



The  
University  
Of  
Sheffield.

***“They will listen to the expert, but not to the parent”:***

Listening to the stories of parents who actively advocate for their  
child’s Autism Assessment.

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All I am is because of you and all I wish to be is because you inspire me every day.  
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## Abstract

**Methodology:** Narrative, thematic analysis, unstructured interviews, constructivist/interpretivist lens

**Key terms:** Autism, autism assessment, autism diagnostic process, advocate, advocating, parents' experiences, parents advocating, parental voice,

**Name of Research Supervisors:** Tony William & Penny Fogg

**Thesis title:** Listening to the stories of parents who have actively advocated for their child's Autism assessment.

**Abstract:** The aim of this research was to explore parents' experiences of advocating for their child's autism assessment. An ontological lens recognising that there are multiple realities which are co-constructed is employed, accepting that epistemologically there is a need for interpretation. Thus, a social constructionist position is adopted with the intention of listening to the stories of parents based upon their lived experiences. Unstructured interviews were conducted and analysed using a thematic analysis approach entrenched within narrative and humanist values. By focussing upon what was said and appreciating parents as agentic beings I recognised their stories as a representation of their lived experiences.

The literature provides a multitude of discourses for and against the diagnosis of Autism. Furthermore, research identifies the difficulties and complexities of receiving an Autism diagnosis. I hope through this journey of exploration and the subsequent body of work I have produced I can maintain the authenticity and integrity of the narrators and their stories. Inevitably I hope, framed by my admiration of positive psychology, that the sharing of the narrators' experiences may allow for: continued discussion, reflection, and empathy upon individuals, more specifically parents, varied positions regarding the Autism assessment and diagnostic process.

I end with a quote which encapsulates how I appreciate the unique and privileged position I hold in being the audience for the narrator's stories.

*"If our preferred story of who we are remains only a conversation in our own head, it will not have the sense of being 'real'. This sense of 'realness' or 'authenticity' only comes when our preferred stories are witnessed and responded to by a significant audience."*

Carey & Russell (2003, p3).

Carey, M. & Russell, S. (2003). Outsider-witness practices: some answers to commonly asked questions. Last accessed at

[https://narrativepractices.com.au/attach/pdf/Outsider\\_Witness\\_Common\\_Questions.pdf](https://narrativepractices.com.au/attach/pdf/Outsider_Witness_Common_Questions.pdf)

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<b><u>Abbreviation</u></b>	<b><u>Meaning</u></b>
<b>ADHD</b>	Attention Deficit Hyperactivity Disorder
<b>ASD</b>	Autism Spectrum Disorder
<b>ADI - R</b>	Autism Diagnostic Interview
<b>ADOS</b>	Autism Diagnostic Observation Schedule
<b>CAS</b>	Critical Autism Studies
<b>CDC</b>	Child Development Centre
<b>DEdCPsy</b>	Doctor of Educational and Child Psychology
<b>DSM-5</b>	Diagnostic and Statistical Manual, Fifth Edition
<b>EP</b>	Educational Psychologist
<b>EPS</b>	Educational Psychology Service
<b>GT</b>	Grounded Theory
<b>ICD-10</b>	International Classification of Diseases, Tenth Edition
<b>ICD-11</b>	International Classification of Diseases, Eleventh Edition
<b>IPA</b>	Interpretative Phenomenological Analysis
<b>OFSTED</b>	Office for Standards in Education, Children's Services and Skills
<b>OT</b>	Occupational Therapist
<b>SALT</b>	Speech and Language Therapist
<b>SEN</b>	Special Educational Needs
<b>SENDSCO</b>	Special Educational Needs and Disability Co-Ordinator
<b>SPLD</b>	Specific Learning Difficulties
<b>TEP</b>	Trainee Educational Psychologist
<b>WHO</b>	World Health Organisation
<b>3DI</b>	Developmental, Dimensional and Diagnostic Interview

*\*Disclaimer\* In line with my philosophical stance and chosen narrative approach, I have used the term narrators to describe individuals who would be traditionally referred to as participants.*

## **Chapter one**

### **Introduction**

My chosen topic of interest arose from my personal experience of advocating for my son's Autism assessment, which subsequently led to a diagnosis of Autism in July 2018. At the time of recognising his presentation of needs I was working as a Special Needs Teacher with children who experienced severe and complex learning disabilities. A large number of the pupils were also diagnosed with Autism. My experiences of encountering Autism as a teacher informed my ability to recognise my son's presentation of needs. I began the process of advocating for his assessment in 2016. At this time, I also accepted a place on the DEdCPsy course at the University of Sheffield. I continued to attend appointments, request referrals and advocate for my son's Autism assessment in whichever way I could. During this time (2017), as a TEP, I began working with the Parent Carer Forum within my local authority. I encountered several parents seeking advice and sharing their experiences of the Autism Assessment Pathway. These experiences in both my personal and professional life ignited the initial embers of my research interest. Coming to the end of my son's assessment journey (2018), I recall the feeling of relief, the journey to securing a diagnosis was long and at times difficult. I recognised that my research would allow me to explore a subject which was personally meaningful, whilst also giving me the opportunity to contribute to the wider field of Educational and Child Psychology. Rudestam & Newton (2007, p.10) share how it *"makes sense to choose a topic that is interesting and personally meaningful."* I was, however, cautious as Stimson (2014, p.618) recommends researchers to be *"wary of choosing something that resonates too closely with your own personal experience."* Whilst

Rudestam & Newton (2007, p.10) further suggest avoiding topics *“linked with emotional issues within your own life.”*

**Reflection:** During this time, I felt excited about my chosen topic of interest, I had come to the end of my son’s Autism assessment journey and succeeded in advocating for his Autism diagnosis. I recognised the topic was personally emotive, however I was positioned in a positive place in my life. I had accepted that my son was Autistic and had achieved the outcome I wanted, in regards to securing my sons diagnosis.

Following supervision with my research tutors and deeper reflection upon my chosen topic I affirmed that I would continue with my chosen area of interest. I recognised how my experiences offered me a unique lens, providing me with some level of intersubjectivity which would allow me to better engage with potential Narrators. I accepted that my subjective experiences relating to the Autism assessment process for my son, had provided me an intersubjective field that I may engage within. Frie & Reis (2001, p.297) share that the *“intersubjective field is an area of common engagement in which my individual subjectivity is articulated and communicated.”* By valuing my subjective experiences I recognised that I had firmly positioned myself as subscribing to interpretivist (relativist), social constructionist values, and resolutely away from *“realist assumptions of positivism”* (Riessman, 2008, p.17) or the notion of objectivity. I recognised that my lived experiences shaped my view of the world and positioned me within my field of study. I found the words of Clandinin and Connelly (2000, p.121) affirmed my position as they share, *“narrative inquiries are always strongly autobiographical.”* Further illuminating that research interests emanate from our own narratives of experience.



## Literature review

Prior to beginning my literature review I chose to search for newspaper articles related to my topic of interest. I used terms such as Autism, Autism assessment and Autism diagnosis as key words in a Google search engine. I recognised how newspaper articles provided a glimpse into prevalent discourses within mainstream society. I appreciated that journalism in its wider sense provides information and knowledge which is readily accessible, far reaching and consumed (Richardson, 2007, p.8).



## Autism

It is important to begin by identifying that the terms Autism, Autism spectrum disorder and Autism spectrum condition will be used interchangeably throughout the body of my work in accordance and reference to the literature I have engaged with. In using the term Autism spectrum condition my intention is not to cause offence. I do not see those on the spectrum as disordered or impaired but rather individuals who see the world through a unique lens (Honeybourne, 2017, p.4). Haroon (2019, p1) identifies the effects of the neurodiversity movement upon terms of discourse related to Autism, sharing that the preferred term is condition rather than disorder. The NHS (2019) identifies that Autism Spectrum Disorder is the medical name for Autism, Haroon (2019, p.1) further affirms that the diagnosis of Autism is a clinical diagnosis.

The term Autism was first used to describe children by Leo Kanner over 70 years ago when he published his seminal journal titled 'Autistic Disturbances of Affective Contact' (Leo, 1943). In his body of work, he described the presentation of 11 children aged between two and eight years of age. He shared how they "*were oblivious to other people, did not talk or parroted speech, used idiosyncratic phrases,*" lined up toys and "*remembered meaningless facts*" (Leo, 1943; Gupta, 2004). Gupta (2004, p.1; Boucher, 2009, p.13) identifies how Kanner described the features of classic Autism with "*uncanny detail*" whilst Silverman (2012, p.34) shares how subsequent generations of psychiatrists would uphold that Kanner "*recognised the essential core of the disorder.*" The current definition of Autism is commonly characterised as difficulties with communication, social interaction, repetitive and restrictive behaviours (National Autistic Society, 2020a; Autism Speaks, 2020a; NHS, 2019; WHO, 2019). The National Autistic Society (2020a) provides a concise definition, sharing that

Autism is *“a lifelong developmental disability which affects how people communicate and interact with the world.”* It is, however, important to outline that Autism is a spectrum condition and can affect individuals in considerably varying ways. It is accepted that Autism cannot be cured and is a lifelong disability, hence individuals will have their own unique strengths and challenges.

## **Epidemiology**

Research data identifies that the prevalence of Autism has dramatically increased in recent decades. This assertion is queried upon the clarity of whether there are increasing rates of Autism or alternatively better public awareness, greater professional recognition and broader diagnostic criteria (Haroon, 2019, p.1). Research by Hansen, Schendel & Partner (2015) supported this suggesting nonetiological factors, such as changes in diagnosis, reporting practices. However, Idring et al (2012, p.1) share that although wider recognition and contemporary changes in diagnostic practices may offer an explanation to some of the rise in ASD incidence, an actual true rise in ASD prevalence has not been disregarded. Lyall et al (2017, p.81) identifies how current prevalence is estimated to be *“at least 1.5% in developed countries.”* The World Health Organisation (WHO, 2019; Mintz, 2018) states that *“1 in 160 children has an Autism Spectrum Disorder.”* whilst the National Autistic Society (2020a) estimates that there are 700,000 children and adults living with Autism in the UK. This approximately equates to one in one hundred people in the UK population as being on the Autistic Spectrum. When considering the high prevalence of adults and young people with Autism in the UK I feel my research enquiry is both relevant, necessary and addresses a contemporary phenomenon. Fitzgerald & Yip (2017, p.xi) share that *“Autism is probably one of the most complex phenomena that exists.”*

Large scale research has illuminated, however, that Autism affects two to three times more males than females (Haroon, 2019, p.1). This may be due to the under recognition of presentation in females or a genuine biological gender difference between the sexes (Haroon, 2019, p.1). Hebron & Bond (2019, p.9) assert that gender differences between boys and girls are recognised as resulting in girls being less likely to be diagnosed concluding that, even when they are diagnosed, Autism research predominantly focuses on boys. Carpenter, Happe & Egerton (2019, p.4) add that traditionally the diagnostic criteria is male orientated leaving girls misunderstood and overlooked for support. Shefcyk (2015, p.132) shares that *“to be a female with an ASD is to be twice excluded: once from the neurotypical female population, and once again from the ASD community.”* When considering my personal experiences as a teaching practitioner both in mainstream and SEN settings I also encountered far less girls diagnosed with Autism comparatively to boys. However, within my research study, of the four narrators taking part, two of them are parents of girls diagnosed with Autism.

### **Aetiology**

The NHS (2019) firmly states that *“Nobody knows what causes Autism, or if it has a cause.”* They do, however, identify that there may be a hereditary factor as it can affect people in the same family (Idring et al, 2012, p.1; NHS, 2019). I was aware of this from my son’s Autism assessment journey as professionals queried if there were any neurodevelopmental conditions present within the wider family identifying heritability risks. I was able to confirm that two of my maternal first cousins were diagnosed with Autism and that I had a diagnosis of ADHD. A comprehensive study of relative recurrence risk of autism with a

sample of 1.6 million families in Sweden, identified heritability of ASD to be approximately 50% (Gaugler et al, 2014, p881; Sandin et al, 2014, p.1776;). The research concluded “*the risk of Autism is increased 10 fold if a full sibling has the diagnosis and about 2 fold if a cousin has the diagnosis*” (Sandin et al, 2014, p.1776; Gaugler et al, 2014, p881).

**Reflection:** Whilst reviewing the literature and exploring the Aetiology of ASD I found the research and data concerning familial prevalence brought strong emotions to the forefront of my mind. I recognised that this was attributed to the fact that I had begun the journey of advocating for my youngest son’s autism assessment after choosing my research topic. He was born in 2018 but shortly after his first birthday due to the significant presentation of needs including self-injuring and sensory headbanging, I had recognised that I would once again have to engage in the autism assessment process. I recall, at this time, considering whether I should reconsider my research interest as the context of my lived experiences had changed. However, I appreciated the unique perspective I had been afforded and recognised the value of my work.

The WHO (2019; Hawkes, 2011, p.22; Idring et al, 2012, 2012,p.1) share that available scientific evidence suggests that genetic and environmental factors are universally recognised as potential causal triggers. Furthermore, genetic research exploring specific genes that may cause Autism is being undertaken across the world (Hawkes, 2011, p.22). It is, however, important to address that “*bad parenting*” does not cause Autism (NHS, 2019; Haroon, 2019, p.1).” Misconceptions regarding Autism, a focus on maternal deprivation and the popularity of a psychoanalytic lens, resulted in the Refrigerator Mother theory which sought to pathologise and blame mothers (Fombonne, 2003, p.503; Haroon, 2019, p.2). The notion, popularised by Bruno Bettelheim in the 1950’s, attributed Autism as an infant’s

response to “*early disturbances of the mother–child relationship*” (Fombone, 2003, p.503; Haroon, 2019, p.2). I was conscious that all four of the narrators in my research identified as female and were mothers. I felt disheartened at the historical context of how Autism was conceived and the way in which mothers were blamed for their child’s symptomology and subsequently viewed as negligent and responsible for their child’s presentation of needs (Bennett et al, 2018, p.61). I sought solace in the fact that conceptions of Autism had developed exponentially moving away from pathologising parents.

### **Diagnosis**

In the UK Autism diagnoses are carried out with reference to diagnostic criteria in either the Diagnostic and Statistical Manual, Fifth Edition (DSM-5) or the World Health Organisations International Classification of Diseases, Tenth Edition (ICD-10) (National Autistic Society, 2020b). Both are internationally recognised as the prominent classification systems and diagnostic criteria for all recognised mental health disorders (Boucher, 2009, p.11). There are a range of diagnostic tools that clinicians may choose to use including the; ADOS, ADI-R, 3Di and DISCO. However, they all assess against the criteria for Autism presented in either the ICD-10 or DSM-5 (National Autistic Society, 2020b). Although it is important to share that the newest edition of the ICD (ICD-11) has been presented to the World Health Assembly and is due to come into effect from January 2022 (WHO, 2018).

### **Why seek a diagnosis?**

I recognised it was important to address some of the reasons why parents may seek a diagnosis of Autism as identified within literature. It is, however, integral to share that this is in no way an exhaustive list or presumptive of why the narrators within my study were

seeking a diagnosis. Crane et al (2018, p.3761) states how *“accessing an autism diagnosis is a key milestone.”* Further sharing that parents hold the assumption that obtaining a formal Autism diagnosis will act as an entryway to help and support (Crane et al, 2018, p.3761). Charman & Stone (2006, p.38) also identify how for many families the primary objective in acquiring a diagnosis for a child in preschool or younger is to gain access to services. Research by Carlsson et al (2016, p.328) recognized that parents anticipated intervention to begin immediately following diagnosis but were left feeling they had to *“fight”* to acquire the resources their child needed. However, research by Crane et al (2015, p158) of over 1000 parents identified that nearly 40% had received no post-diagnostic support.

Murray (2012, p.73) shares how *“ignorance and misunderstanding”* still surround the diagnosis of Autism and can result in painful misrepresentations. Hence why, for some individuals, an Autism diagnosis provides them with a sense of identity and greater understanding of self (Stanton, 2000, p.30). Insider accounts from adults diagnosed with Autism such as Temple Grandin (2006) and Wendy Lawson (2000) identify in greater detail their lived experience and how a diagnosis has aided in personal understanding of their lives. Billington (2006, p.2) describes insider accounts as the first-hand experiences of individuals. He further shares that knowledge is not solely confined to professionals, recognising the experiences and understandings that insiders possess (Billington, 2006, p.2; Moore, 2000). Hacking (2009, p.1467) shares the concept of Autism narrative identifying a shift away from clinicians and theorists to people with Autism or their families sharing their stories about living with Autism. During my reading I recognised that Temple does not romanticize autism nor disregard its impact upon her ability to engage with the social world. She does, however, present a positive view of her self being and self worth, reflecting and

recognising how paradoxically Autism has contributed to this identity formation (Grandin, 2006). Current research by Stagg & Belcher (2019) explored the experiences of nine adults aged over 50 who had recently received an Autism diagnosis. Findings uncovered how individuals had been treated for depression and anxiety and identified that they had experienced feeling like an alien and isolated while growing up. Individuals described the diagnosis as positive, allowing for a reconfiguration of their identity and appreciation of their individual needs (Stagg & Belcher, 2019).

The diagnosis of Autism can also sometimes be helpful for parents in explaining their children's presentation or behaviours. Gray (1993, p.103) identifies how parents can often encounter "*hostile or insensitive reactions*" when in the public domain due to their children's presentation of needs. Further research by Gray (2002) discovered the stigma that parents felt highlighting that mothers were more likely to experience this. His research identified that parents had experienced "*avoidance, hostile staring and rude comments*" (Gray, 2002, p.734).

### **Medical model vs social model**

The terms medical model and social model are notably used to identify opposing views of disability, with the term medical model being expressed pejoratively (Hogan, 2019, pE16). Flavo & Holland (2017, p1) share how the medical model focusses upon assessing and diagnosing medical conditions, viewing the problems as intrinsic to the individuals experiencing them. Baglieri & Shapiro (2012, p16) identify how the medical model constructs those individuals with disabilities as physically defective thereby relegating their needs as being physiological. Disability charity Scope (n.d) share how "*the medical model of*



*disability says people are disabled by their impairments or differences.”* The social model of disability was espoused as a reaction to the medical model and moved away from viewing individuals as needing to be cured so that they may conform to social norms and values. Instead, they viewed societal and environmental factors as contributors to an individual’s disability, identifying the need for change to create a society with greater equality and opportunity (Falvo, & Holland, 2017, p2). Scope (n.d) also share how the social model of disability fundamentally believes that *“people are disabled by barriers in society, not by their impairment or difference.”*

### **Conceptualising Autism**

It is important to identify that the concept of Autism is complex, as there are multiple paradigms and perspectives of understanding that may be adopted. However, Carthaigh (2020, p52) identifies how a biomedical model is the most dominant model of understanding Autism whilst also sharing how this has resulted in a preclusion of alternative lenses by which to consider Autism. However, it is recognised that the conceptual framing of the biomedical lens has been strongly informed by genetic and cognitive theories (Carthaigh, 2020, p54).

When considering psychoanalytic and cognitive paradigms, theories to assist understanding within these models include executive dysfunction, weak central coherence, reduced theory of mind and attachment (Richardson, 2008). Cognitive theories have had practical implications as the differences they identify have become the basis of diagnostic psychometrics (Carthaigh, 2020, p55). Ferster (1961) provided a behaviourist perspective of Autism from a completely learned standpoint, pathologising parents by stating behaviours

are directly related to the amount and type of social control parents have over their child (Hixson et al, 2008, p48). However, subsequent behavioural models have adopted a more interactionist approach recognising the interaction between genetics and the environment such as Lovaas and Smith's (1989) theory of a mismatch (Hixson et al, 2008). During my reading, I found the following illustration by Fletcher-Watson, & Happe (2019, p1) visually depicted how difficult it truly is to capture how one may conceptualise the construct of Autism. Fletcher-Watson, & Happe (2019, p2) further share how there are a range of answers that may be given when asked "what is Autism?" identifying that to provide the right answer it is important to recognise the context and the reasons for asking (Fletcher-Watson, & Happe, 2019, p3).



The medical model aims to define and characterise conditions by standardised measures focussing upon diagnosis and emphasising pathology (Flavo & Holland, 2017, p1). A medical diagnosis is generally recognised as a universal truth, based upon objectivity and science, compared to alternative theoretical perspectives which are more readily open to critique. Thus, the biomedical model is accepted as a powerful paradigm by which Autism may be conceptualised and remains the dominant paradigm of understanding (Carthaigh, 2020, p52). Inevitably, the medical model provides diagnosis and, subsequently, constructs related to the medical understanding of Autism that are also universally recognised, understood and accepted as truth. Bagatell (2010, Carthaigh, 2020, p58) shares how labels offer autistic individuals and their families an explanation for idiosyncrasies. Whilst Jordan (2015)

identifies how diagnosis can ensure professionals don't misinterpret individuals' behaviours as defiant. It is, however, important to acknowledge that by appreciating the existence of a medical model this does not exclude or negate alternative conceptualisations. In my own experience, although I advocated for my son's Autism assessment, I recognised the pragmatic benefits of the medical diagnosis or more specifically the label. Research by Jacobs et al (2019, p1152) identified how parents hoped a diagnosis would exculpate both the child and parents regarding the child's behaviours. Lauchlan and Boyle (2007) share how a diagnosis may provide increased resource allocation whilst Gus (2000) shares it may offer increased peer understanding and acceptance. Jacobs et al (2019, p1152) research concluded that parents valued the diagnosis in a pragmatic way, particularly in its ability to offer support in school and protect relationships with teachers and family members. However, the label did not change the unique individual that my son was nor did the label change the way I viewed him. Yes, I participated in the processes related to the medical model's construction of Autism assessment and diagnosis, however, I equally valued and subscribed to the social model of disability recognising the societal and environmental barriers in the world (Falvo, & Holland, 2017, p2) that disabled my son whilst refuting a within child reductionist view. I appreciated that a medical diagnosis would better allow me to subsequently advocate for my sons needs when considering we live in a society that highly values the medical paradigm. A diagnosis would also ensure my son was protected when considering legislation regarding the Equality Act, 2010. Hence, I reflected that positionality in relation to a medical vs. social model of conceptualising Autism is not simply defined by being situated at polar ends of a spectrum, but it is rather more complex to unpick. I recognised that I had engaged with the medical process as I appreciated the

pragmatic benefits that a diagnosis would offer my son even though I inherently subscribed to a social model of disability.

### **Critical Autism Studies**

I felt it was important to address the alternative position adopted by those who subscribe to the contemporary field of Critical Autism Studies. The aims of which may be best described as to challenge the currently accepted biomedical understanding of Autism (Runswick-Cole, 2016, p.7). They seek to move away from the medical model with its deficit laden criteria and intent on pathologising and labelling individuals (Woods et al, 2018). Positioning themselves within a social model of disability, recognising that it is *“the systems, attitudes and environments”* within society that disable people with Autism (Runswick-Cole, 2016, p.7). Woods et al (2018, p.976) further shares how the *“Re-Thinking Autism Network suggests that Autism is purely a cultural construct.”* However, Stanton (2000, p.30) shares how many of those individuals living with Autism affirm that to *“deny them the label is to deny a valid part of their identity.”* It is important for me to outline that by sharing this contrasting position presented by the CAS movement, I do not intend to cause offence to those who seek and believe in the diagnosis as a truth. I simply aim to provide an alternative lens through which the diagnosis of Autism may be interpreted and conceptualised. I find comfort in the second question presented by CAS:

*“Is a diagnosis of Autism useful in the lives of people so labelled, their families and allies?”*

(Runswick-Cole, 2016, p.7).

Yes.

**Reflection:** It is important for me to highlight that during my extensive reading, I found much of the critique presented by the CAS movement to be aligned with my understanding and conceptions of Autism. However, I also recognised the pragmatic commodity of the Diagnosis when considering the support, I had been able to secure for my son. Although I would position myself as an Ally. I fear whether I would be accepted into the community of practice as I currently continue to proceed in advocating for my younger son's Autism diagnosis.

### **Early diagnosis / Intervention**

Autism is considered something that one is born with, and presentation is described as appearing when children are still very young (NHS, 2019; Canitano et al (2020, p.31; Autism Speaks, 2020a). Signs of Autism are commonly present by the age of two or three, however, developmental delays may appear earlier subsequently resulting in diagnosis as early as 18 months of age (Autism Speaks, 2020a). Although Haroon (2019, p.2) shares that it takes confidence to diagnose a child below the age of two to three years. Clinicians can be reluctant to diagnose younger children, possibly due to concerns regarding the temporal stability of the diagnosis and changes in symptom presentation over time. Guthrie et al (2013) identify how stability of Autism diagnosis for children aged three and above is extensively researched (Woolfenden et al, 2012), however, there is limited exploration for those aged under 24 months. Exploration by Moore & Goodson (2003, p.47), who undertook research with a group of 20 children diagnosed at the age of two, subsequently reassessing them at the age of four-five, confirming that *"early diagnosis of Autism is reliable and stable."* In their research Guthrie et al (2013, p.13) explored the stability of a

diagnosis given to children aged between 15 and 24 months. When reviewed one to two years later stability of Autism diagnosis was 100% confirming that toddlers can be accurately diagnosed (Guthrie et al, 2013, p.1). This is positive when considering research confirms that early diagnosis and intervention can lead to greater positive outcomes in later life for people with Autism (Autism Speaks, 2020a). There is a breadth of consolidated evidence that indicates that early intervention has a significant impact on *“reducing the severity of symptoms and improving social communicative and adaptive skills”* resulting in better functioning abilities and greater independence later in life (Canitano et al, 2020, p.31; Mintz, 2018, p.212; WHO, 2019). Mintz (2018, p.212) shares that early intervention is vital to young people’s prognosis as research studies consistently identify better outcomes for children who receive treatment at a younger age. The WHO (2019) further share that *“intervention during early childhood is important to promote the optimal development.”* However, despite the ability to diagnose reliably in younger children the average age remains later (Matson, 2016, p.1) with the mean age in the UK approximated to be five years of age (Haroon, 2019, p.2).

### **Working with parents**

Mintz (2018, p.214) identifies the importance of working collaboratively with parents during the assessment process when referring to diagnostic criteria *“so they are not receiving the diagnosis, they are also making the diagnosis.”* The suggested notion of taking parents along on the diagnostic journey and working collaboratively is refreshing. As a teaching practitioner prior to my role as a TEP I appreciate the value of positive relationships and engagement with parents and how this can enhance the learning and development of children (Wilson, 2016, p.7). Parents can offer insight into the strengths and needs of their

child, in a range of settings and under all circumstances (Gascoigne, 2012, p.6). Gascoigne (2012, p.6) further identifies how the parent's contribution is vital to the Educational Psychologist's assessment. Mintz (2018, p.214) shares that although professionals may be considered "*experts*" regarding Autism and early childhood development, nobody better understands a child than the parents. He further shares that a diagnosis should rely upon a parent's report hence it is integral for professionals to "*aim to obtain parents' accord*" (Mintz, 2018, p.214)" I found this resonated with the way I worked with parents in my current practice as a TEP and previously as a former teacher. I recalled the key findings of the Lamb report (Lamb, 2009, P.4) which had informed my practice as he shared; "*Parents need to be listened to more and brought into a partnership.*" The Lamb report (2009; Crutchley, 2018, p.20) highlighted how parents had historically felt "*disempowered and excluded*" from SEND support systems sharing that they felt systems were dominated by the voices and perspectives of professionals. Research by Todd & Jones (2003, p.232) exploring mothers' experiences of parenting young people with disabilities was foreshadowed by the fact that professionals appeared to be significant figures in their lives. However, as other literature confirms (Williams & Robinson, 2001), much of these relationships were predominantly negative. Furthermore, they identified that "*conflict and struggle*" (Todd & Jones, 2003, p.232) were accepted as topographies of encounters with the service world.

### **Parents as advocates**

I felt it was important to begin by exploring the term advocate. The Cambridge Dictionary (2020) defines advocate as: "*to publicly support or suggest an idea, development, or way of doing something.*" I have used the term advocate as part of my research title as I wanted to explore the experiences of parents who had consciously supported their children's Autism

assessment. Mintz (2018, p.214) shares that parents are their child's "*primary advocate*." He further identifies how it is important that parents agree with the diagnosis, recognising if they don't then access to specialist services for the young person could be impacted. Research by Woodgate et al (2008 p.1081) also revealed how parents recognised that for their voices to be listened to they had to "*function as advocates*." In the research undertaken by Ryan & Runswick-Cole (2008, p47) they share how parents of children with Autism are protective for a more extended period of time and feel the need to fight on their children's behalf. Much of the language used by the mothers in the research emphasised this concept of fighting for their children.

Ryan & Runswick-Cole (2008, p43) identify how the role of advocate for parents of disabled children develops to a frequency and complexity that others may not encounter. I recognised how this resonated with my own experiences of advocating for my sons. Starr & Foy (2012, p.207) share how "*parents know their children best*" hence when considering this assertion, one would assume that professionals would work collaboratively with parents. Shriburg et al (2013, p.283) presents the family-centred model whereby parents are viewed as "*experts*" in relation to their child and family. Similarly, Mintz (2018, p.213) promotes a parent centred approach to assessment, whereby parents and clinicians can come to a shared understanding regarding the child's developmental challenges. However, research by Woodgate et al (2008 p.1079) identified how parents of children with Autism described their experiences as "*living in a world of our own*." They further shared the failure of systems (referring to the conglomerate of education, health, and children's services) to provide support, identifying them as inaccessible and filled with unsupportive professionals (Woodgate et al (2008 p.1079). Research by Howlin & Moore (1997) exploring almost 1300



parents experiences of the Autism diagnostic process in the UK identified high levels of parental dissatisfaction. Their research recognised the need for parents to persist in securing a diagnosis with only 8% of the sample obtaining a diagnosis when they first sought help (Howling & Moore, 1997, p.158). Furthermore, a quarter of the parents had to wait more than five years to obtain a diagnosis. Although overall, 95% of the sample did eventually succeed in acquiring a diagnosis. Howling & Moore (1997, p.158) share how this identifies that parents are *“astute judges of their children’s development”* whilst concluding that *“early concerns by parents about their child’s development must be taken more seriously”* (Howling & Moore, 1997, p.158).

Russell & Norwich (2001, p1) share that *“Many children who display autistic behaviours at clinical levels do not receive a formal diagnosis.”*. This is unsurprising when considering the data from Howlin and Moores (1997) research which identifies how professionals can dismiss and pacify parental concerns. Parents identified how professionals would placate their concerns with phrases such as *“not to worry”* and that *“he’ll grow out of it”* (Hyman, 2001, p.13, Howling & Moore, 1997, p.143). It is unsurprising then that Doyle & Iland (2004, p.26) identify that parents describe *“the struggle of trying to get an Autism diagnosis.”* However, Cohen (2009, p.19) shares how *“experts are not always right”* sometimes perceiving information through their personal *“bias or prejudice.”* He suggests that *“parents must simultaneously rely on experts, while becoming critical consumers and experts in their own right”* Cohen (2009, p.20). I found Cohens words powerful and attributed his suggestion to the idea of ‘expert by experience’ (Matthies & Uggerhoj, 2016, p.69) recognising how as parents we know our children best and thus are uniquely positioned to advocate on their behalf.

## **Other research**

Howling and Moores (1997, p.135) research was the first and largest research of its kind in the UK exploring over 1200 parents' views of the diagnostic process. I have identified several aspects uncovered within the research throughout the literature review thus far. Crane et al (2015) published their research exploring the experiences of over 1000 parents in securing an Autism diagnosis and results were compared to Howling and Moores initial research. Crane et al (2015, p158) discovered that parents experienced a delay of three and half years between initial contact with healthcare professionals and subsequently securing a diagnosis. Unfortunately, the findings do not indicate a significant reduction in waiting times between the two studies. Furthermore, parents shared that a key cause of their stress was the long wait times they had to encounter (Crane et al, 2015, p159). It is then unsurprising that parental dissatisfaction regarding the diagnostic process was also similar to that identified by Howling and Moore (1997, p.135: Crane et al (2015, p159). When reflecting upon the considerable lapse of time between the two studies it is disheartening that parents continue to experience such delays in securing their child's Autism diagnosis. A result which was significantly higher, but not for positive reasons, was the number of parents dissatisfied with post diagnostic support. Howling and Moores (1997) research identified 35% of parents were dissatisfied whilst Crane et als (2015, p159) research found 61%. This is particularly concerning when considering the prevalence of Autism has increased and there are greater levels of understanding, and knowledge readily available regarding Autism.

I found the more recent research by Crane et al (2018) resonated with aspects of my planned research study. A qualitative study was undertaken with 30 participants (ten adults with Autism, ten professionals and ten parents of children with Autism). Participants were interviewed and subsequently a thematic analysis was undertaken to identify key themes. Crane et al (2018, p.3771) shares that the use of a qualitative methodology *“provided a unique and detailed exploration of the autistic diagnostic process in the UK.”* Crane et al (2018, p.3771) concludes how securing an Autism diagnosis can be extremely difficult for families and autistic individuals, hence it is important to consider alternative ways in which they may be supported through all aspects of the process. I found Crane et al’s (2018) concluding comments emotive and recognised that my research would be well situated in exploring an element of the assessment process, in my case, specifically parents’ experiences of advocating for the assessment.

## Chapter 2 - Methodology

### Positionality

I recognised it was important to begin by identifying my positionality in relation to epistemology (knowledge) and ontology (reality), appreciating that my research would be underpinned by the frameworks I subscribed too. Epistemology refers to the theory of “*knowledge*”: querying what constitutes “*knowledge*”, what may be recognised as knowledge, where knowledge is located, and “*how we can know*”... “*what we can know*” (Lyons & Coyle, 2016, p.11: Killam, 2013, p.7; Barbour, 2014, p.29: Khine, 2008, p.33). Ontology is a philosophical study of being which seeks to explore the nature of reality and how one defines what exists or is real (Lyons & Coyle, 2016, p.11: Killam, 2013, p.7; Barbour, 2014, p.29 Khine, 2008, p.33). There are often two binary positions held regarding ontology referred to as either realism or relativism (also described to as interpretivism). Realist ontology posits the existence of an external world which exists independent of our representations (Nightingale, 2002, p.702). Adopting an objective natural science epistemology, they accept the world comprises of “*structures and objects that have cause and effect relationships*” (Willig, 2013, p.12). They aim to objectively test and measure phenomena seeking to establish universal truths employing quantitative methodology (Barbour, 2014, p29). It is then recognised that one’s ontological position will ultimately determine how objective the relationship between the “*researcher and what can be known is*” (Killam, 2013, p.8).

I was aware from the onset of my enquiry that I positioned myself firmly within relativist ontology considering my research emanated from my own lived experiences, thus I could

not claim an objective position, nor would I choose to do so. I recognised that a traditional natural science reductionist approach would limit my attempt to study a complex social phenomenon (Emerson & Frosh, 2009) as I intended to do. I agreed with Bryman's (2001) critique regarding the adoption of natural science epistemology to study the social world and further criticism of the positivist approach outlined by Mauthner et al (2002, p32) regarding the assertion "*that facts can be gathered objectively.*" Manfra & Bolick (2017, p230) share the postpositivist argument that although traditional positivist work claims scientific objectivity it is in fact "*value laden and inherently subjective.*"

I situated myself firmly within interpretivist epistemology and acknowledged its underlying framework to qualitative research. Tuli (2010, p.100) shares that the interpretivist theoretical framework recognises:

*"the world as constructed, interpreted, and experienced by people in their interactions with each other and with wider social systems."*

I recognised that I did not aim to discover one truth but rather explore the individual experiences of the narrators in my research, providing a space for their complete stories to be heard. My interpretivist position provided me with an ontological lens which recognised that "*multiple, apprehendable, and equally valid realities*" exist dependent upon individuals' lived experiences (Ponterotto, 2005, p.129). Further reading allowed me to recognise that within my relativist position I subscribed to the social constructionist paradigm. Hennink et al (2011, p11) defines paradigms as "*models or frameworks*" whilst Killam (2013, p.5) defines the term as a "*set of beliefs or worldview*" in my interpretation I accepted that a

paradigm provides a lens through which we may see and understand the world. Social constructionism insists upon a critical stance, in the way that we understand the world whilst rejecting positivist objectivity (Burr, 2006, p.2; Hall, 2008, p.54). I appreciated that as the listener and person analysing the stories heard, I would be co-constructing knowledge with the narrators, as Andrews (2012, p39) identifies how social constructionists view knowledge as being socially "*constructed*."

Once I had affirmed my ontological and epistemological positionality, I recognised it was time to decide upon a research paradigm that aligned with my philosophical stance. I considered both Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA) prior to settling upon a narrative approach. I appreciated the inductive reasoning and systematic methodology that GT employed to discover rich data (Bryant & Charmaz, 2007, p1). However, the notion of constructing a theory through my research journey did not resonate with my positionality. I recognised that one of the key differences between GT and IPA was that IPA begins with a research question whilst GT aims to discover a question. I did not feel it was necessary to begin my research with a question as is the case with IPA. I appreciated the inductive idiographic nature of IPA, however, I recognised the core of this method was to explore meanings that individuals assign to their experiences and how they make sense of significant life experiences (Smith et al, 2009, p.1). Following conversations with my research supervisors, a breadth of reading, and significant consideration I recognised that a narrative approach was best suited to my research interest. The aim of my research was to provide a space for narrators to share their individual narratives. I did, however, adopt an element of GT in choosing to not focus upon a specific research question. I had situated my research in the title of my exploration which aimed to

specifically focus upon parents' experiences of **advocating** for their **child's Autism assessment**.

### **Qualitative methodology**

When considering the epistemological and ontological beliefs that I subscribe to it is then unsurprising that my research will be qualitative in nature. Qualitative methods in psychology may still be considered contemporary when recognising that they were historically "*virtually excluded from mainstream psychology*" (Howitt, 2019, p.1). Killam (2013, p.12) identifies how the term quantitative is associated with positivism and qualitative with constructivism. Tolman (1992, p.10) shares how historically, during the positivistic era of psychology, psychologists rejected people themselves were valid sources of psychological data. I recognise how a qualitative methodology is more than just a data collecting technique but rather a way of "*approaching the empirical world*" (Taylor, 2016, p.7). Taylor (2016, p.7) defines how qualitative methodology refers, in the broadest sense, to research that produces descriptive data. Pernecky (2016, p.12) describes how there is an increasing conception that qualitative research is "*complex, muddled and confusing.*" This may be due the sense of security that positivism offered regarding assertions of definitive answers from data and the logic of inductive inference (Stam et al, 1993, p.77).

### **Narrative approach**

An interpretative narrative approach was adopted as I recognised how this fitted with my philosophical understanding of research, and because I appreciated the power of stories. Lieblich, et al (1998, p.2) offers a definition of narrative as "*a connected succession of happenings*" Reissman (2008, p.3) shares how narrative is most often used synonymously

with the word story. For the purpose of my research I subscribe to Labovs (1972: Riessman (1993, p.17) assumption that narratives are stories regarding specific past events. Riessman (1993, p3) identifies that telling stories is a *“universal human activity.”* Whilst Schank & Abelson (1995, p.1; László, 2008, p.7 ) share *“Virtually all human knowledge is based on stories constructed around past experiences.”* Narrative analysis recognises that individuals construct stories to make sense of the world (Sullivan & Forrester, 2019). Billington (2017, p.12) articulates how narrative approaches are embedded within person centred and humanist values. He further recognises the emancipatory potential of narrative approaches and their ability to elicit personal experiences (Billington, 2017, p.12). Narrative approaches are recognised as aligning with social constructionist thinking, recognising the importance of voice, whilst acknowledging the relational encounter between the narrator and listener (Billington, 2017, p.12). Narrative research is recognised for its flexible approach which allows for research autonomy and agency in the way that they engage with the research and analysis process. Narrative research does not claim one correct reading or interpretation of research, however, it is advised that researchers provide a systematic rationale for their chosen method of engaging with the available research (Lieblich, Tuval-Mashiach & Zilber, 1998, p.2).

Although Narrative research has increased in popularity in recent years and is considered to be engaging it is also recognised as being difficult (Andrews et al, 2013). Schiff (2017, p.131) identifies how narrative methods can be a source of anxiety for both researchers and students alike. McQueen & Zimmerman (2006, p476) aim to offer a simple breakdown which I found helpful as a starting point:



1. *“Identifying a research issue*
2. *Selecting participants*
3. *Conducting the interview*
4. *Analysing the narrative*
5. *Reporting findings”*

It is important for me to highlight that the above five step structure is in no way my attempts to oversimplify the complexity of a narrative approach. It just allowed me to provide an overview of steps that may be undertaken as part of the process. It does not, however, account for the detail in which each step is subsequently undertaken which I will aim to elaborate upon in the remainder of this chapter.

### **Data analysis**

When considering the approach, I would use for analysing my data I found myself drawn to Thematic Analysis (TA). I found the approach based upon the steps identified by Braun & Clarke (2013, p202-203) provided me with some level of structure. I have included a table of steps below:

*“Table 9.1- stages of coding and analysis”*

Stage	Thematic analysis
1	Transcription
2	Reading and familiarisation; taking note of items of potential interest
3	Coding – complete; across entire dataset

4	Searching for themes
5	Reviewing themes
6	Defining and naming themes
7	Writing – finalising analysis

Braun, V. & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. London: SAGE

I was initially confused how thematic analysis fitted within my narrative approach. However, during my reading, and following supervision, I recognised that thematic analysis was a tool which could be flexibly utilised with a variety of epistemological positions. Braun & Clarke (2006, p4) identify how TA *“offers an accessible and theoretically-flexible approach to analysing qualitative data.”* Braun, Clarke & Terry (2015, p.95) further share that TA is a technique that allows researchers to identify, analyse and interpret patterned meanings or themes in qualitative data. I recognised, however, that TA is considered a method which offers a fairly low level of interpretation (Vaismoradi, 2013, p.399) compared to GT or IPA. However, my intention was not deep levels of interpretation but rather to listen to the stories and recognise the themes identified. I appreciated that my chosen analysis approach would provide me with some structure in regard to the process, whilst still permitting me to creatively engage with the stories collected. I wanted to respect the holistic stories whilst being able to also focus my analysis upon my chosen area of interest regarding parents’ experiences of **advocating** for their child’s **Autism assessment**. Van Manen (2006, p.720: Elo et al, 2014, p.6) shares how qualitative methods require researchers to employ sensitive, interpretive skills and use their creative talents when engaging with data gathered.

## Quality in research

The quality and rigor of research was historically judged by its validity, reliability, and generalisability in recognition of identifying truth. These terms were entrenched in positivist values associated with quantitative work and experimental psychology. Baumgarten (2010, p.2) shares how constructivist researchers disagreed that validity and reliability were meaningful concepts, instead choosing to develop alternative standards. Riessman (2008, p.184) shares her preferred alternative to the concept of “*truth*” in relation to narrative as “*trustworthiness*” (Nowell, 2017). She further highlights that validity in relation to narrative research is in the trustworthiness of the research which can be achieved by identifying the methodological path undertaken, which is steered by ethical considerations and underpinned by theory to “*story...findings*” (Riessman, 2008, p.184). I found Riessman’s guidance around the concept of validity empowered me in my ability to justify my work. I was able to confidently address all the parameters she identified regarding the trustworthiness of narrative approaches in relation to my research journey.

When considering the nature of my research and the methodology adopted it is evident that I do not aim to search for, or identify, a truth. The use of interviews and my subsequent analysis situates my research in a social constructionist paradigm. I acknowledge that I have co-constructed the research through the process of being a listener during interviews and subsequently during my analysis, thus affirming that my research is not intended to be replicated. I appreciate that the interview is not merely a tool for gathering data but rather a social interaction between two people (Fontana & Frey, 2000, p.646). During the process of analysis, I recognise that I bring my subjective self to the process. Hence, I concede that a greater indicator of quality for my research is reflexivity. Reflexivity is described as a

powerful tool (Watt, 2007, p.83) which can be used in aiding qualitative researchers to address ethical issues (Etherington, 2007).

### **Reflective boxes**

I have included reflective boxes throughout my research in the aim of being transparent and honest. Nowell et al (2017, p.5) identifies how researchers are urged to engage with the research and analysis process as a faithful witness when engaging with data, remaining honest and aware of their own perspectives and pre-existing beliefs (Starks & Trinidad, 2007). Although I have included a reflexive thread throughout my writing, I felt it was necessary to include reflective boxes for poignant times when my personal reflections were particularly emotive. The reflective boxes allowed me to fully share my thought processes, at key times throughout my research journey, whilst ensuring they were contained and separate from the main body of writing. Admittedly, I did at times feel vulnerable and open to judgment, wondering whether I should remove the reflective boxes due to their personal nature. However, I found the words of Ward & Delamont (2020, p98) helped as they share reflective practice refers to the way in which we hold our everyday practice to critical scrutiny. O'Reilly & Kiyimba (2015, p36) also share that the quality markers of rigour for qualitative research are: "*transparency, reflexivity and trustworthiness*" which adequately define the premise of my reflection boxes. The reflection boxes are my intimate thoughts which provide a deeper more personal lens into my thinking during key points in my research journey. Subscribing to interpretivist epistemology and a social constructionist paradigm I hoped that the reflection boxes would allow the reader to better understand my positionality and thinking as I did not subscribe to a realist view of objectivity. I recognised how, by experiencing the information in my reflective boxes, the reader and I were

inevitably engaging in a process of social construction. I wanted to embed my thinking and an element of my humanity within the body of my research as I was not a nameless, faceless, researcher, or a scientist, but rather a conscious being who had feelings and emotions that I experienced during this research journey which were valid and real. Therefore, I believed that the reflective boxes would provide the reader a humanistic, qualitative context and inevitably connect us in some form.

### **Chapter 3 - Procedure**

#### **Narrators**

A purposive sampling approach was adopted during the process of recruiting narrators to take part in my research. Purposive sampling was employed due to the predetermined criteria I had identified was important for narrators to meet in order to be involved in the research (Given, 2008, p.562). The following four criteria were outlined on the invitation to participate poster/leaflet;

1. Are you the parent/carer of a young person with an Autism diagnosis?
2. Have they had a diagnosis for longer than one year and did they get the diagnosis within the last three years?
3. Did you recognise the presentation of needs first?
4. Did you advocate for (encourage/support) the Autism assessment?

Specific criteria was identified due to the nature of my research topic. I recognised that by using a purposive sampling approach my research would not be considered representative (Check & Schutt, 2010, p.102). However, as I have outlined previously the aim of my research was an in depth, contextualised exploration of the topic I had chosen, to further my understanding of individuals' experiences and inform my practice.

I was initially worried that I would not be able to recruit any individuals to take part in the research. However, when considering the information presented on the NAS website I recalled that they estimate there are approximately 700,000 adults and children in the UK living with Autism (National Autistic Society, 2020a). The invitation to participate flyer was sent to the local parent carer forum who subsequently shared this with other parent carer forums nationally. They also posted the flyer on their social media platforms and official website. The poster included my email contact details so potential narrators could choose to contact me to identify their interest. Nine individuals initially contacted me for further information at which point the detailed participants information sheet was sent out. Subsequently, four individuals agreed to be involved in the research. When considering the nature of my research study and the methodology employed, I recognised that a sample of four narrators was sufficient. Unlike quantitative research, which often includes large samples of participants and obtains shallow data, I recognised the value of a small sample group and the potential to generate rich, detailed data (Gratton & Jones, 2004, p.53). Crouch & Heather (2006, P496) identify how a small sample "is the way in which analytic, inductive, exploratory studies are best done."

## **Power**

I was consciously aware that it was important to ensure that all narrators were fully informed and independently chose to take part in the research. Leaving them to make initial contact, based upon the invitation to participate leaflet, demonstrated their agency. Subsequently, once they received the participant information sheet they were asked once again to initiate contact confirming they would still like to participate. Finally, prior to the interview beginning narrators were debriefed and asked to sign a consent form outlining key points related to their involvement. Miller et al (2012, p71) identifies how written consent addresses concerns regarding coercion and safety, aiming to protect both researcher and those taking part in research. I felt that these three steps ensured that narrators were in control and could opt out at any stage. Garner, Wagner & Kawulich (2009, p.91) identify how researchers need to be consciously aware and accountable regarding their duty of care to those involved in research. Narrators were also informed of steps they could take to opt out of the research after they had participated if they felt this was necessary, without any questions or need to explain. It was integral that the individuals taking part did not feel coerced into being a part of this research. By adopting the small steps identified, I attempted to ensure they were agentic in the decisions they made to be involved. Wiles (2013, p.6) shares that the premise of informed consent is to provide clear information to individuals regarding what participating in the research will involve and then providing them with time to decide whether they would like to participate. I recognised that I had successfully ensured I obtained informed consent.

## **Ethics**

To ensure rigour of ethical practice a research proposal was submitted and subsequently processed through the University of Sheffield Ethics board. Recommendations suggested by the board of ethics were considered and acted upon before ethical approval was granted. I was also mindful of the British Psychological Society's (BPS, 2014) Code of Human Research Ethics which aided in guiding my ethical understanding.

I recognised the importance of ensuring narrators information was confidential. Crowther & Lancaster (p.82) share how careful consideration should be given by the researcher to the way in which data is recorded and stored. All interviews and subsequent transcripts were stored on an encrypted, password protected USB stick which was kept in a locked safety container within my home. To maintain anonymity for both narrators and their family members that had been mentioned during the interview process, I used pseudonyms. Wiles (2013, p.7) identifies how anonymity maintains narrator's confidentiality and is the primary way in which researchers aim to protect those involved within research. Given (2008, p16) shares how anonymity protects narrators from potential harm that they could otherwise encounter from the disclosure of their identity. Although I recognised that the nature of my research did not place narrators in harm, I respected that ethically it was my responsibility to ensure confidentiality and anonymity was maintained.

## **Emotional distress**

The safety of the narrators was a key part of my ethical considerations. I acknowledged that the topic I was researching may be emotive for some parents depending upon their experiences of having to advocate for their child. Large scale research by Howlin & Moore



(1997) and Crane et al (2012) identified high levels of parental dissatisfaction regarding the diagnosis process. I was conscious that narrators could bring to the surface deeply embedded emotions. I also recognised that much of the literature regarding Autism diagnosis identifies parents' experiences of grief following receiving an Autism diagnosis. Research undertaken by Bravo-Bentez et al (2019, p.1) of twenty family caregivers of children diagnosed with Autism identified that they "*endure intense and continuous sorrow and grief.*" As a result, I ensured one of the criteria identified for individuals to participate was to have had their diagnosis for longer than a year. I wanted to ensure that parents had been given some time to process their child's Autism diagnosis before choosing to be involved in research. Furthermore, I ensured I was vigilant throughout the interview process and narrators were debriefed before beginning and after we had finished. I also produced an ongoing support sheet with contact details for support organisations along with my own my contact details.

**Reflection:** In the process of attempting to ensure that the narrators were ok I completely lost sense of my own wellbeing. Having once again been positioned as an advocate, I struggled. I was back to the beginning of a journey for my younger son, that I had thought had ended with my older son's diagnosis. I could not have foreseen that I would be back in this position when I had chosen to undertake my research study. I attempted to contain my feelings but struggled and subsequently sought medical advice.

## **Pilot**

Once ethical approval had been granted an initial interview was undertaken with the intention for it to be a pilot study. Salkind (2010, p.502) identifies how a pilot study can allow researchers to evaluate the questions being asked during interviews and change

aspects that may be considered ambiguous. I had chosen to initially undertake a pilot interview to reflect upon my unstructured interview approach and consider whether it was necessary to include questions within the interview process. I was able to transcribe this initial interview and meet with supervisors to discuss some of the poignant initial themes that I was recognising. However, following deep reflection and conversations with my supervisors I recognised the importance of including the rich data gathered from this interview within the main body of my research. The interview allowed me to reflect upon my role as a listener and informed my understanding for subsequent interviews. I recognised that my narrative approach and philosophical underpinnings regarding positionality would not allow me to not value the story shared in the same way that all the other participants stories would be. Furthermore, I recognised that there were no significant changes between my first interview and those undertaken subsequently. I was also uncomfortable with the notion of a pilot study as my reading identified its associations to quantitative positivist research in its attempts to evaluate the “*feasibility, efficiency*” and often “*cost of study methods*” (Hulley, 2007, p.276).

**Reflection:** I recall only choosing to consider a pilot study because I was so nervous about my first interview. Furthermore, peers had suggested that research examiners love to see a pilot study. However, once I had undertaken that initial interview I felt empowered and more confident in my ability. To not value that first interview which in many ways helped to shape my listener identity did not feel right. I recognised that this was my research journey and that I was an agentic, autonomous being who had the power to shape it in the way I saw best. I also recognised how powerful listening to that first story was for me as a novice researcher and I could not disregard this.

## Interviews

Due to the narrative approach I had adopted, I felt that it was important to use unstructured interviews to co-construct data. I recognised that my position as a listener was relational and constituted a social interaction with the narrator. I did not feel it was necessary to have a plethora of questions as I wanted to provide a space for the narrators to share their stories in relation to their lived experiences around the research question identified. I recognised that unstructured interviews also shifted the power balance which may otherwise occur when researchers bombard participants with questions. I wanted my interactions with narrators to be spontaneous and arise from interesting points that I sought further detail upon, whilst actively listening to their stories. Leavy (2004, p.150) shares how, in unstructured interviews, the researcher has very little influence allowing the interview to flow where the participant goes.

I felt unstructured interviews were also important considering all the narrators were female. As a biological male I did not want my presence in any way to inhibit their ability to share their stories. Given (2008, p.127) shares how unstructured interviews are often adopted by *“qualitative researchers who advocate feminist and emancipatory approaches.”* Banister et al (2011, p92) identifies how feminists critique traditional research and interview methods as masculine views of knowledge. Feminists argue it is impossible to put aside ones emotional responses and thus welcome them as part of the interview process. They argue for reciprocity during the interview, suggesting a give and take, and for self-disclosure on the part of the interviewer allowing for trust and empathy, resulting in a yield of thick data (Banister et al 2011, p93). Subscribing to this position, prior to beginning my interviews I shared with parents why I was interested in my chosen topic. I disclosed that I too was a

parent who had advocated for my child's Autism assessment and had subsequently received a recent Autism diagnosis. I recognised that narrators appeared to immediately recognise me as an ally with one parent saying, *"so you get it, you know, you understand."* At this moment I recall feeling like an insider rather than someone observing from the periphery. I found the concept of passionate scholarship resonated with my position at this moment in time as it *"refers to commitment to a personally meaningful and socially relevant topic, close to the heart"* (Heinrich, 2010: Banister et al, 2011, p92: Courpasson, 2013, p.1243).

As part of my interviews I provided some broad headings which narrators could choose to use to guide them in sharing their story if they became stuck. I included the headings within the participant information sheet, so narrators had seen them prior to the interview. The headings provided were:

- Presentation of needs
- Recognising Autism
- Parents' Feelings
- Advocating – how, where, and when
- Professionals and agencies involved
- Securing a diagnosis

As a novice researcher I recalled feeling nervous about the interview process, fearing awkward silences and limited interaction. I felt it was important to be prepared, hence providing the headings listed above. King & Horrocks (2010, p40) share that during research interviews it may be important to formulate and employ many probes and prompts to obtain the fullest account. Dwyer et al (2016, p13) share how narrative researchers may or may not have probes to explore research interests. They go on to state that they may

choose to avoid questions during the interview in attempts to reach beyond the assumptions and constraints embedded within structured interviews (Dwyer et al, 2016, p13). I was also conscious that as a qualitative, narrative listener I wanted to provide a space for narrators to share their stories with limited interjections from myself. I fully subscribed to the narrative psychology belief that people are natural storytellers (Willig, 2013, p152) yet I wanted to be prepared just in case. However, I found that narrators were happy to share their personal stories and did not refer to the headings provided. It was clear that the stories were so deeply personal and emotive that narrators did not need the prompts available. The interviews lasted approximately 30 to 45 minutes and were audio recorded so that they may be transcribed later as part of the analysis.

Upon reflection I now recognise that the narrative prompts I provided had a temporal framework and sequential structure which could inevitably have influenced the way that narrators shared their stories. However, this was not of concern as Luton (2010, p60) shares how narrative enquiry *“incorporates temporality in our understanding of actions and events.”* Although I found during the interviews that the narrators did not seek to look at, or follow, the headings provided it was important to acknowledge this. Nevertheless, I was not concerned because, even if the headings may have provided some structure, they did not detract from my focus which was the content of the stories that were personal to the narrators lived experiences; this is what I was focussed upon as part of my research enquiry and subsequent analysis.

## Analysis

I recognised that the analysis process began for me during the interview itself, as I processed the story being shared it became a part of my episodic memories stored within the hippocampus. I recognised how it would be processed and made sense of through the lens of my own subjective experiences, with a reference point to schemata I had forged through my past encounters. I recognised how the culmination of my social encounters with individuals had shaped my understanding of the knowledge that had been shared. Given (2008, p.468) identifies how *“knowing or understanding is not an individual endeavour but rather is socially situated; knowing cannot exist in a vacuum or a cognitive abstract system.”*

Prior to beginning my transcription process, I would sit and listen to the individual stories that the narrators had shared with my headphones on. I listened to the stories without writing anything down to begin the familiarisation process. I did not rush to transcribe the audio files as listening to the stories via audio was more accessible and less daunting for me.

**Reflection:** I was nervous to begin the process of transcription as a student diagnosed with specific learning difficulties (SPLDs). Having a diagnosis of ADHD and dyslexia I worried about my personal barriers. I recognised that I had to set sufficient time aside to ensure that I was able to transcribe interviews and revisit them to ensure accuracy. My supervisors suggested audio assisted technology but I felt uncomfortable considering using this. In some ways I did not want to be seen as different and, ironically, I wanted to prove myself the same as everyone else. I do not regret my decision to not use assistive technology as I recognise that the time and effort it took to complete the transcripts allowed me to engage in detail with the narrators' stories. However, my view on being seen as the same as everyone else is very much different; I am proud of my identity and individual differences.

Following two weeks of listening to the audio files I recognised it was important to transcribe the audio file into written form. Historically, the transcribing process was viewed

as mundane and passive, however, researchers now accept the active nature of the transcription process (O'Reilly & Kiyimba, 2015, p.115). Miller et al (2012, p.151) identifies how processing data is an active part which begins well before the analysis. Although I found the transcribing process difficult due to personal barriers, I recognised it as a valuable and key step in my research analysis. Stopping, pausing, and starting the audio countless times to ensure accuracy became a habit. I used the rough transcription method favoured by narrative analysts as identified by Riessman (1993: Sullivan & Forrester, 2019, p.217). Sullivan & Forrester (2019, p.217) identify how the cleaning up process of adding punctuation can distort and jeopardise what is being said. Sullivan & Forrester (2019, p.217) share how the transcription process represents collaboration and co-construction between the narrator and listener.

During my analysis process I engaged with each of the seven steps of thematic analysis identified by Braun & Clarke (2013, p202-203). However, for me it was not simply a step by step linear process that ended with the final stage. Although I did engage with the steps identified there were times when I revisited previous stages of the analysis process and found that my thoughts had changed. I accepted this as the iterative inductive process that I subscribed to as a qualitative researcher. During my time engaging with step two and familiarising myself with the stories I began to note down aspects of individual narratives which were evocative for me. I saw this as distinctly different to the steps for my thematic analysis. This process resonated more with my understanding of suggestions from a feminist position regarding emotional responses (Banister et al, 2011, p92).

During the process of coding my data I struggled to decide whether to specifically focus solely on my area of interest or to engage with all interesting codes that I could identify. Given (2008) shares that in thematic analysis the researcher considers the themes in relation to the research question and across the data set as a whole. I decided that I would seek out and code all interesting themes. I felt, as a researcher influenced by narrative, I had to see the holistic story during my analysis. I found the process of coding one that required multiple evaluations in each of the stages, themes were highlighted, named and then changed countless times.

I feel it is important at this point to recognise that in the process of coding, identifying themes and generally analysing my data inevitably my subconscious lived experienced will, to some degree, have influenced my meaning making. It is important for me to highlight, however, that I did not have a question or hypothesis that I began with. My research is merely an exploration of an area I am interested in. Thus, no conscious bias has been knowingly applied in the process of my analysis.

<b>Stage</b>	<b><u>Thematic analysis</u></b>	<b><u>What I did</u></b>
1	Transcription	Prior to the transcription process I spent two weeks listening to the audio files.
		Transcribed the audio files using rough transcription techniques.
2	Reading and familiarisation; taking note of items of potential interest	I engaged with the transcripts reading and rereading them to familiarise myself with the content.
		I noted down aspects from holistic stories that were evocative to me.
3	Coding – complete; across entire dataset	I began highlighting to code the data set.



4	Searching for themes	I named what I had initially highlighted.
5	Reviewing themes	I collated the themes.
		I decided to create a word cloud using individual transcripts to identify which words and phrases were used most.
6	Defining and naming themes	I identified 3 main themes each with a number of subthemes
7	Writing – finalising analysis	I created visual posters of evocative aspects of the holistic narratives for each participant.
		I wrote up the analysis reflecting on theory and research related to my research question.

### **Dissemination of results**

I intend to share the results of my overall study with narrators by creating a visual video which incorporates all aspects of my analysis. I will include the evocative posters, word clouds and overall themes with direct quotations from narrators' stories. I feel a visual representation will allow me to present the results in a creative way. In the interim, considering that narrators have shared their personal stories, I felt it was important to share something that was co-constructed. Thus, I decided to share the evocative posters and each of the participants have provided feedback which I will include within my analysis section. I felt that the evocative posters demonstrated true co-construction as they image parts of the narrative that were evocative and elicited emotional responses from me. Thus, I feel they represent real co-construction between myself and the narrators.

## Chapter 4 - Analysis

Example of one transcript is included within the body of the analysis section; all four transcripts will be included in the appendix for reference purposes.

D4 - Carla – Thematic Analysis transcript

<u>Codes</u>	<u>Interview Transcript</u>	<u>Reflections</u>
<p>A feeling</p> <p>Somethings not right</p> <p>Advocating</p> <p>Presentation</p> <p>Research</p> <p>Somethings not right</p> <p>Dismissed</p> <p>Research</p>	<p><b>Listener:</b> So, thank you so much for agreeing to take part in this research, the title of my project is listening to the stories of parents who actively advocate for their child's Autism assessment. I'm really interested in hearing your story. I've given you a sheet with some headings for prompt. But generally, it's really important for me to listen to your story and provide you that space. So, I hope that's what I'll be able to do. And so, I'll just hand over to you if that sounds okay, unless you have any questions for me.</p> <p><b>Narrator:</b> Absolutely fine this story of ours started and I think as a lot of parents do when it comes to Autism with a gut feeling erm I remember going to Jacks, 18 months assessment and speaking to the health visitor and saying there's just something not quite right, eye contact was hardly there. Errm you'd say his name and you'd hardly get anything. Plus, he was hardly making any other noises that I'd read up about because Jack was my first so ermm I didn't really have anything to go on and I thought, well, hold on, there's something not quite right and I remember going to the 18 month assessment and speaking to them, and all I got was oh nooo no he's fine there's absolutely nothing absolutely nothing and I remember looking it up on the internet like all all worried parents do and thinking hold on he's got quite a few triggers there for early onset Autism. But I was full time teaching at the time, and I thought okay I'll trust their judgment. And you know, everything will be fine no problem anyway. Then it got to about the age of two and we had a health visitor who was also a nursery nurse practitioner. She used to come to</p>	<p><i>This resonates with my own experience; those embodied responses are so important and a physiological response to our feelings and thoughts. I remember that gut feeling.</i></p> <p><i>I have encountered so many parents who share they have researched on the internet. I too did this when my first son</i></p>

<p>Thinking Autism</p> <p>Appointments / Courses</p> <p>Trusting professionals</p> <p>Presentation</p> <p>Practitioners can't say</p> <p>Some things not right</p> <p>Presentation</p> <p>Something not right</p> <p>Advocating</p> <p>For school</p> <p>Contact</p> <p>Waiting</p> <p>Advocating</p> <p>Presentation</p> <p>Advocating</p> <p>Evidence</p>	<p><b>work with him on his speech.</b> And she kept saying, oh, <b>he really likes his Thomas trains, doesn't he? he likes playing with the same thing. He doesn't doesn't like to change does he what he's doing.</b> And we obviously, became very close over the time she worked with Jack. <b>And they said to me, years later I couldn't actually say I think he's got Autism because it will have to come from the parent unfortunately, she said it's not allowed to come from us.</b> So erm anyway, eventually I had some time off with my second one because I was very, very poorly. I had morning sickness so I couldn't teach for the whole well for the last six months of the pregnancy I couldn't teach and it's during that time spending more one on one time with him I thought. <b>No, definitely not ok there's something. He wasn't toilet trained. He was soiling all over the place he still does it now and he doesn't recognize the need to go or why should I go? And he's not bothered. And he likes that routine.</b> If things are different and the world could be collapsing around him. <b>And he gets fixated, so he'll watch the same cartoon, over and over and over and over. And when he did start talking, it was incredibly echolalic in that he would copy exactly what you just said to him ermm straight back. So, at that point, I said to the nursery nurse, I think there's something not quite right.</b> And she said would you mind if I did a quick home assessment next week. I said oh it's absolutely fine. He ticked off the boxes so she said well don't you think he might need to go to, <b>you know for assessment because he'll be going to reception</b> within 12 months. So, I said yes let's get the ball rolling then. So, I managed to get in touch with the hospital and from that day on from the minute that his letter went through. <b>I just phoned the hospital nearly every other week because a friend said it can be a good 12 month waiting list, I thought, NO I'm not having that.</b> If he if he is suffering if he is locked in, which, you know, he could be again <b>because he's very echolalic. And you know he couldn't quite communicate very well at all and I said no. I said this has got to be sorted out.</b> Erm meantime, then I was made redundant. But I thought that I've got to get just got to get this boy sorted. And I was applying for a job one day. Because like you do and he walked into the office and said mummy stop tippy tappy and I thought that's it it's the most he has ever said and here I am looking for a job. I said that's it I'm packing it in. And so eventually we got to see the consultant, the consultant who he is still under. Is very much. <b>Where's the evidence? Have you got any evidence? So, I managed to get hold of reports from nursery and reports from the nursery nurse</b></p>	<p><i>was born, looking for important milestones. I also remember searching the internet when I recognised my second son's presentation of needs.</i></p> <p><i>I understood this because as a TEP I had also been told by colleagues that we do not mention the word Autism. We can discuss presentation but we do not say the word so we don't lead parents.</i></p> <p><i>I can hear the power in the parent's voice, advocating for her son.</i></p>
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Appointments / Courses	<p>practitioner's health and speech and language, then I also managed to get him on to a speech and language course. And every time a course was offered, even if I thought it was going to help or not, I put our name down because I knew if his name disappeared off any list, he would disappear. It wouldn't be found. And I find that. You know, I have to go on courses that I think, well, it's not exactly going to hit him but then I think like he'll get known. Then you find out that there's another course that does fit him and talking to other parents there like oh we didn't know what was coming up. There was a course on food that I went on because of his very limited diet. Some of the parents were like I didn't know they were running that and I thought yeh if it hadn't been for the fact I'd been on the other course the week before and I'd overheard them talking and I said, oh, I'll, go on that. But you do, you have to push yourself. You really have to push yourself forward to get any sort of support. And you almost feel like your pestering. But you've got to keep yourself on the radar and I think that's the one piece of advice I would give anybody is what once you think that that is where you're going. You've got to keep the ball rolling and you've got to keep in contact with everybody and you've got to keep fighting ermm most definitely. So anyway, the consultant on the first bit was like well it might be it might not be, and we'll carry on with the speech therapy and I'll see you again in six months. I thought, right I've got six months now, got six months to really get this evidence together. And, you know, I went to all the speech therapy sessions and I kept saying his specialist wants this all in writing. And is there anything you can give me in writing after every session and I just collected as much paperwork as I could. And then when I saw him, I just presented him with all the paperwork. and he said Oh, yes, yes, you've got all this evidence. But what I did do was I photocopied it all so that nobody could say, oh, no, no, you didn't give us that because my mum was a nurse and she often said its surprising how many how much stuff goes conveniently missing in terms of referrals and things. So, I thought, well, I'm not having that happen to him either. And so, from then, he said, okay, yes, yes, yes so when is he going to start reception. So, he's starting in September and this is like the January before, by this point. So, he said oh right well it will be about 12 months and I thought no I'm not having that. So, I pushed and pushed, got him in for the July. Thank goodness. And we walked in, and they were lovely they were fantastic and after the assessment they basically said we could tell before it even started the</p>	<p><i>Sad to hear that this parent felt that her son would disappear if she didn't stay on the radar.</i></p> <p><i>FIGHT. I remember that feeling, it did feel like a fight.</i></p> <p><i>Attending the appointments and collecting the evidence is all the different ways in which we advocate.</i></p>
Known		
Appointments / Courses		
Support		
Contact		
Known		
Fight Appointments / Courses		
Dismissed		
Advocating		
Evidence		
For school		
Advocating Waiting		

<p>Diagnosis</p> <p>Support</p> <p>Response to diagnosis</p> <p>Diagnosis power</p> <p>Advocating</p> <p>Presentation</p> <p>Appointments / Courses</p> <p>EHCP</p> <p>Education / experience</p>	<p>assessment by the way he walked in. By the way he presented himself and we knew it was going to be a positive result. They were they were fantastic, really really, supportive in how they gave over that news in that they said it was a positive. We now know where we're going. And he is really a specialist. His mind is just so focused. He will be a specialist in whatever he is interested in we were then handed over to a lady who was meant to be the family support worker from the hospital. She said, oh I'll give you all the support you need, and we'll be there for you from day one. She gave us a leaflet and then that was it. She said we'll be in contact with you and I'll always be there for you. So anyway, two weeks after diagnosis, obviously it hit us all pretty hard. So, I tried to give her a ring, because I thought well, she said she would support the family. So, I gave her a ring and it was all like Oh, no, no, no, erm I'm really busy at the minute I'll pass you on. And never heard anything back. So, I thought I'm going to have to erm do this myself. You know I've got my diagnosis you know; he's just finished nursery. We're going into reception and I managed to basically do it myself. So, I got in touch with the local Autism team and I said I really need a home visit. I said he can't go into town centre it's just too busy for him. And plus, because I've got the baby anyway. And so, I would need a home visit, I put my name down for every single erm meeting every single course going. And then when it came to school, I think because I was a teacher, I still am a teacher, qualified teacher. I know the systems and I know what an EHCP is. I know what they mean when they say Ed Psych and things like that because I was head of year as well. So, I had all that prior knowledge of SEN. So, in the end, they couldn't really get past me.</p>	<p>The lack of support available is deflating, considering how parents must feel post diagnosis.</p>
<p>Advocating</p> <p>Support</p>	<p>Listener: Yes.</p> <p>Narrator: And I was able to go in and say right he's got the SALT team coming in. And you know, when are we having an Ed Psych visit you know when he is going to be seen by the Behavioral support team inclusion team. And it's been very much, I think, because of that school see me more as a support rather than somebody who is going to pester.</p> <p>Listener: Yes.</p>	<p>Sound like the parent is empowered since receiving the diagnosis.</p>

<p><b>Support</b></p> <p><b>Advocating</b></p> <p><b>For School</b></p> <p><b>Reason for diagnosis</b></p> <p><b>Presentation</b></p> <p><b>EHCP</b></p> <p><b>Advocating</b></p> <p><b>Positive outcome</b></p>  <p><b>Diagnosis power</b></p> <p><b>EHCP</b></p>	<p><b>Narrator:</b> So, we've got a really open relationship. You know the SENCO also taught my youngest son. He's just going to reception now. And, you know, like she said, they know the family really well and <b>the door is always open they are not afraid to talk to us about anything at all.</b> And they know that we we'll work on it. But again, I think they also know that if they slip up, <b>I would be straight in.</b></p> <p><b>Listener:</b> Yes. Can I ask you in regards to going for the Autism diagnosis, what was the reason why was the diagnosis important to you?</p> <p><b>Narrator:</b> <b>The diagnosis was important for me because I didn't want him going into school with him having a label of him being a naughty child.</b> I knew that if somebody saw a Jack, they would think <b>he's not listening he's not cooperating.</b> I thought no we need to get him on the SEN register because <b>I knew that they would have to have three terms worth of evidence anyway. Before they could even start the EHCP process</b> I thought no I need to get him on the SEN register, and I need to get it done before he starts in the September. So luckily, because he had his assessment July time and I was able then to go into school, about two weeks later before they broke up. <b>And said look this is his diagnosis. This is what they are saying he needs. And I was able to give him as much information as I could, including all the documentation I had, right the way from the past, so that they could get a really good background in terms of what's going to help him when he starts in reception. So, it did work in a positive for Jack and for the school because they said they don't normally get this amount of information. So, when he started, they already had ear defenders in his favourite colour, they already had sensory cushions, they had already got sensory blanket you know they had already gone and purchased things for him beforehand. So that when he started in September, he had everything that he needed. And, you know, box of dinosaurs, box of Thomas toys right near where his space would be, and that's what they've been like they have been Fantastic.</b></p> <p><b>Listener:</b> Did the diagnosis help?</p> <p><b>Narrator:</b> Completely, 100 percent. Because I don't and I honestly and truly believe,</p>	<p><i>Diagnosis strengthens parental voice to be able to advocate.</i></p>
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<p>Dismissed</p> <p>Advocating</p> <p>Age</p> <p>Validation</p> <p>EHCP</p> <p>Advocating</p> <p>Known</p> <p>Professionals voice</p>	<p>because I've seen it myself, throughout the years of teaching and even Secondary. <b>If you haven't got a piece of paper with that diagnosis, nobody wants to listen</b> because it closes the door that <b>EHCP that diagnoses opens, so many doors</b> and people, you know, even in the NHS their whole opinion changes the minute you <b>say you have a diagnosis</b> before then is very much a case of, you know, anxious mum, over anxious. And, you know, you have obviously read about it. And you put two and two together. We think you've come up with seven. <b>Whereas when you've got a diagnosis you know they are a little bit more well yes.</b> This is where we could be going and they are a bit more proactive <b>rather than trying to placate and say, well, you know, I always, make you feel like they will grow out of it.</b> <b>And once you got that diagnosis, there's nothing they can come back at you with, so it does really help, it really does help.</b></p> <p><b>Listener:</b> You have talked about the EHCP process how was that with having a diagnosis?</p> <p><b>Narrator:</b> And in terms of the diagnosis erm I mean, obviously, I know the parents in the school who, you know, who are going through the process, or are trying to get through the process of having an Autism assessment. <b>And the ones who are still trying cannot get an EHCP.</b> They cannot seem to get one. It seems to be with our local area. <b>If you have got a diagnosis, they they will, listen to it, more carefully.</b> Also, the feedback I've had because I know quite a few parents and they have gone to different organizations. They have said they have had the <b>ADOS but because they're still not working with speech and language, because they're still not involved with the Autism team. There EHCPs didn't seem to be pushed through as quickly. It seems to be the more in contact you are, the more agencies more you've got, the ADOS assessment, the more they are willing to listen to you. It's almost as if they will listen to the expert, but not to the parent.</b> You know. And there's another little boy who used to go to Jacks school and I've known this little boy since he was two. He' virtually non-verbal and he couldn't cope in mainstream and they were struggling to get him an EHCP because he didn't have a diagnosis. Parents are gorgeous they are lovely, but they didn't know who to go to and where to go. They didn't know who to pester. They didn't know that there's such a thing as an Autism team. They didn't know there was such a thing as going to the speech and language team, apart from</p>	<p><i>I feel like the parent is pathologised and not believed.</i></p> <p><i>Professionals or practitioner as I prefer, their voice seems to be prioritised. Very much a medical model of working.</i></p>
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<p><b>EHCP</b></p> <p><b>Dismissed / Professionals voice</b></p> <p><b>Positive outcome</b></p> <p><b>Presentation</b></p> <p><b>Self-doubt</b></p> <p><b>Validation</b></p> <p><b>Self-doubt</b></p> <p><b>Validation</b></p> <p><b>Education / experience</b></p>	<p>oh, your sent for you do your six weeks and off you go, and they didn't know all that support was out there. <b>But having an EHCP is vital it does open up doors. But It doesn't matter, they won't believe that your child has got Autism until they have got that ADOS from a specialist.</b> They won't believe it. They should but they do not believe it.</p> <p><b>Listener:</b> So now thinking about having had the diagnosis and securing the diagnosis and having had it for an extended period of time. How is life now? How do you feel about going through that process? Are you glad that you advocated for that assessment?</p> <p><b>Narrator:</b> <b>I am glad that I pushed for that assessment, because he's happier. He's content.</b> And it sound silly but some days before the assessment <b>when he was having a meltdown or banging his head on the walls</b> and I used to think I'm a really bad parent. I can't control this. I can't change it. I can't make him feel any better, <b>whereas getting that assessment. Also make me feel, that yes, your concerns were justified. You son does need extra support and you know you're not you're not going stir crazy yourself.</b> Do you what I mean, because sometimes you think it's all in my own head. Have I just made it up. Is it just that he is naughty. <b>And when you get that assessment where they say, basically you're right, you're thinking, right ok, I was right. It does make things better.</b> And I've seen other children, you know, to people that I know who really struggle they are in mainstream. And they can't get out. And then they're having a hard time being bullied and everything else. Whereas with Jack because of the school I chose and because how I've been with the school, we all work together. I've been able to say oh a child said this today. Can you please do it in circle time, can you please discuss it. <b>I think because I know the terminology and I know the phrasing. And, you know, I could slip in, you know, little buzz words around OFSTED and stuff and just just drop in a conversation and they'll just say, yeah yeah, we'll do that and it's been absolutely fine. No problems whatsoever.</b> And to the point where, you know, the head phoned me last year and said, well, we're having a staff restructure. We're going to keep all of Jacks TAs the same. And we're going to move the year six teacher down to year, two, because that's the one teacher he really does gel with. It's another male teacher he really does gel with and we're doing it for Jack, and I thought. Yeah. That tells you the difference that they have though about Jack. You know,</p>	<p><i>Very difficult and hard to rationalise when you feel alone and not listened too. I remember doubting myself.</i></p> <p><i>Made me think about belonging to a community of practice and whether as a teacher you're an inside or outsider. As a teacher was Carla's voice privileged.</i></p> <p><i>The power of the diagnosis, I understand this. It feels like</i></p>
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<p><b>Diagnosis power / EHCP</b></p> <p><b>Education / experience</b></p>	<p>when there's 20 other the children in that class. They have thought, let's get this child sorted and I think for head to do that. <b>Just tells you the power of having a diagnosis</b> and a <b>EHCP</b> and <b>that knowledge</b>. And having that relationship with them as well, because they also say we know we can talk to you about about anything at all and you understand it. You know, we don't have to water it down, so to speak. And so, we can have open dialogue. And it's just a shame that I think that parents don't are not give those those keys and that terminology to be a help even further. I think if I had not been a teacher, I think it's a two-way thing. I don't think teachers are educated enough Autism. I don't think parents are about what they're dealing with, about how hard it is going to be. And I think there's a lot of work still needs to be done. An awful lot. Yeah. Yeah.</p> <p><b>Listener:</b> Thank you so much for sharing your story.</p> <p><b>Narrator:</b> No Problem, Thank you.</p>	<p><i>your feelings and thoughts are validated and there's greater strength to what you have said.</i></p>
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## Full theme map

I have included below a map of all the themes that I identified as part of my analysis process. It is important, however, to highlight that in recognition of my research interest I will be solely focusing on sub themes related to the overall theme of advocating. This is due to the context of my research enquiry and the title of my project. I do, however, value all the collective themes that have been identified and may address some of those within the discussion section. I recognise that my in-depth analyses has provided me with an abundance of rich data which can be utilised for further research in the future and to inform continuing EP practice.

<u>Theme</u>	<u>Sub themes</u>
<b>Parental concern</b>	Presentation
	Research
	Comparing
	Somethings not right
	A feeling
<b>Advocating</b>	Challenging professionals / systems
	Fight
	Waiting
	Concern dismissed
	Education/experience
	Evidence
<b>Diagnosis</b>	The diagnosis
	Diagnosis power
	Support for school
	EHCP
	Positive outcome
	Funding

Focused theme map addressing the research title;

<u>Theme</u>	<u>Sub themes</u>
<b>Advocating</b>	Challenging professionals / systems
	Fight
	Waiting
	Concern dismissed
	Education/experience
	Evidence

<u>Sub theme</u>	<b>Carla</b>	<b>Bianca</b>	<b>Karen</b>
<b>Challenging professionals / systems</b>	<p><i>"I just phoned the hospital nearly every other week because a friend said it can be a good 12 month waiting list, I thought, NO I'm not having that."</i></p> <p><i>"So, he said [consultant] oh right well it will be about 12 months and I thought no I'm not having that. So, I pushed and pushed, got him in for the July."</i></p> <p><i>"So, I got in touch with the local Autism team and I said I really need a home visit."</i></p> <p><i>"So, he said oh right well it will be</i></p>	<p><i>"I asked for them" [referral to different assessment pathways].</i></p> <p><i>"I just went don't bother I said he's not making, don't even bother because he's not making any progress. Don't bother. I would like to get all the people to come back and. You know, I would like everybody come back. I want to speak to them and I want to see, you know, don't even bother. Come on. I said, how long will we wait for those assessments? When he's year 6 and leaving to secondary. And I've got a kid who's falling apart. So</i></p>	<p><i>"I asked them to keep an eye on her at nursery and just get back to me."</i></p> <p><i>"But I don't know. I just had to keep. Kind of pushing to find out when the appointments were going to be."</i></p> <p><i>"And I said, I'm sorry. No, absolutely not. She's struggled a lot at school. It's affecting us as a family. We can't go anywhere. You know, I'm sorry, but I'm not accepting that, because then, you know, I won't have any contact with you guys. And then I've got to wait however many years until, you know, there's even more signs and she's even worse and struggling even more. And then I've got wait another like what</i></p>

	<p><i>about 12 months and I thought No I'm not having that. So, I pushed and pushed, got him in for the July. Thank goodness."</i></p> <p><i>"But again, I think they also know that if they slip up, I would be straight in."</i></p>	<p><i>we need to have something in place for him at that point."</i></p>	<p><i>year and a half or something to actually get back into the system just for the beginning. So I just said I'm sorry. Absolutely not. Is there anything else that you can, any other kind of assessment you can do? Or, you know, somebody else that can, you know, have input on, she did a different process. And ironically, within two weeks, they had diagnosed her."</i></p> <p><i>"And I'm like, she's struggling at school. Absolutely not. If I'd done what she said, then she wouldn't be where she is today, which still isn't amazing, but she definitely wouldn't have been where she is."</i></p> <p><i>"I was just like, I'm absolutely sorry. But, no, you need to do a different assessment. Or look at it a different way or get somebody else in and look. You know, I don't accept that you want to wait until she's seven to diagnose her. No. Well you need to get back in the system, to look at diagnosing her. No, again, absolutely not."</i></p>
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Reflections - I recognise different forms of challenge. Some subtle such as persistence, some more authoritative. I also recognise a worst case/ scenario catastrophising situation.

<u>Sub theme</u>	Carla	Laura	Bianca
<b>Fight</b>	<p><i>"You've got to keep the ball rolling and you've got to keep in contact with everybody and you've got to keep fighting em most definitely."</i></p>	<p><i>"And it was a constant battle and a constant fight."</i></p> <p><i>"I did not understand how much of a battle and fight it is to get them the support, even with all these letters and the professional help."</i></p> <p><i>"I don't understand how it is such a fight."</i></p> <p><i>"I got brushed off, but I had to keep fighting fighting fighting."</i></p> <p><i>"You know, but at the same time, I knew I couldn't give up because that's my children I'm fighting for"</i></p> <p><i>"But obviously, eventually after getting her speech and language support. And physio and OT and, you know, other paediatric consultants and the psychologist involved, which again was a fight."</i></p> <p><i>"I won't give up. I'll keep fighting."</i></p>	<p><i>"We've got a diagnosis. We're back to school. Brilliant. And then another journey starting. Which is another level of fighting for your child."</i></p> <p><i>"Because I had to fight for Elias."</i></p>

Reflections – Use of emotive language. Language of force resistance from professionals met with resistance from parents.

<u>Sub theme</u>	Carla	Laura	Bianca	Karen
<b>Waiting</b>	<p><i>“because a friend said it can be a good 12 month waiting list”</i></p> <p><i>“So, he said oh right well it will be about 12 months”</i></p>	<p><i>“In the end, the paediatric consultant said to me, right we will do an assessment for Autism. But it’s still an 18-month waiting list.”</i></p> <p><i>“But again, it was an 18-month waiting list. In the meantime, ok 18 months might not sound very long to people, but when you're trying to get your child support in nursery and in school,”</i></p>	<p><i>“And I got a letter saying the waiting list is very long. We'll keep you updated. It was two years before he got seen.”</i></p> <p><i>“I've been waiting two years. I am not changing the appointment and wait another six months.”</i></p> <p><i>“And then for Autism, we waited bang on two years from the moment we got referred.”</i></p> <p><i>“And that, I think, is the frustration you could ring them and say I want my appointment well that’s the waiting list. You won't bypass it.”</i></p>	<p><i>“But it made me feel really frustrated that it was such a long process and she was struggling with school”</i></p> <p><i>“I just had to keep. Kind of pushing to find out when the appointments were going to be. I knew it were going to be a long time until I got one but, it did feel like it took forever.”</i></p>

Reflection – feelings of frustration associated with having to wait.

<u>Sub theme</u>	Carla	Laura	Bianca	Karen
<b>Concern dismissed</b>	<p><i>“and I remember going to the 18 month assessment and speaking to them, and all I got was oh nooo no he’s fine there’s absolutely nothing absolutely nothing and I remember looking it up on the internet like all, all worried parents do and thinking hold on he’s got quite a few triggers there for early on set Autism.”</i></p> <p><i>“So anyway, the consultant on the first bit was like well it might be it might not be, and we’ll carry on with the speech therapy and I’ll see you again in six months.”</i></p> <p><i>“you know, even in the NHS their whole opinion changes the minute you say you have a diagnosis before then is very much a case of, you know, anxious mum, over</i></p>	<p><i>“they were assigned a paediatric consultant and I spoke to them and they kept saying, oh, it’s a phase. She will grow out of it”</i></p> <p><i>“I just noticed the differences, something inside me said something’s not right. Kept talking to the consultants and they were like She’s young she will grow out of it. And I was like look, I know she’s young and, but I feel as a parent something’s not right.”</i></p> <p><i>“You know, so I found that more difficult and getting consultants to listen to me was, Oh, she’s young she’s young. She could grow out of this stage. She could grow out of this phase. I was like, something’s not right. I</i></p>	<p><i>“it was paediatrician. Actually, when I had an appointment and she’s done some tests and some games with him and she says, I’ve got no issue. He can understand everything. But he’s bilingual so he will speak much, much, much later.”</i></p> <p><i>“And then when you speak to your parents, the parents know, they say he will grow out he will grow out”</i></p> <p><i>“They said oh, that’s all right. There are some kids like that. They don’t like having hair cuts,”</i></p> <p><i>“And fairly soon again at that point I just thought something is not ok. But then he’s 5. It’s okay. He’s only little, so he’s only five here. And then we came here and he got in to</i></p>	<p><i>“And at the time, that was kind of thrown off as, it its, probably because she’s got an older sister and her older sister is talking for her but, I knew it, it just didn’t feel like that because she never she never did speak for her.”</i></p> <p><i>“When she did the one at home, I felt the psychologist, I felt that she wasn’t well, she kept saying that there’s definitely a mental health problem there. But she felt that she couldn’t make a specific diagnosis until she was a little bit older. And I said, cause she mentioned, you know, getting referred again when she was 7.”</i></p> <p><i>“She was the one saying, even pointing out more to me even more than what I</i></p>

	<p><i>anxious. And, you know, you have obviously read about it. And you put two and two together. We think you've come up with 7."</i></p> <p><i>"It's almost as if they will listen to the expert, but not to the parent."</i></p> <p><i>"But It doesn't matter, they won't believe that your child has got Autism until they have got that ADOS from a specialist. They won't believe it. They should but they do not believe it."</i></p> <p><i>"rather than trying to placate and say, well, you know, I always, make you feel like they will grow out of it."</i></p>	<p><i>need your support because otherwise she's not gonna get support once she starts school. And it was a constant battle and a constant fight."</i></p> <p><i>"No one was listening to me because from me realising to her, getting the diagnosis. You're looking at probably two and half, three years of constant hospital appointments, speech and language appointments, physio, occupational therapy, psychologists, paediatric consultants and being constantly being told she's young she's will grow out of it."</i></p> <p><i>"but no one was listening to me. She's young, she's young you know, she was born addicted to drugs. You know, she may take longer to catchup. But as</i></p>	<p><i>school. And again, I was like, that's fine, that's fine. You know, he's absolutely fine."</i></p>	<p><i>thought there were, for her to then turn around and say, well, yeah, there's something there but you need to wait. And I'm like, she's struggling at school. Absolutely not."</i></p>
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		<p><i>a parent you know but try to get professionals to listen to you.”</i></p> <p><i>“But you’re getting all these people doubting you. Telling you its normal she will grow out of it.”</i></p> <p><i>“. But getting professionals to listen to you, especially because Hannah was so young when I noticed the changes and differences. I got brushed off, but I had to keep fighting fighting fighting”</i></p>		
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Reflection – Parents are told not to worry age of children chronological age used to dismiss parents concerns.

<u>Sub theme</u>	Carla	Laura	Bianca
Education / experience	<p><i>“And then when it came to school, I think because I was a teacher, I still am a teacher, qualified teacher. I know the systems and I know what an EHCP is. I know what they mean when they say Ed Psych and things like that because I was head of year as well. So, I had all that prior knowledge of SEN. So, in the end, they couldn't really get past me.”</i></p> <p><i>“I think because I know the terminology and I know the phrasing. And, you know, I could slip in, you know, little buzz words around OFSTED and stuff and just just drop in a conversation and they'll just say, yeah yeah, we'll do that and it's been absolutely fine. No problems whatsoever.”</i></p>	<p><i>“I mean I've worked with autistic children before as a support assistant in a school, done a lot of training around Autism in an Autistic school. My brothers Autistic. He's now 28”</i></p> <p><i>“And I just think I've always worked with children with special needs and I did not understand how much of a battle and fight it is to get them the support even with all these letters the professional help.”</i></p>	<p><i>“And at that point, I started working with children with Autism and like realizing and learning and I've done the whole diploma about autism, researching things.”</i></p> <p><i>“we've been in the workplace. What I'm do for living. Being a special needs teacher, knowing what I know now as well,”</i></p> <p><i>“Helps being a teacher of children with special needs. Because I'm sure that if I wasn't, I would get pushed a lot of things more to do but I think they know that, I know what I'm talking about.”</i></p>

Reflection – parents who were teachers were able to advocate in school for quicker results.

<u>Sub theme</u>	Carla	Laura	Bianca	Karen
<b>Evidence</b>	<p><i>“And so eventually we got to see the consultant, the consultant who he is still under. Is very much. Where’s the evidence? Have you got any evidence? So, I managed to get hold of reports from nursery and reports from the nursery nurse practitioner’s health and speech and language, then I also managed to get him on to a speech and language course”</i></p> <p><i>“I thought, right I’ve got six months now, got six months to really get this evidence together.”</i></p> <p><i>“I just collected as much paperwork as I could. And then when I saw him, I just presented him with all the paperwork. and he said Oh, yes, es, you’ve got all this evidence.”</i></p>	<p><i>“Obviously, eventually after three years and her having, obviously OT physio, paediatric consultant, child development CAMHS, speech and language and people going to view her in nursery. I had enough evidence to say look all these people now agree with me you know.”</i></p> <p><i>“I logged everything down on a piece of paper. You know, and every appointment I was like she’s now done this”</i></p> <p><i>“But when a parent is, you know I was showing them video clips, I’d written it all down on a pad”</i></p> <p><i>“Once I got all of them to see her and seeing all their reports. Then I started getting listened to.”</i></p>	<p><i>“So piles of reports all evidence that everybody saying he’s below below below expectation progress. He’s below on this below on that.”</i></p>	<p><i>“Well one of my friends said keep a diary because she’d already been through it all and she just said, you’ll forget a lot of it when you go, so just keep a diary. And she said keep appointments and letters it’s all evidence.”</i></p> <p><i>“Because the way, she had so much evidence given to her. And it was obvious with how she is as a person, you could see how she is.”</i></p>

## Evocative posters and word clouds

During the next part of my analysis I will include the posters that I created during my time reading and analysing the data. I refer to the posters as evocative posters because I included within them aspects of the narrative which warranted an emotional response from me. I found the words of Banister et al (2011, p93) helped to guide me, as she shares feminist epistemologies welcome emotional responses and seek faithful analyses. I was initially nervous about sharing these as they deviated from the structure I had foreseen my research following in regard to the methodology and analysis I had outlined. I recognise now, however, that the feelings of discomfort arose from my indoctrinated knowledge of methodocentrism as a precursor for validity (Weaver & Snazer, 2017, p1056). I appreciated that the methodology was a contextual framework which would aid to guide my choices; however, I did not want it to constrain my creativity (Kara, 2015, p2). Ulibarri et al (2019, p7) share how the structures of modern research do not support optimal creativity. Wegener et al (2019, p2) write how if we are preoccupied with structures of how things should have happened we risk not seeing and engaging with the *“inspirational sources right in front of us.”* Patton (2002, p.513) further shares how creativity plays an important part in qualitative analysis. Ulibarri et al (2019, p7) identify how a *“creative process can yield more creative research content.”* Whilst Wegener et al (2019, p2) identify how creative research is the product of a *“curious, sensitive and playful life as a human being.”*

I found the concept shared by Maclure (2013) fascinating as she describes the **wonder** of data, sharing her belief in its untapped potential within qualitative research. She helps to define wonder as the entangled relation of the data and researcher, existing within bodies and minds. Maclure (2013) shares how we experience wonder in our embodied responses,

such as a gut feeling or increased heartbeat. Daston and Park (2001) also describe wonder, sharing that it is “*cognitive passion.*” It is as much about “*knowing*” as about “*feeling.*” This resonated with how I had developed the posters as a response to my embodied feelings when engaging with the research. The posters were created not in relation to my research question but rather to my initial engagement with the research data and reflection upon key points that warranted an emotional response.

As I reflect upon the posters there is some sense of temporality to the posters in the linear way they almost represent a mini beginning, middle and end. It demonstrates the way in which I have engaged with the story and unknowingly provided a narrative structure to help process my thinking of key parts of the narrator’s complete stories. I was aware that I wanted to share the posters with the narrators as I did not feel just meeting them for the interview was ethical. I wanted the narrators to see the creative interpretation of their story and welcome their feedback. Sharing the posters provided me with peace as the narrators were aware of how I had engaged with their stories. In sharing their stories about themselves in relation to their children they gave me something very personal. I recognised it was important to me, in some way, to demonstrate what I had done and how I had kept what they had given me, i.e. their story, safe.

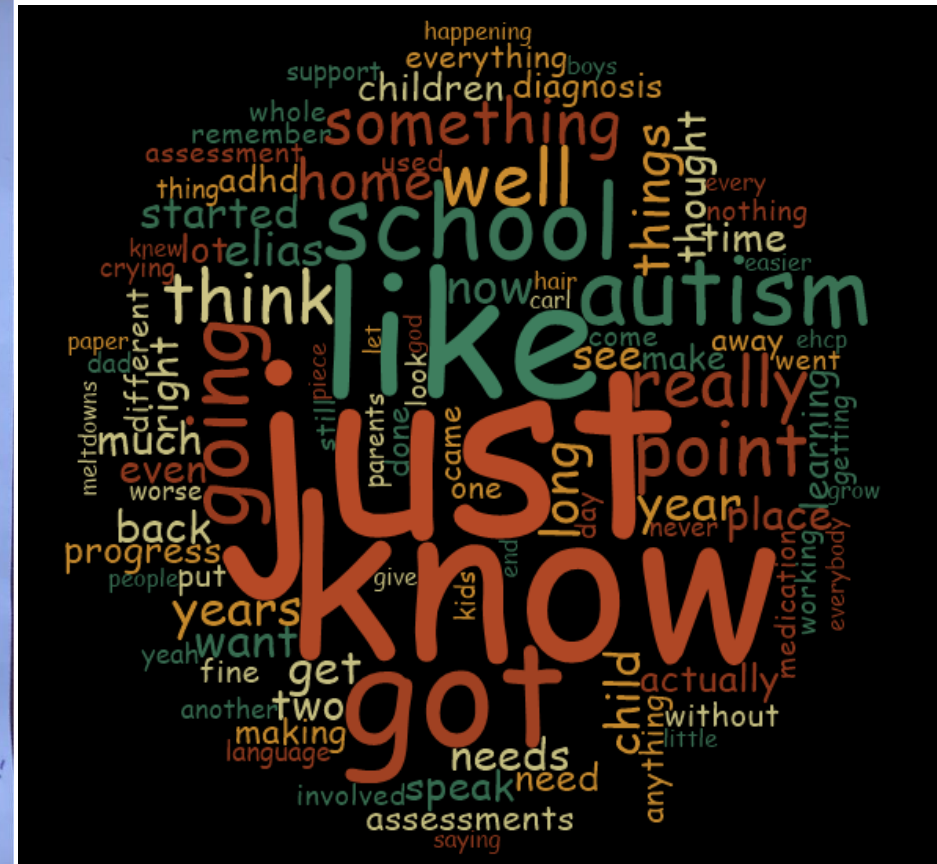
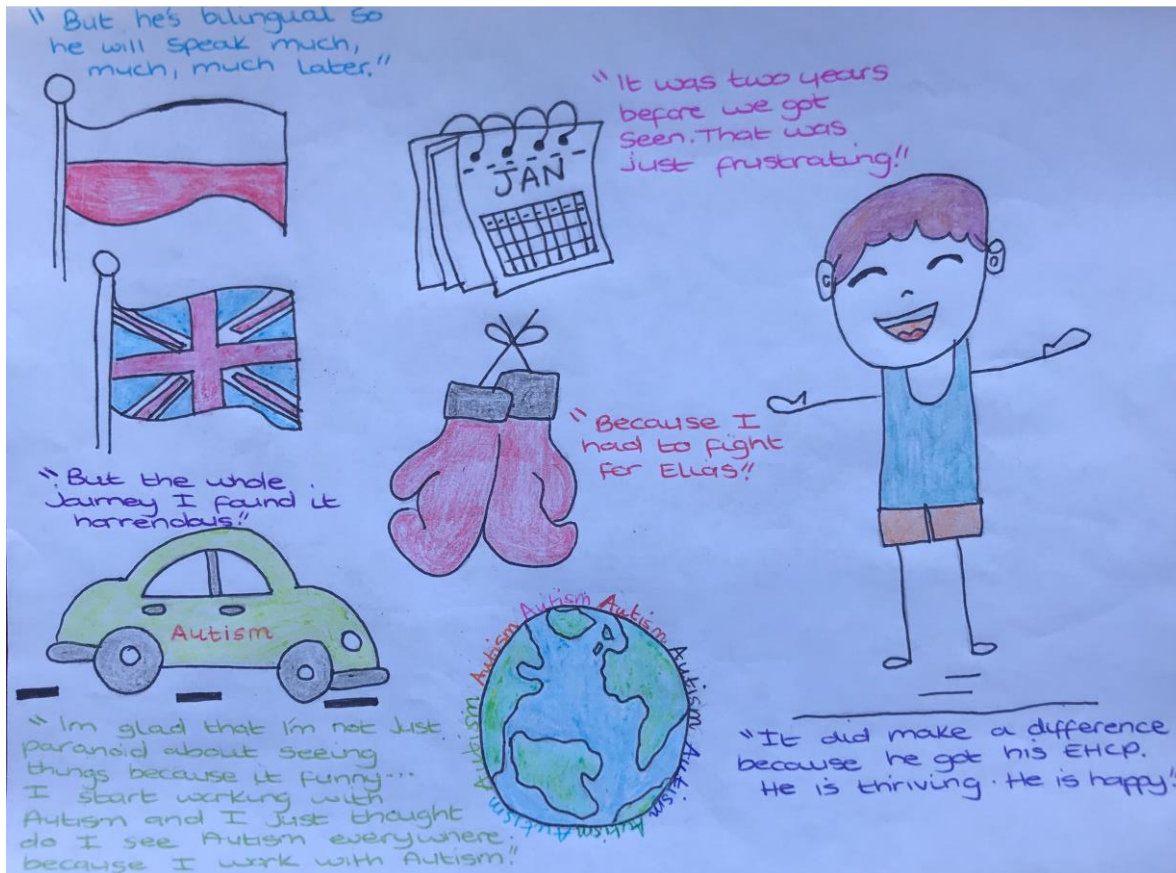
I also used word clouds for their qualitative purpose as I found they captured some of the key words that narrators had used during the interview process. I was not interested in the quantitative numbers but rather I wanted to visually demonstrate the power of the narrator’s words and how they were valued.







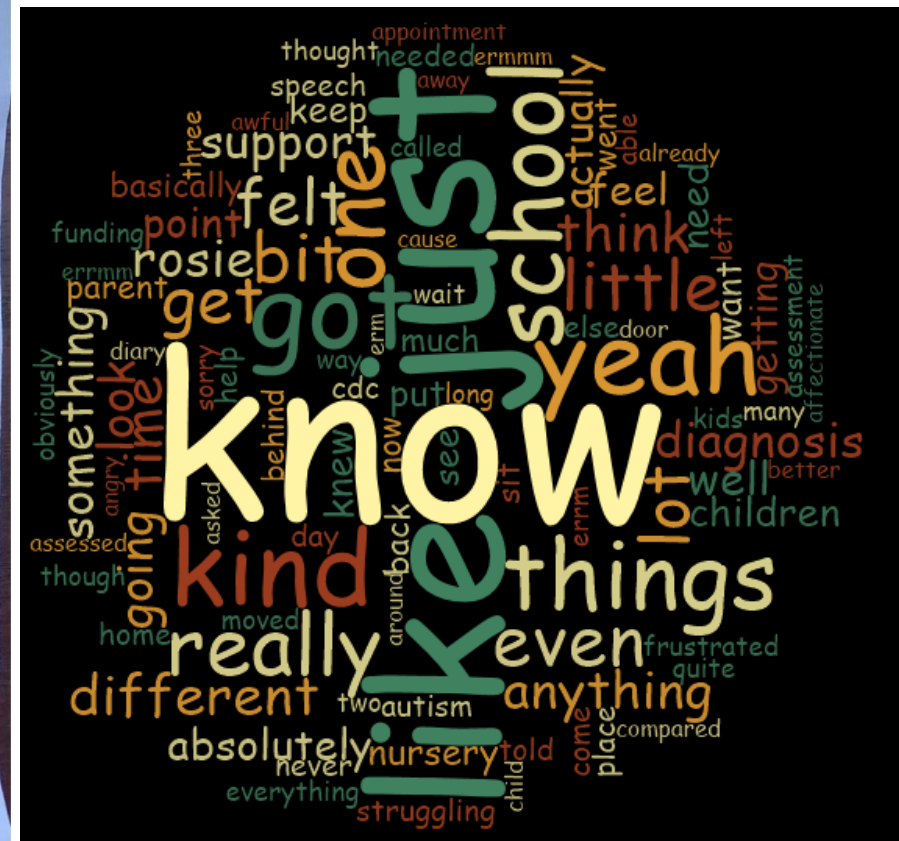
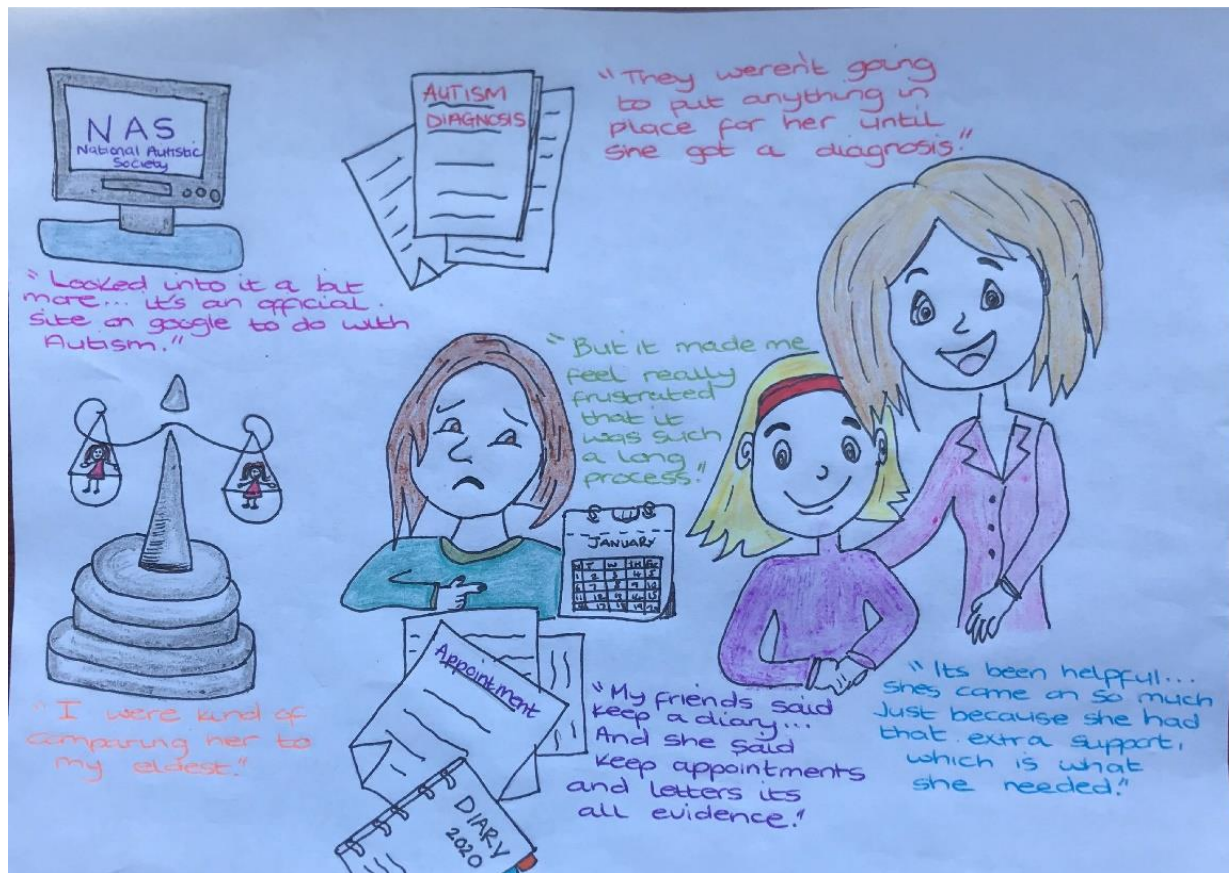
Bianca's evocative poster and world cloud



Bianca – "I feel that you captured so well the key moments of our very lengthy, stressful and emotionally strenuous journey to get adequate help and support for Elias."



Karen's evocative poster and word cloud



Karen – "This picture is an incredibly moving representation of our journey as a family with Rosie's diagnosis. It highlights the success and the downfalls we experienced together."

## Chapter 5 - Discussion

Within this section I will go through each of the themes identified linked to my research title and interpret them, with reference to literature where necessary. I will also identify how this may impact upon EP practice.

### Themes specially related to my research interest

<u>Theme</u>	<u>Sub themes</u>
<b>Advocating</b>	Challenging professionals / systems
	Fight
	Waiting
	Concern dismissed
	Education/experience
	Evidence

### Challenging professionals / systems

**Carla** - *“So, he said oh right well it will be about 12 months and I thought No I’m not having that. So, I pushed and pushed, got him in for the July. Thank goodness.”*

**Bianca** - *“I just went don’t bother I said he’s not making, don’t even bother because he’s not making any progress. Don’t bother. I would like to get all the people to come back and, you know, I would like everybody come back. I want to speak to them and I want to see, you know, don’t even bother. Come on. I said, how long will we wait for those assessments? When he’s year 6 and leaving to secondary. And I’ve got a kid who’s falling apart. So we need to have something in place for him at that point.”*

**Karen** - *"I was just like, I'm absolutely sorry. But, no, you need to do a different assessment. Or look at it a different way or get somebody else in and look. You know, I don't accept that you want to wait until she's seven to diagnose her. No. Well you need to get back in the system, to look at diagnosing her. No, again, absolutely not."*

In each of the extracts shared above it is evident how the parents are challenging the professionals that they are encountering. Carla shares how she pushed and pushed and succeeded in getting an earlier appointment. She uses persistence to support her to successfully challenge professionals and achieve change. However, during the interview process I recall the passion with which she stated, she responded to the professional; **"No I'm not having that."** I recognised this as Carla being direct. Woodgate et al (2008 p.1081) highlight in their research that parents become more direct as a form of challenging professionals. Bianca's extract may be identified as her employing a worst-case scenario or catastrophising narrative to support her in challenging the professionals thinking and the systems she is engaging with. It is evident that the experience she spoke of was a difficult time and that she had been waiting for an extended period of time to get support for her son. Karen shares how she challenged a professional who had suggested possibly waiting for a diagnosis. She repeatedly affirms her position saying 'No' even suggesting a second opinion. She subsequently succeeded in acquiring a diagnosis a few weeks later. In each of the interactions shared above it is evident that the parents are attempting to shift the power imbalance by challenging the professionals. Each of the examples identify unique ways in which parents may challenge professionals or systems. It is important to equally recognise that not all parents will challenge the systems or professionals they encounter in

the same way, if at all. It is, therefore, important for us, as practitioners, to recognise those marginalised voices and how we may support to elevate them.

Research by Todd & Jones (2003) explored mothers' perceptions on their dealings with professionals. Qualitative research was undertaken with 30 mothers of young children with intellectual disabilities. The research study confirmed that *"mothers' dealings with professionals were problematic for them"* (Todd & Jones, 2003, p.229). The research also identified that *"mothers were willing to challenge professional's perspective of their children"* (Todd & Jones, 2003, p.229). The research identifies how professionals were depicted as lacking sensitivity and unwilling to listen to mothers. Research by Woodgate et al (2008, p.1079) of parents with children diagnosed with ASD identified how they felt isolated due to unsupportive systems, referring to education, health and care services. It is evident that much work needs to be done in encouraging systems and the professionals working within them to work collaboratively with parents. Mintz (2018, p.213) promotes a parent centred approach to assessment whereby parents and clinicians work together collaboratively.

When considering the implications to EP practice in relation to the theme of challenging professionals / systems I would like to hope that we, as service who identifies as practitioner psychologists rather than professionals, always aim to work by the values of co-production outlined by the Rotherham Charter (2020) (refer to image below). We aim to foster trusting relationships with all stake holders and recognise that individuals have funds of knowledge they bring with them and are experts by experience on their own lives.



### Fight

**Carla** - *“You've got to keep the ball rolling and you've got to keep in contact with everybody and you've got to keep fighting emm most definitely.”*

**Laura** – *““And it was a constant battle and a constant fight.”*

*“I did not understand how much of a battle and fight it is to get them the support, even with all these letters and the professional help.”*

*“I don't understand how it is such a fight.”*

*“I got brushed off, but I had to keep fighting fighting fighting.”*

*“You know, but at the same time, I knew I couldn't give up because that's my children I'm fighting for”*

*“But obviously, eventually after getting her speech and language support. And physio and OT and, you know, other paediatric consultants and the psychologist involved, which again was a fight.”*

*“I won't give up. I'll keep fighting.”*

**Bianca** - *“We've got a diagnosis. We're back to school. Brilliant. And then another journey starting. Which is another level of fighting for your child.”*

*“Because I had to fight for Elias.”*

The connotations and imagery often associated with the word fight are recognised as being negative. The word is emotive and elicits strong feelings. It is then unsurprising that parents use this word to describe their experiences of advocating for their children. It is evident that parents experience strong emotions when the topic concerns their children; rightly so. When considering the extracts shared above the word fight implies resistance that is being met by force from parents. Having engaged with the complete narratives I recognise that this resistance is from either systems or professionals that parents subsequently feel they have to fight against. The word fight is also used to describe a position or stance the parents have taken for their children in advocating for them. Russell & Norwich (2001, p10) share how parents are clearly fighting to get their voices heard in order to advocate for their

children. Ryan & Runswick-Cole (2008, p43) undertook interviews with 36 mothers of children with autism; they identify how many of the mothers used language related to fighting when describing the ways in which they advocated for their children.

During my exploration of relevant research, I discovered a plethora of articles which identified parents sharing similar experiences and using similar language to describe their experiences. Research by Woodgate et al (2008 p.1081) of 16 families of children living with Autism identified how parents described how they had to become more direct, "*to fight all the battles.*" Parents identified they had to change their behaviour, more specifically around not becoming emotional and being more direct. Carlsson et al (2016, p.328) undertook qualitative research with the parents of 11 children diagnosed with Autism. Parents highlighted that they continuously had to fight for support for their children in every new situation with authorities and throughout the school system. It is alarming to hear that systems are unsupportive to parents and this message is consistent in much of the contemporary literature I have encountered. Although the prevalence of Autism and awareness within mainstream society has increased it is surprising that systems are still so far behind in being supportive and working in collaboration with parents. It is evident that significant systemic change needs to occur so that parents feel supported.

**Reflection:** Whilst exploring this theme I reflected on my practice as a TEP and my experiences of engaging with parents. I recalled some parents who initially may have been direct and firm and later warmed to me. Thinking back now following my discussion surrounding the themes of challenging professionals/systems and Fight I recognise potentially why. If parents' experiences are all based on systems and professionals that they have had to challenge and fight then that is the tool they will use in future encounters with these systems. However, my experiences have taught me that by demonstrating that not all systems are the same we can act as agents of change when it comes to the negative experiences parents may have previously encountered.

### Waiting

**Carla** - *"because a friend said it can be a good 12 month waiting list."*

*"So, he said oh right well it will be about 12 months."*

**Laura** - *"In the end, the paediatric consultant said to me, right we will do an assessment for Autism. But it's still an 18-month waiting list."*

*"But again, it was an 18-month waiting list. In the meantime, ok 18 months might not sound very long to people, but when you're trying to get your child support in nursery and in school,"*

**Bianca** - *"And I got a letter saying the waiting list is very long. We'll keep you updated. It was two years before he got seen."*



*"I've been waiting two years. I am not changing the appointment and wait another six months."*

*"And then for Autism, we waited bang on two years from the moment we got referred."*

*"And that, I think, is the frustration you could ring them and say I want my appointment well that's the waiting list. You won't bypass it."*

**Karen** - *"But it made me feel really frustrated that it was such a long process and she was struggling with school"*

*"I just had to keep, kind of pushing to find out when the appointments were going to be. I knew it were going to be a long time until I got one but, it did feel like it took forever."*

All the narrators identified, in some capacity, a concept associated with time and having to wait. Both Karen and Bianca identify experiencing feelings of frustration as a result of the waiting times. Research by Crane et al (2016, p.160), of over a 1000 parents in the UK, identified *"long wait times as the key cause of their stress."* Crane et al (2016, p.160) confirmed a key finding of their research was that parent typically experience a 3.5 year delay between initially contacting a healthcare professional and finally securing a diagnosis. What was evident from the narrator's stories were distinct differences in regional waiting lists for the diagnostic pathway, as Howling & Moore (1997, p.135) discovered in their

research with almost 1300 UK based parents. It very much felt to be a postcode lottery. Carla identified a 12-month waiting list, Laura 18 months and Bianca two years.

When considering my practice as an EP, waiting times are relevant because a new diagnostic pathway has been created in our local authority where an EP will be a part of the diagnostic process. Being aware of parent's dissatisfaction associated with waiting times will be helpful so this can be avoided as much as possible. Parents dissatisfaction with the overall diagnostic process correlated with waiting times, identifying the longer that they had to wait the more dissatisfied they were with the diagnostic process; this is also highlighted in some of the largest research studies with parents such as Howling & Moore, 1997 and Crane et al, 2016.

**Reflection:** During my time exploring the theme of waiting I reflected on my practice and specifically thought about waiting times for the EPS. Unfortunately, our contemporary status as a traded service has changed our accessibility and the control now lies with schools. Hence it is important for us to encourage schools to listen to the needs and concerns of parents and refer children to our service where necessary. I also considered waiting times in reference to waiting for EP reports, which is often commented upon by stake holders during our service evaluation annually. I have made a commitment to endeavour to reduce waiting times so parents do not have to wait for prolonged periods of time.

### Concern dismissed

Carla - *“and I remember going to the 18 month assessment and speaking to them, and all I got was oh **nooo no he’s fine, there’s absolutely nothing absolutely nothing** and I*

*remember looking it up on the internet like all, all worried parents do and thinking hold on he's got quite a few triggers there for early onset Autism."*

*"So anyway, the consultant on the first bit was like well it might be it might not be, and we'll carry on with the speech therapy and I'll see you again in six months."*

*"you know, even in the NHS their whole opinion changes the minute you say you have a diagnosis. Before then is very much a case of, you know, anxious mum, over anxious. And, you know, you have obviously read about it. And you put two and two together. We think you've come up with seven."*

I found the experience that Carla described regarding the NHS rather emotive. It troubled me that in the process of attempting to advocate for her child she was in some ways pathologised and subsequently labelled, even if only conceptually, as the anxious mother. In this extract it is clear that there is a power hierarchy at play in which the professional attempts to silence Carla's voice.

**Laura** - *"they were assigned a paediatric consultant and I spoke to them and they kept saying, oh, it's a phase. **She will grow out of it"***

*"I just noticed the differences, something inside me said something's not right. Kept talking to the consultants and they were like **She's young she will grow out of it.** And I was like look, I know she's young and, but I feel as a parent something's not right."*

*“You know, so I found that more difficult and getting consultants to listen to me was, Oh, she's young she's young. **She could grow out of this stage. She could grow out of this phase.** I was like, something's not right. I need your support because otherwise she's not gonna get support once she starts school. And it was a constant battle and a constant fight.”*

*“No one was listening to me because from me realising, to her getting the diagnosis. You're looking at probably two and half, three years of constant hospital appointments, speech and language appointments, physio, occupational therapy, psychologists, paediatric consultants and being constantly being told **she's young she's will grow out of it.**”*

*“but no one was listening to me. She's young, she's young you know, she was born addicted to drugs. You know, she may take longer to catchup. But as a parent you know but try to get professionals to listen to you.”*

*“But you're getting all these people doubting you. Telling you its normal **she will grow out of it.**”*

*“But getting professionals to listen to you, especially because Hannah was so young when I noticed the changes and differences. I got brushed off, but I had to keep fighting fighting fighting”*

**Bianca** - *“it was paediatrician. Actually, when I had an appointment and she's done some tests and some games with him and she says, I've got no issue. He can understand everything. But he's bilingual so he will speak much, much, much later.”*

I find it alarming that Bianca was dismissed using inaccurate information regarding speech acquisition skills of bilingual children. Lauren Lowry (2016), Certified Speech and Language Pathologist, identifies that it is a myth that bilingual children speak far later. Typical development of speech ranges between 8-15 months and bilingual children often begin speaking at 11 months, well within the range of typical development. I found that this element of Bianca's narrative made me uncomfortable as a bilingual adult and parent of young bilingual children.

*"And then when you speak to your parents, the parents know, they **say he will grow out he will grow out**"*

*"They said oh, that's all right. There are some kids like that. They don't like having haircuts,"*

*"And fairly soon again at that point I just thought something is not ok. But then he's 5. It's okay. He's only little, so he's only five here. And then we came here and he got in to school. And again, I was like, that's fine, that's fine. You know, he's absolutely fine."*

**Karen** - *"And at the time, that was kind of thrown off as, it its, probably because she's got an older sister and her older sister is talking for her but, I knew it, it just didn't feel like that because she never she never did speak for her."*

*“When she did the one at home, I felt the psychologist, I felt that she wasn't well, she kept saying that there's definitely a mental health problem there. But she felt that she couldn't make a specific diagnosis until **she was a little bit older**. And I said, cause she mentioned, you know, getting referred again when she was 7.”*

*“She was the one saying, even pointing out more to me even more than what I thought there were, for her to then turn around and say, well, yeah, there's something there but you need to wait. And I'm like, she's struggling at school. Absolutely not.”*

Each of the narrators experienced having their concerns dismissed by a professional at some point during their journey. Thus, it then demonstrates the narrator's resilience, perseverance, and commitment to advocating for their children, that all of them finally secured a diagnosis in the end. Much of the ways in which the professionals dismissed narrators' concerns is similar to that identified by a study by Howling & Moore (1997). Howling & Moore (1997, p.143) share how parents were told you **“should not worry”** and **“he'll grow out of it.”** I found it particularly alarming that my research identified that, approximately over 20 years on, professionals were still using similar phrases to dismiss parental concerns as identified by Howling & Moore (1997) in their research. I could not help but also consider how each of my participants held some form of power and/or privilege in comparison to some marginalised groups within society. I recognised at this moment that my own subjective, intersectionality regarding race, religion, disability and ethnicity dominated my mind and I considered how marginalised and underserved groups may respond in such situations with professionals. During my reading, I discovered the work of Sansosti (2012, p.81) who explored the experiences of 16 families during the diagnostic

process. His research identified that families encountered a two year wait for a diagnosis “a delay that was significantly longer for children of African American and mixed racial backgrounds” (Sansosti, 2012, p.81).

Boshoff et al (2018) undertook a qualitative meta-analysis; 22 studies were identified and appraised. Boshoff et al (2018, p.151) identified how *“Parents’ relationships with professionals were negatively affected by a perceived lack of acknowledgement of their concerns.”* Parents also shared instances when their concerns had been disregarded by paediatricians; they identified pressuring them for further assessment and referrals until there persistence paid off and they achieved an Autism diagnosis (Boshoff et al (2018, p.153).

**Reflection:** During my time analysing this specific theme I found it rather emotive. Elements of Carla and Bianca’s extracts made me think about my personal experiences of advocating for my son. The way in which the NHS marginalised Carla’s voice, whilst silencing her with an anxious mother label, was alarming. Having communicated with Carla I was aware of how well she could articulate and thus advocate for her son; whilst Bianca’s concerns about her son’s speech were silenced because he was bilingual. This made me question how my wife would be treated by such systems as a south Asian Pakistani woman who speaks limited English. I recalled how I had encouraged her, and at times translated for her, so that she could speak to professionals regarding our son’s presentation of needs.

### Education / Experience

**Laura** - *“I mean I’ve worked with autistic children before as a support assistant in a school, done a lot of training around Autism in an Autistic school. My brothers Autistic. He’s now 28”*

*“And I just think I’ve always worked with children with special needs and I did not understand how much of a battle and fight it is to get them the support even with all these letters the professional help.”*

**Carla** - *“And then when it came to school, I think because I was a teacher, I still am a teacher, qualified teacher. I know the systems and I know what an EHCP is. I know what they mean when they say Ed Psych and things like that because I was head of year as well. So I had all that prior knowledge of SEN. So, in the end, they couldn't really get past me.”*

*“I think because I know the terminology and I know the phrasing. And, you know, I could slip in, you know, little buzz words around OFSTED and stuff and just just drop in a conversation and they'll just say, yeah yeah, we'll do that and it's been absolutely fine. No problems whatsoever.”*

**Bianca** - *“And at that point, I started working with children with Autism and like realising and learning and I've done the whole diploma about Autism, researching things.”*

*“we've been in the workplace. What I do for living. Being a special needs teacher, knowing what I know now as well,”*

*“Helps being a teacher of children with special needs. Because I'm sure that if I wasn't, I would get pushed a lot of things more to do but I think they know that, I know what I'm talking about.”*



<u>Narrator</u>	<u>Level of study</u>
Carla	Degree level – secondary school teacher of Religious Education & Drama.
Laura	College level - achieving an NVQ 2/3 in childcare learning and development and a focussed module on SEN.
Bianca	Degree in English philology, qualified teacher working in SEN
Karen	College Level 3 humanities access course.

Laura shared her previous job of working in school as a support assistant for a child with an Autism diagnosis. She also identified she had a brother who had a diagnosis of Autism. It is evident that Laura’s experiences may have helped her in recognising her daughter’s presentation of needs early on. However, Laura shared in her story how her concerns were dismissed numerous times by different professionals.

Both Carla and Bianca are qualified teachers. When examining their stories it is evident that their teacher identity has allowed them to forge strong relationships with the schools their children attend.

Current literature identifies that higher levels of maternal education increased the chances of an Autism diagnosis (Mandell et al, 2009, p.496). Research by Lung et al (2018, p.941) identified that, although more children of mothers with lower than average education screened positive for Autism using the MHCAT, more children of mothers of higher education received a diagnosis. Research by Kelly et al (2019) supported similar findings by Mandell et al (2009) and Lung et al (2008) regarding higher maternal education and

increased likelihood of an Autism diagnosis. This may then suggest that parents with higher than average education are able to better advocate for their child's Autism diagnosis. Narrators in my research were all educated at college level or higher, but each of them experienced some levels of difficulty in being initially referred onto the Autism pathway. However, it was evident that both Bianca and Carla had better experiences of advocating in relation to support in school for their children. When considering research presented regarding maternal education one may attribute this is due to their degree level of education. However, I believe it is evident from the extracts presented above that it is in fact their membership to the community of practice of schools, as qualified teachers.

**Carla** – *“And then when it came to school, I think because I was a teacher, I still am a teacher, qualified teacher. I know the systems and I know what an EHCP is”*

**Bianca** – *“Helps being a teacher of children with special needs.”*

Considering the whole narrative for each of the narrators, the diagnosis of Autism appeared to have the most immediate effect for Bianca and Carla in respect of support within school for their children. Laura was still advocating for school to apply for an EHCP at the end of the research and Karen shared she had changed her daughter's school following diagnosis due to a lack of empathy and support for her daughter at her initial setting. She described her daughter as settled in her new school and in a supportive and understanding environment.

## Evidence

**Carla** - *“And so eventually we got to see the consultant, the consultant who he is still under. Is very much. Where's the evidence? Have you got any evidence? So, I managed to get hold of reports from nursery and reports from the nursery nurse practitioners, health and speech and language, then I also managed to get him on to a speech and language course”*

*“I thought, right I've got six months now, got six months to really get this evidence together.”*

*“I just collected as much paperwork as I could. And then when I saw him, I just presented him with all the paperwork. and he said Oh, yes, yes, you've got all this evidence.”*

**Laura** - *“Obviously, eventually after three years and her having, obviously OT physio, paediatric consultant, child development CAMHS, speech and language and people going to view her in nursery. I had enough evidence to say look all these people now agree with me you know.”*

*“I logged everything down on a piece of paper. You know, and every appointment I was like she's now done this”*

*“But when a parent is, you know I was showing them video clips, I’d written it all down on a pad”*

*“Once I got all of them to see her and seeing all their reports. Then I started getting listened to.”*

**Bianca** - *“So piles of reports all evidence that everybody saying he's below, below, below expectation progress. He's below on this, below on that.”*

**Karen** - *“Well one of my friends said keep a diary because she'd already been through it all and she just said, you'll forget a lot of it when you go, so just keep a diary. And she said keep appointments and letters, it's all evidence.”*

*“Because the way, she had so much evidence given to her. And it was obvious with how she is as a person, you could see how she is.”*

Each of the narrators mention the term evidence. I recognise that collecting evidence for parents is their way of counteracting professionals who dismiss their concerns. The evidence serves as a tool, that parents are then able to use, to advocate for their child. Laura shares how she even video recorded her daughter’s presentation so that she could show them to the professionals. However, although the parents are creative in the ways that they are able to advocate for their children, it is frustrating that they are positioned in this way. Carla’s extract identifies a significant power imbalance in the way that the consultant asks for evidence. The purpose of the diagnostic process is to be rigorous and multidisciplinary in

nature. The request for evidence to prove what she is saying connotes a view that Carla is not believed. This does not foster a relationship of equal power, partnership, or co-production. But rather it once again solidifies that professionals position themselves in hierarchal positions of power, rather than working collaboratively.

In relation to evidence, I recognise how, as an EP, our reports can help parents in advocating for their children. Narrators identified collecting reports and visiting numerous professionals as part of their journey. I appreciate that we can help by ensuring the parent's voice is clearly recognised within the body of our reports and by suggesting in our recommendations that young people, where parents feel it is necessary, are referred to the neurodevelopmental pathway.

### **Limitations**

I recognise that not having a research question may be considered a limitation of my work. However, when considering my epistemological and ontological position it is rather simple to understand. My research did not intend to uncover a truth or answer to a question. It sought to explore an area of interest to inform my practice. Salkind (2002, p.10) identifies how some researchers may choose a question whilst others focus upon a subject area under investigation. Bloomberg & Volpe (2008, p.34) further share how the problem being explored in qualitative research should be exploratory and open ended. However, for the purpose of avoiding the wrath of those examining my research, my question could have been:

*How do parents experience the role of advocating for their child's Autism assessment?*

My subjective position, and subsequently interpretative design, may also be considered a limitation, as my research cannot be repeated in exactly the same way as I undertook this project. This is because I recognise, as a qualitative researcher, that I bring myself to the research and through transcription and coding I co-construct the data. Fortune et al (2013, p.232) share how qualitative research is still not considered to be as “*rigorous or reliable*” as classic quantitative research methods that are developed upon the principles of objectivity. I do not subscribe to, or aim for, objectivity, rather I believe in reflexivity, ensuring that I account for all that I do. Those seeking confirmability and objectivity will be disappointed. I recognise that my themes, codes and interpretations are influenced by my lived experiences, as is the premise of qualitative research and thus those reading this work may see a completely different data set. For this reason I have included coded transcripts within the appendix for examiners to better understand elements of my personal research journey. I have also included reflective boxes throughout my research to capture my personal thoughts and reflections during my research journey. A problem associated with subjectivity is the worry of researcher bias. However, I pride myself on being transparent and honest and hope this is recognised during the reading of this research. I believe the trustworthiness of my research is in the way I have documented and shared my journey through the detailed write up of this thesis. I have not only ensured a reflexive thread runs throughout the body of my write up but, subsequently, I have also included reflective boxes which include particularly poignant reflections that shaped my thinking.

My sample consisted of four parents and this may be deemed as a small sample size and thus a limitation of my research enquiry. However, considering ontological and

epistemological axioms related to my interpretivist positionality I would argue that this is not the case. I believe the value of my research is not based upon the size of the sample but rather the authenticity and depth of the individual narratives that each of the narrators shared. Patton (2002) identifies how *“there are no rules for sample size in qualitative enquiry,”* sharing that a small sample can provide richer information regarding a specific phenomenon.

I recognise the lack of diversity when considering the sample of narrators may be considered a limitation of this research. Particularly when considering that I am a Muslim, non-binary, south Asian male diagnosed with ADHD. I recognised during my literature review and engagement with similar research undertaken there was also a consistent underrepresentation of fathers and individuals from the Black, Asian and Minority Ethnic (BAME) community. This alludes to the fact that it is important for researchers to do more to ensure that certain demographics are not underrepresented and underserved. Naively, I had initially assumed that as an insider being both from the BAME community and a father it would make the process of recruiting individuals easier. However, I recognised that it was important for individuals to feel comfortable to engage on their own terms and not coerced due to our shared identity. Upon reflection I now feel that utilising more specific forums that fathers may engage with, such as football clubs and father child groups, may have been helpful. The invitation letter could also have been translated into different languages to increase participation from BAME communities. My invitation was, however, written in English and neutral in asking for parents and carers to participate and not specifically aimed at fathers. Although I recognise it would have been interesting to have had a diverse sample, I am thankful for the parents who chose to participate. In this instance I was not

specifically focussed upon the gender of the parents, nor the ethnicity, but rather just the parents experiences who had advocated for their child's Autism assessment. Furthermore, I found that having a sample of all female narrators allowed me to engage with feminist theoretical perspectives and epistemology which helped to shape my research enquiry. Although one of the narrators was Polish I recognised that, as a white female, she too held certain positions of power and privilege.

The personal context of this research may be deemed too close. However, it is important to highlight that when I began my research journey my life was completely different to where I am today. I had come to the end of my son's assessment journey and he had his diagnosis. I did not ever foresee that I may once again be in the position of advocating for another son's Autism assessment. I do, however, accept that life provided me a unique opportunity to engage with my research through alternative lenses; one which was at the end of my journey of advocating and the other at the beginning. I value the way in which my lived experiences provided me with empathy to engage with the narrators and through adopting a feminist lens I did not feel the need to bracket off my emotional responses; rather I was able to use reflective boxes and incorporate them within the body of the research.

### **Strengths of this research**

The strength of this research that those engaging with it may recognise is the transparency in which it has been written. I feel my reflection boxes identify my experiences which, at times, can be uncomfortable to read. I felt, however, that I had to be honest in addressing my experiences. Chalcraft et al (2008, p.13) share how the power in the process of reflection is the ability to become a systematic enquirer. Sullivan et al (2016, p.50-54) identify how



reflection also allows for critical thought and consideration of power relationships. By being reflective I acknowledged my thoughts and shared them openly, rather than allowing them to fester and affect my research in a biased way. In the process of being transparent I was also aware of my subjectivities and have framed my research by addressing its connections to my lived experiences and life history. Hays et al (2012, p.145) shares how acknowledgement and acceptance of one's subjectivity allows for researchers to be closer to, and intimately understand, the research phenomena. I recognise how my personal links to the research topic afforded me an insider position in some ways which I felt narrators also recognised and appreciated. Peshkin (1988) cited in Hays et al (2012, p.145) shares the concept of 'virtuous subjectivity' suggesting how researcher subjectivity should be embraced. He outlines how, by embracing our subjectivity, we can produce meaningful work which is nuanced. I was empathetic to the experiences of the narrators because I had been through the process. However, I was aware that each individual had their own personal journey. Although my experiences afforded me a shared understanding of key concepts and processes, our journeys were all uniquely different as autonomous, agentic human beings. Understanding my subjectivity through the lens of it providing shared understanding of concepts and processes, and not the same experiences and emotions, allowed me to avoid the potential for transference of my feelings related to my own experiences. During my journey I recognised that this was more than research for me, this was about people's lives. Although the subject of interest resonated with my own past, and at times current, experiences I appreciated that in this moment the stories of the narrators were most important, needing to be heard and valued.

I appreciate that a further strength of my work was the ability to research a topic which was *“interesting and personally meaningful”* (Rudestam & Newton, 2007, p.10) whilst having the opportunity to contribute to the wider field of Educational Psychology. I recognise that my research has the potential to inform practice and contribute to both individual and systemic change. Ruble et al (2005) states that children with Autism are an *“under-identified and underserved group,”* hence by extension I recognise that so are their parents. As a critical social psychologist interested in the emancipation of marginalised and subjugated voices in my practice, I recognise that my research provides a platform from which these voices may be heard. It also allows me to reflect upon my personal practice as a practitioner who often engages with parents of children diagnosed with Autism. Inevitably, I hope that, influenced by feminist epistemology (Litchman, 2006, p.75), my research may influence and contribute to social change and address power relationships that parents face, in particular mothers, in relation to my research.

I am so happy that I was able to share the evocative posters with the narrators; their responses capture my heart and allow me to believe that I was able to engage in something meaningful for both myself and the narrators. Their responses identify that my evocative posters demonstrate true co-construction as I was able to represent their stories in a creative way to make sense of what I had heard. I do not claim to be a researcher, I am a novice, but I allowed my creativity to lead on this approach and I am very proud of this piece of work I have co-constructed.

## **Conclusions and recommendations**

When choosing my research interest, I wanted to ensure that I not only explored a topic which was personally meaningful to me but also one which could contribute to the wider field of Educational Psychology and enhance my personal practice. During my research exploration, I feel I have been able to achieve this on a personal level and now would like to help support change on a systemic level. With current opportunities for a member of the EPS, to work alongside CAMHS in a multidisciplinary team setup, as part of a new Autism assessment pathway I feel my research is relevant and necessary and has the potential to influence new contemporary practice. I intend to share my research findings on our service development day with EPS colleagues. I feel it is also necessary and appropriate to share my research with colleagues who will be a part of this new pathway that our team member will be joining. Furthermore, I do believe that sharing my findings wider with the whole of the CAMHS team in our local authority could offer a real opportunity for conversation, reflection, and inevitably systemic change. Being based in the same building at opposite ends of a long corridor I recognise how I am perfectly situated, no pun intended.

Sharing key themes with professionals regarding parents' experiences of being dismissed, having to challenge systems and professionals, and then inevitably fight for their children, embedded in whole narrative experiences will contextualise the research findings. As Educational Psychologists we can influence change; the data identified in wider themes how all of the parents in my research sought an Autism diagnosis for further support in school. By encouraging schools to be sensitive to the needs of all young people and adopting a social model of disability we can inevitably aim to change parents' perceptions regarding the commodity of a label and its ability to access and provide support resources. It is also

important to address myths that parents are told by schools, such as the need for a diagnosis or any label as part of the EHCP process.

It is recommended that EP's reflect upon the model of Autism that they are engaging with and are aware of the implications of this. It is important to understand the premise of the medical and social models and how at times parents and EPs alike may engage with both constructs and not be firmly situated within one framework of thinking when advocating for young people. EPs may find they are requested to support parents in relation to the biomedical conceptualisation of Autism, during this time it is advised that EPs consider the pragmatic benefits of the diagnosis to the young person and their family and support accordingly. EPs should continue to support and share understanding of the social model of disability and Autism respectfully. Furthermore, it is important that EPs are able to access specific training to further understand the varied conceptualisations of Autism from the diverse frameworks and paradigms that may be employed in the understanding of Autism. There are a range of theoretical accounts that EPs may consider in order to explain the neurocognitive atypicalities young people experience. These models include: executive dysfunction, weak central coherence, reduced theory of mind, and attachment theory (Richardson, 2008). However, it is important that EPs reflect upon the strengths and limitations of these models which often only explain Autism as a single, underlying, cognitive atypicality. It is important that EPs ensure that the voice of the parent/carers and young person is prioritised. Their constructions of Autism should be acknowledged and valued yet challenged appropriately when possibly negative to the overall wellbeing of the young person or their family.

A philosophical shift in the understanding of knowledge, what it is and where it can be found is also important. This does not disregard or diminish the important knowledge, training, experience and understanding that professionals have, which is valued and necessary. However, the shift in thinking is necessary for practitioners and professionals in recognising that parents hold important knowledge, as experts by experience, regarding their children. By valuing parents and working in collaboration we are more likely to provide better outcomes for the young people and communities we serve.

It is integral that as practitioners we recognise the concept of power and how we aim to address power imbalances that may be present in the everyday interactions we engage with. I believe offering alternative ways of working such as the model suggested by Mintz (2018, p.213), which promotes a parent centred approach to assessment, whereby parents and clinicians can come to a shared understanding regarding their child's developmental challenges, allows for collaboration and co-construction. This, however, is based upon the premise of providing space and time for parents to share their concerns and for their stories to be heard and valued.

### **Further research**

My research supports current literature regarding the Autism assessment / diagnostic process and parents experiences of advocating for their children. However, there is limited research exploring the experiences of marginalised voices of BAME communities. It is integral that the qualitative experiences of underserved and underrepresented groups are also recognised, valued, and explored. Underrepresented groups may include a range of

intersectionality. As individuals who may already be acknowledged as being disadvantaged due to embedded prejudice and unconscious bias, I wonder how they would experience the difficulties that narrators highlighted within my research. Supporting bilingual researchers to undertake specific research with underrepresented communities may allow for an insight not readily available and help practitioners to better serve their diverse and multicultural communities.

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Downloaded: 19/08/2020  
Approved: 23/07/2019

Skander Hussain  
Registration number: 160102408  
School of Education  
Programme: DEdCPsy

Dear Skander

**PROJECT TITLE:** Listening to the stories of parents who actively advocate for their child's Autism diagnosis.  
**APPLICATION:** Reference Number 027413

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 23/07/2019 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 027413 (form submission date: 26/06/2019); (expected project end date: 30/08/2019).
- Participant information sheet 1062384 version 2 (13/06/2019).
- Participant information sheet 1066005 version 1 (26/06/2019).
- Participant consent form 1062385 version 1 (22/05/2019).

The following optional amendments were suggested:

*Please consider carefully the suggested amendments made at various stages of the application form above*

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

David Hyatt  
Ethics Administrator  
School of Education

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:  
<https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure>
- The project must abide by the University's Good Research & Innovation Practices Policy:  
[https://www.sheffield.ac.uk/polopoly\\_fs/1.671066!/file/GRIPPolicy.pdf](https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf)
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

# Invitation to participate in research



Image from: <https://www.rosealib.com/stock-photo/892-supper-Engelmann/892-w312-h216-image2014-08-08-08-08-08>

- ✓ Are you the parent/carer of a young person with an Autism diagnosis?
- ✓ Have they had a diagnosis for longer than 1 year and did they get the diagnosis within the last 3 years?
- ✓ Did you recognise the presentation of needs first?
- ✓ Did you advocate for (encourage/support) the Autism assessment?

**If you answered yes to the above questions, then please get in contact for more information about the research project.**

Contact email – [Skander.hussain@rotherham.gov.uk](mailto:Skander.hussain@rotherham.gov.uk)



Image from: <https://www.shutterstock.com/stock-photo/892-supper-Engelmann/892-w312-h216-image2014-08-08-08-08-08>



## Consent Form

<i>Please tick the appropriate boxes</i>	Yes	No
<b>Taking Part in the Project:</b>		
<b>Listening to the stories of parents who actively advocate for their child's Autism diagnosis.</b>		
I have read and understood the project information sheet dated 22/05/2019 or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	<input type="checkbox"/>	<input type="checkbox"/>
I have been given the opportunity to ask questions about the project.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the project. I understand that taking part in the project will include; Interview, audio recording and the opportunity to create a visual representation (collage/mood board) of what an autism diagnosis mean to you.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my taking part is voluntary and that I can withdraw from the study up to 4 weeks after the interview as after this time data will be anonymised and included within the dataset; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	<input type="checkbox"/>	<input type="checkbox"/>
<b>How my information will be used during and after the project</b>		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>
I give permission for the anonymised data that I provide to be presented in other academic forums (e.g., academic journals, at conferences, or in teaching) so it can be used for future research and learning	<input type="checkbox"/>	<input type="checkbox"/>
<b>So that the information you provide can be used legally by the researchers</b>		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	<input type="checkbox"/>	<input type="checkbox"/>

Name of participant [printed]

Signature

Date

Name of Researcher [printed]

Signature

Date

## Participant Information Sheet

**Project title:** Listening to the stories of parents who actively advocate for their child's Autism assessment.

**Researcher:** Skander Hussain

**Project supervisors:** Penny Fogg / Tony Williams

### **Invitation to participate**

You are being invited to take part in a research study. Taking part is voluntary; it is up to you to decide whether to take part. It is important for you to understand what the research is about and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. If anything is not clear to you or if you would like more information, please ask.

My name is Skander and I am currently a 3<sup>rd</sup> year trainee Educational and Child Psychologist on the Doctoral programme at the University of Sheffield. As part of my qualification I am required to complete a thesis under the supervision of academic tutors. This participant information sheet will provide you with further information regarding my intended research project.

### **What is the project about?**

My project is focussed upon listening to the stories of parents who have recognised the presentation of needs and then advocated for their child's autism assessment. I am particularly interested in hearing about parents' journey from the recognition of needs to receiving a diagnosis and the ways in which they had to advocate for their children.

### **What will I be asked to do?**

Participants will be asked to take part in one unstructured interview. The aim is for the interview to be conversational in nature hence the unstructured nature with no specific questions being outlined. There will be broad areas of interest for exploration which I will list below, but no specific planned questions;

- Presentation of needs
- Recognising autism
- Parents Feelings
- Advocating – how, where and when
- Professionals and agencies involved
- Securing a diagnosis

I will also invite participants to create a pictorial collage depicting what an autism diagnosis means to them.

### **How will my information be used?**

The information collected during this study will be used to produce my Doctoral Thesis. Quotations may be used in the writing of my project, but these will as with all data remain anonymous and confidential. The people who might read this in an official capacity are my project supervisor, other members of the Institution of Education staff at The University of Sheffield and external examiners. Additionally, the information may be published in academic journals, presented at academic

conferences, or used for teaching purposes. Although the information may be used for these purposes, you will not be identifiable in any way through these activities. All names will be changed to pseudonyms and there will be no personal data that can identify participants. Only quotations and the themes deduced will be used within the actual body of the written project. Although interviews will be recorded they will be stored safely and transcribed immediately resulting in the interview recordings being destroyed.

### **Will my information be confidential?**

All the information you provide will be treated in confidence. This means that your name will not be passed on to anyone else and your information will be used solely for the research or teaching purposes of the university. All of your information will be stored securely and only my project supervisor and I will have access to each person's individual information. The only time that my project supervisor or I would reveal anything to an appropriate authority would be if you divulge information that we feel could potentially put you or another person at risk of harm. This decision would only be taken following full consultation with my supervisor.

### **Can I change my mind?**

Yes, you can stop taking part in the study at any time. You can also ask for part or all of your data to be destroyed for up to four weeks after you have participated. You can do this without any negative consequences, and you do not need to provide a reason. If you would like to withdraw your data, please contact me on either my email address; [shussain10@sheffield.ac.uk](mailto:shussain10@sheffield.ac.uk) or by mobile [07834838613](tel:07834838613) ensuring you quote your individual participant number. However, participants may only withdraw within a period of 4 weeks after the initial interview has taken place so as to allow for sufficient time period to destroy all data collected that may have already been used within the project.

### **Confidentiality:**

All the information that is collected about you during the research process will be kept strictly confidential and will only be accessible to members of the research team. Pseudonyms will be used to ensure total confidentiality. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this.

### **Legal Basis for Processing my Personal Data:**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>

### **The Data Controller:**

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

### **Who has Ethically Reviewed the Project?**

This project has been ethically approved By The University of Sheffield's Ethics Review Procedure.

### **Who can I contact for further information?**

If you require any additional information about this project or have any concerns please feel free to contact me Skander Hussain on my email address; [shussain10@sheffield.ac.uk](mailto:shussain10@sheffield.ac.uk) or by mobile 07834838613.

<b>Project contact details for further information:</b>	
Researcher – Skander Hussain	Email – <a href="mailto:shussain10@sheffield.ac.uk">shussain10@sheffield.ac.uk</a> Contact number - 07834838613
Research Supervisors – Penny Fogg / Anthony Williams	Email – <a href="mailto:p.fogg@sheffield.ac.uk">p.fogg@sheffield.ac.uk</a> Contact number – 01142228082 Email – <a href="mailto:Anthony.williams@sheffield.ac.uk">Anthony.williams@sheffield.ac.uk</a> Contact number - 01142228119
Joint course leader/ tutor and independent from this research project – Martin Hughes	Email – <a href="mailto:m.j.hughes@sheffield.ac.uk">m.j.hughes@sheffield.ac.uk</a> Contact number - 01142228165

### **What happens next?**

Please think carefully about whether you wish to take part in the study. If you do wish to take part, please use the contact details provided.

Thank you for considering participating.

Kindest regards

Skander Hussain

### **Ongoing support information for participants**

I have provided this sheet with some support networks so that if at any time participants feel distressed or upset as a result of participating in this research study then there is an available support system they may engage with.

#### **Skander Hussain (researcher)**

Telephone: 07834838613

Email: [shussain10@sheffield.ac.uk](mailto:shussain10@sheffield.ac.uk)

As the researcher I will always be available if you need to talk further during any stage of the research journey and once it is completed.

#### **National Autism Society / Autism helpline**

Telephone: (Autism helpline) - **0808 800 4104**

Web - [https://www.autism.org.uk/?gclid=EAlaIQobChMI3YWI6-6v4qIViaztCh1K9qbiEAAAYASAAEgIUyfD\\_BwE](https://www.autism.org.uk/?gclid=EAlaIQobChMI3YWI6-6v4qIViaztCh1K9qbiEAAAYASAAEgIUyfD_BwE)

British charity that provides information and support for young people and adults with Autism and their families.

#### **Mind**

Telephone: 020 8519 2122

Web: [www.mind.org.uk](http://www.mind.org.uk)

Mind is a leading mental health charity, they work to aid individuals who have or maybe experiencing mental distress by providing advice and support to empower anyone experiencing a mental health problem; campaigning to improve services, raising awareness and promoting understanding.

#### **Samaritans**

Telephone: 08457 90 90 90

Email helpline: [jo@samaritans.org](mailto:jo@samaritans.org)

Web: [www.samaritans.org](http://www.samaritans.org)

The Samaritans helpline is available 24 hours a day they provide confidential emotional support for people who are experiencing feelings of distress or despair.

Codes	Interview Transcript	Reflections
<p>Somethings not right</p> <p>Presentation</p> <p>Dismissed</p> <p>A feeling</p> <p>Advocating</p> <p>School identify needs</p> <p>School identify needs</p> <p>Presentation</p>	<p><b>Listener:</b> Thank you so much for coming along and agreeing to take part in the research, erm the title of my project is listening to the stories of parents who actively advocate for their child's autism assessment. Are you happy to continue?</p> <p><b>Narrator:</b> I am, yes that's fine.</p> <p><b>Listener:</b> So, it's completely up to you where you would like to start. I've given you the paper with some headings but it's about sharing your journey and your experience. Does that sound ok?</p> <p><b>Narrator:</b> Yeah, yeah. I guess. I'll start from where there was a main problem and that's when I thought something was not right. And then I'll kind of retrace after a bit of time, I realized oh actually it were identifiable from earlier on. Yeh but it was when she was at nursery. So, she'd been about three it was before she went into Foundation One. <b>Her speech was very delayed. So even at the age of three, she could only really say a few words.</b> And at the time, that was kind of thrown off as, it its, probably because she's got an older sister and her older sister is talking for her but, I knew it, it just didn't feel like that because she never she never did speak for her. So, I knew it weren't that I asked them to keep an eye on her at nursery and just get back to me. Errm and then they said, actually, now you've mentioned it, you know, like a few weeks on they'd like assessed her, and they said, erm yeah, actually we do see what you mean now. You know we thought she'd have come on a little bit more with us helping her but she's not. So, we did go to, we got referred to speech and language therapy. I'll be honest. I found that a bit useless because as soon as we did get the appointment, she was able to speak a little bit more. So, at that point they said, oh, it's probably because she's, you know, quite distracted. So, they gave me a few methods to try getting things out of the, out of the box and getting it to basically sit with that. For, I don't know, two minutes, one day and then the next day sit with her for a little bit</p>	<p><i>Interesting to hear that all narrators shared they recognised something wasn't right.</i></p>

<p><b>Presentation</b></p>	<p>longer. And I have absolutely no idea what the meaning of it were but. Yeah. I just didn't feel I got anything from that for her. So left, moved her away from that. But yeah, like I said, nurse did their own assessments and they've got like different traffic light systems. So, it had different things like toileting erm social development and, you know, different things like that. And she was basically red for everything. Errmm and they said that before she went up to foundation, they said that if ever they have had to sit down with Rosie to go through a few things like words or anything like that, she's had to have one to one support. <b>So they said if she didn't have that one to one support, she wouldn't have progressed that little bit that she did while she was there. Ermm so they actually said to the school, look, she needs a one to one because otherwise she won't progress. She will fall behind even more.</b> And that did become apparent very quickly in foundation. It's more the attention for Rosie, the educational side of it. Yes, she, she is behind on that, you know, quite a lot. But I do think it's because of her attention span.</p>	
<p><b>Presentation</b></p>	<p><b>Listener:</b> So some of that presentation was around school and within the school environment. Was there anything that you had picked up on at home?</p>	
<p>Some things not right</p>		
<p>A feeling</p>		
<p><b>Presentation</b></p>		
<p><b>Comparing</b></p>	<p><b>Narrator: She had a really, really bad temper.</b> She just basically, if there was anything that you asked her to do or, you know, you'd encourage her to, you know, come into the kitchen and choose something. If she didn't want to do it, <b>she would kick and scream and throw things at you.</b> And to say she was only like two or three at the time. I have never known anybody be so strong which. I think that's quite common for children with autism. They're strangely strong. <b>But yeah, it was just her temper. She were having meltdowns all the time. She was lining things up all the time. Well, what in one instance was. There were like a little door, door sensor, and every time she went through that, it beeped. But she, to begin with she was like bobbing under it so it wouldn't beep but then she would get frustrated with herself that she'd just done that. So she'd come back through the door so it would beep again.</b> But yeah, that was a little a little niggly that she had. <b>Spinning things, she loves spinning things. She was very,</b></p>	
<p><b>Research</b></p>		
<p><b>Friends</b></p>		
<p><b>Presentation</b></p>		
<p><b>Research</b></p>		
<p><b>Research</b></p>		

<p>School identify needs</p> <p>Evidence</p> <p>Somethings not right</p> <p>Purpose of diagnosis</p> <p>Presentation</p> <p>Waiting</p> <p>Emotions</p> <p>Diagnosis power</p> <p>Comparing</p> <p>A feeling</p>	<p><b>very obsessed with snails.</b> Absolutely no idea why, but she would for three hours straight. She'd go on trampoline with it. She'd feed it water. She'd have it in her hand, and she would talk to it and although one time she tried to eat a snail. She was like five. But yeah, she was very protective over them for some reason. <b>And like worms if one of them kind of got run over she would be really really distraught shed be like how is it going to get to the other side of the path mummy.</b> And I was like its fine. <b>But anything like that, it took forever to get anywhere because she was so distracted by the smallest of things. If you tried to hurry her along. She would just break down crying and she'd just throw herself to the floor and she'd just sit there on the floor and she'd lie rock a little bit. And she'd make these weird, like a sucking kinda noise. But she does it we her tongue.</b> It's a really weird noise but yeah. She would do that it were like, kind of a pattern that I saw whenever she felt really frustrated. That's what she would do.</p> <p><b>Listener:</b> So at what point did you start thinking about Autism?</p> <p><b>Narrator:</b> Erm it will probably when I had gone to nursery with the speech delay, <b>I knew something wasn't ok, I had a feeling. Because at that point she was already having behavioural problems. Erm she was behind with everything anyway. Her speech at that age should have been much better than what it was.</b> Ermmm and yeah, and <b>I were kind of comparing her to my eldest, you know.</b> I know she's neurotypical, so, you know, maybe I shouldn't have compared. But she was hitting all her targets from being a baby and growing up. <b>And I kind of compared it to her, you know.</b> But Rosie were just very, very behind in everything. Well, yeah, when I kind of <b>looked into it a bit more</b> and <b>I had a couple of friends actually, that they they've got children with autism. And they kept saying, you know, the saw, so many so many traits with Rosie.</b> Errmm like <b>she's very particular with her food. She literally can't sit at the table to eat it. She's up and down a million times. She can't sit and concentrate. She won't look at you either if someone's talking to her. She like gets really nervous and she just like looking away somewhere else all the time. But yeah, the more I</b></p>	<p><i>I remember doing the same comparing my second son to my eldest son why was neurotypical.</i></p>
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<p><b>Diagnosis power</b> <b>Funding</b></p> <p><b>Advocating</b></p> <p><b>Waiting</b></p> <p><b>Support</b></p> <p><b>Presentation</b></p> <p><b>Presentation</b></p>	<p>looked into it and we're like kind of realizing a few things from a being little. So she were a very very unsettled baby.</p> <p><b>Listener:</b> And you say, looked into it. What, where did you look?</p> <p><b>Narrator:</b> I've forgot what it's called ermmm, it's an official site on Google to do with Autism Errm</p> <p><b>Listener:</b> National Autistic Society.</p> <p><b>Narrator:</b> Yeah that's it. So, yeah, kind of like I had a brief look on there about what problems they have because at this point, I tried to kind of keep a diary. Errm I wanted to like see if any if there are any kind of errr comparison to like things from there from being young to when Rosie were young.</p> <p><b>Listener:</b> You said that you kept a diary. What was that for?</p> <p><b>Narrator:</b> Errmm that were later, that came a little bit later on when Nursery said that they recognized a lot of things with her and, you know, she was very delayed in all areas. School the first, parent evening with them. They said instantly, you know, she's a very difficult child and she's got to have things. Just so. Learning wise, she's very behind. And they've seen that she needed one to one support. So, yeah, kind of from them they said try and get a referral. Well one of my friends said keep a diary because she'd already been through it all and she just said, you'll forget a lot of it when you go, so just keep a diary. And she said keep appointments and letters it's all evidence.</p> <p><b>Listener:</b> So you've mentioned that some of your friends were starting to notice stuff. You had noticed and you had brought it to the attention of the school. And you'd started keeping a diary. You had started to look on the National Autistic Society website to see what some of the presentation might be, how did you feel? How were you feeling at that time?</p>	
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<p><b>Support</b> <b>Diagnosis power</b></p> <p><b>Dismissed</b> <b>Age</b></p> <p><b>Advocating</b></p> <p><b>Diagnosis</b></p> <p><b>Evidence / Emotions</b></p> <p><b>Dismissed</b></p> <p><b>Advocating</b></p> <p><b>Advocating</b></p>	<p><b>Narrator:</b> I just kind of wanted to get the ball rolling. Because, I don't know, I just knew something weren't right and I felt like I needed answers because life at home were really, stressful and frustrating because. Even though she were only young. I had to change an awful lot of my day and the way I did things to suite Rosie because otherwise she would have a huge meltdown. And even up until now, she's coping a bit better now with things. But even, even still, my day is very different. My day is very different. I've got I've got to work around Rosie. And I know things to avoid I know what triggers her. And I'm just kinda. Slowly bringing that in. But it made me feel really frustrated that it was such a long process and she was struggling with school and, you know, they weren't going to put anything in place for her until she got a diagnosis and it just felt really frustrating and that, that particular school I've moved them from there, they were awful had absolutely no idea what they were doing. They knew nothing about autism or well anything to do with any kind of disabilities.</p> <p><b>Listener:</b> At what point did you feel sure about Autism? so, you know, when you said that you had conversations with friends, you'd looked on the website, you'd seen the presentation of behaviour. Was there a specific point in time for you?</p> <p><b>Narrator:</b> Ermmm, I think it was when it were before she went to school and so she were going from you know the transition of nursery to school and I'd got there report back and she was red with everything you know and on the table, they had all the children's reports in there. You know, there was some like with a little red on it, obviously. But compared where she should have been. It weren't there so that for me, that were just like. You know, I do a lot at home with her. They've put one to one things in place for her and even at that point, she weren't improving. So then I think that the very definite defining moment was schools first report and that weren't any better. I saw the behaviour at home and had a feeling but seeing the reports just confirmed it because she was struggling there too.</p> <p><b>Listener:</b> Thinking about, so you started to mention the process and the length of</p>	<p><i>Parent feeling frustrated at waiting.</i></p>
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<p>Some things not right A feeling</p> <p>Diagnosis power</p> <p>Positive outcome Funding</p> <p>Diagnosis power Advocating</p>	<p>it and how long it all was. And you also touched upon support and not having that without a diagnosis. Can I ask you to just elaborate on that?</p> <p><b>Narrator:</b> Yeah. They kinda the school. <b>Overlooked difficulties that children had unless they had a diagnosis</b> and they <b>could get funding</b>. And even at that point, children, there were a few children that are severely autistic, and they have had to go to a special school. <b>So obviously they have received funding whilst they were at school. But, they didn't even use that funding for that child.</b> They used in different areas, which I'm pretty sure, they're not allowed to do that. But Yeah. They've had to put extreme measures into that school because they said the report was appalling. But yeah, I don't know. They just didn't just want to put care into kids with special needs.</p> <p><b>Listener:</b> How did you advocate for, the assessment process?</p> <p><b>Narrator:</b> <b>Well, I went through the doctors</b> because school, told me that they can't do it, which I think they can. I think that was just them being lazy. <b>But yeh I went to the doctors and they said absolutely.</b> There's a lot of traits, and even while she were just in there for the 10 minutes, you know, she showed a lot of how she is. So that were a bonus. <b>But I don't know. I just had to keep. Kind of pushing to find out when the appointments were going to be. I knew it were going to be a long time until I got one but, it did feel like it took forever.</b></p> <p><b>Listener:</b> And who did you have to push to find that information?</p> <p><b>Narrator:</b> Err it was CDC. So I kind of felt like I would just left Looming for a while. But they did tell me about the parent carer forum or whatever it's called. Told me about that and said for me to look on there. They told me about the National Autistic Society. <b>So they give me some like support, you know, they kind of signposted me, until I got an appointment with them.</b> I spoke to one of the psychologists on the phone, at CDC, because it was around Christmas and we were going through an awful lot. She were really struggling and <b>she were being</b></p>	
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<p><b>Support</b></p> <p><b>Validation</b></p>	<p><b>very aggressive</b> with her sister and my youngest was just born I think. Yeah. We were going through a lot. <b>And Rosie were just not coping coming out of school and she were doing a lot of things that will like hurting herself. And you know, like at the time we had a cat. And Rosie's not an affectionate child, she wasn't affectionate at that point. And she was sat in the conservatory, and she had, cats called Prince. She was sat stroking him and I just thought oh that is so cute and I just like stepped back. You know, so she didn't see me, and I though this is a rare moment she is being very affectionate and she was stroking him. And then all of a sudden she started punching him in the head. She wouldn't let him go.</b> So obviously, that were like, that were like I really need someone to help me out now, because that's not normal. That's were the psychologist obviously told me about the other things I could look into before I got the appointment.</p> <p><b>Listener:</b> And as part of that journey, waiting for the appointment and getting the appointment. In the meantime, who were the other professionals or the agencies that were involved?</p> <p><b>Narrator:</b> So speech and language and nursery told me about early help, but I can't remember if that was before or not. But basically, no, I never heard anything from them. I've not had contact with them at all. I have had two referrals, so I haven't got a clue what's going on there. But yes, I was having a lot of problems getting Rosie ready in the morning for school <b>she refused to get dressed and then the journey to school.</b> At that point I weren't driving, and it were just I couldn't trust her near a road I'd had my pram at that point with me youngest in it and it were really difficult. And I weren't getting to school till 10:00 o'clock in morning because it was just too much for her. And I just, I needed help. They said they would be able to come to the house and assess how I am with her, how she is in the morning. What changes we could make. And I never heard anything at all. So that were kind of like a lost cause.</p> <p><b>Listener:</b> I'm thinking about all of those things that were going on. Was there</p>	
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anyone that you could speak to that you were able to share how you were feeling?

**Narrator:** Well nursery, I had, I think they are called support workers there, I did self-referral with them. Errrm because the amount of times I'd gone in there crying because I just felt like I were just, you know, school weren't really interested until she got a diagnosis. So nothing was getting put in place, you know. So I were just distraught that she was going to school. I knew she couldn't cope, but they weren't doing anything about it.

**Listener:** So thinking about going through the diagnostic process, how did you advocate?

**Narrator:** The assessment its self through CDC once you know we had actually got in the system, it were really good, you know, that they assessed her and doing the assessment at CDC and at school and then at home. When she did the one at home, I felt the psychologist, I felt that she wasn't well, she kept saying that there's definitely a mental health problem there. But she felt that she couldn't make a specific diagnosis until she was a little bit older. And I said, cause she mentioned, you know, getting referred again when she was 7. And I said, I'm sorry. No, absolutely not. She's struggled a lot at school. It's affecting us as a family. We can't go anywhere. You know, I'm sorry, but I'm not. I'm not accepting that, because then, you know, I won't have any contact with you guys. And then I've got to wait however many years until, you know, there's even more signs and she's even worse and struggling even more. And then I've got wait another like what year and a half or something to actually get back into the system just for the beginning. So I just said I'm sorry. Absolutely not. Is there anything else that you can, any other kind of assessment you can do? Or, you know, somebody else that can, you know, have input on, she did a different process. And ironically, within two weeks, they had diagnosed her.

**Listener:** So I can hear that you really advocated there for, the assessment.

**Narrator:** I felt really angry. Because the way, she had so much evidence given to her. And it was obvious with how she is as a person, you could see how she is. And I just felt really angry, all of a sudden she was really. She was the one saying, even pointing out more to me even more than what I thought there were, for her to then turn around and say, well, yeah, there's something there but you need to wait. And I'm like, she's struggling at school. Absolutely not. If I'd done what she said, then she wouldn't be where she is today, which still isn't amazing, but she definitely wouldn't have been where she is.

**Listener:** When you had that conversation, how did you feel you were listened to at that point?

**Narrator:** I think she got it. I think she were a bit shocked that I'd actually stood up to her because I'm as a person I'm not confident I'm not outspoken or anything. So kind of shocked myself a little bit, but it just came out naturally. I was just like, I'm absolutely sorry. But, no, you need to do a different assessment. Or look at it a different way or get somebody else in and look. You know, I don't accept that you want to wait until she's seven to diagnose her. No. Well you need to get back in the system, to look at diagnosing her. No, again, absolutely not.

**Listener:** Thinking about securing the diagnosis, can you talk to me about how you found that how you felt hearing the news?

**Narrator:** I already knew there was something there anyway, I had a feeling. But it was just hard to explain to people why she does the things she does when your out and people look. You know, it were a bit, felt a bit awkward to say she's got behavioural issues or she's not where she should be. You know, but we know she's getting assessed, you know, felt like quite a long winded thing. So to finally be able to say she's diagnosed with autism. And, you know, she got like a little badge or something, a little card. And I don't know I just felt like that made it so I could breathe a little bit more, you know. I finally could I felt like go to

*Parent felt empowered following the diagnosis.*

school and, you know, and slam the paper on the table and go look now you need to do something, you know. And since she got a diagnosis, I don't know, I felt a little bit more empowered for her so I wouldn't take any crap from the school, basically, you know.

**Listener:** Did things change at school as a result of the diagnosis?

**Narrator:** Slowly. Like I said, there were very shoddy but I had to literally keep at them all the time, so it was very tiring, but I just I won't I wasn't going to let Rosie you know, kind of get kicked side just cause they can't be bothered. Which is that's what it where and they did have a lot of kids in there that that are troubled. So they had a lot on their plate so. But, yeah, well, that's why I moved schools and moved them because she wasn't getting the support she needed.

**Listener:** So thinking back now, over the journey you have shared you've had the diagnosis for a certain period of time. How do you feel about having the diagnosis?

**Narrator:** It's been helpful. Yeah. Yeah. Because, especially with teachers in the new school. They are so understanding. They want to listen to you and they want to put things in place to make things easier for her. Or to help, you know, start to kind of settle in with different things. And they have just been amazing. She's come on so much just because she had that extra support, which is what she needed. You know they have said that they want to point put in for funding you know for a one to one or something. Basically, because she needs someone with her all the time, not only for her behaviour but to help her with her learning, but they're recognizing that. And they're so much more on it than at the school where. And yeah, I do. I do think having a diagnosis kind of gives you that. Power for the kids. So as their parent you've got you've got to, be the one that speaks for them and helps get things in place and if you left it to the teachers. I think it would be a much slower process, you know, because they've got a lot of children to look at and assess, you know, in different many different ways. So as the parent, you need to identify where they're going wrong and you

know what they need to improve on. Because Rosie does need that extra support for her to be on, not even on a level with the other kids. You know, she's still below, but for her to progress, that's all I want. You know, she don't need to be at the same level as everybody else. As long as she's given the right tools to be able to do things. Then that's fine.

**Listener:** So thank you so much for taking part. Is there anything else? Thinking back, anything that when you reflect upon what we've talked about that you'd like to share or add or any question you have for me.

**Narrator:** I don't no, I dwindle when I'm talking. I, it's possibly **nice to have some support, but when I did get the diagnosis, there were I had one phone call after just to see how I was doing. You know, But, I kind of feel like once you got diagnosis, you then kind of just left.** You know, but the parent's forum they're brilliant, you know, because they actively get different groups on and the sibling support group. I asked if they could do something like that last year. You know, so that at least my daughter could understand it more. She's just she was very understanding with it and then all of a sudden, she's really frustrated and angry we her all time. That sibling support group is great. You know she's actually said to me, this sibling support group there is only a few children there and I feel more involved and I feel like I can talk. I feel like that were a massive thing for the parent's forum. But Yeah. **In regard to CDC and CAMHS not really had any support after diagnosis.**

**Listener:** Would that be helpful from them?

**Narrator:** Yeah, I just think the occasional even if it's once a year kind of meeting to see how they're doing, and you know if there's anything that they can do to influence school or outside school. Yeah. Yeah. But everyone says that though when they've had a diagnosis, they kind of feel like they've just got pushed away, forgotten about. It's not. **It's a lot to kind of take on when they have got a diagnosis, even though I've known it all along.**



	<b>Listener:</b> Thank you so much, Karen.	
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B2 – Laura - Analysis

<u>Codes</u>	<u>Interview Transcript</u>	<u>Reflections</u>
<p><b>Presentation</b></p> <p>Some things not right</p> <p>A feeling</p> <p>Education / experience</p>	<p><b>Listener:</b> Thank you so much for agreeing to take part in this research project. The title of my research project is exploring the experiences of parents and carers who advocate for their child's assessment. Do you feel happy to continue?</p> <p><b>Narrator:</b> Yes. Off course.</p> <p><b>Listener:</b> Oh, thank you. So as part of this, I won't be asking lots of questions. The research is very much about your story and your experiences. I might interject in places for further detail about something that you're sharing, but generally the process is that I would just let you share your story. We've talked about some of those prompts, but it's wherever you're happy to start with and take me through that process to the end of securing an Autism diagnosis and where you're at right now. Does that sound okay?</p> <p><b>Narrator:</b> Yeh, I'll start and obviously just but in, feel free to but in and to just ask me.</p> <p><b>Listener:</b> That's lovely. Thank you.</p> <p><b>Narrator:</b> Hannah is adopted, and she was five a week ago. Hannah moved in with me when she was seven months of age. Previous to that, she was removed</p>	

<p>A feeling Dismissed / Age</p> <p><b>Presentation</b></p> <p>Some things not right Advocating / Age</p> <p><b>Comparing</b> <b>Presentation</b></p> <p><b>Presentation</b> Some things not right</p> <p>Appointments / Courses</p> <p><b>Presentation</b></p> <p><b>Waiting</b></p> <p>Advocating Some things not right Waiting / For school</p> <p>Some things not right</p> <p>Dismissed / Age</p>	<p>from her mom at birth and put into foster care. Because while I was, when you adopt, even if you've already adopted before, I've adopted her older sibling, you still have to be assessed again and go through the process. She was in a lovely foster home just seven months. I'd had contact from when she was three months of age and obviously sibling contact because I had adopted her brother. Very good baby very quiet. Bearing in mind she was born addicted and was withdrawing from heroin. Cocaine. Methadone. You have to have professional meetings with paediatric. So, they advise you of those children born addicted. They're high risk of ADHD, Autism, special needs, learning disability. <b>So, Hannah was barely crawling talking and she used to scream for food constantly. So, you'd give her, her breakfast lunch, dinner, snacks, she would throw her plate and bowl scream for more even though she'd had enough.</b> And I just thought I've not seen this sort of behaviour before, <b>some things, not right. I just had a feeling. I mean I've worked with autistic children before as a support assistant in a school, done a lot of training around Autism in an Autistic school. My brothers Autistic. He's now 28 and I just had a feeling.</b> Because they are obviously adopted and born addicted to drugs, they were assigned a paediatric consultant and I spoke to them and they kept saying, oh, it's a phase. <b>She will grow out</b> of it; she still hasn't grown out of it. She still does it now. But we got to the age of two and <b>Hannah still wasn't talking.</b> She started walking at about two. <b>Very, very quiet, apart from the food behaviour, you'd go into a restaurant and as soon as you walk in there and put her in a highchair, she'd try and throw herself out. Throw knives and folks around scream until the food would come. So, going out and socializing become very, very difficult. Socializing around other children, Hannah didn't engage.</b> I just noticed the differences, <b>something inside me said something's not right. Kept talking to the consultants and they were like She's young she will grow out of it. And I was like look, I know she's young and, but I feel as a parent something's not right. And I know you shouldn't compare your children to other children, but there is some sort of guideline where, you know, age appropriate and their development where they should be at what age.</b> Bear in mind, some children are behind, Hannah turned three. She was still the same. <b>Not really talking,</b> managed to, after many</p>	<p><i>Parents experience of working with young people who have a diagnosis of Autism and having a family member with diagnosis really resonated with me.</i></p>
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<p> <b>Some things not right</b>  <b>For school</b>  <b>Fight</b>    <b>Presentation</b>    <b>Diagnosis / Emotions</b>  Some things not right  <b>Dismissed Appointments</b>  <b>/ Courses</b>  Some things not right  <b>Dismissed</b>  <b>Milestones</b>    <b>Presentation</b>  <b>Dismissed</b>  <b>A feeling</b>    <b>Evidence</b>  <b>Diagnosis / Response to diagnosis</b>  Some things not right /  <b>Validation</b>  <b>Diagnosis power</b>  <b>Advocating</b>  <b>Dismissed</b>              <b>Advocating</b>  <b>Presentation</b>  <b>Advocating</b> </p>	<p> meetings with a paediatric consultant, get her onto the speech and language course. Which helped a little bit. Hannah started private nursery about two and a half again. They said her behaviour around food they'd never seen anything like it, I kept talking to the paediatric consultant, because then <b>she started pooing herself and smearing it</b>. She's only done that about four or five times, but I've never had a child do that before. As Hannah started getting a bit older and I'm talking about 3, 3 and a half and <b>I just kept thinking this is not right</b>. She's also very, very small for her age. She's now five, but she wears 12 to 18-month clothes. <b>So, she has had speech language. She has had physiotherapy</b>. She still has all of that every week. I think it was a speech language consultant that agreed with me. Obviously, there's a group of six children in the speech and language. <b>She noticed that Hannah was not engaging with other children. Sometimes she could give you eye contact, sometimes not. Even with her speech</b>. She can talk really well now, but it's like selective mutism as and when she wants to, and it will only be about what interests her. In the end, the paediatric consultant said to me, right we will do an assessment for Autism. <b>But it's still an 18-month waiting list</b>. In the meantime, I had a psychologist for Hannah with her behaviours around food wasn't sure if it is an addiction to, you know, when you're born addicted to drugs, you're quite likely to have an addiction yourself. Or if it was linked to Autism, bearing in mind she didn't have an Autism diagnosis at the time. <b>But I kept saying to a paediatric consultant, speech and language consultant, something's not right</b>. And they agreed to do an assessment. <b>But again, it was an 18-month waiting list</b>. In the meantime, ok 18 months might not sound very long to people, but <b>when you're trying to get your child support in nursery and in school</b>, because they don't level it now, do they? High functioning, you just get your diagnosis and that's it. She can be quite a strong talker now. She will go into nursery she will not cry. She would do her own thing, but that's exactly what she does. She does her own thing. She doesn't apart from food, she doesn't present any other behaviours. You know, she will only attach to adults and not children. Because she wasn't, I would say severe like, head banging shaking, screaming, shouting putting her fingers in her ears. I find that a lot more difficult. <b>I knew and felt something wasn't right</b>, the speech language consultant felt it. The </p>	
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<p><b>Age</b></p> <p><b>Advocating</b></p> <p><b>Funding</b></p> <p><b>EHCP</b></p> <p><b>Funding</b></p> <p><b>EHCP</b></p>	<p>psychologist seeing Hannah and going out and observing her also agreed. When you're on that side of the coin. So, she could be Hannah could be presenting really challenging and difficult behaviours in some areas, but in other areas she could be really, really strong. You know.</p> <p><b>Listener:</b> Yeah.</p> <p><b>Narrator:</b> You know, so I found that more difficult and getting consultants to listen to me was, Oh, she's young she's young. She could grow out of this stage. She could grow out of this phase. I was like, something's not right. <b>I need your support</b> because otherwise <b>she's not gonna get support once she starts school. And it was a constant battle and a constant fight.</b> And it still is now. So, she has had two psychologists. We've done a lot of work with her around her behaviours, around food. Unfortunately, nothing's worked so far. She's had six blocks of speech and language. The last few aimed at social communication skills with other children. Hannah who can now talk quite well now. <b>Just go quiet in a class and just point at things and won't really engage.</b> So, I had their report on my side. Eventually. And then finally a cancellation come up actually otherwise we would actually still be waiting now. They called me from the development department and said we've got a cancellation in two days' time. Can you come? I was like, yes, I will. <b>Hannah had her assessment on that day. And then obviously I was given the diagnosis. I found it, I did cry, but for me, it was more of a relief</b> as in I knew something wasn't right. No one was listening to me because from me realising to her, getting the diagnosis. <b>You're looking at probably two and half, three years of constant hospital appointments, speech and language appointments, physio, occupational therapy, psychologists, paediatric consultants</b> and being constantly being told she's young she's will grow out of it. And me knowing deep down. Actually, this isn't normal behaviour. <b>This isn't how she should be at that age. Yes, children do develop at different stages, but you get to a certain age where, you know they're not reaching certain milestones</b> and <b>they're not communicating with other children. Or you could have a clown, or a fairy or princess do something fun or blow bubbles and Hannah</b></p>	<p><i>The emotive language around battle and fight really highlights the struggle the parents experienced.</i></p> <p><i>Dismissed because of their age and parental voice is not acknowledged.</i></p>
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<p>Advocating</p> <p>Evidence</p> <p>Funding</p> <p>EHCP</p> <p>Education / experience</p> <p>Fight</p> <p>Emotions</p> <p>Purpose of diagnosis</p> <p>Dismissed</p> <p>Fight</p> <p>Evidence</p> <p>Presentation</p> <p>Dismissed</p> <p>Emotions</p>	<p>had no reaction in her face and no excitement, no laughing or giggling. She's very serious, she's quite robotic with her tone of voice very flat toned all those signs screaming out at me but no one was listening to me. She's young, she's young you know, she was born addicted to drugs. You know, she may take longer to catchup. But as a parent you know but try to get professionals to listen to you. Obviously, eventually after three years and her having, obviously OT physio, paediatric consultant, child development CAMHS, speech and language and people going to view her in nursery. I had enough evidence to say look all these people now agree with me you know. Hannah was diagnosed a month before she turned four. I was relieved, to be honest with you, because I knew something wasn't right. But you're getting all these people doubting you. Telling you its normal she will grow out of it. You know, you do think relief. She's now going to get support she needs. Because without a diagnosis you're not going to get any support whatsoever. By this time, Hannah was in a school nursery spoke to the SENCO and I took the diagnosis into school and gave it to them, no one contacted me. So, after a couple of months, I arranged a meeting and said I've given you her diagnosis. You've not contacted me. What are you going to do to support my child? They said Hannah is fine. She doesn't need any more support than her peers. I said she does. She doesn't engage with other children. She won't really talk to other children. She might say, what's your name? You know, very blunt, short sentence. She just wants to be around adults. I said she can't climb on the toilet. She's so small because obviously she's been diagnosed with Autism. I know that main focus, but she has got other things going on around that even now. Hannah is in reception started reception in September, No support, Nothing. I've said, I've met with SENCO. What would you like for your child? I said, well, eventually she is going to need support. You know, I said, her food obsession is so bad. She's thrown a plate across the dinner hall. She's thrown stuff off the teacher's desk, she nicks food daily off other children, out of bins. She asked to go to the toilet. You found her in the kitchen. They couldn't find her for 10 minutes. That's not safe. I was angry. I told them you're not safeguarding what support are you going to do. But you know this food behaviour. We're not sure if it's linked to Autism or. No one knows</p>	
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<p>Something not right</p> <p>Diagnosis power</p> <p>Fight</p> <p>Evidence</p> <p>Age</p> <p>Fight</p> <p>No difference</p> <p>Emotions</p>	<p>even now. Could be to do with her Autism. Its obsessive and autistic children display obsessive behaviour. Hopefully with the right help, <b>she'll grow out of it.</b> Nothing's working at the moment but I'm positive, because if it's behaviour you can change that. Met with an Educational psychologist two weeks ago he'd gone to view both my children in school. He viewed Hannah she didn't engage. Walking around asking what time is tidy up time. Hannah is not destructive she will do as she is told apart from the from stealing food. I don't think that they see she needs any more support because in reception it is all a lot of free play not a lot of structure or demand and she's ok with that.</p> <p><b>Listener:</b> How do you think it will be once she goes into key stage one?</p> <p><b>Narrator:</b> Once she goes into year one she is going to struggle. Because I think a lot of children should have some structure regardless of if they are Autistic or not. But children with Autism need it more so I suppose. <b>I actually made my own visual timetable a year ago and gave it to the teacher. It was never used. I've spoken to her new reception teacher I asked for a meeting. I spoke to her about a visual timetable.</b> She said Oh, we've got one in the class, you know, just one that says carpet time, lunchtime you know <b>I said no Hannah needs a now and then board.</b> A visual timetable for the whole day is not really gonna support her needs. She needs structure right now. You can practice your name right then your gonna do that. And that's what she needs continuously through the day. Because although she's very clever and can tell you it's play time. So, she needs to know herself what she's personally doing. She's walking around doing nothing all day. No, she's not. This is what the teacher said. So, I met with the educational psychologist who had been to see her. Sat down with the SENCO and the teacher with him and said, okay, Hannah is walking around all day doing nothing. She's got no structure. Just, you know, now and then board everything I said he had said. He said, what are you doing to <b>support her needs the SENCO said we've got no funding, so we can't do anything.</b> He said I suggest you ring the borough and put plans in place and get some funding, he said because if not, you need to <b>send off for an EHCP.</b> He just said and we don't want to give them out because it costs us</p>	
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too much money. My heart sank because these children are not a tick the box for me. They're my children and they need the support. He did say to SENCO, if you can't get the funding, **you will have to apply for an EHCP.** We don't give them. We don't have the money, and I thought really you don't care about my child. You don't care about her needs. All you care about **is the budgeting.** I'm assuming they can only spend so much per year on the children in the borough, but I ask are my child's needs are not important. **You know, it's all about money. Money money** bearing in mind I've got letters from other psychologists. OT, physio CAMHS, Child development, genetics consultant a growth consultant. **And they all say to me, Hannah, needs support she needs an EHCP. Even if she didn't have an Autism diagnosis, she should still have an EHCP.** There are other big issues going on now, she's got all the going on and still they're telling me they're not going to apply for one. So now it is just a constant battle of my child needs support, but you don't want to apply for it. **It's all about money and funding.** And that's the point I'm at now. You know I'm speaking up I'm fiery. I have got professionals on my side, but without the school's support and them doing an EHCP, I've not got a leg to stand on. The next stage will be I will apply for it myself. Now that I've got all the professionals on side, but because Hannah can walk and talk, and do as she is told that keeps her under their radar. Whereas if she kicked off every day and started head banging walls properly been violent. She would probably want to apply for one to one support, but because she's not displaying that. Yet, she so desperately needs it, but they're not doing anything about her.

You know they're not even. **I've said, how about you do role play in small groups. You know maybe take her to another classroom out and have some friends do some roleplay encourage her to socialise. How about a little sensory area in the hall? Have some mats, lights, toys, textures, smells, stuff like that a group child so you're not just labelling my child a group of them go out do activities together.** It will all help her while the school decides when they will apply for the EHCP. **It's the school that has to gather the evidence** so even though all this has gone on and we've got professionals agreeing the schools got to gather the evidence. It's such a long process and because of the **funding and the**

*School doesn't seem very supportive.*



**boroughs not wanting to put the money in,** my children have to suffer. Yeah, she's in reception, when my son was in reception, he was meant to get it he's now year two and they still haven't put an EHCP application in yet, you know. So how long has Hannah got to wait before she gets the support and in the meantime her learning. It's not all about the learning for me, it's the whole social communication. You know, how is that being supported, it's actually not and she needs it in all these areas. You know, I'm not expecting my children to be the brainiest, cleverest children in the school. All I'm asking for is that they get the support they need. They've got right to the curriculum the same as all their little friends. For them to be able to be happy, enjoy school life, get the support they need. Not just in learning but socially, emotionally, remember their adopted children as they both know that. But whether how much they understand at the minute Hannah, she's five. She can say, mummy, my mummy. But she's just repeating what I tell her. But as they get older and have a bit more understanding I think they are going to need the emotional support as well. And it may display in their behaviours, **it's so important they get this EHCP.** **And I just think I've always worked with children with special needs and I did not understand how much of a battle and fight it is to get them the support** even with all these letters the professional help. You know, that's been involved and they're all saying, **yes, they need an EHCP, yes, they need an EHCP.** And it's still a battle. And we're going into 2020. How, **I don't understand how it is such a fight,** but I won't give up because these children have got the right to an education and to learn as much as anyone else in this world. You know.

**Listener:** Laura, thinking about advocating because I'm hearing that you have had to advocate a lot, particularly now you're advocating for the EHCP. But, do you know, during the Autism assessment, because you saw so many professionals that you listed, how did you feel that process was advocating to them.

**Narrator:** **Draining, frustrating. Tired at the same time, I knew I would never give up because these are my babies, you know, and you're so passionate because you want what's best for them. And I think I believe in early**

*Diagnosis so they can access early intervention.*



**intervention and the right support they can give a life.** All right. They might be different to their peers. Yes, of course they will. You know, they've got Autism. The world is different in their eyes and in their head, but with the **right support and encouragement from a young age. I believe early intervention is key.** But getting professionals to listen to you, especially because Hannah was so young when I noticed the changes and differences. I got brushed off, **but I had to keep fighting fighting fighting** I logged everything down on a piece of paper. You know, and every appointment I was like **she's now done this, she's pooped herself and smeared it on walls. That's not normal. She's eating out of bins, she's screaming for food and throwing cutlery across a restaurant. You know, I'd take her to playgroups, before she went to nursery she wasn't engaging with other children. She didn't find anything funny.** Please tell me that is not normal. That is not what you would expect a child, I don't like to use the word normal because, everyone is different you know, that's how it was. And it was me over and over again saying it. But it wasn't until Hannah was over the age of three, three and a half that they started listening to me. And I think part of that was she'd started a private nursery two days a week. And I had their reports and I had the psychologist go in to view her and they met her at appointments. She would barely look at them or talk to them but again. **They brushed it off because she's young.** **So, I found it really, really frustrating and I was upset.** I come out of there at times crying my eyes out because I knew I just knew something wasn't right. You know I didn't want my child labelled. You know, more than anything, you want your children to be happy, safe, secure, you know. **But I also knew that without a diagnosis, she's not going to get the support she needs in school.** You know, and it's so difficult, especially around Autism, because every autistic child is different. Not one of them's the same. You know, and I do believe. Well, she's strong in some areas. Now she could talk to the cows come home. She will only talk about what interests her. She won't listen to what you've got to say, or she doesn't even care what you've got to say, you know, as and when it suits her she may not talk at all. But then other areas she struggles like around food and engaging with children and socially, you know. So, she needs a lot of support in some areas. But I think unless you display. Okay. So, there's autistic children. You

*Parent believed that a diagnosis would help get support.*

*Parents voice is not listened to without the*

can see they're severely autistic when they're not severely autistic. I find it harder to get support, to get people to listen to you, you know, because they obviously can do this, this and this. She can do a puzzle. She can remember what's happened that day. But other areas she really lacks in, you know, and it's just like you would not literally bang your head off a wall, but you're like why is no one just listening to me, I'm not making this up. I'd rather my child be healthy and not have to go through all this. **You know, but at the same time, I knew I couldn't give up because that's my children I'm fighting for,** you know, and I know the professionals have got a job to do. **But when a parent is, you know I was showing them video clips, I'd written it all down on a pad and it's all like she's young she will grow out** of it. That's all I got told. That was all I got told. **But obviously, eventually after getting her speech and language support. And physio and OT and, you know, other paediatric consultants and the psychologist involved, which again was a fight. Once I got all of them to see her and seeing all their reports. Then I started getting listened to.**

**Listener:** Thinking now on reflection now that you have had the diagnosis for an extended period of time, and once you got that diagnosis, you've shared how you felt at that point. But now upon reflection ermm can you share how you feel and why it was necessary? Do you still feel it was necessary?

**Narrator:** You know what? Well, it's a difficult one because look Hannah has had her diagnosis over a year now probably about a year and two months. **It's not made one bit of difference.** I still can't get her the support she needs at the minute. **I won't give up. I'll keep fighting.** But I do believe I'm hoping in the long run it will help. But to me, it doesn't matter. She's my child. Autistic or not. It's just Hannah, you know. But. To be honest with you, I thought it might help get her the support she needs in School and it hasn't to be honest. **I do feel deflated.** You know, everything's about you got to get a diagnosis. You can't get support until you do. **Well, actually, I've got a diagnosis and it hasn't made one bit of difference. So, I do feel deflated.** To me, it didn't matter either way. You know I knew she was different, and I support her the best I can. But, you know, you're told

*support of the professionals.*

*Diagnosis doesn't seem to have helped in securing support within school.*

	<p>we can't do anything until you've got a diagnosis at school, but actually, you're still not doing anything now. So, what was the point? <b>You know it is deflating you know.</b></p> <p><b>Listener:</b> Thank you so much Laura, you've shared so much. I just wanted to ask one thing. You know, Hannah being adopted, how was that during this process.</p> <p><b>Narrator:</b> I think it helped because of the history being born addicted to heroin, crack cocaine, methadone. They have to they do initially, you do have a paediatric consultant anyway. And you see someone at the child development centre to keep an eye on their development and because of the history. I do actually believe it helped get more professionals involved. Whereas if you hadn't been born addicted to drugs and I've just gone in there saying my child is acting different blah blah blah. I believe maybe I wouldn't have got as much appointments and professionals involved. I think it would have took a lot longer. I believe that being adopted did help. Definitely.</p> <p><b>Listener:</b> That's really positive to here. Thank you so much for sharing your story it's been a privilege for me to listen to your experiences.</p> <p><b>Narrator:</b> Is there anything you want to ask me?</p> <p><b>Listener:</b> No, you have touched on every single thing in so much detail. I really value being able to have heard your story Laura. Thank you so much.</p>	<p><i>Evident that the complicating factors that the children experienced in their early life meant seeking professional involvement was quicker.</i></p>
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C3 – Bianca - Analysis

<u>Codes</u>	<u>Interview Transcript</u>	<u>Reflections</u>
<p><b>Presentation</b></p> <p><b>Bilingual</b></p> <p><b>Bilingual</b></p> <p><b>Bilingual</b></p> <p><b>Trusting professionals</b></p> <p><b>Comparing</b></p>	<p><b>Listener:</b> Thank you so much for agreeing to take part in this research. I really appreciate it. So the title of the research is exploring the experiences of parents who advocate for their child's autism assessment. I've given you the prompt sheet with headings. But really, in these interviews, it's about your lived experience and your story. And for me, it's really important to capture what happened for you. So I'm going to kind of let you go through that from the beginning in as much detail as you can. And that might prompt and I might ask a little bit more detail about certain things. But, but really, it's a time for me to listen. So, yeah, if you've if you've got any questions, then just please feel free to ask them but otherwise you can start from wherever you like.</p> <p><b>Narrator:</b> So it's really nice and I wanted to do it because to actually talk about the whole story from start to finish. You don't have that many chances you meet people on the way and you just say a bit and then you miss things. And as you start thinking about and I think it I think it can be therapeutic, I'm now at the end of the journey with him. But it's nice to like see where we've gone from and how long and how many years it's took the whole experience. So to start with Erm Elias was born in Wales and we lived in a really little seaside village, it's gorgeous, beautiful place. And but knowing what I know now living in [a city in England] with the access to all the professionals, all the clinics, doctors, Children's Centre, there was nothing like that. So as he was a baby, as long as Elias was fed and watered and cuddled, he did not make a sound. He was the happiest. Baby in the world, honest. It was like a model child's, model new-born. Wake up. Have a poop, feed. Have a cuddle. Go to sleep. At that time Carl was working away as well. We we didn't spend that much time together. So I could do everything in the house with Elias. He would, just as he was growing, would just play sit in the playpen, just engage with his toys. And that was, that's all he did. He never moaned complained cried nothing. But the problem started to show</p>	<p><i>Concerns dismissed due to him being bilingual.</i></p> <p><i>Interesting that the parent dismisses their own feelings as she trusts the</i></p>

<p>Some things not right</p> <p>Dismissed</p> <p>Age</p> <p>Presentation</p> <p>Dismissed</p> <p>Dismissed</p> <p>Some things not right</p> <p>Presentation</p> <p>Some things not right</p> <p>Education / experience</p> <p>Presentation</p> <p>Some things not right / Age</p>	<p>when he wouldn't speak and he wouldn't speak for quite a long time. So I can't even remember what he used to say if I'm honest with you. The basics. Mom, choc choc. Mommy, wow. All very muddled words, repetitions, nothing really from and as you know, as you reflect and there's nothing that he would come out with himself and he's a bilingual child. So I always made sure I spoke to him in Polish and English from birth because that was the advice that was given that you speak both languages. And this way the child will know, two languages, no issue. And I had never had problems. Because I knew he would understand both of them. I'd say something in Polish he would get it, but he would not respond. When I said something in English, he would get it, so simple like, go put in the sink and he would trod away and put in a sink whichever language I said it in. But when the health visitor came, she says, I'm a bit concerned that he's not speaking, and I was put on a waiting list for, It was actually a paediatrician. That's all the access that there was. That's what, he wasn't speech and language, it was paediatrician. Actually, when I had an appointment and she's done some tests and some games with him and she says, I've got no issue. He can understand everything. But he's bilingual so he will speak much, much, much later. So at that point, I'm like yeah. Well if the doctor said so, the doctor said so. And there were situations where my friend used to come with her boy, who was about a year and a half younger and he could speak fully. And Elias is just sat there just making some simple words and not really speaking in a full sentences. But I just thought, you know, she said, so she must know, you know, you just take it on board and you don't want to believe that there's something wrong, do you, you don't want to go, oh, you know, what, there's something wrong. You just think, no, no. He'll grow out. And then when you speak to your parents, the parents know, they say he will grow out he will grow out he'll catch up boys are like that, boys are late talkers. You know all that granny stories about boys and girls speak fast. Boys are lazy. I'm new mom how was I supposed to know, that boys are lazy. I just carried on going. And if I'm honest, there were lots of things between that point and further on. So for example, he didn't like his hair being cut and he used to scream. I remember Carl went to have his hair cut with him. Came back home with half of</p>	<p>professionals advice.</p> <p>Presentation dismissed by hairdressers.</p> <p>Parent dismissed her own concerns due to her child's age.</p>
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<p><b>Presentation</b></p> <p>Some things not right <b>School identify needs</b></p> <p><b>Validation</b> <b>Self-doubt</b></p> <p>Some things not right</p> <p><b>Presentation</b></p> <p><b>Support</b></p> <p><b>School identify needs</b></p> <p><b>Practitioners will not say</b></p>	<p>the head cut and he says we just couldn't do it. I was like he looks silly. We need to go back. So I took him back and then <b>we had to restrain him to have his hair cut.</b> They said oh, that's all right. There are some kids like that. They don't like having hair cuts, but Elias had such thick hair. And every I used to go to Poland. In Poland, 40 degrees heat. I'm not I can't. He will boil over. I mean, the preparation for his haircut was just insane. One person holding one cutting, fruit shoot in one hand loads of chocolate in the other, and he yelled and yelled and yelled at the end three of us had to go for a shower. You know, you've covered in sweat and that. But no that's fine. Some kids are like that. It's OK. Next thing. In a winter long sleeved pyjamas. Summer comes we change to short sleeves. Oh, my god. No. I want a long sleeve. I want a long sleeve. No, Elias because it's hot It's too hot, for Long sleeve. Long sleeve. Long sleeve. <b>And there were those little ritualistic things.</b> I'm thinking wow there's something doesn't add up, and when you know. <b>And I remember as well. And that was quite upsetting when he. There was a period of time when he didn't want to come to me at all. He just wanted to go to his dad. His dad worked away and he would not like me to pick him up. He would not like me to cuddle him. He didn't want me to do anything with him. He just screamed in my arms and wants to go to dad. Just pulling arms out, dad dad dad.</b> And it used to upset me so my much. I'm like OK, I know some children go through phases, that was really like vivid and really strong. It wasn't just I want to go to daddy. He actually didn't want me to touch him. And again, that lasted a few months. It wasn't long, but it was so strong in those months. You just know there's something not right with anything. No. No. <b>And at that point, I started working with children with Autism and like realizing and learning and I've done the whole diploma about autism, researching things.</b> It was very coincidental. I would never said at that point, Elias has got Autism. It's just it's going to be OK. It's going to be OK. It's going to be fine. And I worked two years in the residential home for children, with Autism. And I just thought, oh, like. Realizing that there's that routine and all the symptoms of Autism and the wide spectrum that kids go through. I was learning it was 2012. They were saying you know, it was children with Autism will not look into your eyes and children with autism will not do this and they will not do</p>	<p><i>Validation of parents concerns when a 'professional' shared their concerns.</i></p>
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<p><b>Presentation</b></p> <p><b>Advocating</b></p> <p>Some things not right</p> <p><b>Advocating</b></p> <p><b>EHCP</b></p> <p><b>Advocating</b></p> <p><b>Evidence</b></p> <p><b>Appointments / Courses</b></p> <p><b>Waiting / Emotions</b></p> <p><b>Diagnosis power</b></p> <p><b>Research</b></p>	<p>that. And it wasn't still that much knowledge about that. The spectrum is just so massive that you can't just make it a standard that that's child with autism. <b>And yeh Elias would not look at you as well. No look in your eyes. He was just like fluctuate when you was speaking to ya or interacting with ya.</b> Erm and we relocated quite a lot with Carl because of the company he worked for. That meant we lived in Wales and then Scotland and then we finally moved to [a city in England] and Elias went to school here. <b>And fairly soon again at that point I just thought something is not ok. But then he's 5.</b> It's okay. <b>He's only little, so he's only five here.</b> And then we came here and he got in to school. <b>And again, I was like, that's fine, that's fine. You know, he's absolutely fine. But then I started, well, he's not really like engaging in activities that you would expect him to. So drawing writing reading none of those the speech was still very much at that point, he started to speak, but he was very patchy.</b> It was. Yeah. And, you know you know you know, Elias I don't know. You know, I really don't know what you're trying to say. And then we'll jump on a different subject and different subject and different subject. And I said I can't get anything out of him, really, but I thought let him go to school and settle in one place and see how we get on. <b>And so when they called me from school and just said, you know, we think there's something not right. I was like I thought so.</b> But it was easier as it wasn't easy. <b>It was it was OK to hear it from a school professional, just to say I'm glad they've picked on it</b> I'm glad that I'm not just paranoid about seeing things because it's funny. I don't know how to say it. I start working with autism and I just thought do I see autism everywhere because I work with autism. Do I just. Every little thing that I noticed do I just push it on him that he might be autistic because I've worked with autism. Autism is all I know. And you just question yourself. Do I do the right thing? Because I see a lot or do I just back off. Am I doing the right thing? What if he is? And it's like the triangle. You jumping out everyday? Different. No, he's fine. I'm seeing too much. What if I'm not acting on it? You know, it is just crazy. It's really difficult to describe. But the fact that the school said, you know what we think there might be <b>something not right.</b> And we we need to get involved with more support and assessments. I went that's fine. Let's go for it. Let's see whether there is</p>	
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<p>Thinking Autism</p> <p><b>Education / experience</b></p> <p><b>Emotions</b></p> <p><b>Presentation</b></p> <p><b>Education / experience</b></p> <p>Some things not right</p> <p>Thinking Autism</p> <p><b>Reason for diagnosis / EHCP</b></p>	<p>something going on or not. So the first thing was hearing test he went with flying colours. Yeah. What if he's not hearing properly, he is. But you have to. You will not move anywhere without a hearing test. You just have to have to have a hearing test. We've done that he can hear well. So at that point when he was at school, you know, he was more talking. Like I said, he started talking, but it was very patchy. <b>Err we started having those emotional bits. On top of that.</b> So everything was starting really late. <b>We started crying</b> and I just thought, bloody hell, I had such a placid baby, such a placid toddler we've gone to five. <b>And he's crying about everything and crying and crying and crying.</b> And I just thought again. Well, I had a lucky for four years or five let him have a little cry. You just don't want to accept anything just straight away. You disqualified those excuses that may be he's not. Maybe he's not. Then the SENDCO from school got involved because we were lucky. <b>He's going to school with integrated resources and I'll be forever grateful from school because they actually giving him support in IR without EHCP. So they've accepted him that they've recognized that they've given him so much support in the mainstream classroom,</b> it's no working. We've got actually spaces in integrated resources. We no, we're not getting funding for it. But he needs it. And that is that's why I've always been grateful to them for because not many schools would do it. We're not getting paid for him. So he's not going in there. So he started with going to learning zone. But again at that point I dint really understand. But as we were moving on, like academically, <b>they said he's not making any progress at all.</b> Regardless, what we put in place he is good boy. <b>But he's not making any progress. Year one, well, no progress at all year two no progress at all. Year 3 no progress at all.</b> So we've had three years when they said he's just like stalled. That's it, we just cannot move with him. So educational psychologist got involved. <b><u>And what is the worst part is like they all kinda know, but nobody will say it.</u></b></p> <p><b>Listener:</b> Why do you think they wouldn't say it?</p> <p><b>Narrator:</b> I felt that they were waiting for official diagnosis of things. Because</p>	
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Some things not right

Diagnosis

Waiting

Advocating

Validation

Fight

Diagnosis power

Waiting

Support

Validation

Appointments / Courses

nobody ever mentioned Autism until I says, do you think he is on a spectrum? Because A, B and C. Well, we'll have to wait and see what the diagnosis says. But actually, before we have that SENCO said, we think he's got ADHD. And I said yeh that would make sense because of that fidgety. And he was never as well again with that was never a what we consider naughty ADHD, that we are running and screaming and that I don't like that sense of the expression but some people say the naughty ADHD. It's not that **he just could not concentrate longer than a second on the sentence. That's why he never knew what's going on. Because you started speaking to him, he's lost focus after two seconds. So ok and legs were going when he's on a sofa, just a very moving boy. No concentration at all.** So at that point they said, oh, we need that assessment, that assessment, that assessment, that assessment within probably a month he got referred to ADHD, OT because they thought his dyspraxic erm speech and language and for autism. Lot of things were happening at once. I think I remember just remember feeling so overwhelmed with it all. Because I can't even remember it that much was so much. All at once that it was just unbearable. I was like, bloody hell, what are we going to do how we're going to cope, you know.

**Listener:** And who did the referrals to those different pathways?

**Narrator:** **I asked for them.** But the school did it for me. I said everything at that point when we were all talking that is **something not right.** We are not making any progress. At that point. Oh I missed a bit before the referral. They said, well, we are going to do something what's called my plan. We have to have my plan in place. That's what educational psychologists said. We have to have my plan in place before we will refer you to any other assessments and see if with the really intensive support, he will move on and you had to have it for a year before the referrals were made. And now I remember, at some point **I just went don't bother I said he's not making, don't even bother because he's not making any progress. Don't bother. I would like to get all the people to come back and. You know, I would like everybody come back. I want to speak to**

*Very powerful words,  
parent shares how she*

<p><b>Emotions</b></p> <p><b>Fight Support</b></p> <p><b>Emotions</b></p> <p><b>Positive outcome</b></p> <p><b>EHCP</b></p> <p><b>Education / experience</b></p>	<p>them and I want to see, you know, don't even bother. Come on. I said, how long will we wait for those assessments? When he's year 6 and leaving to secondary. And I've got a kid who's falling apart. So we need to have something in place for him at that point they we're starting to talk. Well, we don't know if we can guarantee IR place anymore because we don't have the <b>EHCP</b>. Oh, my God. So everything just came crumbling so his safe haven learning zone. <b>I'm like, you know that if you take it away from him, I'll have to pull him out of school because he will not cope.</b> Yes, we no but let us fight for it. And that SENCO woman said I will not have him out. <b>Please wait, because I need to fight it all out.</b> And at that point, I just went backwards and forwards with school. I said I would like speech and language, some reports were coming I wasn't even aware somebody came to school to see him. <b>So piles of reports all evidence that everybody saying he's below below below expectation progress. He's below on this below on that.</b> But we still have to put some Lego assessments. And he needs to go for those assessments. And the SENCO, as well, at some point says that's it. I'm bringing them in and they need to refer him and he needs to be referred. And that's that all going on. They can't do one without another. But the one is taking ages. But even though we know the system of going place will not work, the politics are we still have to have it in place for a year before we can do this. First assessment I had through was for ADHD and he got diagnosed with that straightaway. No question. Put on medication, with ADHD. <b>I was put on parenting course before medication.</b> Yeah. Then I got medication. But I know we're focusing on Autism. So that got sorted. He's on a medication that really works. And then for Autism, we waited bang on two years from the moment we got referred. And I got a letter saying <b>the waiting list is very long.</b> We'll keep you updated. <b>It was two years before he got seen. That was just frustrating because you cannot do anything without all those diagnosis in place.</b> So at that point, it was like, I know he's got autism. I know in my heart he's got autism. <b>You know, we've researched it's all, we've been in the workplace. What I'm do for living. Being a special needs teacher, knowing what I know now as well,</b> seeing what's happening at home, the meltdowns started as well. And that was just crazy because the ADHD</p>	<p><i>found the whole journey. She recognises how it may be difficult for others who mat experience barriers themselves.</i></p> <p><i>Parent shares that you should trust your gut. I agree that as a parent you</i></p>
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medication suppressed him all day. By the time it stopped working. **He just was just blowing the biggest meltdowns in the world in a house** and I was like to Carl. **I used to fall and crying and I'm like, I don't know what to do with him.** I have to like I didn't have to ever restrain him. But he was a typical Autism child. I needed a squeeze him. So I invested in a weighted blanket for him and I had to put weighted blanket on him laid down on him on top of him. That's when he would come down every single day. He would not go to sleep. So I co-slept with Elias, probably until last year. Only just started sleeping in his own bedroom. And that's still not plain sailing because in Elias's eyes, he's the same as every adult. He can't see the difference with adults, why are you staying up until 11 and I have to go to sleep. Just a typical Autistic. **Like he doesn't understand the social levels** that we are equal, but we not level mummy can stay till midnight. But you have to go to school and go at 9. So at that point we had that every single day. That was the time, I think, when. When we were going for those meetings, it's clear he's not making progress but a lot of behaviours started. It's like really emerged and meltdowns and changes. So we are going swimming on Tuesday swimming is closed that's its meltdown. So we had to be prepared. Say we are going to swimming on Tuesday unless it's closed. Or Daddy's not back on time. Then we'll go on Wednesday. As long as he knew that there's a possibility that we won't be going, that's fine. But if you said we going we are chuffing going and that's it, you know. So a lot of adjustments that we had to make to our daily routine. And that was the time at school when I just thought, you know, he was not making progress. I think we need to go that official, Dr. route, A.S.A.P. because things are not right.

**Listener:** You said that you did lots of research as well. What did you research? What did you look into?

**Narrator:** Yes. **So those behaviours like and I kind of came back to my diploma that I've done in the past. And just even though you've done it and you know the signs when it comes to your child, I found it's completely different.** You don't want your child to be poorly or have additional needs. It's

*often have a feeling.*

better to see, say. It's just being a child. Like I said, millions and millions and millions of things. But then, like I said. But like I can't really pinpoint it fully. It was the year when I had a mental breakdown because of this. That was the day and we're talking about three years ago when it all just ploughed in at once he wouldn't sleep and meltdowns. He had the asthma on top of it, school was saying, you know, there's **something not right**. I slept with him. And there was millions of things. So had asthma on top so not only did he sleep bad he used to choke half of the night, or it was just horrendous. I think the whole realization and things like things getting worse than easier. Because everybody says, as they, grow it will get easier with Autistic children. It doesn't. As they grow, there are new things emerging and they will always say in Poland small children, small problems, big kids, big problems. And that's what I was finding that year on year on year as he's learning to talk more and interact more and the problems are getting worse not easier. And I think the realization that it's not it's not going to go away is just going to get worse if we don't do anything. I would say about three years ago when it all just came crashing down. And that's that's that's what happens. I think just that just accepting that he's got Autism, even without that diagnose for me, diagnosis at the end was just a formality. **I just wanted that piece of paper in my hand so I can go to local authorities and apply for a EHCP so he can get and supports that he is entitled to enough.** And it was just a formality by the end. It wasn't anything thinking, well, maybe he's not. I think I would have been even more disappointed leaving there thinking he doesn't have autism, because I'm be like what has he got. I you know, it's better to know what we're dealing with. Like we say and then. Then I wouldn't be like, what was his got something. **There's something not right. And we know there's something.** And I think. It is autism and I got diagnosis straight away. **When we finally got there, it was on the day on the spot when they done the assessments and we got diagnosis straight away. And as we left. I'm like, OK.** We went for a meal. It was the biggest winter. It took us about seven hours literally there, assessment and back. We were frozen and we were cold. I says, I'm going. **I've been waiting two years.** I am not changing the appointment and wait another six months. You know, I just I don't give a, I said to Carl. **I don't give a shit. We are going for**

that appointment, even if we're going to kill us. You know, we dragged him for an adventure in the snow. We got diagnosis straight. So there's no question about it. Brilliant. We've got the diagnosis now. Yeah, we've got we've got that now. We've got a diagnosis. We're back to school. Brilliant. And then another journey starting. Which is another level of fighting for your child. I think with that, I like advocating for him. There's nothing I wish I could have done, because if it's two years, it's two years you waited. I in those two years, your child will not get anything extra. Even though the Scarlet A letter, is on the forehead and everybody knows it's Autism. Without that piece of paper in your hands, they get nothing. And that, I think, is the frustration you could ring them and say I want my appointment well that's the waiting list. You won't bypass it. And, you know, working with children with autism as well. I'm also aware that those kids can be the most challenging for families. Nobody will jump start the you know, jump the queue. If you are in the queue and you're in the queue for two years and be in that que you for two years, you struggle. Your family struggles. Child is struggling. You'll get no support whatsoever because you got no. No piece of paper. For me, it was just a piece of paper. I don't think I can read it properly. When he came to the door I said brill. Send the copy to school, send a copy to there, send to there. I really don't think I've read it. It just says he's got autism. Yeah, I know. We knew what would there's nothing different they can say in that piece of paper. Just diagnosed him what we knew before. For he's just got worse and worse and worse. And I just thought, oh my God, what will I do with him? What will I do with him? He couldn't make friends at that point, and the only people he would play was babies or adults because it was easier babies he could look after adults didn't expect too much of him. Peers haven't got a clue if he gets too close in the personal space. You weirdo. You know, there's no point trying. Why they calling me weirdo? Why are they calling me this. Why are they're calling me that. Then he was coming back home and mum was getting. You know because I'm comfortable at home. It's my home I can blow out. So a lot of a lot a lot of things were happening. So who I had involved SENDCO teacher got really involved, speech and language. I've had ADHD nurse involved err neural disability

**doctor erm psychiatrist. Occupational therapist was involved as well. I think that's it, and at the end of the day, when they compounded the whole picture.** They said he's actually so complex that boy, it's all real. We've got autism. We've got ADHD we've got learning difficulties. We've got OT he was borderline dyspraxia, which scored just 1 points on that assessment. So he's still actually got support from occupational therapy school for sessions there and physiotherapist is double jointed in his fingers. He can't ride properly. And then everything else. And at that point I says I don't give a monkey's whether he progresses or not, but we need to give him the best fair chance don't we. You know, it's all right to say then that's what he is. But now what we would do with it, how will we manage it? Like at school they have done wonders with him. And actually, it's the first year now that I don't have meltdowns after school. I was like. And I know why in a summer I had them, but there was no routine in the summer was there. Now we are back at school. I know where I am. I know what I'm doing. He knows that on Monday he scouts and on Wednesday he's running on Fridays playing football. He knows exactly what is happening. And I make sure he knows exactly what's happening at weekend. And I know how to speak to him now. I know how to. **But the whole journey. I found it horrendous. God forbid.** And we see it a lot. God forbid. And I told him that it was a parent who's got learning difficulties themselves because they would not survive that journey or they would have given up a long time ago. **Because I had to fight for Elias.** **And there's no supports like that for parents.** They don't give a monkeys with the parents are different language, disability themselves. You know, parents with learning difficulties do have kids as well. And I just feel there is no consideration how many phone calls you have to make. I can make a phone call, but imagine somebody with mental illness who's got anxiety and making any phone call is just. You know, challenging to them. The whole process was just absolutely shocking, the time scale is just. You can't move. You can't take a step forward without those assessments. And then once you've got those assessments to step forwards, takes as long. As the assessments itself, **I mean I just found it's horrible and I'm glad it's finished.**

**Listener:** Now, looking back, so you've had a diagnosis for an extended period of time. Was it important and did it make a difference?

**Narrator:** **It did make a difference because he got his EHCP.** He got his EHC plan, which reflecting on it should have lasted 20 weeks lasted another year because the local authorities were refusing to accept that he needs to work in smaller groups. There was one appeal that got thrown out of the room, but it was important to get **EHCP**. But that's another new battle. He had seen people, so it still doesn't guarantee. So it's a double whammy. You know, it now got secure place in a school that he's safe in and he's got secure a place in the learning zone, which is integrates resources. **He is thriving. He's happy.** I said I said to school, school for him is school. Home is home. I'm not doing any homework with him at home because at that point, he's exhausted. His medication is not working. I am no medicating him at home. So we are dealing with him at home because he needs to have a reality learning, because if he gets 18 and decides he doesn't want to have medication, which he might as well, he needs to know how to be able to cope with his behaviours effectively without getting arrested retrospectively. So we don't medicate him at home. And I told him that school is school lets him do what he is doing. Teach him. Push him Absolutely. It's not an easy ride. He needs to behave at school. He needs to behave at home. But at home we are family and we just need to relax and breathe. And if it's stressing, it stresses him at home. We're not doing work like that at home, you know. So the school's been brilliant. They really accommodates like all the wishes. **Helps being a teacher of children with special needs. Because I'm sure that if I wasn't, I would get pushed a lot of things more to do but I think they know that, I know what I'm talking about.** What, I know now as well. When I speak to parents, I said trust your gut because autism now is it's such a wide spectrum. You can have a autistic child who will look beautifully in the eyes all the time they're speaking to you yet have a complexity and a range of different needs. And then you have a child who's really high functioning but he won't look you in the eye and it will cause him stress. So those stereotypes of autism. They are. They are aren't they. Everybody thinks they'll be like a rain man can't matches and be outstanding at



	<p>piano. They saying they won't look you in the eye and they'll be a bit awkward. No, you need to spend the day with the with the real illness. And, you know, and forget about the Rain Man movie and everything else when they are fantastic and geniuses. And this that and the other because they are they are fantastic. Not all of them will have those prodigy skills. So I always say now trust your gut. If you thing there is something wrong as a mom. Ninety-nine-point eight percent. It will be wrong.</p> <p><b>Listener:</b> Thank you so much. I really appreciated you taking the time to speak to me. Thank you so much for taking part.</p>	
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D4 – Carla - Analysis

<u>Codes</u>	<u>Interview Transcript</u>	<u>Reflections</u>
<p>A feeling</p> <p>Somethings not right</p> <p>Advocating</p> <p>Presentation</p> <p>Research</p>	<p><b>Listener:</b> So, thank you so much for agreeing to take part in this research, the title of my project is listening to the stories of parents who actively advocate for their child's Autism assessment. I'm really interested in hearing your story. I've given you a sheet with some headings for prompt. But generally, it's really important for me to listen to your story and provide you that space. So, I hope that's what I'll be able to do. And so, I'll just hand over to you if that sounds okay, unless you have any questions for me.</p> <p><b>Narrator:</b> Absolutely fine this story of ours started and I think as a lot of parents do when it comes to Autism with a gut feeling erm I remember going to Jacks, 18 months assessment and speaking to the health visitor and saying theres just something not quite right, eye contact was hardly there. Errm you'd say his name and you'd hardly get anything. Plus, he was hardly making any other noises that I'd read up about because Jack was my first so ermm I didn't really have anything to go on and I thought, well, hold on, theres something not quite right and I</p>	<p><i>This resonates with my own experience, those embodied responses are so important and a physiological response to our feelings and thoughts. I remember</i></p>



<p>Some things not right</p> <p>Dismissed</p> <p>Research</p> <p>Thinking Autism</p> <p>Appointments / Courses</p> <p>Trusting professionals</p> <p>Presentation</p> <p>Practitioners can't say</p>	<p>remember going to the 18 month assessment and speaking to them, and all I got was oh nooo no he's fine theres absolutely nothing absolutely nothing and I remember looking it up on the internet like all all worried parents do and thinking hold on he's got quite a few triggers there for early on set Autism. But I was full time teaching at the time, and I thought okay Ill trust their judgment. And you know, everything will be fine no problem anyway. Then it got to about the age of two and we had a health visitor who was also a nursery nurse practitioner. She used to come to work with him on his speech. And she kept saying, oh, he really likes his Thomas trains, doesn't he? he likes playing with the same thing. He doesn't doesn't like to change does he what he's doing. And we obviously, became very close over the time she worked with Jack. And they said to me, years later I couldn't actually say I think he's got Autism because it will have to come from the parent unfortunately, she said it's not allowed to come from us. So erm anyway, eventually I had some time off with my second one because I was very, very poorly. I had morning sickness so I couldn't teach for the whole well for the last six months of the pregnancy I couldn't teach and its during that time spending more one on one time with him I thought. No, definitely not ok theres something. He wasn't toilet trained. It was soiling all over the place he still does it now and he doesn't recognize the need to go or Why should I go? And he's not bothered. And he likes that routine. If things are different and the world could be collapsing around him. And he gets fixated, so he'll watch the same cartoon, over and over and over and over. And when he did start talking, it was incredibly echolalic in that he would copy exactly what you just said to him ermm straight back. So, at that point, I said to the nursery nurse, I think there's something not quite right. And she said would you mind if I did a quick home assessment next week. I said oh It's absolutely fine. He ticked off the boxes so she said well don't you think he might need to go to, you know for assessment because he'll be going to reception within 12 months. So, I said yes let's get the ball rolling then. So, I managed to get in touch with the hospital and from that day on from the minute that his letter went through. I just phoned the hospital nearly every other week because a friend said it can be a good 12 month waiting list, I thought, NO I'm not having that. If he if he is suffering if he is locked in, which, you know, he could be again</p>	<p>that gut feeling.</p> <p>I have encountered so many parents who share they have researched on the internet. I too did this when my first son was born, looking for important milestones. I also remember searching the internet when I recognised my second son's presentation of needs.</p> <p>I understood this because as a TEP I had also been told by colleagues that we do not mention the word Autism. We can discuss presentation but we do not say the word so we don't lead parents.</p>
<p>Some things not right</p> <p>Presentation</p> <p>Something not right</p> <p>Advocating</p> <p>For school</p> <p>Contact</p> <p>Waiting</p> <p>Advocating</p> <p>Presentation</p> <p>Advocating</p> <p>Evidence</p> <p>Appointments / Courses</p>		

<p>Known</p> <p>Appointments / Courses</p> <p>Support Contact Known Fight Appointments / Courses Dismissed Advocating Evidence</p> <p>For school Advocating Waiting</p> <p>Diagnosis</p> <p>Support Response to diagnosis</p> <p>Diagnosis power Advocating Presentation Appointments / Courses EHCP</p>	<p>because he's very echolalic. And you know he couldn't quite communicate very well at all and I said no. I said this has got to be sorted out. Erm meantime, then I was made redundant. But I thought that I've got to get just got to get this boy sorted. And I was applying for a job one day. Because like you do and he walked into the office and said mummy stop tippy tappy and I thought that's it it's the most he has ever said and here I am looking for a job. I said that's it I'm packing it in. And so eventually we got to see the consultant, the consultant who he is still under. Is very much. Where's the evidence? Have you got any evidence? So, I managed to get hold of reports from nursery and reports from the nursery nurse practitioner's health and speech and language, then I also managed to get him on to a speech and language course. And every time a course was offered, even if I thought it was going to help or not, I put our name down because I knew if his name disappeared off any list, he would disappear. It wouldn't be found. And I find that. You know, I have to go on courses that I think, well, it's not exactly going to hit him but then I think like he'll get known. Then you find out that theres another course that does fit him and talking to other parents there like oh we didn't know what was coming up. There was a course on food that I went on because of his very limited diet. Some of the parents were like I didn't know they were running that and I thought yeh if it hadn't been for the fact id been on the other course the week before and I'd overheard them talking and I said, oh, ill, go on that. But you do, you have to push yourself. You really have to push yourself forward to get any sort of support. And you almost feel like your pestering. But you've got to keep yourself on the radar and I think that's the one piece of advice I would give anybody is what once you think that that is where you're going. You've got to keep the ball rolling and you've got to keep in contact with everybody and you've got to keep fighting ermm most definitely. So anyway, the consultant on the first bit was like well it might be it might not be, and we'll carry on with the speech therapy and I'll see you again in six months. I thought, right I've got six months now, got six months to really get this evidence together. And, you know, I went to all the speech therapy sessions and I kept saying his specialist wants this all-in writing. And is there anything you can give me in writing after every session and I just collected as much</p>	<p><i>I can hear the power in the parents voice, advocating for her son.</i></p> <p><i>Sad to hear that this parent felt that her son would disappear if she didn't stay on the radar.</i></p> <p><i>FIGHT. I remember that feeling, it did feel like a fight.</i> <i>Attending the appointments and collecting the evidence is all the different ways in which we advocate.</i></p>
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Education / experience	<p>paperwork as I could. And then when I saw him, I just presented him with all the paperwork. and he said Oh, yes, es, you've got all this evidence. But what I did do was I photocopied it all so that nobody could say, oh, no, no, you didn't give us that because my mum was a nurse and she often said its surprising how many how much stuff goes conveniently missing in terms of referrals and things. So, I thought, well, I'm not having that happen to him either. And so, from then, he said, okay, yes, yes, yes so when is he going to start reception. So, he's starting in September and this is like the January before, by this point. So, he said oh right well it will be about 12 months and I thought no I'm not having that. So, I pushed and pushed, got him in for the July. Thank goodness. And we walked in, and they were lovely they were fantastic and after the assessment they basically said we could tell before it even started the assessment by the way he walked in. By the way he presented himself and we knew it was going be a positive result. They were they were fantastic, really really, supportive in how they gave over that news in that they said it was a positive. We now know where we're going. And he is really a specialist. His mind is just so focused. He will be a specialist in whatever he is interested in we were then handed over to a lady who was meant to be the family support worker from the hospital. She said, oh I'll give you all the support you need, and we'll be there for you from day one. She gave us a leaflet and then that was it. She said we'll be in contact with you and I'll always be there for you. So anyway, two weeks after diagnosis, obviously it hit us all pretty hard. So, I tried to give her a ring, because I thought well, she said she would support the family. So, I gave her a ring and it was all like Oh, no, no, no, erm I'm really busy at the minute I'll pass you on. And never heard anything back. So, I thought I'm going to have to erm do this myself. You know I've got my diagnosis you know; he's just finished nursery. We're going into reception and I managed to basically do it myself. So, I got in touch with the local Autism team and I said I really need a home visit. I said he can't go into town centre it's just too busy for him. And plus, because I've got the baby anyway. And so, I would need a home visit, I put my name down for every single erm meeting every single course going. And then when it came to school, I think because I was a teacher, I still am a teacher, qualified teacher. I know the systems and I</p>	<p><i>The lack of support available is deflating, considering how parents must feel post diagnosis.</i></p> <p><i>Sound like the parent is empowered since receiving the diagnosis.</i></p> <p><i>Diagnosis strengthens</i></p>
Advocating		
Support		
Support Advocating		
For School Reason for diagnosis Presentation EHCP		
Advocating		
Positive outcome		
Diagnosis power EHCP		
Dismissed Advocating		
Age		
Validation		

<p><b>EHCP</b> Advocating</p> <p><b>Known</b> Professionals voice</p> <p><b>EHCP</b> Dismissed / Professionals voice</p> <p><b>Positive outcome</b> Presentation Self-doubt Validation Self-doubt Validation</p> <p><b>Education / experience</b></p>	<p><b>know what an EHCP is.</b> I know what they mean when they say Ed Psych and things like that because I was head of year as well. <b>So, I had all that prior knowledge of SEN. So, in the end, they couldn't really get past me.</b></p> <p><b>Listener:</b> Yes.</p> <p><b>Narrator:</b> <b>And I was able to go in and say right he's got the SALT team coming in. And you know, when are we having an Ed Psych visit you know when he is going to be seen by the Behavioral support team inclusion team. And it's been very much, I think, because of that school see me more as a support</b> rather than somebody who is going to pester.</p> <p><b>Listener:</b> Yes.</p> <p><b>Narrator:</b> So, we've got a really open relationship. You know the SENCO also taught my youngest son. He's just going to reception now. And, you know, like she said, they know the family really well and <b>the door is always open they are not afraid to talk to us about anything at all.</b> And they know that we we'll work on it. But again, I think they also know that if they slip up, <b>I would be straight in.</b></p> <p><b>Listener:</b> Yes. Can I ask you in regards to going for the Autism diagnosis, what was the reason why was the diagnosis important to you?</p> <p><b>Narrator:</b> <b>The diagnosis was important for me because I didn't want him going into school with him having a label of him being a naughty child.</b> I knew that if somebody saw a Jack, they would think <b>he's not listening he's not cooperating.</b> I thought no we need to get him on the SEN register because <b>I new that they would have to have three terms worth of evidence anyway. Before they could even start the EHCP process</b> I thought no I need to get him on the SEN register, and I need to get it done before he starts in the September. So luckily, because he had his assessment July time and I was able then to go into school, about two weeks later before they broke up. <b>And said look this is his diagnosis. This is what they are saying he needs. And I was able to give him as much information as I could, including all the documentation I had, right the way from the past, so that they could get a really good background in terms of what's going to help him when he starts in reception. So, it did work in a positive for Jack and for the school because they said they don't normally get this amount of information. So, when he started, they already had ear defenders in his favourite colour, they already</b></p>	<p><i>parental voice to be able to advocate.</i></p> <p><i>I feel like the parent is pathologised and not believed.</i></p> <p><i>Professionals or practitioner as I prefer, their voice seems to be prioritised. Very much a medical model of working.</i></p>
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Diagnosis power /  
EHCP  
Education / experience

had sensory cushions, they had already got sensory blanket you know they had already gone and purchased things for him beforehand. So that when he started in September, he had everything that he needed. And, you know, box of dinosaurs, box of Thomas toys right near where his space would be, and that's what they've been like they have been Fantastic.

**Listener:** Did the diagnosis help?

**Narrator:** Completely, 100 percent. Because I don't and I honestly and truly believe, because I've seen it myself, throughout the years of teaching and even Secondary. **If you haven't got a piece of paper with that diagnosis, nobody wants to listen** because it closes the door that **EHCP that diagnoses opens, so many doors** and people, you know, even in the NHS their whole opinion changes the minute you **say you have a diagnosis** before then is very much a case of, you know, anxious mum, over anxious. And, you know, you have obviously read about it. And you put two and two together. We think you've come up with 7. **Whereas when you've got a diagnosis you know they are a little bit more well yes.** This is where we could be going and they are a bit more proactive **rather than trying to placate and say, well, you know, I always, make you feel like they will grow out of it.** **And once you got that diagnosis, there's nothing they can come back at you with, so it does really help, it's really does help.**

**Listener:** You have talked about the EHCP process how was that with having a diagnosis?

**Narrator:** And in terms of the diagnosis erm I mean, obviously, I know the parents in the school who, you know, who are going through the process, or are trying to get through the process of having an Autism assessment. **And the ones who are still trying cannot get an EHCP.** They cannot seem to get one. It seems to be with our local area. **If you have got a diagnosis, they they will, listen to it, more carefully.** Also, the feedback I've had because I know quite a few parents and they have gone to different organizations. They have said they have had the **ADOS but because they're still not working with speech and language, because they're still not involved with the Autism team. There EHCPs didn't seem to be pushed through as quickly. It seems to be the more in contact you are, the more agencies more you've got, the ADOS assessment, the more they are willing to**

*Very difficult and hard to rationalise when you feel alone and not listened too. I remember doubting myself.*

*Made me think about belonging to a community of practice and whether as a teacher you're an inside or outsider. As a teacher was Carla's voice privileged.*

*The power of the diagnosis, I understand this. It feels like your feelings and thoughts are validated and*

**listen to you. It's almost as if they will listen to the expert, but not to the parent.** You know. And there's another little boy who used to go to Jacks school and I've known this little boy since he was two. He' virtually non-verbal and he couldn't cope in mainstream and they were struggling to get him an EHCP because he didn't have a diagnosis. Parents are gorgeous they are lovely, but they didn't know who to go to and where to go. They didn't know who to pester. They didn't know that there's such a thing as an Autism team. They didn't know there was such a thing as going to the speech and language team, apart from oh, your sent for you do your six weeks and off you go, and they didn't know all that support was out there. **But having an EHCP is vital it does open up doors. But It doesn't matter, they won't believe that your child has got Autism until they have got that ADOS from a specialist.** They won't believe it. They should but they do not believe it.

**Listener:** So now thinking about having had the diagnosis and securing the diagnosis and having had it for an extended period of time. How is life now? How do you feel about going through that process? Are you glad that you advocated for that assessment?

**Narrator:** **I am glad that I pushed for that assessment, because he's happier. He's content.** And it sound silly but some days before the assessment **when he was having a meltdown or banging his head on the walls** and I used to think I'm a really bad parent. I can't control this. I can't change it. I can't make him feel any better, **whereas getting that assessment. Also make me feel, that yes, your concerns were justified. You son does need extra support and you Know you're not you're not going stir crazy yourself.** Do you what I mean, because sometimes you think it's all in my own head. Have I just made it up. Is it just that he is naughty. **And when you get that assessment where they say, basically your right, you're thinking, right ok, I was right. It does make things better.** And I've seen other children, you know, to people that I know who really struggle they are in mainstream. And they can't get out. And then they're having a hard time being bullied and everything else. Whereas with Jack because of the school I chose and because how I've been with the school, we all work together. I've been able to say oh a child said this today. Can you please do it in circle time, can you please discuss it. **I think because I know the terminology and I know the phrasing. And, you**

*there's greater strength to what you have said.*

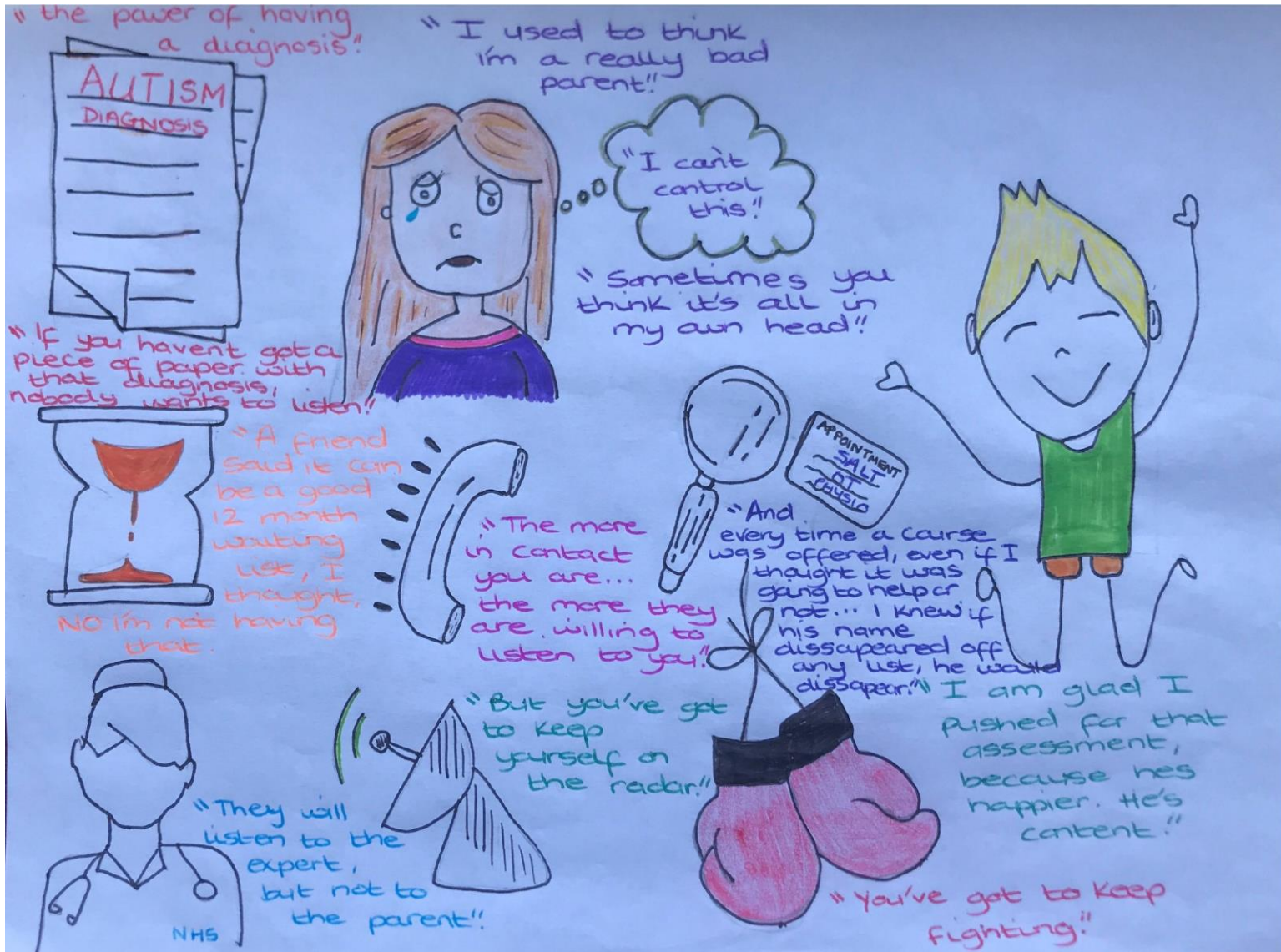


know, I could slip in, you know, little buzz words around OFSTED and stuff and just just drop in a conversation and they'll just say, yeah yeah, we'll do that and it's been absolutely fine. No problems whatsoever. And to the point where, you know, the head phoned me last year and said, well, we're having a staff restructure. We're going to keep all of Jacks TA's the same. And we're going to move the year 6 teacher down to year, two, because that's the one teacher he really does gel with. It's another male teacher he really does gel with and we're doing it for Jack, and I thought. Yeah. That tells you the difference that they have's though about Jack. You know, when there's 20 other the children in that class. They have thought, let's get this child sorted and I think for head to do that. Just tells you the power of having a diagnosis and a EHCP and that knowledge. And having that relationship with them as well, because they also say we know we can talk to you about about anything at all and you understand it. You know, we don't have to water it down, so to speak. And so, we can have open dialogue. And it's just a shame that I think that parents don't are not give those those keys and that terminology to be a help even further. I think if I had not been a teacher, I think it's a two-way thing. I don't think teachers are educated enough Autism. I don't think parents are about what they're dealing with, about how hard it is going to be. And I think there's a lot of work still needs to be done. An awful lot. Yeah. Yeah.

**Listener:** Thank you so much for sharing your story.

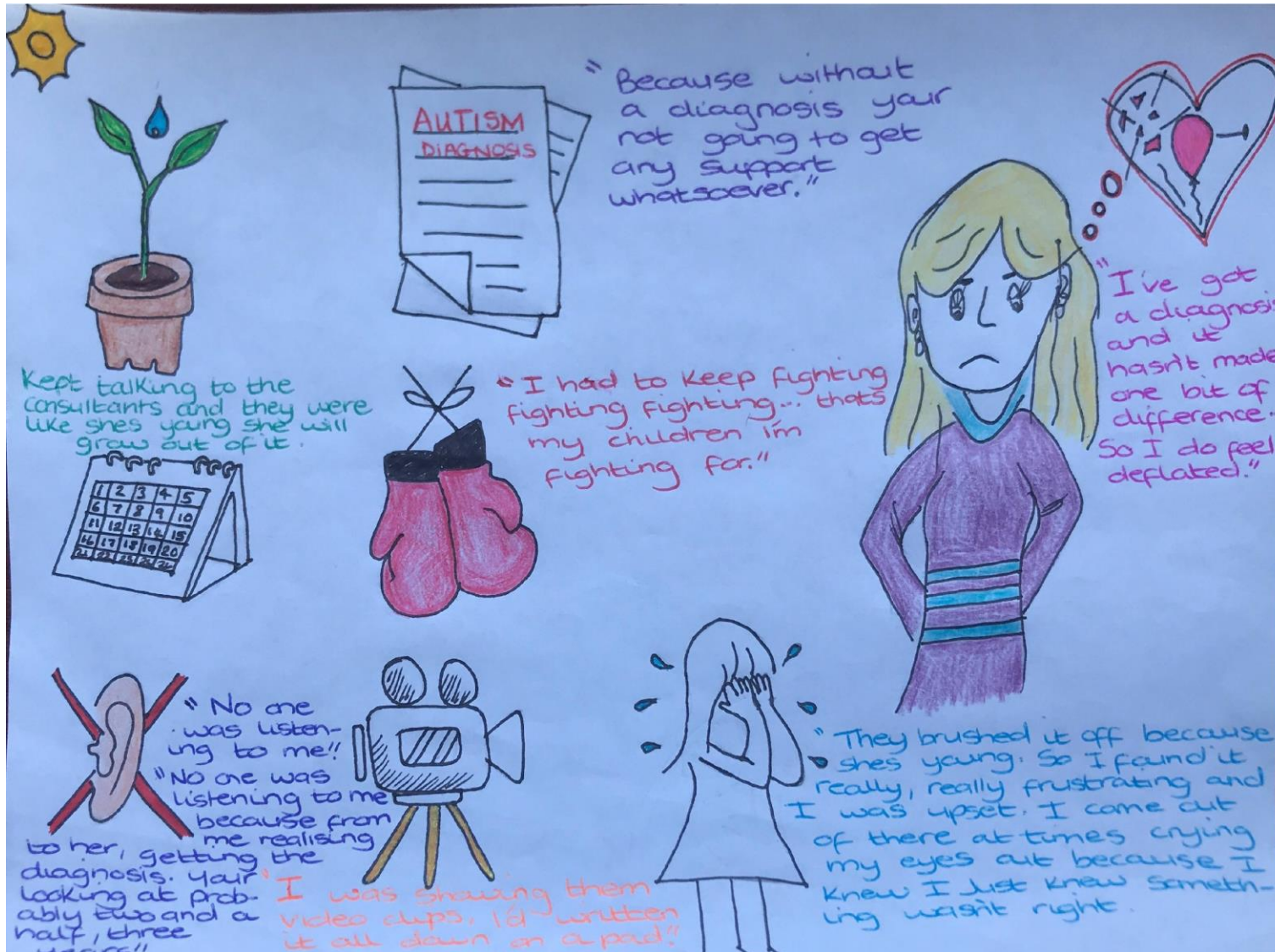
**Narrator:** No Problem, Thank you.

Carla's Poster

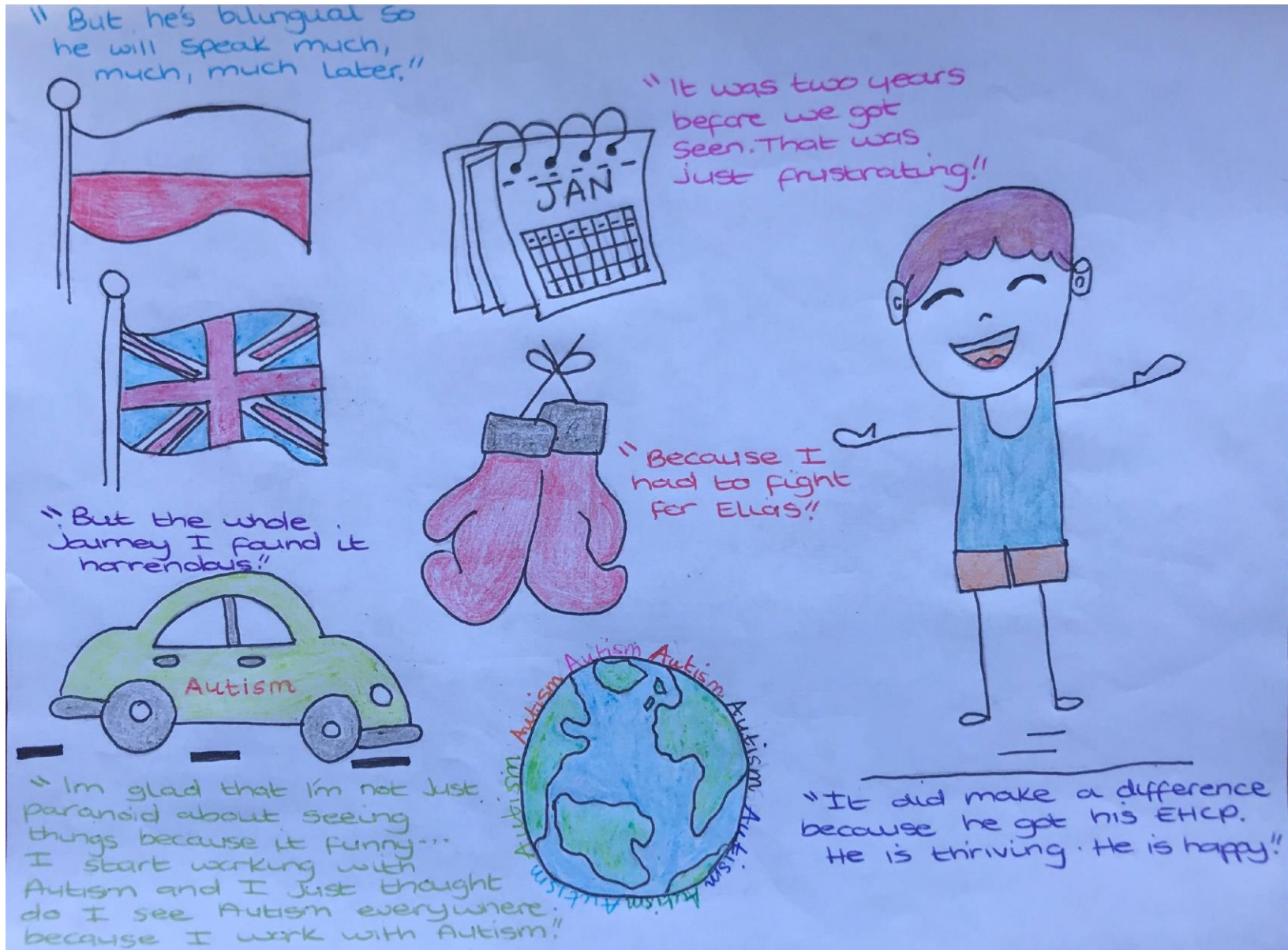




Laura's poster

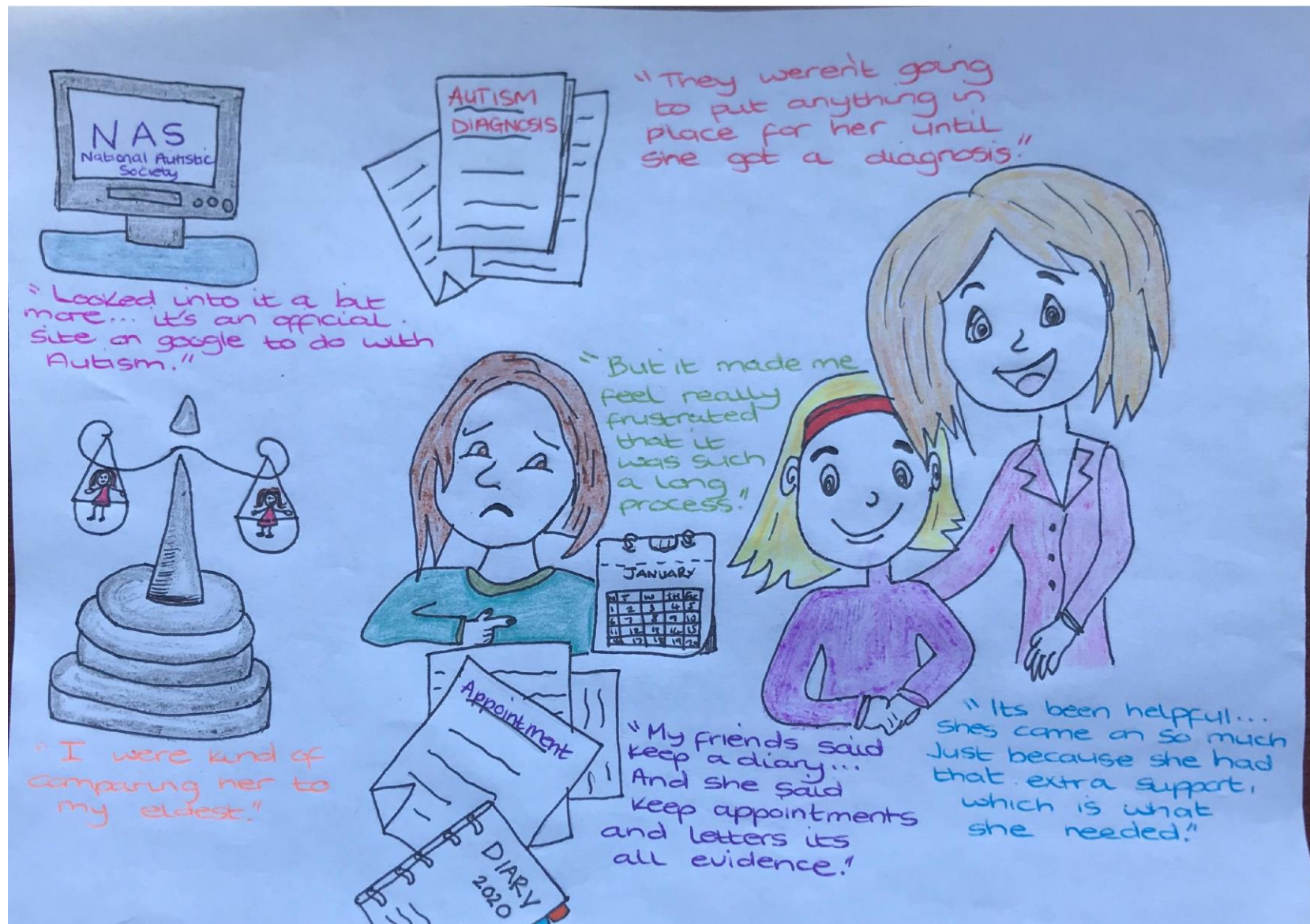


Bianca's Poster





Karen's Poster





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By Danielle Andrews  
Thursday, 19th June 2020, 12:25 pm  
Updated: Thursday, 19th June 2020, 12:43 pm

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***My son's wait for an autism diagnosis was relatively smooth compared to other families - and that's saying something***

Diagnoses matter and not just because of the relief one can provide - it helped my son understand why he has always felt different and it has helped us better understand how to assist him with his issues

[James Moore](#) | @JimMooreJourns | Saturday 22 June 2019 12:03

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