			✓	✓	✓
Empathic, reassuring, compassion	✓		✓	✓	✓		✓			✓	✓
Building a rapport/fostering communication, trust		✓	✓	✓	✓	✓				✓	✓
Personal Clinical Styles								✓			
Aligning parents/ professionals' views	✓					✓					
Clarifying/addressing	✓	✓								✓	
Aligning parental explanation of child to diagnosis	✓	✓								✓	
Parental attitude problematic			✓								

In the study by Nissenbaum, Tollefson and Reese (2002), professionals also discussed the importance of using simple language and of stepping outside the professional role sometimes, by sharing humour and smiles. Paediatricians shared similar views in interviews with Finke, Drager and Ash (2010), important facets identified were listening to, valuing, and following up parental concerns. Good communication with families was also felt to be crucial and central to the diagnostic process; this was identified to be easier when they got to know the child and their family well. However, they highlighted difficulty discussing with parents what the diagnosis of autism meant for their child.

The attributes that professionals displayed were identified to be crucial in several studies. The importance of building a rapport with parents, to make them comfortable, and to become familiar with the family, was identified to be crucial to build trusting relationships by professionals in the studies by Gray, Msall and Msall (2008) and Crane *et al.* (2018). The Crane *et al.* (2018) study identified the importance of aligning parents and professionals' views to establish trust in the process. This is also emphasised to be important to ensure parents feel able to express concerns, for professionals to identify and address reactions to the diagnosis, and to clarifying communication to avoid misconceptions. However, professionals also identified that time constraints hindered this process and some professionals found it difficult to establish positive, professional relationships with some parents. While it was positive professional attributes that were highlighted to support success, it was problematic parental attitudes that professionals identified to hinder the establishment of positive relationships.

3.10.8 Professionals' views on framing autism when disclosing diagnosis to parents

As shown in Table 23, how to frame autism was a consideration across studies. Crane *et al.* (2018) highlighted that to develop a parent-friendly frame, professionals built on the relationships developed during assessment to inform the way they framed autism when disclosing to parents.

Table 23 Professionals' views on framing autism for parents

Framing autism for parents (8 papers, 14 themes occurring 36 times)	**Bartolo (2002)**	**Braun, Dunn & Tomchek, (2017)**	**Crane *et al.* (2018)**	**Finke, Drager & Ash (2010)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Jacobs *et al.*, (2018)**	**Jacobs *et al.*, (2019)**	**Miller (2015)**	**Nissenbaum, Tollefson & Reese (2002)**	**Rogers, *et al.*, (2016)**
Parent-friendly-child centred	✓									✓	
Defocussing bad news	✓										
Focussing on child progress/strengths	✓	✓	✓			✓				✓	
Entwining problems with achievements	✓										
Autism traits	✓									✓	
Difficult to diagnose, define, explain clearly								✓		✓	
Neutral interpretation	✓	✓								✓	
Negative deficit/ disability interpretation	✓	✓								✓	
Core diagnostic features explanation						✓				✓	
Cause, functioning level & prognosis			✓	✓		✓				✓	
Specialist provision	✓						✓				
Criteria & score-based explanation		✓	✓				✓			✓	
Diagnostic team consensus	✓									✓	
Focus on parent coping/ helping to help self	✓		✓					✓			

Bartolo’s (2002) study found that professionals used a parent friendly frame, which involved relating the diagnosis specifically to the child, getting the diagnostic story straight for parents, a focus on the child’s progress, and a de-focussing of bad news. Professionals also used a non-labelling frame, which involved hedging in relation to the prognosis. A hopeful-formulation frame was underpinned by an ability perspective, which focussed on children’s progress and entwining problems with appreciation of achievements. Braun, Dunn and Tomchek (2017) identified very similar framing from the professionals in their study, identifying a positive interpretation, built on an ability and strengths-based perspective, in which positive attributes were emphasised.

Braun, Dunn and Tomchek (2017) also identified a neutral interpretation from some professionals, which was built on criteria scoring, alongside qualitative interpretation of observations that were neither positively nor negatively framed. When professionals used negative framing, autism was interpreted and framed within the context of behaviour as a problem, as a deficit and/or a disability, rather than within an ability framing of the diagnosis.

Gray, Msall and Msall (2008) found that when explanations of autism were based upon the International Classification of Functioning, a strengths-based framework was established. This was similar to the views expressed by professionals in the study by Nissenbaum, Tollefson and Reese (2002), who explained that they highlighted and focussed on the child’s strengths, while also discussing the criteria linked to the child’s behaviours.

3.10.9 Professional views on the impact of autism diagnosis

As shown in Table 24 below, professionals reported a range of impacts on themselves and parents when sharing the diagnosis. Research exploring parental views about professional responsiveness when explaining a diagnosis has suggested a lack of emotional responsiveness from professionals. In the study of Crane *et al.* (2018, p. 3768), for example, a parent reported that their feelings were *'…for the most part, "ignored" by professionals*'. However, Nissenbaum, Tollefson and Reese (2002) reported that professionals in their study experienced significant emotional responses when sharing the diagnosis with parents, suggesting that they too find the experience difficult. Professionals revealed a range of emotional responses including feeling sad and tearful due to their empathy for the family. They also experienced nervousness due to diagnostic doubts and uncertainty about parental reactions. It is therefore unsurprising that they also described physical symptoms related to this stress including nausea, raised heartrate and temperature, changing breathing patterns and headaches.

The study by Jacobs *et al*. (2018) highlighted that professionals observed a dual impact of the diagnosis for parents, devastation and relief. It can be a relief as parents have both recognition of, and explanation for, their children's behaviours. The negative emotional impact of the diagnosis was also discussed, professionals identified a range of parental reactions, including trauma, denial, and guilt (Bartolo, 2002; Nissenbaum, Tollefson and Reese, 2002; Finke, Drager and Ash, 2010).

Despite the problematic emotional impact, practical positive impacts were also discussed. Within the study by Crane *et al*. (2018), for example, professionals identified that parents recognised they needed to reduce their expectations for the child, which could reduce family stress. Within four studies, the professionals identified entitlements to services and access to special educational provision for the child as a key impact of the diagnosis (Bartolo, 2002; Rogers et al., 2016; Crane et al., 2018; Jacobs et al., 2018).

Table 24 Professionals' views on the impact of diagnosis

Professional themes impact of diagnosis (6 papers, 12 themes occurring 22 times)	**Bartolo (2002)**	**Braun, Dunn & Tomchek, (2017)**	**Crane *et al.* (2018)**	**Finke, Drager & Ash (2010)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Jacobs *et al.*, (2018)**	**Jacobs *et al.*, (2019)**	**Miller (2015)**	**Nissenbaum, Tollefson & Reese (2002)**	**Rogers, *et al.*, (2016)**
Emotional, traumatic, denial and guilt 3	✓			✓						✓	
Misperception of the diagnosis, 1										✓	
No longer listening 1										✓	
Dual effect (devastation and relief) 2							✓			✓	
Reduction of expectations 1			✓								
Family/Others reject diagnosis 1			✓								
Entitlements to services for child 3			✓				✓				✓
Access to special/educational provisions 3	✓						✓				✓
Professionals want to offer support but not available/ commissioned 2			✓								✓
Support services needed/ fragmented 3			✓	✓							✓
Adults without learning disabilities underserved 1											✓
Only voluntary sector help available 1											✓

Although professionals identified specialist support as a key positive impact of the diagnosis, they also raised concerns about wanting to offer support, but none being available; services were also identified to be fragmented (Finke, Drager and Ash, 2010; Rogers *et al*., 2016; Crane *et al.,* 2018). Adults without learning disabilities were identified to be particularly underserved. Furthermore, not all families experienced the positive impact that the understanding of others can bring, especially if family members rejected or struggled to understand the autism diagnosis (Crane *et al*., 2018).

3.11 Professional themes disclosure to children

Only two papers were identified that exclusively focussed on professional views about disclosure of diagnosis to children, these are the papers by Fletcher (2013) and Miller (2015). However, although the other papers focussed mainly on presenting the diagnosis to parents, they did occasionally consider CYP. The main overarching themes that professionals discussed, when considering the disclosure to CYP, included framing autism for the child; the need to establish a relationship; disclosure logistics about with whom and where it should happen, and how the approach might be tailored; the final theme is the potential impact on the child.

Fletcher's (2013) paper comprised a review of writing from a range of genres including theory-based papers, information texts and workbooks, autobiographical writing and fiction, in order to provide advice for professionals about sharing the diagnosis. Fletcher's (2013) framework is focussed on framing an Asperger syndrome diagnosis for CYP; therefore the focus is on CYP without additional learning needs or language delay. Miller's (2015) paper presents a programme designed to explain the diagnosis to CYP with their parent present. Although only four cases are discussed, Miller (2015) highlighted that the programme is informed by his work with over two hundred children, while working in an autism advisory capacity. At the time the programme was implemented, the four cases discussed were aged between eight to ten years; three of the children were attending mainstream schools and one was attending a special school. General details about the children's needs were identified for two of the four cases, to highlight the way in which the materials were individualised for each child. However, the programme pre-requisites indicated that to take part, children required:

> … the necessary cognitive and communication skills to understand and discuss concepts used to describe themselves and autism (Miller, 2015, p.80).

Although not specifically stated, this would suggest that, while the programme can be differentiated to an extent, it might not be appropriate for CYP with autism who have intellectual impairment, or those with significant communication needs. However, Miller (2015, p.88) does highlight that, with appropriate adjustment, the programme is sufficiently flexible to meet the needs of children with a range of needs.

3.11.1 Professional views about the logistics of discussion of autism with CYP

As shown in Table 25 below, when considering the logistics of disclosing to children, Fletcher (2013) and Miller (2015) both advised that CYP should be at the centre of the discussions. Professionals contributing to the studies of Nissenbaum, Tollefson and Reese (2002) and Crane *et al.* (2018) also suggested that the child should be included in the autism diagnosis disclosure conference. However, in the other papers, most professionals did not discuss the child when considering the point of disclosure.

Table 25 Professionals' views on the logistics of disclosure to children

Logistics of disclosure to children (6 papers, 11 themes occurring 19 times)	**Bartolo (2002)**	**Braun,Dunn & Tomchek, (2017)**	**Crane *et al.* (2018)**	**Finke, Drager & Ash (2010)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Jacobs Steyaert, Dierickx &Hens (2018)**	**Jacobs, Steyaert, Dierickx & Hens (2019)**	**Miller (2015)**	**Nissenbaum, Tollefson & Reese (2002)**	**Rogers, *et al.*, (2016)**
Rely on parents to disclose to child							✓				
Child at the centre					✓				✓		
In the room at parent disclosure	✓					✓			✓		
Parental readiness and consent					✓				✓		
Gradually throughout assessment										✓	
Child has awareness of Difference					✓				✓		
When knowing the diagnosis will have positive impact									✓		
Understanding emerges within the diagnostic process	✓					✓					
Child can engage/ attend									✓		
Can discuss concepts used to describe self & autism					✓				✓		
Has cognitive and communicative capacity					✓				✓		

In the study by Jacobs *et al*. (2018), professionals mostly indicated that they relied on parents to disclose the autism diagnosis to their child. Professionals who shared their experience of disclosing to children, revealed underlying concerns about a potential negative impact on the child's view of self, as explained in this account:

> I always see these little faces-no, I rather feel it-that a doctor is officially affirming that they are different (Jacobs *et al*., 2018, p. 8).

Such concerns might explain why some professionals might be reluctant to be involved with disclosure of autism to children. However, professionals in the Bartolo (2002) and the Gray, Msall and Msall (2008) studies discussed the way in which the diagnostic assessment process was part of the way in which children would begin to understand their differences.

Although Fletcher (2013) and Miller (2015) discussed individualising the work around discussion of autism, they also both highlighted that the CYP would also require the necessary cognitive and communication skills to understand the concepts discussed. Fletcher (2013) and Miller (2015) identified children's emerging awareness and questioning of difference as the key indicator that the time is right to begin to discuss autism diagnosis with them. When it is thought that knowing about the autism diagnosis might improve the child's everyday life, and the parent is also ready for the disclosure, were also identified as key markers of the time being right by Miller (2015).

Fletcher (2013) also suggested that it is not the right time for disclosure, or discussion of autism, when the child is in low mood. She also cautioned against allowing a negative experience to be the trigger for the disclosure work. Flexibility was highlighted to be important, so the right time is not missed, while still enabling postponement, where there are concerns about children's emotional responses.

3.11.2 Professional views about how to frame autism for the child

Only four papers discussed approaches to framing autism for the child, these papers are identified in Table 26 below. Professionals in the studies by Crane *et al.* (2018) and Gray, Msall and Msall (2008) also emphasised the importance of avoiding a deficit focussed explanation when disclosing to the child.

Table 26 Professionals' views about how to frame autism for the child

Framing Autism **(4 papers, 12 themes occurring 20 times)**	**Crane *et al.* (2018)**	**Fletcher (2013)**	**Gray, Msall & Msall (2008)**	**Miller (2015)**
Everyone is unique		✓		✓
Reinforce own personality; strengths and talents		✓		✓
Discussion of autism traits/characteristics		✓		✓
Autism as a difference		✓		✓
Autism/AS describes people with similar attributes				✓
Challenges are acknowledged		✓		✓
Supporting individual to own understanding		✓		✓
Compensatory strengths for problem solving		✓		
Avoid deficit dominated explanation	✓		✓	
Diagnosis and disability		✓		
Sharing facts about autism		✓		✓
People with autism/AS can lead a happy and fulfilling life				✓

Fletcher (2013) highlighted the importance of reinforcing and helping the child to identify their personal attributes. The focus was on recognition of strengths and differences to highlight the advantages of the diagnosis, as well as acknowledging the inherent challenges that it brings. Fletcher (2013) also suggested collating an evidence-base of positives from others, which can be drawn on when discussing autism with CYP. While difficulties are acknowledged, there was also a focus on compensatory strengths and exploring how these can be used to support development of skills and problem-solving strategies. Fletcher (2013) also cautioned that the different processing style of children with AS results in the potential for information to be partially processed, which can impact understanding, and lead to misunderstanding if the explanation of autism is not correctly framed.

Miller (2015) highlights a similar positive approach, suggesting a programme that begins by exploring the notion that everyone is unique. The child should then be encouraged to identify their own personality talents and differences. A positive focus should be emphasised throughout, for example the individual should be encouraged to recognise themselves as good, loved, and someone who can make their family proud. Miller (2015) also emphasised that autism should be explained as a difference, which describes people who share some similar attributes. Facts about autism should also be discussed, including what it is and is not. Finally, Miller (2015) suggests that positive role models should be drawn on to show that people with autism can lead happy and fulfilling lives.

3.11.3 Professionals' views about how the approach might be tailored for children

Fletcher (2013) also identified the importance of tailoring the approach to the individual's developmental level and their interests, and highlighted that flexibility and creativity are needed to facilitate this. The need to structure sessions was also highlighted, along with the use of visual and kinaesthetic resources to provide an evidence-base that will support understanding, including biographies of others with an autism diagnosis. The need to use vocabulary related to the individual's level of communication, and to the extent of current knowledge of the diagnosis, is also emphasised.

Miller (2015) also highlighted the importance of the professional having expert pedagogical knowledge, which they can apply flexibly to ensure the approach is appropriately individualised for the child. Miller (2015) emphasised the importance of having the right professional demeanour during diagnostic discussions with CYP. Miller (2015) suggested that professionals should remain outwardly calm, confident, and matter of fact in discussing the topic, while remaining positive and reassuring throughout. Getting the communication right was highlighted to be important, for example, by providing additional processing time, and checking understanding of key concepts. Use of simplified literal language was also recommended, as was the use of closed questions with possible responses, where appropriate. Professionals were advised to employ pre-teaching and pictorial representations to support understanding of abstract concepts, such as emotions and personal attributes. Miller (2015) also suggested avoiding too much information and to only include one theme per page when creating resources.

Potential issues are also highlighted, Fletcher (2013) highlighted that individualising the approach means that it is time consuming. Both Fletcher (2013) and Miller (2015) highlighted that the engagement of CYP can be variable, and that it is important not to assume understanding. An element of potential resistance was also highlighted by Fletcher (2013), who identified that some CYP strive to maintain their self-view as close to typical as possible, which can impact on willingness to engage. In addition, Fletcher

(2013) and Miller (2015) both emphasised that there are likely to be only small gains in understanding of autism from a programme of work. Therefore, sharing the work with family and educators was highlighted to be important, to support CYP as they continue with the process of coming to understand autism and what it means to them.

3.11.4 Professional views about the impact of diagnosis on CYP

The impact of the diagnosis for the child was explicitly considered by professionals in three papers, as shown in Table 27 below. Professionals in the study by Jacobs *et al*. (2018) highlighted concerns about the impact of autism disclosure on the self-image of CYP, especially during adolescence. However, views were mixed about whether the impact was generally positive or negative. Those who identified positive impact on self-esteem related this to the understanding of others, which helped to explain difference in behaviours. In discussing the negative impact on CYP, professionals in the Jacobs *et al*. (2018) study also discussed the longer-term impact of the diagnosis. One participant explained:

> …then little by little the child becomes [seen] only [through the lens of] his diagnosis (Jacobs *et al*., 2018, p. 8).

Professionals' views in the study suggested that the diagnosis has a greater psychological impact on adolescents leading to a '... difficult trajectory through puberty' as they are at a critical stage in developing their identity (Jacobs *et al.,* 2018, p. 8).

Table 27 Professionals' views about the impact of diagnosis on CYP

Impact on CYP (3 papers, 11 themes, occurring 21 times)	**Fletcher (2013)**	**Jacobs Steyaert, Dierickx &Hens**	**Miller (2015)**
Problems caused if hidden from child		✓	
Denial	✓	✓	
Surprise			✓
Indifference			✓
Anxiety and/or emotionality	✓	✓	✓
Misperception of the diagnosis, limited understanding	✓	✓	✓
Always seen as the autistic child		✓	
Positive impact on self-esteem		✓	✓
Negative impact on self-esteem		✓	✓
Understands autism	✓		✓
Greater consequence in adolescence due to identity formation	✓	✓	✓

Miller (2015) also identified a range of emotional impacts from the CYP in response to the disclosure of the diagnosis, including indifference, surprise, and anxiety. Positive impacts were identified to be mediated by using positive role models, which were indicated to calm some participants and to result in happiness or excitement in others, for example, due to recognition of the possibility for high intelligence within autism. Increases in children's understanding was, however, indicated to be limited, often to only the 'headline' discussion points.

The practical impact of the diagnosis on opportunities to access additional support was the focus of discussion in most papers exploring professionals' views, which was attributed to a societal pressure on professionals to support children’s access to services (Jacobs *et al*., 2018). However, as discussed by professionals in relation to giving the diagnosis to the child’s parents, access to appropriate services was also discussed as being problematic (e.g., Gray, Msall and Msall, 2008; Rogers *et al*., 2016; Jacobs *et al*., 2018).

3.12 Professionals views: concluding comments

When an autism diagnosis is explained, a lack of emotional responsiveness from professionals has been highlighted by parents, which they have also suggested impacts their subsequent reactions to being told about their child’s autism diagnosis (e.g., Quine and Pahl, 1986; Woolley *et al.,* 1989; Wiggins *et al*., 2006; Finnegan, Trimble and Egan, 2014). Contrary to parental perceptions, professionals also indicated experiencing significant emotional responses when sharing the diagnosis with parents and with CYP. The outward appearance that parents perceive could result from professionals feeling that they have to be seen to maintain a professional demeanour (e.g., Nissenbaum, Tollefson and Reese, 2002; Miller, 2015). However, professionals reported a lack of autism focussed learning opportunities during initial training, and across their careers, is also a possible factor (Nissenbaum, Tollefson and Reese, 2002; Finke *et al*., 2010; Rogers *et al*., 2016; Crane *et al*., 2018). The significance of an autism diagnosis and the potential problematic nature of such a diagnosis was evident within professional perspectives; for example, professionals in the Nissenbaum, Tollefson and Reese (2002) study reported they would be ‘devastated’ if their child received an autism diagnosis. It is perhaps for this reason that, across the studies, professionals suggested they recognised the importance of establishing positive relationships and of good communication to support the most positive disclosure experience for CYP and their parents.

Research such as that by Carlsson *et al*. (2016) found that parents feel that diagnosis is a crucial point, at which they expect their child will gain access to support and appropriate services, but they subsequently feel they are let down by professionals as they are left to manage their child's needs alone. Access to support and specialist educational provision was also the key benefit of autism diagnosis that professionals identified (Bartolo, 2002; Crane *et al*., 2018; Jacobs *et al.,* 2018; Rogers *et al*., 2016). However, professionals also revealed frustration that following diagnosis, while they wanted to refer families to appropriate support, services were difficult to access and fragmented (Crane *et al.,* 2018; Finke, Drager and Ash, 2010; Rogers *et al.,* 2016). Despite lack of services, professionals suggested that the impact of diagnosis was still positive, as CYP were more likely to have adjustments made for them by both educators and parents (Jacobs *et al.,* 2018).

Although there was indication from professionals that a CYP might be included in the autism diagnosis consultation, when the diagnosis was confirmed, in seven of the professional papers there was no discussion about how they explained the diagnosis to CYP. This might be interpreted to suggest that many clinicians expect parents to be the person who will support CYP to understand their autism diagnosis, as identified by professionals in the study by Jacobs *et al.* (2018). Parents have identified that they use their own understanding of the autism diagnosis when supporting their child's understanding, however, they have also identified the need for greater support with disclosure to their child (e.g., Rossello, 2015; Crane *et al., 2019*). It is therefore reassuring to note that parents (e.g., Cadogan, 2015) and professionals (e.g., Jacobs *et al,* 2018) agree on the use of a strengths-based approach to frame autism for children. Professionals revealed that this involves highlighting and focussing on the child's strengths when disclosing the diagnosis to parents (e.g., Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008; Crane *et al.,* 2018; Jacobs *et al.,* 2018) and to CYP (Fletcher, 2013; Miller 2015).

There was agreement that an emerging awareness of difference is a key indicator that it is the right time begin to discuss autism diagnosis with children. However, while Fletcher's (2013) and Miller's (2015) advice, based on their experience of undertaking work related to diagnosis with CYP with autism, supplements the general guidance about how children with autism might be supported to understand their diagnosis (e.g., Fidler, 2004; Jones, 2001; Vermeulen, 2000; Whitaker, 2006), gaps remain in the research evidence base about best practice for disclosure to children to achieve positive outcomes (National Collaborating Centre for Women's and children's Health, 2011).

3.13 Synthesis of findings across the three participant groups

The approach to the analysis and synthesis of findings across all the papers which follows, employed the same approach that was used for the review of each of the individual participant groups above (See Appendix 2.7 Synthesis of themes from papers focussed on CYP's, parents' and professionals' perspectives for details of the synthesis). However, the synthesis of the findings across the three participant groups (CYP with autism, parents of CYP with autism and professionals working with CYP with autism and their parents) was more problematic than the synthesis of papers from each of the individual participant groups, due to the differences in the focus of the topics that were explored with each participant group. Within the papers from each individual participant group, the focus of the topics explored by the researchers were similar in exploring disclosure and learning about an autism diagnosis. However, across the participant groups, there was a greater degree of difference in the way this was explored. While they all provided useful information on how CYP learnt about an autism diagnosis from different perspectives, the studies exploring CYP's perceptions focussed on their perceptions of autism and how they made meaning of their autism spectrum diagnosis. The parental studies focussed on exploring how they told CYP about their autism diagnosis and the impact. While the papers exploring professional perceptions focussed on how they disclosed the diagnosis after making their assessment, these papers mostly referred to disclosure to parents, with only some references to the involvement of CYP.

The synthesis of the literature across the three groups identified similar themes to those identified by the 2012 scoping review. The main difference was that the themes from parental papers focussed on how their children learnt about the diagnosis and the impact on children, rather than parents' experiences of being told about the diagnosis and the impact on the parent. The increased number of papers from children and young people's perspectives covered similar themes to those identified in 2012, however, a new theme that was evident in the 2019 review was how autism is framed. CYP were more likely to discuss how autism was or should be framed, with a focus on strengths rather than deficits, in the additional papers that were identified. This was also discussed more frequently across the papers that explored professionals' views. Greater discussion of the framing of autism, could reflect the changing view of autism that Pellicano *et al*. (2018) have highlighted, which they suggested has been influenced by both the increased engagement of people with autism and their advocates in research and decision making, as well as the debates about perspectives of autism in both the mainstream and academic literature.

The 2019 synthesis of the literature across the three participants' groups identified seven overarching themes that occurred across papers, these were: social influences on identity, agency and identity, perceptions of autism, framing to disclose autism, the positive and negative impacts of learning about diagnosis, disclosure logistics, and service delivery. The themes that were discussed in the papers by all participant groups were: perceptions of autism, framing to disclose autism, positive and negative impact, and service factors. However, as shown in Table 28 below, themes related to the impact of social influences on identity, and the relationship between agency and identity were only shared in the papers focussed on CYP's and parents' perceptions. Only the papers focussed on parents' and professionals' perceptions, discussed themes focussed on service provision related to autism diagnosis. This theme was most comprehensively discussed within the professional papers.

Table 28 Summary of overlapping topics identified through the synthesis of findings across participant groups

Themes	Children	Parents	Professionals
Social influences on identity	✓	✓	
Agency and identity	✓	✓	
Perceptions of autism	✓	✓	✓
Framing to disclose autism	✓	✓	✓
Positive impact	✓	✓	✓
Negative impact	✓	✓	✓
Disclosure logistics		✓	✓
Service factors	✓	✓	✓

The synthesis of themes across the papers focussed on CYP's, parents' and professionals' perspectives, highlighted the impact that experiences of learning about an autism diagnosis can have upon CYP's views of self and subsequently on their identity (e.g., Nissenbaum, Tollefson and Reese, 2002; Molloy and Vasil, 2004; Gray, Msall and Msall, 2008; Huws and Jones, 2008; Baines, 2012; Mogensen and Mason, 2015; Rossello, 2015; Crane *et al.,* 2018; Jacobs *et al.,* 2018). However, the way this was discussed differed. The synthesis highlighted that, across the papers from CYP and parents, a common theme of discussion was the problematic social interactions that CYP with autism can experience, and the negative impact this can have upon their views of self (e.g., Huws and Jones, 2008; Baines, 2012; Ward, 2014; Finnegan, Trimble and Egan, 2014; Huws and Jones, 2015; Jones *et al.*, 2015; Smith-Demers, 2018; Smith et al., 2018). Concerns about social self-efficacy, feeling labelled and stigma associated with autism were common points of discussion within this theme across the papers from CYP with autism and parents. This links with the process of knowing the self, which Foucault (1977, p. 194) believed, was shaped through discourse-based knowledge, which is influenced socially, accepted as a reality, and internalised by individuals. While this specific topic was not explicitly discussed by professionals, they did discuss perceptions of autism in ways that reflected acknowledgement of the potential impact of the diagnosis on the self-perceptions of individuals. When discussing this theme, professionals often referred to medically based frameworks (e.g., WHO, 2018; APA, 2013). As most of the papers exploring professional perceptions were from the medical profession, the medical focus of their perceptions is understandable. However, this medical focus was also linked to themes related to a negative framing of autism, for example, some professionals linked autism with problematic behaviours, and the focus of their perceptions reflected perceptions of autism as a deficit. This links with Foucault's (1974, 2008) notion of bio-power and the technologies that enable measurement and identification, which support the establishment of the norm, and of deviation from this linked to diagnosis, thus supporting the perception of autism as a deficit, and/or disability, to be established. Some professionals, however, also highlighted the importance of framing the diagnosis carefully when disclosing it following their assessments. A common discussion point from professionals when discussing ideas linked with the framing theme was of relating individual traits to the diagnostic framework, however, professionals in some papers also discussed the importance of highlighting strengths linked to autism (e.g., Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008). These professionals often highlighted a framing approach that involved weaving discussion of strengths with medical criteria, which reflected the child's development and behaviours when disclosing the diagnosis (e.g., Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008; Braun, Dunn and Tomchek, 2017). The framing theme was discussed in a similar way across papers focussed on parents' perceptions, especially when explaining how they discussed autism with their child. Like the framing approach used by professionals, they discussed their child's difficulties and/or differences when framing autism for them, but often discussed employing a problem-solving approach when doing so (Finnegan, Trimble and Egan, 2014; Cadogan, 2015; Rossello, 2015; Crane *et al.*, 2019). As professionals highlighted, parents also wove such discussion with their child's positive traits (Finnegan, Trimble and Egan, 2014; Cadogan, 2015; Smith-Demers, 2018; Crane *et al.*, 2019), which they also linked with autism and to positive role models with autism, to influence more positive perceptions for their children (Finnegan, Trimble and Egan, 2014; Crane *et al*., 2019).

There was discussion of themes reflecting the potential for an autism diagnosis to have both positive and negative impacts on CYP across the 3 participants groups. Parents discussed both positive and negative impact, however, the most common reaction that parents discussed their child experiencing was relief (Finnegan, Trimble and Egan, 2014; Ward, 2014; Cadogan, 2015; Smith-Demers, 2018; Crane *et al*., 2019). Although parents discussed rejection of the diagnosis as an impact, this was often transient, and parents highlighted that knowing about the diagnosis led to an improved understanding of self (Finnegan, Trimble and Egan, 2014; Ward, 2014; Cadogan, 2015; Smith-Demers, 2018; Crane *et al*., 2019). Although eleven papers were identified that explored professionals' perspectives on giving and autism diagnosis, only three papers discussed the impact on CYP. Fletcher (2013), Miller (2015) and Jacobs *et al*. (2018) discussed both positive and negative impacts, these three papers also highlighted that there was the potential for the diagnosis to have greater impact on young people's identity construction during adolescence. A key concern of professionals was that for children with an autism diagnosis, once the diagnosis is made, autism dominates others' perceptions of them (Jacobs *et al*., 2018). However, CYP identified that their identity was not dominated by the diagnosis when successes were the focus of the discussion of autism. While CYP with autism discussed concerns about the potential for labelling and stigma, they also highlighted that learning about the autism supported them to make sense of their experiences (e.g., Huws and Jones, 2008; Rossello, 2015). Furthermore, for some CYP, knowing about the diagnosis and their unique attributes gave them a sense of belonging and pride.

Although CYP in the papers identified did not explicitly discuss the logistical aspects of learning about autism (when, where, who and how), they did highlight concerns when they experienced a delay in learning about the diagnosis, this was especially so when the diagnosis had been made some time before it was disclosed to them (Huws and Jones, 2008; Ward, 2014; Rossello, 2015). However, while parents recognised the importance of disclosing the diagnosis to their child as soon as possible (Cadogan, 2015; Rossello, 2015; Ward, 2014; Smith-Demers, 2018; Crane *et al*., 2019), parents also discussed both needing time to process the diagnosis themselves and taking time to research, to seek professional advice, and to prepare to explain the diagnosis to their child (Ward, 2014; Rossello, 2015; Smith-Demers, 2018; Crane *et al*., 2019). Parents were also concerned to ensure the emotional readiness of their child and indicated that their child asking questions was the time they felt it was right to tell them (Ward, 2014; Smith-Demers, 2018). Therefore, several factors were related to the delay that CYP experienced. Parents also wished that they had known sooner, and some parents also retrospectively regretted the delay in telling their child (Finnegan, Trimble and Egan, 2014; Rossello, 2015; Smith-Demers, 2018; Crane *et al*., 2019).

The national guidance highlights the importance of having the child at the centre of discussions about the outcome of their autism assessment (National Institute of Health and Care Excellence, 2011b) and some professionals explicitly advocated this when discussing disclosure of a diagnosis (Nissenbaum, Tollefson and Reese, 2002; Fletcher, 2013; Miller, 2015; Crane *et al.*, 2018). However, this was not discussed in most studies involving professionals, suggesting that many professionals did not reflect on children's needs when considering the point of disclosure. Although mostly in the context of explaining the diagnosis to parents, professionals did recognise the potential impact of the diagnosis. Therefore, an important theme that most professionals discussed, in relation to creating a positive disclosure experience, was the importance of building relationships, communicating effectively and demonstrating empathy during disclosure (e.g., Bartolo, 2002; Nissenbaum, Tollefson and Reese, 2002; Finke, Drager and Ash, 2010; Fletcher, 2013; Rogers, *et al*., 2016; Crane *et al*., 2018; Jacobs *et al*., 2019). Furthermore, professionals highlighted that they find the disclosure of an autism diagnosis stressful (Nissenbaum, Tollefson and Reese, 2002; Rogers *et al*., 2016; Jacobs *et al*., 2019) and that they are aware that this is the case for parents (Bartolo, 2002; Nissenbaum, Tollefson and Reese, 2002; Finke, Drager and Ash, 2010). The synthesis highlights that this perspective runs counter to the perceptions of some parents, who reported poor communication from professionals about their child's diagnosis and of a lack of empathy from professionals (Finnegan, Trimble and Egan, 2014; Rossello, 2015; Crane *et al.*, 2019). The synthesis has shown elements of agreement and of difference in the perspectives of the three different stakeholders involved in the diagnosis and disclosure of autism to CYP, highlighting the importance of understanding the perspectives of all those who are involved in the processes. Furthermore, the synthesis has also highlighted the influence of factors beyond the actual process of diagnosis, such as the influence of society perspectives, the views of peers, and of young people's comparisons with peers. Thus, reflecting the influence of the systems in which humans interact with each other, as identified by Bhaskar (2011). The influence of what Bhaskar (1975) described as the three ontological layers can be seen within the real (structures and systems), the actual (events created by structures and systems), and the empirical (events that can be experienced, described and observed). This is helpful in identifying the social practices that influence young people's understanding of their diagnosis and responds to the critical realist philosophy inherent within the research process in identifying the people who have the agency and power to make a difference (Scott, 2010, p. 5). This includes parents as well as those who work within the structures and systems related to autism diagnosis, and those involved in the events that influence CYP's understanding of autism.

3.14 Review conclusions

This literature review has shown that coming to understand an autism diagnosis can have psychological impact on children and young people (e.g Huws and Jones, 2008, Ward, 2014; Cadogan, 2015). The research informed by CYP with autism, parents of children with autism, and professionals, consistently identified the potential for both positive and negative impact (e.g., Nissenbaum, Tollefson and Reese, 2002; Huws and Jones, 2008; Miller, 2015; Jacobs *et al*., 2018). Across the papers, a common theme identified by the three key stakeholders was the impact of the autism diagnosis on CYP's views of self, which can be seen to link with the notion of personal identity constructs (Kelly, 1955). When discussing autism, CYP discussed this in relation to their social experiences and the communication they heard about autism. Their perceptions indicated that these experiences shaped the self-narratives and the subsequent self-views they developed, which therefore points to the potential of the language and subsequent framing of autism to impact the identity development of CYP with autism (Baines, 2012; Huws and Jones, 2015; Jones *et al.,* 2015). This links directly with notions about the right time to disclose the diagnosis to CYP, there was agreement between the views shared by parents and professionals that an emerging awareness of difference was a key indicator that it is the right time to begin to discuss the autism diagnosis with children (e.g., Fletcher, 2013; Miller, 2015). Although there was an indication that a CYP might be included in the clinical consultation meeting when the diagnosis was confirmed, there was little discussion from professionals about how to explain the autism diagnosis to CYP. There was also agreement within the literature from parents (e.g., Crane *et al.*, 2019) and professionals (e.g., Crane *et al.,* 2018; Jacobs *et al,* 2018; Nissenbaum, Tollefson and Reese, 2002) to suggest that most clinicians expected parents to be the person who would support CYP to understand their diagnosis. Parents (e.g,. Ward, 2014; Cadogan, 2015) and some professionals (e.g., Fletcher, 2013; Miller, 2015; Crane *et al.,* 2018; Jacobs *et al.,* 2018) agreed that discussion of autism diagnosis with CYP should highlight and focus on the child's strengths.

The research studies exploring the views of CYP have mostly used qualitative interview-based approaches and focussed on CYP's general perceptions about autism, rather than specifically about their experiences of learning about their own diagnosis (e.g., Molloy and Vasil, 2004; Baines, 2012; Jones *et al.,* 2015). Studies that have explored parents' and professionals' views have also been dominated by qualitative interviews, however, a small number of online surveys have also been employed. This research has mostly explored parents' own experiences of learning about their child's autism diagnosis, or about professionals' views of making an autism diagnosis and disclosing it to parents. However, a few studies have explored parental and professional experiences of discussing autism with a child, these studies indicated the importance of open communication and of positively framing the autism diagnosis (e.g., Cadogan, 2015, Crane et al., 2019, Fletcher, 2013; Miller, 2015). Nevertheless, the evidence base relating to CYP's views about how they learnt about an autism diagnosis and the impact of their experiences is still small, but it is increasing. The National Collaborating Centre for Women's and Children's Health (2011) also highlighted that there was very little evidence from parents or professionals about how best to inform children and young people about an autism diagnosis, and about the impact that it might have upon them. While this evidence base is growing, it remains limited due to the homogeneous nature to the samples. Across the evidence base about children and young people's experiences in relation to autism diagnosis, there is sample bias towards the experiences of those CYP with autism who are cognitively able (e.g. Molloy and Vasil, 2004; Jones *et al*, 2015; Rossello, 2015). Information from parents of CYP with autism diagnosis is also dominated by the views of mothers, fathers are under-represented, as are parents from minority ethnic groups (e.g., Crane *et al.,* 2019). Bias was also identified across the papers exploring professionals' perspectives as the professional participants were mostly medical professionals.

Due to the practical difficulties in obtaining information from individuals whose diagnosis implies they might have a range of verbal, social, cognitive, and developmental difficulties (APA, 2013; WHO, 2018), there has been a focus on collecting the views of parents of CYP with autism, professionals involved in diagnosing autism, or adults with autism, rather than CYP with autism (Ashby and Causton-Theoharis, 2009). The key stakeholders are CYP with autism, their parents and professionals involved in diagnosis and post diagnosis support. Where researchers have explored views from these key stakeholders, they have mostly been explored without reference to the other key stakeholders. However, researchers such as Huws and Jones (2008) have successfully used interviews to understand CYP's views of an autism diagnosis. Their participants identified feeling '*shock,* *disappointment and disbelief'* after the diagnosis was disclosed (Huws and Jones, 2008, p. 104), demonstrating that they can elucidate understanding of the impact of diagnosis on CYP. Therefore, in recognition of the importance of collecting young people's views, while also recognising the difficulties that might be experienced, within the empirical study that is described below, young people's experiences were explored by collecting information about their experiences from three key participant groups: CYP who have been informed about an autism diagnosis; parents who have knowledge of their child's experiences in relation to this process and of the impact on the child; and professionals who have been involved in diagnostic processes and/or who provided support following a diagnosis.

3.15 Research Questions

At the start of the study, after reviewing the literature, the research questions were structured as follows:

1. What are young people's experiences and views of an autism diagnosis?
2. How do parents and professionals discuss the diagnosis with young people on the autism spectrum?
3. What factors influence young people's understanding of an autism diagnosis and how does this impact their view of self?
4. How do experiences prior to diagnosis, and when finding out about the diagnosis, impact children and young people's views after they are told about an autism diagnosis?

Although additional studies were identified to have been undertaken through the 2019 systematic review, this did not change the focus of the empirical study, as the data had already been collected. The aim of the 2019 systematic review was to ensure that all recent and relevant research, which might support understanding of children's experiences had been incorporated, and to ensure that the discussion of the findings was fully informed by all the available evidence. By drawing together and synthesising the available evidence, this enabled it to be considered alongside the evidence from the empirical study described below and, as Gough, Oliver and Thomas (2018, p.2) highlight, this enables factors to be identified to support or cast doubt on the 'veracity of individual claims'. The focus remained to explore how best to inform CYP about an autism diagnosis, and to understand the impact that learning about the diagnosis might have upon them. However, early during the process of the study and through research supervision, the structure of the research questions was simplified to make the focus clearer. The more focussed research questions were:

1. What are children's and young people's experiences and views of an autism diagnosis and how does this impact their view of self?
2. How do parents and professionals view children's experiences of autism diagnosis?
3. How do parents and professionals support children and young people to understand an autism diagnosis?

The next chapter gives details about the research design and methods, and about the characteristics and recruitment of participants.

CHAPTER 4: METHODS

4.1 Introduction and overview study phases

This chapter provides details of the research design, methods, sample, and procedures utilised within the study. After summarising the phases of research, the research design is considered in detail, beginning with the philosophical basis of the study and then the methods employed. The overall aim of this research was to identify influencing factors that impact children's and young people's (CYP's) understanding and views of autism, after being given an autism spectrum diagnosis. Table 29 below, provides an overview of the methods employed to explore each of the research questions.

Table 29 Approaches employed across the study to explore the research questions

Research Question	Methods used
1. What are CYP's experiences and views of an autism diagnosis and how does this impact their view of self?	• Preliminary study: focus group to explore CYP's views about an intervention aimed to support understanding of autism • Thematic analysis of published accounts by young people where they share views about having autism • Focus group to explore CYP's views about the online survey design and CYP's views of autism diagnosis • Online survey for CYP to collect their views about diagnostic experiences and having an autism diagnosis • Interview with a young person about diagnostic experiences and having an autism diagnosis • Systematic literature review of young people's views of the autism diagnosis and experiences related to it
2. How do parents and professionals view children's experiences of autism diagnosis? 3. How do parents and professionals support children and young people to understand an autism diagnosis?	**Parents** • Preliminary study: joint focus group for parents and professionals about the impact of a programme to improve children's understanding of their autism diagnosis • Online survey for parents about their child's experiences before diagnosis, when learning about diagnosis and after diagnosis • Parent interviews about their child's experiences relating to autism, their diagnostic experiences, the impact on their child of learning they have an autism diagnosis and how they discuss autism with their child • Systematic literature review exploring parental approaches to discussing autism with their child and their views upon the impact on the child. **Professionals** • Online survey for professionals about work that they undertake with CYP and others in relation to helping CYP to understand an autism diagnosis • Professionals' interviews about their work which supports children's understanding of diagnosis • Systematic literature review of professional views about giving an autism spectrum diagnosis and their views about the impact of the diagnosis on young people

Figure 4 below, shows the chronology of the different phases of research that were undertaken for this study.

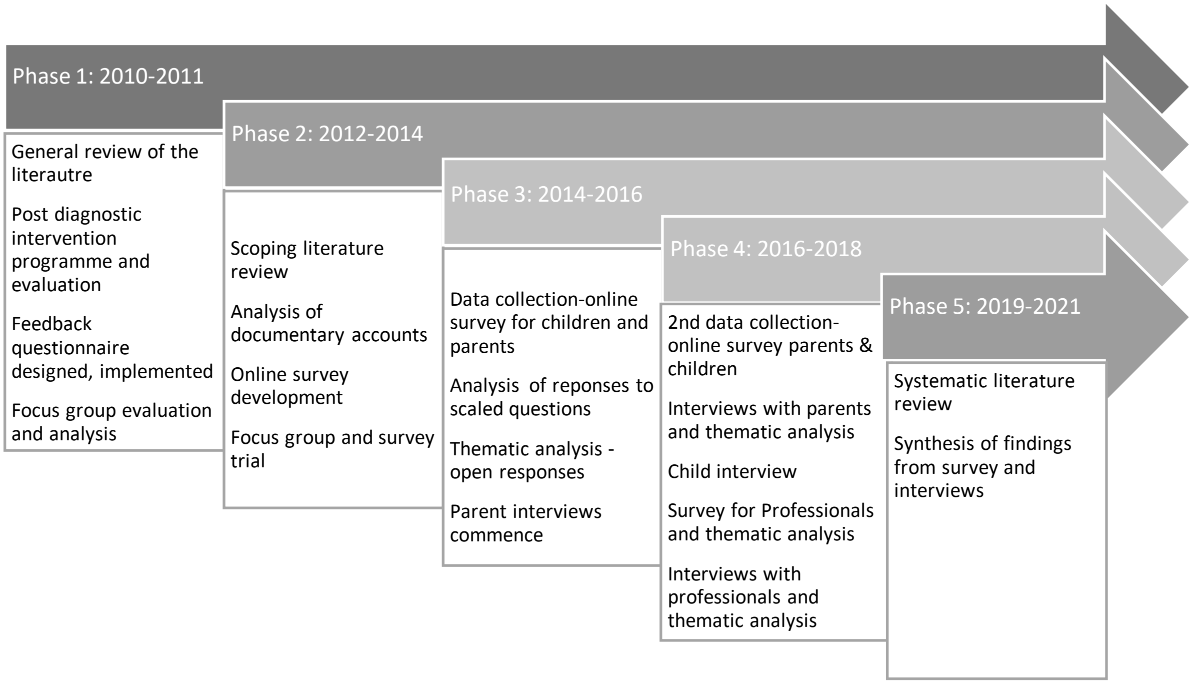


Figure 4 Summary of the Stages of Data Collection

As shown above, a mixed methods approach was utilised across the phases to understand CYP’s experiences prior to being told about an autism diagnosis, when finding out about an autism diagnosis, and after learning about the diagnosis. The initial research plan, in Phase One, was focussed on my professional practice at that time, which involved developing and delivering a programme to support parents and children’s understanding of autism, following a diagnosis for the child (Ethical Approval Number: ERN_11-0332). However, a change in career necessitated a change of approach to explore the same research topic. Nevertheless, the information gained from Phase One was valuable, it therefore served as a useful exploratory pilot for the main study. The sessions for the Phase One local authority intervention programme for CYP and their parents were held in the same location, and at the same time, but were delivered separately to enable the information and approach to be tailored to the different needs of parents and CYP. An educational professional (teacher or teaching assistant), who worked with each child, was also invited to take part in the programme, alongside the parent. At the end of the programme, two focus groups explored views about the impact of the programme on CYP's understanding of autism. One focus group was undertaken with the CYP who attended, the second with a group of parents and professionals. The views shared were used to support improvements to the programme, and to inform the initial development of the main study that followed (See Appendix 4: summary of the preliminary study).

During Phase Two, as I was no longer working on the understanding autism programme that had aimed to support CYP with autism and their parents, following a diagnosis, the focus of the research changed. The redesigned study still aimed to explore how CYP learnt about their diagnosis, but a different approach was planned to explore the topic (Ethical Approval Number: ERN_13-0961). During this phase, the 2012 scoping literature review was undertaken. The online survey's and interview frameworks were also designed; these were based on the understanding gained from the Phase One understanding autism intervention programme (See Appendix 4: summary of the preliminary study), the 2012 scoping literature review, and from analysis of a documentary film by the Autism Education Trust (Receiving and Understanding a Diagnosis, 2012) about CYP's views of their autism diagnosis (See

Appendix 5: analysis of documentary film and conference paper). The aim was to ensure the survey statements and interview questions were based on perceptions of CYP with autism. Another reason for undertaking the analysis of the AET documentary was to develop my experience of undertaking thematic analysis.

The survey was then piloted with a small group of young people with an autism diagnosis, and their views of the survey were explored through a focus group. Before the focus group, the participants completed a draft copy of the survey. The focus group immediately followed to explore the participants' views about autism, as well as their views on the survey. They were asked about the relevance of the statements, ease of completion of the survey, and about the terminology used. Changes were made to the survey based upon this feedback. (See Appendix 6: focus group procedures, findings and draft survey with amendments identified).

During Phase Three, data was collected through an online survey and interviews, which collected parents' and children's views about CYPs experiences in relation to their autism diagnosis (See Appendix 7: online survey for CYP; Appendix 8: online survey for parents). The survey for parents also provided an opportunity for them to share any views they felt relevant to CYP's experiences in relation to the diagnostic processes, and their child's experiences of learning about autism. The interviews were designed to probe topics of interest that were emerging from the survey (See Appendix 9: interview schedule for CYP; Appendix 10: interview schedule for parents). The first parent interviews were also undertaken during this phase.

During Phase Four, as participation in the online survey and interview had been low, but the information that was coming from participants was useful, it was decided to re-run the survey and to undertake more interviews. Efforts were renewed to advertise more widely to inform parents and children with autism about the research study, and to seek their participation with the online survey and the interview. After further advertising of the survey, the second period of data collection from CYP, and parents of CYP with autism, took place. As the 2012 scoping review of the literature and analysis of the first responses to the online survey highlighted that professionals had a key role in how children learnt about an autism diagnosis, a survey and an interview schedule was also designed to explore professional perceptions (Appendix 11: professional survey; Appendix 12: interview schedule for professionals). The data from the professional survey and interviews was collected at the end of this stage.

Despite advertising the research widely, participation of CYP in the online survey remained low, and only one young person volunteered for interview. However, since the scoping review of the literature in 2012, further studies had been published. These included some interesting small-scale qualitative studies by other doctoral researchers, which explored CYP's experiences of having autism. Research studies had also been undertaken that had explored parental views of discussing autism with a child, including a large-scale study (e.g. Crane *et al*., 2016). More evidence was also beginning to emerge about professionals' views of giving an autism diagnosis (e.g. Rogers *et al*., 2016). Therefore, in Phase Five, as more published research was available that could inform understanding of children's diagnostic experiences, and how they were told about an autism diagnosis, a more focussed systematic review was undertaken in 2019 to identify the main themes that were being recognised across studies (The methods used for this review were explained in Chapter 3).

4.2 Introduction to research philosophy and methodology

This section outlines the philosophical stance underpinning the design for this study, to demonstrate the interlinking rationale for the critical realist philosophy, the pragmatist epistemology, and the corresponding mixed methods employed. After outlining the philosophical basis, each phase of the research design and implementation is considered in detail

The philosophical assumptions that underpin the methodological approach are significantly important factors in all research. Research philosophy can be understood as the product of the ontological, epistemological, and axiological assumptions that underpin research; the what, the how and the accepted wisdoms that define the basis of the study. Laclau and Bhaskar (1998, p. 11) define ontology as the ‘theory of being’. Ontology therefore describes assumptions about the actuality, or reality, of the world and society (Zachariadis, Scott and Barrett, 2013). Epistemological aspects relate to the researcher’s ideas about the ‘what’ and ‘how’ of knowledge, what it is and how it can be developed and understood when defining the phenomenon being considered. Axiology outlines the decisions that emerge from the inherent value system, about what knowledge is respected and the related ethical values. It is therefore the researcher’s philosophy, the ontological assumptions, informed by axiological influences and judgements, which define the research paradigm and the researcher’s subsequent methodological decisions (Denzin and Lincoln, 1994; Mertens, 2007; Pathirage, Amaratunga and Haigh, 2008).

4.2.1 The philosophy that informs this research

Within the context of this research, ontologically I accept that an autism diagnosis is a ‘real-world’ phenomenon, experienced by individuals whose development, when assessed by methods based on normative development (Tunç *et al*., 2019), are considered to be different in the key areas of development identified by the diagnostic criteria (e.g. APA, 2013; WHO, 2018). However, I also believe that understanding of autism is socially influenced, therefore the diagnosis will be experienced and interpreted through perceptions that are socially constructed, which have ‘real-world’ impact. Epistemologically, as a socially influenced experience, I believe that the experience of the autism diagnosis can be best understood through the perspectives of the CYP with autism, by considering their perceptions about being told they have autism and the impact it had upon them. CYP’s experiences of their autism diagnosis happen in a social context with their parents, and relevant professionals. Therefore, the perceptions of their parents and professionals were also identified to be important, as they will have experienced and influenced the diagnostic process alongside the child. They will also influence CYP’s experiences in relation to autism through, for example, providing information and support to the child about the reasons for assessment, at the point of diagnosis, and after the diagnosis has been made.

As a parent of a child with autism, I have experienced the processes and impact of an autism diagnosis. As an educational professional and advisory teacher working with

CYP with autism and their parents, I have also been involved in the diagnostic process and have supported CYP and their parents as a follow up to the diagnosis. I am therefore personally and professionally committed to exploring the elements that contribute to best practice for supporting CYP's understanding of an autism diagnosis. It is because of my personal and professional experiences, that I believe that CYP who have experienced an autism diagnosis, and those who are involved alongside them, can best inform the research questions. It is their lived experience that can support other parents and professionals, who are preparing to inform a child about a diagnosis, about when and how they might do this successfully.

The axiological considerations and judgements I have made in development of this study, have been impacted by my experiences and my inherent value system, which has led me to adopt a transformative research paradigm for this research. The transformative research paradigm, as described by Mertens *et al*. (2010, p. 195), is one that aims to recognise ‘power differences and the ethical implications’ of issues such as ‘discrimination, oppression, [and] misrepresentation’, which individuals with a range of specific characteristics might experience, if their views are not considered during social encounters, service user experiences, and through research processes. I firmly believe that it is important to listen to the views of CYP. Children who have been told about an autism diagnosis hold valuable knowledge about their experiences. Furthermore, they have the right to inform and participate in activity that directly affects them. This right is embedded in the United Nations (1989) *Convention on the rights of* *the child* (Article 12). Considering these perceptions and the research aims, the research paradigm adopted for this research is summarised below in Table 30.

Table 30 A summary of the research paradigm employed for this research, based on Crotty (1998, p.296); Scotland (2012, p. 13); and Guba & Lincoln (1994, p.170)

Research Paradigm Terminology	**Ontology**	**Epistemology**	**Theoretical Perspective/s**	**Methodology**	**Methods**	**Sources**
What the terminology means:	What is reality?	What and how can I know reality/knowledge?	The approach I have used to explore the research question	The procedures I have used to acquire the knowledge	The tools and resources I have used to acquire the knowledge	What data was collected and how was it analysed?
How it applies to this research:	Critical realism: it is shaped by political, cultural and social values – manifested as a shared understanding Reality is continually socially constructed **and** under internal influences Reality related to autism is constantly renegotiated and influenced by changing contexts such as diagnostic criteria and cultural change and individual experience	Pragmatism How autism is understood by and discussed with CYP on the autism spectrum Exploring views related to autism and autism diagnosis Review literature, structures & processes related to autism	Deweyan Pragmatist: research through design Emancipatory disability theory Critical ethnography	Methodological pluralism: mixed methods design	Systematic literature review Online survey with scaled response closed questions & open questions allowing in-depth responses Focus groups & Interviews	Perceptions of autism and autism diagnosis via: Systematic literature review following PRISMA protocol Descriptive summary of survey responses to scaled questions Thematic analysis of open questions Thematic analysis of interviews

A discussion of the ideas summarised in Table 30 follows, to explain the rationale for the research paradigm, by considering the philosophy which underpins it. This includes my philosophical assumptions about the world (ontology), how I believe we can come to know that world (epistemology) and the nature of that knowledge. This will demonstrate the way in which my philosophy connected with the research aims and methods employed, as well as the potential influences upon the decisions made in adopting and implementing the paradigm outlined.

4.2.2 Theoretical perspectives

While considering children's views was recognised to be crucial in undertaking this research, gaining insights into CYP's understanding of autism and an autism diagnosis, was anticipated to be potentially problematic, and has indeed proved to be so. Robson (2002, p.4) cautions researchers about the complex nature of 'real-world' research and the difficulty that can be experienced in drawing conclusions in relation to social research, because it is generally difficult to control and frequently 'messy'. In his introduction to the republished 'Reclaiming Reality', Bhaskar (2011) suggests that the social sciences do have the potential to interpret and even to change the world. His challenge to the social scientist is to 'reclaim reality'; by transcending the problems and scientific philosophies that have dominated the 'field' of research. Therefore, to create a rationale for the critical realism that Bhaskar (2020, p. 113) suggests '…can facilitate the understanding of persons and improve their lives', the section that follows will first consider the underlying philosophy of critical realism, before considering how this influences the other elements of the research paradigm, the epistemology and methods employed.

4.2.3 Critical realism

In adopting a critical realist philosophy, I accepted that it is because of the many past and contemporary decisions made by people and society that the reality of the diagnostic experience of autism, and views of autism, are constructed. Bhaskar (2008; 2011, p. 1) suggested that such underlying philosophies should be taken seriously because they form the basis of what is considered as science or knowledge, in addition to which political systems it legitimates. Bhaskar (1975, pp. 46-47) identified three ontological layers: the real (structures and systems), the actual (events created by structures and systems), and the empirical (events that can be experienced, described and observed). As Scott (2010, p. 5) highlighted, the 'critical' aspect within critical realism understands that the ontological layers are not static. Therefore, the world will be in a continuing state of flux and will always be open to critique and to replacement, as this reflects how the 'events' are experienced, observed and understood. Critical realists accept that understandings of the world cannot be infinite because objects do exist regardless of whether we perceive them. Critical realists therefore accept object reality, while focussing on social practices, in the belief that people have the agency and power to make a difference.

4.2.4 Pragmatism as the epistemology

I am aware that there is disagreement about whether pragmatism is considered an ontology or an epistemology. For example, Morgan (2007) highlights, that pragmatism does not adopt an ontologically driven view or focus upon types of causation. Peirce (1905), whose views are credited as a key philosophical source of pragmatism, suggested it did not require a position on the reality of the physical world because it had no metaphysical implications. Mead (1934), however, suggested an ontological basis, explaining that a coin on the floor is real, but might mean different things to different people. Thayer (1982, p. 5), in discussing another of the early pragmatist theorists: William James, highlighted that James regularly demonstrated that pragmatic truth and verification are closely interrelated. DeForge and Shaw (2012, p. 92) develop this idea and highlight that a pragmatist epistemological approach to enquiry would explore the ‘…experiences of the participants’, which would be ‘contextualised to inform future […] practices…’ This can be seen to link directly with the aims of the research, and the critical realist view that people have the agency and power to make a difference. Therefore, an important understanding, and a key basis for the approach adopted for this research is that all who experience autism, as well as those involved in and around autism diagnosis, have the agency and power to make a difference. Furthermore, as De Forge and Shaw (2012, p. 92) suggest, because critical realism and pragmatism both adopt ‘…tentative realist ontologies, alongside subjective, critical epistemologies…’, as a combined ontological and epistemological approach, they can be more successful in providing greater depth of understanding and of influencing ‘…practice and⁄or policy change, informed by both formal, explicit knowledge and by experiential, tacit knowledge’. It is therefore young people’s experiences of autism and diagnosis, and of those involved alongside them, that can provide the depth of understanding for this study.

4.2.5 Pragmatism and methodology

The positivist paradigm views reality as universal, objective, and quantifiable, therefore, within this perspective, it is possible to identify reality through scientific methods (Guba, 1990). The epistemological stance that constructivism takes, however, recognises that meaning is co-constructed through interaction between participant and researcher (Hayes and Oppenheim, 1997). Guba and Lincoln (1989) suggest that because reality is constructed through interactions, there will be as many such constructions as there are individuals. Ashworth (2003) highlights the importance of considering the person as a perceiver, conceiver, or constructor of his or her world. As this research considers CYP with autism diagnosis, the perceptions, and constructions of CYP with autism were a highly pertinent consideration. Gaining an understanding of the way CYP with autism understood the diagnosis, themselves, and their world in relation to their autism diagnosis was a central aim of the research. The experience of the diagnostic processes was understood to be both socially influenced and unique. However, it was understood that it will also be influenced by shared cognitive understandings, and differences in processing style that CYP on the autism spectrum experience, which have been identified as impacting their perceptions of the world (e.g., Happé and Frith, 2006; Mottron et al., 2006; Pellicano and Burr, 2012).

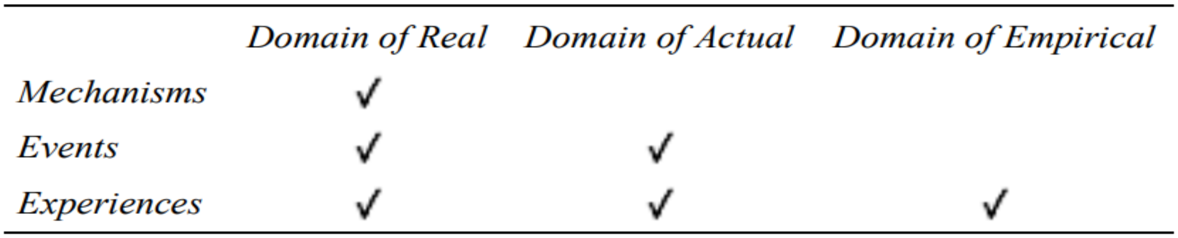
Pragmatism has also been suggested to have an epistemological basis which combines methodologies as an effective approach to explore phenomena (Greene and Caracelli, 1997; Cresswell, 2009). Laing (1967, p53) highlighted that an ‘ontological discontinuity’ exists between the way people experience the world and the way things behave in the world, distinguishing between reality and interpretation of real experiences. Therefore, as De Quincey (2005) suggested, reality is an experienced reality to which linguistic and other interpretations can be applied. Morgan (2007) suggested that because positivist and constructivist tendencies are neither complete, nor mutually exclusive, well-designed mixed methodologies can provide the most comprehensive evidence that is both generalisable and contextualised.

4.2.6 Critical realism & pragmatism

By combining both a critical realist ontology and a pragmatist epistemology, I have therefore, embraced a more comprehensive way in which to understand the world, as suggested by Badley (2003). Furthermore, as suggested by Morrison (2001), the flexible approach undertaken has enabled multiple perspectives to be explored about what is important to the topic being considered.

Table 31 below presents Bhaskar's Reductive Framework (1975, p. 2), showing the way in which the three ontological domains of the real, the actual and the empirical corresponds to the mechanisms, events, and experiences in critical realist ontology.

Table 31 Bhaskar's Reductive Framework showing the three ontological domains



	Domain of Real	*Domain of Actual*	*Domain of Empirical*
Mechanisms	✓		
Events	✓	✓	
Experiences	✓	✓	✓

In relation to autism diagnosis and diagnostic processes, the domains of the **real,** the **actual,** and the **empirical,** and the relationships between the mechanisms, events and experiences that have informed this research are explained below and summarised in Figures 5 and 6 below, and Table 32 below.

The real (structures and systems), for example:

- Internationally agreed autism diagnostic criteria (e.g. APA, 2013; WHO, 2018) and the national and local diagnostic pathways for autism (NICE, 2011b; 2017)
- Education and schooling systems; Code of Practice for the identification of special educational needs and disabilities (Department for Education and Department of Health, 2015), health and social care services and their systems: National Occupational Standards (NOS) (Skills for Care and Skills for Health, 2012)
- The family; classroom groupings; diagnostic teams

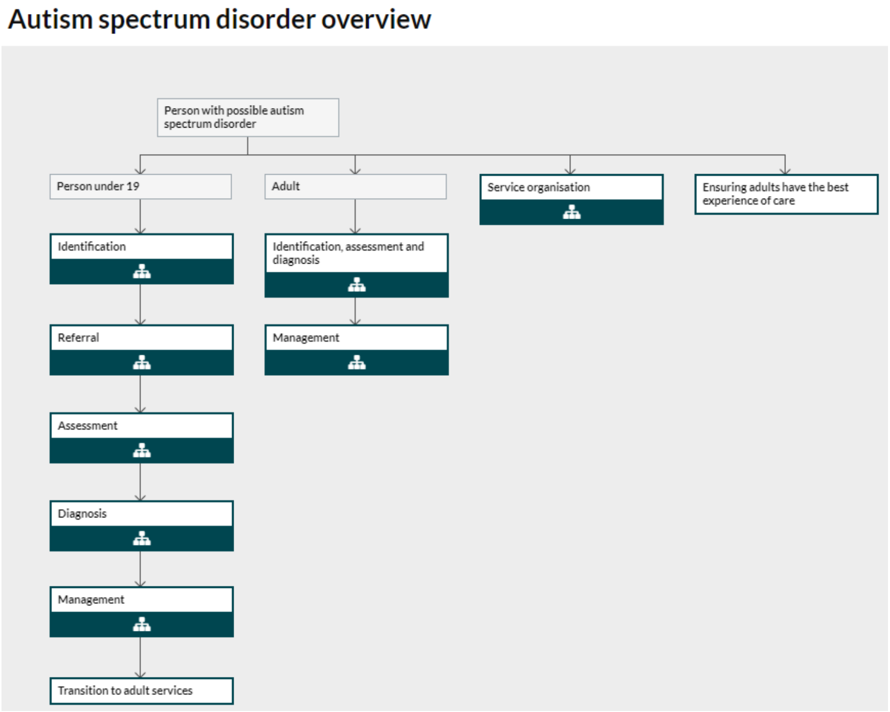


Figure 5 Structures and systems identified in the diagnostic pathways for autism (NICE, 2019a)

- **The actual** (events created by structures and systems):
    - Daily experiences within early years and school provision
    - Meetings and provision through educational assessment and provision in relation to Code of Practice for SEND
    - health provision through appointments with general practitioners and specialist services. For example: paediatrics, speech and language therapy services, and child and adolescent mental health services, and appointments with service professionals involved in the autism

diagnostic assessment and diagnostic disclosure. This is shown below as an event that stems from the NICE (2019a) Pathway:

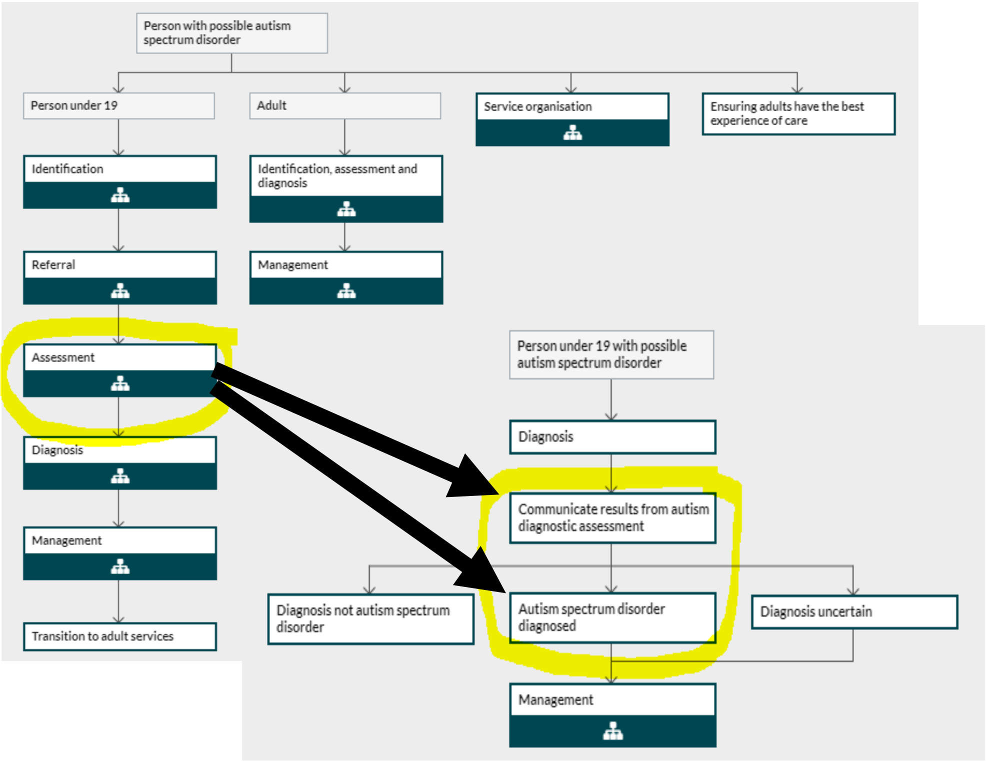


Figure 6 Events that stem from the structures and systems in the diagnostic pathway for autism (NICE, 2019b)

- **The empirical** (events that can be experienced, described and observed):
  - Experiences described by young people, or through parent and professional observations and explanations related to events, such as:
    - Interaction with educators within early years settings, schools and post 16 settings
    - Home interactions and experiences

        - Health-based assessments
        - Meetings with professionals-while being assessed
        - Being told about the autism diagnosis
        - Meetings, training, and therapy focussed on post diagnostic support
    - Impact on young person described by others or observed via an assessment scale, questionnaire or in narrative form.

Table 32 Summary of Bhaskar's (1975) ontological layers, as applied to this research topic

		Domain of real	**Domain of actual**	**Domain of empirical**
Mechanisms	National & local structures and systems for diagnosis • Autism Diagnostic criteria • Education, health and social care services • National and local diagnostic pathways for autism • Code of practice for SEND	✓		
Events	Events created by structures and system • School lessons and learning situations • Diagnostic assessment and disclosure meetings • Post diagnostic support	✓	✓	
Experiences	Which can be experienced, described and observed • Being assessed • Being told about an autism diagnosis • Discussions with parents • Interactions with educators and peers • Feelings because of the above	✓	✓	✓

My beliefs have been shaped, not only by personal experiences, but also from professional experiences, which have been influenced by educational theory and practice. It is such experiences that Habermas (1984, p. 200) highlights can lead to 'naive familiarity', which can be difficult to escape, and which might implicitly influence interpretations and actions. Habermas (1984) emphasised that learning can be shaped implicitly and explicitly, as we organise our knowledge. From a research perspective, it is a reminder that learning can only be objective if undertaken at the conscious level, which is recognised as crucial to interpretation during the process of analysis.

4.2.7 Why the aims and values informing research approaches must be explicit

Axiology is predominantly concerned with the aims of research and whether it is to explain, predict or understand the world (Lee and Lings, 2008). The researcher's underlying values are axiological concerns, as they are likely to impact upon all aspects of the processes involved (Li, 2016). Toe (2008, p.57) suggested that the underlying values of all researchers are of paramount importance when they relate to human groupings, especially when interpretation leads to suggestions of the group being 'problematic or inferior'. While I do not believe that individuals with autism are either problematic or inferior, this view is an important factor to consider. Spivak (1988, p. 24) used the term 'epistemic violence' when exploring such issues within context of colonialism with the 'Third World'. Teo (2008) later applied this concept to research methods and analysis, whereby the researcher's values are seen to influence data interpretation by preventing the researcher from recognising valid alternative interpretations. To avoid 'epistemic violence' within disability studies, Scully (2008) suggested that for a researcher to be consistent to ‘disability ethics’, analysis of data should take place in a way that is:

> …conscientiously attentive to the experience of being or having a non-normative embodiment (Scully, 2008, p. 25).

It was to be consistent with this view, that I developed the survey statements based upon the views of young people with autism, which were obtained through the preliminary study, the literature based on young people’s views, and analysis of published accounts (See Appendix 5: analysis of documentary) and feedback from a focus group.

Bourdieu (1990) emphasised that we are not always aware of perceptions because of the ‘pre-reflexive’ processes involved in articulating meaning, which, he suggested, are deep rooted from our earliest experiences and the everyday practices of human activity. An ethical approach to research, would therefore involve the researcher being explicit in terms of axiological influences that might influence epistemological decisions. As suggested by Finley (2002, p. 531), by ‘outing’ potential influences upon pre-reflective processes that might shape interpretation, the researcher will be more aware of potential bias, making it more likely that the pre-reflective interpretations are replaced by the reflective. In undertaking this study, I was aware that the very nature of these deep-rooted influences meant that they might not always be fully apparent to me. Nevertheless, as suggested by Knight (2002), by monitoring, recording, and reflecting on views that challenged my assumptions, when undertaking fieldwork and the data analysis process, it was hoped that flawed assumptions were identified and potential bias reduced, as methodological influences and decisions were clearly identified and transparent. The methodology section, which follows, will demonstrate the steps taken, which linked directly with both the philosophical foundation of the research and facilitated the research outcomes to be met.

4.3 Methodology

In using the concurrent, embedded, epistemological approach described above (Cresswell, 2009), the research was designed to be a mixed-methods study to provide a comprehensive basis for comparison across participants, while also providing a depth of understanding about the ‘real world’ implications of the process of coming to understand an autism. The main variables, experiences of the processes compared to impact, were explored using scaled responses, collected through the online survey. Open survey questions and semi-structured interviews were also employed to provide greater depth in telling of experiences, thus enriching the analysis, and understanding. Mixed-methods studies often use surveys or questionnaires alongside interviews or focus groups. In addition to using mixed methods across the tools used for collection of data (survey, interviews and focus groups), within this study, the online survey was also designed to employ mixed data sets. The survey sought responses via both closed and open questions, this is an approach that has been employed successfully by other researchers (e.g. Roberts, Hunter and Cheng, 2017). Surveys are also often combined with qualitative methods such as focus groups (e.g. White et al., 2016), or interviews (e.g. Pellicano, Dinsmore and Charman, 2014). Hammond and Wellington (2020, p.174) have highlighted that while surveys and questionnaires can be useful to explore patterns across participants, the more in-depth data provided by interviews and focus groups can facilitate a greater understanding of the behaviours, thoughts and attitudes of participants. As identified by Hammond and Wellington (2020), it was to gain both an overview of patterns across participants and an in-depth understanding of experiences that a mixed approach was undertaken.

The pragmatist research paradigm also acknowledged the ‘real world research problems’, which were documented through the research journal and considered reflexively, to ensure their influence was considered (Tashakkori and Teddlie, 2003). When difficulties occurred in terms of the recruitment of young people with autism, the flexibility offered by the mixed-methods, pragmatic approach meant it was possible to adjust in response to the ‘real world’ issues encountered. Thus, the systematic review was undertaken to draw all the evidence together from the increased number of small research studies that had been published since beginning this study and undertaken by other researchers concurrent with this study.

4.3.1 Mixed methods, credibility, and transparency

Although Robson (2002) suggested there are advantages to pragmatic mixed methods approaches, he cautioned that flexible designs must also meet ‘good practice’ expectations and consider how possible threats to validity and generalisability can be minimised (Clark-Carter, 1997). Robson (2002) highlighted a range of features that characterise ‘good’ flexible designs, these include, following at least one recognised research tradition, rigorous data analysis and discussion of findings, which moved from the specific to the general. The pragmatic methodological approach adopted for this study is in keeping with Robson's (2002) recommendations, in embracing 'methodological pluralism', because it provided a broader perspective than could be offered by single method designs (Azorín and Cameron, 2010, p. 95).

4.3.2 Critical realist and pragmatist influences

This mixed methods study is underpinned by a critical realist philosophy and a pragmatism epistemology. Critical Realists, such as Archer *et al.* (1998), hold that the world exists beyond our understanding. This enables critical realist researchers to adopt pragmatism in their epistemology and the methodology that is most appropriate to the focus of their enquiry. This has led some, such as Sayer (1992) and Oliver (2012), to suggest that critical realism does not have robust methodological tools. Bryant (2009) emphasised that, for pragmatists, knowledge is understood through theories, which are merely ways of conceptualising current understanding, rather than being fixed and forever truths.

> Pragmatist stance helps correct this since it emanates precisely from a concern with knowledge as a continuous social activity. (Bryant, 2009, p. 108).

However, as emphasised by Charmaz (2007, p. 110), there are also 'ambiguities and tensions', which must be considered when developing theory. Bryan (2009) therefore emphasised that the researcher's knowledge and preconceptions are key factors, which must be considered through researcher reflexivity. Elder-Vass (2007) suggested that the critical realist reductive framework, as described above, should be considered as researchers analyse their data at the three levels of the observable, the actual and the real.

Cohen and Crabtree (2006) identified four key elements required to establish trustworthiness within research to be credibility, transferability, dependability, and confirmability, which are summarised in Table 33 below.

Table 33 Elements required to establish trustworthiness

Key element and contribution to trustworthiness	**Approaches**	**Suggested methods**
Credibility to increase confidence in the actuality of findings	Prolonged Engagement	Sufficient experience from the field to fully understand the phenomenon of interest
	Persistent Observation	To understand multiple influences contextual factors that might impact upon the process being considered
	Triangulation	Multiple data sources to aid rich, robust, comprehensive and well-developed understanding rather than for validation
	Peer Debriefing	Discussion with a neutral peer to explore reflections about the research processes, which might otherwise remain implicit within the researcher's mind
	Negative case analysis	Searching for and discussing elements of the data that contradict patterns emerging from data analysis.
	Referential Adequacy	Archiving a portion of data to be analysed when preliminary findings are established. Data is then analysed to consider validity of findings.
	Member checks	Interpretations are checked with participants either formally or informally during fieldwork.
Transferability to demonstrates applicability beyond the specific research context	Thick description	Thick description from fieldwork to make the context explicit
Dependability to establish consistency in findings and showing they are replicable	External audit	A neutral researcher examines both the professes and findings to explore whether the findings are supported by the data
Confirmability to demonstrate neutrality and that findings are informed by the participants	Audit trail	Lincoln and Guba (1985) suggest including: • raw data • data reduction summaries and notes on theories • data synthesis including category structure, themes, definitions and relationships • notes on processes, including about methodology procedures, design, materials & reflexive notes, ideas and motivations • notes about development of tools, for example pilot forms, preliminary schedules
	Triangulation	Four types of triangulation: • Methods – showing consistency of findings generated by different data collection methods • Sources - showing the consistency of data sources from within the same method • Analysis- using multiple observers and analysts • Theory - using multiple theoretical perspectives to examine and interpret the data
	Reflexivity	Reflection and monitoring for preconceptions and possible bias and being explicit about influences (Malterud, 2001)

Based on guidance by Cohen and Crabtree (2006)

The methods section that follows, will show how the trustworthiness of this research study has been established, by demonstrating how the elements suggested by

Cohen's and Crabtree's (2006) framework have been embedded within and/or demonstrated by the approaches adopted for the research.

4.4 Research methods

After discussion of the research methods, the approach adopted to journal thoughts, influences and experiences relevant to the research will be explained, then the initial fieldwork and pilot study are outlined. In moving forward to describe the development of the main study, the processes involved in designing the survey and interview questions are explained. This aims to demonstrate how the views of the CYP with autism have been drawn upon to influence the refinement of the research tools. The recruitment processes are then outlined for the key stakeholders: CYP with autism, parents of CYP with autism, and professionals who work with them. By being transparent about the methods and by drawing on the views of the research subjects to inform the methods used, the relevance of the research, which has been identified as essential, will be demonstrated (e.g.: Edelstein, 2014; Gerrard, 2015; Dennhardt *et al*., 2016). Furthermore, the processes related to Malaurent's and Avison's (2017) third R of research, reflexivity, will be demonstrated throughout. After outlining the ethical considerations, the chapter concludes by considering the reliability, validity, and trustworthiness of the study. This will be summarised by revisiting each of the trustworthiness elements suggested by Cohen and Crabtree (2006).

4.4.1 Surveys

While Hammond and Wellington (2020) identified that the aim of surveys is usually to find out how people view certain topics or about the reasons for their actions, they also highlighted that surveys are also useful for both exploring and describing topics of interest. Couper and Miller (2008), however, suggested that the main benefit of surveys is that they are low cost and are therefore more accessible for unfunded and low-cost research than telephone or face to face survey methods. Furthermore, software improvements for online survey design have made their creation, the extraction of data, and data analysis more efficient (Wright, 2005). Wright (2005) has highlighted other benefits related to online surveys, for example, in a short amount of time, they offer researchers the opportunity to reach targeted individuals through online groups for individuals who share similar interests, which might be related to activities and interests, or to factors such as health and disability. Wright (2005) also highlighted their benefit in enabling participation of those that might be hesitant to participate in person, and those who would feel uncomfortable discussing personal issues face to face. As this research study aimed to explore the views of people with autism, who might experience discomfort with methods such as face to face interviews due to the differences they experience in relation to social communication (APA, 2013; WHO, 2018), this was considered a particularly pertinent benefit.

Couper and Miller (2008) have highlighted the importance of explaining the approach to sampling and design so that the potential limitations can be understood. One of the main issues they highlighted was that of representation within the population of interest

(Couper and Miller, 2008, p. 832). For example, while access to the internet is now available to large proportions of the general public, internet poverty has been, and remains, a significant issue for those on low incomes (e.g., Anderson, 2005; Lucas, Robinson and Treacy, 2020), meaning that the views of people experiencing poverty and with low incomes might be underrepresented. To counter this issue, Couper and Miller (2008) highlighted that providing participants with a choice of modes for participation was beneficial, not only to provide different types of data, but also to provide an alternative method of participant for those without internet access. The combination of online survey and interviews used in this study, therefore also provided the opportunity for participation for those experiencing internet poverty who might not be able to participate online.

Hammond and Wellington (2020) and Wright (2005) have highlighted several issues related to both surveys in general and to online survey participation. A general issue highlighted is that responders might not be accurate in their provision of information. For example, when participants contribute to surveys related to health or disability, those without a definite diagnosis might still feel they should participate as they perceive that they have the specific illness or disability, or that they might be diagnosed soon. As proof of diagnosis was not required of participants within this study, it was recognised to be a potential limitation. However, participant information related to this research did highlight that the research was for participants with a diagnosis, or parents of CYP with a diagnosis and those working with them. At the beginning of the survey, participants were also required to identify their specific diagnosis, which again emphasised the need for diagnosis. Another major limitation highlighted by several researchers is that of self-selection bias, whereby some people, perhaps those with strong views or an intense interest in a topic are more likely to participate. As discussed in Chapter Two, it is known that some people with autism have strong views about the diagnosis (See for example: Armstrong, 2011; Giles, 2013; Kenny *et al.,* 2016; Browne, 2017; Limberg, 2019; Pesce, 2019; Robison, 2019), therefore, this is also a limitation that could have impacted participation within this study. Wright (2005) also highlights that frequent requests for participation posted on websites and interest groups can mean that some potential participants become fatigued with requests and therefore do not take part. Therefore, while some participants are more likely to respond, others are likely to ignore participation requests, which can lead to a systemic bias. However, this same potential bias applies equally to postal surveys. For quantitative researchers who wish to make generalisations based on probability, this is particularly problematic, but as this research does not make such generalisations it is less problematic. Furthermore, when the researcher's aim is not to make probability-based generalisations, Wright (2005) suggested that replication and triangulation are useful methods to provide a more reliable understanding of the participants and topic under consideration. Due to the differences in social development that are identified in relation autism (APA, 2013; WHO, 2018), it might be that being able to participate without having to interact socially was preferable to some of the participants with autism. For example, good participation rates have been shown in recent online surveys exploring the views of people with autism (e.g., Kamio, Inada and Koyama, 2013, Jones *et al*., 2014; Kenny *et al*., 2016).

Therefore, as online surveys have been found to be useful in ensuring a high rate of return (e.g., Williams and Wilkinson, 1995; Avis *et al*., 1997; Calnan, 1998; Cox, 2003; Wright, 2005; Kamio, Inada and Koyama, 2013, Jones *et al*., 2014; Kenny *et al*., 2016), this method was utilised as a data collection tool, while also employing triangulation via both participants (children and young people with autism, parents and professionals), and the data collection methods (online survey with closed and open questions and interviews). It was also decided to use an online survey tool to facilitate greatest participation by publicising the research through websites and support groups related to autism, which potential participants were anticipated to be likely to access. Furthermore, as many support groups use a combination of face-to-face meetings, social media and e-mails to transfer information between their members, it was anticipated to be likely to be the most efficient method. It was anticipated that such groups would consider the research sufficiently pertinent and potentially beneficial to secure their agreement to send out the research information. In line with ethical considerations, which are outlined in detail below, and as an incentive to internet gatekeepers, the research invitation to participate offered to provide feedback about the research to those groups and organisations that advertised the research, and to the participants those who took part. As advocated by Couper and Miller (2008), the approach to sampling and design are detailed below so that all the potential limitations are identified.

4.4.2 Interviews

Tracy (2019, p.155) has highlighted that the main purpose of interviews is to '… stumble upon and further explore complex phenomenon that may otherwise be hidden or unseen”. A key benefit is the opportunity they provide participants to share their perspective, but it is also highlighted that the researcher always holds the balance of power within an interview (Tracy, 2019). While this is recognised, it is because of the potential for participants to share useful perspectives that might not have been recognised as pertinent in designing the research that this method was employed. Furthermore, rather than an inflexible, structured interview with tightly scripted questions, a semi-structured approach was used that comprised broad questions with a series of prompts to stimulate lively and comprehensive coverage of the topic, which has been identified to be more likely to enable the researcher to gauge the emotional impact (Tracy, 2019). This decision was also made with awareness of the potential for unstructured the interviews to make the analysis more difficult (Brinkmann and Kvale, 2015). Nevertheless, as semi-structured interviews could provide scope for interviewees to introduce their own unique ideas, they were felt to be most appropriate. Furthermore, employing the same key topics for discussion, enabled the analysis and comparison to follow the same structured approach. To facilitate meaningful discussion, a responsive approach was undertaken, which Rubin and Rubin (2011) highlight facilitates positive and reciprocal interview relationships, by being unwaveringly respectful to the interviewees and their contributions. Furthermore, this responsive approach does not aim to camouflage researcher bias, such as shared experiences with interviewees. The researcher can be open about them and their views within the interview, but it does require the researcher to be reflexive. The reflexive approach adopted to support this is outlined in Section 4.5 below.

4.4.3 Focus groups

Focus groups are considered by some as a variation of an interview, which aim to generate rich information about specific topics, via participatory discussion, to facilitate sharing of experiences, views, and concepts (Kinalski *et al*., 2017). As focus groups involve interaction between participants, however, Kruger (1994) suggested they should be considered as group discussions rather than interviews. It was for the discursive value of focus groups that they were employed at the beginning of the research process, to ensure that the design was informed by those whose experiences it sought to investigate. As Morgan and Spanish (1984) identified, the most significant advantage of the focus group is it is an especially useful method for illuminating the unexpected, due to focussing more on values and priorities of the participants than those of the researcher. By gaining the views of CYP with autism and parents of CYP with autism about the experience of learning about the autism diagnosis, it was anticipated that topics of importance to the participants, which might otherwise have been missed, could be uncovered. In the later stage of the design phase, a focus group was also used to explore perspectives on the survey design, due to the practical advantage focus groups also offer, to gain multiple views in one place, at one event, thus it was easier to organise and efficient in terms of time (Stokes and Bergin, 2006). However, as Stewart and Shamdasani (1990) have highlighted, the main reason for employing focus groups was that they facilitate the snowballing of discussion ideas. However, it was also important to consider potential problems with focus group dynamics, for example, some participants might be more socially confident to share their views and social conformism can also be problematic, if participants feel pressure conform to dominant viewpoints (Rezaei et al., 2021). Furthermore, the pace of discussion might also mean that highly pertinent topics might be passed over, which Acocella (2012) warned can mean that the focus topic might not be fully explored, if the topic is not tightly focussed and of interest and relevance to the participants. As suggested by Parker and Tritter (2006), these issues were addressed through careful design that managed the group dynamics, for example, by asking questions and using a visual framework to structure the discussion, and by engaging specific participants to balance the contributions.

In this study, as highlighted by Parker and Tritter (2006), by obtaining the data through the mix of methods described above, methodological triangulation has been incorporated, which can provide a greater balance and a more complete picture of the topic being considered, by enabling comparison across methods. However, each method has potential strengths, issues and limitations, the sections that follow explain how these methods were implemented within this research to maximise the benefits and in recognition of the potential limitations.

4.4.4 Thematic analysis

Thematic analysis was the approach undertaken to explore all the qualitative data that was collected via the different methods employed in this study (e.g., open survey questions, interviews and focus groups, and analysis and synthesis within the review). Braun and Clarke (2006, p.78) describe thematic analysis as the foundational method for qualitative analysis, a core skill that can provide a basis for other forms of analysis, which can be applied to any methodology. Fundamentally, it is an approach to analyse data that identifies, organises and presents themes (Braun and Clarke (2006, p. 79). Unlike other approaches, such as Interpretative phenomenological analysis (IPA) and grounded theory, thematic analysis is not linked to a specific methodology and analysis does not need to be directed towards pre-identified theory. Therefore, thematic analysis is flexible, which makes it especially appropriate for research based on a pragmatic epistemology that utilises mixed methods. Furthermore, thematic analysis can straddle empiricist and constructivist dichotomy because it accepts that individuals interpret their experiences considering social experiences, but also remains focused on both the limits of reality and the material within the data (Braun and Clarke, 2006, p. 81). Therefore, thematic analysis was identified as the most appropriate method for the qualitative analysis within this study. Thematic analysis also avoids searching for specific themes and interpretation during analysis, which reduces the likelihood of subjectivity (Braun and Clarke, 2006). I wanted the approach to analysis to produce a rich description of all the data, but to present it in a way that identifies the most pertinent themes, which Braun and Clarke (2006, p. 83) highlight is especially useful when exploring topics about which little is known. The approach used in this study, followed the 6 steps identified by Braun and Clarke (2006, p. 87). Step One involved familiarisation through listening to and transcribing recordings, or reading the data to get an overview, while noting initial ideas; in Step Two, initial themes were identified across the data with examples; in Step Three, connections between themes were identified and linked with overarching themes. The initial themes therefore became the sub-themes and the overarching ones the main themes. These themes were then reviewed, and a table produced to map the analysis (Section 4.4.22: Analysis of online surveys, and Table 36 below, provides a worked example of this approach). The analysis was continually refined as the different data sources were explored from each group of participants. In the final phase, examples of participants' spoken, and written, ideas are presented and are considered against the research questions and literature in order to draw conclusions. These same three steps were also applied across the data from each stage of the individual studies, across the three key stakeholders, to synthesise the findings from the three different perspectives: CYP with autism, parents of CYP with autism, and professionals who work with them. Further details of the synthesis are provided in the introduction to Chapter Eight, before the synthesis is presented. Braun and Clarke (2006) also emphasised the importance of an ongoing process of reflexivity throughout the research, therefore, a research diary was maintained throughout.

4.4.5 The research diary

The use of a research diary has been advocated, especially within qualitative research to demonstrate rigour, but also to support reflection on thoughts, feelings, readings, methods and fieldwork, and to support transparency (Kiyimba, Lester and O'Reilly, 2019). O'Reilly and Parker (2014), for example, highlighted three main reasons for keeping a diary: recording of factual information, such as events, actions, decisions; fieldwork: to record reflexivity, such as responses, feelings and reactions during interviews; and to note how this reflexivity informed the decisions made to in light of reflection. As suggested by Gibbs (2007), a large bound notebook was used initially, but because it was cumbersome, it was difficult to maintain in this format. I have, however, maintained notes throughout, albeit in a range of formats. Therefore, although not necessarily uniformly structured, reflection on factors that might influence the process has been a consistent element throughout. Appendix 13: extracts from the research journal, provides a selection of reflections, which I recognised have had the potential to influence the research process. This includes reflections on interactions with colleagues, anonymised reflections on interactions with CYP during advisory work, and during my work within higher education, as well reflections in response to fieldwork and data analysis.

4.4.6 Preliminary intervention study: Kids Autism Training (KAT)

The main aims of the preliminary study (Appendix 4: summary of the preliminary study) were to trial and evaluate a programme for CYP, which supported them to understand an autism diagnosis. The preliminary study also explored whether the evaluation questionnaire, which was used to collect the views of participants, was appropriately constructed. As this was focussed upon the impact of the programme on CYP's understanding of their autism diagnosis, the findings were relevant to the online survey that followed. It was identified that the evaluative questionnaire was too long, and that the wording needed to be clearer.

As suggested by Polit *et al*. (2001), the preliminary study proved useful and informed the development of the online survey that followed. The CYP involved in the preliminary study indicated they found it easier to discuss their feelings in relation to tangible skills and interactions; their descriptions linked with Bandura's (1997) concept of self-efficacy. Therefore, self-efficacy was adopted as the most appropriate concept to explore change within, through the online survey.

4.4.7 Online survey design

The preliminary study and initial review of the literature provided valuable insights into the process of coming the understand autism. In the literature, understanding of an autism diagnosis had been identified to be a gradual process, rather than a one-off event (Huws and Jones, 2008). Therefore, to explore CYP's experiences of an autism diagnosis, the online surveys were structured to seek perceptions about experiences before the diagnosis, when finding out about an autism diagnosis, and after the diagnosis is known. This structure was used for the CYP survey and the parental survey (See Appendix 6.6 Annotated draft survey from focus group feedback; Appendix 6.7 Summary of key considerations and changes made based on the suggestions from CYP via the focus group; Appendix 7 Online survey for children and young people; Appendix 8.1: Annotated draft of online survey for parents and Appendix 8.3: Final version of the survey for parents).

4.4.8 Online survey: structure and statements

An overarching concept that was apparent from the preliminary study and the literature review was self-efficacy, which is understood as an individual's perception of their ability to achieve goals (Flammer, 2001). Bandura (1997) identified that perceived efficacy can influence learning within the specific skill areas considered. The before and after diagnosis sections of the survey explored CYP's self-efficacy in relation to social interaction, emotional management, and academic ability. The finding out section explored who explained the diagnosis; how information was provided and CYP's perceptions of this experience. The post-diagnosis section additionally asked about changes in support and understanding of others since finding out about the diagnosis. The survey statements were based on three sources of information: CYP's experiences and feelings about themselves in response to the preliminary study; information identified by the initial literature search in 2012; and initial analysis of young people's views and experiences shared via a documentary undertaken for the Autism Education Trust (*Receiving and Understanding a Diagnosis*, 2012) (See Appendix 5: Analysis of documentary and (Appendix 4.1) related conference paper). The aim was to build on the factors of importance, which had already been identified by CYP in the limited literature that was available at that time. The parent survey was designed to mirror the same structure and content as the survey for CYP.

4.4.9 Online survey statements

The specificity of self-efficacy to certain types of skills means that to explain or measure individual self-efficacy in a meaningful way, the self-efficacy measure must be tailored to the specific skills and activities under consideration (Forsyth and Carey, 1998). The survey statements were therefore constructed to explore self-efficacy in relation to key academic and social skills, which the initial preliminary study had identified as being a focus for CYP with autism. The aim was to explore whether there is a relationship between the diagnostic processes, the support experienced to understand the diagnosis, and self-efficacy. Bandura (2006) highlights that analysis across different areas of functioning has confirmed that self-efficacy has an influential role in human self-development and adaptation to change. Following the approach identified by Bandura (2006), a scale was used to explore the levels of participants' self-efficacy in relation to the survey statements. Scales have been advocated to be useful to support CYP with autism to rate experiences and share emotional responses (Buron and Curtis, 2003; Gillott, Furniss and Walter, 2003). Scales have also been identified as useful within survey research, providing a simple method for collecting participant responses, in a numerical form (Clark-Carter, 1997). A Likert scale was designed to avoid the issue inherent in scales with an even number of responses, which require a positive or negative response. Croasmun and Ostrom (2011) highlighted that even numbered scales can force responders to adopt a positive or negative stance, which might be at odds with actual views. An odd number of response categories was designed, as recommended by Croasmun and Ostrom (2011), to ensure responders were not forced to respond in a way they did not agree with. As advised by Robson (2002), statements were also drafted using simple clear language and avoiding jargon.

4.4.10 Pilot study for the survey

Two focus group discussions involving young people with autism were organised, implemented and qualitative analysis undertaken, to support refinement and improvement of the online survey. The focus group participants attended a mainstream grammar school, which had a support provision for CYP with autism. Although information was not collected about the CYP's level of ability, they had all passed the entrance exam and were of at least average intellectual ability.

In line with the ethical approval for the study (Appendix 14: confirmation of ethical approval), permission was first sought and granted by the head teacher (Appendix 6.1: letter to headteacher). Focus group participants and their parents were provided with information about the research focus and aims, the ethical and consent/assent arrangements, and the focus groups procedures (Appendix 6.2: research information for children and parents and consent and assent forms). Five parents consented to their child's participation and five young people assented to participate.

Consent and assent were obtained in advance of the focus group. Before commencing the focus group, participants were also reminded that participation was voluntary. They were given the opportunity to ask questions, before assenting verbally that they were still willing to take part. Participants were also reminded that an audio recording would be made and about how to withdraw, if they subsequently changed their mind.

Participants were informed they could decide not to contribute to specific discussion topics, and that they could leave the focus group at any point. Confidentiality was also discussed to reassure participants. There all agreed not to discuss any information provided by other participants, outside of the focus group.

4.4.11 Focus group procedures

After discussion with staff who knew the participants well, it had been decided to undertake two small focus groups with a group of three young people in group one, and two participants in group two. Staff from the school indicated that two of the volunteers were especially anxious in larger groups. As social experiences have been identified as significant in shaping the self-perceptions of CYP with autism, the small groups were organised for the focus group to reduce social anxieties and the potential for negative social experience (Huws and Jones, 2015; Jones, Gallus, Viering, *et al*., 2015). Unfortunately, as one volunteer from the planned group of two was ill and could not take part, the other pupil was offered the opportunity to join the larger group or to take part individually. He preferred to answer the focus group questions individually. The second focus group, therefore, became a one-to-one interview, however, the same questions and approach was utilised for both the focus group and individual interview.

As advised by Eaton (2017) the focus group questions aimed to be exploratory and open to support discussion, while avoiding influencing responses. The focus group framework was semi-structured and comprised six main sections with further prompts to encourage richer contributions in relation to the topics to be discussed (Appendix

6.3: focus group schedule). The main areas of discussion were the participants experiences before they knew about their diagnosis; finding out about an autism diagnosis; changes since finding out; and the scale for the questionnaire. The participants were also asked to share any other thoughts or perceptions that they felt were pertinent.

4.4.12 Conducting the focus group discussions

I was able to draw upon prior experiences of working with CYP with autism as a class teacher and an advisory teacher when planning and running the focus group sessions. Each discussion was limited to one hour to coincide with the school's midday break.

Participants were asked to complete a paper copy of the draft survey and to share their thoughts upon the content, and ease of completion, after each section of the survey. All participants managed to complete the survey with only minor clarification required. Where clarification was required, notes were taken about suggestions from the young people, which they felt would improve the clarity. Participants also suggested alterations to the scale, so that it was possible to select either 'not sure' or 'not relevant' to make the distinction clearer for survey respondents (For example, Appendix 6.5: focus group transcript; lines 69-76; 249-252; 349-356; Appendix 6.4: focus group visual prompt and recording sheet). Finally, the notes that had been taken during the focus group were shared with the participants. They were asked whether the notes appropriately reflected the ideas they had shared. Amendments were made as suggested by participants until all participants were satisfied that their views were reflected in the notes (For example, Appendix 6.5: focus group transcript; lines 257-285).

4.4.13 Analysis of the focus group feedback

The focus group recordings were transcribed in verbatim, except for participant names, for which pseudonyms were substituted to maintain participant anonymity. Transcripts were imported into NVivo 10 Plus (QSR International Pty Ltd, 2012) and content analysis was undertaken. The focus group participants identified several proofing errors and improvements in formatting, some rewording of the statements was suggested for clarity, and preferences for the survey scale were identified. Improvements were made to the final draft of the survey in line with the suggestions made by the focus group participants, prior to launching the survey (For full details of see Appendix 6.6 Annotated draft survey from focus group feedback; Appendix 6.7 Summary of key considerations and changes made based on the suggestions from CYP via the focus group; Appendix 7 Online survey for children and young people).

4.4.14 Implementing the online survey

The online survey for CYP with autism and their parents ran concurrently from 1st October 2014 to 23rd March 2015; the second data collection period was from 1st May 2017 to 30th September 2017. The findings from the first analysis of the CYP and parent survey informed development of the online survey for professionals, which collected data between 1st May 2017 to 30th September 2017. Recruitment to the online survey sought participation from the three key stakeholders: young people with a known autism spectrum diagnosis, who were aged 8-19 years, parents of CYP with autism, and the professionals who work with CYP with autism. It had been hoped that parent-child dyads would participate, however, only one parent/child dyad participated. The others were not related.

The invitation was open to all CYP on the autism spectrum within the identified age group. As the online survey required participants to read statements and answer open questions in writing, 8 years of age was identified to be a time when reading levels are likely to be sufficient to read and understand the questions (Wonnacott *et al*., 2016). The focus age range was also that within which CYP were most likely to have been made aware of their diagnosis. When the study was designed, the autism prevalence was identified as higher for males, with a 4:1 gender ratio (National Collaborating Centre for Women's and Children's Health, 2011), the aim was to mirror this ratio within the survey sample.

While participants were not asked about their perceived, or assessed, level of ability, the quality of the written and verbal responses reflected that they generally fall within the broad average, or above, level for the age-range of the study. As anticipated, by focussing on this age-range, they were able to explain their experiences and provide written narrative-based evidence (Baron-Cohen, 2000). Alongside the request for participation in the online survey, potential participants were also invited to participate via interview if preferred. There were no plans to exclude participants with additional learning or communication needs. A visual prompt had been designed to support CYP with autism for the interview (See Appendix 6.4: visual prompt for the CYP interview).

4.4.15 Recruitment to the study

The online survey was advertised via the webpages of two national charities (National Autistic Society and Research Autism) in 2014 and 2017. The advertisement was displayed on sections of their webpages where opportunities for participation in research related to autism were advertised (Appendix 15: research information and consent/assent for parents and CYP; Appendix 16: research information and consent for professionals). As participation was low, information about the research was also posted on a platform for students who were also undertaking post-graduate study related to autism, alongside a request for support with dissemination of the research information to potential participants. My research supervisors also disseminated information about the research through their contacts with students and autism focussed organisations. As I had undertaken an autism advisory role in three different local authorities, I was able to gain support from colleagues within the teams with the dissemination of information. Flyers advertising the research were also distributed at 3 large research events and a conference related to autism to generate interest. An internet search was also undertaken to identify the main contact for communication and autism focussed local authority teams across England and Wales. In 2014, I was able to identify the contact details of eighteen teams, via this internet search, and e-mails were sent to the contacts identified. Professionals from eleven autism outreach teams indicated they would disseminate the research information to schools so that information could be sent out to parents (in line with the ethical requirements). This information was provided in paper form inside an envelope, which schools then addressed and disseminated to specific parents. Colleagues from the outreach team also provided information about the research to the parents that they encountered during their daily activities. Two support groups for parents of children and young people on the autism spectrum, from different parts of the England (North West and South East), also agreed to send out the research flyer to all members with their regular online newsletter. As participation was low across the participant groups, a further effort was made to advertise the research again in 2017, via the two websites and the contacts I had initially approached in 2014. I was also able to identify a further fourteen outreach teams in 2017, who were also contacted and asked to disseminate information about the research to potential participants. In 2017, it was perhaps because of the changed requirements following the implementation of the Special Educational Needs and Disabilities (SEND): 0-25 years, Code of Practice (DfE & DoH, 2015), which meant that local authorities were required to provide information about their local offer for SEND, which made it possible to identify more autism outreach teams. In 2017, the information about the research also sought participation from professionals in either the online survey or interview. Despite these renewed efforts to encourage participation from parents and CYP in 2017, only five more young people and thirteen more parents participated in the online survey. When the research was advertised in 2014 and 2017, CYP and parents had been invited to take part via either the online survey or interview. Only three parents have volunteered to participate in an interview following the recruitment activities in 2014 and no CYP had volunteered. Following the 2017 recruitment activities, one young person volunteered to be interviewed and three more parents also volunteered to share their perspectives and experiences for the study via interview. Despite the large number of professionals, support groups, and school contacts who were provided information about the research, the majority did not respond; however, they might still have chosen to disseminate the research information (See Appendix 17: record of recruitment activities). Four professionals from schools offered to send information out to parents of pupils within their settings. Two SENCOs and two specialist teachers disseminated the information, with the agreement of the setting's headteacher.

In line with the ethical agreement, parents were the ultimate gatekeepers for the provision of information about the research to CYP, all invitations to participate were disseminated to parents via the above means. This was a requirement of ethical approval, to enable parents the opportunity to decide whether it was appropriate for their child to participate. As described above, survey participants were recruited through purposive, snowball sampling, which Smith, Flowers and Larkin (2009) suggest is likely to represent the perspective of a particular group, rather than being representative of a population. While this is recognised as a limitation, it was anticipated to also increase the likelihood that the topic of autism diagnosis was of recent, or current, relevance to participants, therefore facilitating better recall.

Only eleven young people took part in the young person's online survey. It was hoped that participation would be greater, it is possible that the participation rate was influenced by the ethical safeguards. Ethical safeguards are discussed in depth below; however, the safeguards for this study, which are recognised as being highly appropriate and necessary, placed constraints upon the way that information was provided to CYP who were potential participants. Mason (2009) and Collings, Grace and Llewellyn (2016) are amongst the growing number of researchers who have used the term ‘gatekeeper’ to describe the situation where adults, usually the parent, are responsible for deciding on the appropriateness of consenting to a child taking part in research. Researchers have also applied this term to professional gatekeeping roles. Hill (2005), for example, describes it as a process which might put such professionals in a position of power, as they decide whether to provide information to potential participants. When they do provide this information, it is suggested that they might, for a range of reasons, chose to provide information about the research to only a selection of potential participants. Such gatekeeping decisions can impact negatively upon the participation in research. It is not possible to know whether participation of CYP in this study was so low as very few CYP were told about the research, because parents and/or professionals chose not to provide them with the information. However, I did have the opportunity to discuss the potential for children’s participation in an interview with parents when I contacted them to organise the parental interviews. Of the nine parents that I spoke with when attempting to arrange interviews, six told me they had not told their child about the research and had therefore also not asked them to take part in an interview. There were similarities in the reasons that parents offered, three parents explained they did not feel it was a good time for their child’s participation, each of these parents explained that this was due to concerns about their general wellbeing. Two other parents indicated that they felt their child would struggle to manage an interview situation due to their autism related social needs. However, one of these parents had given the research flyer to their child in case they wanted to participate in the survey, but they were unsure if they had taken part. One parent indicated that they had not told their child because they were struggling to process the information about their autism diagnosis and any mention of autism triggered further upset. Of the two parents that had shared the information with their child, the parents of the child who chose not to participated indicated they he had said he was not interested in it. While I was only able to discuss children's participation with a small number of parents, their responses did reveal that parental gatekeeping decisions could have influenced the participation of CYP. While it is also understandable that parents wish to protect their child, as Sparrman (2014) discovered when exploring children's views about sexuality, parents hold the balance of power in relation to decisions that are perceived to relate to sensitive topics; a relationship in which Foucault (1978) would identify CYP's position as the subject. This potential limitation is explored further within the discussion of the study limitations in Chapter 8.

4.4.16 Online survey design for CYP and parents

The focus group participants had completed a paper version of the draft survey but identified their preference would usually be to access the survey online. Online surveys have also been identified to be most useful for generating a high rate of return (e.g. Cox, 2003; Crane *et al*., 2016). The survey was created using the Jisc Online Survey (Formerly known as the Bristol Online Survey); it was designed to enable CYP and parents of CYP with autism to rate the same concepts. The CYP survey asked participants to rate the statements in relation to themselves. The parent survey asked participants to rate statements about their child (Appendix 7: online survey for CYP;

Appendix 8: online annotated draft and final survey for parents). While the concept was the same for each question, the wording of the statements that were written for parents to rate was slightly different to facilitate this, examples of the differently worded statements from the surveys are outlined in Table 34 below.

Table 34 Example survey statements rated by young people and their parents

Survey Section/Number	Young People Survey Statements	Parent Survey Statements
Pre-diagnosis/1.3	I was confident when chatting with people in my class	S/he was very confident around other children
Pre-diagnosis/1.5	I knew I was different to other young people	S/he was always asking why s/he was different to other people
Finding out/2.4	The doctor or other specialist was able to tell me lots of helpful information	My child was given lots of helpful information by the specialist
Finding out/2.7	Finding out was a real surprise to me, I didn't realise that anyone thought I had autism	Finding out about the autism diagnosis came as a real surprise to my child
Post-diagnosis changes/3.8	Since finding out about the autism diagnosis: the teachers/tutors give me more help	Since finding out about their autism, I have noticed that my child gets more help from teachers/tutors
Post-diagnosis changes/3.10	Since finding out about the autism diagnosis: I get these negative ideas about myself, I sometimes think I'm never going to achieve anything	Since finding out about their autism, I have noticed that my child thinks negatively about their future

Parents and young people were asked to rate the statements via a scale, as shown in Figure 7 below. The mid-point on the scale is scored with the neutral score to prevent artificial lowering or raising of scores when in fact a participant's view is neutral.

Negative Scoring	5	4	3	2	1	3	3
Scale	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other
Positive Scoring	1	2	3	4	5	3	3

Figure 7 Online survey scale and scoring

Some researchers advise against 'not sure/undecided' as a mid-point and suggest use of 'neither agree nor disagree' as a neutral point (e.g., Chyung *et al*., 2017). However, feedback from CYP with autism via the focus group, when trailing the survey, indicated that they found this to be confusing and that their preference was for ‘not sure’. They also felt that having an option for responders who felt the question was ‘not relevant’ to them was important. Focus group participants also identified the need for an ‘other’ option, to ensure responses fitted individual circumstances. I had observed that two of the CYP who trialled the survey found it very difficult to move beyond questions, when they did not feel they had a suitable response option. Ensuring the survey was easily understood, and did not cause stress for CYP with autism, were considered the two most important factors in making this decision. Furthermore, scales with seven points have been shown to be more likely to meet the objective reality of experiences, while also increasing the likelihood of meeting the normality assumption (Cohen, Manion and Morrison, 2000; Preston and Colman, 2000). The survey statements asked the participants to rate their agreement or disagreement with statements in relation to their experiences. In the pre-diagnosis and post diagnosis sections, this explored academic and social self-efficacy. The finding-out section asked participants to rate how positive their experiences were of finding out about the diagnosis. The statements contained a mix of positively and negatively phrased statements, as advised by Chen, Rendina-Gobioff and Dedrick (2010), to reduce the likelihood of response bias, which can happen when participants agree or disagree with items regardless of content. The inclusion of negatively phrased statements can act as ‘…cognitive speed bumps…’, which encourage greater control and cognitive engagement (Podsakoff *et al*., 2003, p.884).

4.4.17 Qualitative survey questions for CYP and parents

Each section of the survey concluded by asking participants open questions, which participants could answer in as much depth as they felt appropriate. Three of the open questions related to the main sections of the survey: pre-diagnosis; finding out; post-diagnosis. The final section provided the opportunity for participants to contribute any other information that they thought was relevant. The specific wording of these questions is shown below in Table 35.

Table 35 Online survey open questions

Survey Section/Number	Young Person Survey Open Question	Parent Survey Open Questions
Pre-diagnosis	In your own words, please tell me what things were like for you before your autism diagnosis.	In your own words, please tell me what things were like for your child before the autism diagnosis.
Finding out	Tell me in your own words about your experiences of finding out about your autism diagnosis.	Tell me in your own words about your child's experiences of finding out about their autism diagnosis.
Post-diagnosis	Tell me in your own words about what has happened since you found out about your autism diagnosis. *For example, have you had any extra help? Have you noticed anything different about how you feel about yourself? Have you noticed any differences in the way people behave towards you?*	Tell me in your own words about what has happened since your child found out about their autism diagnosis. *For example, have they had extra help? Has their behaviour changed? Are they more positive? Have you noticed any differences in the way people behave towards them?*
End of Survey	If there any other information that you would like to tell me, please write in the box below:	If there anything else that you would like to tell me, p*lease write in the box below:*

4.4.18 Parent survey trialling

Three parents trialled the online survey. Their views were sought in relation to ease of completion of the survey and about the survey construct. Their feedback indicated that they felt the questions were appropriate and relevant in relation to their children's experiences of autism diagnosis and discussing autism with CYP. Robson (2002) identifies this simple but important approach as appropriate to ensure face validity. As the parents had identified only one minor proofing error, further feedback was sought through the research supervision process. My research supervisors were both experts in the field of autism, the improvements they suggested were actioned to improve the clarity of the statements within the parent survey (For full details of amendments see Appendix 8.1 First draft of online survey for parents with revision annotations; Appendix 8.2 Summary of key considerations and amendments to the parent survey).

4.4.19 Disseminating the survey and related ethical safeguards

Ethical approval for this study required that the research information and survey link be directed to parents rather than being sent directly to young people. Parents were provided with the child-friendly version of the research information, and the survey link. Parents were advised to only inform their child about the research if their child already knew about their diagnosis, and they were able to discuss their diagnosis without experiencing upset or distress.

The principle of ensuring the assent from young people under 16, and consent of those over 16 was also be upheld. In line with guidance, at the beginning of the survey, they were asked to confirm that they wanted to take part and were reminded that they did not have to take part if they do not wish to (The British Psychological Society, 2014). The rights of, and protections for, the participants were emphasised in the research information and at the beginning of the surveys. Young people were also advised to speak with their parents/guardians about the research, if they have not already done so, before completing the survey.

Participants were asked to create a code at the beginning of the survey to enable them to take part anonymously. This also facilitated the identification of their data if they later decided to withdraw their consent. All the survey data is stored within password protected electronic folders within the University database. Access is secure through official username and password. The management of the system requires regular password updates as a security measure. In line with the Code of Practice for Research (University of Birmingham, 2010), data will be securely maintained for a minimum of 10 years and accessible to university supervisors and examiners.

4.4.20 Professional survey design and trialling

The professionals' online survey (Appendix 11: online survey for professionals) requested details about the professional role, length of service, professional development related to autism, and experience of working with CYP with autism. The survey content focussed on how they supported children to understand the diagnosis. Open questions asked professionals to explain how they worked with children to help them to understand an autism diagnosis. Closed questions explored the type of resources they used to support discussion of autism. Participants were given the opportunity to provide further information after all closed questions. Professionals were also asked their views about what they felt best supported a positive understanding of autism, and any factors that they felt led to a negative outcome. Professionals were asked about advice they would offer to others who were about to inform a child about an autism diagnosis.

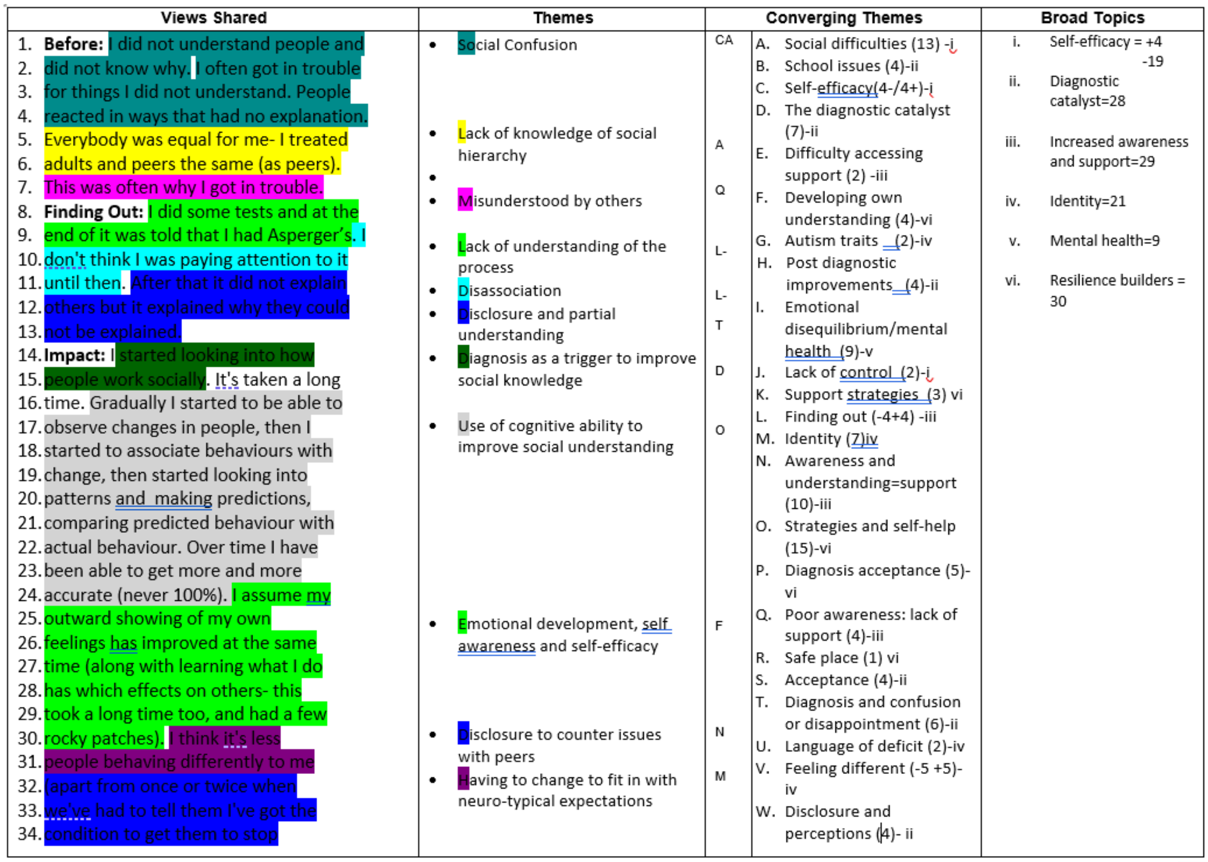
The Jisc Online Survey for professionals was trialled by 3 professionals who completed a draft survey that included questions about issues and the ease with which they were able to complete the survey. Feedback was positive, professionals identified that the questionnaire was easy to complete and was appropriate to the focus of the research. However, they did identify that the free text box was missing for question 3c, about the specific resources that they found particularly helpful. This was rectified within the final draft. No other amendments were made to the final draft.

4.4.21 Analysis of the online surveys

Participant responses for all the survey responses to the scaled questions are presented descriptively in the results sections that follow, including the number of responses to each point on the scale (See Appendix 18: results of CYP survey; Appendix 19: results of the parent survey; Appendix 20 results from the professional survey). Responses to the open survey questions were analysed using thematic analysis, as these sections of the questionnaire aimed to understand specific experiences in relation to autism diagnostic processes and the impact of these experiences (For example, see Appendix 18: results of CYP survey). As advised by Braun and Clarke (2006), inductive thematic analysis was selected as the appropriate method for the qualitative analysis, as it aims to avoid interpretation during analysis to reduce the likelihood of subjectivity. Elo and Kyngäs (2008) described the inductive approach as one that organises data by using open coding, before creating categories and moving towards abstraction where concepts are identified.

After the initial simple analysis of themes was completed, a process of continual comparison was undertaken, moving from simple thematic analysis to an iterative process (Corbin and Strauss, 2008). Table 36 below demonstrates this process; it is a small extract from the summary table of the analysis of one young person's response to the open survey question (See Appendix 18.1: analysis of qualitative survey data from CYP). The first column of Table 36 shows the young person's comments, column two shows the initial themes identified, column three groups converging themes and column four identifies the overarching themes.

Table 36 An extract from the thematic analysis of young people’s open responses to illustrate the iterative process of analysis in action



Views Shared	Themes	Converging Themes		Broad Topics
1. **Before:** I did not understand people and 2. did not know why. I often got in trouble 3. for things I did not understand. People 4. reacted in ways that had no explanation. 5. Everybody was equal for me- I treated 6. adults and peers the same (as peers). 7. This was often why I got in trouble. 8. **Finding Out:** I did some tests and at the 9. end of it was told that I had Asperger’s. I 10. don't think I was paying attention to it 11. until then. After that it did not explain 12. others but it explained why they could 13. not be explained. 14. **Impact:** I started looking into how 15. people work socially. It's taken a long 16. time. Gradually I started to be able to 17. observe changes in people, then I 18. started to associate behaviours with 19. change, then started looking into 20. patterns and making predictions, 21. comparing predicted behaviour with 22. actual behaviour. Over time I have 23. been able to get more and more 24. accurate (never 100%). I assume my 25. outward showing of my own 26. feelings has improved at the same 27. time (along with learning what I do 28. has which effects on others- this 29. took a long time too, and had a few 30. rocky patches). I think it's less 31. people behaving differently to me 32. (apart from once or twice when 33. we've had to tell them I've got the 34. condition to get them to stop	- Social Confusion - Lack of knowledge of social hierarchy - - Misunderstood by others - Lack of understanding of the process - Disassociation - Disclosure and partial understanding - Diagnosis as a trigger to improve social knowledge - Use of cognitive ability to improve social understanding - Emotional development, self awareness and self-efficacy - Disclosure to counter issues with peers - Having to change to fit in with neuro-typical expectations	CA A Q L- L- T D O F N M	A. Social difficulties (13) -i B. School issues (4)-ii C. Self-efficacy(4-/4+)-i D. The diagnostic catalyst (7)-ii E. Difficulty accessing support (2) -iii F. Developing own understanding (4)-vi G. Autism traits (2)-iv H. Post diagnostic improvements (4)-ii I. Emotional disequilibrium/mental health (9)-v J. Lack of control (2)-i K. Support strategies (3) vi L. Finding out (-4+4) -iii M. Identity (7)iv N. Awareness and understanding=support (10)-iii O. Strategies and self-help (15)-vi P. Diagnosis acceptance (5)-vi Q. Poor awareness: lack of support (4)-iii R. Safe place (1) vi S. Acceptance (4)-ii T. Diagnosis and confusion or disappointment (6)-ii U. Language of deficit (2)-iv V. Feeling different (-5 +5)-iv W. Disclosure and perceptions (4)- ii	i. Self-efficacy = +4 -19 ii. Diagnostic catalyst=28 iii. Increased awareness and support=29 iv. Identity=21 v. Mental health=9 vi. Resilience builders = 30

Themes were selected because of the richness of the information and the way in which they connected with the account (Smith, 1999). Themes were identified in this way for each participant and considered against responses from other participants to identify convergence and the overarching broad topics. Analysis of the qualitative data was undertaken in the same way for each of the online surveys for CYP, parents, and professionals. To illustrate the themes and to demonstrate transparency, in the results chapter that follows, examples of participant’s quotations are provided, with the theme identified, to illustrate the process of analysis. Themes that emerged from the analysis were discussed during supervision and with colleagues, all of whom held specialist autism qualifications.

4.4.22 Interviews

Braun and Clark (2005) suggest that semi-structured interviews are an appropriate method to seek participant perceptions for thematic analysis. They have also been used successfully with CYP with autism (e.g., Huws and Jones, 2008). The CYP's interview schedule (Appendix 9: interview schedule for CYP) encouraged them to reflect upon their experiences before and after diagnosis, to recall how they learnt about the diagnosis, and to give their current views about autism. The design of the parents' interview schedule (Appendix 10: interview schedule for parents) encouraged them share their recollections of their child's experiences prior to the autism diagnosis, to explain how the autism diagnosis was shared with their child, and to reflect on the impact of the diagnosis for their child. The design of the professional interview differed (Appendix 12: interview schedule for professionals), as the focus was upon professional experiences of the diagnostic process, and their own professional practices when sharing the diagnosis with young people or discussing autism with them. The interview schedules were designed to enable some flexibly during interviews. Nevertheless, each schedule was generally followed sequentially, as highlighted by Frith and Gleeson (2012), this facilitated the ability to cross reference participant contributions during analysis to identify similarities and differences in experiences shared.

The interview schedules were developed around the topics considered within the questionnaires but comprised broader questions to enable participants to provide richer and more specific details related to their own circumstances. Once developed, the interview schedules were evaluated by specialists in the field of autism to ensure face validity. Face validity is the extent to which a measure investigates the intended topic (Hardesty and Bearden, 2004). Through the Ph.D. supervision process, the draft surveys were evaluated by two experts in the field of autism (Kerstin Wittermeyer and Glenys Jones). Feedback was focussed on face validity as well as general advice about phrasing of questions to ensure successful responses

4.4.23 Checking the robustness of the interview schedule

To explore whether the parent and professional interview schedules generated useful responses, related to the research purposes, the 'interview the interviewer' process was undertaken. Chenail (2011) suggests that interviewing the interviewer enables the same rigorous testing of the interview schedule and technique, without the ethical and problematic practical issues of a pilot study. Following the procedures outlined by Chenail (2011), I took the role of a participant for both the parent and professional interviews; a professional colleague took on the role of the interviewer. This approach is suggested to be a more ethical and responsible approach, which is also unique in providing the interviewer with a valuable insight into the experience of being interviewed using the interview schedule designed (Chenail, 2011).

The interviews were implemented following the schedule, as they would be used with participants. I answered as a parent in the first interview and a professional in the second. The interviews were recorded. After the interview, the colleague who undertook the interviewer role provided feedback to identify aspects of the interview schedule that might need to be reconsidered, the analysis identified key learning about the interview schedule, process and improvements identifies (Appendix 21: interview the interviewer analysis of the process). The perspective of the interviewer and interviewee was considered, to identify implications for practical procedures in the field. This process was undertaken for the parent interview in Autumn 2014 and for the professional interview in Spring 2017.

4.4.24 Interview the interviewer evaluation

As shown in the interview the interviewer analysis, after undertaking the parent interview for this process, a change was made to the last question, which seemed to change topic suddenly from the rest of the interview. The draft schedule had a question about how young people might be encouraged to participate in research. As the previous questions focussed upon the participant's views of their child's experiences in relation to autism diagnosis, this was identified as a divergence. It was removed from the final interview schedule. It was also felt that the interview schedule ended abruptly, therefore a final open question was added, which gave the participants the opportunity to add anything else that they felt would be useful to the research. As the interviewee, my tendency to provide ideas related to questions that would come later in the interview was also noted. It was felt, however, that this was inevitable to some extent. The interviewer was able to use the schedule as a check list, ensuring all planned topics were covered during the interview. Therefore, it was not felt necessary to reorder the questions. The interviewer also queried whether taking part in the interview had had an emotional impact upon me, as an interviewee. Although not distressing, it did cause me to reflect on how I had shared the diagnosis with my own son and to wonder whether I had overly focussed on the medical aspects of his diagnosis (epilepsy). This led to further discussion with my own child about autism, which was felt to be a positive outcome.

This same interview the interviewer procedure and evaluative reflection was followed for the professional interview. Although the interview schedule was felt appropriate and useful, it was identified that participants might feel concerned if, after reflecting upon their practice, they felt there were gaps in their knowledge about how to support young people to understand the diagnosis. Therefore, professional participants were also offered information about sources of guidance and resources to support young people to understand a diagnosis, which they could follow up. As advised by Tashakkori and Teddlie (2003), full reflexive notes were taken during this process to provide the transparency to support appropriate trustworthiness in the research processes.

4.4.25 Interview procedures

Participants had the option of either a face-to-face, telephone or Skype interview, at a time and place most convenient to them. All parents opted to be interviewed in their home. Three out of five professionals chose to be interviewed via telephone. Two professionals opted for a face-to-face interview.

All participants were reminded about the research aims and the ethical arrangements in relation to confidentiality and anonymity. They were also reminded about the procedures for withdrawal, should they later wish their data to be withdrawn. They were also reminded they could end the interview at any time and could skip questions if they were not comfortable with the content. Participants were asked for consent to make a digital recording of the interview and it was explained that their information might be included as direct quotes when the research was written up. They were reassured, however, that all data would be anonymised so that no link could be made to them as the source. Therefore, all the names used within this study have been changed and only pseudonyms are used.

Interview questions were asked following the order of the interview schedule. When participants began to provide information prior to questions being asked, they were encouraged to continue to maintain the flow of their thought processes. If the participant had already discussed a question topic, the question was still asked to ensure participants had provided all the information they might wish to provide. In addition to the ethical procedures described above, as identified to be good practice by Decker *et al*., (2011), parent participants were provided with useful sources of information and advice about sharing a diagnosis with a young person with autism.

4.4.26 Interview analysis

Interviews were transcribed in verbatim, prior to analysis being undertaken. The interview responses were analysed in the same way as the written responses described above, using inductive thematic analysis which moves from specific to general (For an example of this process see Appendix 22: example of interview transcript and process of analysis). As suggested by Braun and Clark (2006), transcripts were read in their entirety for meaning before exploring themes. Themes were identified first in each of the interviews, similar themes were then linked within and across each of the interviews, to create overarching broad topics. It is in this final process of coding that Strauss and Corbin (1994, p. 277) identify as the point at which any relationships are identified between themes or constructs.

4.5 Ethical considerations

The ethical approach adopted for this research applied to each of the phases outlined. The application for ethical review was approved by the University of Birmingham, Ethical Review Committee (Appendix 14: confirmation of ethical approval). The key ethical considerations for the study were to ensure the safety of participants, that consent was appropriately informed, and that privacy and confidentiality were provided. In line with guidance, the physical and psychological wellbeing of participants was considered paramount (British Educational Research Association, 2011; Economic and Social Research Council, 2010; University of Birmingham, 2010). Participation in research can trigger volunteers to self-reflect, which might cause upset for some participants. However, Martin *et al*., (2001) identify a range of benefits for participants, including feeling they had made a useful contribution to the research topic and the cathartic impact of discussing past events. Furthermore, the literature review by Decker *et al.,* (2011) highlights a range of benefits, such as self-knowledge, relief, and increased understanding of the research topic, which can result from participation.

They further suggest that an ethical balance between risk and research priorities can be achieved by ensuring participants are well informed about the research focus and processes, in addition to providing useful information as part of the debrief.

A potential for psychological impact has been identified when helping CYP to understand autism (National Institute of Health and Care Excellence, 2011b). Therefore, a specific risk that was considered possible during this research was that the CYP who participated might experience psychological distress from thinking about, writing about, or discussing the autism diagnosis. The diagnosis of a child can also be an emotional event, this was therefore also a possibility for parents in considering the diagnosis of their child. The risk was minimised, however, by ensuring the invitation to take part was given to parents, rather than young people directly, so that parents could decide whether their child was emotionally ready for participation. The ethics committee also felt that my experience of working with CYP with autism and my professional qualifications helped to mitigate the risks. As an advisory teacher for autism, I regularly undertook one to one interviews with CYP with autism and their parents for assessment purposes, initiated therapeutic approaches to support CYP's emotional understanding, and provided specialist support in both one to one and group situations to help CYP to understand their diagnosis. As the research aimed to explore the views of participants who had already experienced the process of disclosure, it was anticipated that their emotions might be less 'raw'.

During all phases of the research, parental consent and the young person's assent was sought in line with guidelines (University of Birmingham, 2010). The research information exemplar from the World Health Organization-Research Ethics Committee (2002) was used as a framework to create the research information and consent forms for the study, which included information about the research aims and participants' rights. The information and assent forms for CYP were designed to be accessible for CYP with autism, using images and simple language to support understanding (Paxton and Estay, 2007).

An explanation about the research focus was also provide to the participants at all phases of the research, alongside information about ethical safeguards, data protections, and signposting to reading materials and sources of help in relation to understanding an autism diagnosis (See Appendix 15: research information and consent/assent for parents and CYP; Appendix 16: recruitment information and consent for professionals).

4.6 Methodological conclusion

To draw conclusions, the validity, reliability and ultimately the trustworthiness of research are essential considerations to explore whether the research investigated the ideas and concepts that it aimed to explore, and to demonstrate that the methods were appropriate to the nature of the data and the population considered. This section will summarise the approaches used to ensure trustworthiness.

4.6.1 Validity and generalisability

To reduce the likelihood of researcher bias, participants can be engaged to review the interpretations made by the researcher, this is usually referred to in the literature as ‘member checking’ or ‘participant validation’ (Birt, 2016, p. 1802). Riessman (2008) and Yardley (2008) argue that it is not always appropriate or ethical, as the researcher’s ideas might contradict those of participants and, regardless of whether the researcher’s interpretation is valid, the participant might find the interpretation problematic and wish to alter it. Hallette (2013) suggests this might influence participants to reflect further on their contributions and their interpretations might alter. It was felt especially inappropriate to undertake this process with CYP with autism, as CYP on the autism spectrum are known to have shared cognitive differences that impact upon their perceptions of the world (Happé and Frith, 2006; Pellicano and Burr, 2012). It was felt to be more ethically appropriate to check their meaning with the CYP with autism during the focus groups and interviews, as part of the process, rather than revisiting the ideas later, which might have proved a challenge to those taking part (See Appendix 6.5: focus group transcript, for example lines 257-285). To maintain participant anonymity for those who took part in the online survey, member checking was not possible for the analysis of the open responses. However, validation of participants’ meaning was checked during interviews with parents and professionals. Participants were also provided a copy of their interview transcript and the analysis. They were invited to feedback upon accuracy of the record and my interpretation of their meaning (Appendix 23: member check record). As identified to be a potential problem by other researchers (Birt *et al*., 2016), some parents and one professional did not respond. Only one participant identified minor amendments which were proofing rather than interpretative (See comments from a professional participant in the left-hand column within Appendix 21: example of interview transcript and analysis).

While it is hoped that this indicates that participants agreed with the interpretation, which was supported by the checking process undertaken during the interview, it is possible that despite reassurances, participants might have felt unable challenge my interpretation.

4.6.2 Dependability and consistency

The online questionnaire scale was constructed to focus on elements of efficacy relevant to autism. Forsyth and Carey (1998) and Bandura (2006) identify that when self-efficacy is explored using scaled statements, it is crucial to ensure that the scale was specific to the self-efficacy context and the relevant focus of the skills explored. Although the concept of reliability stems from quantitative research, the basic premise is important to all research. Rather than reliability, Lincoln (1995) suggested that dependability and consistency are more appropriate elements to consider for qualitative research. However, Ellis (2016) draws dependability and consistency together with several other factors under the heading of trustworthiness, which is suggested as the key concept when considering the quality of qualitative research methods. Therefore, as this research has mostly employed qualitative methods, the trustworthiness of the methods is an important concept to consider.

4.6.3 Trustworthiness

Through the reflexive process and methods outlined below in Table 37, I have aimed to provide transparency to demonstrate trustworthiness. Lincoln and Guba (1985) suggest that trustworthiness can be identified by four key elements: credibility, transferability, dependability, and confirmability.

Table 37 Elements employed within this research to establish trustworthiness

Key element & contribution to trustworthiness	Approaches	Suggested methods	Methods used within the study
Credibility to increase confidence in the actuality of findings	Prolonged Engagement	Sufficient experience from the field to fully understand the phenomenon of interest	Fifteen years of experience working with CYP with autism and their parents. This includes work within the field that the research study explored, e.g. working with CYP with autism to support understanding of autism & autism diagnosis. Regularly discussed disclosure with parents and provided advice for parents and educators to support this process. Involvement in procedures related to local diagnostic pathways, including diagnostic clinics during assessment and outcome meetings
	Persistent Observation	To understand multiple influences contextual factors that might impact upon the process being considered	Comparison across cases, data type and stakeholders Systematic literature review and analysis. The field experience described above has facilitated continual observation across professional casework involving more than 400 young people and their parents/carers in 3 different local authorities, including during the research process.
	Triangulation	Multiple data sources to aid rich, robust, comprehensive and well-developed understanding rather than for validation	Multiple data sources including: • Online survey data closed responses • Online Survey open responses • Interviews • Each source from 3 participant groups: • young people who know about their autism diagnosis; • parents of young people who know about a diagnosis • professionals involved in the diagnostic process or support for young people related to this

Key element & contribution to trustworthiness	Approaches	Suggested methods	Methods used within the study
	Peer Debriefing	Discussion with a neutral peer to explore reflections about the research processes, which might otherwise remain implicit within the researcher's mind	Discussions with colleagues also involved in work related to autism diagnosis- as demonstrated within the research diary Discussion with PhD research supervisors, who were able to offer critical feedback on the research process, analysis and ideas I was sharing, which served to highlight assumptions and caused me to reflect more broadly (Smith, Flowers and Larkin, 2009)
	Negative case analysis	Searching for and discussing elements of the data that contradict patterns emerging from data analysis	Positive accounts within AET Documentary Receiving and Understanding a Diagnosis (2012) compared to Armstrong's (2011) account of receiving a diagnosis (See Appendix 5: analysis of documentary and (5.1) related conference paper). This was undertaken during the data analysis and is demonstrated through the reflexive notes taken during the research process and within the report. Across the three participant groups, the positive impact was the focus of the main themes, however, the variation in views was highlighted, including the negative impact and experiences reflected in some participant's views.
	Referential adequacy	Archiving a portion of data to be analysed when preliminary findings are established. Data is then analysed to consider validity of findings.	Two interviews (Parent and professional) were reserved for analysis until after the qualitative survey data other interview scripts had been analysed and themes identified. Comparison of themes between the interviews, survey data and thematic analysis of the literature. Analysis using NVivo checked against hand coding (e.g. See Appendix 20: results of the parent survey).

Key element & contribution to trustworthiness	Approaches	Suggested methods	Methods used within the study
	Member checks	Interpretations are checked with participants either formally or informally during fieldwork.	Focus group notes checked with participants Interview transcripts and analysis shared with parents and professionals and feedback sought on agreement/ disagreement with themes identified. Clarity about meaning sought during interviews and notes made to support this.
Transferability to demonstrates applicability beyond the specific research context	Thick description	Thick description from fieldwork to make the context explicit	Methods and tools described in detail in main body and appendix section Reflection on the research process is supported through the research journal during practice with young people and adults with autism in my current role in HE. Participation via the online survey appeared to support CYP to provide rich data, which could be usefully applied to other research that seeks views from CYP with autism but without intellectual impairment.
Dependability to establish consistency in findings and showing they are replicable	External audit	A neutral researcher examines both the professes and findings to explore whether the findings are supported by the data.	As the research has been undertaken as part of a Ph.D. study supervision and Viva examination support this process Initial analysis was discussed with a professional colleague and during supervision process

Key element & contribution to trustworthiness	Approaches	Suggested methods	Methods used within the study
Confirmability to demonstrate neutrality and that findings are informed by the participants	Audit trail	Lincoln and Guba (1985) suggest including: • raw data • data reduction summaries and notes on theories • data synthesis including category structure, themes, definitions, and relationships • notes on processes, including about methodology procedures, design, materials & reflexive notes, ideas and motivations • notes about development of tools, for example pilot forms, preliminary schedules	Full appendices include all the listed elements. Appendix list and contents provides a complete list that includes all the elements identified by Lincoln and Guba (1985)
	Triangulation	Four types of triangulation: • Methods – showing consistency of findings generated by different data collection methods • Sources - showing the consistency of data sources from within the same method • Analysis- using multiple observers and analysts • Theory - using multiple theoretical perspectives to examine and interpret the data Four types of triangulation: • Methods – showing consistency of findings generated by different data collection methods • Sources - showing the consistency of data sources from within the same method • Analysis- using multiple observers and analysts • Theory - using multiple theoretical perspectives to examine and interpret the data	Multiple data types including: • Online survey data closed responses • Online Survey open responses • Interviews • Each source from 3 participant groups: • Colleague analysed section of data and provided feedback. • Discussion of themes with experts in the field during research supervision • Use of two different processes of analysis and hand coding- both beginning with clean data. Coding compared after both processes completed.

Key element & contribution to trustworthiness	**Approaches**	**Suggested methods**	**Methods used within the study**
	Reflexivity	Reflecting upon and monitoring for preconceptions and potential bias and making any influences explicit (Malterud, 2001)	Demonstrated through reflection within the research notes/journal

Based on guidance by Cohen and Crabtree (2006)

As suggested by Cohen and Crabtree (2006), and demonstrated in Table 37 above, the credibility of the research is supported through the research design which triangulates the data. My experience of explaining an autism diagnosis to CYP prior to, and throughout the research process, adds to the credibility in relation to interpretation of the views shared. Confidence in the findings is also supported through the audit trail, triangulation of participant views and approaches for data collection, while reflexivity is shown in the research diary. The study findings have informed creation of guidelines for parents and professionals (Appendix 25: research summary and guidance for parents and professionals who wish to discuss an autism diagnosis with a child or young person), thus demonstrating transferability beyond the specific research context. Dependability was established through the consistency in findings, when compared across the participant stakeholders, different data types, and the wider evidence identified by the systematic review of the literature. Transparency within the process of analysis, with specific examples, demonstrates confirmability by showing how findings are informed and contrasted across three participant groups. Together, the above approaches show that the research study and findings to be trustworthy.

The results from each of the participant groups are presented across the next three chapters. Chapter Five presents the results from CYP, Chapter Six from parents of children with autism and Chapter seven from professionals.

CHAPTER 5: RESULTS – CHILDREN

5.1 Introduction

The views of the children and young people (CYP) who participated in the study are summarised within this chapter. Information regarding CYP participants and the modes by which they shared their views are explained next, followed by the results from the online survey. The responses to the closed survey statements are presented first, followed by the qualitative responses that were provided through the open questions within the survey and through interview. The results in this chapter address the following research question.

> What are children's and young people's experiences in relation to an autism diagnosis and how does this impact their view of self?

5.2 Participants: CYP survey and interview

The CYP's participant details are provided in Table 38 below and are organised to illustrate their demographics in relation to the format by which participants contributed: online survey or interview. Of the eleven CYP survey participants, nine provided qualitative responses to the open questions, five were male and four were females. Only one young person participated through interview.

Table 38 CYP survey and interview participants

Method of Participation	**Participant Group**	**n=**	**Diagnosis**	**Age of the young person with autism**	**Gender**	**Area**
Online Survey	Young People	11	ASD=3 AS=6 Autism=2	Average: 4 yrs 3 mths Youngest: 9yrs 1mth Oldest: 18yrs-9mths Range: 9yrs 8mths	4 Females 7 Males	South East=5 Yorkshire & Humber=2 South West=2 NorthWest=2
Interviews	Young People	1	Autism	15 yrs	1 male	South East= 1

KEY: Autism Spectrum Disorder= **ASD;** Asperger syndrome= **AS**;

5.3 Results from the online survey for children

It was hoped that participation in the online survey would have been greater, however, only 11 CYP took part. It is likely that the participation rate was influenced by the ethical safeguards, which placed constraints upon the way that information was provided to CYP. The ethical approval required that the research information could only be provided to CYP's parents, so that parents could decide whether they felt it was an appropriate for their child to consider taking part; Chapter 8 considers the implications more fully.

When participating in the survey, CYP were asked to rate their experiences by showing their level of agreement or disagreement to statements about experiences before their diagnosis, when finding out about their autism diagnosis, and after their diagnosis. Each statement was scored, and a total score calculated for all the statements within each section, to give an overview of how positively participants viewed their experiences. The responses to the scaled statements are presented descriptively below, with total numbers and percentages summarised.

5.3.1 Autism diagnosis: scaled responses to young-person's online survey

Responses from CYP to the online survey showed that nine out of eleven of the participants rated their experiences more positively after learning about the diagnosis, than before the diagnosis. As shown in Table 39 below, the average scores for most CYP's responses suggested their experiences were less positive before learning about their diagnosis than after they had been told about it.

Table 39 Young persons' scaled scores relating to the positivity of their experiences

	Before diagnosis	Before %	Finding out about diagnosis	Finding out %	After diagnosis	After %
1. F	56	74.66	75	60	60	66.66
2. F	37	49.33	78	62.4	59	65.55
1. M	26	34.66	77	61.6	58	64.44
2. M	30	40	85	68	72	80
3. M	33	44	63	50.4	34	37.77
4. M	32	42.66	113	90.4	76	84.44
5. M	28	37.33	84	67.2	51	56.66
3. F	23	30.66	84	67.2	59	65.55
6. M	28	37.33	109	87.2	52	57.77
7. M	40	53.33	89	71.2	68	75.55
4. F	29	38.66	102	81.6	67	74.44
Mean	32.91	43.87	87.18	69.75	59	66.26
Median	30	40	84	67.2	59	65.55
Mode	28	37.33	84	67.2	59	65.55
Max	56	75	113	90	76	84
Min	23	31	63	50	34	38
Range	33	44	50	40	42	46

The detailed results from each section of the survey are summarised below. Statements where most participants (seven participants or more, which is approximately two-thirds) showed agreement or disagreement are highlighted in green.

5.3.2 Before diagnosis: views identified through the young person online survey

A summary of results from the before diagnosis statements are shown below in Table 40. Results suggest that CYP's experiences were problematic prior to the diagnosis. Most participants indicated that they felt misunderstood. All except one of the participants agreed, or strongly agreed, that they felt that no-one understood them and that they were struggling at school.

Table 40 Before diagnosis-green shading show statements on which more than half of the CYP agreed

	Survey Statement	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree
1	I didn't know anything about autism	4	4	0	1	1	1	0
2	I was confident about my ability	1	2	0	1	1	4	2
3	I was confident when chatting with class peers	0	3	0	0	1	3	4
4	I worried about many things	7	0	0	2	0	2	0
5	I knew I was different to other young people	5	2	0	1	0	2	1
6	I didn't have much confidence in myself	5	3	0	2	0	1	0
7	Everything was fine	0	2	0	1	0	4	4
8	I never worried about anything	0	1	1	0	0	1	8
9	I struggled to get on with other people	5	4	0	0	0	2	0
10	I had no idea that I had autism	6	3	0	2	0	0	0
11	Nothing ever seemed to work out as I hoped	1	5	3	1	0	1	0
12	I was doing well at school	1	1	2	0	0	3	4
13	I felt that no-one understood me	5	5	0	0	0	1	0
14	I felt 'normal'	0	2	0	3	0	2	4
15	I was finding school difficult	8	2	1	0	0	0	0

Most participants (nine out of eleven) also had no idea that they had autism. However, eight CYP also identified that they did not know anything about autism, therefore, it is understandable that they did not suspect that they might have autism. Struggling to get on with other people was a common experience, nine out of eleven participants agreed with this statement. Eight also identified lacking confidence. Feeling different and worrying about most things was something that seven young people identified with.

5.3.3 Learning about an autism diagnosis: views from the CYP's online survey

In their responses to the statements about learning about their autism diagnosis, as shown in Table 41 below, more children reported positive experiences than negative. While there was also a lot of variation in CYP's experiences, overall, they reported more positive than negative experiences.

Children and young people mostly reported that they were told about the autism diagnosis by their parents (nine participants) and by professionals (eight participants). When rating their experiences of finding out about the diagnosis, all except one of the participants disagreed or strongly disagreed that they were only told negative information about the diagnosis. Children and young people mostly found learning facts about autism helpful (nine participants). Learning about the diagnosis also appears to have supported children's and young people's self-awareness; eight participants agreed or strongly agreed that it helped them to see the evidence about who they are, and eight agreed it helped them to put their experiences into perspective.

Table 41 Children's and young people's survey responses: finding out about an autism diagnosis

Finding out about an autism diagnosis statements	5trongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1. My parents told me about my diagnosis	7	2					1
2. My parents explained the diagnosis very clearly	2	3	3			1	1
3. A doctor or autism specialist told me about my diagnosis	4	3	1			2	
4. The doctor or other specialist was able to tell me lots of helpful information	2	2	3	1	1	3	
5. Going through the diagnostic process helped me to put my experiences into perspective	3	4	4				
6. I was given lots of helpful information leaflets			1	3		4	2
7. Finding out was a real surprise to me, I didn't realise that anyone thought I had autism	2	3	1	1		3	1
8. Finding out has been a very positive experience	5	2	2	1	1	1	
9. When I found out, it made me feel like I had been given a label	2	1	2	1	1	3	1
10. Being told I had autism provided me with what felt was like a fresh start	1	3	2			4	1
11. Finding out about autism was a difficult process, which involved many assessments and meeting	3	3	3			1	1
12. When they told me, I thought they had got it wrong			4	1	1	3	2
13. When I found out, I felt that I needed to look for information about autism, so I understood what it meant	2	1	2			4	1
14. I used the internet to research information about autism	2	2	1	1		3	1
15. When they told me about the autism diagnosis, I felt empowered	1	3	3	1		2	1
16. I was helped to understand autism and to recognise all the things I'm good at	2	5	1			3	
17. Finding out, helped me to see the evidence about who I am	3	5		2		1	
18. All I was told was about the negatives related to autism	1					8	2
19. Accessing websites/blogs/tweets created by other people with autism has been really helpful in coming to terms with my diagnosis	2	3	2	2		1	1
20. Knowing the facts about autism has really helped me	5	4	1			1	
21. Reading the information about the diagnosis was like creating a big mental list of things that I struggle with	4	2	3			2	
22. It was reading information books about autism that has helped me to understand	3	2	1			4	1
23. All I was told about the diagnosis was vague, unclear information	1		1			4	5
24. When I was told I had autism, it made me feel highly confused	1	1	3			3	3
25. The doctor/autism specialist helped me to understand the autism, to feel confident in myself and to understand there is no such thing as a 'normal' person		3	2	1		4	
26. Reading books written by other people with autism has helped me to understand autism more than anything else	4	1				5	1

5.3.4 After diagnosis: views from the CYP’s online survey

After the diagnosis, most CYP reported that they had better self-awareness. As shown in Table 42 below, all agreed that they understood the autism diagnosis, their differences and why they sometimes experience upset. Most of the participants were also able to recognise positive aspects of their experiences of being on the autism spectrum; eight agreed or strongly agreed that they understood their different thinking styles and that this was the reason for their strengths. Eight of the participants also agreed, or strongly agreed, that they were better understood by their family, and seven participants identified greater levels of support at school or college. Seven of the participants also agreed, or strongly agreed, that they had accepted their diagnosis and did not feel labelled. However, two participants disagreed that they had accepted the diagnosis and two also agreed that they felt labelled. As for finding out about diagnosis, CYP reported their experiences were more positive after the diagnosis than before it. Out of the eighteen statements in this section of the online survey, twelve of the statements were rated more positively than negatively by participants.

Not all CYP reported positive experiences; some participants agreed that they sometimes felt negative about themselves and worried about future perspectives. Two participants also reported feeling labelled. While three CYP identified receiving professional help to support their understanding of the diagnosis, seven CYP either disagreed or strongly disagreed that they had received support.

Table 42 After diagnosis: views from the children and young people's online survey with greatest level of agreement

	After diagnosis statements from the survey	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1	I get more support at school/college	4	3	1	1	1	2	1
2	None, it has not made any difference to me	1	1	2	0	0	3	4
3	I've been able to access support from a specialist to help me to understand what the diagnosis will mean for me	0	3	2	0	0	7	0
4	Nothing has changed at home	2	3	0	0	1	6	0
5	I feel like I've been labelled, and the label becomes a source of attention	1	1	2	0	0	4	3
6	I notice all the things that I'm good at and I know that my autism is part of what gives me these strengths	3	2	3	0	1	2	0
7	I feel like I have something to blame for my problems	2	4	1	0	1	2	1
8	The teachers/tutors give me more help	3	4	0	1	1	2	1
9	I understand it now, I know why I'm different and why I get so upset	5	6					
10	I get these negative ideas about myself; I sometimes think I'm never going to achieve anything	5	1	2	0	0	3	0
11	Now I've accepted it, I realise that it is not the end of the world, it is just a different way of thinking	3	4	1	1	1	2	0
12	I feel like a valuable individual	3	3	2	1	0	2	1
13	I feel different but in a good way, I don't want to be just like everyone else	3	3	3	0	1	1	0
14	It has really helped to boost my confidence	1	3	3	0	1	3	1
15	My family are much more understanding	2	6	1	0	1	2	1
16	We do not argue as much	1	2	3	1	1	2	2
17	I feel that I can be a success and I am happier in myself	3	3	2	0	1	0	2
18	I know that I think differently and that this is the reason for my strengths	4	4	1	0	1	0	1

5.4 Qualitative responses from CYP about autism diagnosis

The open questions were included to enable participants to clarify responses to the scaled questions. It is apparent from the responses that the CYP who participated were extremely articulate when writing about their experiences, their views and their feelings when sharing their views in response to the open questions.

5.4.1 Children's and young people's qualitative comments from the online survey

Discussion of the themes identified within the written information provided by CYP follows, beginning with the most commonly occurring theme and progressing to the least common. Within each theme, the discussion is focussed on how the theme relates to the chronology of the diagnostic experience: experiences before diagnosis are considered first, CYP's experiences of learning about their autism diagnosis are considered next, their experiences after the diagnosis are considered last. To illustrate each theme, examples of the views shared by CYP in response to the open questions are provided. As all participants provided this information anonymously, all names used to refer to the CYP are pseudonyms. The detailed responses to the open survey questions have been included as they were written by the participants and every effort has been made to transcribe interviews as spoken by participants. Although I am aware that *[sic]* can be used to highlight spelling or grammatic errors within quotes, this approach has not been used within this thesis. This decision was made as I felt it was inappropriate to ask for participants' perceptions of this sensitive and important topic, then to undertake an editing process that would highlight errors related to communication. As the content of participants' views was the focus of the research rather than the participants' communication skills, such an editing approach seemed to be inappropriate to the nature of my research philosophy. I agree with Mitford's (1963, p.29) sentiment on this topic:

> "I do not like the repeated use of *sic*. It seems to impart a pedantic, censorious quality to the writing. I have throughout made every effort to quote the funeral trade publications accurately; the reader who is fastidious about usage will hereafter have to supply his own *sics*."

However, some editing was necessary, as CYP occasionally mentioned specific people, services or educational provisions. Therefore, for confidentiality purposes, where this information was shared, the data was anonymised by substituting names of specific people or organisations with a general term, such as a professional title, a type of educational provision, or specialist service; an asterisk (*) marks places where the names of people or organisations have been substituted for a generic term. It was also necessary to omit some sections of quotes to maintain a focus on the most pertinent elements of the discussion topic, while providing as much of the participants' views as possible. For clarity, ellipses … are used to mark where the beginning and end of a quote has been shortened. However, to differentiate a pause or hesitation, an ellipsis within square brackets […] is used where a section of a quote has been cut from the centre of a sentence. Square brackets are also used to identify if a word or phrase has been inserted for clarity.

Six main themes emerged from the analysis: self-efficacy; resilience building; increased awareness and support; the diagnostic catalyst; identity and mental wellbeing. The themes are summarised in Table 43 below.

Table 43 Extract from the analysis of the qualitative views shared by children and young people via the online survey

Themes	Converging Themes		Broad Topics
• Autism-family trait • Improved self-awareness & happier • Lack of support • Peer awareness enabling strategy implementation • Feeling different • Poor social understanding overcome by cognitive strategies • Peer awareness enabling strategy implementation • Diagnostic conversation with parent • Diagnosis is not a problem • Positive view of self • Awareness of self-help strategies • Lack of understanding/patience by teachers • Coping strategies and self-efficacy • Peer awareness enabling strategy implementation • Home/family=safe place/understanding • Coordination & Energy: the importance of physical activity • Rules and routines as imposed supportive strategies • Coordination & Energy: the importance of physical activity • Rules and routines as imposed supportive strategies	G P E N M O K L + P CP O Q O N R O K O O	A. Social difficulties (13) -i B. School issues (4)-ii C. Self-efficacy(4-/4+)-i D. The diagnostic catalyst (7)-ii E. Difficulty accessing support (2) -iii F. Developing own understanding (4)-vi G. Autism traits (2)-iv H. Post diagnostic improvements (4)-ii I. Emotional disequilibrium/mental health (9)-v J. Lack of control (2)-i K. Support strategies (3) vi L. Finding out (-4+4) -iii M. Identity (7)iv N. Awareness and understanding=support (10)-iii O. Strategies and self-help (15)-vi P. Diagnosis acceptance (5)-vi Q. Poor awareness: lack of support (4)-iii R. Safe place (1) vi S. Acceptance (4)-ii T. Diagnosis and confusion or disappointment (6)-ii U. Language of deficit (2)-iv V. Feeling different (-5 +5)-iv W. Disclosure and perceptions (4)- ii X. Diagnostic delay (3)-iii Y. Life goes on (1)-vi Z. Positive relationships crucial (4) vi	i. Self-efficacy = +4/-19 ii. Diagnostic catalyst=28 iii. Increased awareness and support=29 iv. Identity=21 v. Mental wellbeing=9 vi. Resilience builders =30

5.4.2 Children’s and young people’s qualitive comments: self-efficacy theme

Nineteen themes relating to negative self-efficacy were identified across the participant views. Four participants discussed experiences linked to positive self-efficacy. Three participants wrote about experiences and feelings that were impacting negatively upon their self-efficacy before they learnt about the diagnosis. For example, Karl revealed negative perceptions about his ability prior to diagnosis:

> I thought I was unintelligent and slightly insane. (Appendix 18.1, Karl, lines 64-65)

Kai discussed difficulties with social interaction that influenced her views of her social skills:

> I did not understand people and did not know why I often got in trouble for things I did not understand. (Appendix 18.1, Kia, lines 79-81)

Feeling different to peers was also an experience that impacted participant's views of themselves in a negative way, as explained by Adam:

> I felt different to everyone, I was the odd one out! (Appendix 18.1, Adam, lines 163-164)

Other people's reactions to the diagnosis might also impact self-efficacy. When finding out about the diagnosis, Claire spoke of her father's response to her diagnosis:

> I looked to my father second. I just remember thinking he looked disappointed. I wanted to cry. (Appendix 18.1, Claire, lines 117-120)

However, Claire's explanations demonstrate that she has been able to adjust to the diagnosis and in reflecting on her own strengths, as she wondered why the diagnosis took so long:

> … being a bright, articulate girl is probably what left me undiagnosed for so long. (Appendix 18.1, Claire, lines 229-232)

5.4.3 Children's and young people's qualitative comments: the diagnostic catalyst

The diagnosis as a catalyst for change was a common theme across participants (occurring thirty times). For most participants, the diagnosis led to either better understanding or increased support. Some participants discussed the way in which diagnosis led to changes in others' understanding, or the help they received, as well as with their school placements, as explained by Claire who:

> …began to get more help at school. I began to behave better. I managed nine GCSE's, in the end. (Appendix 18.1, Claire, lines 246-247)

Sally made similar links between her diagnosis, a move to a special school, and increased support (Appendix 18.1, Sally, lines 343-348). She went on to explain how the diagnosis has helped her to make sense of her experiences and helped others to understand her better:

> I understand why I sometimes find social situations daunting and exhausting. I understand why other people may perceive things differently to me. People tend to be more supportive. (Appendix 18.1, Sally, lines 353-358)

James discussed how the diagnosis led to a move to a new school with smaller classes (Appendix 18.1, James, lines 169-172) and how, as a result, the diagnosis improved social experiences and his sense of belonging.

> I feel like I belong somewhere, even if to others it is a weird place, I have one. I have made friends with ASD and also I have finally made a group of friends who all know I have Asperger's. (Appendix 18.1, James, lines 173-178)

Rob linked his diagnosis with increased familial understanding and fewer family disagreements. He also identifies it with improved understanding of himself.

> We do argue much less now. I feel happier in myself knowing why I am different. (Appendix 18.1, Rob, lines 4-6)

It was apparent in the accounts that participants' self-views could be influenced by interaction with others. Improved understanding of others was also indicated by some participants to influence improved social experiences and increased self-efficacy.

5.4.4 Children's and young people's qualitative comments: mental wellbeing

Prior to the diagnosis, the impact of not understanding their differences, and not being understood, appeared to impact negatively on the wellbeing of some of the participants. This was evident in their explanations, appearing to impact their self-efficacy, and to influence their developing sense of self. As shown by Claire's writing about her experiences before the diagnosis, compared to those afterwards. Before the diagnosis she writes:

> I was bullied and generally misunderstood. I knew I was different but couldn't understand why. I struggled to cope at school and at home (Appendix 18.1, Claire, lines 329-333)

However, through learning about the diagnosis, she writes about being able to make sense of her experiences (Appendix 18.1, Claire, lines 339-342). After the diagnosis, although difficulties with social interaction remained, her improved self-awareness and other people's understanding made them easier to manage. While some lingering self-doubts are evident, her attitude is much more positive in looking forward to her future:

> I'm learning all the time. Sometimes now I think I might actually get somewhere significant. It's all been about learning and being patient and just realising that sometimes you have to take a deep breath, accept things are not what you thought or hoped they would be and start over. (Appendix 18.1, Claire, lines 339-342).

John and James also reveal how peers' and teachers' views negatively impacted their experiences within their school settings before the diagnosis, which had a detrimental impact on their wellbeing:

> School, I hated the place, it had horrible teachers who were always in your face and shouting, and a horrible bully who just lashed out at me and talked crap to me. (Appendix 18.1, John, lines 304-309)
>
> I had depression I was at *mainstream school […] school was tough. (Appendix 18.1, James, lines 168-170)

These views contrast sharply with views they share after they had learnt about the diagnosis, which shows how autism has been positively encompassed in their self-views:

> Right now I feel happy, I mean I don't mind being unique, and I can't even think of being a normal person. (Appendix 18.1, John, lines 311-315)
>
> I have made friends with ASD and also I have finally made a group of friends who all know I have Asperger's (Appendix 18.1, James, lines 176-183)

These descriptions point towards a more positive self-narrative, in relation to their autism diagnosis. John's view is reflective of hearing discussion of autism as a positive difference, being 'unique', perhaps influenced through discussion with parents, teachers and other professionals. While James reveals improved peer friendships and openness about his diagnosis in his new school, suggesting the positive influence of a school ethos where differences are understood.

5.4.5 Children’s and young people’s qualitative comments: increased awareness and support

For some participants, support had been practical and for others the discussion of support is focussed on the understanding of others. All the participants wrote positively about the support they have experienced:

> I have had a LOT of extra help, almost indispensable. (Appendix 18.1, Kia, lines 118-120)

Sally also experienced additional support at school following her diagnosis, indicating she:

> received one to one support. I also received support from a residential training facility […] I have accessed one to one support through the *specialist service provider. (Appendix 18.1, Sally, lines 347-352)

The diagnosis was identified to be a trigger for both increased support and understanding. Brogan, for example, wrote about the way in which peer knowledge of the diagnosis has improved their understanding and willingness to provide support.

> When I get angry and don’t know why, I have a code word now and say it to my friends and they leave me alone […] I don't always understand why they do or say something but I will tell them […] and they will usually try and explain to me. (Appendix 18.1, Brogan, lines 37-46)

While Claire explained how she benefitted from improved understanding of her parents and her sibling:

> My father is quietly supportive, I think. My mother is actively supportive. She advocates for me whenever I need it (and sometimes when I don't), and […] My brother's good about it too. He knows good stims and bad stims and when I'm anxious or when I'm happy, and when it's OK to tease and when I just can't deal with him. (Appendix 18.1, Claire, lines 250-264)

The more positive experiences related to social interaction with others, after learning about the diagnosis, appeared to support improved wellbeing.

5.4.6 Children's and young people's qualitative comments: diagnosis and identity

Positive and negative experiences related to social interaction with others, and feeling different, impacted the participants' developing identities, but experiences were varied. Coming to understand what a diagnosis means was sometimes a process that took time. Kai's account shows that she eventually developed a more positive relationship with the diagnosis.

> Asperger's is part of this- I find it indispensable in how I exist and react to the world, if a barrier to social activities. Others are alien and unknown- difficult to understand and interact with easily […]. However, this makes successful friendships and bonds that much more valuable. (Appendix 18.1, Kai, lines 126-134)

Kia further explains:

> If there was a "cure" to autism, I would never consider it. (Appendix 18.1, Kai, lines 161-162)

However, not all young people's perspectives reflected a positive impact. On finding out about his diagnosis, Karl describes how he felt:

> …sad for myself because it didn't make me feel better about being different (Appendix 18.1, Karl, lines 68-70)

Karl's emotional response suggests that the diagnosis did not help his self-view. He continued to feel different from peers, and his perception of this difference was problematic for him. He goes on to reveal his ongoing uncertainty about the diagnosis.

> I haven't accepted my diagnosis yet so I'm unsure of how to feel… (Appendix 18.1, Karl, lines 71-72)

However, it is experiences before the diagnosis that Claire distances herself from, when she did not understand why her experiences differed to those of peers.

> Before my diagnosis, I was angry, lonely, and constantly anxious. I was only 11 when my mental health collapsed. I was depressed, and it made me do and say things that I regret to this day because they were the words and actions of a person who I categorically am not. (Appendix 18.1, Claire, lines 190-198)

When being told about their diagnosis, some participants identified the need to search out information, while others felt they knew enough, but were open to learning more in the future.

> I haven't done any research on Asperger's because mum told me all I need to know for now and maybe when I am older I will do some if I feel I need to then (Appendix 18.1, Brogen, lines 18-22)

However, for Sally, the need to know more and understand autism was immediate:

> Although it was a long-winded, exhausting process to be diagnosed, I was relieved. I was on the path to self-discovery. My emotions started to make sense. I began to research the condition endlessly. (Appendix 18.1, Sally, lines 336-342)

Claire describes how she also searched for information and identifies this process to have been helpful.

> I spent the next few weeks finding out everything I could about autism and what it meant. I think maybe those few weeks helped. (Appendix 18.1, Claire, lines 240-244)

Most of the participants wrote confidently and positively about the relationship they had with their autism diagnosis, some appeared to have fully incorporated it into their identity. While John's account reveals uncertainties, it also highlights that the pressure to conform is lessened:

> I feel good about being autistic. Always trying to fit in can severely scar your personality (Appendix 18.1, John, lines 315-317)

Claire describes how she was labelled before the diagnosis and relief in learning about the diagnosis.

> I'll never be able to shake the labels I picked up in the days before anyone had any understanding of why I thought and behave the way I do, and they're all negative. I'm growing up now, and I'm moving on, and I'm learning (Appendix 18.1, Claire, lines 198-204)

The negative social experiences, feelings of difference and struggles related school that the participants identified, appeared to impact their identity as well as their general level of wellbeing. However, as shown in the accounts above, once the diagnosis was understood, most of the participants were more positive. Some also developed compensatory strategies, which supported them to overcome previous difficulties. These strategies appeared to boost the participants' wellbeing and might be considered as factors that increased their resilience.

5.4.7 Children's and young people's qualitative comments: resilience building

Resilience is associated with protective factors that can be biological, psychological, or social. Seven of the nine participants who shared qualitative accounts suggested they were accepting of the diagnosis, feeling positive about themselves and about their future. These participants revealed several factors that they appear to link with an improved understanding of themselves. Self-help strategies were a commonly discussed theme. Kai identified use of social observation as a proactive strategy that has supported the development her social understanding.

> I started looking into how people work socially […] I started to be able to observe changes in people, then I started to associate behaviours with change, then started looking into patterns and making predictions, comparing predicted behaviour with actual behaviour. Over time I have been able to get more and more accurate (never 100%). (Appendix 18.1 Kai, lines 93-103)

Kai goes on to explain how this improved social self-efficacy has improved her self-view more generally through:

> recognising behaviour and reacting accordingly, leading them to react differently to me. I've had better social success which makes me feel better about myself.

Claire also identified proactive strategies that she employed to cope with difficult experiences.

> I make sure to do things I enjoy, and I'm learning to talk about my problems. It's going to be OK. (Appendix 18.1, Claire, lines 290-301)

Brogan writes of very practical strategies involving exercise that helps with her coordination and excess energy to support her concentration:

> I do lots of swimming as I am good at it and I do at least one activity a day after school as I have a lot of energy and it all helps with my coordination. (Appendix 18.1, Brogan, lines 48-52)

What is also evident in the CYP’s accounts is that their understanding of autism has supported their understanding of the reasons for the difficulties that they sometimes experience. As a result, they could identify and employ strategies to counter these difficulties, therefore, there is also an element of agency suggested across the accounts. The accounts demonstrated that an autism diagnosis can be a challenge to some CYP's view of self, which can negatively impact self-efficacy. However, for some participants, the feeling of difference was more problematic to self-efficacy prior to diagnosis, as they struggled to understand differences from peers. While being told about their autism diagnosis did not have an immediate positive impact for all participants. However, over time, most participants found that the improved understanding of self that knowing about the diagnosis supported, had a positive impact. As they began to engage with strategies and were understood better and supported more appropriately by others, this appeared to improve their self-views and their general wellbeing.

5.4.8 Interview with a young person

Only one young person volunteered to be interviewed. This was my first meeting with the young person, which might have impacted his confidence in sharing his views with me. At times he discussed his experiences and perceptions confidently, while at other times he found it more difficult to explain his ideas.

Robbie was diagnosed at 4 years old. His parents discussed the diagnosis with him, towards the end of primary education, when he was aged between 10 and 11 years old. Robbie is interested in fairgrounds, especially ghost trains. He regularly visits fairgrounds; he knows a fairground ride owner and has sometimes helped to set up and run the rides. When interviewed, Robbie was fifteen years of age. He had been struggling to manage the demands of secondary education due to social anxieties and was accessing his educational setting on a part-time basis.

Due to his age, Robbie was unable to remember the diagnosis. Although he remembered experiencing some difficulties in primary school, after moving school, he felt he received better support as staff at the new school appeared to understand him better. Overall, Robbie identified mixed views of his school experiences, some staff being supportive and others less so (Transcript 1, lines 253-254).

He has some friends and keeps in touch with a friend he has known since primary school. Robbie was also positive about friendships at the time of the interview, identifying that his friends valued his knowledge. He has discussed his diagnosis with some peers, if he felts they knew about autism generally, but he did not feel that friends knowing about the diagnosis impacted their interactions.

> They're nice to me either way, though. (Transcript 1, lines 451-452) …
> They like what I know. (Transcript 1, line 459).

Robbie's mother told him about the diagnosis. He identifies with the lead character in the television series Sherlock Holmes, which his mum employed to help to explain his differences. When discussing learning about his diagnosis, Robbie appears to find it difficult to remember or to explain how he felt. His discussion perhaps suggests he had mixed feelings. When asked how he felt when he learnt of the diagnosis, he identified feeling:

> In the middle, really. (Transcript 1, lines 319)

When prompted further, he replied:

> I don't remember what I was feeling about it at the time. I've moved on now […] I want to forget about those times. (Transcript 1, lines 324-326; 328-329)

Robbie later explained that he has learnt about his diagnosis over time. During the interview it was apparent that the term he used to name the diagnosis was important to him, when I used the term autism, he corrected with ASD:

> So, were there books about people with Autism? (Transcript 1, Interviewer, lines 476-477)
>
> No, more like a book about people with ASD. (Transcript 1, lines 478-479)

Robbie identified books as a source of useful information. When asked how he felt about the diagnosis, he identified increasing positive views, although his feelings were difficult to explain:

> I don't know. I just got more positive about it as I went on. (Transcript 1, lines 486-487)

When considering changes since learning about the diagnosis, Robbie identified similar improvements to those identified by the young people who completed the survey, these included improved support and understanding from teachers (Transcript 1, lines 513-514). Robbie also shared positive aspirations for his future, identifying a desire to go to college and to work on improving the design of fairground rides.

5.5 Discussion: What are children's and young people's experiences in relation to an autism diagnosis and how does this impact their view of self?

The findings from this study revealed that most of the CYP who participated were less positive when describing their experiences before learning about their diagnosis, than after they had learnt about it. As also identified by Huws and Jones (2008; 2015), Baines, (2012), and Jones *et al*. (2015), some participants indicated negative perceptions about themselves. Within this study, this was mostly when discussing experiences prior to the diagnosis, for example, indicating feeling they were different, misunderstood by others, and struggling at school.

All except one of the young people who participated in this study indicated that they lacked awareness of autism before they were diagnosed, and therefore did not suspect that they might have autism. However, most participants also discussed feeling different prior to their diagnosis. Huws and Jones (2008, p.104) identified autism as an ‘absent presence’ in their participants’ narratives when they reflected on their pre-diagnosis experiences.

When discussing learning about their diagnosis, the participants in this study identified parents as the main providers of information about their autism diagnosis. Parents in the study by Crane *et al*. (2019) also indicated they were more likely to disclose the diagnosis to their child than professionals. However, most CYP in this study also indicated that professionals had also had a role in telling them about the diagnosis. In their free text responses, some participants discussed being in the room when the diagnosis was given. The current guidance suggests that CYP should be included in the meeting when the outcome of assessment is given (National Institute of Health and Care Excellence, 2011, s 1.81). It might be that CYP interpreted the question differently to parents; CYP might perceive their presence at the post assessment conference as a professional having a role in disclosure, while parents might feel they do the in-depth work to support understanding.

Whether being present at this moment was positive for any of the CYP in this study was not evident in their responses, it was only discussed by a few children. However, being in the room when the diagnosis was given might not always be a positive experience; for example, one of the young people poignantly describes seeing the look of disappointment on her father's face when the diagnosis was given. Another young person described her parents lack of acceptance of the diagnosis when they were told. Therefore, being with parents in the meeting to discuss the autism assessment outcome might be problematic for some CYP. Currently there is no comprehensive evidence about the impact of the inclusion of CYP in the diagnostic conference when disclosure is given. Research about parental experiences, however, has highlighted that professionals can be insensitive, thus increasing parental distress at this crucial point (Brogan and Knussen, 2003; Finnegan and Trimble, 2014). Therefore, it also seems likely that when children are also included in the diagnostic conference alongside parents, at least some CYP's disclosure experiences might also be problematic. For example, if the child or their parents become distressed, this could negatively impact their processing of the diagnosis information. Furthermore, a negative emotional response from a parent, while understandable, might influence how the child or young person subsequently views the diagnosis.

While most of the CYP who participated in this study indicated they accepted the diagnosis, a few indicated they had not. Those who suggested they did not accept the diagnosis were also less positive than the other participants about their future. These findings reflect the findings from similar research, which suggests that the more positively young people discussed their autism diagnosis, the more positive they tend to be about their future (e.g. Molloy and Vasil, 2004; 201Jones, *et al.,* 2015; Rossello, 2015; Gaffney, 2017).

Regardless of their acceptance of the diagnosis, all the CYP reported that they understood the autism diagnosis and had improved self-awareness from knowing about it. Furthermore, most of the participants in this study agreed that they were able to make connections between their autism diagnosis and their strengths. This reflects the findings of Jones *et al*. (2015), who also reported that once the participants knew about the autism diagnosis, they were able to consider their own behaviours and interactions with others, and link these to the traits associated with autism.

Most of the CYP who took part also identified improved understanding by family members, and within their educational setting. Improved understanding, within education following the diagnosis, also resulted in additional support at school for most of the participants. However, as identified by Huws and Jones (2008) and Gaffney (2017), this was not the case for all participants. Those young people who reported lack of improvements in the understanding of others after diagnosis, and in their experiences of support, continued to feel misunderstood and unsupported.

Reflecting their responses to the closed questions, and previous research by Rossello (2015), the themes identified in the responses to the open questions suggest an increased positive view of self, after learning about their autism diagnosis, which was evident in most of the CYP's accounts. Three overarching and interlinked topics were evident: Theme One: self-efficacy, resilience and taking control; Theme Two: the diagnostic catalyst, increased awareness and support; Theme Three: identity and mental wellbeing). These themes are discussed in the section that follows.

5.5.1 Children's and young people's views: self-efficacy, resilience and taking control

It has been suggested that individuals with positive self-efficacy are more likely to be proactive in problem solving, whereas those who view themselves and their capacity negatively do not have the confidence required to act independently (Flammer, 2001). This relates to Bandura's (1977) self-efficacy concept, which combines the perceived ability to achieve an ambition and the required agency to pursue it. As also identified in the research of Rhodes *et al.* (2008), the accounts shared by young people for this study revealed that the diagnosis was a challenge to the self-perceptions of some of the participants. The diagnosis therefore had the potential to impact negatively upon self-efficacy. However, when they wrote about negative experiences and feelings that were impacting their self-efficacy, they were mostly describing their experiences before they learnt about the diagnosis. The young participants discussed, for example, feeling unintelligent, different, and confused by others' reactions to their behaviours. As suggested by Huws and Jones (2008), experiences have the potential to impact young people's self-views and identity. Negative social experiences were common points of discussion by participants in this study. As highlighted in the systematic review of Jones *et al.* (2015), where discussion of autism and the social context was negative, CYP were more likely to distance themselves from the diagnosis. Conversely, the more positively CYP discussed their social experiences and their autism diagnosis, the more positive they were about their future (Jones *et al*., 2015; Rossello, 2015).

Responses from some young people in this study, identified being labelled due to their different social behaviours before any diagnosis had been made. A tension was also evident between the young people's difficult experiences and their emerging acceptance of their diagnosis. The experiences explained by young people within the survey reflected the issues identified in Whitaker's (2006) analysis, which highlighted the influence of deficit focussed language that some CYP used to describe themselves, autism, and its related features. Some of the terms the young participants applied to themselves before the diagnosis included weird, unintelligent, stupid, and awkward. Such viewpoints are a potential challenge to the developing view of self and have the potential to negatively influence self-efficacy. Although autism is sometimes identified as a hidden disability due to apparent lack of physical differences (Thomas, Reddy and Sagar, 2015, p.119), the comments from the young participants in this research demonstrate that, even before their diagnosis was given, they were keenly aware of differences from peers, and also felt that peers were aware of their differences. In the context of physical disability, Thompson's (1997) participants' views of self were shaken by their diagnosis. However, the participants in this research revealed that their views of self were more likely to be shaken before the diagnosis was made, when they were struggling to understand differences from peers, without the understanding of the reasons for these differences, which a diagnosis can provide. Understanding an autism diagnosis in a problem context was a key theme identified by Gaffney's (2017) research with young people on the autism spectrum, this theme summarised the difficulties that her participants were already experiencing before, and at the point of, diagnosis. As most of the young people in this study also described problematic experiences prior to their diagnosis, especially with peer relations, many of the participants in this study also learnt about the diagnosis within a problem context.

The social model of disability identifies the cause of disability as being due to the expectations of society, and the limitations this causes, which can exclude individuals from social activities (UPIAS, 1976). As identified in Mogensen's and Mason's (2015) study with teenagers on the autism spectrum, some of the participants' comments suggest that they found the diagnosis oppressive. Prior to their diagnosis, most of the young participants in this study identified feelings of exclusion from social activities, which impacted negatively on their social self-efficacy. Similar experiences were reported by Bagatell (2007), which led her to suggest that the identities of people with autism are socially influenced and constructed. Prior to their diagnosis, many of the views shared by participants suggest that the identities they were constructing for themselves at this time were influenced by these negative interactions and experiences of the social world.

5.5.2 Children's and young people's views: the diagnostic catalyst, increased awareness and support

Jutel and Nettleton (2011, p. 794) described diagnosis as a 'starting point' and 'the foundation from which sense-making and experiences are crafted'. This was evident in most of the young people's accounts, suggesting that the diagnosis was a catalyst for change. The participants indicated positive communication about the diagnosis, especially from their parents but did not discuss exactly what they were told. Some participants also indicated being present when their parents were told about the diagnosis or being told by their parents. Upon learning about the autism diagnosis, some young people identified that they took the initiative in searching out information from online sources about autism. This is reflective of the adolescent health seeking behaviours identified by Gray *et al*. (2005), although not in the context of autism. Gray *et al*. (2005) also identified the place of both the internet and young people's agency in their information-seeking behaviours about health-related matters. As also identified in the research by Jones *et al.* (2015), although the participants reported learning about the diagnosis from parents, their comments suggest that coming to understand how it related to them, included identifying their own traits, linking them to information about autism and making comparisons with peers. The systematic review of Jones *et al*. (2015, pp. 1496-1497) also identified a similar process of social construction, whereby recognition of their own unique behaviours and characteristics supported self-awareness, which was then supported by reflection and comparison with peers with and without autism. As also identified by Rossello (2015) the process that young people described within this study, demonstrated that coming to understand an autism diagnosis is a process which takes time and is socially influenced.

Huws and Jones (2008) suggested that their participants' views about the diagnosis were mixed. The participants in this study also had mixed views, however, most participants were able to identify some positive impacts. For example, learning about the diagnosis was discussed by CYP as a catalyst for an increased understanding of their needs in relation to autism (awareness) by others, and to increased support for some. Some of the participants discussed increased understanding of teachers and support with learning. A few young people also indicated moving schools to access a special school setting. Access to support for their mental wellbeing was also something that a few participants identified. Some of the young people also identified that their family's knowledge of their autism diagnosis appeared to facilitate an increased understanding, thus supporting improved family interactions. For most participants, the diagnosis was a catalyst for improved positive experiences in their main childhood environments: school and home. Research exploring resilience factors that influence outcomes for CYP with autism by Seltzer *et al*. (2003) has emphasised that both positive parenting and access to inclusive school environments has the greatest impact on more resilient outcomes. More recently, Woodman *et al*. (2015) identified similar positive outcomes for both positive parenting and school environments. However, this latter research identified that alongside full school inclusion, it was the amount of parental praise that children with autism received that had the greatest impact on positive outcomes. As children notice and ask questions about their differences during childhood, the findings of Woodman *et al*. (2015) further support the importance of positive communication with CYP about themselves and their diagnosis.

5.5.3 Children and young people’s qualitative comments: identity and mental wellbeing

After the diagnosis, most of the CYP discussed improvements in their social and emotional understanding, and their learning. When young people described improvements in their capabilities in this way, this was often linked with their understanding of their differences related to autism. This understanding of their previous experiences supported their application of new learning, or new approaches, to problematic situations. In this way, they were also showing greater resilience in dealing with the difficulties they encountered. Rutter (2006, p.2) has described resilience as an ‘interactive concept’, whereby ‘relatively positive psychological outcomes’ occur despite stressful or adverse experiences. This has been identified as a resilience factor whereby successful coping with negative experiences leads to increased resilience in future. Following their diagnosis, the participants discussed some approaches that appear to reflect improved resilience, such as: closer monitoring of others’ social interactions to develop their own social understanding; applying new emotional management strategies; and developing strategies with their peer group to manage social difficulties. Such strategies appear to reflect the protective elements of agency and resilience. A sense of agency was also identified to positively influence the participants’ perspectives of self in the research by Mogensen and Mason (2015). A sense of agency has also been identified to be important for positive outcomes in the context of an ADHD diagnosis, as identified by McMaugh (2011) and Singh (2011). Within most of the CYP accounts for this study, it was evident that the participants’ understanding of their autism diagnosis also facilitated a more positive view of self, as they were able to identify with positive autism related traits and strengths. Furthermore, some of the young people's perspectives were moving beyond acceptance, to demonstrate what Parsole (2015, p.351) identified as agency, in moving towards a 'cultural understanding of autism'.

Research has also shown that school children view lack of social skills in their peers with ADHD and autism as intentional and problematic (Smith and Williams, 2005; Campbell and Barger, 2011). This might help to explain some of the negative social experiences and feelings of difference related to social interaction that the participants identified prior to the diagnosis, and why negative experiences such as this can impact the sense of self and identity development. Cooper, Smith and Russell (2017) explored the identity of adults with autism, finding they had both lower self-esteem and greater levels of problematic mental health experiences; however, where autism identity was positive, this served as a protective or resilience factor for mental health. In this study, CYP's responses suggested that knowing about the diagnosis reduces the feeling that they must conform to others' social expectations, while also reducing the expectation of others that they do conform. Peer awareness of autism has been shown to support peer understanding. Research by Campbell *et al.* (2004) showed that providing school children information to raise awareness of autism improved their attitudes towards peers with autism.

5.6. Conclusion

The views shared by CYP in this study suggested that their experiences in relation to an autism diagnosis and the impact on their self-views are mixed. Following diagnosis, most of the participants shared more positive views about the relationship they had with their autism spectrum diagnosis. Most had accepted the diagnosis, and some had fully incorporated it into their identity. However, a few young people revealed uncertainties and even indicated total rejection of the diagnosis. This combination of responses to the diagnosis reflects similar research findings about young people's views (e.g., Huws and Jones, 2008; Jones *et al*. 2015; Molloy and Vasil, 2004). As suggested in the study of autism identity by Cooper, Smith and Russell (2017), connection with autism as part of individual's sense of self was associated better outcomes in terms of self-esteem and wellbeing. Shakespeare (1996) highlighted the importance of people with impairments being able to exert agency and suggested that, through such agency, a more positive self-identity could be constructed. As also identified in Baines' (2012) study, the young people with autism who contributed to this study demonstrated they were not isolated from the sociocultural process of identity development. Although at the point of contributing to this research, not all the participants had accepted their diagnosis, most indicated that they had. Furthermore, some of the participants were also confident in asserting their own identify, and of including autism as a positive element of their identity. As one of the participants explained, it is '*indispensable in how I exist and react to the world* (Kia, Appendix 18.1, lines 122-124).

Therefore, while reactions to diagnosis can vary, it is by ensuring that the social contexts that CYP experience before diagnosis, at the point of diagnosis and beyond it, reflect a positive understanding of the differences that are experienced in relation to autism, that positive views of autism and self are more likely to develop.

CHAPTER 6: RESULTS – PARENTS

6.1 Introduction

The findings from parents who participated via the online survey and interviews are presented in this chapter. Information regarding participants and the modes by which they shared their views are explained first. As the parents' survey and interviews were designed to enable them to provide their views of their child's experiences before the diagnosis, during the diagnostic process, and after the diagnosis, the participants responses are presented in this order. Responses to the survey's closed statements are presented first, followed by responses to the open questions. The final part of the chapter presents the views shared through the interviews. The findings in this chapter aimed to address research questions two and three:

- How do parents and professionals view children's experiences of autism diagnosis?
- How do parents and professionals support children and young people to understand an autism diagnosis?

6.2 Overview of participants

The parent participants are summarised in Table 44 below and are organised to illustrate the demographics in relation to the format by which participants contributed: online survey or interview. There were thirty participants for the parents' online survey and six parents participated via interview. One of the parents participated in both the survey and an interview.

Table 44 Parent participants: online survey and interviews

Method of Participation	Participants	n=	Diagnosis	Age of the young person with autism	Gender of children	Area
Online Survey	Mothers: 27 Fathers: 3	30	ASD=20 AS=6 Autism=4	Average:13 yrs 4 mths. Youngest: 5 yrs3 mths Oldest: 19yrs 0 mths Range-13yrs 9mths	Males 21 Females 9	South East= 22 Wales=1 London=3 West Midlands=1 North West=1 South=1 North East=1
Interviews	5x Mothers 1x Father	6	ASD=3 ASD/SPD=1 ASD/ADHD=1 AS=1	P1. Female: 6.2 years P2. Male: 15 years P.3 Male: 13.11 years P.4 Male: 15.6 years P.5 Female: 11.6 years P.6. Male: 12 years	Females=2 Males=4	All England 3=South East 1=South 1=West Midlands 1=South West

KEY: Autism Spectrum Disorder= **ASD;** Asperger syndrome= **AS**; Sensory Processing Disorder=**SPD;** Attention deficit Hyperactivity Disorder=**ADHD**

Twenty-six parents provided qualitative responses to the final question of each section of the online survey.

6.3 Parents' online survey results

As the aim of each section of the survey was to explore how positively or negatively parents rated their child's experiences relevant to an autism diagnosis, a summary score was calculated for each parent for each section of the survey. There were a different number of statements in each section of the survey, therefore, responses were calculated as a percentage to compare how positive experiences were before and after the diagnosis.

As shown in Table 45 below, participants' scores indicated that most parents felt their children's experiences improved after diagnosis. The range reflects the large difference in parents' ratings of their child's experiences.

Table 45 Parent survey: scores relating to the positivity of their child's experiences

Parent	Before Scores	Before %	Finding Out	Finding Out %	Post Diagnosis	Post Diagnosis%
1.	26	34.66	91	72.8	72	75.79
2.	39	52	79	63	66	69.47
3.	42	56	73	58.4	60	63.16
4.	25	33.33	86	68.8	74	77.89
5.	23	30.66	86	68.8	54	56.84
6.	39	52	83	66.4	78	82.11
7.	29	38.66	79	63.2	72	75.79
8.	31	41.33	77	61.6	65	68.42
9.	40	53.33	68	54.4	56	58.95
10.	35	46.66	63	50.4	52	54.74
11.	29	38.66	75	60	43	45.26
12.	23	30.66	91	72.8	71	74.74
13.	23	30.66	73	58.4	53	55.79
14.	43	57.33	94	75.2	75	78.95
15.	41	54.66	66	52.8	64	67.37
16.	30	40	83	66.4	68	71.58
17.	50	66.66	80	64	67	70.53
18.	38	50.66	84	67.2	58	61.05
19.	49	65.33	75	60	58	61.05
20.	42	56	54	43.2	49	51.58
21.	35	46.66	76	60.8	68	71.58
22.	28	37.33	84	67.2	65	68.42
23.	32	42.66	80	64	57	60
24.	43	57.33	86	68.8	73	76.84
25.	37	49.33	58	46.4	66	69.47
26.	23	30.66	75	60	85	89.47
27.	20	26.66	93	74.4	82	86.32
28.	56	74.66	59	47.2	66	69.47
29.	39	52	74	59.2	76	80
30.	39	52	98	78.4	87	91.58
Mean	46.64	34.97	78.1	62.47	66	69.47
Median	36	47.99	79	63.1	66	69.47
Mode	39	52	86	68.8	66	69.47
Max	56	94.66	98	78.4	87	91.58
Min	20	26.66	54	43.2	43	45.26
Range	36	68	44	35.2	44	46.32

Twenty-seven out of thirty parents rated their child's pre-diagnostic experiences lower than their post-diagnostic experiences. This suggests that their social, emotional, and academic experiences were more positive after the diagnosis than before it. Statements in the 'finding out' section of the survey were designed to capture how positive this experience was in terms of the support that their children were provided and how positively the diagnosis was framed. Twenty-one parents rated their child's experiences of finding out about the diagnosis at a level that suggested experiences were more positive than negative (60% or above of the possible score).

The details of each section of the survey responses are explored next. Full details can be found in Appendix 19: results of the parent survey.

6.3.1 Before autism diagnosis: parent views of their child's experiences

The responses about experiences before diagnosis are shown in Table 46 below, most commonly occurring responses are highlighted. When responding to questions about their child's experiences before the diagnosis, twenty-three out of thirty parents indicated that their child had no knowledge of autism before the diagnosis. Twenty-five parents also indicated that their child did not have any suspicions that they might be on the autism spectrum. However, three either disagreed (n=2) or strongly disagreed (n=1) that their child had no idea that they might be on the autism spectrum before the diagnosis. The results indicated that out of the parents who responded, only a small number felt their children had any awareness of the possibility of autism generally, and in relation to their own circumstances, before being diagnosed. This would suggest that the diagnosis was likely to be a surprising revelation for the majority. However, just over half of parents (n=16) also indicated that they disagreed that their child was feeling 'normal' prior to their diagnosis and just over half of the parents (n=16) also indicated their child felt misunderstood. This might suggest that children had a sense of difference from peers, which they felt others did not understand.

Table 46 Before diagnosis: parents' views of their children's experiences

Statement	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1. S/he didn't know anything about autism	20	3	2	0	0	3	2
2. S/he was very confident around other children	0	5	1	0	0	8	16
3. S/he was very confident about his/her ability	3	5	4	1	0	8	9
4. S/he worried about many things	14	7	4	0	0	4	1
5. S/he was always asking why s/he was different to other people	4	4	4	1	1	6	10
6. S/he didn't have much confidence in him/herself	11	6	3	0	1	7	2
7. Everything was fine	0	1	1	0	0	12	16
8. S/he never worried about anything	1	3	0	0	0	8	18
9. S/he struggled to get on with other people	14	8	4	2	1	1	0
10. S/he had no idea s/he had autism	22	3	2	0	0	1	2
11. Nothing ever seemed to work out for my child	8	10	3	1	0	6	2
12. S/he was doing really well at school	1	3	3	2	0	6	15
13. S/he felt that no-one understood	8	8	6	1	0	4	3
14. S/he felt 'normal'	2	3	9	0	0	6	10
15. S/he was finding school difficult	16	7	2	0	2	1	2

6.3.2 Before autism diagnosis: social and emotional experiences

Responses indicated that most parents felt their child's social experiences and emotional responses were often negative before the diagnosis. Only five parents felt their child was socially confident. Twenty-two parents (strongly agree: n=14; agree: n=8) felt their child viewed their social experiences negatively. Over two-thirds (n=21) indicated that their child worried about many things (strongly agree: n=14; agree: n=7) and twenty-eight parents did not agree that their child perceived everything to be fine prior to their diagnosis (disagree: n=12; strongly disagree: n=16). Just over half of the parents felt that their child lacked confidence in themselves (strongly agree: n=11; agree: n=6).

6.3.3 Before learning about their autism diagnosis: academic experiences

A similar pattern of negative perceptions was also indicated about children's academic experiences prior to their diagnosis. As shown above in Table 46, over two-thirds of parents (n= 23) identified that their child was finding school difficult prior to the diagnosis (strongly agree: n=16; agree: n=7). A similar number (n=21) disagreed that they were doing well at school (disagree: n=6; strongly disagree: n=15). Overall, most parents felt their child had a sense of feeling different and they mostly rated their child's social, emotional and academic experiences negatively prior to the diagnosis. These results are very similar to those shared by the CYP in their online survey responses.

6.3.4 Finding out about an autism diagnosis

As shown in Table 47 below, parents' views about their children's experiences of finding out about an autism diagnosis were more mixed than they were about their child's experiences before the diagnosis. The responses indicated that parents were the main providers of information about the autism diagnosis for the child. Eighteen parents indicated that they disclosed the diagnosis as soon as the diagnosis was made (strongly agree: n=11; agree: n=7), while eleven indicated that their child beginning to ask questions was the catalyst for disclosing the diagnosis (strongly agree: n=4; agree: n=7).

Table 47 Parents' views of their children's experiences of learning about an autism spectrum diagnosis

Statement	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1. The doctors and other specialists were able to tell him/her lots of helpful information	0	2	2	2	2	15	8
2. I/we told my child about their diagnosis as soon as it was confirmed	11	7	1	1	2	5	3
3. I/we told my child about their diagnosis when they started asking questions	4	7	2	10	2	4	1
4. Finding out seemed to help him/her to put his/her experiences into perspective	8	9	2	2	2	6	1
5. My child was given lots of helpful information by the specialist	0	3	1	2	1	13	10
6. Finding out about the autism diagnosis came as a real surprise to my child	2	3	10	5	0	5	5
7. Finding out has been a very positive experience for my child	6	7	6	3	3	4	1
8. When s/he found out about the diagnosis, s/he felt like s/he had been labelled	1	2	7	4	0	9	7
9. Being told s/he had autism provided him/her with what felt like a fresh start	3	7	11	3	1	3	2
10. Finding out about the diagnosis was a difficult process that involved many assessments and meetings	10	7	1	4	1	5	2
11. When my child was told about the diagnosis, s/he didn't believe they had autism	2	1	5	6	0	8	8
12. When they found out, s/he felt the need to look for information on the internet	0	1	5	8	0	7	9
13. The diagnosis has helped to empower my child, as they were helped to understand the autism and to recognise all their strengths	5	11	2	3	1	7	1
14. Finding out, helped him/her to understand their experiences and difficulties	6	12	5	2	1	3	1
15. My child has only been told about the negative aspects related to autism	1	0	2	3	0	12	12
16. Accessing websites/blogs/tweets created by other people with autism has helped my child to understand the diagnosis	1	7	8	8	1	3	2
17. Knowing the facts about autism has really helped her/him	5	9	7	3	0	5	1
18. Reading the information about the diagnosis seemed to highlight all the problems related to autism to my child	4	10	8	3	0	3	3
19. It was reading information books about autism that has helped him/her to understand	2	4	6	2	1	11	4
20. All s/he was told about the diagnosis was vague, unclear information	2	9	4	4	1	7	3
21. Finding out about the diagnosis made my child feel highly confused	0	3	9	3	1	7	7
22. The doctor/autism specialist helped my child to understand the autism.	0	3	3	4	0	10	10
23. Finding out about the diagnosis from the doctor/autism specialist has helped increase his/her confidence	4	3	4	5	1	7	6
24. Information about the diagnosis highlighted that there is no such being as the 'normal' person	5	3	8	7	0	5	2
25. Reading books written by other people with autism has helped my child to understand the autism	1	9	6	5	1	6	3

Some parents indicated that professionals were also involved in helping their child to understand the diagnosis. However, two-thirds of parents also did not agree that their child had received support to understand the diagnosis from a doctor or specialist (disagree: n=10; strongly disagree: n=10). Only three parents felt that their child had received useful information from the specialist who made the diagnosis. Twenty-four parents disagreed that the child had only been told negative information (strongly disagree: n=12; disagree: n=12). While most children were not provided information from their specialist at the point of diagnosis, parents felt that when information was provided it was likely to be positive.

More than half of the parents (n=17) indicated that finding out about the diagnosis enabled their child to put their experiences into perspective (strongly agree: n=8; agree: n=9), but the same number overall, also described the diagnostic procedure as a difficult process for their child to experience (strongly agree: n=10; agree: n=7). Ten parents disagreed that the diagnosis was a surprise to the young person at the point at which they were told. This differs from ratings about their child's awareness prior to the diagnosis, it is possible that the diagnostic process might have had a role in preparing some of the young people for the diagnosis. Finding out about the diagnosis appeared to have been useful for some CYP, as just over half of parents (strongly agree-n=5; agree-n=11) felt that the diagnosis helped their child to recognise their strengths. Discovering information about autism was indicated by fourteen parents to have helped their child (strongly agree-n=5; agree-n=9). Only three parents reported that their child did not accept the diagnosis (strongly agree-n=2; agree-n=1).

The sources of information that parents suggested that their children accessed to support their learning about autism varied. As shown in Table 47 above, the main sources of information identified were books written by people on the spectrum (N=10) and social media (n=7). Only one parent indicated that their child had accessed information about autism from other online sources. Five parents reported being unsure whether their child had accessed information via the internet. Eight parents indicated exploring the internet for information was not relevant to their child. It might be that parents believed they were too young, or that they did not have the relevant reading skills to access information in this way.

6.3.5 Parent views on changes for their child after an autism diagnosis

Comparison of the before and after ratings from parents indicate that most (n=24) parents felt their children's experiences were more positive after the autism diagnosis, than before it. Improvements were seen in the understanding of others and the support the child was able to access. As shown in Table 48 below, when considering specific aspects of their child's experiences post-diagnosis, the most reported improvement was that CYP's needs were better understood by their family, which was identified by twenty-seven parents (strongly agree: n=9; agree: n=16).

Eighteen parents reported that they got more help from teachers or tutors (strongly agree: n=14; agree: n=4), while twenty-two reported more general support at school or college (strongly agree: n=17; agree: n=5).

Table 48 Parent survey responses on changes for their child after an autism diagnosis

Statement	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1. Gets more support at school/college	17	5	1	1	1	1	2
2. Has not changed at all	4	7	3	3	1	9	4
3. Has been able to access support from a specialist to aid understanding of the diagnosis	6	4	4	4	0	8	4
4. Is just the same at home as they were before the diagnosis	8	9	0	0	2	6	5
5. Feels that they have been labelled	0	4	8	2	1	6	14
6. Is better at noticing all the things that they are good at and know these strengths are part of the autism	3	9	9	2	1	5	2
7. Feel that the autism is the cause of all of their problems	1	2	9	2	1	10	4
8. Gets more help from teachers/tutors	14	4	5	1	0	5	1
9. Understands why they are different from peers	7	14	6	1	1	2	0
10. Thinks negatively about their future	3	5	5	3	4	8	5
11. Thinks they are never going to achieve anything	2	5	4	2	2	9	6
12. Accepts the diagnosis	10	12	2	2	1	2	1
13. Has realised they just have a different way of thinking	9	14	4	2	0	1	0
14. Feels like a valuable individual	4	10	7	2	1	7	0
15. Has a greater level of confidence	4	10	5	2	1	6	2
16. Is better understood by the whole family	9	16	0	1	1	4	0
17. Has fewer disagreements with other family members	4	8	3	4	1	9	1
18. Feels they can be a success and are happier	4	8	8	1	2	7	1
19. Understands that they think differently from peers and that this is the reason for many of their strengths	8	9	7	1	1	5	0

When considering the direct impact on their child, twenty-two parents identified that their child had accepted the diagnosis (strongly agree: n=10; agree: n=12), twenty-three (strongly agree: n=9; agree: n=14) felt that their child related the diagnosis to a different way of thinking. Over two-thirds of parents (strongly agree: n=7; agree: n=14) indicated that their child now understood differences between themselves and peers. Parents also indicated that their child's understanding of the diagnosis enabled them to be more observant to the things that they were good at (strongly agree: n=3; agree: n=9), and more confident (strongly agree: n=4; agree: n=10). This increased positivity might be explained by relating differences in thinking to individual strengths (strongly agree: n=8; agree: n=9). When considering the future, some parents felt their child viewed this positively, for example, believing their child felt like a valuable individual (strongly agree: n=4; agree: n=10), and that they could be successful and happy (strongly agree: n=4; agree: n=8).

Fewer parents indicated negative outcomes after their child learnt of their diagnosis, however, three parents indicated that their child felt labelled; three indicated that their child felt autism was the cause of all of their problems (strongly agree: n=1; agree: n=2). Furthermore, eight parents indicated that their child felt negatively about their future, following the diagnosis (strongly agree: n=3; agree: n=5), and seven indicated that their child felt that they would never achieve anything (strongly agree: n=2; agree: n=5). As processing a diagnosis has been identified to take time, it seems likely that the age of diagnosis and how recently children had been diagnosed would impact their perceptions.

6.4 Thematic analysis of parents' responses to the open survey questions

Parental responses to the open questions were carefully analysed for themes, converging themes and broad topics, these are shown in Table 49 below. When including parents' written comments from the survey, and their spoken contributions from interviews, the approach used was the same as that used for the contributions from CYP, which is explained fully in Chapter 5. The responses to the open survey questions were processed in the same way as the comments from children and young people, they are included exactly as written by the participants and edited only for confidentiality purposes (identified with an asterisk*) within the appendix. Where comments are included in the thesis below, ellipsis […] within square brackets show where a section was cut from the middle of a quote to focus on the main point of discussion. Ellipses … not within square brackets, denote pauses in speech during interviews. Words in square brackets show where a word has been inserted for clarity.

Parents' extended responses reflected their responses to the main survey statements, more negative themes were discussed by parents before diagnosis (one hundred and forty-one) than after it (thirty-six). There were also twice as many positive themes identified after the diagnosis (eighty-four compared to forty-two before). Details of the thematic analysis are available in Appendix 19: results of the parent survey. Themes relating to the period before the diagnosis are discussed first below, followed by the themes relating to their child's experiences of finding out about the diagnosis. Finally, parents' views about changes their child experienced after the diagnosis are considered.

Table 49 Summary of thematic analysis of parental responses to the open questions

Before diagnosis themes Pos= 42/Neg=141	Finding out themes Pos= 105/Neg=65	After diagnosis themes Pos=84; Neutral=26; Neg=36
1. Ability/Difficulties Pos= 7/Neg=18	1. Diagnostic Processes Neg x25 Pos x25	1. Skills and strategies Pos=13;
2. Self-views Pos= 2/Neg=5	2. Resources Neg x2 Pos x5	2. Understanding of others Pos=23; Neutral=9; Neg=22
3. Social experiences Pos= 3/Neg=23	3. Explanation & understanding Neg x3 Pos x28	3. Diagnosis as a catalyst for change Pos=40; Neutral=8; Neg=7
4. Identity/Difference Pos=0 /Neg=27	4. Engagement Neg x0 Pos x6	4. Self-views (awareness/ efficacy/identity) Pos=8; Neutral=9; Neg=7
5. Feelings Pos=3 /Neg=29	5. Support Neg x12 Pos x5	
6. Uneven profile Pos=0 /Neg=3	6. Skills Neg x0 Pos x14	
7. Understanding Autism Pos=8 /Neg=19	7. Impact Neg x1 Pos x9	
8. Diagnosis Pos=15 /Neg=15	8. Identity Neg x22 Pos x13	
9. Support/Understanding Pos=4 /Neg=2		

6.4.1 Before autism diagnosis: parents' views of their children's experiences

All thirty parents provided information for the first open question about their child's experiences before the autism diagnosis. Parents' explanations of their child's experiences were largely negative. While one hundred and forty-one themes were negatively framed, only forty-two positive themes were identified.

The most common themes discussed by parents were related to their children's general well-being, these themes included their child's self-views, their abilities and difficulties, their differences from peers and uneven profiles. Parents discussed the emotional impact that these perceptions had. When sharing ideas related to these themes, parents often compared their child to peers. Children's comparisons of self to peers were also a commonly occurring theme.

6.4.2 Before diagnosis: parents' views of their children's well-being

When discussing their child's feelings prior to the diagnosis, parents mostly described negative feelings, which were often related to their child comparing themselves to peers. Parents identified more negative emotions (18 occurrences) than positive (3 occurrences) when discussing their child's experiences before they knew about their diagnosis. The terms used to describe children's views of self, their feelings, emotions, and experiences before the diagnosis included: stupid (2), anxious (2), exhausted, emotionally fragile, isolated, distressed, angry (2), frustrated (2), struggling, withdrawn, thick, retard, labelled and unsettled. However, a few parents identified more positive feelings: happy (2) and confident. For example, Parent 1 explained that despite trying to help her child to understand differences from peers:

> …she felt very alone and under pressure to be 'normal' which left her exhausted and anxious. (Appendix 19.1, lines 7-10)

Parent 8 also described her daughter's negative feelings, including her comparative criticality of self:

> She was very self-critical about things like her sensory sensitivities and couldn't understand why she was the only one to find things so hard, and blamed herself, even hitting her own head in frustration. She was very angry and explosive at home. (Appendix 19.1, lines 101-109)

Parent 26 explained similar negative experiences for her son, but the comparisons were influenced by the negative impact of peer bullying:

> He called himself "thick" and "stupid". When my son asked me what a “retard” was, I realised he was being labelled as one. (Appendix 19.1, lines 283-287)

Parent 22 described the negative impact that their child’s own continual self-comparison had on her emotional wellbeing*:*

> She was 'different' to her peers and would become distressed and withdrawn. (Appendix 19.1, lines 255-257)

Children were also compared to peers by their parents, as shown in Parent 5’s account:

> He was significantly behind his peers academically and socially pretty much at every mile-stone of his life. (Appendix 19.1, lines 56-59)

Frustration related to low self-efficacy was also commonly discussed. Parent 14 highlighted the frustration and anger that their son felt when he was finding it difficult to explain his feelings:

> He struggled to express what he felt and couldn't often find the right words or make sense of what he felt. He got angry and vented this by punching himself, hitting his head against a wall and tearing/damaging things. (Appendix 19.1, lines 162-169)

There were very few positive emotional experiences discussed by parents, except when linked with lack of self-awareness. For example, Parent 10 explained that while her son appeared happy, there were social difficulties:

> My child and I had no idea about autism. He seemed to be happy at school but complained [about] being bullied by a specific child and his group of friends. (Appendix 19.1, lines 114-120)

Social difficulties were discussed by most parents, this was one of the most commonly occurring themes.

6.4.3 Before diagnosis: parents' view on their children's social experiences

Parents frequently described problematic social experiences, while a distinct theme, comparisons also occurred within this theme. Parent 3 explained that despite the support offered, struggles with peer relationships continued. These difficulties were linked to the child's growing view of himself as different to peers:

> … and he received support for his social skills. Socially he struggled more as he got older and he became more aware of his differences. (Appendix 19.1, lines 21-25)

Parent 8 described her daughter's desire to fit in with peers and highlighted a similar growing recognition of difference from peers:

> She wanted to be like everyone else, as she saw it and to have friends, but was increasingly aware she couldn't cope with things as well as the others, isolated herself at school. (Appendix 19.1, lines 93-99)

Growing isolation was a common experience due to social difficulties, as explained by Parent 17:

> Our son was becoming more isolated in class. This had happened gradually over some years but became obvious. (Appendix 19.1, lines 213-219)

While some parents described isolation as imposed by peers, Parent 18, explained how their son increasingly isolated himself. Explaining that he was:

> … not able to make friends, bullied, etc. Liked to be on his own, did not like to take part in any sports games, always played on his own and would shut himself away in his bedroom. (Appendix 19.1, lines 115-124)

6.4.4. Before diagnosis: understanding autism

Parents also discussed finding it difficult to understand their child's needs prior to the diagnosis. Some parents did not suspect autism until differential development was identified by professionals, as explained by Parent 10:

> School had always reported that my child was happy and got on with a wide range of children. So, when they suggested there was an issue with friendships after 5 years of primary school this was quite surprising to us. (Appendix 19.1, lines 122-129)

Some parents also discussed their own experiences before the diagnosis. The period of uncertainty before the diagnosis was long for some parents, as explained by Parent 10:

> She eventually discharged my son after 18 months with no mention of ASD. He then saw a dietician for a further 18 months who then suggested something underlying (ASD still not mentioned). He finally received a diagnosis when he was 10. (Appendix 19.1, lines 138-146)

Although Parent 26 had clearly suspected their child had autism, the decision to seek the formal diagnosis was because:

> … an official label would potentially discredit any other unofficial ones that were being attached to him. (Appendix 19.1, lines 287-291)

Some parents also indicated that although a diagnosis had been made, they had not yet told their child (e.g. Parent 24, Appendix 19.1 lines 264-267).

6.5 Finding out: analysis of open questions

Twenty-nine parents provided information for the open question about finding out about an autism diagnosis. As there were more not relevant, and not sure responses, to this section of the survey, the open responses were particularly useful to understand parental approaches when telling their child about autism. Thematic analysis identified eight broad themes, in order from the most to the least discussed theme, they are: the diagnostic processes, identity, explanation and understanding, support, skills, impact, resources, and children's engagement with the process.

6.5.1 Finding out: the diagnostic process

The diagnostic process was highlighted as long and problematic by some parents. Furthermore, the purpose of the diagnostic assessment was not always discussed with the child, as explained by Parent 3:

> He found the whole experience very confusing, however, as its purpose was not explained to him by any of the doctors or specialists and I only talked to him after the diagnosis was confirmed. (Appendix 19.2, lines 17-22).

Parent 9 also explained that her child was not informed about the purpose of the diagnostic assessment until after the diagnosis was made. Even when the diagnosis was made, explanation had only been partial:

> She still is unaware of her diagnosis and has never questioned why she sees doctors etc. I have explained some of it to her and she hasn't made any comments about it. (Appendix 19.2, lines 92-96).

Although Parent 9 explained that her child did not ask questions about the diagnosis, it cannot be assumed that the child was not wondering why they are being assessed. The timing of the diagnosis could also be problematic for children, as explained by Parent 25:

> Didn't really register at first; diagnosis came at the end of Year 6 so the focus was on secondary transition. Found it very difficult to accept

> process as she had/has a strong desire to be the same as everyone else. (Appendix 19.2, lines 244-250).

When the child is developing their sense of self, it might be more difficult for some young people to accept. However, despite the diagnostic process taking a long time and coming late in the child's development, the impact could be positive, as explained by Parent 1:

> … it came after years of CAMHS meetings and discharges when she was 16. We left the diagnosis meeting and she laughed and smiled and felt a great sense of relief. (Appendix 19.2, lines 1-5)

6.5.2 Finding out: parental explanations about diagnosis

The approach used for explanation to support understanding was a factor discussed by most parents. Most parents indicated that they were the main provider of the explanation about the diagnosis.

Parents often linked the age at which the diagnosis was made to when and how the young person found out about the diagnosis. When the diagnosis was made at an earlier age, finding out was described as a more gradual process. Parent 4 described a continual and ongoing process:

> As my child was diagnosed at 5 (he is now 13) he has been told age appropriately about his autism continually after diagnosis to this day. (Appendix 19.2, lines 37-40).

Parent 3 also explained that it was not only the explanation that was a lengthy process but her son's processing and coming to understand accept the diagnosis that was also a gradual process:

> It has taken a while but five years on he does accept that he has high functioning autism. (Appendix 19.2, lines 29-31).

Explaining about autism, and CYP coming to understand the diagnosis, as an ongoing process was a common theme. Twelve parents indicated that ongoing discussion was important when explaining how they supported their children to understand the diagnosis. Despite the ongoing explanations, some parents continued to feel that their child's understanding was limited, as explained by Parent 5:

> Even though we told him and still continue to talk about his autism he doesn't really understand. (Appendix 19.2, lines 41-43).

Nine parents discussed lack of help or advice about how to explain the diagnosis to their child. Parent 26, for example, was only provided with a booklist (Appendix 19.2, line 251). As a result, some parents discussed their own endeavours to find information to support their explanation, as explained by Parent 13:

> The information we were given was limited by the consultants. We have had to do a lot of research to enable us to inform him. My son only knows what we have told him. (Appendix 19.2, lines 121-124).

Parents described a range of strategies to support their child's understanding. Ten parents indicated focussing on the positive features of autism as a key strategy to help their child to understand the diagnosis. Parent 17 explained how this positive focus has helped their son to understand differences compared to peers.

> We, post diagnosis, have endeavoured to highlight the positive sides to this diagnosis and to this condition. Overall, I fell it has been helpful for him to know that he has this condition. He can see that is why his reactions to some events or his interest in certain topics are not the same as peers or others around him. (Appendix 19.2, lines 178-185).

A focus on being different regularly occurred in parents' accounts of their explanations for their child, as Parent 8 explains:

> I've been able to explain more about why, and that her way of thinking and processing is not less, just a bit different. Though she's found it hard at times and wishes she was like everyone else, she's slowly starting to see the positives such as original thinking. (Appendix 19.2, lines 84-91).

Seven parents also discussed making a positive link between the diagnosis and strategies, as Parent 15 explained:

> I don't go on about labelling everything as being 'his autism'. I say, 'I understand why you want to make as much noise as possible right now, please go into the garden/room and be noisy there'. (Appendix 19.2, lines 153-156).

Parent 30, explained how they focussed on positive strategies to help their son to overcome the autism related difficulties he experienced:

> We told our son when he was 10 and able to understand...and did do it in a very positive way, telling about all the things he could do and not focussing on the difficulties but explaining why he had these difficulties and teaching him strategies to overcome them. (Appendix 19.2, lines 298-305).

A few parents also highlighted the importance of not allowing the diagnosis to be used as an excuse. Parent 15, for example, explained their focus was on helping him develop alternative behaviours.

> It's a reason for his behaviour not an excuse. So we focus on the unwelcome behaviours, and alternatives. (Appendix 19.2, lines 165-269).

Parent 28 linked a delayed telling their son about the diagnosis to worries about the diagnosis being used as an excuse for behaviours:

> WE have never given him the opportunity to "get out" of things because of his diagnosis and chose not to tell him for about 4 years. (Appendix 19.2, lines 282-285)

Many parents utilised their children’s behaviours and differences related to autism, which occurred during daily activities, as opportunities to support their explanations.

6.5.3 Finding out: resources used by parents

Only three out of the thirty parents specifically mentioned resources. While some parents mentioned looking to the internet for information for themselves, this was not discussed as a resource used for children. The only physical resource that parents discussed was books. Parent 6 explained that reading a book about autism with their daughter led to her making the link to herself without further prompting:

> … we read a book called 'I have Autism, What's that?' And without any prompting my child recognised that the book was about “someone like me”. (Appendix 19.2, lines 50-53)

However, two other parents described less success when they employed books to support their children’s autism diagnosis, Parent 10, for example explained how they:

> … explored ASD together with various aged-related books. He found a lot of books too childish; he wouldn't use social stories. (Appendix 19.2, lines 100-103)

Parent 20 indicated that her son actively avoided books related to autism due to lack of acceptance of the diagnosis.

> … he didn’t really understand and wouldn’t read books. He was in denial, still is a bit. As he is able to act Neuro typical quite well when with people outside the home. (Appendix 19.2, lines 204-209)

Parent 20 felt that masking own behavioural traits related to autism appeared to suggest denial of the diagnosis and concern about other people’s expectations.

6.5.4 Finding out: parents views on their child's engagement when learning about an autism diagnosis

Nine parents described some level of disengagement or lack of interest during assessment appointments, including during the appointment at which the diagnosis was made. Parent 2 explained that, as the diagnosis was so late, the specialist also emphasised the importance of a speedy disclosure:

> My son seemed not terribly interested but was taking in what was said. The doctor left it to me and my husband to explain the diagnosis to our son and emphasised that we needed to tell him straight away. (Appendix 19.2, lines 9-14)

Sometimes the disengagement was due to the child's developmental level, as explained by Parent 19:

> Still unaware, despite going to an autistic unit [and] his peers talking about their autism- he just is who he is. (Appendix 19.2, lines 193-195)

Parent 23 indicated their son's level of engagement related to his general difficulties in communicating his feelings:

> He doesn't talk about it much as he doesn't talk about anything much so it is sometimes difficult to know what he's feeling and if you ask him, he finds it difficult to put it into words too. (Appendix 19.2, lines 232-236)

6.5.5 Finding out: impact of the diagnosis on their child

Many parents described positive impact from learning about the diagnosis, for example, Parent 14 explained:

> It opened the way for him to feel ok about his behaviours, feelings and actions. […] He is so much happier. He has far less angry outbursts and is able to communicate his frustrations quite clearly […] He feels he has a reason for "odd" behaviours and rather than making him odd, it explains exactly who he is. (Appendix 19.2, lines 138-144)

Parent 1 also described a positive impact on her child:

> She stopped trying to hide from her autism and started making positive decisions about her life. (Appendix 19.2, lines 5-8)

This account reflects the impact that the young people described, whereby the knowledge created a sense of agency that enabled their child to move forward in taking control.

6.5.6 Finding out: access to autism specific support

As discussed by CYP in their online survey, parents discussed increased access to practical support following the diagnosis. Parent 18 explained how her son began to carry an ASD awareness card in case he needed to communicate his needs:

> I think he knows a little about his problems and he does take his police ASD card when he goes out. (Appendix 19.2, lines 190-192)

Meeting others on the autism spectrum was a factor that Parent 26 identified to be the key factor to support understanding of the diagnosis:

> My son knew he was different [...]. He listened to the doctor but nothing really resonated until he met others like him at *the support group. (Appendix 19.2, lines 253-261)

6.5.7 Finding out: processing and Identity

When discussing the diagnosis with their child, eight parents discussed how learning about their autism diagnosis had a positive impact on their child’s self-views, linking this with their identity. Five parents discussed positive impact, five a mixed impact and three discussed negative impacts. Parent 14 described a positive impact from the explanation, which had a normalising impact on her child’s identity:

> It's the best thing for him. He feels normal by being told he is different! (Appendix 19.2, lines145-146)

Parent 7, who has twin daughters, explained how following the diagnosis, features related to the diagnosis were linked to the difficulties being experienced, which had a positive impact as it helped to explain the difficulties they experienced:

> They really took it well [and] it answered many questions for them, i.e. they no longer think they are "weird" (as branded by other children), they know there is a reason for their ways [and] feelings. (Appendix 19.2, lines 61-70).

6.5.8 Finding out: developing skills

As CYP identified, eight parents also discussed the way in which learning about the diagnosis influenced their child to work on developing their skills, either because they encouraged their child to do this, or because their child made this decision for themselves. Parent 14, for example, describes how by taking control and developing strategies, skills were developed:

> It also empowered him to take control of his anger, learn coping strategies to deal with anxieties around animals and food. His social skills have improved immensely. He is self-confident and able to make contact with new people. (Appendix 19.2, lines 131-138)

However, some parents discussed concerns about the impact of finding out about the diagnosis on their children’s identity. As Parent 10 explains, this was linked to the child’s feelings of difference:

> On the whole, I would say it's been a negative experience, apart from he understood at the time of diagnosis why he felt so mad and out of synch with his peers (Appendix 19.2, lines 106-110).

Parent 5 also explained that despite knowing about the diagnosis, her son continued to view it negatively:

> … some aspects of autism just can't be helped! He always had a very negative view of life before the diagnosis anyway, but as he has got older he becomes more negative. (Appendix 19.2, lines 40-43)

Parent 3, however, indicated that development was a factor for her child:

> Since he hit puberty (after his diagnosis) he has become more negative and anxious in general but I don’t think this is because he is aware of his condition, more that he has the condition.” (Appendix 19.2, lines 13-16)

This serves to highlight the many overlapping factors that might impact a child’s experience of coming to know about and autism diagnosis, in the above case, his mother felt it was not knowledge of the autism diagnosis that impacted but developmental factors.

6.6 Changes after the diagnosis

Twenty-seven parents shared their views about changes in their child’s experiences after the diagnosis. Four main themes were identified, these are skills/strategies, understanding of others, diagnosis as a catalyst for change, and self-views (awareness/identity/efficacy). There was some overlap between parents’ comments about their child’s finding out experiences and their experiences post diagnosis. This was particularly evident in comments about the impact of the understanding of others, which was the most discussed theme. Parents’ discussion of this often linked directly with diagnosis as a catalyst for change, which was the second most discussed theme. The impact on children’s ‘identity and self-efficacy’ was the third most discussed theme, this was often linked with discussion of the least common theme: children's skills and strategies.

6.6.1 Understanding of others

Most parents (19 out of the 27 that responded to this question) explained that following the diagnosis, other people showed greater levels of understanding and therefore made greater levels of adjustment. As explained by Parent 1, this led to adjustments being made within education and to further investigation of needs:

> Moved to college a year early and then was able to access the disabled students' allowance […], gave her a mentor for her first year at least. Was assessed as having dyslexia which gave her access to more time for assignments. Tutors try to be understanding and differentiate work for her (Appendix 19.3, lines 1-7)

Similar impacts were described by Parent 12 (Appendix 19.3, lines 93-97) and Parent 23 (Appendix 19.3, lines 202-203). Parent 7 also explained that improved familial understanding also had a positive impact on her twin daughters:

> Family members now realise that there is a reason why my children have not ever spoken to them & realise that they are not just rude or ignorant. (Appendix 19.3, lines 54-57)

However, parents explained that lack of understanding could still be problematic post-diagnosis. Some identified the invisible nature of autism as a causal factor for the lack of understanding of others, as explained by Parent 8:

> Unfortunately, because our child is of average intelligence and able to mask her difficulties to a degree, school staff continued to feel not much support was needed (as do extended family) which meant school continued to be extremely difficult, school refusal worsened till we decided the only way to preserve mental and emotional wellbeing was to home educate. (Appendix 19.3, lines 62-69)

A similar view was expressed by Parent 9, who explained that this meant that social and emotional needs were neglected:

> I feel that at school she is let down by her teachers as she is academically good, they seem to ignore the fact that her social skills need attention and that she has high emotional needs. (Appendix 19.3, lines 118-121)

It was also due to lack of visible signs of autism that some parents felt the need to explain their child's behaviours to others, even while feeling this should not have to be the case, as explained by Parent 19:

> Occasionally I feel the need to explain to others about his condition if they find his behaviour or conversation strange, but I don't feel comfortable having to excuse him as he won't have done anything wrong ... (Appendix 19.3, lines 170-175)

Pressures related to societal expectations continued to be experienced as problematic by some parents, despite the diagnosis.

6.6.2 Diagnosis as a catalyst for change

The diagnosis was seen to be the point at which changes were experienced by many families. Often the changes that were experienced led to positive outcomes for the child, as Parent 1 explained:

> Things and life for my child did become simpler [...]. He is currently entering year 9 at a mainstream HS with an Autism Resourced Provision that I cannot speak highly enough about! He is now learning about himself as well as academically what he is very good at and the self-esteem and confidence is increasing. (Appendix 19.3, lines 17; 30-35)

Therefore, the diagnosis was a catalyst for several positive improvements for her son. The diagnosis was seen by many parents to have influenced improvements in educational provision. However, access to other support and specialist services was also discussed. For example, Parent 6 explained that in addition to extra school support, her child was also able to access support groups for social and emotional regulation (Appendix 19.3, lines 46-48). While Parent 4 discussed support for family members:

> My mother and husband went on a course to help them understand why my son does what he does. (Appendix 19.3, lines 40-42)

However, Parent 7 explained that while some teachers displayed improved understanding, others were felt to be '…oblivious to their problems' (Appendix 19.3, lines 60-61).

While the diagnosis had the potential to improve experiences across settings, this was not the case for all. Furthermore, some parents appeared to have anticipated improvements, but experienced disappointment when this did not happen.

6.6.3 After diagnosis: changing skills and strategies

Parents were generally more positive in discussing their children's skills and strategies after the diagnosis than before the diagnosis. However, some dissatisfactions were also evident.

Parent 25 explain a very positive impact, especially on social interaction:

> My son's sense of humour has come to the fore; he laughs at himself but in a good way. He also recognises autistic traits in others; again in a good way. Two short years ago he would sit with his head on a table and hands over his ears. He is now confident that he can contribute socially at least in short bursts. Phenomenal! (Appendix 19.3, lines 216-220; 223-231)

The development of new strategies was also identified as a response to diagnosis, as explained Parent 18:

> … he has changed to move himself away from problems to control his frustration (Appendix 19.3, lines 166-168)

Parent 14 described how the diagnosis led to therapy and this has improved confidence and communication skills (Appendix 19.3, lines 182-184). An element of agency for their children was also evident in the way that parents described the impact on their child, as discussed by Parent 21:

> He has now decided he wants to work to make things less difficult for himself. (Appendix 19.3, lines 118-121)

6.6.4 Self-views and confidence

The diagnosis was seen to impact positively on some children's self-views. Parent 4 explained how this impacted positively on her child:

> He is now learning about himself as well as academically what he is very good at and the self-esteem and confidence is increasing. (Appendix 19.3, lines 33-35)

A similar impact was described by Parent 6:

> My child has grown in confidence, made good progress academically and succeeds in maintaining friendships. (Appendix 19.3, lines 49-51)

This was recognised to be of ongoing importance for children, as explain by Parent 23, who felt that it would support a more balanced understanding of self:

> It's not just for now but for his future so he will always know why he might struggle with certain things or why he's really good at others. (Appendix 19.3, lines 204-206)

However, four parents discussed worrying that their child might use the autism diagnosis as an excuse for problematic behaviours, as explained by Parent 22:

> He sometimes uses his autism as a reason why he isn't good at something like friendships. (Appendix 19.3, lines 196-197)

Some parents felt that their child was simply not interested in the diagnosis, as explained by Parent 2:

> Seems uninterested in hearing about autism and others on the spectrum… (Appendix 19.3, lines 118-121)

Views about the impact of the diagnosis and young people's responses to it appeared to reflect great variation in experiences. However, more parents chose to write about positive impacts. Those parents whose views were less positive, often identified a lack of support for their child following their child's diagnosis.

While expereinces relating to the diagnosis might influence self-efficacy and other self-views, other factors that children expereince are also likely to have had an impact. Some parents added comments to identify this specifically. For example, when answering question 4 about whether there were changes after the diagnosis at home, Parent 3 explained:

> No, but mainly due to age and hormones (Appendix 19.3, line 7).

All the potential bio-psycho-social factors that might impact any child, will also be factors that will impact children with autism. Parent 3 clearly felt that the changes identified were developmental rather than being specifically linked to the child's awareness of the autism diagnosis. Some CYP might also have other identified needs which could also influence their views. When discussing whether her son blames autism for his difficulties, Parent 28 highlihgted that her son also has neurofibromatosis type 1 (NF1):

> He tries, however, we won't hear of it. Then he blames NF1 instead!! (Appendix 19.3, lines 18-19).

General personality, or psychology factors, were highlighted by Parent 3 when discussing whether their child was thinking positively about the future:

> He thinks this way anyway. He doesn't blame his autism. (Appendix 19.3, line 29).

Similar views were also shared by Parent 5, in response to whether there were fewer arguments with other family members following the child's diagnosis:

> He can disagree with fresh air. (Appendix 19.3, line 43).

Therefore, while experiences were rated more positively after learning about a diagnosis than before the diagnosis, factors unrelated to the diagnosis can also influence the way children process information about an autism diagnosis.

6.7 Parental views: anything else

As summarised in Appendix 19.4 results of the parent survey: additional comments, many of the additional ideas shared by parents had already been discussed by parents in other sections. However, a new theme was identified related to parental worries about how their child might 'move on' during the next phase of development. Concerns about 'moving on' were discussed by eleven parents. Parents discussed their worries about the difficult balance between supporting their child to develop independence, while also protecting them. This balance was effectively summarised by Parent 26, who also identified pride at the progress made:

> Letting go as a parent of someone with autism is extremely hard. The first time that my son travelled independently, by train […] was both thrilling and nerve-wracking experience for me […]. Just writing this now has reignited my pride in my son. (Appendix 19.4, lines 380-387; 411-413).

Parent 30 shared similar experiences and explained how by providing practice opportunities, they were able to support their child's developing independence:

> By doing something lots of times with our son we have found he can then do this by himself i.e. getting a flight overseas, which we have done many times to and from the same airport so he is now confident to make that journey on his own and meet us there. (Appendix 19.4, lines 434-443)

Eleven parents also re-emphasised the difficulties that they had experienced with the diagnostic processes and accessing support after the diagnosis had been given.

6.8 The parent interviews

Parental interviews aimed to explore parental views about their children's experiences at home and at school in relation to the point the autism diagnosis was made. Parents were also asked about the impact of knowing about the diagnosis on their child's view of self, as well as how knowing about the diagnosis impacted the support they received and the views of key people in their lives. Parental interviews were analysed for themes within and then across the interviews. After providing information about the participants, themes identified relating to the period before the diagnosis are discussed, followed by the themes relating to children's experiences of finding out about the diagnosis. Finally, parents' views about changes their child experienced after the diagnosis are considered.

6.9 Parent interview participants

Six parents participated in an interview to discuss their child's experiences. The details of the parents and their children are provided in Table 50 below.

Table 50 Demographic details of the parents interviewed and their children

Parents' relationship to child	Child's pseudonym	Child's gender	Child's diagnosis	Child's age when parent interviewed	Child's age at diagnosis	Who disclosed to child	Child's age when told about the diagnosis
Parent 1 Mother	Rosie	Female	ASD	6 years 2 months	6 years	Mother	Ongoing
Parent 2 Mother	Robbie	Male	ASD	15 years	4 years	Mother	Between 10 - 11 years old
Parent 3 Mother	Stephen	Male	AS & dyslexia	13 years 11 months	About 9 years old	Both parents	3 or 4 months after diagnosis
Parent 4 Mother	Peter	Male	ASD	15 years 6 months	Almost 14 years old	Mother	Straight after diagnosis
Parent 5 Mother	Jasmin	Female	ASD & SPD	11 years 6 months	Just under 8 years old	Professional: assessment outcome meeting	Parent and child told together
Parent 6 Father	Michael	Male	ASD & ADHD	12 years old	Between 7-8 years old	Father	Straight after diagnosis

KEY: Autism Spectrum Disorder= **ASD;** Asperger syndrome= **AS**; Sensory Processing Disorder=**SPD;** Attention deficit Hyperactivity Disorder=**ADHD**

6.10 Parent interview findings

The parents interviewed revealed that their children's experiences were more positive after diagnosis than before, however, problems relating to children's social experiences, professional understanding of children’s needs, and access to support were highlighted. Figure 8 below, summarises key elements about children’s experiences relative to their diagnosis, and those of their parents, which were identified to be similar across both the online survey and the interview accounts.

The structure highlighted in Figure 8, has been used to guide the discussion that follows about the information shared by parents through the interviews. Experiences before diagnosis are discussed first, followed by experiences of disclosure of the diagnosis and support for children to understand the diagnosis. The final section considers parental views about the impact of the diagnosis for their child.

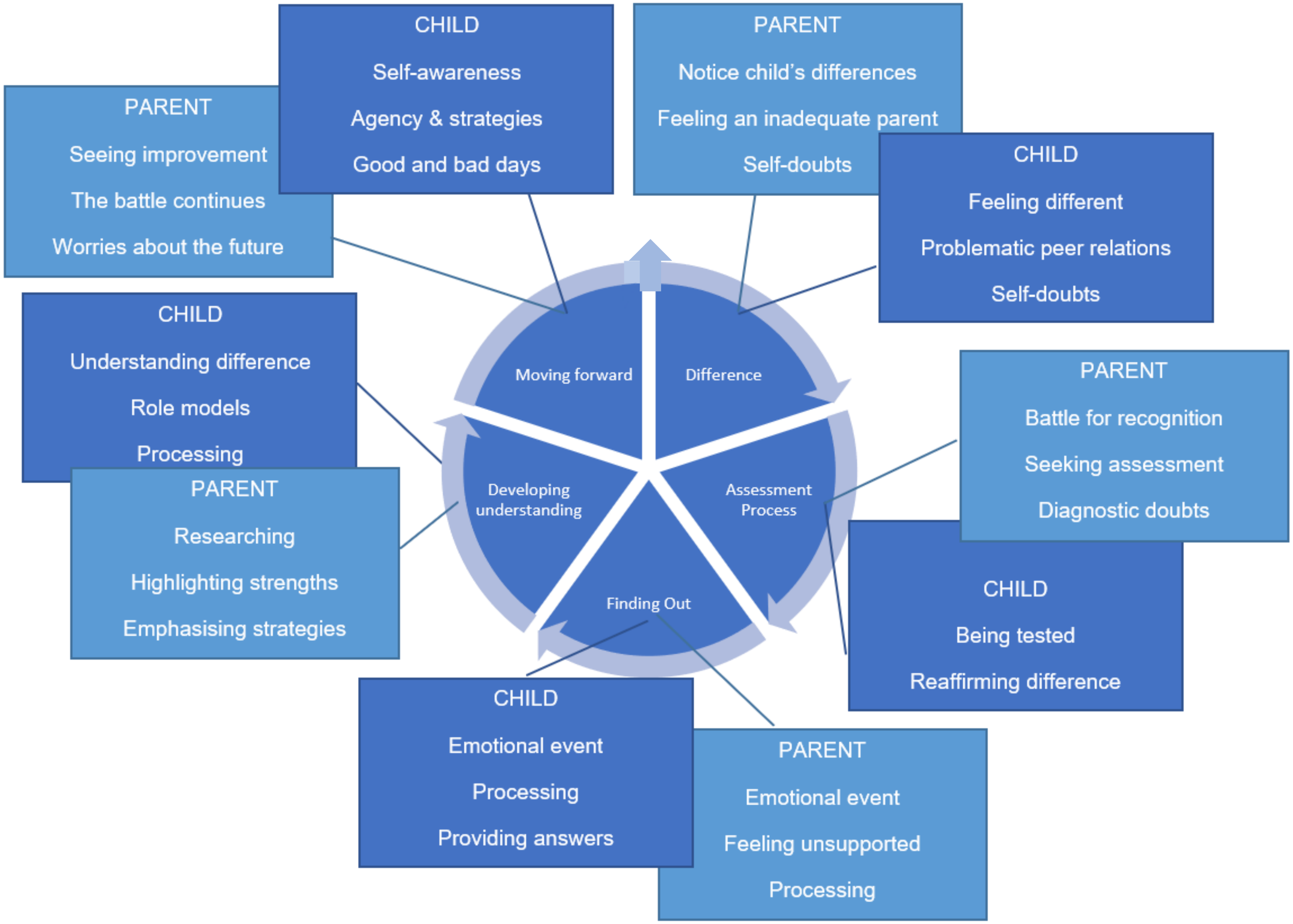


Figure 8 Parent views of their child's diagnostic experiences`

6.10.1 Parent interviews: before diagnosis

Within the interviews, all the parents identified observing differences in their child's development before the diagnosis, but there was a lack of recognition of their children's needs by others, which had a negative impact on their child.

Rosie was diagnosed at six years old. Her mother explained that she had an awareness of seeing doctors and being assessed, but at the time of the interview, she had not been told she had autism. However, her mother was in the process of supporting her understanding by discussing differences with her. Her mother explained that before the diagnosis, people applied other labels to Rosie:

> I think before she was diagnosed, people labelled her […] as naughty. Her playschool, her dad […] And I think that changed once she had the diagnosis. That it was, kind of, they had to listen … (Transcript 2, lines 46-55)

Rosie continued to have problems when interacting with others though and her mother continued to find it difficult to explain her behaviours to others:

> It's really hard with her because she would be aware if someone was looking at her […] she would go and spit at them or something. (Transcript 2, lines 61-66)

Other parents also discuss difficulties due to the attitudes of other people. Robbie was approximately four years old when he was diagnosed. His mother told him about the diagnosis when he was between ten and eleven years old. Before the diagnosis, she was aware that Robbie was developing differently, she explained that she felt judged by others because of this:

> … people made me feel like I wasn't a very good parent. Quite frequently when he was a young child […]. “Why isn’t your child doing that and why is he behaving in that way?” I felt quite alienated as a parent. (Transcript 3, lines 5-12)

Robbie’s mother explained that her family were against her seeking assessment to explore the developmental differences that were causing her concerns:

> … family were quite against anything being an issue. Older members of the family in particular were quite horrified at any suggestion […]. I was made to feel that if I went down the route trying to find out then I was going to make life difficult for him and he would be ridiculed. (Transcript 3, lines 19-27)

Some of the other parents also explained that extended family found it difficult to understand or accept their child’s differential development. Stephen was 13 when I interviewed his mother. He was diagnosed at nine years and was told about the diagnosis a few months later, when he was also identified to have dyslexia. His mother explained that when he was younger, she had noticed that his development differed from other children in the extended family:

> … it was like a child should blossom and he kind of didn’t. And he would go up to children and they would just kind of walk off. […] he only had about three words until he was four years old […] My nephew and my cousin […] they loved to talk. (Transcript 4, lines 254-263)

Stephen’s mum recalled that he saw a speech and language therapist who suggested Asperger syndrome as a possibility. However, not all professionals recognised his needs:

> … he went for speech therapy. They picked up on the eye contact […] but they signed him off. (Transcript 4, lines 452-460)

Stephen’s mother was initially relieved that no diagnosis was given:

> I was relieved to think when I found out Stephen probably didn’t [have autism]. I know I really didn’t want him to have it. (Transcript 4, lines 194-196)

Stephen was diagnosed following a second autism assessment. Despite his father having an Asperger syndrome diagnosis, the problematic assessment and experience of initially being told he did not meet the criteria seems to have caused some lingering doubts about the diagnosis:

> He doesn't really tick a lot of the… you know, I did think he might… actually be a bit atypical because there's a few things he does which… . Because they said he didn't fulfil the triad of impairments the first time round and I'm still not completely convinced he does. (Transcript 4, lines 973-979)

Other people’s reactions to the diagnosis were also a concern for both Stephen and his mother. They did not want other members of the family to know about the diagnosis in case they did not accept it:

> And I can't bear to hear my mum say, oh, no he's fine. There’s nothing wrong with him […]. I just don’t want that conversation with her. (Transcript 4, lines 916-920)

Peter also experienced a late diagnosis. His mother explained that following a traumatic event for his family and a sudden home move, Peter struggled to cope with the changes in his life and to make new friends. His transition to secondary education was also problematic and he experienced some bullying. His mother felt that her concerns were not taken seriously by the teachers, who did not recognise the difficulties Peter was experiencing. She was also worried about her son being labelled:

> When I raised this, their response was its character building […]. And I said, you know what, it's not character building, it's bullying. And I didn't want to speak to the school and pre-empt a problem and sort of say, oh

> my son's a bit strange… because that's labelling them and that's making the school judge him in a different way. (Transcript 5, lines 207-226)

For Peter's mother, the balance between having his needs met and identifying her concerns was also difficult to negotiate:

> The aggression and anger was still there to a degree, he was still quite insulated, insular and isolated [...] I went to the GP and raised all these concerns. […] we were waiting ages […] and in the meantime, CAMHS got involved with a bit of anger management. (Transcript 5, lines 419-422; 225-227)

Jasmin was diagnosed just before she was eight years old. Her mum explained that she was experiencing a difficult time at school because staff lacked understanding of her needs and peer relationships were problematic:

> There was a lack of understanding there, and it was very much that masking/camouflaging her anxiety. And the teacher, well she's beautiful, and … and would say: 'Its fine, its fine!' But it wasn't fine [...], she was getting a lot of harassment, bullying […] the school were not dealing with very well [...]. (Transcript 6, lines 110-124)

These experiences had a negative impact on Jasmin's view of herself:

> She would say: 'I'm weird!' […] and she would hear things around her that were very negative. (Transcript 6, lines 149-154)

Michael was diagnosed at approximately the same age as Jasmin, just before his eighth birthday. His father told him about the diagnosis almost immediately. Michael was twelve when I interviewed his father. Michael's father described the difficult experiences that the family had prior to the diagnosis:

> We'd been treated really badly. We'd been sent to a parenting class [...]. He can't stand doors being shut, or feeling that he is going to be trapped in somewhere […] So these behaviours, they linked it back to us being bad parents, they did that all the way through the diagnosis (Transcript 7, lines 153-167)

Michael’s father felt that a crisis came at around the same time as his diagnosis, when due to the invisible nature of his autism, his needs were not recognised, and support was not in place:

> When he was eight, when he tried to hang himself. The fact that he had fallen out with a friend […]. He doesn’t know that they don’t get him. And he can feel quite isolated by that and […] teasing, like he had the problem. But because he presents like he is able, people just look at him and think, yeah he’ll just be able to cope. (Transcript 7, lines 445-476)

Across the interviews, all the parents discussed how other people did not understand their child’s differences. This lack of understanding from family members, professionals, and the child’s peers can be seen to have had an impact on both parental wellbeing and children’s wellbeing.

6.10.2 Parent interviews: child’s experiences of learning about an autism diagnosis

When discussing their children’s experiences of learning about their autism diagnosis, parents discussed the assessment process to be significant in highlighting potential differences. Parents also discussed encouraging their child to focus on strengths, the use of context specific explanations, and drawing on role models with autism to support understanding.

Although Rosie had not been told she had autism, her mother explained that she had been discussing differences with her. It was the assessment process, however, which she felt first caused Rosie to begin to ask questions:

> Well, going to the appointments, I don’t think she really had any understanding of what they were for […], she doesn't really like hospitals

> and doctors and things. […] she just kept saying: “Why are we going?” And I said: “Just because, you know, when you get angry and sad and things, they just want to talk to you about that.” (Transcript 2, lines 149-154)

However, Rosie has heard her mum discussing autism and had also started to show some understanding of difference.

> She will tell people her brain is different. And she will say her brain is like Jack's, which is another little boy in her class with autism. (Transcript 2, lines 8-17)

The diagnostic process was also discussed by other parents as beginning to raise their child’s understanding of their differences. Peter’s mother explained that he was aware of the purpose of the assessment:

> Yeah. He knew he was being tested for autism because initially we went to *the clinic because of his anger, his sort of starting to self-harm. […] while we were there, I raised a question about some of the things over the years. And I pointed at autism […] and I asked whether that was a possibility […]. (Transcript 5, lines 106-122)

Peter enjoyed some of the assessment activities:

> In fact, he'd come back from some of the tests and say oh they were quite surprised because I scored really high on that one, mum. (Transcript 5, lines 466-470)

However, he had not been at the final meeting when the diagnosis was given. Therefore, his mother explained the diagnosis to him immediately afterwards:

> I said they have confirmed that you do have, you know, high-functioning ASD. And he was more interested in the fact that it was high functioning. He said: “Oh well, you know, that explains everything”. (Transcript 5, lines 502-510)

However, Peter was not provided any support from professionals to understand the diagnosis:

> His question to me […] was: “Where do I go? What do I do?” And I actually asked the question in one of the [parent training] sessions: “Where do young people go to find out more about what they've been diagnosed with?” And the answer was: “There is nothing at all”. So, we kind of sorted our own things really. (Transcript 5, lines 4-22; 62-64)

Peter has, however, had support for his social and emotional development through both social groups and counselling at the local child and adolescent mental health services, which his mother feel has been very successful in supporting his emotional development:

> … the therapy that he received at *clinic with the […] training psychotherapist, that probably helped Peter immensely to understand how irrational his fears are and how to work on overcoming them. (Transcript 5, lines 825-829)

Peter’s mother explained that because he volunteers at a charity, he has contact with other people with autism, and this has supported his processing of the autism diagnosis:

> …going to *local clubs, because he mixes with other young people who have learning difficulties […] including autism […]. When Peter is being asked to support the younger children, I'm guessing that […] *John will coach him on that and discuss what their needs are. So that's probably […] helping him to understand his own diagnosis, I suspect… (Transcript 5, lines 804-822)

She feels this has supported his understand of both himself and autism:

> I think he feels comfortable now because […], he's surrounded by people like him and he can see that by comparison, he's quite a lot more able than some of them […]. He's about to do Maths A Level next year and his Maths tutor, who he absolutely loves, is autistic […]. And I think Peter sees all this as positive. So…, Peter has got some good role models […]. (Transcript 5, lines 978-992)

This opportunity to interact with positive role models with autism, also appeared to have supported Peter to maintain positive ambitions for his future (Transcript 5, lines 4-22; 62-67).

Stephen also has experience of other people with autism, as his father has an Asperger syndrome diagnosis. Stephen's mother explained how she made the decision to tell him:

> … it felt like the right time. I sort of had to […] because Stephen's behaviour had gone a little bit off the scales […]. We actually printed something off the internet and gave it to him to have a look. I think that's what might have prompted us to do it, that we found something we felt was right (Transcript 4, lines 139-154)

Stephen's mother also explained that he immediately made a connection with his father's diagnosis and appeared pleased to share the same diagnosis. However, this was a worry for her, as Stephen's father has also experienced mental health needs and she worried that Stephen might make negative associations due to this:

> I think he kind of knew. It's like, you know, he likes second-guessing […] "No, oh yes! I've got Asperger's! I'm like Dad! I've got what Dad's got!" That kind of helped, but at the same time, because John has had a, had a breakdown ... (Transcript 4, lines 224-732)

His mother came back to this later in the interview to explain:

> … and he's got the mental health needs, *his dad. Stephen knows that... He did once say: "Am I going to be like Dad?" [I said:] "No, not like him because it's a completely different situation. Your dad had no support." (Transcript 4, lines 751-755)

Stephen’s views of the diagnosis appeared to be mixed. When he had positive experiences, he could be positive about the diagnosis. However, at difficult times, he linked these difficulties to the diagnosis:

> He talks about being autistic, but often it's quite angrily. If I'm honest, it's, like, when things aren't going right: “Oh, that's because I'm autistic” […]. And he has said he doesn't want to have Asperger's sometimes. But then, […] we told him […], he could be very bright. And so that’s when he's saying: “That's my Aspie brain!” (Transcript 4, lines 839-849)

Stephen also accessed some support for his emotional and social development. Through a social group, he had met some people with autism and his mother felt this had a positive impact on his understanding:

> But then he met […] other children in the class and said: Oh yeah, they're like me and they're really nice. And I said: “[…] you're really nice, you know?” And then also we did an emotional regulation group [...] and he met […] three of the boys on it were from his school. So, I think he's like: “Yeah, they're quite cool actually, aren't they?’” (Transcript 4, lines 939-950)

Although Stephen was beginning to make some positive associations with traits related to his diagnosis, he remained concerned about other people knowing about his diagnosis. His mother had therefore respected this wish and had not told her mother or other family members at the time of the interview:

> I've not told her [Stephen’s grandmother] and my sister as well. I think, to be honest, I mean, they know… Stephen's different […] he didn't want anybody to know about him having Aspergers.[…]. Fine with the dyslexia. (Transcript 4, lines 922-929)

This might suggest that he was aware of negative perceptions of autism. Stephen’s mother explains that she continued to focus on discussing his strengths with him and employs opportunities to share positive role models:

> And I showed Stephen the…'Rosie-My Autism and Me' video by that girl. Because that girl is really funny. She's very cool […], but her little brother, he was covered in soap suds. It's quite obviously the other extreme. So, it kind of puts the scale on it. (Transcript 4, lines 224-732)

However, Stephen's mother also felt that autism is difficult to explain. She felt that help from professionals would be useful for Stephen because she was too close and she felt independent support would give him ownership of the diagnosis (Transcript 4, lines 1118-1135).

Other parents also indicated that professional support is insufficient. Robbie's mother explained that, as his diagnosis came early, there was no follow up about supporting understanding of diagnosis. Explanation was left to the family and no guidance was given in relation to this. Robbie's mother explained that she told him about the diagnosis when she felt the time was right. When watching the BBC TV Series: Sherlock, Robbie recognised similar traits in himself, to those that were presented by the Sherlock character. This opportunity was used as an opening point for the discussion of autism. Although she has regularly discussed autism with him, Robbie's mother also felt that she was not always the right person to support him to understand the diagnosis. However, his primary school teaching assistant was very supportive, Robbie's mother provided books about the diagnosis and his teaching assistant would go through the books with Robbie:

> … when they have so many anxieties over different things, it's difficult […]. I don't always think it is as beneficial when coming from the family. I think sometimes it needs to be presented in a way from somebody neutral. (Transcript 3, lines 345-349)

Robbie also had some counselling support, which also facilitated links to be made with his autism diagnosis:

> A little bit from a […] clinical psychologist […] helping him understand his emotions and managing them through a sort of a CBT type approach, but we sort of reflected on the autism aspects throughout that. (Transcript 3, lines 149-155)

Robbie’s mother felt that this work had a positive impact by helping him to understand how to respond to different situations more effectively. Robbie’s learning was identified to be ongoing and to have also been supported through his interactions with peers:

> I think it has helped. And I think it's helped him being in a provision with other young people with the same diagnosis. Because it's helped him see similarities and see that he has things in common with other people of a similar age […]. (Transcript 3, lines 183-196)

Robbie’s mother believed that he had undertaken some research himself, as he had spoken to her about the achievements of other people with autism and other topics that she had not covered with him (Transcript 3, lines 168-170). She also felt that Robbie found interaction with peers with autism useful. When considering how Robbie felt about his future, his mother suggested he was generally positive, perhaps naively so:

> So I think he's […], I don’t think he's worried. I think he thinks it will be sorted: ‘Somebody will help me through this’. (Transcript 3, lines 202-206)

As for parents who shared views via the survey, the future was a source of uncertainty for Robbie’s mother. She was especially concerned about whether he would find the right pathway for his future:

> Because he has so many skills that I don’t feel the education system is set up for. And so I want him to find a pathway for the rest of his life that acknowledges and utilises those strengths. (Transcript 3, lines 317-321)

While Robbie’s mother recognised his many strengths, whether they would be recognised by society so that he could find a career that would enable him to utilise his strengths, remained a concern for her.

Jasmin’s mother has also focussed on ensuring that discussion about the diagnosis focuses upon her strengths. Although Jasmin was at the diagnostic conference, her mother does not feel that she really understood what she was being told:

> … she sat at the table and we discussed it openly […] with the paediatrician. How much of that she actually understood, I’m not sure […]. When we got home […], I asked if she understood this, and there wasn’t really too much that she did understand. (Transcript 6, lines 111-119)

Jasmin’s mother has spent time searching for the right material to support her understanding. She identified some films that she feels have been effective in supporting her understanding:

> Well, I heard about this short […] documentary […] “Meet Saffron: … inside the colourful mind”. And it described a girl, the same age and very similar to my daughter, with the same traits I suppose. And we watched it together and I tried to explain that there are other girls like her[...]. Followed up [with a short presentation]: “Amazing Things Happen” [...]. It talks about how children are all different shapes and sizes… some children think like an Xbox and some children think like a PlayStation. And I still run that analogy through now […]. You’re different, just as clever, you know it’s just that you process things differently. (Transcript 6, lines 26-52)

While she was trying to support Jasmin’s understanding from the point of diagnosis, Jasmin’s mother explained that it was a process that took place over time, as the right resources were identified. Her focus of discussion with Jasmin had been on difference and her strengths were continually discussed and highlighted:

> Because I've read a book quite recently […] called "M for Autism". And it's not just about saying you're kind, but affirmations about the values that you hold and the things that you do as well. (Transcript 6, lines 70-75)

This inspired Jasmin's mother to create a visual presentation to support this, so these positive ideas were regularly reinforced through an accessible format:

> I did actually create a PowerPoint slide about her […]. And I put it beside her bed and it says things like: "I love my family and I like to laugh. I like jumping up and down. I have an amazing imagination, I'm not neuro-typical, I'm autistic. I'm not different but unique. I love facts. I love styling hair. I love routine." […] and we'd just read those together […] just to continually tell her how great she was really […]. (Transcript 6, lines 86-102)

Therefore, while the diagnosis can support the understanding of others and enable appropriate approaches to be identified, awareness of the different ways that it can be experienced by individuals is crucial. This has enabled Jasmin to move forward positively:

> *She's confident, she's caught up on a lot of the work that she has missed, they are now talking about her doing her GCSEs, which was not even on the cards at one point. She has just started learning Spanish.* (Transcript 3, lines 258-263)

Understanding what motivates Jasmin has been important, as this has secured her interest in moving forward positively, as has feeling a sense of belonging. When asked whether the topic of her diagnosis has been discussed with her peers, this was felt to be irrelevant in her current school due to the nature of the provision:

> Because she goes to the school […], which is designed for children with high-functioning autism, Aspergers and anxiety […], it just doesn't because it's just not like a them and us, it's just us. (Transcript 3, lines 412-417)

However, as well as the focus on the positives in relation to the autism diagnosis, as identified by other parents, Jasmin's mother also focussed discussion on supporting her daughter to problem solve difficulties relating to the diagnosis, this was also felt to be crucial:

> We talk a lot about strategies, more so as she getting older, about social strategies and coping with things and things that come up we talk through. (Transcript 6, lines 418-21)

While Jasmin is generally doing well and thinking positively about herself, social interaction was still difficult for her to negotiate. However, it was also very important to her. Therefore, her mother explained that she is constantly aware and watchful, to ensure the support is there for her when needed, which she felt was essential to maintain Jasmin's wellbeing (Transcript 6, lines 462-477).

Michael's father explained similar experiences with his son. He also explained that autism is more likely to arise as a topic of conversation if Michael is experiencing difficulties:

> No, it only comes up if he's struggling with something…, then he'll…, he does tend to blame it on things. If his behaviour is poor, he'll say: "It's because I'm autistic". He kind of uses it as a get out sometimes… I do say to him, although your autistic, you do know the rules, what's right and wrong. […]. Then we'll talk through how he is going to sort that out … (Transcript 7, lines 343-352)

When Michael does discuss problems related to autism, his parents aim to refocus his thinking on how to move forward to resolve the difficulties. Michael's father feels that the way he discussed the diagnosis with him, has an ongoing positive impact on his understanding. Michael was initially shocked when he was told about the diagnosis, however, he was supported to understand it as a difference in thinking rather than as an illness, which was his initial concern:

> I had to word it really carefully, when I first mentioned autism, it was as if I'd given him a terminal illness. He was very upset, and I had to explain it and the only way I could at the time […]. I told him he had a different brain […]. If he meets someone else with needs, he asks if they have a different brain. It's a way he kind of handles and processes it [...]. I think the neurodiversity element of it… is the way he actually sees himself. (Transcript 7, lines 17-33)

This focus on difference, mirrors the approaches described by the parents in the other interviews. Michael's father felt this approach has been successful and has supported his son to process and understand the diagnosis:

> I don't think I'd change anything because I think it went quite well. It seemed to calm him, he wasn't anxious about it, once he had time to process … (Transcript 7, lines 505-508)

Michael's father also identified that although his son is not especially interested in discussing his diagnosis, it did come up in relation to general life experiences. At these times, his son was happy to discuss ideas related to the diagnosis and, in this way, his understanding is being supported. For example, on a visit to a café that had been set up to be autism friendly, Michael discussed elements of the environment that he appreciated and those that were of no importance to him. His awareness of his own autism traits was especially evident in such discussions:

> …café for autistic children in our area. We talked about it then […]. I was saying what about the lights […] they have dim lights and he said: "I like bright lights, so I'm not bothered by that". And he said: "I like the music

> that was playing quite in the background, and they have a sensory area". He begins to talk about his own individual needs that he has. (Transcript 7, lines 357-367)

Michael shows that he is processing his diagnosis and what it means to him in this way. While he was not particularly interested in discussing autism, when he felt there was a useful purpose to the discussion, he was relaxed in discussing it. He also wanted to help other people to understand and was therefore happy to take part in an interview for his father's workplace newsletter (Transcript 7, lines 512-522).

Michael's father explained he focussed on supporting him to recognise and utilise his strengths:

> Again, we always recognise the fact that he is really good with animals so he kind of gets quite proud of himself about those aspects of his life really […], that he can handle pretty much any animal. (Transcript 7, lines 485-492)

Across the parent interviews, they identified supporting their children to understand autism as a difference. They also all spoke about the ways in which they encouraged their child to recognise their strengths. While all the parents discussed that knowing about autism and/or their differences supported their children to understand themselves, they all also highlighted that their children still experienced frustration and difficulties at times, especially in relation to social interaction. At these times, the children often discussed or made association with their autism diagnosis negatively. However, when problems occurred that children related to traits associated with autism, parents encouraged them to focus on strategies to overcome the difficulties that they were experiencing. Overall, a focus on autism as a difference, encouraging children to focus on strengths and problem solving, rather than difficulties, was the key approach that all the parents employed to support their child to understand their diagnosis and to move forward from it positively.

6.10.3 Parent interviews: impact of an autism diagnosis

The key theme that parents discussed when considering the impact of the diagnosis was the improved understanding of others, which could lead to better provision being made. The child's understanding of self was also positively discussed. Unfortunately, after the diagnosis was known by others, ongoing difficulties were still experienced and often related to lack of adjustments and support. Parents discussed an ongoing battle to access support and services for their children. They also discussed worries about their children's futures.

Rosie's mother feit that the diagnosis had mixed impact on her experiences. One positive impact for Rosie was improved professional understanding:

> … when Rosie […] had got her diagnosis […] and I'd said to the teacher, you know, she has autism and she didn't say anything, but her face kind of said it. Like really? […] And a couple of months later she said: "Oh, I've just done training on autism in girls and […]. I can now see it… I wouldn't have realised…but now it's been picked up I can see it. (Transcript 2, lines 629-650)

Rosie also had some support from the class teaching assistant, who also has a child with autism. Her mother felt her understanding had made a big difference to Rosie:

> She's really like helping her and supporting her, but I'm worrying that that's not going to continue, obviously, once Rosie moves up through the school. (Transcript 2, lines 191-194)

Through this support, Rosie was being supported to develop her social and emotional understanding. However, as this support was not organised through any standardised process, her mum felt it was just coincidental and she worried about whether the correct support would be in place in the future:

> … she's doing mind maps about feelings…, not to use hurting hands, how to use helping hands… We're getting books on anger and things like that […]. I think that's where my worry…is…, when Rosie moves up, because she's not gonna have her. (Transcript 2, lines 235-249)

When she has asked staff about an assessment for a formal assessment of Rosie's support needs, she feels that her concerns are brushed aside because Rosie is an able girl with autism:

> They just say: 'Oh, she's academic so she's fine'. […] because I keep saying, yes, but socially she is not. Academically […] she is very bright, but as I'm saying to them, she is still not toilet trained. (Transcript 2, lines 255-265)

Understanding autism in children without intellectual impairment can be problematic for siblings' understandings. Rosie's siblings had continued to struggle to accept the diagnosis. They had not been provided with any support or information from professionals to support their understanding:

> I know it's not really just about Rosie, but her siblings […] They don't get it […] and they will just see Rosie as a spoiled child. Which will cause a lot of meltdowns […] (Transcript 2, lines 397-417)

Even adults within the extended family found it difficult to understand her diagnosis. Rosie's mother felt that it was because she was generally an able girl that understanding was particularly problematic:

> … my mom's a foster carer […]. She specialises in special needs. And she's had some real, like, the other end of the scale… autism. And I think because Rosie's not like that […]. She looks normal. They just can't… accept that. (Transcript 2, lines 462-477)

Being a girl with autism, but without intellectual impairment, was also something that Jasmin's mother felt had impacted the understanding of others. Even after her diagnosis was known, Jasmin continued to experience difficulties at school as peers and school staff struggled to understand her:

> No, the diagnosis didn't help at all. It was quite a small rural school and they were doing quite a lot, all of the time, for the boys […] My daughter was the only girl [...]. They would just go against the things they were supposed to do. So her anxieties then rose and she was struggling [...]. (Transcript 6, lines 185-202)

Jasmin became so anxious that she refused to go to school, and she was eventually excluded. However, after she moved to a small independent school that caters for children with autism, her needs were better understood and met:

> … seven in her class. And the amazing teacher, they really just gave her the confidence and the surroundings to let her be her. The understanding, the kindness and obviously the structure that she needed […]. A whole year on it is like a completely different child. (Transcript 6, lines 247-258)

Both Rosie's and Jasmin's mothers identified a similar lack of understanding about the female presentation of autism.

The interviews with the parents of the boys with autism, who also did not have intellectual impairment, revealed similar experiences. For Stephen, the main positive impact was identified by his mother to be the ability to access support for his mental health, through child and adolescent mental health services (Transcript 4, lines 762-768). The support that Stephen had accessed did not automatically follow his diagnosis though. His mother had been proactive in seeking support and ensuring that it was available for him. This was something that she felt was crucial, to ensure he had strategies in place to support him emotionally, rather than waiting for his mental health to become a problem. Support at school had also not been easy to access. He had accessed some support for his social development through groups at school, however, his mother did not feel this would continue due to financial constraints (Transcript 4, lines 1063-1077)

Stephen’s mother also felt that more support at home, and with regards to peer awareness, was something that would have supported the understanding of family and peers:

> They really need to see them at home […], that's really kind of missing […]. The other thing that I think is really missing is an opportunity where health professionals can come in and talk to the rest of their peers without them being there. It's been really difficult because it would have made things easier. (Transcript 4, lines 1467-1479)

Like Rosie and Jasmin’s parents, she also felt that greater professional understanding was crucial to ensure that children were not allowed to fail:

> … when you're doing teacher training, if they were to sit in on diagnostic procedures, it just would fill in so many gaps […]. Seeing as in education where you fail and you're dealing with a failed child […]. I don’t think there's enough […] training meetings in a schools [...]. (Transcript 4, lines 1509-1521)

Frustration with the system was evident in the interview with Stephen’s mother. This came from concern for her child, who she felt had been let down by the system:

> Because that's what happens. I'm still going into different teachers […]. It's frustrating. I'm critical of the system just because I think […] the child matters […]. (Transcript 4, lines 1869-1875)

Parents appeared to feel that basic autism awareness training was not sufficient. However, when they discussed professionals who had more in-depth knowledge of the range of needs across the autism spectrum, they felt that their children's needs were better understood and met.

Improving others understanding of autism was a positive impact that was hoped for, however, Peter's mother explained it had not improved his siblings understanding.

> I've obviously changed the way I deal with him because I know […] that he can't take lots of information, he needs short, sharp bursts […]. I wish it would change […] my daughter's perception of him […]. She has an understanding I suspect, but it doesn't make her any more tolerant really. (Transcript 5, lines 618-633)

He also benefited from counselling after the diagnosis, however, unfortunately this meant that he missed school lessons:

> And he was doing very well in school […]. As a result of the diagnoses, he was referred to therapy for his animal fears and his food phobias […] and he got on so well with his trainee, psychotherapist. Peter absolutely loved him, and it worked a treat. He did so…so well…[but] he missed Tuesday mornings for months on end (Transcript 5, lines 640-650)

Peter was not provided any support to help him to maintain previous progress with the subject he had missed, which his mother felt impacted his grades (Transcript 5, lines 673-677). His mother felt that this was further compounded because teachers did not appreciate the difficulties that Peter had with organising his own learning or ensuring the transfer of information between school and his parents.

> So, it's just now starting to come out that he has no memory. So, when you ask him to do homework, it gets forgotten. When you ask him to hand in an important piece of paper for trip or something, he forgets to hand it in. (Transcript 5, lines 754-759)

However, at the time of the interview, his mother felt there was a new willingness for the setting to make accommodations for Peter. Overall, Peter's mother felt that the impact of knowing about his diagnosis had been positive. He was positive about his diagnosis and confident about his future. He was planning to move forward with A Levels and was inspired by his tutor with autism towards a career in architecture:

> But I think he feels relaxed in his own skin now, certainly that's how I feel that he is. When I see him with young people, like when I drop him off for his Duke of Edinburgh expedition and I see him messing about […] and I'm thinking, this is Peter! [...] He's come out of his shell. (Transcript 5, lines 893-903)

For Peter, the diagnosis meant he began to access settings with others on the autism spectrum, which provided positive role models for him. He had also had successful experiences through work experience and volunteering. These experiences, and the mental health support, appeared to have enabled him to see himself more positively, his self-efficacy appeared to have improved. His mother certainly feels that he and his family have been able to move forward positively since learning about the diagnosis (Transcript 5, lines 1217-1218).

Robbie's diagnosis has been known since he was four years old. Knowing about the diagnosis was felt to have been helpful for his mother and the immediate family. However, his mother was uncertain about how useful it had been in supporting appropriate understanding at school:

> I think they had some basic training, but it was all very much at surface level. 'Oh yes, we know that they do this, and we know that they might have this.' But actually [in] individual situations they didn't seem to apply that understanding […]. (Transcript 3, lines 122-127)

However, when staff had good understanding of his individual needs, support was better:

> They were better when he had the teaching assistant…Because she really understood not just about autism, but about him. Actually, what were the triggers for him [...]. So, there was a bit more than just that surface level understanding of: 'Oh, yes, I know about ASD!' (Transcript 3, lines 132-141)

While Robbie had been able to access some support for his emotional development through child and adolescent mental health services, his mother highlighted that there was little support for parents about how to deal with the diagnosis and how to move forward positively from it:

> It just didn't feel enough just sending me the leaflets. This is what it is, this is a course you can access […]. I was thinking some sort of counselling maybe would have helped. It was tough initially to try to think positively about how I could move forward. (Transcript 3, lines 120-130)

Lack of support from professionals was also something that was shared as a concern by Michael's father. He had mixed feelings about the impact of the diagnosis in supporting access to appropriate education, adjustments, and services. The diagnosis had made it possible for Michael to access special educational provision, initially at a special school, and later at an autism provision attached to a mainstream school:

> … if he hadn't had the diagnosis, he would not have got into the good school he was at. (Transcript 7, lines 143-145)

The special school was recognised to have been of great benefit for Michael, as the staff understood his needs well. His father explained that even with knowledge of Michael's diagnosis, staff have not always known how to support Michael and were unwilling to implement strategies (Transcript 7, lines 123-135). While access to a special school provision was one of the benefits, Michael's father felt that lack of understanding in education, and lack of support from other professional services, continued to be a problem after the diagnosis was made (Transcript 7, lines 521-528).

6.10.4 Conclusion from the parent interviews

When discussing their children's experiences of coming to understand the diagnosis, the parents all identified that professional support specific to this was not offered. However, some children accessed some professional support that aided their understanding of diagnosis through other interventions. However, parents were the key providers of information about the diagnosis. This is something they appear to be doing well, by consistently encouraging their child to recognise their positive traits. Parents also advocate shifting the child's focus away from their difficulties and towards the strategies that they can employ to overcome them. All the parents also highlighted that engagement with, or learning about, other people with autism, through a range of different opportunities, provided useful support for their children to understand their own diagnoses. This engagement with others with autism happened through interaction at school, via support groups, and through short documentaries about people with autism. In one case, it also happened through discussion of an environment for people with autism. Parents discussed two main ways that this supported understanding: firstly, by supporting their children to understand the many ways that autism might impact an individual; and secondly by providing positive role models of people with autism. They highlighted that this was an important learning experience that supported their children to process what autism might mean for them.

While a lack of professional support specifically to support understanding of the diagnosis was highlighted, parents also indicated that their child had some professional input, via outside agencies, with aspects of their social and emotional development. They highlighted that this was often beneficial in supporting their child to engage with positive self-help strategies. This knowledge of strategies, alongside the child's knowledge of their autism diagnosis and related strengths, appeared to facilitate a developing self-awareness and agency to move forward positively. However, parents did also highlight that their children could still experience problems, especially socially, and this could trigger self-doubts about the autism related differences that they experienced. Parents worried about the impact of these difficulties on their children. Parents also discussed their efforts to pre-empt such difficulties, to avoid a negative impact on their wellbeing. They also discussed their ongoing advocacy to ensure their children were understood and that appropriate adaptations were made for their needs. While parents discussed some positive support, they also discussed their ongoing difficulties in securing the right provisions for their children. While the diagnosis was mostly viewed positively in supporting their children's and others understanding, parents also highlighted that the diagnosis did not automatically mean their child's needs were well understood or appropriately met.

6.11 Discussion of the main findings related to parental perceptions

While research question one for this study sought to explore children's experiences of autism diagnosis, research question two sought to understand parents' (and professionals') views of children's experiences of autism diagnosis. Research question three sought to understand how parents supported CYP to understand an autism diagnosis. Parental views related to research questions two and three are discussed in detail in the section that follows.

6.11.1 Parents' perspectives on children's experiences of autism diagnosis

Before the diagnosis, most parents identified that their child was finding school difficult. Most parents also reported that their child did not have any awareness of autism generally, or in relation to their own circumstances, before being diagnosed. Despite this, as identified by parents in Cadogan's (2015) study, most parents felt their child had a sense of feeling different and this provided a motivation for parents to disclose the diagnosis to them.

Most parents rated their child's social, emotional, and academic experiences negatively prior to the diagnosis. Feeling different has been identified to be problematic for young people with other long-term conditions, and to impact on their wellbeing (Young *et al*., 2004; Lambert and Keogh, 2015). Parents in this study also discussed the negative impact that problematic social experiences had upon their children. As also identified by the parents in Ward's (2014) study, providing an explanation for their child to support their understanding of the social and other difficulties, was a motivation for parents to tell their child about the diagnosis.

Following the autism diagnosis, most parents rated their children's experiences more positively than before it. As identified by Smith *et al*. (2018) and Crane *et al*. (2019), most parents felt their child had a better understanding of self and accepted the diagnosis. Improvements were also seen in the understanding of others and the support the child was able to access, this was especially in relation to support within education. When considering specific aspects of their child's experiences post-diagnosis, as identified in Cadogan's (2015) study, the improvement reported by most parents was that their child's needs were better understood by their family following the diagnosis. Many parents also reported that their child got more help from individual teachers or tutors, and most parents also reported that their child got more general support at school or college. However, parents identified that the diagnosis did not always lead to more support. As also identified in Legg and Tickle's (2019) systematic review of parents' experiences following an autism diagnosis for their child, only a few parents identified gaining access to specialist support following the diagnosis and some parents discussed disappointment due to lack of support.

When considering the direct impact on their children's general wellbeing and identity, most parents felt that their child was accepting of the diagnosis. Parents felt that their children related the diagnosis to a different way of thinking and indicated that their children now understood differences between themselves and peers. As identified in the research of Crane *et al*. (2019), parents appeared to feel that learning about their autism diagnosis was illuminating for their child and had the potential to be empowering. For example, some parents indicated that their child's understanding of the diagnosis enabled them to recognise things that they were good at, which could boost confidence. A similar number also felt that their child was positive about the future and could be successful and happy. Therefore, as identified in the findings of

Cadogen (2015) and Rossello (2015), parents views suggested that knowing about a diagnosis could have palpable positive impacts.

However, not every parent rated their child's perspectives more positively after the diagnosis than before it. The consistent feature in the views of the parents who did not rate their child's experiences more positively after the diagnosis was in relation to their child's lack of engagement with the diagnosis. In this study, some parents indicated their children had no interest in discussing their autism diagnosis. Parents in Cadogan's (2015) study also reported lack of interest in discussing the diagnosis, however, time to think and process the diagnosis was highlighted as part of the process of coming to understand the diagnosis. Therefore, although active engagement might not be seen in relation to discussion of autism, this does not mean that CYP are not processing the information provided.

Some parents also indicated ongoing concerns about lack of understanding by professionals, family members, or peers despite the diagnosis. The invisible nature of autism was highlighted as a potential reason for this. For example, one parent discussed having to continue to fight to get the right support for her son; she had been told that he was 'not disabled enough' for support. (Transcript 5, lines 281-282). Therefore, for these parents, it appeared that the diagnosis was not perceived to have been useful for their child. Crane *et al*. (2016) also identified that following their child's diagnosis, a key dissatisfaction for parents was unsatisfactory support or lack of support for their child. It is therefore understandable that if parents do not feel the diagnosis has supported their child's understanding, and there have not been any changes in the support available for their child, they were unlikely to feel that the diagnosis had been of benefit to them. Furthermore, in this study, just over a quarter of parents indicated that their child felt negatively about their future. The survey by Crane *et al*. (2019) also found that some parents felt their child was worried about their future. Therefore, this is an important element that parents, and professionals, might need to explore with CYP, so that they can identify whether this is a concern they need to address.

6.11.2 How parents support children and young people to understand an autism diagnosis

Parental responses indicated that they were the main providers of information about the autism diagnosis for the child. More than half of the parents indicated that they disclosed the diagnosis as soon as the diagnosis was made and just over a third of parents indicated that their child asking questions was the catalyst for disclosing the diagnosis. This reflects the findings of the larger survey undertaken by Crane *et al.* (2019), which also found that parents were the main providers of information for children about their diagnosis and they mostly told their children straight after the diagnosis. As identified in similar research (Smith *et al*., 2018), some parents also discussed needing time to process the diagnosis themselves, prior to discussing the diagnosis with their child. A few parents indicated that professionals were also involved in helping their child to understand the diagnosis. However, as also identified in the study by Crane *et al*. (2019), most parents did not feel that any useful information had been provided by the specialist who made the diagnosis. More than half of the parents described the diagnostic process as difficult for their child. Previous research has identified that the diagnostic process can be problematic for parents of children with autism, and for people with autism who were diagnosed as adults (Crane *et al.,* 2018; Jones *et al*., 2014). A few parents indicated that the diagnosis was a surprise to the young person at the point at which they were told, however, most parents did not think their child had any suspicions that they had autism before the diagnosis. It is possible that the diagnostic process played a role in preparing some of the young people for the diagnosis. This was specifically identified by parents during the interviews for the children whose diagnosis came later.

Parents' responses suggested that talking about autism was the main approach that most parents use to explain the diagnosis. This was also the identified in Cadogan's (2015) study. However, as identified by Ward's (2014) study, a few parents also explained that they supplemented their explanations with other resources. Not all parents had told their child specifically about the autism diagnosis. When they had not yet disclosed the diagnosis, as identified by the parents in the study of Crane *et al*. (2019), parents identified that their child was not developmentally ready for disclosure. However, a few parents identified that although they had not discussed autism with their child, they were beginning to discuss differences with them. Parents also identified that discussion was ongoing and tailored to be developmentally appropriate for the child, as also identified in the study by Smith-Demers (2018). The importance of individualising the approach in this way has also been identified in previous research that explored parental approaches (Crane *et al*., 2016), and has also been emphasised by professionals (e.g., Fletcher, 2013; Miller, 2015; Rogers *et al.,* 2016). In the qualitative information provided by parents, their responses suggested that explaining an autism diagnosis to their child was something they appeared to be doing well. Parents highlighted the importance of focussing on strengths and consistently encouraging their child to recognise their positive traits. Most parents also indicated that when discussing difficulties related to autism, they focussed upon encouraging their children concentrate on the strategies that they can employ to overcome them, rather than the problem. These positive approaches have also been identified in others' research (e.g., Crane *et al*., 2016; Miller 2015). Furthermore, as highlighted in the research by Seltzer *et al*. (2003) and Woodman *et al*. (2015) creation of a positive home environment through positive praise has been identified to be a key factor in resilience and improved outcomes for children with autism. By focussing their communication with their child on the strengths that they have, which relate to the autism diagnosis, parents are providing a form of positive praise, which links with the resilience boosting positive home environment identified by Woodman *et al*. (2015).

As advised by parents in the study by Smith-Demers (2018), some of the parents in this study identified doing their own research, either to prepare themselves, or to find information for their child. Parents in Smith-Demers (2018) study also advised other parents to prepare themselves with resources to support the disclosure. A few parents in this study discussed specific types of resources, such as information books, books written by people on the spectrum, as well as online sources, such as documentary videos, that were created by people with autism. Parents also all highlighted that engagement with peers and with positive role models with autism provided useful support for their child to understand their own diagnosis, this has also been highlighted to be useful by professionals (e.g., Fletcher, 2013; Miller, 2015). Parents discussed two main ways that engagement with others with autism supported understanding: firstly by supporting their children to understand the many ways that autism might impact an individual, and secondly by providing positive role models of people with autism. As identified in the research by Finnegan, Trimble and Egan (2014, p.85), parents indicated they utilised role models to help their child to recognise that people with autism could be successful.

Only a small number of parents identified that their child had accessed information about autism from online sources, which differs from similar small-scale research undertaken previously (e.g., Cadogan, 2015; Smith-Demers, 2018). However, some parents were unsure whether their child had accessed information in this way, it might be that more children were accessing information in this way but at times when parents are not present. This could be an area of concern, as research by Reichow *et al.* (2012) explored the quality of autism websites and identified that while some websites, such as government websites, were accurate, other websites had greater chance of being inaccurate. They also highlighted that their findings pointed to the importance of provision by professionals of information to ensure accurate understanding. Poor quality websites might also present negative perceptions and experiences, especially if selling non-evidence-based products. If young people are accessing information from inaccurate and/or overly negative sources, this might influence the development of a negative perception.

As identified in the study of parent views by Crane *et al.* (2016), most parents in this study also identified a lack of support, information, and guidance from professionals with the process of supporting their child's understanding of the diagnosis. However, some parents did indicate that their child had input from professionals with aspects of their social and emotional development, this was sometimes from professionals outside of education. They highlighted that this was often beneficial in supporting their child to engage with positive self-help strategies. Parental explanations suggested that knowledge of strategies that were learnt through professional support, alongside the child's knowledge of autism, appeared to facilitate the child's sense of agency, enabling them to move forward positively. The employment of problem-solving approaches, to support their children to move forward from difficulties related to their autism diagnosis, was also described by many parents in this study; this was often focussed on supporting their children's social and emotional understanding. This approach reflects the interaction identified by Todd and Shearn (1997, p.290) between parents and their children with intellectual impairment, whereby parents discussed their 'developmental work' to support their children to understand and address their cognitive and emotional difficulties. Similar views were also identified in the research by Mogensen and Mason (2015). Many of the parents and young people's explanations that were shared for this study, also suggested that some CYP independently adopted a problem-solving approach to improve problematic behaviours that involved monitoring and adjustment. It might also be useful for professionals developing programmes that support children to understand their diagnosis to consider using similar approaches, so that discussion of difficulties can be followed with problem solving approaches.

6.12 Conclusion

Parental views were very similar to those shared by the CYP. As identified by the CYP, most parents identified that their child's post-diagnostic experiences were more positive than their experiences before the diagnosis. Supporting CYP to recognise their strengths linked with autism, as well as encouraging them to develop positive strategies were the key approaches that parents employed to support their child's understanding of the diagnosis. These approaches are like the approaches that parents described in Cadogan's (2015) study. Some parents also highlighted that their children could still experience problems, especially socially, and this could trigger self-doubts about differences that they experienced in relation to their autism diagnosis. Parents worried about the impact of these difficulties and discussed their advocacy to ensure that their child was understood and to ensure that appropriate adaptations made for their needs. As identified by the study of Crane *et al*. (2019), while some parents discussed positive support through services such as CAMHS, their children's schools and voluntary organisations, parents also revealed frustration due to ongoing difficulties in securing the right provisions for their children. Therefore, while the diagnosis was mostly viewed positively in supporting their children's and others' understanding of their needs, parents also highlighted that the diagnosis did not automatically mean their child’s needs were well understood, or appropriately met. Research, such as that by Seltzer *et al*. (2003) and Woodman *et al*. (2015), has highlighted that in addition to positive home environments, inclusive school environments area a key factor in developing resilience and improved outcomes for children with autism. Therefore, in addition to direct support for the child, ensuring professionals’ and peers’ understanding of autism could also be an important consideration to explore when CYP’s self-efficacy is low, or their knowledge of an autism diagnosis is impacting negatively on their views of self.

CHAPTER 7: RESULTS – PROFESSIONALS

7.1 Introduction

The findings from professionals who participated via the online survey and interviews are presented in this chapter. Information regarding participants and the modes by which they shared their views are explained first. Findings from the survey are presented next, followed by the views shared through the interviews. The findings in this chapter aimed to address the following research questions:

- How do parents and professionals view children's experiences of autism diagnosis?
- How do parents and professionals support children and young people to understand an autism diagnosis?

7.2 Overview of professional participants

Professionals were asked to share their views either through the online survey or an interview. Two professionals participated in both the survey and an interview. Although the focus for both was to explore professional involvement and approaches to support CYP's understanding of an autism diagnosis, the survey aimed to gain a brief overview of the type of provision being offered, while the interviews aimed to gain a deeper insight into the specific approaches that professionals used.

Table 51 Professional participants: online survey and interviews

Method of Participation	n=	Professional Role	Number of young people supported	Age range supported	Area of workplace
Survey	9	Specialist Teacher = 4 Specialist support Practitioner = 2 Social Worker=1 Home Link Worker=2	Less than 5=3 5-10=3 20 plus=3	0-5 = 6 5-10 =7 11-5 = 6 16-18 = 7 18+ = 6	Yorkshire =3 East of England=1 South East=3 Wales=2
Interviews	5	Specialist teacher x 3 2x Female 1 male Highly Specialist Speech & Language Therapist X1 (Female) Independent Autism Consultant X1 (Male)	250 plus	2x 0-18 yrs 1 x 5-18 years 1 x Early years-11years	Yorkshire x1 South East x2 East of England x1 Ireland x1

As shown in Table 51 above, participation in the professionals’ online survey was low. However, using the lower range that professionals identified, the approximate number of children that the survey participants had supported to understand their diagnosis was over one hundred children in the preceding year.

Table 52 below summarises the participant details and shows that most of the professional participants (n=5) were from local authority specialist teacher services. The specialist teachers identified key elements of their roles to include provision of advice and support for educators and parents; training for professionals and for parents; diagnostic work; as well as provision of interventions for young people. Some of the specialist teachers also identified providing some specific interventions and approaches for young people, these included Theraplay (Booth and Jernberg, 2010); nurture groups (Bennathan and Boxall, 2000); peer support; peer awareness raising and youth work.

Table 52 Online survey: information about professional roles

What is your current role?	Additional information about role	Location	Approximately number children supported to understand an autism diagnosis within the last year	Age range of the young people supported
1. Specialist Teacher (Autism)		Yorkshire	Fewer than 5	0-4 years,5-10 years,16-18 years, Over 18 years
2. Specialist Teacher (Autism)		South East	Fewer than 5	0-4 years,5-10 years,11-15 years,16-18 years
3. Specialist Support Practitioner (Autism)	Academic and practical mentoring for students at ks5.	South East	20 or more	16-18 years, Over 18 years
4. Specialist Teacher (Autism)		Not given	20 or more	0-4 years,5-10 years,11-15 years,16-18 years, Over 18 years
5. Specialist Teacher (Autism)		North East	5-10	5-10 years,11-15 years,16-18 years, Over 18 years
6. Other (please state)	Autism social worker	Wales	20 or more	11-15 years
7. Specialist Support Practitioner (Autism)		Wales	Fewer than 5	0-4 years,5-10 years,11-15 years,16-18 years, Over 18 years
8. Other (please state)	Home school link worker (attendance and behaviour)	South East	5-10	0-4 years,5-10 years
9. Specialist Teacher (Autism)		North East	20 or more	11-18 yrs

The autism social worker and home-school link worker identified a very similar focus for their roles, to that identified by the specialist teachers. Specialist support practitioner roles were focussed within education and were identified to involve academic support and practical mentoring for students.

7.3 The professionals' survey

This section presents the survey results, beginning with information about the way in which the participants work with CYP with autism and the specific support they offer to support CYP to understand the diagnosis. This is followed by professionals' views about the approaches they believe are most effective in supporting CYP to understand the diagnosis, as well as factors they feel can be detrimental. The final sections focus upon how professionals liaise with others in relation the CYP's understanding of their autism diagnosis and their views about service provision.

Professionals' written comments from the survey are included exactly as written by the participants within the appendix. As for CYP and parent participants, where the quotes included in the thesis below are edited for confidentiality purposes, this is shown with an asterisk (*). Ellipsis within square brackets […] show where when a section of a quote has been omitted from the middle of a sentence. Pauses within the participants' spoken contributions within sentences are shown by ellipses …, but without square brackets.

7.3.1 The professional survey: supporting children to understand an autism diagnosis

When providing details of the approaches that the professionals used specifically with CYP, as shown in Table 53 below, most professionals identified using a range of published resources. These resources included: fiction and non-fiction books; biographies and auto-biographies about people with autism; film clips and web-based information. Some participants explained that they use a variety of materials and adapt them to the needs of the individual.

Six professionals created bespoke resources to support children's understanding, however, not all provided details about the nature of the resource. The specific bespoke resources that were described included a 'strengths and difficulties work-book', a slide show presentation that was used with both students and their teachers;

and a resource focussed on five core differences related to autism and how these might impact people differently.

The professionals identified that work focussed on helping children to understand an autism diagnosis involved working with parents and other professionals, as well as directly with the CYP. Professionals explained that they discussed with parents how to share diagnosis and provided literature or programmes to support this. Some professionals indicated that they created specific resources or guidance, which they gave to parents to support them to help their children to understand the diagnosis. Four participants identified that they also provided guidance to other professionals about how to support children's understanding of the diagnosis. For example, as shown in Table 53 below, Participant Five, stated that guidance was provided for both parents and professionals which advised use of a 'difference not deficit model', which employed positive role models and a problem-solving approach.

Table 53 Online survey: information about the specific support professionals offer that helps children understand diagnosis

Participant	The work professionals do that helps young people with autism to understand their diagnosis	Resource professionals use (or advise others to use) to help young people to understand their autism diagnosis	Specific resources & approaches
1	Direct support practitioner to complete interventions such as 'All About Me' Work with parents to enable them to support children's understanding	Film clips; Non-fiction/information books about autism, Fiction texts about autism A published workbook about autism, Websites	NA
2	Discussing with parents how to share diagnosis. 1-1 work with primary age child to explain diagnosis. Providing literature to support understanding.	Non-fiction/information books about autism Autobiographies/biographies about people with autism, Bespoke resource I created	Strengths and difficulties work-book, with info tailored to the individual. Also signposted to talks by Dean Beadle, which helps parents and children to see a more positive side to their diagnosis. He is an inspirational adult with ASD who gives talks locally and wider afield. Not necessarily the most helpful but 'My book of Autism Heroes' parents have found helpful to share with their child.
3	An introduction to autism programme that I have written to help them self-advocate. Training for teachers, both general and student specific ie "he hates flies and wasps and should not sit near an open window"	Film clips, Non-fiction/information books about autism, Websites Bespoke resource I created	I have put together an introduction to autism presentation that I use for students and teachers National Autism Society you tube clips. The series of 4 involving an adult male.
4	Direct work with parents, families and other professionals Write programmes - guidance	Film clips, Non-fiction/information books about autism Fiction texts about autism, Autobiographies/biographies about people with autism, A published workbook about autism Leaflets Websites, Blogs, Social media, Bespoke resource I created	
5	Training for professionals and parents including experience of diagnosis and presentation of it in a positive way. Difference not deficit model consistently promoted and key positive role models highlighted. Explanation of reasons for difficulties alongside strategies to deal with them.	Film clips, Non-fiction/information books about autism Fiction texts about autism Autobiographies/biographies about people with autism A published workbook about autism, Leaflets, Websites Bespoke resource I created	I usually take aspects of a variety of published materials such as I am Special and adapt to the specific needs of the young person. I haven't found a one size fits all as all out YP are different so always take what's useful.
6	Direct work with some individual to explore the core differences of living with autism and how this presents for them and then how people can best support them	Film clips, Non-fiction/information books about autism, A published workbook about autism, Leaflets, Websites, Bespoke resource I created	Autism STAR - 5 core differences and how this presents for the individuals I am Special Peter Vermeulen has proved very useful But I usually pick and mix
7	I support and provide resources for parents/carers to use with their children to support their understanding of autism.	Film clips, Non-fiction/information books about autism, Fiction texts about autism, Autobiographies/biographies about people with autism, Leaflets, Websites	
8	I often find teachers don't get how a child with autism sees the world despite their teaching qualifications	Non-fiction/information books about autism	10 things every child with autism wishes you knew
9	Advice for parents about discussing diagnosis I work directly with young people and create resources to support this	Film clips, Non-fiction/information books about autism, Fiction texts about autism, Autobiographies/biographies about people with autism, Bespoke resource I created	

7.3.2 The professional survey: approaches advised to support CYP's understanding of an autism diagnosis

The main topics advocated by professionals to support CYP to understand the diagnosis included focussing on areas of difference and the child's strengths. As shown in Table 54 below, practical self-help strategies were also identified by professionals as an area of focus. Two professionals identified focussing on the interests of the young person. For example, an analogy related to different processing formats of Apple Macintosh computers, compared to the Windows operating system was used by one professional. Participant Two suggested providing the opportunity for young people to regularly discuss their thoughts with a trusted person, highlighting the importance of ensuring they were no misunderstands, such as thinking they might be medically unwell. This was also highlighted as a potential issue by Participant Three when identifying factors that they felt can negatively impact CYP.

As shown in Table 54 below, professionals' views about factors that influence CYP to understand the diagnosis positively, were very similar to those that parents identified. In addition to the focus on difference rather than deficits, and highlighting individual strengths and successes, positive role models were identified to be useful. Other factors highlighted by professionals included: the importance of getting the timing right for the individual; the importance of the young person's social network; autism awareness within schools and the education system; and positive support from parents. The main factor that professionals agreed might impact individuals negatively, was a lack of understanding by the important others within the environments that CYP access, including at home, within educational settings, and wider society. Other factors highlighted that might impact individuals negatively included late diagnosis and poor explanation by others.

Table 54 Professional views: topics discussed about diagnosis with CYP and positive and negative influences

	Topics	Important factors that support a young person to accept and/or feel positive about their diagnosis	Factors that contribute to an autism diagnosis having a negative impact upon a young person's view of self
1	focus on differences teaching practical strategies can use themselves	Positive links to others with ASC Emphasising difference over difficulty Providing practical strategies & exemplifying ways in which pupil has made progress so pupil can relate to these	Lack of understanding of those surrounding pupil Late diagnosis Focus upon difficulties associated with ASC
2	Strengths and difficulties. Focussing on the scientific angle for a child who was interested in that aspect. How they experience their ASD. How others might experience ASD. Focussing on positive aspects and strengths. That it continues throughout life but making sure they are not scared or misunderstand and think they might be medically unwell. Giving them the opportunity to think/talk things through with a trusted person regularly. Get their views on what they think about their diagnosis. Signposting to further support.	Positive role models Focussing on the individual's positive characteristics and strengths A positive attitude from parents and carers	Negative attitude of those around them. Negative experiences from others regarding their strengths and challenges Being 'abandoned' after diagnosis
3	I explain that autism is a different operating system, like pcs and macs. I refer to fight/flight and explain that we who are autistic have bucket loads of trigger hormone, whereas the others have just a little. I explain that we are logical and systematic, and that the others emotional vagaries are hard for us to understand.	1. It has benefits- dedication, loyalty, completion of tasks, etc 2. Unique. Vive la difference! 3. Others with autism have been hugely successful. I have a famous faces montage on my office wall.	Parents thinking that it limits a child. Poor support causing stigma in schools, leading to bullying. Not properly explaining to a child. One student thought he had a brain tumour and was going to die because no one told him why he was different.
4	No topics entered	That it's a difference not a deficit That others have been successful That is only part of their identity not all of them	Negative delivery Lack of support following diagnosis and looking for information e.g., trawling the internet
5	Four areas of difference and their impact in individual Sex and relationships, Puberty Emotional recognition and regulation Sensory differences Asking for help,	Positive role models Highlight strengths Different not less	negative parental views often voiced when child present feeling misunderstood despite diagnosis adjustments not being made to enable the YP to engage
6	Core differences Sensory differences Being different is ok	Their own level of understanding Parent support Level of anxiety	Society understanding Parent acceptance Individual's understanding
7	Communication and social interactions.	Being accepted in a school environment Autism awareness within schools and the education system Having a social network	Not being heard and considered at school due to lack of autism awareness.
8	I advise others to look at NAS website	Never discuss it in a negative context Play to their strengths Celebrate their successes however small	Adults lack of understanding
9	-Identify the young person's strengths, interests -4 areas of difference and the positive aspects of these traits -Strategies	Timing-diagnosis and disclosure not too late Also, at a time when they are not experiencing any other pressures or mental health needs. Generally, a focus upon positives and possibilities.	The opposite to when it works well- late diagnosis can be problematic but not for all. People around them are also important for positive reassurance so if that isn't provided, it can be problematic.

Professionals were also asked about their access to training specifically related to support for CYP to understand an autism diagnosis, and about their confidence level for providing this support. As shown in Appendix 20 (Results from the professional survey), the availability of training for participants was variable, fewer than half (n=4) accessed training regularly or often. Confidence levels also varied, however, more than half (n=6) felt they were moderately or extremely skilled when undertaking this work.

7.3.3 Professional liaison with others about children’s understanding of diagnosis

Professionals also discussed how they indirectly supported CYP to understand an autism diagnosis through advice for parents who wished to discuss autism with their child. Some professionals identified joint planning with parents and providing them the opportunity to discuss their approach, as well as through provision of parent training. Professionals also identified that written information might be shared, such as reports and general information. Training for other professionals was also identified as an approach that supported information sharing about approaches to understand an autism diagnosis. One professional identified using liaison with settings as an opportunity to encourage awareness raising for peers.

Professionals also provided information on the ways in which they evaluated their work with young people. Most professionals identified that it was evaluated informally through discussion with the young person, their parents or the other professionals involved, such a child’s teacher. Professionals also identified that evaluation was undertaken as part of their wider work with the young person, which was reviewed more formally through the review cycle.

7.3.4 Service provision to support children's understanding of diagnosis

Professionals explained that requests for support with CYP's understanding of an autism diagnosis were mostly made when CYP were experiencing low self-esteem, anxiety, low mood or presenting unusual behaviour. These requests were identified to come from both parents and other professionals, or to be identified as a need through the professional's own assessments, when working with the child for a different purpose.

Professionals also shared their views about factors that might deter young people from engaging with support to understand an autism diagnosis. The child or their parent not being emotionally ready, or not accepting the diagnosis, were the factors identified by most professionals. Three professionals also highlighted not being developmentally or cognitively ready to understand the information about the diagnosis. Recognition by school settings was also identified, although not explained fully, this seems to relate to settings not recognising CYP's need for support and therefore not requesting it. Concerns about emotional wellbeing needs were also identified as a factor that might prevent, or delay, work focussed on discussing autism, however, it was indicated that while work related to wellbeing might be prioritised, support to understand diagnosis would follow when appropriate.

Factors that professionals identified that encouraged young people to engage with strategies focussed on understanding diagnosis related to socially influenced views. For example, whether the needs of the individual were recognised, especially when the CYP was perceived to be academically able. How the CYP viewed the diagnosis was also important, and this was influenced by how positively their peers, parents, and educators viewed autism. Thus, it was highlighted that for CYP to be able to move forward positively after diagnosis, the focus of intervention, training and support should be targeted beyond the individual, to include all of the important people in the environments that they encounter.

7.4 The professionals' interviews

The section that follows presents the findings from the professionals' interviews. The roles of the professionals who were interviewed are explained first. The themes they identified are discussed next, in the order that they related to the professionals' support for CYP to understand an autism diagnosis, that is, from referral to impact. Themes discussed include factors that professionals felt contributed to positive and negative outcomes. Finally, the broader work that professionals engage in that they also felt supports CYP to understand their autism diagnosis was discussed.

7.4.1 The roles of the professionals interviewed

The five professionals interviewed included three advisory teachers for autism, a highly specialist speech and language therapist, and an independent psychologist who identified that he also has an autism spectrum diagnosis. Table 55 below provides an overview of their roles and experience.

Table 55 Overview of professional's roles and experience

Participant	Role & length of service	Age-range of children worked with	Role focus	Training related to autism	Personal connection to autism
Professional One	Advisory teacher 8 years	Early years to post 16	Local authority service Advice/training for schools & other professionals Advice training for parents Interventions for CYP with autism	M.Ed. Autism (children)	No
Professional Two	Independent Psychologist (Over 10 years)	5 to 18 years	Often commissioned by Local authority Diagnostic work and assessments Support following diagnosis Developed a programme to support children post diagnosis for a local authority	PhD (Autism focus) Autism Diagnostic Interview, Revised (ADI-R)	Has an Asperger syndrome diagnosis and a daughter with autism
Professional Three	Advisory teacher & Head of service (10 years)	5 to 16 years	Local authority service Support for children and parents following diagnosis Advice for schools	M.Ed. Autism (children)	No
Professional Four	Advisory Teacher (5 years)	Early years	Local authority service Advice/training for schools & other professionals Advice training for parents Interventions for CYP with autism	MA Enabling Learning (Autism focus)	Has a son with autism
Professional Five	Highly specialist speech and language therapist (12 years)	Early years	Local authority early intervention service Speech and language therapy Diagnostic work Advice and training for parents and professionals	PhD (Autism focus) Autism Diagnostic Interview, Revised (ADI-R)	No

As shown above, the speech and language therapist and psychologist had undertaken additional training related to diagnosing autism, as well as their general qualifications. They therefore had experience of the assessment and diagnosis of children on the autism spectrum in addition to working with them to support their understanding of the diagnosis. The speech and language therapist discussed her work with a post-diagnostic service, which included providing training and support to parents, and educators, for children following an autism diagnosis. The role also involved direct work with the children and occasional involvement pre-diagnosis. In addition to diagnostic work, the psychologist also worked with CYP following their diagnosis and provided training and guidance to their parents and the professionals working with them. The advisory teachers for autism all described their roles as wide-ranging, they worked directly with CYP with a diagnosis of autism, this was mostly focussed on support for their social and emotional development. They also provided training and guidance to the parents of CYP with autism to support their understanding of autism and of strategies to aid their child's development. The advisory teachers also provided advice for educators, related to the needs of specific children, as well as providing general training for educators and other professionals working with CYP with autism.

The interviews were focussed specifically on the work that professionals did that helped to support CYP to understand the diagnosis. As shown in Table 56 below, the main themes professionals discussed also included the wider elements of their roles that did not directly involve CYP, but which they felt had a direct impact on CYP coming to understand an autism diagnosis.

Table 56 Professionals views on helping children and young people to understand an autism diagnosis

When and how do they get involved to support understanding of autism diagnosis?	The approach that professionals identify to support CYP's understanding of diagnosis	Resources used and advised	Factors leading to positive impact	Factors leading to negative impact
How do you get involved? Child struggling and not understanding diagnosis/self Linked to work about social and emotional development Parents or professionals ask for advice or help with disclosure Commissioned by local authority Interdisciplinary and person-centred discussions Regular multi-disciplinary reviews and family contact enable the topic to come-up when needed Parents and educators not sure how to support children's understanding Anxiety about child understanding and reactions Worries about relationships lacking understanding of self **When should it happen:** Parent/ child ready Developmental appropriateness Child asking questions about self Child identifies with others with autism If there is a risk of accidental disclosure Child observed difficulties signal need to discuss diagnosis To support problem solving moving forward	Autism is part of the person Having autism is ok What autism is not Difference/brain difference Individuality is good Neurodiversity Different strengths and difficulties Strengths and interests and where these can lead Positive role models-biographies Developmentally and situationally specific Person-centred Based on formative assessment Individualised approach crucial Holistic Knowing the individual	Bespoke resource or booklet Information or images of people with autism the child shares an interest with Autism Education Trust videos of positive role models Luke Jackson video Welton (2003) Can I Tell You About Aspergers Evans & Lesko (2014) An Aspie's Guide to Living with Personal Management Issues Been There. Done That. Try This! Vermeulen (2013) I am Special Workbook Social stories Scales linked with contextualised examples Attributes cards Session schedule and cue cards Sorting activities Presentation about the child	Positive successful role models with autism Positive focus to move forward from Learning from others' experiences Understanding that ups and down are normal life experiences Combination of things that make the difference Different in each case Work needs to be tailored to the individual. Needs to be developmentally appropriate Professional has to have the ability to personalise it Supporting understanding of self as a good person and positive traits is important Recognise challenges related to autism but also that this is ok Ensuring parents and educators understand how to respond to discussion around disclosure Getting the language and communication right: calm and matter of fact Explanation of autism is tailored to the individual Best practice is built on good relationships, preparation and information from all key people	Problematic diagnostic experiences Unexpected autism diagnosis Diagnosis might not be accepted if parents do not have faith in the process Parents not being supported to understand diagnosis sooner Parents need time to process-readiness Parental support to recognise child strengths Lack of/poor information about autism leading to misunderstanding Training poor quality for professionals Not enough professional understanding of young people's experiences Lack of immediate support post diagnosis Society view of autism as a deficit Lack of understanding about emotions and processing of people with autism

7.4.2 Professional's views: how and when they become involved

The professionals indicated a range of different service remits that led to their involvement with work related to children's understanding of the diagnosis. However, once they were involved, the approaches they identified using to support CYP to understand the diagnosis shared a high degree of similarity.

Professional One, a specialist teacher working with children across the educational age-range and through to further education, indicated that work specifically relating to children's understanding of their autism diagnosis was not usually part of the intended purpose of her role. Despite her role remit, she explained that support to understand autism regularly emerged as a focus of work, often when the child's need was initially identified to relate to their social and emotional development or wellbeing. This was identified to occur most frequently with adolescents. It had also increasingly occurred when working with young adults, since the age range she supported was extended to twenty-five years, in line with the SEND Code of Practice (Department for Education and Department of Health, 2015). Professional One gave the example of a young person who had just received the diagnosis aged twenty-one years:

> … and is really, really quite distraught about it. Really questioning her sense of self; questioning the last so many years and obviously quite angry about the treatment she received. So, I would possibly have more of a therapeutic CBT approach, or we'd be looking at the positives and looking at strategies to help to deal with and live with the difficulties. (Transcript 8, lines 122-132)

Professional Two, an independent psychologist, who also has a diagnosis of autism, explained that he provided a range of services through commissioning from the NHS, local authorities, and other organisations, as well as for individuals and their families. His work involved training, mentoring, counselling but primarily autism diagnostic work. He explained that all his work played a role in supporting CYP to understand their diagnosis:

> … all of my diagnostic work for young people actually incorporates a degree of helping them to come to terms with and understand their diagnosis. And over and above that, families as well, because I see that as an integral part of my diagnostic work. (Transcript 9, lines 25-31)

Professional Three, an advisory teacher, who had retired shortly before the interview was the only advisory teacher to identify that work relating to diagnosis had been a key element of the role. He identified he had worked with over two hundred young people, and this had been a focus for his work because:

> … this is obviously an issue everywhere for children that just didn't know why people were coming in to work with them, why they were being supported, why they had the difficulties, there were parents who didn't know how to go about telling their child and schools as well. There was an anxiety around the whole thing. "How would we explain it?" "How might the child react?" "What effect might that have on their future relationships?" (Transcript 10, lines 41-53)

Professional Four and Professional Five both had roles focussed on early years. They both indicated that their roles did not usually involve work directly with the young person to support their understanding of the diagnosis. However, they felt that their work with parents and other professionals had an impact on the way in which young people were supported to understand their diagnosis, as they provided advice about this to parents and, to a lesser extent, other professionals:

> … most of them were quite young children so I think it was more initially around supporting the parents. With the slightly older children, in primary

> schools, we talked about when was the right time … (Transcript 11, lines 49-56)

Professional Five described similar support and advice for parents but her service also had a social worker who would work directly with the child. Therefore, her role was to identify the need and to coordinate the support (Transcript 12, lines 53-57).

There was general agreement from all five professionals that the right time to tell the child about the diagnosis would vary. However, there was also agreement that the child and their parents should both be at a point of readiness. This was largely identified to rely on the readiness of parents, who were recognised to often require time to process the diagnosis themselves:

> Most of the time with the parents, as they had just been given the diagnosis, they're working on that for themselves trying to understand the diagnosis and understand what's going on … (Transcript 12, lines 56-81)

Professional Two identified that having the opportunity to work with the family, and the child, through the assessment process for the diagnosis was an important way that he could support them be ready. He felt this supported a more positive acceptance:

> … to work with the family leading up to diagnosis and beyond, which is absolutely fantastic, and ideal! Because […], you can invest so much in those kind of processes at the time, but the moment of: 'Yes, your child is on the autism spectrum', You know, it's not such a kind of body blow [for the] family. (Transcript 9, lines 212-220)

The key factor that all five professionals indicated should point to it being the right time to tell the child was when the CYP was beginning to recognise differences between themselves and peers. Professionals also highlighted that it was crucial to young people's wellbeing that they are helped to understand and contextualise such feelings with an understanding of their diagnosis. Professional One explained how this might be differentiated for different phases of development:

> For the early years' youngsters, we celebrate difference and that's just it, we're all different. I think peers generally are becoming... a lot more understanding. I think it's when the youngsters are starting to struggle, and they're not actually sure why themselves […]. I would very strongly feel that the youngster, at the right time, needs to know. I think it can be a relief for them to understand why they are finding things particularly difficult, as long as it's done in a positive way […] youngsters can be quite relieved. (Transcript 8, lines 357-377)

However, Professional Three also identified other specific factors that were important to consider, which might also point to it not being the right time:

> … there's a whole range of issues that are just about the child readiness, when the circumstances arise. If a child's going through a particularly a bad time, we might want to consider leaving it. But I think one of the big issues there though is the possibility of accidental disclosure. That in the meantime the child finding out. I mean, the main criteria that I've got around the child is being able to understand how people are different as well. (Transcript 10, lines 410-423)

Therefore, the 'right time' was seen to relate to the individual's phase of development, as well as their individual circumstances and level of wellbeing. However, the need for this decision to be made on a case-by-case basis was emphasised by all professionals. For some young people, a time when they were feeling negative about themselves might be the wrong time. Yet, for another child, the diagnosis might be the information that they needed to contextualise their experiences, which might have provided a sense of relief and self-awareness.

7.4.3 Professional's views: approaches to explaining autism to young people

The need to individualise for each child was also a key point that professionals agreed upon, when discussing their approaches. They also agreed that encouraging the child to recognise autism as a difference, or a neurodiversity, was important. A focus on the children's strengths and helping them to recognise that their strengths were linked to autism was also identified to be crucial, rather than just focussing on the difficulties experienced. Professionals also highlighted that positive role models were important as they could help children to recognise that people with autism can live rewarding successful lives.

Professional Two gave the following example of how he approached the work:

> I worked on a one-to-one basis […], talking about their autism and how it might have impacted them [...]. I'm not just talking about in a negative way here, you know, the positive outcomes of them being on the autism spectrum. (Transcript 9, lines 72-79)

Professional Four also advises parents to focus on strengths and to draw on positive role models:

> …highlighting all of the things that are actually real strengths for them, and I found that actually telling them about other people, famous people that they can relate to, that also have a diagnosis but have also been successful in their lives. (Transcript 11, lines 196-205)

Professional Three described a comprehensive person-centred approach that was based on formative assessment, to ensure the approach was developmentally and situationally specific. Prior to implementing the approach, he meets with the parent to seek their views on what they think will work well for the child. Parents were included in the session with the child. Time was also spent observing the child and building a relationship with them, to enable the approach to be personalised. Professional Three highlighted the need for professionals to understand autism specific pedagogy, so they have the skills to ensure the key messages are understood. He describes how he focussed his work:

> First of all, preparing the child for the disclosure […] a whole session about themselves and who they are […] done positively […] that they're a good person, so they're aware of their personal traits. Things like whether they're hardworking, quiet, untidy… who they are and reach the conclusion that they're good person, who's loved by the people around them [...]. So we try to list up to 10 attributes of the child related to their personality. And then up to 10 strengths, like working with things and objects, or computers […]. And then looking for a handful of their key autism related challenges and explaining that we all have things that are difficult. So it could [be] playing and joining in with other children. It's also made clear to them that's part of them… It's okay, that other people have strengths and weaknesses. (Transcript 10, lines 580-620)

It was during a second session that the autism diagnosis was explained to the young person. Professional Three explained how he used a clear structure for both himself and the child:

> And to speak very slowly at that point. Being matter of fact, calm and collected, having a script ready so that you know exactly what you're going to say at the moment that the diagnosis is given. Telling the child we found out all these things about you last time and we'd go through some […] The child would have a schedule so they'd know what's coming, a letter A or AS for Asperger's syndrome on the schedule and say: "I'm going to tell you something new and interesting about yourself and it will be okay. This thing called A or AS that you've got…" And I just read that bit off then: "You have autism. It's okay to have autism and I'm going to tell you a bit about that in a minute. But first of all, we're going to talk about some famous people with autism." (Transcript 10, lines 638-675)

Professional Three's approach is highly individualised, with a focus on strengths, individual traits, and links to successful role models.

As can be seen in Appendix 22 (Example of interview transcript and analysis), the professionals had similar views about the type of resources that they found useful. However, there was variation in the specific resources named. All of the professionals agreed that there was no single resource that could be successful for everyone. A resource that three professionals identified was the workbook by Vermeulen (2000; 2013): I am Special. However, none of the professionals interviewed used the whole workbook, but used it as a source of ideas. Professional Three discussed the book as a positive source of information, which was useful to inform development of a bespoke booklet, which he based his sessions with children around. He also identified that it was used as a source of guidance:

> I think that's a point Peter Vermeulen made in his 2013, 'I Am Special'. There is no good telling people with autism that they're okay if their daily lives are not okay. Furthermore, some of them might…attribute everything negative in their life to their diagnosis. So, it's about helping them to see all these positive things, referring them to the booklets in the future, developing the booklet later. (Transcript 10, lines 857-871)

However, Professional One indicated she felt that Vermeulen's (2013) book suggested an overly negative approach, which was too deficit focussed:

> I've bought the new 'I Am Special' resource. When I started looking at that, there was an enormous focus on difficulties, a great long list of things that the youngster would tick to agree that they found difficult. I don't agree that that's a good way to start to work with the young person. I always take aspects of the resources that I feel are going to be personal to that young person; that it's always got the real positive slant. (Transcript 10, lines 166-180)

While there was variation in the resources indicated, resources that could be used to highlight positive traits or role models were highlighted to be the most useful.

7.4.4 Professional’s views: factors influencing a positive understanding of the diagnosis

Positive relationships were a factor that all professionals agreed are important to develop with the young person and all the people who support them. Professional One highlighted the importance of being person-centred when building the relationship with the young person:

> I always think the first thing is that relationship; that real kind of mutual, respectful, positive regard. It’s giving that young person the time. It’s being available when you say you’re going to be available; listening to the young person and then working on what it is that they’re giving to you through their words, or their behaviour, and then unpicking that with them. (Transcript 8, lines 879-888)

Professional Two suggested the importance of the wider relationships to ensure there is a positive environment to best support the child’s progress:

> … getting the child to understand their world and engage with it positively. And getting the family to be able to support them. Because, you know, the work that I do in supporting young people often is…working with the parents…to actually get them to understand more about how their child might perceive the world. It's not just about working with the child. It's more to do with…the family around the child and how they support them. (Transcript 9, lines 489-502)

Focussing on the positives when working with the child was also a strategy agreed by all professionals, this was extended to advice for their parents:

> So, it’s about helping them to see all these positive things. […] giving them opportunities to succeed, emphasising when they’re doing things positively. […] making sure they have plenty of opportunities in their lives to do the things that they enjoy doing and gain pleasure from and that they succeed in. (Transcript 10, lines 867-879)

Professional Three also highlighted the importance of involving the people who will be supporting the child in their main environments: home and school. Prior to working with the child, he met the child's parents and school staff to gain their perspectives and involves them in the sessions related to the diagnosis work. As well as informing the child about the diagnosis, he modelled how to discuss autism with the child for their parents and a key educator:

> … over three one-hour sessions with the child and at least one of their parents there because they needed to carry this on afterwards. So it's like an apprenticeship approach, somebody from the school will be invited to the last session when the child presented with the book […]. Then the booklet is given to the child within the final session and it's read through. School and parents can continue it afterwards. (Transcript 10, lines 121-130 & 150-153)

Building these positive relationships was something that Professional Three highlighted to be essential to his approach, which was working so effectively, as it increased the likelihood that the positive approach would be continued. (Transcript 10, lines 1241-1283).

Professional Five also highlighted the importance of the relationship with the child and their family, along with the professional having the right understanding and interpersonal skills to facilitate this:

> A key person who has a good relationship with the child and the family. It takes time to develop that relationship…and that key person has to demonstrate, good communication skills, good listening skills, basically good interpersonal skills overall. Obviously providing the therapies when needed, based on evidence… They need to be well informed first. It is about giving them information… based on their needs [...]. I guess, it is all about partnership working really…this is where I have seen most improvement and that the child is moving forward. (Transcript 12, lines 516-552)

As shown in Table 56 above, the factors that professionals felt most influenced the child to develop a positive understanding of autism were the approaches that they used and advised others to use. Positive successful role models were highlighted, so that CYP learn from others' experiences, as was the importance of personalisation and ensuring the approach was developmentally appropriate. Drawing on approaches recognised to be good practice by people with autism was also highlighted. This included structure, using visual strategies and simple clear explanations. Supporting the young person to recognise their strengths was a key focus for professionals. However, professionals also emphasised that it was important to recognise challenges related to autism, to reassure young people that challenges were a normal part of life, and to provide them with strategies that will support them to move forward positively.

7.4.5 Professionals' views: factors contributing to a negative view of the diagnosis

It is perhaps unsurprising that factors that professionals felt might impact negatively were the inverse of those that impacted positively. All professionals discussed the potential influence of the views of the people around the young person. When those around the young person viewed autism negatively, professionals felt this could influence young people's acceptance of the diagnosis:

> I think the way it's presented to the child. I think the parental attitude. I think it's those discussions between parents within earshot of the child. Or professionals talking about the child when the child is in the room, with negative connotations; it undoes a lot of the hard work. (Transcript 8, lines 638-646)

Another factor that could impact the views of young people and parents was their diagnostic experiences. Where experiences had been negative, professionals identified that this could impact on their engagement with services, their understanding of autism and their acceptance of it. For example, Professional One identified this to be problematic for a young person she was working with who had just received a late diagnosis:

> Massive anxiety, loss of a sense of self really; anger, real anger and sadness, and disappointment that nobody, nobody spotted her and helped her, when she was younger. "I've got to this age now, and despite all the bullying and despite this and despite that [...]" Some people would say: "Oh, you haven't got autism." She was told she hadn't, historically. I think anger and sadness, and frustration that your life has got so far, and it's been very, very difficult. You probably haven't achieved in the way that you want to achieve and been treated very unfairly by teachers and by peers; and nobody has done anything. (Transcript 8, lines 638-646)

The diagnostic experience can also negatively impact parents' acceptance of the diagnosis and their engagement with services:

> How the diagnosis process was carried out had a huge impact upon how the family progressed and came to understand the diagnosis. The assessment process itself, I heard a lot of stories [from parents] about the negative impact of that diagnostic process. So, whether it was done too quickly. In terms of the type of assessments they used, they would comment that: "They just came out to visit us once, then they saw the child in the clinic, the child was having a bad day and then I came out of there with an autism diagnosis" (Transcript 12, lines 609-633)

As explained by Professional Five, when the parents are not accepting of the diagnosis this was also likely to impact the support for the child:

> First is the impact on the child because they are not receiving as much service […] When they refuse parent training, when they are very angry; those are the very hard to engage parents. When they have invested

> their energy into things like fighting for services […]. When you realise, in terms of the services that you do provide, maybe those services need to be redirected into trying to engage the parents. (Transcript 8, lines 437-457)

The general lack of understanding of autism was also identified to be problematic and a factor that could negatively impact young people’s experiences related to their autism diagnosis. A factor discussed by professionals was the general view of autism as a deficit and the lack of good quality training to support professionals’ understanding.

> I think, actually, some of the training that goes on is actually quite poor […] but what I'm aware of is that the kind of… the understanding of what the children are actually experiencing, how they're perceiving the world… It's actually sometimes a little far off the mark. (Transcript 9, lines 173-185)

The association of autism as a deficit was also identified to be problematic for parental acceptance:

> They're not suddenly dealing with somebody who is disabled or impaired, but somebody who perhaps just has a different way of thinking and perceiving the world to the majority. You know I come across an awful lot where there is this notion of well, the child can't go into denial because that's who they are. Family or one member of the family does and it has an incredibly negative impact on that individual. And then professionals, I think, are put in really difficult situations because professionally they're expected to make a difference, reasonably so, but actually, there may be somebody back at home who perceives this as quite a negative thing and therefore there is that tension. Your support tends to get shifted away from the individual who has had the diagnosis. (Transcript 9, lines 761-790)

Of concern for the professionals was that something must go wrong before support was provided rather than being available to support the wellbeing of parents and young people, immediately following an autism diagnosis. This was something that professionals came back to at the end of the interview, when they were given the opportunity to highlight anything else that they felt was important. Of the four who provided further ideas, all re-emphasised that there was not enough support post diagnosis. Professional Five also highlighted the need for training for interpersonal skills, highlighting how crucial they were to professionals' work with families and young people:

> I think there is the need for professionals to be trained how to deliver the information. So, professionals are not really trained around children and how they might ask questions around that. You might be in a situation where the child asks a question and you do not know what the parent has told them. You might be afraid to say something back, you might need to have a discussion with the family. The child might have told you something in confidence and might not want you to discuss it with the family, you are confused in that situation. (Transcript 12, lines 1129-1144)

Communicating effectively with parents was also recognised to be crucial to avoid misunderstanding and hurt:

> [Professionals] […] need to be really conscious about what they say to parents as they will remember, and you do not know what someone is going to pick up on and remember. […] it is just being more aware about what you say as it will be remembered. Basically, because one psychologist said…, and it is their job to tell you this, but it is the two words that were said, not how you said it […]. So it is just being really aware [...], the thing is about assessment and diagnosis, there is no opportunity to develop a relationship with the family at that point, you have just met them. (Transcript 12, lines 1203-1222)

Relationships were also something that professionals identified to be important when evaluating their work.

7.4.6 Professional evaluation of their work about autism diagnosis, their training, and their confidence

As shown in Table 57 below, the professionals' approaches to evaluation was mostly based on formative assessment that required good interpersonal skills, such as communicating effectively with the child and enabling them to feel sufficiently confident to share their thoughts and feelings with professionals.

> So, trying to assess how much of it they understand as they go along and then listening to their questions and their responses. I mean, I've often picked up that children haven't accepted their diagnosis […], even when they haven't said that directly. It's just things like a child […] would say: "Well, it means I can't socialise as well with other people". And then he would say: "So I've been told." So, then you're thinking, right, you're not recognising this in yourself, are you? (Transcript 12, lines 1323-1340)

Professional One also highlighted their evaluation was formative and relied heavily on their interpersonal skills:

> What the youngster is saying and how they are presenting [...]. We've got all these psychological assessments […] I've kind of moved away from those slightly now, because I tend to go with body language. What they're saying and what they're doing, what they're not doing. I'm looking at behaviour. I'm looking at ability to engage. I'm looking at whether they're getting out of bed and getting into school in the morning or not… everything is very formative […]. It's all coming back to that relationship and knowing that person, and looking for those positive moves, those changes. (Transcript 8, lines 935-969)

None of the professionals had training specifically related to how to explain autism to a child or young person, but as shown in Table 57 below, they all had specific training to understand autism, and approaches that were successful to employ with children with autism. This was the key learning they drew on when supporting children to understand the diagnosis.

> I haven’t had any specific training around it. I had a lot of training around autism strategies and therapies and approaches. Most of it based on my own experience [...]. (Transcript 12, lines 136-144)

Table 57 Professionals’ themes: evaluation of autism diagnosis work, training, and their confidence

How do you evaluate the work around the diagnosis, specifically?	Training for autism disclosure	Confidence with disclosure work
Observing and listening to young person Psychological assessments of self, used but less valuable Child behaviours and communication best guide Formative assessment Formative decisions about when child ready to discharge from support Observing and listening to young person Looking for signs of positive or balanced view of self Relationships and knowing the individual crucial for good formative assessment	No specific training about supporting understanding of diagnosis Taught and self-study. Confident because of personal connection to autism Combination of learning sources National strategy guidance needed. Understanding of disclosure through work with other professionals Lots around autism and approaches to draw from	Complex role makes it difficult to be confident. Individual nature of autism means there is never one approach. Continually learning and listening to individuals to ensure right support. Unexpected questions about diagnosis can shake confidence. Combination of understanding individual with autism and interpersonal skills crucial. Anxious to get it right. Weight of responsibility can cause stress

Professionals revealed a clear awareness about the potential impact of their work relating to supporting CYP’s understanding of the diagnosis. They were, however, able to draw on their training and experiences and felt sufficiently confident to undertake the work as a result. Professional Two and Four were also able to draw on their personal experiences of autism and both highlighted that this made a positive difference to their work. Not becoming over-confident was something that Professionals One and Three highlighted to be important to prevent complacency, due to the potential impact of their work, as Professional Three explained:

> Well, what I felt of it it’s a massive responsibility. You’re telling somebody else’s child and that’s going to be life changing in a lot of cases for the child and the parent. And the anxiety, I think it’s important that you’re anxious about every single case that you were leading it. Because just

> because you did successfully before doesn't change that. I've been fortunate not a lot has gone wrong here, but fortunately it's always been manageable. But there could always be the next case. (Transcript 10, lines 300-314)

Being mindful of the explanations given, what is said and how it is said was recognised as important by all the professional interviewed. All the professionals suggested that learning about their diagnosis was important for young people and was something they could move forward positively from. Professional Three also felt it was important to re-affirm that it helped children make sense of their experiences:

> Another thing, that can influence how a child responds, is they are aware of their difficulties beforehand [...]. It's important to ascertain beforehand exactly what the child knows about themselves including their awareness of their differences and challenges […]. If they don't know, people need to start labelling those for them in the context of everyday life, so that they can come along with that and they don't have to get into denying and saying, no, that's not the case… not accepting the diagnosis or finding it difficult to talk about. (Transcript 10, lines 1604-1650)

The idea of autism as an absent presence was emphasised to be important before children knew about the diagnosis, as they would be questioning the differences between themselves and peers. While this might be worrying for the young person, when there is no recognition of their differences, the impact of the diagnosis and acceptance of it was suggested to be potentially more problematic.

Finally, the general lack of support and guidance was something that professionals felt would impact the ability of parents and young people to move forward positively after an autism diagnosis:

> I don't think there is enough, in particular for parents, or young people. I cannot think of anything specific unless something goes wrong, so they then get referred to somebody else […]. It isn't there immediately, which

> hadn't occurred to me really until today… Oh my goodness, it is a real shame! (Transcript 11, lines 288-299)

It was also for this reason that Professional One concluded by highlighting that what was really needed was a guidance document to support professionals with the work they undertake related to helping CYP to understand their diagnosis.

7.5 Discussion of the main findings related to professional perceptions

This section explores how the findings from professionals' views address the research questions about what might impact CYP's understanding of, and response to, an autism diagnosis, and the most useful approaches to support CYP to understand their autism diagnosis and to move forward positively from it.

7.5.1 Professionals' perspectives on children's experiences of autism diagnosis

Clinical guidance is clear that professionals have a key role in both making the diagnosis and communicating the diagnosis to children and their parents (NICE [GC128], 2011b: p.6; sec: 1.1.6). The information provided by professionals for this study reflected the findings from the parent and child participants, as well as previous research relating to professional views, professionals felt that learning about an autism diagnosis was important for CYP and their parents, as it helped them to make sense of their experiences (Nissenbaum, Tollefson and Reese, 2002; Jacobs *et al*., 2018; 2019). However, as also identified by Rogers *et al*. (2016), professionals highlighted problems related to diagnostic processes, which they felt made the diagnosis problematic for CYP and their parents, the main concerns were long waits for assessment and delayed diagnosis. Of concern for some professionals was that not enough support was available for children and their parents following a diagnosis, this has also been identified in wider literature (e.g., Rogers *et al*. 2016; Crane *et al*., 2018). Some professionals voiced the concern that something must go wrong before professional support can be accessed. The issue of care being compromised by shortage of trained staff, and of insufficient services to refer to, has also been highlighted in similar research that explored professional views (e.g., Finke, Drager and Ash, 2010; Rogers *et al*., 2016; Jacobs *et al*. 2019). Readiness for diagnosis was also identified as a crucial factor that might impact diagnostic experiences for CYP and their parents, for example, children being developmentally ready to learn about the diagnosis, and emotionally ready, were highlighted to be especially important by Fletcher (2013) and Miller (2015) for both children and their parents.

Professionals indicated that requests for support, to help CYP with understanding of an autism diagnosis, were most likely to come from parents and other professionals, when children were experiencing low self-esteem, anxiety, low mood or presenting unusual behaviours. The previous literature identified that parental recognition of such issues was a crucial trigger for professional concern (e.g., Finke, Drager and Ash, 2010; Jacobs *et al*., 2018; 2019). Most of the professionals who participated in the survey and interviews also identified that the work they undertook, which was focussed on helping children to understand an autism diagnosis, involved working with parents and other professionals, as well as directly with the child or young person; this approach has also been identified within earlier research (e.g., Nissenbaum, Tollefson and Reese, 2002; Fletcher, 2013; Miller, 2015). Some professionals identified that providing direct support for parents to help them to understand how to share the diagnosis with their child, was an important element of their role (Fletcher, 2013; Miller, 2015). However, most professionals indicated that the main way they supported parents was by providing guidance and by signposting parents to appropriate literature, this reflects the findings of other research that explored professionals' views (e.g., Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008; Finke, Drager and Ash, 2010). As advocated by Fletcher (2013) and Miller (2015), a few professionals in this study indicated that they created bespoke resources, or guidance, for parents to support them to help their child to understand the diagnosis. Guidance was also sometimes provided for other professionals about talking to children about an autism diagnosis.

The quality of children's diagnostic experiences might, however, be variable, professionals who contributed to this research mostly identified they were confident when discussing autism with children and young people, however, levels of confidence varied. As identified by previous studies, professionals identified lack of training related to how to share diagnosis, as well as a general lack of continuing professional development opportunities (e.g., Nissenbaum, Tollefson and Reese, 2002; Finke et al., 2010; Rogers *et al*., 2016; Crane *et al.*, 2018).

The main factor that professionals agreed that might influence a negative repose to an autism diagnosis was a lack of understanding by the important others within CYP's environment. Professionals identified that children might experience this lack of understanding at home and within educational settings. Late diagnosis and poor explanation by others were also factors that professionals felt might impact CYP negatively. Professionals identified the main factors that might deter young people from engaging with support to understand an autism diagnosis to be the child or their parent not being emotionally ready. As identified by Fletcher (2013) and Miller (2015), the 'right time' was seen to relate to the individual's phase of development, as well as their individual circumstances, and their level of wellbeing. However, some professionals identified that, if there was a concern about the CYP's or their parents' readiness for the autism diagnosis to be discussed, they would still support the child by focussing on understanding of individual differences. Professionals also identified the importance of liaising with parents and knowing the individual, because the right time for one individual, might be the wrong time for another.

7.5.2 How professionals support children and young people to understand an autism diagnosis

When preparing to work with CYP to understand an autism diagnosis, professionals identified the importance of following a person-centred approach with CYP and their parents, based on formative assessment, to ensure the approach was developmentally and situationally specific. Building positive relationships with the young person and all the people who care for them was highlighted to be important by all the professionals. The three most important factors that professionals highlighted that were important to achieving the most positive outcomes, when supporting children to understand the diagnosis, included the use of a strengths-based focus, drawing on positive role models, and the use of a problem-solving approach when exploring challenges that young people experience. Professionals also identified the use of published resources to support the understanding of CYP. The resources employed different formats, including fiction and non-fiction books; biographies and auto-biographies about people with autism; film clips and web-based information. As also identified by parents, the resource books and film clips professionals identified were often focussed in providing positive role models for the child. These approaches mirror those suggested by the parents in this study, and from previous studies exploring the views of parents (e.g. Smith-Demers, 2018; Crane *et al*., 2019) and professionals (e.g. Fletcher, 2013; Miller, 2015).

Professionals also highlighted that it was crucial to young people's wellbeing that they were helped to understand and contextualise their feelings about the diagnosis. As also highlighted by Jacobs *et al*. (2018) and Miller (2015), professionals emphasised the importance of providing the opportunity for young people to regularly discuss their thoughts about their autism diagnosis with a trusted person, which they identified also helped to ensure they were no misunderstandings about the diagnosis, such as CYP thinking they might be medically unwell. Although professionals highlighted this to be crucial, they also identified the concern that there was insufficient support available for CYP and their parents following an autism diagnosis, unless something goes wrong. This mirrors the concerns raised by parents in this study, many of whom had not received support from professionals, which has also been identified by parents in other studies (e.g., Crane et al., 2019; Finnegan, Trimble and Egan, 2014; Rossello, 2015).

7.6 Conclusion

The information provided by professionals for this study mirrors the findings from the parent and child participants, and that of previous research, indicating that learning about an autism diagnosis was important for CYP, as it helped them to make sense of their experiences (e.g., Nissenbaum, Tollefson and Reese, 2002; Jacobs *et al*., 2018; 2019). Professionals advocated a positive person-centred approach that was developmentally appropriate and tailored to the individual, which emphasised positive traits related to autism and highlighted positive role models, as well as providing guidance to overcome challenges. As identified in other studies, professionals mostly supported parents with the process of disclosure to the child by providing guidance about how and when to disclose, and signposting to useful resources for the CYP and their parents (e.g., Nissenbaum, Tollefson and Reese, 2002; Gray, Msall and Msall, 2008; Finke, Drager and Ash, 2010). Some professionals worked directly with CYP but identified that this support was usually triggered in response to the young person experiencing difficulties, which were often impacting their wellbeing. Professionals were therefore concerned that not enough support is available for children and their parents following a diagnosis, as has been identified in wider literature (e.g., Rogers *et al*. 2016; Crane *et al*., 2018). Therefore, while professionals can play a key role in ensuring that CYP and their parents are appropriately supported to understand autism following the diagnosis, professionals identified a gap between the practice advocated within the clinical guidance (NICE [GC128], 2011b) and the practice they can offer within the constraints of their service remits.

CHAPTER 8: SYNTHESIS OF FINDINGS ACROSS STAKEHOLDERS

8.1 Introduction to the synthesis of findings

After analysis of the findings from each of the individual stakeholder participant groups, the key findings from the surveys and interviews were compared across the key stakeholders and are presented below. The analysis of the qualitative themes from the open survey questions and interviews employed the same process of thematic analysis that was used for each individual stakeholder groups (See Appendix 24: Synthesis of findings across participant groups). The synthesis highlighted a high level of agreement across the three stakeholders: CYP with autism, parents of CYP with autism, and professionals. Despite the professional survey having a slightly different focus, there was a high level of similarity in the views that professionals shared, with those of CYP with autism and parent stakeholders. Professionals and parents were also asked to explain how they helped children and young people with autism to understand their diagnosis, the views they shared were also most closely aligned.

As the online survey for CYP with autism and parents of CYP with autism were very similar, it was possible to directly compare the responses to the scaled survey questions. In each section, these are presented first, followed by the synthesis of the qualitative data from both the open survey questions and the interviews. As the professional survey was qualitative, the themes from the professionals' survey and interviews were synthesised with the qualitative data from CYP's and parents' experiences before diagnosis, when CYP found out about diagnosis, and after the diagnosis. Due to the focus of the professionals' survey and interviews, their perspectives about how they became involved with CYP in relation to the diagnosis were synthesised with themes from CYP's and parents' experiences before the diagnosis. Professionals' perspectives about the work they undertook that supported CYP's understanding of autism were synthesised with the information about CYP's experiences of learning about the diagnosis and parental perspectives of this. In the final section of the synthesis, professional perspectives about the impact of the diagnosis are synthesised with CYP's and parental perspectives of CYP's experiences after the diagnosis.

The synthesis chapter therefore follows the structure of the survey and interviews, with the synthesis of stakeholders' perceptions of CYP's experiences before diagnosis being presented first. Perceptions of CYP's experiences of learning about the autism diagnosis, and how parents and professionals supported this, are presented next. Finally, the impact of knowing the diagnosis and experiences after diagnosis are summarised.

8.2 Synthesis of findings: perceptions of CYP's experiences before diagnosis

As shown below in Table 58, the structure of survey enabled direct comparison of responses from CYP with autism and parents. The statements where most participants agreed or disagreed with the statements are highlighted (Blue = more than 2/3 agree;

Green = more than ½ agree). Statements where there were similar levels of agreement in parent's and children's views are highlighted in yellow.

Table 58 Online Survey: Before diagnosis-CYP's and Parents scaled responses

KEY	Statements about which CYP and parent participants mostly agreed	More than 2/3 agree	More than ½ agree

	CYP Survey Statement	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree	Parent Survey Statement	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree
1	I didn't know anything about autism	4	4	0	1	1	1	0	S/he didn't know anything about autism	20	3	2	0	0	3	2
2	I was confident about my ability	1	2	0	1	1	4	2	S/he was very confident around other children	0	5	1	0	0	8	16
3	I was confident when chatting with class peers	0	3	0	0	1	3	4	S/he was very confident about his/her ability	3	5	4	1	0	8	9
4	I worried about many things	7	0	0	2	0	2	0	S/he worried about many things	14	7	4	0	0	4	1
5	I knew I was different to other young people	5	2	0	1	0	2	1	S/he was always asking why s/he was different to other people	4	4	4	1	1	6	10
6	I didn't have much confidence in myself	5	3	0	2	0	1	0	S/he didn't have much confidence in him/herself	11	6	3	0	1	7	2
7	Everything was fine	0	2	0	1	0	4	4	Everything was fine	0	1	1	0	0	12	16
8	I never worried about anything	0	1	1	0	0	1	8	S/he never worried about anything	1	3	0	0	0	8	18
9	I struggled to get on with other people	5	4	0	0	0	2	0	S/he struggled to get on with other people	14	8	4	2	1	1	0
10	I had no idea that I had autism	6	3	0	2	0	0	0	S/he had no idea s/he had autism	22	3	2	0	0	1	2
11	Nothing ever seemed to work out as I hoped	1	5	3	1	0	1	0	Nothing ever seemed to work out for my child	8	10	3	1	0	6	2
12	I was doing well at school	1	1	2	0	0	3	4	S/he was doing really well at school	1	3	3	2	0	6	15
13	I felt that no-one understood me	5	5	0	0	0	1	0	S/he felt that no-one understood	8	8	6	1	0	4	3
14	I felt 'normal'	0	2	0	3	0	2	4	S/he felt 'normal'	2	3	9	0	0	6	10
15	I was finding school difficult	8	2	1	0	0	0	0	S/he was finding school difficult	16	7	2	0	2	1	2

While there was some variation, responses to the questions about CYP's experiences before the diagnosis showed a good level of general agreement between CYP and parents. There was agreement that most CYP did not have much knowledge of autism before their diagnosis and therefore they also did not suspect that they had autism. There was also agreement that many CYP lacked social confidence and were concerned about their general abilities, which was impacting their social and academic self-efficacy. However, while more than half of the CYP reported that they felt different to peers, more than half of the parents indicated that they did not feel that their child was feeling different to peers, which would suggest that some children might not communicate feelings of difference to their parents. However, as most of the CYP participants and parent participants were not related, the reasons for these differences could have been related to other factors.

As shown in Table 59 below, across the key stakeholders, the qualitative data also reflected agreement in the themes identified about CYP's experiences before their diagnosis. Nine main overarching themes were identified across the participants' responses related to children's experiences before their diagnosis, these were self-efficacy/self-views, identity, social experiences/awareness, school difficulties, autism awareness and support, emotional disequilibrium/mental health needs, appropriate strategies/understanding, the language of deficit/disorder, and accessing professional support.

The synthesis of findings highlighted agreement in the perspectives shared within the qualitative data by CYP with autism, and parents of CYP with autism, that their experiences were less positive before learning about their diagnosis, than after they had learnt about it. As also identified by Huws and Jones (2008; 2015), Baines, (2012), and Jones et al. (2015), the CYP who participated indicated negative perceptions about themselves, using the language related to deficit or disorder in describing themselves.

Table 59 Summary of the synthesis of themes about experiences before diagnosis and triggers for professional involvement

Before diagnosis: Overarching themes across stakeholders	Before diagnosis: CYP's themes	Before diagnosis: parent's themes	Before diagnosis: professionals' themes
Self-efficacy/self-views	Self-efficacy	Ability/Difficulties Self-views Uneven profile	Child struggling and not understanding diagnosis Worries about relationships
Identity	Identity	Identity/Difference Differences to peers apparent but misunderstood and stigmatised Parent and child feeling alienated and problematised	Child lacking understanding of self
Social experiences /awareness	Social difficulties	Ability/Difficulties Social experiences Problematic social and emotional experiences	Involvement linked to work about social and emotional involvement
School difficulties	School difficult	School and general difficulties	NA
Autism awareness and support	Poor awareness: lack of support	Understanding autism Lack of/good professional or family understanding and support	Child not understanding diagnosis
Emotional disequilibrium/ mental health needs	Emotional disequilibrium/mental health needs	Problematic emotional experiences Feelings	Anxiety about child understanding of autism and emotional reactions
Appropriate strategies/ understanding	Appropriate strategies/ understanding		Parents and educators not sure how to support children's understanding
Language of deficit/disorder	language of deficit/disorder	Parents and child problematised Diagnosis	NA
Accessing professional support	NA	Lack of professional support	Parents or professionals ask for advice or help with disclosure Commissioned by local authority Interdisciplinary and person-centred discussions Regular multi-disciplinary reviews and family contact enable the topic to come-up when needed

The qualitative responses from CYP with autism and parents of CYP with autism indicated that CYP were most negative when discussing their experiences and their self-views prior to the diagnosis. For example, CYP indicated feelings of difference, being misunderstood by others, and of struggling at school. Parental responses corresponded with the perceptions of CYP. Before diagnosis most parents identified that their child was finding school difficult and negatively rated their child's social, emotional, and academic experiences. Some parents also discussed having a sense that their child was feeling different. As identified by Cadogan's (2015) study, this influenced some parents to seek an assessment, or to disclose the diagnosis to their child if their child's diagnosis had already been made but their child did not yet know. Professionals also discussed the potential negative impact that late diagnosis or not being told about an autism diagnosis might have on CYP, as they would be questioning the differences between themselves and peers. Professionals felt this might be worrying for the young person, especially when there is no recognition or explanation of differences they were experiencing. Professionals also felt that in these circumstances, the impact of the diagnosis and acceptance of it could be more problematic.

However, as identified by wider research about parental perspectives (e.g., Guinchat, 2012; Ryan and Salisbury, 2012; Crane et al., 2018), some parents also reported raising concerns with teachers and other professionals, such as teachers or general practitioners, but feeling that their concerns were not taken seriously. Some CYP also reflected on the lateness of their diagnosis and lack of understanding of the needs of people with autism, especially females and those without intellectual impairments. Professionals in this study also highlighted concerns about the systems in place related to autism diagnosis, which resulted in long waits for assessment and delayed diagnosis, which they felt made the diagnosis problematic for CYP and their parents, as also identified in the study by Rogers *et al*. (2016). Bourdieu's (1993) perspectives would suggest that, in these circumstances, the parents were powerless due to the powerful positions that educational and medical professionals held within the fields related to assessing and monitoring children's development, and the diagnostic processes and provision. The synthesis of the CYP's and parents' views highlighted awareness of difference, because of the social experiences that CYP had before their diagnosis. Although the autism diagnosis had not been given, as Huws and Jones (2008, p.104) described, autism was an 'absent presence' for CYP and their parents before the diagnosis. Some parents reported feeling that their child was being labelled before their diagnosis and hoped that the results of the assessment would discredit the unofficial labels that had been applied to their child. This corresponded with the experiences and perceptions that were shared by CYP, some of whom discussed feeling that labels had been applied to them before their diagnosis and used negative language such as unintelligent, insane, odd, and different, when describing themselves. Foucault (1977) emphasised the role of both power and social relationships in the construction of identity, as through social experiences and institutional cultures, dominant views are imposed (Holland *et al*., 1998). As identified elsewhere (e.g., Huws and Jones, 2008, Smith and Williams, 2005; Campbell and Berger, 2011), in this study, the views shared by CYP with autism, parents and professionals highlighted that before their diagnosis, CYP's problematic interactions with peers and the social and cultural expectations that they found it difficult to understand, influenced their negative self-perceptions. Furthermore, professionals were critical of the organisational systems within which they worked, which reflected the experiences that CYP and parents described. The synthesis therefore emphasised the ways that the ontological layers, described by Bhaskar (1975), interacted and overlapped to influence the social and diagnostic experiences of CYP, and of parents seeking diagnosis for their child. Professionals also identified that their involvement was usually triggered because CYP were experiencing difficulties. After working with young people who were experiencing difficulties, some professionals also highlighted that it became apparent that the CYP's difficulties were linked with their understanding of themselves, or with the diagnosis when it was known, and that this was impacting their wellbeing.

In summary, the nine main overarching themes identified by the synthesis, relating to the period before the autism diagnosis, revealed that CYP's difficult social and school experiences, was impacted by poor understanding of their needs by peers, their families, and professionals, which meant they experienced lack of understanding and support. The self-perceptions that CYP shared within this study also highlighted the influence of deficit focussed language, which was also identified to be an issue by Whitaker (2006). This impacted on CYP's self-views, which led to poor self-efficacy and a sense of emotional disequilibrium, which had a negative impact on CYP's identity development.

8.3 Synthesis of findings: perceptions of CYP’s experiences of learning about their autism diagnosis

The synthesis of findings related to CYP’s experiences of learning about an autism diagnosis revealed greater variation in the perspectives shared than those related to experiences before and after the diagnosis, as shown below in Table 60. Most CYP and parents agreed that it was parents who told CYP about their autism diagnosis, and most parents did this straight after their child’s diagnosis, this was also identified by Crane *et al*. (2019). More than half of the CYP also reported that a professional had also discussed their diagnosis with them. It is not clear what the nature of this discussion was, as the CYP did not add details within the qualitative section. As advocated by Fletcher (2013) and Miller (2015), some professionals explained that they discussed with parents about how to share diagnosis and provided literature or programmes to support this. However, as identified in other studies (e.g., Nissenbaum, Tollefson and Reese, 2002; Finke et al., 2010; Rogers *et al*., 2016; Crane *et al.*, 2018), some professionals did not feel they had received sufficient training focussed on supporting parents or CYP to understand diagnosis.

The CYP with autism who took part indicated that they had not been provided with helpful general information leaflets. However, some professionals indicated that they created specific resources or guidance, which they gave to parents to support them to help their child understand the diagnosis. While some professionals reported providing this support, more than half of the parents who took part in the survey did not feel that professionals had provided useful information for their child, which has also been identified by parents in other studies (e.g., Crane et al., 2019; Finnegan, Trimble and Egan, 2014; Rossello, 2015).

Table 60 Finding out: CYP’s and parents’ survey scaled responses

KEY	Statements about which CYP and parent participants agreed	More than 2/3 agree	More than ½ agree

CYP Statements: Finding out about my autism diagnosis statements	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree	Parent Statements: Finding out about my autism diagnosis statements	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree
1. My parents told me about my diagnosis	7	2					1	I/we told my child about their diagnosis as soon as it was confirmed	11	7	1	1	2	5	3
2. My parents explained the diagnosis very clearly	2	3	3			1	1	I/we told my child about their diagnosis when they started asking questions	4	7	2	10	2	4	1
3. A doctor or autism specialist told me about my diagnosis	4	3	1			2		Finding out about the diagnosis from the doctor/autism specialist has helped increase his/her confidence	4	3	4	5	1	7	6
4. The doctor or other specialist was able to tell me lots of helpful information	2	2	3	1	1	3		The doctors and other specialists were able to tell him/her lots of helpful information	0	2	2	2	2	15	8
5. Going through the diagnostic process helped me to put my experiences into perspective	3	4	4					Finding out seemed to help him/her to put his/her experiences into perspective	8	9	2	2	2	6	1
6. I was given lots of helpful information leaflets			1	3		4	2	My child was given lots of helpful information by the specialist	0	3	1	2	1	13	10
7. Finding out was a real surprise to me, I didn't realise that anyone thought I had autism	2	3	1	1		3	1	Finding out about the autism diagnosis came as a real surprise to my child	2	3	10	5	0	5	5
8. Finding out has been a very positive experience	5	2	2	1	1	1		Finding out has been a very positive experience for my child	6	7	6	3	3	4	1
9. When I found out, it made me feel like I had been given a label	2	1	2	1	1	3	1	When s/he found out about the diagnosis, s/he felt like s/he had been labelled	1	2	7	4	0	9	7
10. Being told I had autism provided me with what felt was like a fresh start	1	3	2			4	1	Being told s/he had autism provided him/her with what felt like a fresh start	3	7	11	3	1	3	2
11. Finding out about autism was a difficult process, which involved many assessments and meeting	3	3	3			1	1	Finding out about the diagnosis was a difficult process that involved many assessments and meetings	10	7	1	4	1	5	2
12. When they told me, I thought they had got it wrong			4	1	1	3	2	When my child was told about the diagnosis, s/he didn't believe they had autism	2	1	5	6	0	8	8
13. When I found out, I felt that I needed to look for information about autism so I understood what it meant	2	1	2			4	1	NA							
14. I used the internet to research information about autism	2	2	1	1		3	1	When they found out, s/he felt the need to look for information on the internet	0	1	5	8	0	7	9
15. When they told me about the autism diagnosis, I felt empowered	1	3	3	1		2	1	The diagnosis has helped to empower my child, as they were helped to understand the autism and to recognise all their strengths	5	11	2	3	1	7	1
16. I was helped to understand autism and to recognise all the things I'm good at	2	5	1			3		Finding out, helped him/her to understand their experiences and difficulties	6	12	5	2	1	3	1
17. Finding out, helped me to see the evidence about who I am	3	5		2		1		Information about the diagnosis highlighted that there is no such being as the 'normal' person	5	3	8	7	0	5	2
18. All I was told was about the negatives related to autism	1					8	2	My child has only been told about the negative aspects related to autism	1	0	2	3	0	12	12
19. Accessing websites/blogs/tweets created by other people with autism has been really helpful in coming to terms with my diagnosis	2	3	2	2		1	1	Accessing websites/blogs/tweets created by other people with autism has helped my child to understand the diagnosis	1	7	8	8	1	3	2
20. Knowing the facts about autism has really helped me	5	4	1			1		Knowing the facts about autism has really helped her/him	5	9	7	3	0	5	1
21. Reading the information about the diagnosis was like creating a big mental list of things that I struggle with	4	2	3			2		Reading the information about the diagnosis seemed to highlight all the problems related to autism to my child	4	10	8	3	0	3	3
22. It was reading information books about autism that has helped me to understand	3	2	1			4	1	It was reading information books about autism that has helped him/her to understand	2	4	6	2	1	11	4
23. All I was told about the diagnosis was vague, unclear information	1		1			4	5	All s/he was told about the diagnosis was vague, unclear information	2	9	4	4	1	7	3
24. When I was told I had autism, it made me feel highly confused	1	1	3			3	3	Finding out about the diagnosis made my child feel highly confused	0	3	9	3	1	7	7
25. The doctor/autism specialist helped me to understand the autism, to feel confident in myself and to understand there is no such thing as a 'normal' person		3	2	1		4		The doctor/autism specialist helped my child to understand the autism.	0	3	3	4	0	10	10
26. Reading books written by other people with autism has helped me to understand autism more than anything else	4	1				5	1	Reading books written by other people with autism has helped my child to understand the autism	1	9	6	5	1	6	3

The differences between parents' and professionals' views about the support and information provided might relate to the specific roles of the professional participants, as they were all professionals who had a specific role in supporting CYP with autism and their families following their diagnosis. However, in this study, the information from parents of children with autism, was mostly focussed on the support they got from the professionals who were involved in the assessment and diagnosis of their child. Previous studies exploring professionals' perspectives have also tended to focus on their direct involvement in the autism assessment and disclosure during the assessment outcome meeting (e.g., Nissenbaum, Tollefson and Reese, 2002; Jacobs *et al*., 2018; 2019), rather than the support they have provided to support understanding of the diagnosis.

Within the qualitative data from both parents and CYP, some participants identified that children were in the room during discussion of the results of the diagnostic assessment. Where details were given in the qualitative information, the information from parents and CYP mostly indicated that although present, active involvement of the CYP did not appear to have been a key focus of the meeting. This reflects findings of Nissenbaum, Tollefson and Reese (2002, pp. 35-36); although their parental and professional participants had differing views of whether the child should be present when the diagnosis was given, professionals' discussion was only focussed on how they explained to parents and families, explanation to the child was not discussed.

Although more than half of CYP and parents in this study reported that the diagnosis was a difficult process, children mostly reported that finding out was a positive experience because the disclosure enabled them to make sense of their experiences. As identified by professionals in previous studies (e.g., Nissenbaum, Tollefson and Reese, 2002; Jacobs *et al*., 2018; 2019), professionals in this study highlighted the importance of positively focussed discussion of the diagnosis. CYP's and parents' responses reflected the views shared by professionals, as they also mostly indicated that discussions about autism that CYP experienced was positively focussed. This positive focus and hopeful messages were identified to be crucial to support positive understanding, as identified in previous research (e.g., Bartolo, 2002; Brogan and Knussen, 2003; Harnett and Tierney, 2009). Furthermore, most CYP, parents and professionals agreed that knowing about the autism diagnosis enabled CYP to put their experiences into perspective, which had a range of palpable positive outcomes, as also identified across the same participant stakeholders in previous research (e.g., Cadogen, 2015; Rossello, 2015; Smith *et al*., 2018; Crane *et al*., 2019).

Although the diagnosis was identified to be helpful by CYP, they also reported that when reading information about autism, they felt that it focussed their thinking on things that they found difficult. Therefore, even though parents and professionals might focus their discussions positively, CYP and parents of CYP with autism reported mixed perceptions of written information. While some of the CYP and parents reported that information that they read about autism was useful for their understanding, half of the CYP reported that they felt written information about autism presented a negatively focussed perspective. Half of the parents also report that they did not feel that the written information they were provided supported their child's understanding. As the provision of written information is highlighted to be important within the guidance for professionals (NICE,2011b), it is a concern that this was not available for all participants, as also identified in previous research (e.g., Nissenbaum, Tollefson and Reese, 2002; Hennel *et al*., 2016). Furthermore, the concerns shared by CYP about the negative focus of written information, highlights the importance that professionals should also place on ensuring the written guidance that they provide is positively focussed.

As shown in Table 61 below, five overarching themes were identified within the qualitative data about CYP's experiences of finding out about the diagnosis: impact of disclosure, impact factors, how autism is framed, identity, and disclosure resources and strategies.

When discussing the impact of disclosure, CYP with autism and parents of CYP with autism described a range of positive and negative impacts and emotional responses that CYP experienced. A range of emotional impacts has also been identified by other researchers (e.g., Huws and Jones, 2008; 2015; Baines, 2012; Jones *et al*., 2015). Emotional responses included feelings of relief and realisation, as well as shock and dissociation from what they were being told. CYP with autism and parents also described that learning about the diagnosis was a catalyst for positive change for some CYP; the positive changes described included improvements in the understanding of others, improved self-awareness and self-efficacy. A similar impact was identified in the systematic review of Jones *et al*. (2015, pp. 1496-1497), who suggested that for individuals with autism, having an explanation of their own unique behaviours and characteristics supported self-awareness, which is then supported by reflection and comparison with peers with and without autism.

Table 61: Summary of the synthesis of themes about experiences of finding out about an autism diagnosis

Overarching themes	Finding out themes from CYP with autism diagnosis	Finding out themes from parents of CYP with autism diagnosis	Finding out themes from professionals
Identity	Comparison and difference Self-views Levels of acceptance	Varied impact on child's identity Negative emotions/views of self: feeling different, negative peer comparisons, negative impact on self-esteem/self-efficacy Positive emotions/views of self, positive comparison to peers and role models with autism. Improved skills/ self-efficacy fitting in Acceptance over time x13/A	
Impact of disclosure	Range of emotions: relief to dissociation Others understanding Catalyst for change Feeling different and/or inferior Understanding the diagnosis Range of acceptance Coping strategies and self-efficacy	Immediate impact both positive & negative: Varied emotions: Disassociation/disinterest, struggling, realisation & relief Recognition of skills/ Improved self-efficacy/awareness & neg impact on self-views Diagnosis a catalyst for positive change—e.g. engagement with strategies	
Impact factors	Impacted by disclosure processes Lack of understanding of the process Disclosure by professionals and parents Impact of others' reactions to disclosure Process emotionally draining Researching autism	CYPs varied engagement Skills Influence of diagnostic processes Problematic diagnostic processes and child not actively involved General/other support rather than specific to understand diagnosis Parent/child supported by charitable group to understand diagnosis No support for child to understand the diagnosis Lack of time/capacity/involvement from professional to explain diagnosis to child Parental explanation/support for child's understanding of diagnosis	Diagnostic delay How autism is framed Strategies Positive focus on skills Peers & role models
Understanding/ framing autism	Researching the diagnosis Self-study Relief and understanding of self	Framing autism-focus on strengths Research about autism undertaken by child Positive disclosure experience and positively focussed explanation	What autism is/is not Difference/brain difference Individuality/neurodiversity Different strengths and difficulties Strengths and interests and where these can lead Positive role models-biographies
Disclosure resources & strategies	Self-study Comparison to others	Specific resources Being with peers with autism supports understanding	Person-centred: developmentally and situationally specific Holistic Knowing the individual Bespoke resource or booklet Information or images of people with autism the child shares an interest with Videos of positive role models Specific books Social stories Scales linked with contextualised examples Attributes cards Session schedule and cue cards Sorting activities Presentation about the child

As identified in previous research (e.g., Huws and Jones, 2008; 2015; Jones *et al*., 2015; Mongensen and Mason, 2015), the information provided by parents and CYP with autism also highlighted the varied impact that learning about the diagnosis had on CYP's identity and their acceptance of autism as part of their identity. Both CYP and parents discussed the way that CYP's improved understanding of self, led to greater engagement with strategies. Sometimes these were strategies that had been advised by others, however, some CYP demonstrated agency in identifying and engaging with strategies for themselves.

The impact of being told about the diagnosis was not positive for all, some CYP and parents of CYP with autism reported that the learning about the diagnosis had a negative impact upon CYP's self-views and increased their feelings of difference and inferiority, as also identified by previous research (e.g., Huws and Jones, 2008). Both CYP and parents reported that CYP made comparisons between themselves and others. These comparisons were both positive and negative. Negative comparisons led them to feel different and to focus upon the things that peers could do that the CYP with autism found difficult, which had a negative impact on their views of self. Gaffney's (2017) research highlighted that when children experienced the diagnosis in a problem context, they were more likely to view the diagnosis negatively. A similar link was identified in this study in the accounts of both CYP and parents, however, it was when the CYP's view of self, reflected negative self-efficacy that the diagnosis appeared to have the most detrimental impact. Jones *et al*. (2015) identified similar perceptions in their participants' self-narratives, which they identified to change over time. They identified how their participants began to make sense of the diagnosis in relation to self in three key phases: firstly, acknowledging the label, then making links between their unique characteristics and autism, which led to greater self-awareness and to reflection on the implications. A similar pattern of change was identified in this study, it was when CYP were able to recognise their strengths and also to make positive comparisons to peers, especially when they had positive role models with autism to relate to, that CYP's views of self were more positive. CYP whose discussion was focussed more on their abilities and strengths were more likely to be accepting of the diagnosis. As also identified by Jones *et al.* (2015), some participants identified a greater feeling of belonging, as they identified with similar traits in peers and/or role models with autism; thus, for some, the impact of learning about the diagnosis was the re-shaping of their identity in a positive way.

Factors that parents, professionals and CYP discussed that influenced CYP's understanding of the diagnosis included the disclosure processes, especially delayed diagnosis, as identified in previous research (e.g. Rogers *et al*., 2016). CYP's explanations sometimes revealed a lack of understanding of the process. The information that parents and professionals shared suggested that most CYP were not given a full explanation of the assessments that they were undertaking. Therefore, they were mostly unaware that they were being assessed to explore whether they might have autism. Most parents' also shared experiences and feelings that suggested they found the process as emotionally draining for themselves and their child. Nevertheless, even when CYP discussed the diagnostic process as being confusing or difficult, some

CYP still experienced relief when the diagnosis was explained to them, because it helped them to understand themselves. For example, after explaining it was a difficult process, one young person described it as a ‘voyage of discovery’. However, some parents also explained that their child appeared to lack interest in either the process or the diagnosis. The reason for this was unclear within the information provided by participants. Delayed processing for individuals with autism has been identified in research exploring differences in processing of speech (e.g., Prizant, 1982; Jorgensen et al., 2021), visual information (e.g., Harms et al., 2010), and processing of complex information (e.g., Minshew, Goldstein and Siegel, 1997). Therefore, the apparent lack of interest that parents report might reflect these differences in processing information. However, some CYP and parents reported that CYP were not informed about reason for the assessments that they had been undertaking, which might also influence engagement with the process. As identified in previous research (e.g., Jones *et al*., 2015; Rossello, 2015), parents and CYP’s accounts also suggested that for many CYP, coming to understand the diagnosis was a process that took time. Some parents and CYP also reported that that finding out about the diagnosis was difficult for CYP. As also identified as an issue by professionals, most parents reported that no support was offered to their child to understand the diagnosis and they often felt that professionals lacked either the time or the capacity to explain the diagnosis to their child. CYP mostly discussed parents’ explanations of the diagnosis rather than professionals.

Parents' and professionals' perceptions about what they did, or felt, would most positively support CYP's understanding of autism were very similar. The key factor that was identified by both was the way that autism is framed when it is explained to the CYP. As identified by previous studies exploring the views of parents (e.g., Smith-Demers, 2018; Crane *et al*., 2019) and professionals (e.g., Fletcher, 2013; Miller, 2015), in this study, parents and professionals agreed that there should be a focus on the CYP's strengths and skills to help them to make links between these and the autism diagnosis. Both parents and professionals advocated discussing autism as a difference rather than a deficit, and some professionals also advocated the concept of neurodiversity to support the understanding of CYP. This positive focus on difference was also evident in the perspectives of CYP, especially within the positive accounts where CYP's perspectives reflected a positive perspective of autism and greater acceptance of the diagnosis. Tailoring the information for the individual, was highlighted to be important by both parents and professionals. Parents and professionals both also highlighted the positive impact that role models with autism can have, and they returned to this when discussing resources, such as videos by people on the autism spectrum and biographies about them. This linked closely with the views shared by CYP, who explained how they compared themselves with peers, which was linked most closely with positive perceptions when they were discussing positive role models with autism. While professionals and parents sometimes discussed specific resources, as identified in other research (e.g., Smith-Demers, 2018; Crane *et al*., 2019), both parents and professionals discussed tailoring resources for the individual to make sure they were developmentally appropriate. Although, within the responses to the scaled questions, many parents were unsure or felt that their child had not undertaken their own research about the diagnosis, several children reported that they had undertaken their own research; this is reflected in wider research about adolescent health seeking behaviours (Gray *et al*., 2005). Some parents also discussed encouraging their child to make links between their own traits and those of positive role models, which they researched with their child. While some parents had not asked their child whether they had undertaken their own research, some parents felt they might have; for example, if their child had developed knowledge about autism that parents had not shared with them, they felt that it was very likely that their child had conducted their own research. As advised in the literature from professional's perspectives (e.g. Fletcher, 2013; Miller, 2015), some parents also discussed working with CYP to create their own presentation about autism, and how it related to them, as a useful approach to support their CYP's understanding of autism.

8.4 Synthesis of findings: perceptions of CYP's experiences after their autism diagnosis

As shown in Table 62 below, there was agreement from most CYP and their parents that, after the diagnosis, CYP with autism were better understood and got more support at school or college. CYP and parents also reported greater understanding at home. This reflects previous research across the three stakeholders' perspectives, that knowing about the autism diagnosis also improved other peoples' understanding of CYP with autism (e.g., Campbell, 2004; Fernell, Ericksson and Gillberg, 2013; Finnegan, Trimble and Egan, 2014; Crane *et al*., 2019). Most CYP with autism and parents reported that CYP had a greater understanding of themselves and their differences from peers following the diagnosis. Furthermore, as identified by Gordon *et al*. (2015), the perspectives of both parents and CYP highlighted that a positive focus in parental explanations, which explored both strengths and differences related to autism, helped CYP to gain a better understanding of self. This was also reflected in the approaches that professionals in this study, and in previous research, have identified that they used, and advocated, to support the understanding of CYP (e.g., Nissenbaum, Tollefson and Reese, 2002; Fletcher, 2013; Miller, 2015). In addition, half of the CYP identified their differences as positive, and identified that they did not wish to be like everyone else. Professionals who contributed to this study also suggested that diagnostic experiences could impact the views of CYP and their parents, and the outcomes they experienced in relation to their diagnosis. Where experiences had been negative, professionals identified that this could impact on the engagement of parents with services, and their understanding of autism and their acceptance of it.

While most CYP and parents indicated that the diagnosis was not perceived as a label, as also identified in research by Mogensen and Mason (2015), a few CYP and parents did identify this to be a concern. In addition, more than half of the CYP reported that they had doubts about their future potential. Nevertheless, despite these doubts, more than two-thirds of CYP with autism and parents reported that they perceived differences linked to autism as a strength. Therefore, understanding autism as a reason for their differences appeared to facilitate more positive self-perceptions and self-efficacy, especially when positively framed.

Table 62 Online Survey: After diagnosis-CYP's and parents' scaled responses

KEY	Statements about which CYP and parent participants agreed	More than 2/3 agree	More than ½ agree

	After diagnosis statements from the CYP survey	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree	After diagnosis statements from the Parents' survey	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1	I get more support at school/college	4	3	1	1	1	2	1	Gets more support at school/college	17	5	1	1	1	1	2
2	None, it has not made any difference to me	1	1	2	0	0	3	4	Has not changed at all	4	7	3	3	1	9	4
3	I've been able to access support from a specialist to help me to understand what the diagnosis will mean for me	0	3	2	0	0	7	0	Has been able to access support from a specialist to aid understanding of the diagnosis	6	4	4	4	0	8	4
4	Nothing has changed at home	2	3	0	0	1	6	0	Is just the same at home as they were before the diagnosis	8	9	0	0	2	6	5
5	I feel like I've been labelled, and the label becomes a source of attention	1	1	2	0	0	4	3	Feels that they have been labelled	0	4	8	2	1	6	14
6	I notice all the things that I'm good at and I know that my autism is part of what gives me these strengths	3	2	3	0	1	2	0	Is better at noticing all the things that they are good at and know these strengths are part of the autism	3	9	9	2	1	5	2
7	I feel like I have something to blame for my problems	2	4	1	0	1	2	1	Feel that the autism is the cause of all of their problems	1	2	9	2	1	10	4
8	The teachers/tutors give me more help	3	4	0	1	1	2	1	Gets more help from teachers/tutors	14	4	5	1	0	5	1
9	I understand it now, I know why I'm different and why I get so upset	5	6						Understands why they are different from peers	7	14	6	1	1	2	0
10	I get these negative ideas about myself, I sometimes think I'm never going to achieve anything	5	1	2	0	0	3	0	Thinks negatively about their future	3	5	5	3	4	8	5
	NA								Thinks they are never going to achieve anything	2	5	4	2	2	9	6
11	Now I've accepted it, I realise that it is not the end of the world, it is just a different way of thinking	3	4	1	1	1	2	0	Accepts the diagnosis	10	12	2	2	1	2	1
12	I feel like a valuable individual	3	3	2	1	0	2	1	Feels like a valuable individual	4	10	7	2	1	7	0
13	I feel different but in a good way, I don't want to be just like everyone else	3	3	3	0	1	1	0	Understands that they think differently from peers and that this is the reason for many of their strengths	8	9	7	1	1	5	0
14	It has really helped to boost my confidence	1	3	3	0	1	3	1	Has a greater level of confidence	4	10	5	2	1	6	2
15	My family are much more understanding	2	6	1	0	1	2	1	Is better understood by the whole family	9	16	0	1	1	4	0
16	We do not argue as much	1	2	3	1	1	2	2	Has fewer disagreements with other family members	4	8	3	4	1	9	1
17	I feel that I can be a success and I'm happier in myself	3	3	2	0	1	0	2	Feels they can be a success and are happier	4	8	8	1	2	7	1
18	I know that I think differently and that this is the reason for my strengths	4	4	1	0	1	0	1	Has realised they just have a different way of thinking	9	14	4	2	0	1	0

Most CYP reported that they felt they were happier in themselves and felt that they had the potential to be successful, however, this was not the case for all CYP.

Furthermore, most CYP and parents also identified that they felt they had been labelled. The mixed perceptions shared by CYP and their parents, but with more participants identifying a better understanding of self after learning about the autism diagnosis, is also reflective of previous research (e.g. Huws and Jones, 2008; Baines, 2012; Rosello, 2015; Jones *et al*., 2015; Mogensen and Mason, 2015; Rossello, 2015).

Synthesis of the qualitative themes from CYP, parents and professionals identified a greater number of themes than the perceptions they shared when discussing experiences before the diagnosis, and when finding out about the diagnosis. Eleven themes were identified: skills and strategies, understanding/expectations of others, diagnosis as a catalyst for change, self-views (awareness/efficacy/identity); support/training, peers with autism - role models/friendships, whether to tell others, perceptions of autism and emotional understanding and impact. However, only three themes were identified across all three stakeholders, as shown in Table 63 below, these were: skills and strategies, the understanding and expectations of others, and support and training.

As Ward (2014) identified, parents' and children's acceptance and positive perceptions of autism were linked to the way in which parents discussed the diagnosis positively with their child. Parents and professionals also discussed the difficulties that were experienced by CYP; however, this was often linked with reassurance that all individuals experienced both strengths and challenges. Furthermore, parents discussed utilising the occurrence of challenging experiences to support their child's understanding of their diagnosis and the related skills and strategies they might draw on to overcome them.

When discussing their perceptions following the diagnosis, CYP who contributed to this study were often able to make connections between the skills they had, which they were able to relate to their autism diagnosis. Parental explanations also identified similar observations when discussing the impact on their child. CYP with autism and parents also discussed engagement with strategies to overcome factors linked to the diagnosis, such as poor social understanding. This was often linked with the young person's strengths, which they were able draw on to implement strategies.

Therefore, after learning of the diagnosis, the increased understanding of self that most CYP discussed, and that parents described their child experienced, appeared to influence the feeling that they had the capability to influence change, which relates to Bandura's (2001) concept of self-efficacy. When CYP or parents discussed factors linked with self-efficacy, they often linked this with changes in approaches, habits, or behaviours that the young person engaged with after learning about the diagnosis, and the agency that CYP described about doing so also appeared to enhance their wellbeing. Bandura (2006) emphasised that self-efficacy can indeed have such wide-ranging influences, including on behaviours, ambitions, hopes and social engagement (Bandura,2006, p.309). However, a small number CYP, and parents of CYP with autism, also identified that negative self-perceptions persisted or increased after learning about the diagnosis. Negative views of self were sometimes linked with negative perceptions of with autism and related concerns about the potential for stigma.

Table 63 Synthesis of CYP’s, parents’ and professionals’ perspectives: after diagnosis

Overarching themes	Themes from CYP with autism- experiences after diagnosis	Themes from parents of CYP with autism- experiences after diagnosis	Themes from professionals- experiences after diagnosis
Skills and strategies	Poor social understanding overcome by cognitive strategies Awareness of self-help strategies Coping strategies and self-efficacy Use of cognitive ability to improve social understanding Emotional development, self-awareness and self-efficacy Rules and routines as imposed supportive strategies Coordination & Energy: the importance of physical activity	Child’s skills and strategies Parental supportive approaches	Recognise challenges related to autism but also that this is ok
Understanding/expectations of others	Peer awareness enabling strategy implementation Lack of understanding/patience by teachers Having to change to fit in with neuro-typical expectations Peer awareness and acceptance Benefit of sibling understanding Positive relationships Negative impact of conforming	Understanding of others improved Others’ lack of understanding	Not enough professional understanding of young people’s experiences Lack of understanding about emotions and processing of people with autism
Diagnosis as a catalyst for change	Peer awareness enabling strategy implementation Diagnosis as a trigger to improve social knowledge Improved social understanding Diagnosis as a trigger for self-improvement	Diagnosis as a catalyst for change Diagnosis enabled positive change Needs were met more appropriately Positive impact on young person’s skills	
Self-views (awareness/ efficacy/identity)	Improved self-awareness & happier Feeling different Diagnosis is not a problem Positive view of self Diagnosis, difference and inferior Challenge of diagnosis and feelings of uncertainty Uncomfortable acceptance Positive acceptance	Self-views (awareness/ efficacy/identity) Negative impact on young person Identity Acceptance of diagnosis/recognised positively Processing/Disassociation from autism Ambitions	
Support/training	Lack of support Diagnostic conversation with parent Home/family=safe place /understanding School-support without diagnosis Support indispensable Increased support post diagnosis Parental support and advocacy Parental support important -positive understanding	Support became available Mistreatment Parent/own approach to resolve difficulties Still unable to access correct support Family support important	Explanation of autism is tailored to the individual Best practice is built on good relationships, preparation and information from all key people Ensuring parents and educators understand how to respond to discussion around disclosure Approach/factors are individual and developmentally appropriate Professional has to have the ability to personalise it Parental support to recognise child strengths Training poor quality for professionals
Peers with autism - role models/friendships	More comfortable relationships with others of similar need Relationships with others of similar need Comparison to others on spectrum Spectrum relationship supports understanding		Positive successful role models with autism Learning from others’ experiences
Whether to tell others	Disclosure to counter issues with peers Uneasy balance between disclosure and perceptions	Explaining to others/ disclosure	
Perceptions of autism		Autism used as excuse Nature of autism problematic	Lack of/poor information about autism leading to misunderstanding Getting the language and communication right: calm and matter of fact understanding of self as a good person and positive traits is important Positive focus to move forward from Society view of autism as a deficit

Overarching themes	**Themes from CYP with autism- experiences after diagnosis**	**Themes from parents of CYP with autism- experiences after diagnosis**	**Themes from professionals- experiences after diagnosis**
Emotional understanding and impact		Problematic emotions	Understanding that ups and down are normal life experiences Problematic diagnostic experiences Diagnosis not accepted if parents do not have faith in the process Unexpected autism diagnosis Parents need time to process-readiness

Professionals also discussed a general lack of understanding of autism by other professionals to be problematic for CYP, which they felt could negatively impact young people's experiences related to their autism diagnosis. A factor discussed by professionals was the general view of autism as a deficit and the lack of good quality training to support professionals' understanding. Foucault (1977) highlighted the notion of bio-power, which was linked with medical systems such as diagnosis, and suggested that the perceptions communicated by professionals in positions of power, could be influential within discourse and social experiences, as they might be accepted as a reality, and internalised by the individuals concerned. As Davidson and Orsini (2013) have suggested, the dominant constructs that CYP and parents in this this study discussed, which they heard from professionals and others, had the potential to influence either negative or positive perceptions of the diagnosis and their self-views. Within this study, the accounts of CYP with autism and the observations of parents, suggested that the perceptions of autism that CYP develop, can impact their self-identity. The perspectives that they shared also suggested that these views were amassed gradually through interaction with others, from feedback related to these interactions, and the thought processes that had taken place in response to their social experiences. These findings reflected the process of knowing the self, which Foucault

(1977) suggested was shaped through discourse-based knowledge, which is influenced socially through the reality that the individual experiences through discourse and social interactions (Pitsoe and Letseka, 2013).

The impact that knowing about the diagnosis had on the understanding and the expectations of others was also discussed by all three stakeholders. The most positive perspectives that CYP shared were often linked with discussion of improved peer awareness, which some CYP also found to enable their implementation of strategies. Peer awareness of autism has been shown to support peer understanding; for example, research by Campbell *et al.* (2004) showed that providing school children information to raise awareness of autism improved their attitudes towards peers with autism. As Ward's (2014) study highlighted, some CYP were able to access beneficial support from peers once they understood the diagnosis. Furthermore, as Ward (2014) also found, some CYP also benefitted from interactions with peers with autism once they knew of their own diagnosis.

The understanding of other family members and of tutors and teachers was also discussed by both CYP and their parents. As identified in the study by Crane *et al*. (2018), CYP and parents discussed the way that better understanding improved interactions with family members and reduced family stress. Most CYP discussed positive impact, as did many parents. However, as identified by Finnegan, Trimble and Egan (2014), CYP and parents also highlighted an ongoing lack of understanding by teachers and others, and of the ongoing expectation that they should conform. While most parents also highlighted that the understanding of others improved, some parents felt that their child’s educators continued to lack understanding of their child’s needs. Similar views were also shared by professionals, who felt that other professionals lacked understanding of young people’s experiences and emotions. This reflected the experiences that have been shared by professionals in previous research, who raised concerns that there was a lack of access to autism training (Nissenbaum, Tollefson and Reese, 2002; Finke *et al.,* 2010; Rogers *et al*., 2016; Crane *et al*., 2018).

As identified by Crane *et al*. (2019), across the views shared by the three key stakeholders, parents were identified to be the main providers of information about the autism diagnosis for CYP. CYP mostly identified that the diagnostic conversations with their parents were positive and important to their understanding. Parents discussed the ongoing support that they provided for their child to help them to understand their diagnosis. Professionals’ perceptions were mostly focussed on how they supported children’s understanding of the diagnosis; they identified that the best practice was built on good relationships with CYP and their parents, as well as good preparation based on information from all key people involved with the child. This was often linked with a person-centred approach, when working with CYP and their parents, to support CYP’s understanding of the diagnosis, as this enabled support to be personalised and developmentally appropriate. Some professionals’ perspectives also reflected those of parents, as they highlighted that ongoing support from parents that enabled CYP to recognise their strengths was crucial for positive outcomes. As Cadogan’s (2015) study highlighted, some parents in this study had linked their strengths focussed approach with support for their children with the development of problem-solving strategies, such as advanced planning for events and finding alternative access methods. This positive support from parents was also reflected in the views shared by CYP, some of whom explicitly identified that their parents focussed on their strengths linked with autism, and they also discussed their home environment as a safe place where they were understood. In England, the SEND Code of Practice highlights the importance of professionals recognising parents as crucial key advocates for CYP with special educational needs (DfE and Department of Health (DoH), 2015). Some CYP in this study also highlighted their parent as their key advocate, and this was mirrored by parents who discussed having to advocate for their child to help them to resolve difficulties at school.

As entitlement to services, and access to special educational provision, have been identified as key reasons for seeking diagnosis by parents in this study and previous research, they are anticipated as positive impacts that should follow the diagnosis (e.g., Bartolo, 2002; Rogers et al., 2016; Crane et al., 2018; Jacobs et al., 2018). Although some CYP in this study identified that they received support at school before the diagnosis, some CYP in the study also explained that the support they received increased after their diagnosis, and this was the main positive impact they described. Furthermore, some CYP also identified that the increased support that they received was indispensable. Most parents and professionals also indicated that increased support was an important positive impact of the diagnosis. However, some parents highlighted that their child did not receive any support, which has also been identified in wider literature (e.g., Rogers *et al*. 2016; Crane *et al*., 2018). Unfortunately, a small number of parents also felt that their child continued to be mistreated within education due to lack of understanding by professionals, which is perhaps reflective of the lack of access to appropriate training that educational professionals have described (Cooper and Jacobs, 2011). This lack of access to training has been identified by the wider group of professionals who were involved in the diagnostic process in previous studies (e.g., Nissenbaum, Tollefson and Reese, 2002; Finke *et al.,* 2010; Rogers *et al*., 2016; Crane *et al*., 2018). Foucault (1982) highlighted that systems, such as educational and medical systems, and the practices and attitudes that they control, create the cultural spaces of influence within society. The experiences that CYP with autism, and parents of CYP with autism, who took part in this study have described were varied. Nevertheless, they were reflective of the positive or negative cultures they experienced within education settings and/or through the autism diagnostic process, and these culturally influenced experiences affected the perspectives of autism they described.

8.5 Conclusions from the synthesis of findings

The synthesis of views from CYP with autism, parents of CYP with autism and professionals who work with them highlighted the significant impact that the layers of experience can have at each stage during CYP’s diagnostic journey. For example, some parents described how they raised concerns about their child’s development with teachers and other professionals, however, their concerns were not taken seriously because professionals did not recognise the difficulties their child experienced. Furthermore, the synthesis highlighted that the processes of influence on CYP’s perceptions of autism did not always begin at the point of learning about the diagnosis, experiences before the diagnosis are also of significance. Professionals also identified that CYP were most likely to be referred to them for support in relation to their diagnosis when they were experiencing difficulties. Prior to their diagnosis, many of the views shared by CYP with autism, and parents of CYP with autism also suggested that the identities that CYP were constructing for themselves were often influenced by negative interactions and social experiences. CYP with autism and parents made comparisons with peers without autism before diagnosis, these comparisons often emphasised a deficit focus. As Foucault (1977; 1982) suggested, CYP's perceptions were influenced by the language and labels that they had heard generally in their environment, and sometimes to those that were applied to them by others before their diagnosis was known. CYP then applied these labels to themselves in their narratives of their pre-diagnosis experiences. The perceptions that CYP described suggested that before they were told about their diagnosis, they viewed their differences in comparison to peers as problematic. Therefore, as also identified by Gaffney's (2017) study, some CYP and parents in this study also identified that the diagnosis was experienced within a problem context. This was reflective of autism as an 'absent presence' prior to the diagnosis, which was also highlighted in Huws & Jones' (2008) analysis of young people's experiences.

As identified by other researchers (e.g., Huws and Jones, 2008; 2015; Baines, 2012; Jones *et al*., 2015) CYP with autism and parents of CYP with autism described a range of emotional impacts from learning about the diagnosis. Emotional responses ranged from relief to shock, and sometimes reflected dissociation from the diagnosis. However, as also identified by Jones *et al*. (2015), most CYP with autism and parents also described that learning about the diagnosis could be a catalyst for positive change for CYP; the positive changes described included improvements in the understanding of others, improved self-awareness and increased self-efficacy.

Following the autism diagnosis, most participants indicated improved understanding by others, including by peers, which was also identified in the study by Campbell (2004). For those CYP who experienced improved understanding from others, this led to improved social experiences. As identified by previous research (Jones *et al*., 2015; Crane *et al.,* 2019), most CYP and parents also identified that an improved understanding of self often followed on from learning about the diagnosis. Furthermore, as identified by Flammer (2002), this improved understanding of self, appeared to boost CYP's self-efficacy which led to increased agency and to engagement with self-help strategies; a similar impact was also evident in the views shared by CYP in the studies of Cadogen (2015) and Mogensen and Mason (2015).

However, not all CYP with autism who took part experienced the same positive impact from learning about the diagnosis, and few CYP had negative perceptions of the diagnosis and did not accept the diagnosis they had been given. A small number of parents also described a similar impact for their child. Furthermore, the professionals who took part in this study also identified that their involvement was usually triggered because CYP were experiencing difficulties. However, professionals and parents were also able to identify many ways that they had been able to support the CYP and make a positive difference over time. As Davidson and Orsini (2013) suggested, the synthesis of the views shared for this study also highlighted that CYP’s and parents’ positive and negative perceptions of autism were influenced by their experiences within both the education and health systems. Therefore, CYP’s experiences related to their autism diagnosis can disable them through the negative perspectives of autism and the resulting diminished self-view they develop, but they can also enable them when a positive view of autism is advocated and reflected in their social experiences.

CHAPTER 9: DISCUSSION AND CONCLUSIONS

9.1 Introduction

This study is, to my knowledge, the first study to have combined perspectives from the three key stakeholders involved in both the autism diagnosis of children and young people (CYP) and the support they receive to understand that diagnosis. The study has amalgamated the evidence in two ways, firstly by drawing together the existing research evidence from each of the key stakeholders, secondly through analysis of the views of these key stakeholders within the empirical part of this study. This chapter will discuss the key findings and their implications, before considering the limitations of the study and making suggestions for future research. The study concludes by highlighting what these findings suggest for parents and professionals who will support CYP to understand their diagnosis in the future. This chapter will show that by combining views, a more holistic understanding of the factors linked to the research aims has been gained. The research aims were:

- To understand what is currently known about CYP’s experiences of being given an autism diagnosis and how they are supported to understand it.
- To identify factors that might positively influence CYP’s understanding of an autism diagnosis and their view of self.

9.2 Making connections: CYP’s experiences of autism diagnosis

The integrated views of the three key stakeholders, from both elements of this study, have highlighted the way in which their different experiences and involvements with the diagnostic process, and young people’s learning about autism, interact and can influence each other’s experiences and perceptions. The experiences described by CYP with autism, parents of CYP with autism, and professionals who worked with them highlight the complex social influences upon CYP’s understanding of their autism diagnosis. Of particular significance, was the evidence of agreement identified across the key stakeholders suggesting that, for many CYP, being told about the diagnosis can improve both their self-awareness and self-efficacy, which can lead to changes in behaviour associated with improved resilience. However, not all CYP experienced this positive impact, the findings from this study highlighted that negative social experiences and societal views about autism could also be detrimental to outcomes.

Furthermore, this thesis has also drawn together the existing evidence from previous studies, which together represent the views of ninety-one CYP with autism (65 males; 26 females, aged 9-21 years), six-hundred and seventy-five parents (606 mothers; 69 fathers) and over one-hundred and sixty professionals. Although the findings cannot be generalised to the population of CYP across the spectrum of needs, they do highlight consistency of experience, of impact and of approaches, which provide a useful starting point for those planning to support CYP to understand an autism diagnosis.

The rich data shared by the participants in this study, highlighted the significant impact that the layers of experience, which the participants described, had at each stage during CYP's diagnostic journey. For example, as shown in Figure 9 below, parents described how they raised concerns about their child's development with doctors, teachers, and other professionals; however, their concerns were not taken seriously because professionals did not recognise the difficulties their child experienced. Foucault (1977) highlighted the notion of bio-power, linked with the role and power of medical professionals and medical systems, and their impact on medical processes such as diagnosis. Foucault (1977) also highlighted that the perceptions communicated by professionals in positions of power, could be influential within discourse and social experiences, as they might be accepted as a reality, and internalised by the individuals concerned. However, in this study, before diagnosis, the parents, of CYP who were later diagnosed with autism also discussed the conversations that they had with non-medical professionals, such as early years educators and teachers, in which they sometimes felt that their concerns about their child's development was not taken seriously and acted upon by professionals. In these interactions, Bourdieu (1993) would also suggest that parents were powerless, due to the powerful positions that both educational and medical professionals held within the fields related to the diagnostic processes and provision. Bhaskar (1975, pp. 46-47) identified similar influences, which he linked with three ontological layers that interact and overlap to influence social perceptions, the real (structures and systems), the actual (events created by structures and systems), and the empirical (events that can be experienced, described and observed), this study demonstrates the way in which these different layers influence the diagnostic experiences of CYP with autism and their parents.

Figure 9 below highlights key points of interaction between the key stakeholders, which influenced the perceptions, directly and indirectly, that CYP with autism and the parents of children with autism developed in relation to the diagnosis. Bourdieu (1993) suggested that social experiences and institutional pressures interacted to shape the discourses and everyday practices that influence and shape beliefs, values, and predispositions: our habitus. The key experiences highlighted in Figure 9 show the significant impact that these layers of experience can have on CYP and parents of CYP with autism during their diagnostic journeys.

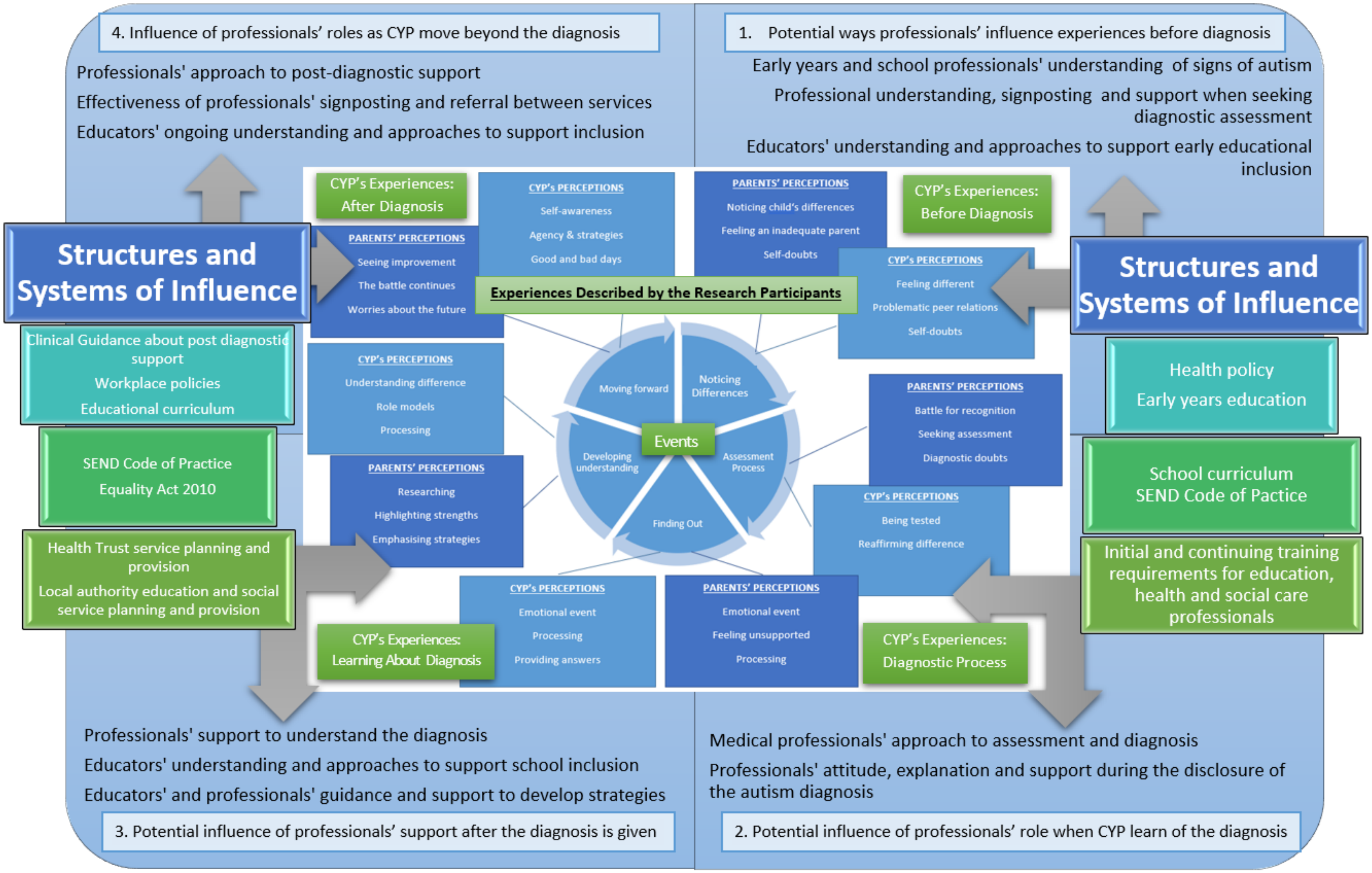


Figure 9 Autism diagnosis: CYP's experiences and the influence of stakeholder interactions

What is striking when exploring the views across the study participants and previous research papers, is the consistency in the perceptions shared across the key stakeholders. As identified by parents in the study by Crane *et al.* (2019), the views of each participant group in this study also suggested that CYP's identity and mental wellbeing can be impacted positively and negatively by experiences related to their autism diagnosis. These findings are supported by the previous research related to CYP with autism (Huws and Jones, 2008); parents of CYP with autism (Cadogan, 2015; Rossello, 2015) and professionals who work with them (Nissenbaum, Tollefson and Reese, 2002; Jacobs *et al*., 2018). As Erikson (1968) proposed, the findings highlight that the sense of identity that CYP with autism develop is amassed gradually through interaction with others, from feedback related to these interactions and the thought processes that take place in response to social experiences. The crucial points of influence, which are identified above, show where professionals can influence parental perceptions and where parents, peers and professionals, can positively or negatively affect CYP's experiences and perceptions of their autism diagnosis. As Foucault (1982) highlighted, systems such as educational and medical systems, and the practices and attitudes that they control, create the cultural spaces of influence within society. The experiences described by CYP with autism and parents of CYP with autism in this study, were reflective of the positive or negative cultures they experienced within education settings and/or through the autism diagnostic process, and these culturally influenced experiences affected the perspectives of autism they described.

Holland *et al.* (1998) suggested that identity is formed by both the individual's view of self and by the perceptions of others. The construction of individual identity has been identified as both a highly complex and highly social process, in which self-efficacy and other self-views shape identity through their definite relationships to others' views (Mishler, 1999). Therefore, as suggested by Davidson and Orsini (2013), because perceptions and discourses are influenced by the structures, events and experiences, negative discourses can disable CYP, through the understanding of autism and the resulting self-view they influence CYP to develop, but they can also enable by advocating a positive view of autism. However, this process of influence does not always begin at the point of learning about the diagnosis, experiences before the diagnosis are also of significance.

9.2.1 Influencing factors: before diagnosis

Before diagnosis, children described feeling different and of struggling to understand their differences. Parents discussed how other people did not understand their child's differences, leading to problematic experiences for CYP, and to parents feeling judged by others because of the developmental differences that their child displayed. The vocabulary that CYP used to describe themselves within the survey (e.g., weird, unintelligent, stupid, and awkward), reflected the deficit focussed language that Whitaker's (2006) study also identified, highlighting the socially influenced self-perceptions that the CYP held. Erikson (1968) suggested that his patients, who had recent disabling injuries due to conflict, experienced an identity crisis because they no longer felt they belonged or had a sense of what the future held for them (Friedman

1999). However, because of their problematic social experiences, the accounts of CYP with autism often depicted a similar crisis before learning about their diagnosis. Verbrugge and Jutte (1994, p. 3) described disablement as the impact of ‘acute conditions’ on the ability to act within society in ‘personally desired ways’. Before diagnosis, the social experiences of CYP with autism led to feelings of difference and corresponding struggles to fit in with peers, which were often linked with feelings that were indicative of low levels of self-efficacy. The problematic social experiences of CYP were also highlighted by the parents within this study and within the literature (Baines, 2012; Huws and Jones, 2008; Jones *et al*., 205). Similar experiences were reported by Bagatell (2007), who suggested that the identities of people with autism are socially influenced and constructed. Prior to their diagnosis, many of the views shared by CYP with autism, and parents of CYP with autism, suggest that the identities they were constructing for themselves at this time were often disabling and influenced by these negative interactions and experiences of the social world. Huws and Jones (2008) used the concept of ‘biographical disruption’ when an autism diagnosis causes a re-appraisal of self. The views of CYP in this study suggested that the negative interactions they experienced before they knew of their diagnosis were also causing ongoing ‘biographical disruption’, as they struggled to understand themselves.

Parents and professionals, who contributed to this study, also agreed that problems related to diagnostic processes were common, which could make the diagnosis problematic for CYP and their parents. The main concerns were long waiting times for assessment and delayed diagnosis. Many CYP had experienced feelings of difference and poor social self-efficacy for extended periods before they learnt about the diagnosis and, therefore, before they had an explanation for their differential experiences. Some participants in Huws and Jones (2008 p.102) study explained similar self-perceptions, prior to being told of the diagnosis; autism was therefore identified by the authors as an 'absent presence' in their lives. Scheff (1974) highlighted that the impact of disability can be twofold, in creating a negative self-fulfilling prophecy, which in turn influences the perceptions of others. Before diagnosis, a lack of understanding from family members, professionals, and the CYP's peers, had an impact on both parental wellbeing and CYP's wellbeing. Therefore, as also highlighted by (Gaffney, 2017), CYP with autism, and parents of CYP with autism, often experienced the autism diagnosis within the 'problem context' created by their difficulties understanding social expectations, their struggles to fit in and to make sense of these experiences, but without understanding of the cause of these experiences, which made them feel different.

9.2.2 Influencing factors: learning about and autism diagnosis

The CYP who participated in this study, with one exception, indicated that they were provided with positively focussed explanations of autism. As identified in other studies (e.g., Gordon *et al*., 2015; Mogenson and Mason, 2015; Rossello, 2015), most also reported that they found learning about autism helpful. Learning about the diagnosis also appears to have supported CYP's self-awareness. As also identified in the research by Jones *et al.* (2015), and Huws and Jones (2015), although the participants reported learning about the diagnosis from parents, they suggested that coming to understand how it related to them involved identifying their own traits, linking them to information about autism, and making comparisons with peers. The systematic review of Jones *et al*. (2015, pp. 1496-1497) also identified a similar process of social construction, whereby recognition of their own unique behaviours and characteristics supported self-awareness, which was then supported by reflection and comparison with peers with and without autism. As identified by Rossello (2015), the process that young people described within this study demonstrated that coming to understand an autism diagnosis was a process which took time and was socially influenced.

Although some CYP in this study, and previous research (e.g., Huws and Jones, 2008; Jones *et al*., 2015; Mogensen and Mason, 2015), have highlighted that they can develop negative self-perceptions in relation to an autism diagnosis, a positive finding was that the parents and professionals who participated in this study advocated a positive strengths-based approach when discussing autism with CYP. A positive strengths-based approach is also advocated in wider research exploring parents (Crane *et al*., 2019) and professional’s views (e.g., Bartolo, 2002; Gray, Msall and Msall, 2008; Jacobs et al., 2018). The professionals who participated in this study were mostly specialists in autism and might therefore be expected to advocate this positive good practice. Research studies that have considered the perceptions of professionals with a wider range of relevant roles, but with less specialist knowledge of autism, have identified that professionals tended to use deficit-focussed language in their reports and their communication with parents (e.g., Nissenbaum, Tollefson and Reese 2002; Braun, Dunn and Tomcheck, 2017). Therefore, some parents might experience explanations about their child’s autism diagnosis from professionals that are negatively focussed.

This study, like that of Crane *et al.* (2019), identified parents as the main sources of information for the child about their autism diagnosis. Fortunately, the CYP and parents who participated in this study mostly experienced and advocated a positive focus when discussing autism and the diagnosis. However, if some parents based their explanations on those provided by professionals, which sometimes employed deficit focussed language related to diagnostic criteria, it is possible that explanations of autism for some children will be based on similar negatively focussed explanations. Furthermore, as the NICE (2011b) clinical guidance for diagnosis of autism advocated inclusion of children within the diagnostic conference, children might also hear deficit focussed explanations directly from professionals (Nissenbaum, Tollefson and Reese 2002; Braun, Dunn and Tomcheck, 2017). Some parents in this study, and the wider literature (Lutz, Patterson and Klein, 2012), describe responses such as grief, guilt, anger and disappointment upon learning about their child’s diagnosis. Furthermore, as some CYP are with their parents at the point at which a diagnosis is given, they might observe their parents’ reactions. For example, in this study, Claire vividly recalled the look of disappointment in her father’s face on learning of her diagnosis (Appendix 18.1, lines 117-120). Therefore, if children are present at this time and observe negative reactions, or hear negatively focussed explanations, these observations might influence the perceptions of autism that they take forward from this experience. As highlighted by Whitaker (2006), and Huws and Jones (2008), negatively focussed discussion and language related to autism diagnosis can influence CYP to develop negative perceptions of autism, which can lead to lower self-efficacy (Flammer, 2001). Therefore, a factor that might influence outcomes is the way in which CYP hear about the diagnosis in relation to themselves, in addition to the general views of autism that they hear from media sources and other people with whom they interact.

Fortunately, most participants in this study identified that being told about the diagnosis, was as a catalyst for positive change for CYP, leading to better self-awareness because CYP were able to make sense of their experiences. Although not in the context of autism, Gray *et al*. (2005) identified the place of both the internet and young people's agency in their information-seeking behaviours about health-related matters. Upon learning about the autism diagnosis, some CYP in this study stated that they took the initiative in searching out information from online sources about autism. While most participants in this study found learning about the diagnosis useful, a few participants identified that the diagnosis was a challenge to their self-views. As identified by Molloy and Vasil (2004), the views shared within this study and earlier research suggested that a relationship existed between CYP's self-views and the extent to which they perceive their diagnosis as a disability. Similar findings have been identified by other studies involving both CYP and adults with autism (e.g., Thompson, 1997; Bagatell, 2007; Huws and Jones, 2008; Rhodes et al., 2008; Gaffney, 2017).

Maynard and Turowetz (2019) have highlighted that autism diagnosis is interactive, involving others as part of the assessment process, through the stories that they share to inform the assessed. The success of a diagnosis is therefore dependent on the success of this interactional process, in which factors related to the diagnostic criteria are discussed. This relates to Foucault's (1977) concept of bio-power, which suggested that the perceptions communicated by medical professionals in positions of power are influential within discourse and social experiences. However, it is professionals and parents involved in the assessment, who share knowledge about the individual in relation to social expectations beyond the assessment process. CYP's understanding of autism could therefore be influenced through the symptomatic and deficit focussed narratives that they hear during the diagnostic process, which are often focussed around the diagnostic criteria (Maynard and Turowetz, 2019, p.93). Foucault (1977) emphasised the role of both power and social relationships in the construction of identity. Through social experiences and institutional cultures, dominant views are imposed as cultural constructions, rather than personal ones (Holland *et al*., 1998), as suggested in relation to the medically influenced construct of autism (Armstrong, 2011; Davide-Rivera, 2012; Robison, 2012; Case, 2013).

As identified elsewhere (e.g., Smith and Williams, 2005; Campbell and Berger, 2011), views shared by parents and professionals for this study also highlighted that CYP's problematic interactions with peers, linked to lack of peer awareness, can also influence negative self-perceptions. Across the three key stakeholders, the significance of interactions with others, to shape outcomes in relation to having autism and learning about an autism diagnosis were evident.

9.2.3 Influencing factors: after diagnosis

Following the autism diagnosis, most participants indicated improved understanding by others, including by peers, which was also identified in the study by Campbell (2004). This improved understanding led to improved social experiences that combined with the better understanding of self, which learning about the diagnosis brought (Jones *et al*., 2015; Crane *et al.,* 2019), appeared to boost CYP's self-efficacy (Flammer, 2002). This improved self-efficacy led to increased agency and engagement with self-help strategies; a similar impact was also evident in the studies of Cadogen (2015) and Mogensen and Mason (2015). The evidence suggests that improved experiences and self-awareness can provide a boost to CYP's resilience and their general wellbeing, as has also been identified by adults with autism (Cooper, Smith and Russell, 2017).

However, as also identified by Huws and Jones (2008), while most young people described improvements following the diagnosis, some participants discussed themselves, their diagnosis and their futures less positively. As suggested by Mogensen and Mason (2015) and Gaffney (2017), when CYP's views about autism and themselves were negative, they were more likely to reveal negative perceptions and to distance themselves from the diagnosis. Therefore, as illustrated in Figure 9, the influence of the three ontological layers described by Bhaskar (1975): the real (structures and systems), the actual (events created by structures and systems), and the empirical (events that CYP with autism, parents of CYP with autism and professionals experienced, described and observed), were evident in the empirical data from the participants in their explanations of their experiences and observations. These influences were evident before the autism diagnosis, and when finding out about the diagnosis and they continued to influence outcomes following the diagnosis.

Clinical guidance is clear that professionals have a key role in both making the diagnosis and supporting CYP and their parents to understand the diagnosis (NICE [GC128], 2011b: p.6; sec: 1.1.6). However, some professionals in this study reported that providing direct support for CYP to support their understanding of the diagnosis was not included within their service's remit. However, all professionals identified that they were able to provide support indirectly through the guidance they provided for parents of CYP with autism and their teachers. As also identified within the literature, their guidance advised positive and open communication with the young person about their autism diagnosis (e.g. Cadogan, 2015, Crane et al., 2019, Fletcher, 2013; Miller, 2015). Even when support to understand the diagnosis was not part of their remit, professionals in this study reported that when CYP were referred to them following the diagnosis, they often identified that the young person was struggling with issues related to their self-efficacy and self-esteem, which often linked with their perception of the diagnosis. In these circumstances, they incorporated guidance related the diagnosis within their support for the young person. When support was provided, the three most important factors identified by professionals when helping children to understand the diagnosis included the use of a strengths-based focus, drawing on positive role models with autism, and use of a problem-solving approach when exploring challenges that the CYP experienced.

Unfortunately, most parents and professionals in this study agreed that not enough support was available for children or parents following a diagnosis, which has also been identified in wider literature (e.g., Rogers *et al*. 2016; Crane *et al*., 2018). They were also concerned that something must go wrong before professional support could be accessed. The issue of care being compromised by shortage of trained staff and of services to refer to has also been highlighted in similar research that explored professional views (e.g., Finke, Drager and Ash, 2010; Rogers *et al*., 2016; Jacobs *et al*. 2019). Therefore, this would suggest that those CYP who do experience an identity crisis, like that described by Erikson (1968), due to difficulties in accepting and coming to terms with the diagnosis, are likely to find it difficult to access support with both their understanding of the diagnosis, or with the related mental health difficulties that can be experienced when negative self-views develop. Therefore, as highlighted by Davidson and Orsini (2013), the structures, events and experiences identified above, can disable CYP through both their influence on the understanding of autism and the resulting self-view they develop, and by impacting the support and services that they receive. However, regardless of the limitations of service remits, there are many potential points at which parents and professionals can make a difference. Table 64 below summarises what this study suggests is important for positive outcomes for CYP with an autism diagnosis at key points in relation to their autism diagnosis.

Table 6464 Factors identified that support best outcomes for CYP

What is important for positive outcomes for CYP with an autism diagnosis before they are diagnosed	What is important to improve positive outcomes during the diagnostic process?	What is important to positive outcomes when parents and professionals are communicating with CYP about their autism diagnosis?	What is important to positive outcomes beyond the diagnosis?
• Early identification, supported by more training for professionals across childhood services, to improve understanding about the range of ways that autism might present in individuals. • Improved peer awareness of autism, or neurodiversity more generally, which could be supported by the development of good quality diversity and equality teaching and learning materials for all school children. Materials that follow a spiral curriculum to ensure regular engagement with the topic and progression to develop understanding across childhood are likely to be most effective. • Autism friendly educational environments, facilitated through training for professionals about strategies and adjustments than can be implemented when developmental differences are identified, to ensure that early years, school-based and other childhood settings are inclusive. • Good signposting to sources of good quality information, support, and guidance for parents of children demonstrating differential development	• Better preparation of parents about the process and the emotions they might experience when their child receives a diagnosis (and if they do not). This should include information to help them to consider whether they will be emotionally ready for the child's inclusion in the meeting when they are first told the outcome of the assessment. • Guidance for parents with children undergoing assessment about support they might access and strategies they might implement for children with social communication difficulties, this should include the importance of positive communication about the child's strengths and regular praise. • Professional communication with CYP about the purpose of assessment, which is appropriately differentiated to the CYP's development. • Professional guidance for parents and/or communication with CYP about the autism diagnosis, which is appropriately differentiated and focusses on the strengths that are identified during assessment, as well as immediate guidance about how the child might make improvements in relation to any difficulties that are identified.	• Parent and child readiness. • When a professional is involved, time to develop a relationship with the young person, and to develop understanding of their strengths, interests, and their needs. • A person-centred approach to ensure explanation about autism is developmentally appropriate and draws on specific contexts and interests related to the individual. • Preparatory work, before disclosure of the diagnosis, to help the CYP understand that difference is a positive facet of human development and that diversity is positive (If a child is not developmentally ready, this could be a focus of support until they are ready). • An approach for discussion of autism that employs a strengths-based focus that draws on positive role models, which makes links between the individual's strengths and their specific interests. • An emphasis on problem-solving, when discussing the differences in development, and challenges that young people experience related to their autism diagnosis. • Calm, clear delivery of information about autism (Parents and professionals might benefit from preparing a script of key points they wish to say, including how key points will be phrased). • Developmentally appropriate approaches for the individual, such as: visual prompts to support communication of key ideas, visual prompts to provide a structure; a list of discussion points; and emotional scales to support discussion of feelings. • Information for parents and CYP about appropriate websites, blogs, documentaries, or books that contain accurate, positive information about autism and/or positive role models with autism. • Parents should be included in sessions when diagnosis is delivered by a professional, and information should be shared with the child's setting, to ensure consistent information and views are shared with the young person.	• The opportunity for the child or young person to revisit information, to ask questions, and to raise uncertainties with a trusted adult, who is aware of the information that has been shared with the child. • Signposting to further good quality information, support, and guidance. • Support for the young person's social and emotional development • Good signposting and referral systems should further professional support be needed. • Improved peer awareness of autism, or neurodiversity more generally, which could be supported by the development of good quality diversity and equality teaching and learning materials for all school children. Materials that follow a spiral curriculum to ensure regular engagement with the topic and progression to develop understanding across childhood are likely to be most effective. • Autism friendly educational environments, facilitated through training for professionals about strategies and adjustments than can be implemented when developmental differences are identified, to ensure that early years, school-based and other childhood settings are inclusive.

9.3 Limitations

When this study was designed, there was little research related to children's and young people's experiences of autism diagnosis; furthermore, the limitations that the systematic literature review highlighted in 2019 were not as well understood. Participation was lower than anticipated within the empirical part of this study, with only twelve CYP, thirty-six parents and fourteen professional participants. It is therefore acknowledged that the findings will not be sufficiently robust to enable generalisations to be made, however, generalisations do not aid understanding of individual experiences (Trochim, 2006). One of the most widely acknowledged factors related to understanding people with an autism diagnosis is that it is important to understand individual experiences (e.g., Autism Education Trust, 2012; Tantum, 2012; Roth, 2010). The qualitative elements of this study have enabled a greater focus on understanding the range of factors that might impact individuals. Therefore, while it is acknowledged that it is not possible to generalise the results of the survey, the patterns that emerged from the survey were useful in identifying possible influencing factors, such as the diagnostic process, circumstances and strategies related to finding out about the diagnosis. The in-depth analysis enabled greater understanding about the way that these factors have influenced individuals.

As Queirós, Faria and Almeida (2017) have highlighted, studies such as this with sampling methods that enabled participants to decide whether or not to take part, rather than have a specific sampling approach, such as random sampling, risk incorporating bias, such as self-selection bias. As Olsen (2008) highlighted, this can produce biased data, especially if participants only elect to participate as the focus of the research is of a concern to them. Furthermore, it is acknowledged that the participant sample within this study is both small and is more homogenous than anticipated. Therefore, this study shares similar limitations to several studies identified through the literature review. For example, as identified by Cadogan (2015) and Crane *et al.* (2019), the sample size is small, especially CYP and professional participants. While the sample of parents is larger, it is relatively homogenous, as it comprises mostly mothers. The findings from parents, therefore, mostly reflect the views of mothers, and the views of fathers might differ. Furthermore, the range of presentations of autism that are seen across the spectrum are not evenly represented. All the CYP who participated in the online survey were able to share their views in writing, which required a good level of reading and communication skills. Some of the parent participants indicated that their children had a greater level of needs, identifying that their child had autism with intellectual impairment, however, most parents discussed needs relating to children with autism but without intellectual impairment or significant communication needs. Previous research studies that have explored the views of people on the autism spectrum have also tended to be self-selecting and can be dominated by adults with autism who have average, or above, language and learning ability; such limitations are identified within the work of Kenny *et al*. (2016) and Crane *et al*. (2019). It might also be that parents of those children with autism for whom the impact of autism on their child's communication and learning is greater, did not participate as they had not discussed autism with their child and/or they felt that telling their child about their diagnosis was not of relevance to their child. This has been identified in relation to children with different diagnoses, for example, many parents of children with intellectual disability have reported that they did not discuss a diagnosis with their child to protect them (e.g., McEnhill, 2008; Bernal and Tuffrey-Wijne, 2008; Tuffrey-Wijne *et al*., 2013; Goodwin *et al*., 2015). In addition, participants in the interviews were all from a white ethnic background. Data related to ethnicity was not collected for the survey, therefore whether the sample is ethnically diverse is unknown. However, given the lack of ethnic diversity in other studies that have collected views related to autism diagnosis, such as that of Crane *et al*. (2019), it would also seem likely that the survey participants were also not ethnically diverse. Therefore, as suggested by Queirós, Faria and Almeida (2017), to minimise the limitations influenced by self-selection, the existing data was drawn on to consider the relationship between the study findings and the existing literature. However, as discussed above, the literature review also highlighted similar limitations within the studies identified, such as self-selection and homogenous samples. Therefore, this does not address the homogenous nature of the sample and the related bias. The review by West *et al.* (2016) highlighted that, across studies, individuals with autism from minority ethnic groups were less likely to participate in research related to autism and autism interventions. They therefore suggest that that it is crucial to work together with people with autism from minority groups to explore how recruitment to research focussed on autism can be improved.

Russell *et al.* (2019) have also highlighted that although intellectual disability occurs in approximately 50% of individuals with autism, they are also difficult to recruit due to ethical issues related to capacity. Furthermore, their families can also be difficult to recruit as they might have less time and fewer resources to facilitate participation. Russell *et al.* (2019) have identified that engaging with gatekeepers at the highest level of organisations can increase likelihood of provision of information to potential participants, and they also identify that small payments to cover practical elements related to participation, such as travel and time are also beneficial. Furthermore, Russell *et al.* (2019) suggested that future research funding should require the inclusion of individuals with autism with intellectual impairment within research and assert their agreement with the findings of the review by Mullhall *et al*. (2018), which suggested that to redress the bias within autism research, exclusionary recruitment approaches should be employed. This study might have reduced the bias in the sample, towards individuals with autism but without co-occurring intellectual impairment, by utilising a purposive sample so that the participation of individuals with autism with and without co-occurring intellectual impairment was more balanced. For example, as suggested by Sharma (2017), at the later stages of the research, when readvertising the research, the participation of CYP and parents of CYP with autism and intellectual impairment might have been specifically sought. However, all sampling methods have limitations and, as Sharma (2017, p. 751) identified, purposive sampling can significantly increase the likelihood of researcher bias.

Gaining the participation of CYP with autism was particularly problematic, this might have been linked with the ethical safeguards, which placed constraints upon the way that information was provided to the CYP who were potential participants. Within this study, the parents rather than professionals were ultimately responsible for deciding on whether to pass on information about the research to their child, they therefore held the key gatekeeping role (Hill, 2005). As identified by other researchers (e.g., Sparrman, 2014; Collings, Grace and Llewellyn, 2016), my discussions with parental interview participants led me to believe that parents choosing not to tell their child about the research might have been a factor in the low participant rate. Most of the parents I contacted to organise interviews told me they had not informed their child about the research. They mostly explained that this was due to wellbeing concerns for their child, which meant it was not the right time for their child's participation. Some parents were also concerned about their child's social anxiety. This highlights the ethical considerations that need to be negotiated to both facilitate rights and enable safeguarding protections, and is a situation in which a power asymmetry appears evident (Farrell, 2005). In this situation, Foucault (1978) would identify parents to hold the balance of power and children to be the subjects. Researchers such as Bessant (2006) have argued that despite the rights afforded to CYP (United Nations, 1989), and their often willingness to take part, parental gatekeeping and the need for their consent means that their involvement in research is often severely constrained, especially when the research topic is of a sensitive nature. However, some CYP did take part in the survey for this study, and these participants were able to write confidently about their experiences. This might suggest that parents might have been more willing to provide the information about the online survey to their child, than to consider asking their child to participate in an interview. It is known that CYP with autism often experience social anxiety (Spain *et al*., 2018), therefore, it is understandable that parents might have felt that taking part in an interview might have been a problematic experience for their child. As identified by Russell *et al.* (2019), the modes of participation offered might also influence decisions about engagement with research by individuals with autism. Another recent review has also identified that across other participant groups (Poynton, DeFouw and Morizio, 2019; Nicolaidis *et al.*, 2020), researchers might be successful in gaining the participation of individuals with autism through online surveys. However, as identified by Nicolaidis *et al.* (2020) who explored the use of online surveys for research involving adults with autism, care would be needed to ensure careful design to maximise the usefulness of online methods, and to ensure that this did not further marginalise some participants, such as those with autism and intellectual and/or communication impairments. While a small number of CYP with autism took part in the online survey, as suggested by the research of Nicolaidis *et al.* (2020), had further adaptations been made to the survey, greater participation might have been supported.

Due to the small homogenous nature of the sample, it is recognised that generalisation of results from the empirical element of the study is not possible. However, the synthesis was undertaken following a critical realist perspective that focussed on mechanisms (Sayer, 1992). These mechanisms are associated with causal powers and liabilities, such as the power or ability to perform a function. Bhaskar (1998) specifically notes, however, that when influential social structures are identified, causal power does not imply that it will occur, rather that it has the potential to enable or constrain, in relation to the phenomenon being considered (Volkoff and Strong, 2013).

Those mechanisms that occur with some regularity imply that this is not an accidental or random occurrence (Manicas, 2006). Furthermore, these mechanisms, or structures, “could be physical, social or psychological, and may well not be directly observable except in terms of its effects (e.g., social structure)” (Mingers, 2000, p.1262). In the case of autism, some examples of these mechanisms include the social experiences of children at school and the corresponding psychological impact on the child, and the professional response to parents who seek professional assistance to understand the differences that they perceive within their child.

Furthermore, most of the data provided for this study was qualitative, which has proved valuable in achieving the aim of qualitative research, which is not to generalise findings but to support understanding of complex activities, processes and experiences through intensive study of a particular phenomenon (Dzakiria, 2012, p. 41). The participants in both the interviews and the online surveys provided rich qualitative data, which supported deep understanding of CYP’s experiences of being told about an autism diagnosis from the perspective of three key stakeholders, and about how they were supported to understand it by their parents and professionals. Baker and Edwards (2012) identified a wide range of suggestions for sample size in their review of the literature related to qualitative research, they suggest the number of participants can range from 12 to 101. Across the different forms of participation in this study, these parameters were met. Sandelowski (1995) suggested the importance of ensuring participant numbers were small enough to enable a full understanding and appreciation of the richness of the data, but which were large enough to provide ‘a new and richly textured understanding of experience' (p. 183). Therefore, while the findings are not generalisable, the data collected does provide a rich understanding of a range of experiences of coming to understand an autism diagnosis, which might suggest mechanisms of influence. The number of participants who provided qualitative information is similar to the numbers recruited for doctoral work, and for published research, which employs a qualitative approach and thematic analysis (e.g. Fugard and Potts, 2015; Huws & Jones, 2008; Ward, 2014; Alexander, 2017). Furthermore, the pragmatic approach to the research meant that when problems occurred with recruitment, a refocussing on the qualitative information was possible.

The systematic literature review also drew together the previous evidence-base in a comprehensive way, which has facilitated a deeper understanding of the multi-layered influences that impact the way CYP come to know about and to understand their autism spectrum diagnosis. Gough, Oliver and Thomas (2018, p. 1) suggested that systematic reviews are useful for gathering and examining what is already known from existing literature. It is important to highlight, however, that the potential for engagement with the existing literature also has the potential to influence and impact the analysis of the empirical data. For this study, an scoping literature review was undertaken before the empirical element of the study, and a systematic review was undertaken in 2019, after the data had been collected and the analysis was largely completed. Some qualitative approaches, such as grounded theory, argue against engagement with the prior literature (e.g., Glaser and Strauss, 1967; Glaser, 1998; Holton, 2007), to ensure that the findings emerge from the data. As Dunne (2011) identified, however, there are several important reasons to consider the literature before undertaking research, these include exploring the topic to contextualise it, to gain theoretical understanding, to orientate the researcher to important considerations, and to enable them to create a rationale for the study. Engagement with the literature can also help the researcher to be aware of preconceptions that might influence their interpretations, rather than necessarily meaning they will be unconsciously influenced by them (Maijala, Paavilainen and Astedt-Kurki, 2003). Exploring the literature also highlights gaps related to the topic of interest, it can therefore also help to ensure that replicating prior research is avoided and can help the researcher to understand how the phenomenon has been explored previously, thus methodological pitfalls might be reduced (McGhee, *et al*., 2007). Furthermore, Strubing (2007, p.587) highlighted that the most important point to consider is not whether the literature should influence the data analysis, but that 'proper' application is made of prior knowledge. Within this study, as the literature had been fully engaged with to inform the development of the research, and throughout the research process, it is acknowledged that there was the potential for confirmation bias, due to prior knowledge of other research findings, which might have influenced the analysis, albeit unconsciously (Schwind and Buder, 2012). However, this potential was recognised and, as suggested by Dunne (2011), every effort was made when analysing the data to ensure that all the ideas that the participants shared were considered. This aimed to ensure that, as far as possible, the themes came from the data, rather than being influenced by preconceived ideas formed through exploration of the literature. Furthermore, as identified in Table 37, which identified the approaches undertaken to ensure trustworthiness, the analysis included comparisons across the different sources of participant data, and also employed automated analysis using NVivo software (QSR international, 2012), to reduce the risk of important themes being overlooked. Nevertheless, as identified within the research literature (e.g., Glaser and Strauss, 1967; Glaser, 1998; Holton, 2007), it is acknowledged that engagement with the literature is likely to have influenced the research process at all stages.

9.4 Recommendations: what practical actions or future research should follow?

Future studies are needed that help to develop understanding of the way in which experiences and views of autism diagnosis vary across genders and ethnic backgrounds, and about how this might influence the way in which autism is discussed with young people. There is also little evidence about how autism is discussed and understood by children with autism who also have intellectual impairment and communication needs. Research that explores the understanding of CYP with these needs would be highly valuable, especially by parents and professionals who wish to support these young people to understand their diagnosis and to develop a positive sense of self.

9.5 Reflections on the research process and the impact

In reflecting on the research process, I feel there are two key factors that are of importance for all researchers, their learning from the process and the impact on future research decisions. Within this section, I will therefore reflect on what I have learnt and what would I do differently because of my learning from this process.

9.5.1 What I have learnt

Undertaking this research has been an interesting and at times a moving experience. It has been a privilege to listen to the stories of all the participants. I have learnt from every one of the stories they shared. Despite the evidence that suggests that CYP with autism experience emotions differently (e.g., Silani *et al*., 2008), the children and young people who participated provided great depth in their online survey responses about both their social experiences and the feelings they experienced as a result. Influenced by my previous psychologically focussed studies, I created a survey with options for responding via a scale, as I felt this would best support the participation of CYP with autism. I also included four open questions in the survey in case CYP wanted to provide further information or clarification, I had observed this was important during the focus groups activities. However, as many of the CYP with autism that I have worked with during my work within schools had identified a dislike for writing, I did not anticipate such depth in their responses to the open survey questions. In fact, as this section was optional, I did not expect many of the participants to respond to the open questions at all. However, I was wrong, it was the open questions, in both the CYP's and the parents' surveys, that I feel have provided the most useful data from the online survey. Therefore, methodologies that provide CYP with autism the opportunity to share narrative accounts through online and other technologies could be a promising methodology for future research, when seeking to understand their perceptions.

However, I acknowledge that the methodology would not be appropriate for all people across the autism spectrum, unless carefully constructed as suggested by *Nicolaidis et al*. (2020) and combined with accessibility software.

The professionals who participated in this study were also generous in sharing the details of their practice, which they felt best supported outcomes for CYP with autism and their families. As evident within the wider literature (e.g., Fletcher, 2013; Miller, 2015), professionals often revealed their dedication and a passion to ensure that their practice achieved these aims. They also revealed great empathy and respect for the parents they worked with and appreciated the hardships that parents often experienced when they were trying to ensure their child's needs were met. As identified by Nissenbaum, Tollefson and Reese (2002), professionals recognised the importance of establishing positive relationships with parents and of using an enablement framework when discussing children. However, professionals in the studies of Nissenbaum, Tollefson and Reese (2002), and Jacobs *et al.* (2018), also reported feeling emotional when disclosing a diagnosis. Nevertheless, they also discussed feeling that they needed to maintain a professional persona when discussing the diagnosis with parents. It is perhaps this juxtaposition that some professionals find difficult to negotiate, which might explain why parents in this study, and the wider literature (e.g., Finnegan, Trimble and Egan, 2014; Rossello, 2015; Crane *et al*., 2019), have suggested they found professionals to be cold, or to lack empathy, when presenting the diagnosis at the end of the autism assessment.

As a parent of a child with autism, I shared great empathy with the parents as they told their stories about their child's experiences, and when they shared their frustrations about their battles to have their child's needs met. Therefore, I have learnt how hard it can be to maintain the role of a neutral researcher. I endeavoured to follow Knight's (2002) advice by monitoring, recording, and reflecting on the views that challenged my assumptions, when undertaking both fieldwork and the data analysis process. However, I am certain there were times when parents perceived my unspoken agreement. Nevertheless, I believe that it was because parents were able to perceive my empathy that their accounts were so rich. As Baxter and Babbie (2003) identified, qualitative research interviews are designed to develop a rapport and to encourage in-depth recounting. It is because this requires active and supportive listening, that Rossetto (2014, p. 483) likens the process to therapy, which provides a corresponding therapeutic outcome. All the participants indicated that the interviews had been a positive experience for them and that it had been good to share their experiences. I valued the opportunity to listen to their powerful stories and I feel that it also resulted in a positive outcome for me. It is important to highlight that when I set out to explore this topic, it was not undertaken because I wanted to learn how to share a diagnosis with my son. I had already disclosed the diagnosis to my own child, I felt that our discussions had been successful, and I did not connect the research with my own experiences. Nevertheless, the interviews and the analysis of the participants' accounts certainly caused me to reflect on my own experiences of 'battling the systems'. More significantly, it also encouraged me to reflect on the discussions that I have had with my own son about his diagnoses. Like many people with autism, he has a co-occurring diagnosis of epilepsy. My reflections have helped me to recognise that our discussions have tended to overly focus on the physical and medical aspects of his epilepsy, rather than elements of his characteristics that link with autism. On reflection, I believe that this focus has been influenced because of the cognitive decline he has experienced in his functioning, which means he now also has significant intellectual impairment. Therefore, it has been easier to explain aspects such as seizures and medical treatment, as they are more tangible, as he can perceive them more easily. However, this is something we are now exploring together.

9.5.2 What would I do differently because of learning through this process?

Through undertaking this research, I have learnt that, while the way children learnt about the diagnosis was important, CYP's views about their diagnosis were influenced by much more than the way that they were told about it. As Bhaskar's (1975) critical realist perspective suggests, the structures and systems linked to diagnosis also impacted significantly, as they influenced the views of autism, difference and disability that CYP and their parents encountered within society.

My decision to employ mixed methods led to the critical realist philosophy that has helped me to recognise the wider influences on the perceptions that children developed as they are learning about their autism diagnosis. This process has also helped me to recognise the importance of building the research approach around the perceptions of CYP with autism. Their contributions to the design of the survey were invaluable but limited by my inexperience as a researcher. I believe I might have gained so much from the process, if I had been better prepared for their contributions.

For example, in retrospect, it would have also been useful to gain their perspectives about the research information that was used to advertise the research to other CYP with autism. I also feel I have been most comfortable when engaging with qualitative methods for this study, and I believe that the most powerful data came through the qualitative methods. If I was planning this study now, I would design it using a participatory action research approach. As outlined by Guy *et al.* (2020), I would ensure that future studies were also embedded within practice, as I feel this would ensure the greatest relevance to the participants whose perspectives were being sought. In addition, maintaining close links with practice would also provide the greatest opportunity to influence meaningful changes in relation to future practice. Furthermore, I believe that the participation of CYP might have been improved, as CYP and their parents might have been more comfortable to participate with a researcher with whom they were already familiar, and about a topic about which they had shared experiences. However, as Bourke (2008) identified, in participatory research power relationships can also be messy and complex to negotiate, therefore, it would be important to plan carefully with individuals with autism, and their families, to ensure that participation was genuine and ethically sound.

As Robson (2002) suggested, I have learnt that real world research processes can be messy. The most problematic aspect has been securing sufficient volunteers to take part, especially CYP. It is, I feel, the ethical constraints that meant that the invitation to take part in the research had to go to parents, rather than directly to CYP, which has impacted their participation more than any other factor. While I did recognise that this could compromise the rights of CYP to share their views on an important experience of significance to them, I chose not to challenge this, as I also recognised the need to protect CYP. However, I have increasingly felt that I should have challenged this and identified further strategies that would have satisfied ethical concerns and gained approval for advertising the research in places that CYP could have accessed information about it directly. Research is beginning to identify ways to facilitate the inclusion of individuals with autism, MacLeod's (2019) review of the literature, for example, highlighted that factors such as paying attention to power relationships and offering different forms of participation were important within participatory research. In addition, den Houting *et al.* (2021) also recently explored the perspectives of individuals with autism about participatory research, they identified that while individuals with autism might value participation, it can be a difficult process for them, and one in which there are still power issues to overcome. However, as MacLeod (2019) identified, participatory research involving individuals with autism is a relatively new approach and therefore one about which there is still much to learn. This learning is most likely to be successful when undertaken together with individuals with autism and their families. As advocated by Heath *et al*. (2007), in future, I will strive to stand by my personal philosophy by seeking ways to ensure that CYP are afforded their rights to opt in or out of research that is of relevance to them. As good ethical practice guidance advocates (e.g., British Educational Research Association, 2018; Economic and Social Research Council, 2021) communicating with precision about what the research process entails is crucial. The study by den Houting *et al.* (2021) also suggests that provision of comprehensive information about the research processes might provide individuals with autism greater reassurance about what they are volunteering for. Furthermore, as suggested by MacLeod's (2019) review, if they can identify, within the research information provided, a participation mode by which they would be comfortable to take part, participation might be increased. Therefore, ensuring that both the information about the research process, and the modes of participation, are fully accessible for CYP with autism across the spectrum could support increased participation. As identified by others, this will require the development of a wider range of participatory methods (e.g., Burke, 2008; Lewis, 2009; MacLeod, 2019; Stans *et al*., 2019) and better communication about these options for participation. While I felt that I had provided sufficient detail about the research process when designing the study, and I had prepared accessible resources to support participation, finding different ways to communicate all of this succinctly, in ways that were accessible to the range CYP with autism who might have considered participation, might also have secured greater participation. Furthermore, I did not seek the views of CYP with autism when compiling the research information. Had I also sought their perspectives and advice on the information provided about the research, it might have been more accessible and perhaps more likely to encourage participation.

9.6 Conclusions

As the first study to explore how CYP experience an autism diagnosis and are supported to understand their autism diagnosis from the combined perspectives of CYP, parents and professionals, this study demonstrates both the complexity of the process, and significantly, the many points of influence upon outcomes. The findings suggest that learning about an autism diagnosis is a process that takes time, which is influenced by many conversations and experiences. During this process, CYP's mental wellbeing can be impacted positively, and negatively. For example, before diagnosis, CYP with autism, and parents of children with autism, described negative experiences, such as, problematic interactions with peers, which can be detrimental to their self-efficacy and mental wellbeing. Furthermore, despite parents often recognising their child's need many years before they were diagnosed, their worries about their child were often not accepted by professional. Therefore, appropriate responses such as referral for assessment were often not actioned by professionals. This meant that for some CYP within this study, diagnosis was delayed. For these CYP, the problematic and unexplained experiences caused by the 'absent presence' of autism (Huws and Jones, 2008), had the potential to impact CYP's views of self for extended periods of time. While the diagnosis can come as a shock to CYP, it can also be a relief, as it can help children to understand their previous difficult experiences. The views shared by CYP and the parent participants in this study suggest that the 'absent presence' of autism before diagnosis, appeared have a greater disabling impact on CYP's developing view of self, than being told about their diagnosis. This might reflect the difficulties they experienced from feeling unable to act within society in 'personally desired ways' (Verbrugge and Jutte, 1994, p. 3).

When I set out to explore this topic, I was an advisory teacher for autism. It was because parents were regularly asking me for advice and guidance about whether they should disclose the autism diagnosis to their child, and how they should tell them, that I set out to explore this topic. Parents were especially worried that if they did not explain autism in the right way to their child, this might impact their child negatively. Considering the findings from the participants who took part in this study, and from the systematic literature review, I would now feel more confident in addressing parents' questions and concerns. I would highlight that they should tell their child about their diagnosis, and that this should happen as soon as they feel emotionally ready. Children have a right to know about important issues that impact them, furthermore, there is evidence that not knowing might have a greater negative impact than knowing about the diagnosis. However, I would advise that, as a first step, they support their child to develop a positive sense of self, by highlighting their strengths and exploring differences. I would highlight that the evidence suggests that most parents do a good job in supporting children to understand an autism diagnosis (e.g., Finnegan, Trimble and Egan, 2014; Cadogan 2015; Crane *et al*. 2019). However, I would also ensure they understood that there is evidence that some CYP can experience difficulties related to their diagnosis, and that some CYP find it difficult to accept that they have autism, but this might change over time (e.g., Huws and Jones, 2008). Therefore, some CYP may take more time to process the information that will eventually help them to relate the diagnosis to their own experiences. I would reassure parents that across the growing body of research evidence from CYP, parents and professionals, there is evidence that knowing about the diagnosis can facilitate improved self-awareness for children (Huws and Jones, 2008; Cadogan, 2015; Gordan *et al*., 2015; Rossello, 2015), and that this can support CYP's agency in moving forward positively due to this new understanding. I would also explain that research has shown that, even when a child responds negatively to the diagnosis when they are first told, over time, they do often adjust their views and move forward positively (Huws and Jones, 2008). Finally, I would advise parents that they are most likely to support their child to move beyond a negative response by boosting their child's confidence, by encouraging them to focus on strengths, and encouraging them to develop positive strategies for elements of their experience that are troubling for them. I would also highlight the research by Woodman (2015), which has identified that by providing constant positive praise, they will be providing the positive home environment, which will best support resilience and positive outcomes for CYP with autism.

When liaising with professionals, I would also emphasise the many ways in which they too can influence CYP's experiences and perceptions of their autism diagnosis. Professionals can advance a positive view of autism and neurodiversity in their interactions with CYP with autism, their peers, and with the families of CYP with autism. Furthermore, by ensuring that they were aware of the many varied ways that autism might present, they can support early identification by recognising CYP whose developmental profile might indicate that exploration of their social communication differences and cognitive processing style is appropriate.

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