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Missing: The autistic girls absent from mainstream secondary schools

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Declaration of Original Authorship

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Abstract

There is evidence that a growing number of autistic adolescent girls stop attending mainstream secondary schools in England, but little is known about why this is happening or what needs to change. This research used a mixed methods approach to understand and explain this phenomenon, and to make recommendations for change.

The historical underdiagnosis of girls has meant their stories have been absent from research into autism and into the ways in which they are excluded from education. This study therefore positioned the voices of these absent girls as key to understanding their lack of access to education and engaged them as participants and co-collaborators in knowledge production. Lived experiences and personal constructs of school were explored over three sessions of semi-structured interviews with 10 adolescent autistic females. The girls generated timelines to chart pathways to absence, identifying both positive and negative events in their histories, and these guided discussions and analysis. Of the eight girls who completed all three interviews, all self-identified as cognitively able.

Scale and context were provided by an analysis of secondary data retrieved from the Department for Education (DfE) and National Health Service (NHS). DfE data (2009-2017) established that the number of autistic female pupils at mainstream schools in England is increasing, and that adolescent autistic girls were more likely than autistic boys or non-autistic boys or girls to be persistent absentees. Data (n=4448) from one NHS Trust in the SE of England (2012-2018) showed that the mean age of referral for girls was decreasing, but that boys were still referred and diagnosed younger, and that there were wide discrepancies in rates of referral between different regions. A more detailed analysis of data from 2016 (n=408) found that schools were less likely to refer girls for an assessment of autism than other main types of referrer. Case studies of the NHS records of eight autistic girls revealed that the girls' voices were absent in documentation about them until the point of assessment, as well as from decisions about their needs in school.

My original contribution to knowledge is that, in contrast to much of the literature on school non-attendance, the autistic girls in this study wanted to be in a school, learning. Disengagement was a gradual process for most, and this research shows the multiple, often subtle ways in which autistic girls can be excluded from mainstream education, sometimes unnoticed, with health and social consequences. The girls were not rejecting education, but an ethos and an environment that were profoundly damaging to their mental health. The lack of support and understanding they experienced were partly the result of their voice being undermined or overlooked, contrary to UK legislation and the United Nations Convention on the Rights of the Child (UNCRC).

Key recommendations were to prioritise wellbeing, provide autistic-led training for all staff, become more curious about why some autistic pupils take the actions they do and take action to protect and support them. Alternative provision that meets academic needs in a smaller nurturing environment must be made available for those autistic Children and Young People (CYP) for whom mainstream will not adapt to care for. Underpinning all these recommendations is the need to truly listen to the voice of the autistic Young People (YP). This is a rights issue.

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List of Acronyms

AET	Autism Education Trust
AS	Asperger Syndrome
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
BAME	Black, Asian and Minority Ethnic
CAG	Confidentiality Advisory Group
CAMHS	Children and Adolescent Mental Health Service
CCC	Children's Communication Checklist
CCG	Clinical Commissioning Group
CME	Children Missing (from) Education
CYP	Children and Young People
DfE	Department for Education
DfEE	Department for Education and Employment
DSE	Disability Studies in Education
DoH	Department of Health
DSM	Diagnostic Statistical Manual
EHCP	Education, Health and Care Plan
EWS	Education Welfare Service
FOI	Freedom of Information
HFA	High Functioning Autism
HRA	Human Rights Act
HTS	Home Tuition Service
IFL	Identity-First Language
LA	Local Authority
NAS	National Autistic Society
NT	Neurotypical
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
PFL	Person-First Language

PNT	Predominant Neurotype
PRU	Pupil Referral Unit
RiO	An electronic patient record system used in the NHS
RQ	Research Question
SAP	School Attendance Problems
SCQ	Social Communication Questionnaire
SDQ	Strengths and Difficulties Questionnaire
SE	School Exclusion
SEN	Special Educational Needs
SEND	Special Educational Needs and Disability
SNACK	School Non-Attendance Checklist
SR	School Refusal
SRAS	School Refusal Assessment Scale
SRB	School Refusal Behaviour
SW	School Withdrawal
TR	Truancy
UNESCO	United Nations Economic, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund (formerly United Nations International Children's Emergency Fund)
UoR	University of Reading
WHO	World Health Organisation
YP	Young Person

Chapter 1: Introduction

1.1 A growing phenomenon

> If she threw desks around, threw bricks at a wall, she would be put in a unit and looked after. Where is the support for girls like her? (Mother of autistic[1] girl not attending school. Personal communication, June 2016).

In January 2016, I was advised by the Lead Educational Psychologist of a Local Authority (LA) in the South of England that a 'growing number' of adolescent autistic girls were missing from education in her LA, were very vulnerable, and were proving difficult to place. At the same time, through my work as an autism specialist practitioner with a local charity and from membership of national groups on social media platforms for parents of autistic girls, I had anecdotal evidence that they appeared to be struggling to attend mainstream secondary schools across the country. These girls were not formally excluded but called school 'refusers', with sporadic to zero attendance and no or limited access to alternative provision. The information from these various sources suggested the absence of autistic girls was a widespread issue.

However, the absence of adolescent autistic girls from school seemed largely unrecognised and unreported in stories about autism and exclusion. Published national tables on exclusions (DfE, 2020c) and absences (DfE, 2020a) do not present findings by sex and primary special need so there are no published statistics to reveal the extent of the problem in England. Informal exclusions by schools and self-exclusions are, by their nature, rarely recorded. Little research appeared to exist on the phenomenon, which was surprising given that children not attending school is an issue typically viewed with concern. Ofsted's National Director of Social Care wrote of the risk of the underachievement of children and young people (CYP) out of school, with no access to formal qualifications needed for future employment, and of their vulnerability to abuse and neglect at home or exploitation in the wider community (Schooling, 2017). Once out of school, children are 'pre-disposed to long-term non-attendance' (Stirling, 1998, p.56), which is linked to poorer life outcomes. For autistic CYP, these include 'social isolation, peer rejection, lowered grades, and a greater risk for mental health' (Wilkinson, 2008, p. 3).

My interest in the issue was also personal. I have an autistic daughter, whose diagnosis at the age of five instigated my research journey into the educational experiences of autistic girls which was the focus of my Master's dissertation (Moyse, 2013). During this period, I was also clinically assessed and

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[1] I use the identity-first term of 'autistic' to describe the girls, as opposed to 'girl with autism', as it the preferred term of many autistic people (Kenny et al., 2016) and of the girls interviewed for this study.

diagnosed as autistic[2]. At the time I began my doctoral research, my daughter was in Y6 and about to transition to a mainstream secondary school. This further motivated my drive to understand the phenomenon of why some autistic girls might stop attending school.

I therefore came to this study in the position of 'insider researcher' (Stewart, 2010, p. 15). As a practitioner, I brought with me powerful stories about girls I had never met, of school lives protected or conflicted, of families desperate for change. As a mother, I brought my daughter's year of struggling to attend primary school, the lessons her teachers and I learnt on our journey together, and her experiences as she transitioned to secondary school. As an autistic woman, I brought my own mixed memories of challenges, successes, and failures at school. These conversations and events all shape my understanding of autism, and throughout this research I remained conscious of the need to be open and reflexive to the voices of the participants in my study, whilst acknowledging my own beliefs.

1.2 Focus and position of the thesis

The focus of this research is to explore and understand the phenomenon of adolescent autistic girls who stop attending mainstream secondary schools and identify possible changes that could be implemented to prevent or reduce this problem. In order to address these trends, it is important to present a number of critical and overlapping issues which help to position this thesis.

1.2.1 Non-attendance as a rights issue

> Children do not lose their human rights by virtue of passing through the school gates (UN Committee on the Rights of the Child, 2001, para. 8).

The view of this thesis is that non-attendance of autistic girls is first and foremost a rights issue. The right to an education is prescribed by the Human Rights Act 1998 (Protocol 1, Article 2) and Article 28 of the UNCRC[3] (UNICEF, 1989). The UNCRC has been ratified by 194 countries including the UK and the right to an education is one of 54 Articles that describe the rights to which every child is entitled (UNICEF, 1989). Additional Articles pertinent to the focus of this thesis are Article 12, the right to express a view and have it heard and taken into account ; Article 23, which includes 'effective access to…education' for disabled children; and Article 29, 'the development of the child's personality, talents and mental and physical abilities to their fullest potential' including 'equality of sexes' (UNICEF, 1989, pp. 5-9). Furthermore, equality of access to a mainstream education is supported by the Salamanca Statement and Framework (UNESCO, 1994). These rights demonstrate international

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[2] The clinical diagnosis I received was Asperger Syndrome (AS), a type of autism. AS was removed as a separate category in the Diagnostic Statistical Manual-5 (DSM-5) (see section 1.3).

[3] United Nations Convention on the Rights of the Child (UNCRC).

acceptance of the need to make educational provision for autistic girls and are situated next within the English legislative landscape.

Profound changes in the understanding and legislation of children's rights in the late 1980's, via the Human Rights Act 1998, The Children Act 1989, and the UNCRC (UNICEF, 1989) were also central to the international adoption of the British model of autism (see section 1.2.2) 'as part of a model legal and psychological framework model for recognising both disability rights and children's rights' (Evans, 2017).

The Education Act 1996 details the rights and responsibilities of parents and LAs for the education of a child in England. Parents and carers are legally responsible for making sure that CYP receive suitable education 'by regular attendance at school or otherwise' (Section 7), and their wishes around the type of provision must be met 'so far as that is compatible with the provision of efficient instruction and training and the avoidance of unreasonable public expenditure' (Section 9). LAs, meanwhile, 'must ensure there is enough education provision in their area' (Ryder, Edwards, & Rix, 2017, p. 10):

> The schools available for an area shall not be regarded as sufficient for the purposes of subsection (1) unless they are sufficient in number, character and equipment to provide for all pupils the opportunity of appropriate education (Section 14).

The rights established by the UNCRC are echoed in the Children and Families Act 2014, which states in Section 6 Part 3, para. 19 that LAs 'must have regard' to supporting the development of each CYP 'to help him or her achieve the best possible educational and other outcomes'. The Equality Act 2010 states that LAs and schools must 'have regard' to the Special Educational Needs and Disability (SEND) Code of Practice (DfE & DoH, 2014, p. 13) and that schools should make special provision in the form of 'reasonable adjustments' to address any special educational needs (p. 17). Legal statutes therefore support the position of this thesis that autistic girls have a legal right to attend school.

Despite this clear legal provision, the potential for conflicts and tensions between parties remains. There may be difficulties if parent and school do not agree on the type of provision a child requires, what constitutes a 'reasonable adjustment' or what best outcomes look like for the CYP. Decisions around suitable provision may be led by finance rather than need, whilst parents may be prosecuted if their child does not attend school (DfE, 2019a), even if the provision is not considered by the parents or Young People (YP) to be suitable.

Autistic girls are additionally protected in law by the Equality Act 2010 under two protected characteristics of sex and of disability, with disability defined here as 'a physical or mental impairment' that has a 'substantial and long-term adverse effect' on daily living (Government Equalities Office, 2011, p. 7). There are difficulties in noting this section of the Act, not least because some autistic people do not regard themselves as disabled, and because the term 'impairment' may imply a deficit understanding of autism (see section 1.2.2). I include it here, however, because being autistic is a lifelong condition and the disabling effects of the world we live in can be daily and severe. In addition, the protections afforded by this Act are essential to the provision of suitable education for autistic girls, as schools must not discriminate against them in terms of their treatment or their access to learning and other services (Section 85, 2), meaning they '**must** make reasonable adjustments' (DfE & DoH, 2014, p. 17). Protection against discrimination is further afforded by the HRA 1998 (Article 14) and the UNCRC (Article 2).

Furthermore, significance is placed on the need to involve the child or young person and their parents in decisions about the services and support provided to them. One of the key recommendations from the Lamb Inquiry (2009), part of a response by the UK government to a House of Commons report on SEN, was for schools to strengthen the voice of CYP to help provide them with a better service. The SEND Code of Practice (DfE, 2014b) relating to Part 3 of the Children and Families Act 2014, later provides statutory guidance on this, stating that Local Authorities must make sure that CYP are given 'the information, advice and support necessary to enable them to participate in discussions and decisions about their support' (p.21).

Current legislation therefore overwhelmingly protects the right of an autistic girl to a suitable education, with equal access to services and protection from discrimination on the grounds of sex and disability, and validates pupil voice as an essential part of ensuring suitable educational provision for autistic girls per their rights. This is important in terms of understanding whether the law in England provides suitable protection for these girls in school, or redress and support once they are no longer attending. My personal experience, however, questioned if this was indeed happening in practice.

These rights and recommendations informed questions I needed to ask during my research and were central to the choice of a participatory methodology and the prioritisation of pupil voice in my main data collection. The choice of narrative interviews and topical life histories is 'rooted in the concept of standpoint epistemology', which argues that 'authority over knowledge is created through direct experience of a condition or situation' (G. Russell, 2020b, p. v) and therefore positions the autistic girls as experts on their own lives.

1.2.2 Autism as social construct

Autism was first proposed as a childhood diagnosis by Kanner (1943), whose descriptions of a group of eight boys and three girls with a 'desire for aloneness and sameness' (p. 249) and the seemingly 'innate inability to form the usual, biologically provided biological affective contact with people' (p.

250) from birth, led to him distinguishing autism from childhood schizophrenia. These children are frequently referenced as being 'emotionally and intellectually impaired' (Timimi & McCabe, 2016, p. 31), though observed behaviours perhaps 'created the impression of feeblemindedness' alongside other acknowledgements of 'silent wisdom' (Kanner, 1943, p. 226). Witnessed atypical behaviours were pathologized. Severity of needs were assessed by these observations, rather than by how life was experienced by the individual.

A broader understanding of autism as a spectrum developed over time to include CYP apparently cognitively able. Asperger's 1944 paper described four boys with social communication that was 'naïve' and 'inappropriate', with intense interests but abilities in the borderline to superior intelligence range (Wing, 1996, p. 20). Work in the 1970's by Wing and Gould led to the description of a condition Wing (1981) called Asperger Syndrome (AS) for children who had the same pattern as those in Asperger's study, and a later conclusion that 'if we had included children in mainstream schools, we would certainly have found more with Asperger Syndrome' (Wing, 1996, p. 21).

Since then changes, such as revised diagnostic criteria and (arguably) a growing awareness of the condition amongst doctors and schools, have contributed to autism no longer being regarded as a rare condition (Grinker, 2008). A review of 43 studies since 1966 put the prevalence of autism at 1 in 150 of the population (Fombonne, 2009), whilst later studies have found it to be just less than 1 in 100 in England (Brugha et al., 2011) and as high as 1 in 27 for immigrant, multi-ethnic children aged 2-5 years in Sweden (Linnsand et al., 2020). Grinker (2008) argues that this 'is evidence not of tragedy, but of good' with higher prevalence figures 'a sign that we are finally seeing and appreciating a kind of human difference that we once turned away from' (p. 6).

However, autism is still commonly and diagnostically regarded as a deficit. It is currently diagnosed using either the DSM-5 from the USA (American Psychiatric Association, 2013), or the International Classification of Diseases v11 (ICD-11) from WHO (World Health Organisation, 2020), inclusion in which positions autism as either a mental illness or disease. In England, CYP are assessed for autism by the Child and Adolescent Mental Health Services (CAMHS). It is defined by the National Autistic Society (NAS) in England as 'a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them' (NAS, 2017). It is understandable, therefore, that 'the reaction to autism is often as if it *is* a mental illness or disease' (Chown, 2016, p.293).

However, it is important to note that the DSM was created to determine eligibility for services[4] and was at least partly driven by financial motivation (to categorise or preclude cover by insurance companies). There is therefore an argument that autistic symptoms 'become a "disease" through social and political processes' (Aronowitz, 2001; G. Russell, 2020a, p. 299). This is supported by autistic adults who say they have 'biological differences in cognition, brains, and genes' that lead to oppression and stigmatisation yet also have 'valuable differences that should not be cured but instead supported with rights and accommodations' (Kapp, 2020, p.viii). A 'championing of the idea of autism as biochemical "difference" rather than illness' led to many autistic people believing the 'entire concept of autism' should be de-medicalised (Evans, 2017):

> At its core, this is a debate about rights. It is part of the democratisation of the topic of autism, which was, in its previous incarnation, limited to medical, psychological and government officials.

Criticism of the DSM-5 for the involvement of over-influential pharmaceutical companies and for medicalising 'patterns of behaviour and mood that are not considered to be particularly extreme' (NHS, 2013), further suggests the diagnostic process is 'political and scientific' (Kapp & Ne'eman, 2020, p.186). An understanding of autism as a social communication and interaction deficit, that positions the fault within the autistic individual, denies the mutuality of misunderstandings and difficulties with reciprocity 'between people of different dispositional outlooks' that are more accurately explained as a 'double empathy problem' (Milton, 2012, p. 884-5) between people. This is supported by recent research by Crompton and Fletcher-Watson (2019). Indeed, as Evans (2017) states, a deficit definition of autism has 'more to say about the society that has fabricated it' than about the child it purports to describe.

It is widely accepted that autism is a 'heterogenic, dimensional' condition (Westwood, Mandy, & Tchanturia, 2017, p. 1), with some arguing that this very heterogenity is problematic as it means autism-specific interventions are hard to devise and that the term has little prognostic value (Timimi & McCabe, 2016). However, current interventions that focus on conformity are not necessarily in the interest of the individual. Research into interventions that seek to reduce autistic traits and normalise 'challenging' behaviour found them to be unproductive (Reichow, Hume, Barton, & Boyd, 2018; Sandbank et al., 2020) or even damaging (McGill & Robinson, 2018). Assessing 'hierarchical levels of severity' (Baxter et al., 2015, p. 602) to determine need is also problematic, given the impact on

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[4] The DSM-I was created from three separate systems for the classification of mental illnesses in the USA, drawing heavily on that used to diagnose US servicemen post WWII (Deyoung, n.d.).

functioning of external factors such as the environment (Bogdashina, 2003) and social context (G. Russell, 2020a).

Whilst acknowledging that other interpretations are possible, this thesis positions autism as both a constructed and a neurodevelopmental difference. My ontological position is constructivist and interpretative, based on my belief in 'socially constructed multiple realities' (Patton, 2002, p. 134). It recognises that some autistic people regard the condition as disabling (Kansen, 2016), but also that it is a positive identity for many autistic people, for whom difficulties are the product of a socio-political construct that values conformity and pathologizes individual differences.

1.2.3 Missed and misdiagnosed girls

Sex as a protected characteristic (Equality Act 2010) and gender as a social construct are both important aspects in situating this thesis. Autism is typically stated to have a male-to-female ratio of 4-5:1 that is lower when accompanied by cognitive learning difficulties, and highest with average to high IQ (Fombonne, Quirke, & Hagen, 2011), suggesting relatively few autistic female pupils may be found in mainstream schools. However, recent studies have found that autistic females – particularly those who are cognitively able, like the girls in this study - have been underdiagnosed and are underrepresented in the literature (Gould & Ashton-Smith, 2011; M-C. Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). Further and more recent population-based studies have suggested a more accurate male-to-female ratio of 2-3:1 (Baxter et al., 2015; Y. S. Kim et al., 2011; Loomes, Hull, & Mandy, 2017; Mattila et al., 2011), and that the ratio decreases with age (Rutherford et al., 2016), suggesting differences in referral rates for assessment. Government statistics show that whilst the numbers of both male and female autistic pupils[5] grew rapidly from 2010 to 2016, the proportion of autistic females to males increased year on year (see Appendix 1.1).

Reasons for missing numbers of diagnosed autistic females include that they have been 'research orphans' (Klin, 2007, in Bazelon, 2007), thought to have been too few in number or too hard to recruit to include in studies (Watkins, Zimmermann, & Poling, 2014). This contributed to a male-centric understanding of autism and diagnostic bias, that might help account for why females are less likely to be diagnosed as autistic than males, even when presenting with the same symptoms (Dworzynski, Ronald, Bolton, & Happé, 2012; G. Russell, Steer, & Golding, 2011). In addition, autistic girls are diagnosed when they are older than boys (Begeer et al., 2013; Giarelli et al., 2010; Rutherford et al., 2016), and sometimes only after the identification of a secondary mental health condition (Westwood, Mandy, Simic, & Tchanturia, 2017; Wilkinson, 2008).

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[5] With autism stated as the primary need.

Autistic females who are cognitively able may appear to have 'better superficial social skills' (Wilkinson, 2008, p. 3), resulting in later referrals for assessment, or the implications of a diagnosis being misunderstood (Moyse & Porter, 2014). Many mask or camouflage difficulties (Bargiela, Steward, & Mandy, 2016; M. Dean, Harwood, & Kasari, 2016; Meng-Chuan Lai et al., 2017; Mandy, 2019), and parent-reported measures suggest that autistic girls mask more than autistic boys (Ormond, Brownlow, Garnett, Rynkiewicz, & Attwood, 2018), perhaps as a coping strategy to hide social confusion (Tierney, Burns, & Kilbey, 2016). Some girls learn or mimic society's gendered expectations (Faherty, 2006; Wagner, 2006), and become quiet observers and social chameleons who internalise[6] frustrations until they get home (Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). They also exhibit more female-associated or gendered interests (Hiller, Young, & Weber, 2014; McFayden, Albright, Muskett, & Scarpa, 2018) that may be unremarkable to others. As such they may be perceived as requiring fewer adjustments (Attwood, 2006; Hiller et al., 2014; Krahn & Fenton, 2012). This has implications for the identification of need and provision of appropriate educational support for autistic girls, as difficulties may be underestimated or overlooked even with a diagnosis (Moyse, 2013).

This is particularly relevant at secondary school, when the challenges of adolescence are exacerbated for autistic girls (Stewart, 2010). Issues such as a higher motivation for friendships than autistic boys, coupled with the increased complexity of socialising and resolving conflict with female peers (A. Cook, Ogden, & Winstone, 2017; Nichols, Moravcik, & Tetenbaum, 2009; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016), 'sex-specific puberty issues, and sexual vulnerabilities' (Cridland, Jones, Caputi, & Magee, 2014, p. 1261) and wanting to 'fit in' all become more pressing and are exhausting (Bargiela et al., 2016). The demands on executive functioning and daily living, which autistic girls may find more challenging than autistic boys (White et al., 2017), become greater at a time when CYP are expected to be more independent (McLennan, Lord, & Schopler, 1993; Nichols et al., 2009; Solomon et al., 2012). In addition, autistic females without intellectual disability are more likely than autistic males or non-autistic peers to experience mental health issues such as anxiety, self-harm, eating disorders, suicidal ideation and attempts at suicide (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2018; Cassidy et al., 2014), described by some as a result of 'pretending to be normal' (Bargiela et al., 2016, p. 3281).

In summary, the social constructs of gender and autism appear to contribute to the under and late diagnosis of autistic girls and to an accurate assessment of their needs in school, particularly if they

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[6] The internalisation of difficulties and distress is not unique to autistic females, but common to their presentation. Some autistic males also internalise distress, but it is beyond the scope of this thesis to discuss this in further detail.

are cognitively able. These raise questions about differences in expectations of female pupils at school compared to males, and the influence of a gendered understanding of autism on the identification of needs and provision of support, particularly for an autistic girl who may experience personal daily challenges that have little impact on her teacher or her class. My study takes a feminist standpoint and participatory research approach to address these issues, using mixed methods to analyse quantitative data on male and female referrals and diagnoses from an NHS autism assessment database, whilst prioritising the personal narratives of autistic girls.

1.2.4 The politics of policy

The 2016 White Paper 'Educational Excellence Everywhere' gave a Government commitment to inclusion for all pupils, 'wherever they are educated' (DfE, 2016b, p. 100) but failed to say how this would be done in practice. Under this premise, it is perhaps the 'system' not the school that is inclusive, leaving the door open for SEND pupils to be displaced from one school to be educated in another. This is particularly problematic given the current culture of accountability in schools in England, which measures performance primarily by exam results. Pupils who do not meet expectations of academic success may be encouraged to leave (or discouraged from applying). There is some evidence of this (Ryder et al., 2017) not least from the current Head of Ofsted, who recognised and criticised the practice by some schools of 'moving out pupils who would drag down results' (Spielman, 2017), the National Director of Education who condemned schools who 'off-roll' pupils in an attempt to demonstrate success (Harford, 2017) and the Timpson Report on exclusions (Timpson, 2019).

This climate of performativity has been compounded by cuts to school budgets (NAHT, 2018), which inevitably leads to competition for scarcer resources within schools. Autistic females may find themselves in a 'hierarchy of needs' (Moyse, 2013, p. 49), with support prioritised for those CYP who have the biggest impact on the efficient delivery of a lesson. Males are 'almost certainly' over-represented in Special Educational Needs (SEN) provision (H. Daniels, Hey, Leonard, & Smith, 1999, p. 194), which implies some females with SEN are either not identified or are not considered to have needs that warrant additional support.

The requirement by the Children and Families Act 2014 for LAs to identify all children with SEND and promote integration of service providers, needs to be seen in parallel with the drive for savings and efficiency during this time. The Act states children with SEN in mainstream schools can 'engage' in the full range of school activities with their non-SEN peers, as long as they do not interfere with 'the provision of efficient education for the children with whom he or she will be educated, and…the efficient use of resources' (p. 30). This creates a tension between economic factors and outcomes and implies the right to education for CYP with SEND can be overridden by the rights of CYP without SEND.

Furthermore, the requirement to make reasonable adjustments could be interpreted as determined by the available resources, rather than individual needs, hence causing a tension for individuals between the appropriate provision and one that is seen to be affordable by education professionals.

1.3 Significance and outcomes of study

> Assumptions that everyone wants, needs and values the same things must be confronted and reframed to determine their applicability to any individual (Iemmi, Knapp, & Ragan, 2017, p. 19).

Research by the London School of Economics and Political Science (LSE) calculated that in 2014, the social cost of autism in the UK was £32 billion (Iemmi et al., 2017). The amount spent on supporting each one of the UK's 700,000 autistic people, meanwhile, was just £6/autistic person/annum (Autistica, 2016), suggesting a disconnect between distribution of resources and the needs of the individual. 'Better targeted support' had been suggested in an earlier report (NAO, 2009, p. 4), but the study by Iemmi et al (2017) found this and other recommendations still needed actioning. Effectively targeting resources is particularly important in the current era of austerity and shrinking budgets for public services, and how these resources are distributed within schools is influenced by data collected on schools, pupils, and their characteristics. The decisions about what data to collect at national level informs the focus of educational policy and the distribution of resources, and such decisions are therefore inevitably political.

Government statistics are published annually to show numbers of exclusions (DfE, 2020c) and absences (DfE, 2020a). These show that permanent and fixed period exclusions are increasing, and that the proportion of these at secondary schools is growing (DfE, 2016c). Authorised absences have declined since 2006/7, unauthorised absences have increased, and persistent absenteeism is currently similar for boys and girls (DfE, 2020e). However, these published data do not provide statistics on autistic girls, and this absence of data is problematic: 'Not to be counted can be considered as an extreme form of discrimination' (Mittler, 2015, p. 85). There is therefore a gap in our knowledge about how many autistic girls are not attending school.

Research into autistic girls, and into inclusive education, have been identified as priorities by the autism community (Autistica, 2016; Milton & Bracher, 2013; Pellicano, Dinsmore, & Charman, 2014). Access to education as a rights issue (see section 1.2.1) and the current government focus on academic success, exclusion and attendance as school performance indicators provide dual and contrasting rationales for the absence and potential underachievement of some autistic girls at secondary school to be addressed. Understanding why they stop attending requires listening to 'the one voice that has been traditionally silenced' – in this case the voices of the autistic girls – and acknowledging their experiential expertise in the production of knowledge (Milton, 2014, p. 800). As such, previous research that sought to understand educational experiences by prioritising the voices of autistic CYP (Hummerstone & Parsons, 2020; Humphrey & Lewis, 2008a; Parsons, Lewis, & Ellins, 2009; Wood, 2017) and specifically autistic girls (Goodall & MacKenzie, 2018; Honeybourne, 2015; Myles, Boyle, & Richards, 2019) was particularly relevant to this study.

Little research exists currently on the non-attendance through the formal exclusion of autistic CYP (Brede, Remington, Kenny, Warren, & Pellicano, 2016; L. Gray, 2018) and specifically autistic girls (Sproston, Sedgewick, & Crane, 2017). The girls in my study did not fall into this category, however, being more accurately described as non-attenders. The literature on autistic CYP absent from school is also brief, and notably based on use of the arguably pejorative term 'school refuser'. These few studies are based on parental views (Munkhaugen et al., 2019), teacher and parent views (Munkhaugena, Gjevikb, Prippc, Sponheimb, & Disethd, 2017) or on statistical analysis (Ochi et al., 2020), with pupil voice remarkable for its absence. Existing research that includes autistic girls absent from school has been found only within the study on exclusion by Sproston et al (2017), in which two female participants were described as having self-excluded.

My study builds on this existing research by addressing this second gap in the literature, namely understanding the absence of some autistic girls from mainstream schools by giving precedence to their voices, but also by placing them in the study as authentic participants (Pellicano, 2016) and co-creators of knowledge. The thesis constructs new understandings of the phenomenon through an analysis of these girls' experiences and by challenging the dominant constructs that non-attendance at school is a fault within the child, and necessarily a negative outcome.

1.4 Research aims and objectives

The main aim of my thesis was to understand why some adolescent autistic girls stop attending mainstream secondary schools from the perspective of the girls themselves. I also had two secondary aims. The scale of school absenteeism for autistic girls was unknown and I wanted to clarify the extent to which it was a problem. I also wanted to investigate patterns and omissions in autism referral and diagnostic data, for school-age females compared to males, as part of comprehending how support is identified and what provision is made for these girls in school.

Research Questions:

- What is the scale and context of the issue of adolescent autistic girls who stop attending mainstream secondary schools?
- What can be learnt from the personal narratives of some autistic adolescent girls about why they stopped attending such schools?
- How can the experiences of the young people in this study inform educational policy and provision in schools?

My initial objective was therefore to retrieve and analyse secondary data from the autism assessment pathway of an NHS Trust, looking specifically at patterns in referral and diagnosis variables for school-aged females compared to males. I also wished to consider a few patient records as case studies, to understand whose voices contributed to the provision of appropriate support. The findings were used to reflect on the adjustments that could usefully be made to the referral process for girls, particularly with regard to training for school staff on understanding how autistic girls may present in school compared to at home.

My next objective was to collect a range of primary data from a sample of adolescent autistic girls, who had begun mainstream secondary school but who were not currently attending. I wanted to understand their personal constructs of their ideal school, and to help them make sense of the events that led to them being absent from school. Disengagement is a process, and my research illuminates when and why it began for the girls in my study. The findings from this part of the study were used to identify experiences that were challenging or engaging, plus provision that helped, support that did not, and ideas about what might have helped. It is hoped these outcomes may alert schools to the signs and situations that can ultimately lead to the breakdown of a placement, as well as shine a light on examples of best educational practice as experienced by these girls.

This is therefore a mixed methods study, with a focus on a constructivist paradigm, which enables me to consider both how society constructs meaning and how the girls in my sample construct meaning based on their experiences.

1.5 Overview of the thesis

The thesis contains seven chapters. This first chapter has set out the non-attendance of autistic girls as a rights issue and outlined legislation governing the education of autistic CYP in England. It has provided a short history of autism, as it relates to this thesis, positioning it as a social construct. The late and under diagnosis of girls has been presented, together with specific challenges they may face in secondary school, and the potential impact of these issues has been noted. The political nature of educational policy has been reflected upon, particularly regarding current performance indicators and scarcity of resources. The research aims and objectives have been established and potential gaps in knowledge and the significance of this study have been presented.

A review of the literature follows in Chapter 2. This chapter considers what was known about the number of autistic female pupils in school, and the size of this group in proportion to autistic males and non-autistic females, by examining Government statistics to look for patterns and trends in the numbers of male and female autistic pupils on roll since 2009. It then considers the two principal ways in which autistic girls can be missing from school in the light of DfE figures for exclusion and absenteeism. This establishes what was known about the scale and the context of the issue to be studied. Studies about autistic CYP who were excluded or absent from school are noted, with a particular focus on previous research that explored why autistic girls were no longer in school. This review also considered the different methodologies employed and the extent to which value was given to the voice of the YP. Gaps in knowledge revealed by the literature search are identified.

Chapter three describes the research paradigm adopted, and the rationale for the mixed methods approach selected. It explains the choice of a participatory framework and the prioritisation of the autistic girls' voices as key to answering the second research question. It details the use of an Autistic Advisory Group and the different methods of data collection and retrieval employed. The section on data analysis illustrates how this was undertaken in collaboration with the girls who participated in the research, with the meanings they generated informing the final research question. This chapter also considers ethical considerations, which were particularly important given the age of the girls and the potentially traumatic nature of their previous school experiences, ways in which imbalances of power were addressed, and issues of validity.

The results of the research are split across two chapters. Chapter four brings together findings that answer the first research question. This begins with an examination of DfE data of pupils absent from schools in England, which was acquired through a Freedom of Information (FOI) request. Patterns in NHS data on the referral to the autism assessment pathway of school-aged females compared to males, and trends on diagnosis, are presented next. Finally, a case study analysis of a sample of eight individual NHS records is provided. These results combined to provide context and highlight the significance of the study, as well as to generate questions and enable comparison with the primary data that followed.

Chapter five presents the findings from a series of interviews with ten adolescent autistic girls who were no longer attending a mainstream secondary school. It begins with the girls' personal narratives, providing a 'space' for their voices to 'stand on their own' (Seal, 2014, p. 16). This placement signifies the value placed on hearing their stories and the meanings they ascribed to their experiences as key to understanding their absence from school. It presents findings from an exercise about their personal constructs of school, and of an analysis of their time at school using a topical life history approach. Individual characteristics relevant to this study are also given.

The Discussion chapter interprets the two preceding results chapters, drawing together common themes that emerged using the different methods and data collection tools. Tensions and contradictions are revealed, which appear to have been instrumental in the absence of the sample of autistic girls from school. Implications of these findings are considered with reference to the work of Paulo Freire on education as oppression, and to the work on agency by Albert Bandura.

Chapter seven concludes the thesis. It reviews the key findings and principal contributions to knowledge. It makes five major recommendations, based particularly on the learning from the girls who participated in this study, to inform the future practice of teachers and clinicians. The successes and limitations of the chosen methodology in answering the research questions are stated next. Finally, suggestions for further research are made, based on queries that have arisen as a result of these investigations.

Supplementary information can be found in the appendices, which follow the references.

Chapter 2: Literature review

2.1 Introduction

> The lack of discussion of girls acts as a silent 'unsaid' that serves to further marginalise them (L. Russell & Thomson, 2011, p. 294).

This chapter considers what is currently known about how and why some adolescent autistic girls stop attending school and provides additional contextual information about the possible scale of the issue. It begins with studies that have analysed data for sex differences in the age at referral and diagnosis and presented possible explanatory variables. It then considers two key ways in which CYP can be absent from school, namely by exclusion or by absence. These sections define both terms and provide an extended understanding of their meaning. Literature relevant to each term and specifically to autistic CYP is then described, with a focus on methods and methodology. Studies that focus on autistic girls are analysed in most detail, given the dearth of research in this area and the focus of this thesis. Statistical information published by the government is given at the end of the sections on exclusion and absence. Finally, gaps in the literature and the implications for this research project are presented.

2.2 The diagnostic picture

Existing literature presents conflicting findings on sex differences at referral for an autism assessment and diagnosis. Some studies such as those in the US by Wiggins et al (n=115) and by Giarelli (n=1497) and in the UK by Brett et al (n = 2134) have found no sex differences in the mean age at first evaluation (Giarelli et al., 2010) or diagnosis (Brett, Warnell, McConachie, & Parr, 2016; Fountain, King, & Bearman, 2011; Giarelli et al., 2010; Wiggins, Baio, & Rice, 2006). By contrast, other research has found that males were diagnosed younger than females (Begeer et al., 2013; Shattuck et al., 2009). The difference in findings between the Giarelli and Shattuck studies is of interest as the same data was retrieved by both, but the sample used was different. One sample (n=1497) was of the CYP in the dataset with a documented diagnosis (Giarelli et al., 2010), whilst the other (total n=2568) also included 'censored cases' of CYP who met the criteria but had not yet been diagnosed (Shattuck et al., 2009, p. 475).

A few variables have been suggested to explain differences in age at diagnosis, but these do not always correlate with sex differences. In one study, high SES children (identified as white with well-educated, older, wealthier parents) were diagnosed 16 months earlier than low SES children (identified as Hispanic, living in poor areas with poorly-educated immigrant parents) in 1992, and by six months in 2000, but there was 'no effect for sex' (Fountain et al., 2011, pp. 507-508). However, higher IQ *has* been found to make diagnosis less likely in females than males (Giarelli et al., 2010) and to be a factor in a later diagnosis in females (Shattuck et al., 2009). Giarelli et al (2013) suggest this may be due to differing social expectations of boys and girls as well as boys displaying more 'externalising behaviours' (p. 114). The large-scale study (n=2275) in the Netherlands by Begeer et al. (2013) found that the mean age of females diagnosed with AS was 1.8 years older than that for males given the same diagnosis. These findings are noteworthy and suggest the value in considering the educational implications for cognitively able autistic girls of a delayed diagnosis. They noted that SES, ethnicity, and the presence of another co-occurring condition may contribute to a delay in autism diagnosis for females, though these elements were not investigated.

More recently, an analysis of a nationally representative sample of 150 cases in Scotland by Rutherford et al. (2016) found significant sex differences between children aged up to 9.11 years (n=46, of which seven were female) and adolescents aged 10 - 18.11 years (n=40, of which 12 were female) in both age ranges at referral and at diagnosis. They identified that the sex ratio decreased with age, replicating the finding from an earlier study by Idring (2012), from 5.5:1 (0 - 9 age group) to 2.3:1 (11 - 18 age group), and also that there were no sex differences in wait times for assessment.

This suggests that autistic girls are under-identified in pre-school and primary years, because they are not referred to the autism pathway (perhaps because they are non-white or from a lower SES) or because they are assessed as not meeting the criteria for a diagnosis at a younger age. The relatively small sample size, however, suggests a larger scale investigation of these issues would be beneficial, looking in more detail for explanatory patterns within the dataset. In addition, the lack of qualitative data means it is not possible to draw conclusions about why females are under recognised by referrers, or whether some types of referrers are better at recognising potentially autistic girls than others.

2.3 How are the girls missing?

There are fundamentally two ways in which autistic girls can be recorded as missing from school: they can be excluded, or they can be absent. This chapter examines the existing literature on these two routes out of school, both of which contain diversity, thus providing the context for the study and for the place of the experiences of autistic girls within it.

It begins with studies that evidence the formal exclusionary process by which a school may remove a child on a fixed term or permanent basis, and of unofficial practices and 'mini exclusions' (Wood, 2019, p. 68). These include the use of part-time timetables, managed moves and being 'moved off-site while they continue to be recorded as attending school' (Children's Commissioner, 2017, p. 2). The second section examines studies on absence from education. This includes non-attendance that is recorded by school and registered as authorised or unauthorised, and other, informal ways in which absence can occur, such as not being engaged in a lesson or present on the playground. Gaps that were addressed by this research are then identified.

2.3.1 Searches

A comprehensive literature review was conducted in 2017. The purpose was to explore previous research into the non-attendance of autistic adolescent girls at secondary schools, through exclusion or absence. Initial searches looked more widely to include studies with adolescent girls who were not autistic, and with adolescent autistic males and females. This previous body of knowledge provided a baseline in terms of current understanding.

Terms for the initial searches were established (see Appendix 2.1) and searches were conducted using Boolean search modes in Feb-June 2017. An initial search of the Education databases (British Education Index, Child Development & Adolescent Studies, Education Abstracts, Education Research Complete, Educational Administration Abstracts, ERIC) was then completed. Book reviews and newspaper articles were excluded. Other databases used were Google Scholar, Web of Science and EThOS. The literature review also incorporated 'grey literature', such as conference proceedings, regulatory documents, and government statistics. The searches were limited to research from the year 2000 onwards, although older seminal works were included. Studies that did not include CYP of school age were excluded, as were studies that were not directly relevant to the themes of exclusion or absence from school (see Appendix 2.2 for the results of these searches). New papers were read throughout the research period. A final literature search was completed in July 2020 (see Appendix 2.3), and relevant studies are included within this chapter.

2.3.2 Exclusion

2.3.2.1 Fixed-term and permanent exclusions.

Exclusion from maintained schools and Pupil Referral Units (PRUs) in England is governed by the Education Act 2002. Section 52 (10) of the Act states that exclusion must be 'on disciplinary grounds' and may be permanent or for a fixed term. The latter means a child can be excluded from school for up to 45 days per annum, although these days do not have to be consecutive (DfE, 2015b) and for parts of a day such as a morning session or lunchtime period (both classified as half a day), as well as for a whole day.

Any exclusion is subject to the legislation previously noted and must be 'lawful, reasonable and fair' (DfE, 2015b, p. 4). The School Discipline Regulations 2012, pertaining to the Education Act 2002 on pupil exclusions, further guide Heads and Local Authorities at the point of any exclusion. These regulations include the need to record the exclusion, to provide and mark suitable schoolwork after the sixth consecutive day, to find alternative provision, and to advise parents/guardians of the right to appeal the decision. Particularly relevant aspects for this study are the duties placed on schools for the provision of education whilst a pupil is excluded.

The protected characteristics of sex and disability (see section 1.2.1) mean autistic girls should not be discriminated against by schools either because they are female or because they are autistic. The Equality Act 2010 states pupils must not be treated 'unfavourably because of something arising in consequence' of disability (Section 15) and schools must ensure 'that their policies and practices do not discriminate against pupils by unfairly increasing their risk of exclusion' (DfE, 2015b, p. 9). Schools are also instructed to 'take positive action to deal with particular disadvantages' or 'needs' of a group (DfE, 2015b, p. 9). This legislation is supported by statutory guidance in the SEND Code of Practice that says schools must make 'reasonable adjustments' to meet their needs and again, importantly, that these adjustments must be 'anticipatory' (DfE & DoH, 2014, p. 17).

Taken together, the argument follows that proactive needs-led provision should be made by schools as part of their responsibility to support autistic girls who are at risk of exclusion because of their SEN.

2.3.2.2 'Mini exclusions'.

> Exclusion can be the result of disciplinary procedures, but it can occur through feelings of isolation, disaffection, unsolved personal, family or emotional problems, bullying, withdrawal or truancy (Osler, Street, Lall, & Vincent, 2002, p. 2).

Exclusion, however, is a 'multi-faceted phenomenon' (Wood, 2019, p. 65). Broadening the definition of exclusion to include the absence of inclusion, where inclusion is defined as 'presence, participation, acceptance and achievement' (Humphrey, 2008, p. 42), reveals other ways in which pupils can be excluded from education.

These include removing a child from class (Osler et al., 2002), seating them away from peers (Wood, 2019), encouraging pupils to stay away from school to avoid the formal process of exclusion (Hilton, 2006) and the use of part-time timetables (Parkes, 2012). Such practices may be carried out with good intentions and the exclusionary aspect of the outcome may not always be considered an issue. Pupils can also be excluded from the 'processes of learning even though some of them may be in school or recorded as being in school' (Osler et al., 2002, p. 13), and from a failure to make necessary provision to enable access to the curriculum.

It may include 'managed moves', which is the movement of a pupil from one school to another setting, and is 'a voluntary agreement between schools, parents/carers and the pupil and often used to prevent permanent exclusion' (Graham, White, Edwards, Potter, & Street, 2019, p. 60). Whilst it can be positive, the procedure is problematic when it is perceived to be more for the benefit of the school than the child, and where the school acts to ‘discourage students from attending school and/or encourage parents to voluntarily withdraw their child from school’ (Loizidou, 2009, p. 20); a practice known as ‘off-rolling’ (Timpson, 2019).

Some informal exclusions may be illegal, as in the case of an SEN child being asked to stay at home during an Ofsted inspection (Children's Commissioner, 2013), or being sent home before the end of the school day and having the absence recorded as authorised (Children's Commissioner, 2017) rather than as an exclusion (Timpson, 2019). CYP with identified SEN are disproportionately represented within those illegally excluded (Children's Commissioner, 2013), often because ‘the school does not feel able to cope’ (Children's Commissioner, 2017, p. 4).

It is illegal ‘to exclude a pupil simply because they have additional needs or a disability that the school feels it is unable to meet’ (DfE, 2015b, p. 6), to informally exclude a pupil ‘regardless of whether they occur with the agreement of parents or carers’ and to exclude any pupil, ‘even for short periods of time’ without it being officially recorded (DfE, 2015b, p. 6). However, the NAS reports that the practice of informally excluding autistic pupils is widespread, with over one third of children and young people in their survey informally excluded at least once (Moore, 2016). A 2017 report on the exclusion of autistic CYP estimated 26,000 had been ‘unlawfully denied a full education’ (Ambitious About Autism, p.3) in the previous year, suggesting they are a particularly impacted group.

In summary, the definition of exclusion employed in this part of the thesis encompasses both formal and informal practices and stems from the position that the act of exclusion is outside the control of the child.

2.3.2.3 Excluded children and young people.

A great deal of literature exists already on the exclusion of CYP from school, including some recent wide-ranging and high-profile reviews, and the disproportionate number of males and CYP with SEN who are excluded is established. The recent Timpson Review on school exclusions for example, commissioned by the then Secretary of State for Education, concluded that CYP with some characteristics were more likely to be excluded than others, including those with ‘some types of SEN, boys, those who have been supported by social care or are disadvantaged’ (Timpson, 2019, p. 9). This finding is supported by an extensive literature review by Graham et al. (2019), who found evidence that ‘increasing numbers of children experience intersecting vulnerabilities’ (p. 16), and that factors including SEND and sex could potentially combine to drive exclusion.

These gendered differences may also form part of the explanation for why some girls *are* excluded. A large-scale qualitative study that examined the views of permanently excluded CYP, teachers and caregivers[7] on reasons for being excluded, and how it made them feel, found that most of the male and female Key Stage 4[8] CYP perceived their exclusions were for non-conformity with school rules (such as having their hood up, wearing make-up or having their mobile phone out) rather than on behavioural grounds (Martin-Denham, 2020). This is interesting given the reason for exclusion most frequently recorded by schools is 'persistent disruptive behaviour' (DfE, 2019b).

Teachers may class problem behaviours differently in girls and boys. Girls who behave contrary to social and political expectations of the 'feminine role' are perhaps more likely to be seen as 'deviant' and may be unreasonably penalised by schools, even when those same behaviours would be accepted as expected behaviour from boys (Osler & Vincent, 2003). This is demonstrated in a study that found boys were referred for behaviour that challenged and for poor academic results, whilst girls were 'described in terms of their appearance and sexuality' (Crozier & Anstiss, 1995, p. 36). A case study of two girls placed off-site in alternative provision found that not conforming to gendered stereotypes of sexuality and identity could result in exclusion, with schools understood as 'institutions which reproduce the social order' and 'which are bent towards reproducing the 'normed' gendered aspects of this.' (Carlile, 2009, p. 35).

Reasons why the exclusion rate of females is lower than males are less clear. The seminal piece of research into patterns of exclusion from school experienced by females (Osler et al., 2002) found that whilst exclusions could be for disciplinary reasons, 'many of the difficulties experienced by girls in school are of a hidden nature and may lead to self-exclusion or unofficial exclusion' (p. 2). Girls' were treated differently to boys by staff and by peers in school, and their problems were 'invisible', with resources more likely to be used for boys and girls less likely to ask for help. These findings are supported by later research, which added that unequal access to the Educational Psychology Service affected the targeting of external resources and support for girls (Rouse, 2011). A more recent mixed methods study also found that girls are excluded in different ways to boys, with 'rates of school moves and early exits[9]' higher for girls (Social Finance, 2020, p. 2). An IPPR report suggested that observed behaviours and impact on others were influential factors, with boys more likely to externalise distress than girls, and girls more likely to respond by 'being withdrawn and self-harming' (Gill, Quilter-Pinner, & Swift, 2017, p. 18); they 'cause damage to themselves' (Graham et al., 2019, p. 22). Absences and internalisation are considered further in section 2.4.2.

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[7] Term used in the study.

[8] Key Stage 4 (KS4) describes the two-year period of study for formal examinations for young people aged 14-16 years.

[9] An early exit was defined as leaving mainstream before the Y11 census.

2.3.2.4 Excluded autistic children and young people.

Studies into the exclusion of autistic CYP similarly show examples of official and unofficial statistics. In 2019/20, 72% of autistic CYP (n=108,481) attended state-funded mainstream primary and secondary schools (DfE, 2020b). Autistic CYP are disproportionately excluded in comparison to other children, even when increases in the autistic population are accounted for. A 2013 survey of 500 families (Ambitious about Autism, 2013) found 23% of parents said their autistic child had been excluded, with 4 in 10 of these reported as informal (and illegal) exclusions. Later reports on formal exclusions stated autistic CYP are three times more likely to be excluded than neurotypical CYP (Ambitious About Autism, 2017), and found that exclusions of autistic CYP rose by 56% (from 2,831 to 4,485) in England in the five years from 2011-16 (Ambitious about Autism, 2018). Another data analysis also identified that autistic CYP (and those with MLD[10]) were more likely than those without SEN to be excluded (Hatton, 2018). These statistical reports are important and concerning, though sex differences in exclusion rates are not discussed.

Whilst the focus on much research about autistic CYP and education has been inclusion (Dillon, Underwood, & Freemantle, 2016; Humphrey & Lewis, 2008a, 2008b; Symes & Humphrey, 2010; Wood, 2017) and best practices (Guldberg et al., 2011; Hoy, Parsons, & Kovshoff, 2018; Jones et al., 2008; Keen, Webster, & Ridley, 2016; Parsons et al., 2011) few qualitative studies exist on those who have been excluded from mainstream schools. A key study is that by Brede et al (2016), which explored pathways to reintegration for nine cognitively able, autistic YP (one female) aged 10-18 at the Inclusive Learning Hub, within a NAS[11]-run school. An important aspect of this research was the inclusion of the voices of the YP. In semi-structured interviews they were asked, for example, for their views of the Hub and how it differed to previous schools, whilst it was their parents who were asked about their child's experiences of previous schools. Pupil and parent narratives of previous educational experiences were 'often-harrowing' (Brede et al., 2016, p. 24) and associated with a decline in mental health, with bullying, conflict, exhaustion, and a perceived lack of help and understanding from staff that amounted to abuse in some accounts. By contrast, the Hub was regarded as a safe environment, evidenced by positive attitudes and attendance, although 'getting children to engage in academic work seemed to be more challenging' (Brede et al., 2016, p. 37). Although one of the participants was female, 'to preserve anonymity of the young people involved, all students are referred to as male' (Brede et al., 2016, p. 15), meaning that the girl's voice and her specific experiences cannot be identified.

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[10] Moderate Learning Difficulties

[11] National Autistic Society

A second important qualitative study (Goodall, 2018b) was published after the primary data collection for this thesis had been collected. 12 autistic YP (two females) aged 11-17 years were interviewed, seven of whom had been officially excluded from school and were in alternative provision, whilst the other five were being home-schooled at the time of the research. The study is notable for the use of an autistic advisory group when planning, the prioritisation of pupil voice, and for the interesting participatory methods used to encourage and enable communication. These included two diamond ranking activities: important aspects of school (enablers) and worries about school (barriers), which used characteristics identified by the researcher (rather than by the YP) as influential. Key findings were that the YP felt dread, misunderstood and isolated in mainstream, with a perceived lack of support and understanding from staff, as in Brede et al's study (2016). Positive experiences of school, and of primary school, were not collected.

Only one study (Sproston et al., 2017) was found that focused entirely on the experience of autistic girls who had been excluded. Eight girls (aged 11-18) and their parents were interviewed about past and present experiences of school that were both negative and positive. Five of the girls had been excluded, one had been part of a managed move that failed and two had withdrawn from school. Interviews with the girls lasted between 14-57 mins (mean=31.38, SD=13.35), suggesting that shorter sessions may have benefitted from the use of different tools or methods of communication to increase the number and length of responses. Using pupil voice to capture the lived experiences of these girls provided powerful accounts, although the use of parent interviews meant that discrete understandings of the two groups (and the individuals within them) were not possible to determine. Key arising themes of the impact of the environment, relationships and staff responses are supported by previous research into autistic experiences at school (Cridland et al., 2014; Humphrey & Lewis, 2008a; Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012; Tomlinson, Bond, & Hebron, 2020), and strengthen the view that autistic and non-autistic YP who are excluded from school share common experiences.

In summary, previous studies have provided the scale of the issue of exclusions for autistic CYP, but not specifically female autistic pupils. This suggests that formal exclusion is possibly not a major cause of absence from school for them. Qualitative studies have offered much-needed perspectives on school from autistic CYP who have been excluded, though the voices of only two girls who had stopped attending school were identified in the literature when planning the research in this thesis.

2.3.2.5 Government statistics on exclusion.

The government publish annual statistics on pupil exclusions that present figures in categories such as gender[12], primary special need or by school type. These show that pupils with SEN are vastly over-represented, with for example 45% of all permanent and 43% of all fixed term exclusions in 2017/18 (DfE, 2019b), despite only forming 14.6% of the population (DfE, 2018d). However, the reports are not sufficiently nuanced to show the interaction of categories, i.e., autistic females at mainstream secondary schools.

2.3.3 Absence

2.3.3.1 Types of absence.

> Children who spend significant and continuous periods absent from school rolls present a stark example of those who continue to remain outside initiatives of inclusion and whose absence has barely touched government agendas (Broadhurst, Paton, & May-Chahal, 2005, p. 106).

Government guidance on absence statistics (DfE, 2019a) states that a school must register attendance twice a day, at the beginning of the morning and the afternoon sessions. Responsibilities for absent CYP are different for schools and for parents. Schools must identify the reason, mark the absence as authorised or unauthorised and check safeguarding. Authorised absences are most commonly categorised for illness (DfE, 2020e), with other reasons including medical/dental appointments, study leave and being excluded without alternative provision. Unauthorised absences are typically for holidays that were not agreed, where no reason or an unsatisfactory[13] reason is given, and for lateness.

It is the responsibility of the parent to give a reason for their child's absence. However, the simplistic method of recording absence as authorised or unauthorised is unhelpful (Reid, 2008) and problematic. The reasons for some absences could be inaccurately recorded and categorised through misunderstanding or misinterpretation. An absence recorded as authorised may 'effectively sanction' a child's absence without it being properly investigated (Hilton, 2006, p. 298). This may mean, for example, the inability of a YP to arrive before registers are closed in the morning due to school-based anxiety is recorded as an unauthorised absence, whilst a YP who misses the whole day's sessions for the same reason may be recorded as an authorised absence due to illness. In each case, the reason for absence is not addressed and therefore barriers to attendance cannot be identified and removed.

These terms are not sufficient to encompass all types of absence from school, however. Some absences are Children Missing Education (CME), who the government defines as 'children of compulsory school age who are not registered pupils at a school and are not receiving suitable

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[12] The term used in the DfE documentation.

[13] As judged by the school.

education otherwise than at a school' (DfE, 2016a, p. 5). Internal absences, defined 'as any absence by pupils between the school's twice-daily registrations' are not published as the DfE 'only record and measure the registrations required by law' (DfE, 2019a, p. 32). These could be child-led - such as being present but not participating in a lesson or leaving part way through – or school-directed. They encompass 'illegal exclusions, non-existent elective home education, unsuitable part-time timetables and non-attendance' (Ryder et al., 2017, p. 9), which may be 'as significant as formal disciplinary exclusion processes if they deny or restrict an individual's access to education' (Osler et al., 2002, p. 2). This thesis supports this wider interpretation.

2.3.3.2 Respite or refusal?

A YP who does not go to school is variously described in the literature as a truant, school refuser, self-excluder, and non-attender. Each term brings with it a value judgement and implied explanation that may vary depending on whether it is said by the YP or someone describing them. It may be the pathologized *action of* the 'disaffected' and/or 'troublemakers' (Padfield, 2001, p. iii), or a *reaction to* a toxic school environment. This not only indicates where the problem is thought to be located, and the solution or intervention required, but also with whom responsibility for 'fixing' it lies.

Terms are used 'inconsistently' or 'interchangeably' in different papers (Heyne, Gren Landell, Melvin, & Gentle-Genitty, 2019, p. 8). Truancy has been described within a neo-Marxist framework (Sun, 1995) as an act of resistance carried out by pupils 'to avoid their schoolwork and to win physical space from the oppressive conditions of the institution' (Olafson, 2006, p. 32). However, girls' 'anecdotes of truancy' presented by Olafson (2006, p. 31) revealed multiple meanings of resistance, from the overt subversion of norms, to avoidance of participation or social pressures. Berg (1997), meanwhile, uses observed behaviours to differentiate between 'school refusal' and 'truancy'. The latter is defined as 'when children stay off school and attempt to conceal the fact from their parents', or more widely as 'unwarranted absence', and is often accompanied by antisocial behaviour (Berg, 1997, p. 91). School refusal (SR) is distinguished as absence without antisocial behaviour and with the knowledge of parents, in a child who prefers to be at home and who is distressed by the idea of attending school. Physical symptoms may be present, such as a headache or not eating, and a mental disorder may be attributed. Nonetheless, the long-term outcome for SR compared to truancy is said to be 'very good' (Berg, 1997, p. 90). It is notable that in neither case is the reason for non-attendance ascribed to the school.

Kearney and Hugelshofer expand the term to 'school refusal behaviour' (SRB) to describe 'a continuum of attendance' (2000, p. 52). This ranges from those YP who miss all or part of a school day, to those who only get to school in the morning after 'highly problematic misbehaviors', to those who 'attend school with great dread and with constant pleas for future nonattendance' (Kearney & Hugelshofer, 2000, pp. 51-52). This breakdown is useful in expanding an understanding of self-exclusion as an active process that may or may not result in attendance each day, and at cost to the child. However, the word 'refusal' suggests an undesirable stubbornness in the child (Pellegrini, 2007), implying that the problem is situated within the child – it is 'child-motivated refusal' (Kearney, 2007, p. 53) and still potentially stigmatizing. Therefore, reintegration to school is focused on correcting behaviour, rather than addressing the environment.

A third and more recent perspective describes the 'nature' of four types of 'school attendance problems' (SAPs) rather than attributing the term to a person. School refusal (SR) is therefore refusing; truancy (TR) is concealing; school withdrawal (SW) is withdrawal by parents and school exclusion (SE) is exclusion. This is combined with an approach that concentrates on the 'function of absenteeism' (Heyne et al., 2019, p. 8) and led to the development of the School Non-Attendance Checklist (SNACK). This identifies 14 possible reasons for non-attendance (plus the option to select 'other'), each assigned to one of five classifications: 'non-problematic absenteeism', 'SR', 'TR', 'SW' and 'SE'. However, 'SR' is the only category available for CYP who find it 'hard to go to school or to stay there' or are 'upset/anxious/scared about school' (Heyne et al., 2019, p. 28). This terminology is challenging, as is the portrayal of parents as playing a major role in 'SR', being overprotective, complicit, and condoning their child's non-attendance. Absence for respite - a 'mental health day' - is identified as 'SW', which is associated with being for the parents' benefit. Absence because of unmet needs at school is an option if the school requests the child stay away, but not if it is the response of the YP. None of the categories accommodate in-school factors.

Missing from all these interpretations are the voices of the YP who are absent.

2.3.3.3 Absence of CYP from school.

Absence from school is a growing problem, one that is starting sooner and is increasingly including girls and those with disabilities. There has been an increase in 'disaffected youngsters both boys and girls', with the sex ratio changing from around 20:1 (m:f) to girls being slightly more likely to be 'truants[14]' than boys (Reid, 2012b, p. 213). Disabled pupils in elementary schools in the USA were found to have considerably higher rates of absenteeism than the general population (Gottfried, Stiefel, Schwartz, & Hopkins, 2017). These findings are supported by government statistics for England, which show that absence and persistent absence rates for boys and girls are similar, and that these rates were higher for CYP with identified SEN (DfE, 2020e, pp. 7-8). Non-attendance now begins earlier, with around 35% of CYP showing patterns of absenteeism in primary school (Reid, 2012b). These studies reinforce the need for research that seeks to understand the absence of disabled girls from school,

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[14] Terminology used by the cited author.

and specifically for a study with autistic girls, as Gottfried et al's (2017) study differentiated by five broad groups of disability within which autism was not identified. The work by Reid (2012b) highlights the need to choose research methods that reflect a period of history that encompasses primary as well as secondary years.

Some types of absences by their nature mean they neither appear in official statistics on attendance nor have legal recourse. Absence from particular lessons is identified in one study as the greatest reason for pupil absence (O'Keeffe, 1993, cited by Reid, 2012b), whilst another found this strategy used by girls, as well as tactics such as overstating illness or attending registration but then going home (Osler & Osler, 2002). However, data on such absences may not be collected by schools. Indeed, the number of CYP missing education 'has been widely described as poorly recorded, conflicting and unreliable', and there is no process within government 'for the systematic collection, analysis and publication of data on the numbers of children missing education' (Ryder et al., 2017, p. 19). Unrecorded absences are problematic as 'data are essential to measure inequalities, to target social policies and monitor implementation as well as to design remedies including positive action measures' (Open Society Foundations, 2014, p. 5).

A recent large scale, quantitative secondary data analysis from the Education Policy Institute (EPI) investigated 'unexplained exits', defined as when a pupil has 'moved to a different school or left the state school system entirely for unknown reasons' (Hutchinson & Crenna-Jennings, 2019, p. 7). It found that about 10% of the Y11 cohort in 2017 had 'experienced an unexplained exit at some point during their time at secondary school' (Hutchinson & Crenna-Jennings, 2019, p. 9). Of these, approximately 40% had not gone back to a mainstream school by the spring term, meaning the chance of 'successful reintegration' was low (Hutchinson & Crenna-Jennings, 2019, p. 24). This emphasizes the need to understand why these YP are missing, and what changes need to be made to prevent this from happening.

A focus on categorisation and statistics dominates much of the earlier research about CYP who are absent from school and is perhaps a reflection of the pathologizing approach discussed in section 2.3.3.2. A review of 155 peer-reviewed studies found they did not:

> Reveal anything about what happens in real life in schools around the world…It is a good guess that if a study of real-life interventions in schools nowadays had been conducted, it would have resulted in a picture of counting, more regulations and disciplinary restrictions (Ekstrand, 2015, p. 474).

However, qualitative studies such as the seminal work by Osler and Osler (2002) are more revealing. The study involved 81 girls, some of whom had experienced exclusion whilst others had not, from a variety of educational settings and from six parts of England. All participated in small focus group discussions and 58 were interviewed. 57 of the girls had experienced some form of exclusion, with almost half of these (n=28) self-excluding or internally excluded by school. Findings revealed that girls often withdrew and self-excluded when they experienced problems at school such as bullying, social isolation and family issues. This behaviour is contrary to that typically expected of boys, who are more likely to be disruptive in school and as a result are formally excluded in higher numbers (DfE, 2020c):

> Our research shows that teachers are often able to ignore the types of behaviour commonly exhibited by girls in difficulty, which may disrupt an individual's learning but are likely to have a lesser impact on class discipline than physical aggression (Osler, 2006, p. 574).

The presence of the girls' voices is a powerful aspect of the study, though their use solely to exemplify different identified themes means the individuality of each girl's experiences is not represented, nor what they mean for each YP.

A variety of reasons for pupil absence are provided in the literature. Reid, a leading academic in the field of truancy and absenteeism, found explanations given by YP included bullying (Reid, 2012b), boredom and mental health issues; it was 'a psychological plea for help' (Reid, 2012a, p. 336). Bullying is a theme in another study that compared the school life of girls with boys (Osler & Vincent, 2003). This found that the type of bullying experienced by girls was different to that experienced by boys – it was psychological, not physical - and was not regarded as severe a problem by staff as it was by the girls. Relational aggression and the use of friendship groups 'as a means of exercising power and control over each other' (Osler & Vincent, 2003, p. 55) is also noted in a study on the friendship differences of autistic and non-autistic girls (Sedgewick et al., 2016).

Other possible factors in the absenteeism of girls include the issue of identity, linked to the concept of belonging (Head & Jamieson, 2006; Hyde, 2017), and concern over what peers think of them can lead to a reluctance to attend school (Heyne, Sauter, Ollendick, Widenfelt, & Westenberg, 2014). Having a poor self-identity is symptomatic of some girls in Pupil Referral Units (PRUs), who can 'rarely think of something positive to say about themselves' (E. Williams, 2002, p. 3). Girls encountering difficulties at school often behave in ways that don't impact on the teacher (Lall, 2007; Moyse & Porter, 2015; Osler, 2006), which may reduce the likelihood of them being identified as struggling and then receiving the support they need to stay present. It may also be the case that, once out of school, girls who internalise worries and problems continue to be overlooked and not in need of attention or resources. Russell (2002, p. 24) found that Sarah, a 15-year-old girl who had been out of school for two years, appeared to be regarded by social services as 'not sufficiently disturbed' to receive assistance as she was not homeless, a drug user, being abused or involved in crime.

The themes of power and resistance are raised in Ekstrand's research review (2015), presented by one researcher as energy: the forces that draw YP to school or alienate them (Strand, 2013, cited by Ekstrand, 2015). Truancy is seen as 'resistance and a demonstration against traditional school culture, class reproduction, and bad treatment', with YP 'questioning the legitimacy of the educational system' (p. 473):

> It is not a healthy protest, given that the school is seen as important, but it is nevertheless a protest. The individuals who absent themselves experience schoolwork as meaningless, entailing no challenges, and react to it (Ekstrand, 2015, p. 473).

Protest is seen as resistance and learning in school is rejected, with some CYP believing they have no power to change their educational path, as they have already experienced difficult situations that are outside their control. School may appear 'simply not relevant' for some pupils, who can become virtually detached from all 'social systems' (Broadhurst et al., 2005, p. 107). These beliefs may be related to feelings of low self-worth and lack of belief in their own educational abilities. Reid's 1980's study (Reid, 2012a) supports this, finding that pupils who were persistently absent 'had statistically lower academic self-concepts and general levels of self-esteem than their counterparts' (Reid, 2012b, p. 212), though it is not clear whether these developed before or because of non-attendance, and a link has been found between underachievement and unauthorised absence (Hancock, Gottfried, & Zubrick, 2018). However, whilst one of the girls in Olafson's (2006) study intended to challenge authority, others 'continued to be concerned about their academic progress' (p. 45). This was also the case for most of the young women in Dhilion's (2011) study, who were clear about the value of education, but who 'talked at length about the various mechanisms of exclusion that contributed to a disconnection from school' (p. 112). Absenteeism can be seen to involve diverse individuals with different attitudes to learning and a variety of motivations for non-attendance.

Absence is increasingly understood by some to be not simply a fault within the child or the result of poor parenting, but the result of a range of complicated and interrelated factors that include the school and wider society (Broadhurst et al., 2005; Ekstrand, 2015; Ryder et al., 2017). A Canadian study (Dhilion, 2011) that used personal narratives to explore access to education for homeless young women (n=118, aged 12-24) found that 'the life-trajectories of these young people were repeatedly being shaped by social forces outside the realms of "personal choice" and "individual accountability"' (p. 111). Ekstrand (2015) found that the most important factor was the schools themselves, with 'relations and feelings in education and learning situations' of far more significance than 'registration, control, and measures of absenteeism' (p. 472). There is specific acknowledgement that in-school factors can lead to 'significant differences' between schools in absentee rates (Reid, 2012a, p. 336) and that absenteeism may be a strategy used by some CYP who have ‘failed to find appropriate support’ in school (Osler, 2006, p. 581).

In contrast to this, an Australian study into 14-15 year olds (n=3,537) found that 90% of absences were with parental consent and that most reasons for non-attendance were outside the school’s control (Hancock et al., 2018). These included illness, family events and personal feelings such as tiredness and anxiety. The views of YP were captured amongst those of parents, teachers, and researcher observations, and the method chosen for YP was an online frequency survey that captured the number of absences and late arrivals and considered an association with achievement. Of note is the finding that illness was negatively associated with academic success, with the suggestion that being absent through illness is accepted and normalised by schools who make no attempts to help YP catch up with missed work. However, the quantitative approach of this study means that important nuances and deeper meanings are missing, and the causes for the illness (if genuine) are unstated.

Finally, absences from school as involving ‘processes of disengagement’ (Broadhurst et al., 2005, p. 106) is a key concept present in some of the literature. This is important as it indicates there is not necessarily one but multiple points in a YP’s school history that lead to their final absence from school (Reid, 1985, 2012b). This presents a strong recommendation for qualitative research methods that can span a period of time. Narrative accounts of some CYP missing from education have found that disengagement can be temporary, perhaps as a result of a short-term problem at home or school, or permanent (Broadhurst et al., 2005). A small study identified the stories (from six to 19) within each of the narrative accounts of four girls who were persistent absentees (Smith, 2014). Her research focused on the voice of the individual and how each interpreted their experiences. This revealed their heterogeneity, with separate key themes of family breakdown, difficulties with friendships and managing physical illness, and the need to ‘look beyond child motivated factors’ (Smith, 2014, p. 88). Exploring pathways out of school was the central aim of a larger piece of research in England (Ryder et al., 2017), which worked with 17 YP (nine females) to draw their routes out of education. These were typically chronological, either mainly pictorial or mainly handwritten, and captured such events as house moves, family separations and, in the case of a late diagnosed autistic girl, her self-harm and suicide attempts. This presents as a powerful research tool, though limited by it being a single interview of just 30 minutes.

In summary, a search of the literature on CYP absent from school has revealed non-attendance takes a variety of forms and that there is a lack of data on numbers of informal absences. Qualitative studies have shown that non-attendance is a pathway or process, that can be temporary or permanent, and the use of personal narratives has identified the stories are individual stories. The use of pupil voice is powerful though interviews were short, and responses sometimes lacked detail, suggesting a longer time for discussions would be beneficial. Some reasons for absences appear to be gendered. In-school factors, including how schools can move away from a purely within-child understanding of absenteeism, the associated school response to that and the influence of power, plus the value attached to learning by the absent pupil, emerged as areas that would be useful to consider in this research.

2.3.3.4 Absence of autistic children and young people.

> Even the most able children with autistic disorders may find mainstream school intolerable (Wing, 2007, p. 32).

The experiences of autistic and non-autistic CYP absent from school share some differences and some commonalities. Firstly, attendance at mainstream schools for autistic YP without Learning Difficulties is thought to be more challenging (Wing, 2007). The Norwegian study by Munkhaugena et al. (2017) found that 'school refusal behaviour' (SRB) was 'pervasive' amongst cognitively able, autistic young people aged 9-16, when compared with their peers (Munkhaugena et al., 2017, p. 31). SRB in 216 pupils (autistic YP n=78) was assessed over twenty days by teachers, who found this present in 42.7% of autistic pupils compared to 7.1% of non-autistic pupils. These findings are supported by a larger scale UK study (Totsika et al., 2020) which measured frequency and category of absences using Heyne's SNACK list (see section 2.3.3.2). 486 parents/carers of autistic CYP on a school roll participated. Of these, 152 had autistic daughters and 102 parents had children with an intellectual disability[15]. The study found that attending a mainstream school was the variable with the highest relative risk for total days absent and for persistent absence, and that SR was the reason given for 43% of the days missed. Less than 1% of absences were reported as TR (truancy) whilst about 9% of absences were categorised as SW (school withdrawal). Interestingly, there was no association between school withdrawal and any of the variables, which included child age, being a boy and having an intellectual disability, 'suggesting that other factors need to be explored' (Totsika et al., 2020, p. 9). The authors also postulate that the true percentage of school withdrawal could be higher, if withdrawal is linked to parental disaffection with school but not education:

> Parents of children with ASD often report that they withdraw their children from school to home-school them because they feel the school cannot adequately meet their child's needs (Totsika et al., 2020, p. 9).

Research into home-schooling and autistic CYP is therefore relevant when considering absence from school, as this may be the conclusion of absenteeism. A small qualitative study on parent-reported

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[15] Terminology used by the authors of the study.

reasons for home schooling autistic boys highlighted the negative impact of the physical school environment on their child, based on their sensory processing differences (Kendall & Taylor, 2016). This is supported by multiple other studies (Ashburner, Ziviani, & Rodger, 2010; Stewart, 2012; Tierney et al., 2016). For some parents, the decision to home educate was made because they believed the school was either unwilling or unable to provide an effective education for their children (Hurlbutt, 2011). Some parents perceived teachers lacked autism knowledge yet found there was an 'unwillingness on the part of the staff to listen' to their suggestions, and to their concerns that their children felt disliked and experienced stress (Kendall & Taylor, 2016, p. 308). A study on the views on home schooling of parents of CYP with disabilities or special needs (48% of whom were autistic) found many withdrew their children from school 'after serious concerns about their children's health and happiness' (Parsons & Lewis, 2010, p. 84), including their child's mental health, stating they felt they had 'no alternative' (p. 81). Kendall and Taylor's study (2016), supports this finding, reporting that seven of the eight participants felt they had 'no other choice…it was a case of home education by default' (p. 303). This concern is shared in a Children's Commissioner Briefing which notes that 'children are falling out of mainstream schools into home education, sometimes under pressure and when it is not in their best interests' (Children's Commissioner, 2017, p. 3). Findings on autistic girls were not reported separately in these studies.

Literature that categorised non-attendance as SR identified different factors associated with absenteeism and autistic pupils. A study that compared autistic pupils aged 9-16 with SRBs (n=33, females=6) with those without SRBs (n=29, females=3), all with IQ ≥ 70, found that 'social impairment, executive deficits, and emotional problems are associated with SRB in students with ASD' (Munkhaugen et al., 2019, p. 8). The low number of females meant sex differences could not be analysed. However, a larger, more recent Japanese study provided some findings by sex (Ochi et al., 2020). This was a record review study of 237 CYP aged 6-18, who were all psychiatric outpatients and identified as school refusers of 30+ days/year, that compared the characteristics of autistic (n=94, female=27) and non-autistic pupils (n=143, female=94). SR was found to begin at age 12.6 years ± 2.2, over a year earlier than the non-autistic YP, further indicating the value of research into absences at primary school. Contrary to the study by Munkhaugen et al (2019), this research looked at factors outside the child. Bullying was 'significantly associated with school refusal' (Ochi et al., 2020, p. 5) for both males and females, with times of transition and physical symptoms (that may be linked with anxiety) additionally associated for females.

The challenge of the transition from Year 6 (ages 10-11 years) to Year 7 (ages 11-12 years) for autistic girls is also identified by Tierney (2014), who found a poor transition had a catalysing effect, precipitating a deterioration in mental health and the need for professional services. Though Tierney's

(2014) qualitative study focuses on social coping strategies during adolescence, rather than non-attendance, information on participant characteristics identifies three of the ten girls as no longer attending mainstream schools. Evidence pertinent to this thesis includes one of these girls, home schooled from the age of 13, who described being mislabelled by teachers and rejected by peers. A second girl was diagnosed once she began secondary school and struggled with the 'stress and chaos' (Tierney et al., 2016, p. 80) she experienced. Other studies have noted the energy this can involve, with exhaustion 'from maintaining a social pretence' being another reason for SR or TR (Horlock, cited by Egerton & Carpenter, 2016, p. 10).

Another small-scale qualitative study in England (Gregory & Purcell, 2014) looked instead at 'extended school non-attenders' (ESNA). Five parents and three YP were interviewed, one of whom was identified as an autistic girl (two YP were not interviewed). The research found that the YP experienced one or more of six themes: a disrupted start to school; fear of a teacher or peer; anxiety; isolation; limited social interaction; self-harm. However, despite concluding that 'each case is different and complex' (Gregory & Purcell, 2014, p. 48), requiring the consideration of multiple factors including pupil voice to understand ESNA, it is not possible to discern individual experiences as participants are not pseudo-anonymised. Whilst this may have been to prevent recognition of individuals, given the working location of the first author, the loss of individual voices seems contrary to the purpose and intention of seeking the perspectives of the children interviewed, and means that it is not known which, if any, of the quotes were made by the autistic girl.

The final study (Goodall, 2018a) was published once data collection for this thesis had been completed and shares a similar participatory framework, with methods planned with an advisory group of three autistic YP. Twelve YP aged 11-17 were interviewed about their experiences of mainstream school. None were in mainstream school at the time, instead attending either Alternative Provision (AP)(n=7) or a home study group (n=5, two of whom were girls). Interviews were conducted over three sessions, using a mix of questions, drawing, activities, and diamond ranking, all of which aimed to aid communication and participation. The responses of the girls are also reported in a separate paper (Goodall & MacKenzie, 2018), which highlights the impact of their school experiences on their wellbeing, with the girls' voices describing feelings of 'dread', 'fear', 'despair', being 'drained' and 'angry' (p. 9). The study concludes that the girls did not have access to the type of inclusive environment, 'a sense of belonging and feeling that they matter as persons' (Goodall & MacKenzie, 2018, p. 13), that is essential for pupils to thrive and for learning to take place. This piece of research demonstrates the power of a participatory approach and of authentically listening to the voices of autistic CYP.

2.3.3.5 Government statistics on absence.

As per formal exclusions, statistics on pupil absences are published annually by the government. Two key measures of absence are captured. The first is overall absence, meaning the total of all sessions missed. The second is persistent absence, which equates to being absent for 10% or more of the annual sessions. It is again possible to view absenteeism by 'gender[16]', by primary special need or by school type. These show that in 2018/19, for example, the absence rate was 4.7% for all pupils, and 19.1% for persistent absentees (DfE, 2020e). Males and females had comparable rates of persistent absenteeism, at 11.1% and 10.6% each. Pupils with SEN had higher rates of absence than those with no identified SEN. In 2018/19, the persistent absence rate for students with an EHCP or Statement was 24.6%, whilst it was 9.0% for those without identified SEN (DfE, 2020e). However, the published tables do not enable a view of absence rates specifically for females who are autistic and who attend secondary schools.

2.4 Implications of the literature

A search of the existing literature in the field, including the most recently available studies, identifies that most research focuses on the process of exclusion as actioned by schools, and that most exclusions are of boys. Numerous factors were found that may contribute to a YP not attending school. Although helpful in exploring the topic, the literature is very limited when investigating the phenomenon of autistic girls who are no longer in education. The few studies of autistic girls who have been excluded find that some of the participants self-exclude or are withdrawn from school and are sometimes home schooled. No studies were identified that exclusively looked at the non-attendance of autistic girls who were not excluded by school. This represents a gap in the literature.

Participatory research has been discussed in a particularly relevant piece of research by Goodall (2018a) and the importance of pupil voice in understanding non-attendance has been stated by several studies. However, no studies used personal narratives to demonstrate the unique lived experiences of autistic non-attenders. In addition, none of the studies involved the autistic YP participating in knowledge construction through the analysis of their own experiences.

There are also gaps in knowledge that could be addressed using secondary quantitative data. Nationally published statistics on absence do not include data on the numbers of autistic girls who are absent from school, or persistently absent, meaning there is a gap in knowledge about the scale of the issue and whether absence is an issue that disproportionately affects autistic girls. Existing literature that considers sex differences in referral and diagnosis is conflicting, with particularly little evidence on the influence of the type of referrer.

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[16] The term used in the DfE documentation.

2.5 Summary

This chapter has presented a review of the most pertinent literature on autistic girls who had stopped attending mainstream school. Several gaps in knowledge have been identified. The next chapter presents the methodology chosen to answer the research questions.

Chapter 3: Methodology

3.1 Introduction

This chapter establishes the overall approach to the study and sets out the rationale behind the research processes chosen. The research paradigm and methodological stance employed are discussed within a set of interrelated assumptions that are the basis for educational research. These relate to the nature of reality, or knowledge; how 'what is assumed to exist' is known (Waring, 2017, p. 16); and the process of getting to this knowledge. Beliefs based on these assumptions ultimately led to decisions about the most appropriate data to collect to answer the research questions in this study, how to collect it, and how such data should then be analysed. The reliability and validity of data retrieved and collected are considered, and ethical issues specific to research involving CYP are addressed.

3.2 Research paradigms and methodological approach

All research is designed to better understand the world in which we live, and therefore an understanding is first required of how we currently see the world, how this informs our studies, and the benefits of a deeper understanding (Cohen, Manion, & Morrison, 2000). The term 'research paradigm' is used to define this perspective. It is widely attributed to Kuhn (1962), and describes 'a loose collection of logically related assumptions, concepts, or propositions that orient thinking and research' (Bogdan & Biklin, 1998, p.22). More simply, it is the researcher's lens for making sense of the world. The paradigm selected is important because it 'sets down the intent, motivation and expectations for the research' (McKenzie & Knipe, 2006), and is the stance from which the methodological approach and methods of data collection develop (Crotty, 1998).

3.2.1 The nature of the social world

Competing paradigms provide alternative theories for how the social world operates. Each one addresses questions of ontology, epistemology, and methodology to provide a particular world view. Two fundamental and opposing paradigms seek to define the nature of the social world, and these are used to begin to position this study. The first is positivism, which is associated with the French philosopher, Comte, who wanted to move knowledge production away from attempts to gain it 'by reason alone' (Cohen et al., 2000, p. 8). The term suggests that there is a 'singular objective reality that exists independent of individuals' perceptions of it' (Waring, 2017, p. 16). This perspective argues that 'the social world can be studied in the same way as the natural world, that there is a method for studying the social world that is value-free, and that explanations of a causal nature can be provided' (Mertens, 2005, p. 8). Authentic knowledge is arrived at via scientific processes of empirical observation and testing, proving reliability and validity. Processes to explain phenomena involve the quantification of data and the search for relationships which can prove or disprove hypotheses.

Results or ‘truths’ can be generalised because contextual information is disregarded, and should therefore give ‘a firm basis for prediction and control’ (Cohen et al., 2000, p. 10).

There are difficulties in using a positivist paradigm in social science, however. Critics of positivism argue against the reductionist nature of the approach and the focus on objectivity (Giddens, 1995), itself a ‘polite delusion’ (Raymaker & Nicolaidis, 2013, p. 170). Such a perspective seeks generalisable laws or facts, which limits the type of data that can be collected to study a phenomenon. It is seen by some as a factor in dehumanisation, precluding ‘notions of choice, freedom, individuality and moral responsibility’ (Cohen et al., 2000, p. 17). Trying to find truths by quantifying the views of a population is problematic, as it implies that ‘truth itself needs to have the multitude on its side’ (Kierkegaard, 2013, p. 128). This has implications for the value of democracy and the possibility of inclusion. Other critics have contended that science cannot capture the essence of humanity, as it does not answer questions around beliefs and opinions, nor explain 'our unique ability to interpret our experiences and represent them to ourselves' (Cohen et al., 2000, p. 19). Essentialist determinations about the experiences of a social group ignore the intersectionality of (e.g.) gender and disability (L. Brown & Boardman, 2011). This is exemplified by different beliefs and personal experiences of disability, within which the disabled researcher is also located (Seymour, 2007, p. 1192).

The phenomenon studied involves a rights issue: the marginalisation of autistic girls to the extent that they were missing the education to which they are entitled. As such, an evaluation of existing statistical data (and that which was omitted from collections) was an important part of the study. It is this data that informs policy and practice, as well as the context for this research. However, a purely positivist approach would not take full account of the individual and unique experiences of autistic girls who were no longer attending school and could reinforce stereotypes and further marginalise them. Voices could be captured and coded, but a qualitative method was required to pull the resulting categories apart, to illuminate the complexity of experiences and heterogeneity of the group and understand why these girls were absent, in particular, from their own points of view.

The opposite perspective is that of constructivism, which argues that there are multiple realities based on individual stories (R. G. Dean & Rhodes, 1998). People ‘perceive and interpret social facts’ from their own standpoints in order to create meaning (Corbetta, 2003, p. 24), and therefore reality is ‘socially constructed’ (Mertens, 2005, p. 12). Researchers following this paradigm do not begin with theories to explain situations, but look to generate an understanding of a phenomenon during the research process (Mackenzie & Knipe, 2006). Personal meanings are thought to be created through ‘social interaction with others and from their own personal histories’ (Creswell & Plano Clark, 2011, p. 40), with individuals ‘determining categories and shaping or constructing realities’ (Waring, 2017, p.

18). In this paradigm, differing results are valued in order to deepen an understanding of a phenomenon (Weber's *verstehen*), so the objective is to gather a richness and diversity of qualitative data, or 'thick descriptions' (Geertz, 1973). The subjective views of participants are thus central to this understanding (Creswell, 2014), and how meanings are interpreted. The paradigm recognises that the observer is not neutral, as she brings her own values and interests to the project, and that the approach enables questioning of assumptions (R. G. Dean & Rhodes, 1998). Methods are qualitative, not quantitative, whilst conclusions may be more interpretative than conclusive and are largely non-generalisable (Cohen et al., 2000).

Critics of constructivism argue that findings using this paradigm are not authentic knowledge precisely because of their lack of generalisability and reliability, and findings are often regarded as inferior and only supplemental to quantitative research (Trainor & Graue, 2014). Concerns are raised about the accuracy of the data captured by qualitative means: that participants may be 'falsely conscious' (Cohen et al., 2000, p.23; cite Rex, 1974), may remember wrongly, or may simply lie. There is also an uneasiness about the inevitable bias of the researcher, who may misinterpret qualitative data, leading to distorted accounts and conclusions. This is compounded for some by the approach's 'double hermeneutic' (Giddens, 1984, p. xxxii) of interpreting new meaning from already interpreted accounts. Interpretative research that prioritises the lives of individuals can also risk ignoring the impact of imposed social structures, and become too narrowly focused (Cohen et al., 2000).

Adopting a purely constructivist approach would enable a focus purely on the voices and narratives of individual autistic girls, and as such is particularly suitable for research with marginalised groups. It would allow the exploration of differences and similarities in the pathways that led them to stop attending school, and to investigate nuanced understandings of barriers to attendance and how to overcome them. However, without statistical data to provide background and the scale of absenteeism by autistic females compared to males, and to enable the exploration of sex differences in the referral and diagnostic process, the research questions cannot be fully answered, and the phenomenon not fully explored.

Debates and challenges between qualitative and quantitative researchers in the 1980's and 1990's - the 'paradigm wars' (Denison, 1996) - represented the (on-going) conflict between those wanting a scientific basis for understanding the social world, and those who believe in multiple realities. However, both these paradigms have been described as too prescriptive, and criticised for being 'incomplete accounts of human behaviour' on their own (Cohen et al., 2000, p. 28). As a result, new ways of viewing the world (e.g. post-positivism) have evolved out of existing paradigms – the paradigm shift identified by Kuhn (Bryman, 2008). A third research approach is seen as developing significantly from the 1990's (Denscombe, 2008): the mixed methods or mixed model approach (Tashakkori & Teddlie, 1998).

Mixed methods research has evolved from early definitions that highlighted the simple mixing of methods used (Greene, Caracelli, & Graham, 1989), to an understanding that such an approach could more expansively incorporate research philosophy and design (Creswell & Plano Clark, 2011). The key principle of combining quantitative and qualitative data is that it can 'provide a more complete understanding of the research problem than either approach by itself' (Creswell & Plano Clark, 2011, p. 8).

Using mixed methods can create tensions and contradictions, for ontological and epistemological reasons (D. E. Gray, 2014). A study by McMahon (2007) used mixed methods to explore the culture of rape myths with student athletes, to 'understand the definition, function, and salience of rape myths', whilst supporting 'feminist principles of giving voice to participants and accounting for context' (p. 358). The results of one method contrasted with those of the other, which some could view as negating the validity of the findings. An alternative interpretation sees this difference as a vital part in knowing and understanding the issue being studied. Sedgewick et al (2016) used mixed methods to investigate gender differences between autistic and non-autistic CYP and their friendship experiences. In this study the perspectives of different stakeholders were captured using quantitative methods, whilst the qualitative data contributed to confidence in the results due to the 'broad consistency' of findings across the two measures (p. 1305).

In summary, a mixed methods approach can enable 'multiple ways of seeing and hearing; multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished' (Greene, 2007, p. 20). This stance is supported by Iemmi et al (2017) and their large-scale report into autism 'evidence-based and cost-effective practice' (p. 5), who argued that a mixed methods approach was essential. This is the stance taken by this thesis.

3.2.2 A participatory approach

The existing body of autism research has many examples of practices that have excluded autistic people from the planning, processes, and creation of knowledge. This has led to some inevitable misinterpretations of meaning and culture, derived from 'quote-mining' and 'fishbowling' (Milton & Moon, 2012; Milton & Sims, 2016, p. 524). The result has been to 'further disempower those already frequently overlooked in key decision-making processes that shape their lives' (Milton, Mills, & Pellicano, 2014, p. 2650).

A participatory framework was therefore chosen in which to situate the study, which links the creation of knowledge to power and control (Tandon, 1981) and seeks to challenge traditional research relationships and existing views on what constitutes valid knowledge (Raymaker & Nicolaidis, 2013). It assumes that research is political as it addresses power imbalances (Creswell & Plano Clark, 2011), with the researcher seen as a partner in the process. It differentiates itself by conducting research *with* participants, rather than *on* them, often motivated by social justice (Oliver, 1997).

The active participation of autistic people is regarded as essential in creating meanings that reflect individual realities, and challenging dominant views about them (Milton & Bracher, 2013; Mogensen, 2010). Placing autistic people as collaborators and co-producers of knowledge within the research process enables a recognition of them as 'experts on their own lives' (Gorin, Hooper, Dyson, & Cabral, 2008, p. 282). Lived experience and subjective knowledge are held to be not just equally valid in comprehending a phenomenon as objective knowledge, but essential to the deep understanding required for change.

'Participation is the fundamental right of citizenship' (Hart, 1992, p. 5), and it is apposite to empower autistic girls to participate in research about how they have been excluded from school, and from their basic right to an education. It also connects with the principle of the involvement of CYP in decision-making about meeting their needs, as stated in the SEND Code of Practice (DfE & DoH, 2014). Studies have shown that input from autistic pupils 'greatly improves the chances of finding viable solutions to real problems' (Iemmi et al., 2017, p. 23), such as making support more appropriate to student needs (Bolic Baric, Hellberg, Kjellberg, & Hemmingsson, 2016) and re-engaging with education (Ryder et al., 2017). This demonstrates how the validity of the knowledge produced can be increased through participation and the inclusion of multiple voices and result in effective change:

> How can our work be seen as reliable if participants, who hold a unique knowledge set relating to personal experience of that situation are not involved in that process? (T. Cook, 2012, p. 10).

There are challenges, however. Research findings must be 'credible to stakeholders and policy makers' (Creswell & Plano Clark, 2011, p. 43) as well as those directly involved. Care must be taken to ensure involvement is truly participatory and not merely tokenistic (Hart, 1992; Lundy, 2007), by seeking to 'overcome the power differentials that exist between autistic people and established authorities' (Milton et al., 2014, pp. 2650-2651). Hart's (1992) Ladder of Participation identifies degrees of participation based on who initiates and directs the research, and suggests the minimum required for a project with CYP to be participatory is for them to be informed of the purpose of the project, to have consequential roles within it, and to give their own consent to take part. However, this minimum does not fully address imbalances of power present in many studies with CYP, and therefore arguably is insufficient for authentic participatory research. This thesis positions autistic YP as central to the understanding of the phenomenon under investigation, with their roles here encompassing the direction of methods, their interpretation of their own data and the formulation of recommendations for change.

3.2.3. The centrality of pupil voice

> The power imbalance shifts if those with least power have a voice that can be heard (Murray, 2020, p. 284).

More research into the experiences of autistic children has been done by asking for the views of the parents, than the views of the children. When the views of autistic children are captured, it is often the words of parents or professionals that are included in summaries, rather than the child's (see eg Brede et al., 2016; Cridland et al., 2014). As a result, policies around inclusion and integration have in the past largely been made on the basis of 'the needs of pupils as perceived by other people' (John, 1996, p. 181). There is therefore a need for more research into the 'real-life experiences' of autistic children 'from their own perspective' of mainstream education (Carrington & Graham, 2001, p. 47).

Autistic children are therefore often 'hidden voices' (Ainscow, 2007, p. 3) and the voices of girls (Maguire, 1987; Osler, 2006) and autistic girls (as evidenced by the literature review) particularly so, despite the view of some key academics in the field of disability and education stating that 'the importance of seeking children's views directly cannot be overestimated' (Parsons & Lewis, 2010, p. 84). Difficulties with social communication and interaction - markers of autism - have often been used to justify the lack of direct participation in research by autistic CYP. However, literature by autistic people, both verbal and non-verbal (Higashida, 2013; C. Kim, 2012, August 26; Sequenzia, 2017), demonstrates that autistic people have things to say and wish to be heard.

This requires autistic CYP, who 'would not otherwise be heard due to their position outside the established hierarchies of scientific decision-making' (Pellicano & Stears, 2011, p.278) to have a voice. Lundy (2007) asserts that, whilst the 'right to express a view' and 'to have the view given due weight' (p. 931) are provided for by Article 12 of the UNCRC (UNICEF, 1989), in reality these rights may be given only superficial attention by others. The Committee on the Rights of the Child (UN Committee on the Rights of the Child, 1997) recognises that disabled and disenfranchised CYP (such as autistic girls) may experience a 'double denial' of their rights because of 'an even deeper inability to accept the child's competence' (para. 334). Lundy's (2007) model addresses these issues, with provision based on 'space and voice' (the opportunity and support to speak) plus 'audience and influence' (to be heard and have views actioned, if apt) (p. 933). This model influences the methods and methodological approach of this thesis. It involves working from a perspective of 'presuming competence' (Biklen & Burke, 2006, p. 166) and necessitates careful consideration of appropriate methods.

3.2.4 Challenges and solutions

The communication and interaction differences of autistic YP has led to limited participation in some previous research (Preece & Jordan, 2010) and therefore interview techniques need to be modified to enable autistic YP to take part (Lewis & Porter, 2007). Differences in the way autistic YP prefer to communicate may mean that 'they know more than they can say or, conversely, say more than they understand' (Lewis, 2009, p. 4) unless research methods are chosen that reflect these preferences. Articulating thoughts involving complex emotions may be particularly hard (Losh & Capps, 2006) and exacerbated under the pressures of time, an unfamiliar environment and an unknown interview schedule. Trying to decode nonverbal communication may be an added difficulty (Harrington, Foster, Rodger, & Ashburner, 2014), and an unnecessary and excessive drain on energy levels.

Providing options for ways of participating is also one important way of addressing the power imbalance between researcher and participant (Seale, Nind, & Parsons, 2014): 'autistic individuals should have the agency to choose what is right for them' (Parsons, Yuill, Good, & Brosnan, 2020p. 226). Involvement in the way that is most accessible may enable autistic YP to recreate their identities in ways that are more empowering (Benford & Standen, 2009; Brownlow & O'Dell, 2002, p. 692). There is some evidence that using digital technology for research with autistic people can be advantageous (J. Davidson, 2008; Parsons, Yuill, Brosnan, & Good, 2015), and can give autistic people 'the strength to insist on the validity of our own experiences and observations' (Blume, 1997). It can help to reposition the participants as collaborators (Brownlow & O'Dell, 2002), functioning as a tool to facilitate knowledge co-construction (Guldberg, Parsons, Porayska-Pomsta, & Keay-Bright, 2017) in a medium in which they may be experts (Parsons & Abbott, 2013).

There are additional potential benefits, such as being able to read and revise answers before posting, addressing many autistic people's need for perfectibility (Benford, 2008; Benford & Standen, 2009; Chown, Beardon, Martin, & Ellis, 2015). Online communication can see a 'power shift', from the fastest/loudest talkers, to the faster typists and most confident users of IT. The 'less spontaneity of response' (Bryman, 2004, p. 478) means that the difficulties of processing and responding in fast-paced conversations (Nichols et al., 2009) are eased.

Giving participants the choice over interview location can be empowering (Charmaz, 2012), be it physical or virtual. Online communication allows the immediate external environment to be controlled, so being overloaded by sensory input can be prevented, and reduces the energy drain of engaging in-person social interaction (Blume, 1997; Müller, Schuler, & Yates, 2008). It allows for 'social and emotional distancing' (Chown et al., 2015), as it removes non-verbal communication. This means potential difficulties in decoding the non-verbal communication of others, such as body posture and facial gestures (see Bolte, 2004; Harrington, 2014; Murray, 1997; Smith Myles, 2005; Swettenham, 1996) are avoided, and participants do not need to think about the messages their own bodies are sending: 'You can be seen as yourself' (Benford & Standen, 2009, p. 50).

There are mixed views on the appropriate style of interview questions, from support for open, non-judgemental questions that 'encourage unanticipated statements and stories to emerge' (Charmaz, 2006, p. 26) to the belief that autistic YP would prefer the structure offered by statements or closed questions (Lewis, 2009). The challenge for this research lay in finding methods that provided for both possibilities in order to help participants 'articulate his or her intentions and meanings' (Charmaz, 2006, p. 26), and these are presented in section 3.3.2.

3.2.4 Summary

This section identified mixed methods as the most appropriate methodological approach for this thesis, so that both quantitative and qualitative data could be drawn upon to answer the research questions (see section 1.4). Such an approach enables the 'uncovering relationships between variables through quantitative research while also revealing meanings among research participants through qualitative research' (Bryman, 2006, p. 107). It explained the choice of a participatory approach informed by emancipatory research design, both of which are inherently suitable for research with marginalised populations, and the reasoning for the prioritisation of the voices of the autistic girls in this study.

3.3 Data collection methods

The quantitative and qualitative aspects of the study had an independent, sequential design (McMahon, 2007), with both contributing to the overall understanding of the phenomenon. The primary data collection was qualitative, and innovative methods were used 'to produce new knowledge about persistent educational problems' (Trainor & Graue, 2014, p. 268). Secondary data retrieval provided statistical information relevant to the first research question, and case study data to inform research question two.

3.3.1 Secondary data

3.3.1.1 Statistics on persistent absenteeism.

A Freedom of Information (FOI) request was made to the Department for Education's Schools Census Statistics Team (see Appendix 3.1). This requested data on the numbers of male and female autistic pupils who were persistent absentees at mainstream schools from 2009-17. The response also provided the number of male and of female autistic pupils on roll at mainstream secondary schools in England over the same period.

This information was required to understand whether the school population of autistic girls was increasing, thereby indicating a growing need to plan specifically for their educational needs, and if persistent absenteeism was a greater issue for autistic females than for males.

3.3.1.2 Statistical data on referrals for an assessment of autism.

Secondary data on autism referrals to an NHS Foundation Trust in the SE of England were requested (see section 3.6.1.1 for details on ethics), with the support of the Neurodevelopmental Lead for the Trust. The Trust serves a population of approximately 900,000, which represents about 1.3% of the population of England. It may not be representative of all NHS Trusts. It has a number of Clinical Commissioning Groups (CCGs) and the county is served by a similar number of unitary Local Authorities.

Data provided were that which could be automatically retrieved from the NHS RiO database, and was anonymised at source by the NHS analyst who ran the extraction. The resulting dataset was a population sample of total referrals of CYP to the autism assessment pathway by financial year from April 2012 – March 2018[17], totalling 6103 records. Records for children who were aged 1-4 years on referral (n=1455) or diagnosis (n=1) were then removed, as the dataset for this age range was not held on the RiO database and therefore incomplete. Referrals for YP aged 19+ were also removed (n=2).

The remaining dataset was then cleaned, removing entries where ‘entered in error’ was stated in the reason for discharge (n=53), the referral date or the diagnosis date was before April 2012 (n=2 and n=11 respectively) and entries for CYP who were normally resident outside of the Trust boundary (n=131). This left a final dataset of 4448 (see Appendix 4.1). The dataset provided information on the number of referrals and the numbers of CYP diagnosed as autistic by sex, ethnicity, year, and CCG, as well as the opportunity to analyse waiting time between referrals and assessment. This data was used to look for sex differences in referral and diagnosis rates over time.

A second dataset that required manually accessing patient records was requested for one year between 2012-2018, to consider other factors that contributed to a referral. Due to restrictions on access without consent (see section 3.6.1.1), the retrieval of data was actioned by two members of the Autism Assessment Team (AAT) and then anonymised at source. The calendar year 2016 was selected by AAT as some data for this year had already been retrieved for a different project, and therefore less time was required to complete the request. This dataset provided information on the

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[17] Data were requested for the period preceding the date of the request, to include the year prior to the publication of DSM-5.

type of referrer, the age at referral by referrer, whether the YP had been or was currently on a different diagnostic pathway, whether an observation in school formed part of the assessment, and whether the assessment involved a second opinion.

The dataset (n=408) was cleaned prior to analysis. Records for children who were referred at the age of four years or younger, and therefore not of school age[18](School Admissions, n.d.), were removed first (n=68). Incomplete records for which no sex (n=18), referrer (n=5) or outcome (n=2) were listed were also deleted. Details of the final dataset (n=315) are provided in Appendix 4.5.

3.3.1.3 Qualitative data from NHS patient records.

A purposive sample of ten individual records was sought to explore pathways to diagnosis and to look for evidence of school attendance and each girl's voice. This aimed to meet the objective of understanding any delays in the referral process and how this might impact on provision of support in school.

This was not required to be a representative sample, given the heterogeneity of the population. However, records for girls diagnosed at both primary and secondary schools were sought, to extend the diversity of the sample. After obtaining ethical approval for this part of the research (see section 3.6.1.1), 10 families were initially selected by two members of the Autism Assessment Team using the provided criteria (see Table 3.1).

Table 3.1

Selection Criteria for Case Studies

Selection criteria
Female at birth
Clinical diagnosis of autism (including Asperger Syndrome) from an NHS Trust
Diagnosed between 2012 - 2018
Diagnosed whilst of primary school age (maximum of five girls required)
Diagnosed whilst of secondary school age (maximum of five girls required)
Aged 11+ years at the time of data retrieval

They phoned the parents to ask permission for the record of their autistic daughter to be accessed as part of this study, and a further four families were contacted once some of the original 10 had declined. This process ensured the confidentiality of the data prior to consent being given to access

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[18] Remaining in the dataset are 26 records of children aged 4 years 1 month – 4 years 11 months at referral. It is possible that not all these children were at school at the time of their referral. The youngest child referred by a school in the dataset was aged 4 years and 2 months.

the patient record. Further information on the purpose of accessing the records, plus consent forms for the parent and for the autistic girl, were then posted to each family who showed interest (see Appendix 3.2 to Appendix 3.5). Of the 14, six either declined to participate during the call or did not return the consent form for the YP. Three parents said they did not want to raise the subject with their daughter to ask for their consent. No reason was given by the other three parents. Access[19] was granted by eight parents and their daughters, and these records were the basis for the case studies. Four of the girls were diagnosed whilst still at primary school; the other four at secondary school.

All documents within a record were read and reviewed whilst on an NHS site, and notes taken on the research laptop. Each girl's record was given a pseudonym at the beginning of the data retrieval. No personal identifiers were recorded, and files were password-protected (see section 3.6.4 for further discussion of ethical considerations). Documents examined were correspondence, the Children's Communication Checklists (CCC) from the school and the parents, the Social Communication Questionnaire (SCQ) and Strengths and Difficulties Questionnaire (SDQ) completed by parents, the observation notes from school (if applicable), the screening questionnaire from the parents, and the developmental history and ADOS assessments completed by the clinicians (see section 3.4.2.1 for further comment on these tools).

3.3.2 Primary Data

> Right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced (D. Williams, 1996, p. 14).

As part of the intention to involve autistic people in every aspect of the study, an Autism Advisory Group (AAG) of three adolescent autistic girls was formed to provide input into the research methodology and methods selected for the collection of primary data, the choice of themes and questions, and what to do or provide during interview to help reduce likely anxiety (Chown et al., 2017; Milton & Bracher, 2013). They checked access arrangements for the interview room at the University and for the text messaging facility of Skype. They suggested ways of reducing anxiety (see Appendix 3.6 for the visual guide created for participants attending the University). They helped to write participant information sheets and checked items for ambiguity (Harrington et al., 2014). They also participated in piloting the chosen techniques, trialling the processes to identify flaws, omissions and ambiguities that could be addressed before the main data collection (see Appendix 3.7 for

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[19] To adhere to NHS and ethical protocols I was given an honorary contract as an Assistant Psychologist with the NHS and provided with training before accessing the RiO database. I was only entitled to view the records of those girls for whom consent had been provided, and an automatic log of my usage on the system was kept.

amendments). All three girls were already known to the researcher (see section 3.6.1.2 for ethical considerations).

Purposive sampling strategies were used for the primary data collection. Mogensen (2010), in her study of autistic YP's experiences of identity, noted that sample size is often connected to the resources available for the study. Lone researchers tended to have sample sizes of one to five (Moyse, 2013; Sayman, 2015; Stewart, 2010), whilst larger scale projects of up to 60 people tended to be conducted by two or more researchers (Bargiela et al., 2016; Calder, Hill, & Pellicano, 2013; Humphrey & Lewis, 2008b). However, multiple authors have collaborated on smaller samples of less than five (Carrington & Graham, 2001; Dudova, Kocourkova, & Koutek, 2015), and single authors have worked with larger samples (Cridland et al., 2014; Sedgewick et al., 2016).

A large enough sample was required for the 'data collection and analysis [to] reciprocally inform and shape each other' (Charmaz, 2012, p. 293), so that theory (grounded in the data) emerges from this iterative process of data analysis. This is referred to as theoretical saturation, where 'new data no longer suggest new theoretical insights' (Bryman, 2016, p. 412) and the size of such a sample varies according to the heterogeneity of the sample and the scope of the project, plus 'adequacy is dependent not upon quantity but upon the richness of the data' (Goodson & Sikes, 2001, p. 23).

Other researchers have acknowledged the difficulty of engaging young people who are out of school (Broadhurst et al., 2005; Loizidou, 2009; Rouse, 2011), and particularly of autistic girls out of school (Gregory & Purcell, 2014; Sproston et al., 2017). This has often led to sample sizes being limited. Requests for help in finding participants were sent to local autism charities and Local Authorities (see Appendix 3.8), and posts placed on the social media pages of two large groups for the parents of a) autistic girls and b) CYP who struggled to attend school, with posts on one group attracting 66 responses. Whilst it was expected that 'snowball sampling' (Bryman, 2016), regarded for its value in accessing 'hidden populations' (Noy, 2008, p. 330), would have a role in attracting participants, it is possible that the fact the researcher is a member of the autistic community was also influential.

35 people requested further information (see Appendix 3.9 and 3.10), which was posted out with consent forms (see Appendix 3.11 and 3.12) for parents and daughters to both sign and return in an enclosed stamped addressed envelope. Some of these people's daughters did not meet the eligibility criteria (see Table 3.2) and so were unable to progress.

Table 3.2

Selection Criteria for Life History Interviews

Criteria
Aged between 11 and 16 years
Clinically diagnosed as autistic by a certified professional
Had enrolled at a mainstream secondary school but are not currently attending
Live in England

Of those who did, 14 parents and 12 girls returned consent forms. The two girls for whom consent forms were not received were withdrawn from the sample. One parent withdrew consent before the first interview, as she felt her daughter was not mentally strong enough to participate at that time. The final girl was withdrawn as it was not possible to set up the first interview.

This left a sample of 10 girls[20] (see section 5.3 for participant characteristics). Although a diversity of sample was neither sought nor achieved, the sample was felt to be large enough to illuminate the expected heterogeneity of experiences, and also not so many that the number would 'lead to less rigour in other ways' (Braun & Clarke, 2006) and reduce the effectiveness of the analysis. Also, whilst it was not a saturation sample, the design of the study meant it had strong 'information power' per the model suggested by Malterud et al (2016, p. 1757).

The data collection process (see Figure 3.1) was planned around three individual sessions per participant (see section 5.1 for details on interview locations), as a fundamental aspect of participatory research is the opportunity to discuss and create meaning over multiple opportunities, rather than during a single data collection event (T. Cook, 2012).

3.3.2.1 Personal constructs of the ideal school.

The first interview consisted of eliciting personal constructs (Kelly, 1955) of each girls' ideal school. Personal Construct Psychology was originally developed by Kelly to 'understand the child's unique perspective on life' (Moran, 2001, p. 600) and is based on the concept that 'we develop and build our theories about life into a system of constructs that encapsulate our experiences' (J. Williams & Hanke, 2007, p. 54).

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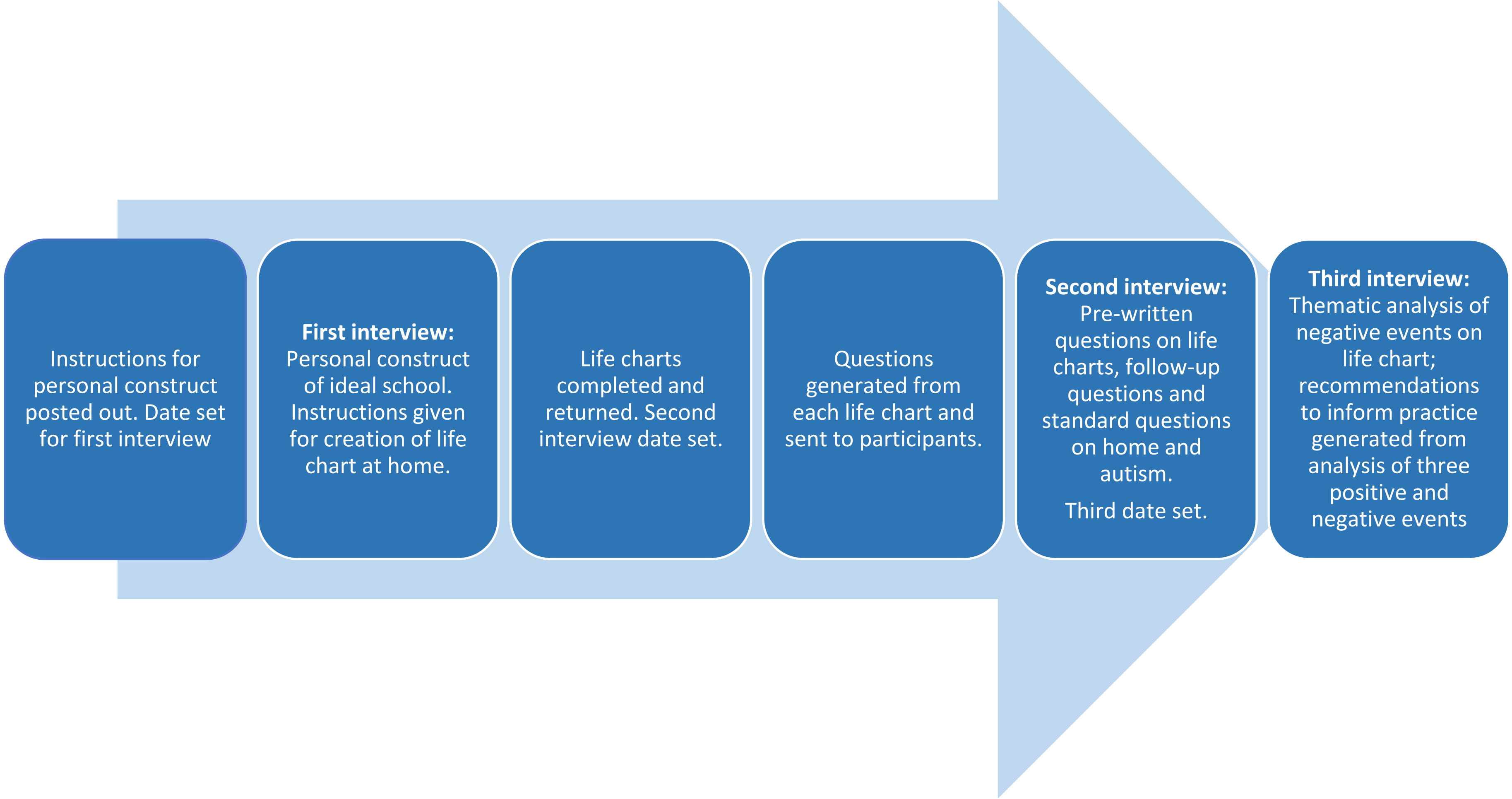
[20] All ten participants were female at birth. The pronouns she/her are used for nine participants. One participant now identifies as gender-fluid and uses the pronouns they/them. 'Girl' or 'female' are used per the description of the project and stated criteria for the sample, except for specific references to the participant identifying as gender-fluid.

Figure 3.1

Primary Data Collection Process



Instructions for personal construct posted out. Date set for first interview

First interview: Personal construct of ideal school. Instructions given for creation of life chart at home.

Life charts completed and returned. Second interview date set.

Questions generated from each life chart and sent to participants.

Second interview: Pre-written questions on life charts, follow-up questions and standard questions on home and autism.

Third date set.

Third interview: Thematic analysis of negative events on life chart; recommendations to inform practice generated from analysis of three positive and negative events

The method has informed research into absenteeism (Reid, 2012a) and been used successfully in previous studies with autistic YP (Moran, 2001; J. Williams & Hanke, 2007), helping them to engage in a way that has personal meaning for them (Moran, 2001) and supporting them to articulate their views in ways that make sense to them (J. Williams & Hanke, 2007).

Moran's (2001) example of the Ideal Self was used to help formulate the instructions for this exercise, which instead explored the Ideal School. This asked the girls to first describe the sort of school they would *not* wish to attend, as finding out what they didn't want can be useful in understanding the whole construct (Burr, 1995), and then asking about their *ideal* school. The original design by Williams and Hanke (2007), who used personal constructs to explore the individual perceptions of an ideal school with 15 autistic YP at mainstream schools, was extended in the version used in this study (see Appendix 3.14) to help them 'audit' the provision they experienced (J. Williams & Hanke, 2007, p. 133).

Personal constructs have the potential to identify possible solutions and support change (Moran, 2006), which made the technique a good choice to help answer the third research question about improving provision in schools. It was positioned as the method for the first interview, when the girls might be most anxious, because it could elicit views without asking directly about personal experiences. It helped 'set the tone' (Moran, 2001) for subsequent sessions by demonstrating that the girls' constructions were valid personal truths and that there was no 'right' answer (Burr, 1995). In addition, it positioned the research as exploring external factors for the girls' absence from school, rather than as the result of personal deficits.

The personal construct exercise (see section 5.4.2 for further details) was designed to scaffold responses so that the girls were supported to respond within their level of comfort. Nine themes were provided in advance (see Appendix 3.14). During interview they were asked to say/draw three things about each theme (for example, 'the classroom') for each type of imaginary school (see Appendix 3.15 for the process). This enabled the girls to raise issues of relevance to them, rather than reply to predetermined points based on assumptions. In addition, three standard specific questions relating to each theme were prepared, but not shared ahead of the interview, and all the girls were asked to answer these once they had given open responses (see Appendix 3.13). This meant that girls unable to respond to the open question were able to participate and there was a means of comparing some answers from each girl. Whilst the girls were told they could draw or write answers, drawing was used rarely and only to clarify a verbal or written description.

Diamond ranking was then used by the girls to prioritise their answers about the sort of school they wanted to attend, after selecting the nine answers they felt were most important in their own ideal school (see 5.4.1 for further details). Diamond ranking is a 'thinking skills tool' used for 'eliciting constructs and facilitating discussion' (J. Clark, 2012, p. 223). The activity meant the girls could ascribe 'levels of importance' (Goodall, 2018b, p. 10) to items, and further supported the girls' active participation in knowledge creation (Grover, 2004).

First interviews lasted for between 45 minutes and 81 minutes, with a mean average duration of 66 minutes for the eight in-person interviews, and of 96 minutes for the two girls who were interviewed via Skype messenger. One of the participants, Alex, completed the diamond ranking part of the exercise in an additional session (51 minutes).

3.3.2.2 Life histories.

> Disabled children and young people have powerful and insightful comments to make about their educational provision and future plans when given the opportunity to do so (Parsons et al., 2009, p. 53).

There is a growing movement in the field of disability studies that has embraced personal narratives in response to dominant research methodologies that have historically removed marginalised individuals from studies about them, and which have been 'disconnected from the immediate realities and complexities' of their lives (Valente & Danforth, 2016, p. 6). Participants are the tellers of their stories and do so in ways that make sense to them. As such life histories have been the method of choice for many studies seeking to validate the views of minority groups, based for example on autism (Casement, Carpio de los Pinos, & Forrester-Jones, 2017), gender and autism (Pesonen, Kontu, & Pirttimaa, 2015), sexuality (Koecher, 2015), Deaf culture (Najarian, 2008) and disability (Seal, 2014).

These narratives or life histories enable consideration of those voices that 'have been muted or silenced' (R. G. Dean & Rhodes, 1998, p. 257) and challenge assumptions by making the reader take the perspective of the informant, which 'forces us to re-examine our preconceptions' (Goodley, 1996, p. 335). The method enables the construction of personal experiences as stories, 'set within specific social relations and historical contexts' (Seal, 2014, p. 84). Each person is seen as 'the expert of their personal experiences' (Cridland et al., 2014, p. 1263) and research concerns how these experiences are interpreted, and with the 'meanings about the self and about relations with others' they are ascribed to their stories (Loizidou, 2009, p. 25). This exploration of 'sense-making' acknowledges that 'a person's world is therefore one of personal meanings' (Lawthom & Tindall, 2011, pp. 6-7), and that this knowledge is valuable and valid. Fundamental to narrative research is the belief that life histories are unique and will give rise to different stories, as 'each young person has their own story to tell' (Steer, 2000, p. 2). Studies that include a number of life histories enable the recognition of 'both the commonalities and diversities of participants' experiences' (Cridland et al., 2014, p. 1263).

A key aspect of participatory research is the opportunity to discuss and create meaning over multiple opportunities, rather than during a single data collection event (T. Cook, 2012), making personal narratives a fitting method for this study. Two interview sessions were planned and a topical life history approach chosen, which 'does not aim to grasp the fullness of a person's life, but confronts a particular issue' (Seal, 2014, p. 85); the girls' experiences of school. Timelines have been used effectively in earlier research with autistic CYP, to facilitate recall and to help identify events during different stages of a child's school career (Bolic Baric et al., 2016), and enable multiple possible reasons for absence to be captured, rather than a single 'trigger point' (Reid, 2012b, p. 214). The NCB Children Missing Education report (Ryder et al., 2017) meanwhile, used a 'pathways' technique, which used drawings to capture major past experiences from the child's perspective to show the child's route out of school. The concept was used in a similar way for this study, which uses the term life chart, drawing on doctoral work by Majid (2018, February 15).

The girls were asked to construct a life chart at home after the first interview marking on their memories of positive and negative events or experiences of school, in chronological order. A list of FAQs, an example life chart and a template were provided (See Appendix 3.16 to Appendix 3.18). The life chart allowed the girls to indicate the significance of each entry by inclusion and by its positioning on the chart. It also addressed possible difficulties in recalling events from memory and narrating personal events (B. T. Brown, Morris, Nida, & Baker-Ward, 2012; Harrington et al., 2014, p. 155; Preece & Jordan, 2010) by enabling them to build the chart over time and away from the pressures of the interview space. Completed charts were posted back to the University in a provided stamped addressed envelope or emailed to the project address. Questions were then written for each girl, based on their chart, and emailed to them before the second interview along with standard questions about their home life and about their views on autism (see Appendix 3.19).

The second interview asked all the girls set questions on home life, and then used the individual questions generated by each girl's personal life chart. This meant the girls directed the discussion on their school experiences, whilst the chart also facilitated conversation, encouraged reflection, and prompted further memories. In the third interview the girls were asked to identify themes in their negative experiences by colour-coding the events on their charts (see Appendices 5.3 and 5.4 for examples). They were then asked to select three of the negative events and describe what they thought the school could have done differently to prevent it from happening, or to reduce the impact. Next, they chose three positive events and identified why they went well, and what the school did that was helpful. This method recognised the value of using stories for the co-creation of knowledge (Parsons, Guldberg, Porayska-Pomsta, & Lee, 2015) and demonstrated the valuing of the girls' personal experiences as a route to change by illuminating their 'wants and needs' (McCormack, 2009,

p. 107). A standardised checklist, the Strengths and Difficulties Questionnaire (Goodman, 1997), was administered at the end of the final interview (see Appendix 3.20). This was in anticipation of comparing results with those from the case studies see sections 3.4.2.1 and 5.4.3).

Participants were given the opportunity to process and reflect back on their interview by emailing later thoughts to a project email address or posting them to add to the overall richness of the data (none did). This was not to change or dilute the raw data captured during the interview sessions, but to acknowledge that thoughts and understanding do not always occur in the moment.

The narratives and participant analyses were used to help answer research questions two and three, by exploring their experiences and learning from them to improve provision.

3.4 Data Analysis

3.4.1 Secondary quantitative data

The NHS datasets were cleaned prior to analysis (see sections 4.3.1 and 4.3.2). The datasets from the NHS were analysed using mainly descriptive statistics, as their size meant even small differences might be statistically significant, but not practically relevant. RStudio was used to make a Chi squared analysis of categories of referrer. The age of the CYP at referral, based on the three main types of referrer, was examined with separate univariate ANOVAS on the outcome variables using SPSS. FOI data were analysed using descriptive statistics.

3.4.2 Qualitative data

3.4.2.1 Case Studies.

An initial framework of questions to ask of the data was constructed in Microsoft Excel (see Table 3.3).

Table 3.3

Initial Framework of Questions to Guide Interrogation of the Data

Initial Framework
When were concerns first raised?
How long between then and first referral being made?
What reasons can be inferred to explain delay?
Whose voices heard in the documentation?
Is there evidence of the girl's experiences of home and school life?
Barriers and challenges
Strengths & interests
What is missing from the record that I would expect/hope to see?

These were based on findings from the analysis of the quantitative data, and in anticipation of the life history interviews. Each girl's patient record was then accessed, and each document within the record read and reviewed (see Appendix 3.21 for the process). Evidence was analysed as it was retrieved, and further areas of investigation added as they emerged from the data (see Appendix 4.10 for example data). Data were then thematically analysed (see section 3.4.2.2 for further details on Thematic Analysis; see Appendix 4.11 for example themes).

The results of the checklists (CCC, SCQ and SDQ) did not ultimately form part of the analysis, as records did not contain the same checklists, and not all checklists were scored. Comparisons were thus not possible.

3.4.2.2 Life History Interviews.

The girls led the thematic analysis of the events on their life charts, and the identification of key positive and negative experiences from which to construct their recommendations. Thematic Analysis (TA), 'a method for identifying, analysing and reporting patterns (themes) within data' (Braun & Clarke, 2006, p. 79) was used to investigate the qualitative data using Braun and Clarke's (2006) six phase process (see Table 3.4). The 'organic approach to coding' (Clarke & Braun, 2016, p. 1) and inductive process suited the interpretive, constructivist paradigm. A decision was made to code all the interviews together, rather than maintain a separation between the personal construct exercise (first interview) and the life history interviews (interviews two and three). This was in recognition of the value of the contributions by two girls, Sally and Emily, who took part in the first interview only.

Initial nodes were created in NVivo 12 for social communication, interaction, and the sensory environment, consistent with the participants' autism diagnosis and per the literature. Additional nodes were created for the categories of questions in interview 1; the personal construct of the ideal school exercise (see Appendix 3.14). Themes within their experiences identified by participants during their third interview (see Appendix 5.2) formed the basis of further initial nodes, along with 'absence', 'gender' and 'exclusion'. Themes were mapped in NVivo 12 and different iterations of the map created as the process of analysis continued and themes were redefined (see Appendix 3.22 for an example).

Personal narratives (see section 5.2) were produced after phase five, once the data was well-known, to illustrate individual themes 'using excerpts of participants' own words to exemplify their attitudes and experiences' (Howard, Katsos, & Gibson, 2019, p. 1872). The content of each narrative was determined by cross-referencing notes made during the initial reading of narratives and subsequent coding; results of the individual diamond ranking exercise about their ideal school; the participant's own thematic analysis of their life chart events; and the most common nodes for each participant. The excerpts were selected to provide something of the essence of each participant's school experiences.

Table 3.4

Phases of Thematic Analysis (Braun & Clarke, 2006) for Primary Data Collection

Phase	Description of the process with the girls	Description of the process without the girls
1. Familiarise yourself with the data	Negative events and experiences on each life chart were read and discussed in interview three.	Primary in-person interview data was transcribed verbatim, taking care to retain the original character (Poland, 1995), into Word documents using Dragon Naturally Speaking v12. Text from interviews conducted via Skype Messenger was captured from the screen and placed into Word using Snag-it software. Email submissions of answers were copied into Word. All transcripts were then reviewed several times to check for accuracy and to become familiar with the data (Reissman, 1993). Thoughts, patterns, and queries that emerge during this process were collected in a notebook created for each participant, to inform the analysis.
2. Generate initial codes	The girls began to code each event on paper, creating or merging codes as required.	All data was read and reviewed to facilitate initial 'open coding' (Creswell, 2014) and begin the process of organising the data. 497 free nodes (or codes) were created across the entire dataset.
3. Search for themes	The girls identified key themes from the codes on their chart, and from the positive and negative experiences they selected.	Nodes were reduced initially by merging similar nodes and eliminating nodes not central to the research questions, and then by grouping by emerging themes. 27 trees (or themes) remained. This was done through a process of reading and re-reading transcripts, reviewing the life charts and ideal school constructs, and looking for relationships between nodes (Bazeley, 2007). Mind-maps in NVivo and rearranging coloured post-it notes on a wall were used to help the process.
4. Review themes	Themes were checked by re-reading each negative event on the life chart and considering whether all themes were relevant and independent.	Extracts for data within each theme were checked for internal homogeneity (Braun & Clarke, 2006, p. 91), and themes reworked using mind-mapping where necessary. All data was frequently re-visited to check that emerging themes were representative of the whole collection, and as new links generated new connections. Different iterations of the thematic map were produced to aid the development of ideas and concepts.
5. Define and name themes	Themes confirmed by the girls.	Final themes established and named. *Personal narratives produced*.
6. Produce the report	Recommendations prepared.	Final analysis written up using example extracts of data, linking to the research questions and to the literature review.

Small, omitted sections of text in the narratives are indicated with '…'; larger sections by the start of a new paragraph. Short pauses are shown using commas and full stops. Pauses of more than four seconds and the researcher's voice have been removed in these excerpts but are shown within quotes where they are used in subsequent sections. Words have been added in square brackets to aid clarity where the researcher's question has been omitted.

3.5 Issues of validity

The secondary data have been provided or recorded by a range of different people, possibly in different roles, in different years and locations. As such, inter-rater reliability is low as the data almost certainly contain inconsistencies (Bryman, 2016) and it is thus difficult to generalise across NHS Trusts. However, the data do have ecological validity, as it is data that are routinely collected by the Trust in question and is data on which the CCG makes decisions about the service it provides. By remaining clear in how the data are used and providing clear process, I have enabled others to follow the same procedures. This enables others to reach the same conclusions and create consistency.

Qualitative data, meanwhile, is inherently open to criticism from those searching for 'truths'. Responses given in interviews may vary depending on the interviewer, with the possibility that the participants may give different answers to another researcher (Platt, 2012). Responses may not be the same if the questions are asked again in a week, or a month later. Replies can be shaped by events immediately preceding the interview, and by the feelings of the girls about their lives at that moment. They may say one thing and mean another, through difficulties in communicating thoughts accurately or perhaps as an intent to mislead.

The primary data consists entirely of the views and experiences as reported by the participants, in contrast to most studies about the experiences of autistic CYP. The lived experiences of the girls are accepted as valid and free-standing. They do not need others to speak for them or against them; they are empowered to tell their own stories, and for them to be heard.

The purpose of the interviews was to create individual narratives with each participant and generate meanings together through the process of exploring their 'situated experiential realities' (Holstein & Gubrium, 1995, p. 9). Opportunities for reflexivity were formalised in the structure of the final interview. Individual findings are not generalisable. This does not negate the shared autistic identity of the girls, or the validity of the meanings they created, but reveals their heterogeneity. The richness of the data is intended to provide needed recognition of the diversity of experiences of autistic girls, which is important in challenging stereotypes about autism.

3.6 Ethics

The choice of a mixed methods approach meant there were several different ethical issues to consider. The use of NHS patient data involved the anonymisation of records, issues of consent and access to a confidential patient database (RiO). Enabling the participation of the girls whilst protecting their vulnerability as an already marginalised population (Powell & Smith, 2009; Sandbæk, 1999) required process for ongoing consent, and for clarity on the potential risks and benefits of taking part. 'Respect for human dignity' (Waltz, 2007, p. 359) was a fundamental principle in the design of the research, and the belief that 'individuals should be treated fairly, sensitively, with dignity, and within an ethic of respect and freedom from prejudice' (BERA, 2011, p. 5) was a core thread running throughout the project. Ethical approval for this research was granted by the Ethics Committee at the Institute of Education, University of Reading (see Appendix 3.23). Advice for the use of NHS data was provided by the NHS Confidentiality Advisory Group (Appendix 3.24). A copy of the Secretary of State for Heath Approval Decision is provided in Appendix 3.25.

3.6.1 Consent

3.6.1.1 NHS data.

Permission to enter the CAMHS site and study data from the autism assessment pathway was granted by the Research and Development Department of the selected NHS Trust. The NHS Health Research Authority classified the study as a service evaluation, and therefore it did not require review by an NHS Research Ethics Committee. An application for advice on consent and the use of NHS data was made to the NHS Confidentiality Advisory Group (CAG) and reviewed on 27th April 2017. Queries raised were addressed in a formal reply in writing. The following clarifications were provided:

1. The retrieval of six years of quantitative data from the autism assessment records at an NHS Trust would be by an NHS analyst, anonymised at source and contain no personal identifiers.
2. Further quantitative data for assessments made in one calendar year (2016) would be extracted by a member of the autism assessment team, anonymised at source, and contain no personal identifiers.
3. Consent would be sought for the purposive sample of 10 full patient records from the pathway.

Based on these clarifications, the NHS CAG advised the application did not require support under the Regulations, as there would be 'no disclosure of patient identifiable data without consent' (personal communication, 07/07/2017). The CAG additionally agreed that accessing the records as part of the study was in the public interest (Data Protection Order 2000, 417, paragraph 9).

The purposive sample was identified using provided criteria by a member of the autism assessment team, who then contacted each parent/carer with details of the research, and a request for consent from them *and* their daughter. The written content of the email, an information sheet and consent forms, were provided to and sent by CAMHS, so details of individuals were not disclosed prior to receiving consent. 10 families were contacted initially, followed by a further four families as some did not wish to bring up the topic with their daughter or failed to return the forms.

The project was supported by the Neurodevelopmental Lead of the selected NHS Foundation Trust.

3.6.1.2 Life histories.

The Autism Advisory Group (AAG) of girls were all invited to participate in the project via their mothers and were previously known to the researcher. This meant that the girls were potentially less anxious and more open to making suggestions towards the methods and research tools employed. The AAG also participated in the pilot study, which focused on testing the methods initially selected rather than on detailed data collection.

Recruitment for the life history interviews was through email requests for participation via autistic groups, Local Authorities, and local charities for CYP with SEN. This meant respondents were predominantly parents/carers and effectively 'gatekeepers' to the project, with the ability to influence consent or dismiss it, however well-meaning (Lewis, 2009; Powell & Smith, 2009). Participants and their parents were given full information on the purpose of the study (see Appendices 3.7 – 3.8), the methods to be used, how the data would be stored and processed, and how the findings would be disseminated (Bryman, 2012).

Parental consent was theoretically sufficient and could overrule dissent from a child (Research Ethics Committee, 2010), but the nature of this study meant voluntary informed consent was sought from each participant in the life history interviews, plus their parent or guardian (see Appendices 3.9 – 3.10). They were advised that they could withdraw their consent to participate at any point, without consequence, and that any data collected from them would be destroyed. These aspects were also the case for the AAG. A number of different strategies were employed to ensure that the girls' consent was fully informed and active (Loyd, 2013; Preece & Jordan, 2010), informed by the advisory group. On-going consent was sought from the girls at the beginning of each interview and periodically through each session (Roberts-Holmes, 2005) using consent cards (see Appendix 3.26).

3.6.2 Risks

The choice of a participatory framework reduced 'the likelihood of ethical trespass' (Raymaker & Nicolaidis, 2013, p. 177). The research was planned 'with an 'ethic of care', with a clear intent of 'avoiding harm' (Gorin et al., 2008, 285; Yudell, Tabor, Dawson, Rossi, & Newschaffer, 2013). This was important, given the age of the participants, the potentially distressing subject matter, and the stress and exhaustion generated by interaction and reflexivity, and the possibility that the girls could experience uncomfortable feelings of exposure afterwards.

There was a risk that the girls might have said more than they understood or understood more than they were able to say (Lewis, 2009). This was addressed by offering a range of communication mediums and the use of visual methods. The girls were also invited to consider adding further details or clarification after interviews via post or email, in recognition of their differing processing speeds, later recall of important events or in case there were particular experiences they preferred to share asynchronously, for example (none did). The girls who elected face-to-face interviews were invited to bring a named 'trusted other' to accompany them during the sessions. This was for safeguarding purposes, to help reduce their anxiety and to aid communication. Of these, three girls opted not to have their accompanying parent in the room or within earshot during interview. The two girls interviewed online had a parent present with them. All conversations (face-to-face and online) were recorded to enable accurate transcription, plus allow the inspection of a full record of proceedings if required. Care was taken to actively listen to each girl and not over-project, to avoid their misrepresentation (Waltz, 2007).

Participants were reminded that they were in control of what they chose to disclose, and that everything they said, wrote or drew would be treated as confidential, unless it represented a safeguarding issue. Personal participant data were kept separately from data collected during the research stage, from which any personal identifiers were removed (University of Reading, 2016), so research data and findings were non-attributable. Safeguarding training was refreshed prior to data collection, and Ruth Pearse, CEO at Parenting Special Children, and the charity's designated Safeguarding Lead, agreed to provide advice and direction regarding any safeguarding concerns (none identified). A leaflet detailing external support services (see Appendix 3.27) was made available to the girls at the end of each interview, in recognition of the potentially distressing subject matter (Spiers, 2015; Stewart, 2012).

Lone worker recommendations were followed (Health and Safety Executive, 2013; Wrixon, 2016). These included: sharing plans, such as providing a supervisor with the schedule of interview appointments and travel itinerary; minimising risk, for example by taking the seat nearest the door; putting in place monitoring systems, such as advising a supervisor once the interview was over and the building had been vacated; and planning for unforeseen circumstances, for example by carrying a charged mobile phone.

3.6.3 Power

The power dynamic between a researcher and an oppressed minority can be problematic, and ‘the issues of power are evident even in participatory visual methods’ (Khoja, 2016, p. 318). Participatory research stops seeing participants as ‘raw data’ (Raymaker & Nicolaidis, 2013, p. 169) and positions the researcher as ‘working for individuals on the spectrum instead of against them’ (p. 184), as a ‘member of the same community’ (Rose, 2018, p. 766). Research with autistic CYP requires additional ethical considerations due to their ‘historical disenfranchisement’ within it and because of ‘unique autistic experiences’ (Cascio, Weiss, & Racine, 2020, p. 1677), such as communication methods or differences in processing sensory input.

The advisory group of girls helped keep the research focussed, relevant and accessible. They provided sensitive input into the wording of participant information and advised on practical arrangements to reduce anxiety and enable participation. A pilot study with the advisory group tested methods, and feedback from the girls was incorporated into the process for the main data collection (see Appendix 3.7).

Participants in the primary data collection were invited to communicate using the method with which they felt most skilled or comfortable (Morrow, 2008). At the start of each interview, they were reminded of the purpose of the session and of how to provide on-going consent using coloured traffic light cards (see Appendix 3.26). They were also given cards showing symbols of a clock and a question mark. Online participants were invited to use emoticons, or emojis (see McCoyd & Kerson, 2006). This enabled them to request clarity on something they did not understand, to say they were okay or state they wanted to take a break or stop, through speech or non-verbally using the cards or symbols.

Activities and questions were provided in advance with the aim of building trust, reducing anxiety, and providing thinking time. Life charts were constructed by the girls away from the interview space, with individual questions generated thereafter on the events each girl marked on her chart. This gave them control over what was later discussed, as well as the power to show the significance and value to them of each experience. The girls were given the option to remain silent or to say, ‘I don’t know’ or ‘I do not want to answer’ during interview to follow-up questions that sought to extend or clarify answers to aspects of their conversations (Lewis, 2009; Spyrou, 2016).

3.6.4 Data management

Section 33 Exemption of the Data Protection Act 1998 applied to the processing of NHS data for research purposes. The large dataset with no personal identifiers was transferred to the research laptop as an encrypted file. Patient identifiable data for the case studies was only accessed on site at an NHS location, and pseudo-anonymised before being recorded on the research laptop. All pseudo-anonymised data was held within access-controlled files on the University of Reading's OneDrive (cloud storage). Pseudo-anonymised data will be kept until this thesis has been examined and revised and will then be securely disposed of according to the University of Reading's Records Management Policy.

All data (personal and that collected during the study) for the 10 girls who were interviewed was kept on a secure laptop or in a locked filing cabinet at the University of Reading's Institute of Education. Soft copies were password protected by file and by device. Personal data was kept separately from data collected during the research stage, from which any key personal identifiers were removed (University of Reading, 2016). All data was stored in accordance with the Data Protection Act 1998. The University protocol for disposing of confidential waste was followed as required.

Enabling interviews to be held online raised additional issues of IT security, which were addressed with guidance from the University's Information Management and Policy Services (IMPS) (personal communications, September 2017). Skype Consumer was identified as the only solution available to students that would meet data protection and functionality requirements. Participants were asked to choose pseudonyms and not reveal identifying information during interview. A project Skype account was set up and participants' parents were invited to set up a Skype account to use solely for this project, so that the contact link could be removed at the end of the data collection. Typed conversations were moved into NVivo using Snagit, any identifiers removed, and Skype recordings deleted. Skype was only accessed with secure connections.

A dedicated email inbox hosted by the UoR was created for the collection of data for this project. Emails sent from this account complied with the University's encryption policy (IMPS, 2015), whilst incoming emails containing sensitive data were managed by 'truncating threads' where necessary (personal communication, March 2017). The UoR was the Data Controller of all information gathered online.

3.7 Potential limitations

Do we recount the past, or create the past in our narratives? (Mantel, 2017)

One potential limitation of collecting life histories is that the girls may misremember or remember things differently at the time of interview to the way they would have remembered them a week, a month, or a year before. They may have changed how they feel about a situation, and these feelings could have evolved through several states of belief about this event. They may recall things they were told at the time as things they said themselves. Collecting life histories over a series of interview sessions may result in participants thinking differently about things in subsequent interviews, (Charmaz & Belgrave, 2012). However, the girls' narratives provide an insight into their worlds as they interpret them at one moment in time and are not intended to be exhaustive: ‘What is important is to understand why they present their stories like they do’ (Goodley, 1996, p. 344). They are an opportunity to hear the girls’ voices, and the method is chosen to reflect this and to best answer the Research Questions. This ‘fluidity’ does not reduce the importance of their stories, but accepts that memories are necessarily reconstructed and reflects the evolving nature of subjective accounts, placing them in the context of their life now. As such, all raw data will be accepted as the truth for each girl at that date and time.

Conducting research with participants who may find it difficult to recall events (Harrington et al., 2014), articulate their thoughts, or express complex emotions, can be problematic (Preece & Jordan, 2010). However, ignoring such groups of people because of these difficulties suggests their lived experiences are not part of the human condition. A major benefit in using the life history method is that it enables YP who have felt silenced and marginalised to have a voice and acknowledges that dominant methodologies have previously removed them from research into their lives. The use of a participatory research framework from planning to analysis aimed to address these issues.

3.8 Summary

This chapter identified the constructivist paradigm that underpins the thesis, and the reasons for the choice of a mixed methods approach and participatory framework. It recognised the voices and experiences of autistic girls absent from school as previously unheard or overlooked and positioned them instead as central to understanding the phenomenon investigated. The methods employed, with the input of the AAG, and the steps taken to address potential barriers and challenges to participation, are a contribution to knowledge regarding this type of research. Furthermore, the plan for thematic analysis to be conducted by the participating girls, on the significant events they recorded on their life charts, led directly to the co-creation of knowledge and the formation of recommendations based on authentic lived experiences.

The rationale for the use of secondary DfE and NHS data was presented, and the methods of retrieval described. The processes used to analyse both the quantitative and the qualitative data have been explained, and questions of validity addressed. In addition, a number of key ethical considerations have been presented. These include issues of consent to access secondary data, and initial and ongoing consent with the girls who participated in the interview stages. Potential risks of participation were considered, from the perspectives of the girls and of the researcher as lone worker. Crucially, given the marginalisation of this group of YP, attempts to address inherent power imbalances have been outlined. The chapter concluded with thoughts regarding the limitations of the design.

Chapter four presents the findings from the analysis of the DfE and NHS secondary data.

Chapter 4: Analysis of secondary DfE and NHS data

4.1 Introduction

The previous chapter explained the methodology for this two-part study. This chapter will present findings from the analysis of secondary data, which aimed predominantly to address the first research question (see Section 1.4 for Research Questions) by providing scale and context around the issue of autistic girls absent from school.

The first section (4.2) presents findings on autistic pupil enrolments at state schools in England and of pupil absenteeism, from an analysis of data retrieved from the DfE via a Freedom of Information (FOI) request. Percentages of autistic pupils by sex, compared to the whole school population, are provided over an eight-year period. Figures for absence from school are provided for persistent absenteeism, where a trend of absence has therefore already been established. Figures for autistic females who are persistently absent are shown, and comparisons made between the figures for autistic females and those for autistic males, and for autistic females and non-autistic females.

The results of the analysis of data retrieved from autism assessment pathway of an NHS Foundation Trust in SE England are presented in section 4.3. This analysis looked for patterns in the data based on differences between females aged 5-18 years compared to males, for referrals and diagnoses of autism from the year ending 2013 (when the criteria for the diagnosis of autism changed).

The final section (4.4) presents the findings of eight case studies, written from an analysis of eight individual records from the large dataset used in section 4.3. These case studies charted the pathways to diagnosis using the documents held in each girl's file. Emerging themes from these pathways inform the primary data collection presented in Chapter 5.

4.2 Autistic pupil enrolments and absenteeism

A Freedom of Information (FOI) request was made to the DfE for the number of pupils enrolled at State-funded secondary schools in England, identified as being autistic as the primary SEN, who had been recorded as persistent absentees annually since 2009-10 until the date the data was requested, 2017. The data on persistent absenteeism is set against total enrolments of these pupils to provide context. It is important to note that the figures provided do not include autistic pupils who have dual or multiple diagnoses and for whom autism is not identified as their primary need. As such these represent minimum numbers and identify that DfE statistics cannot be relied upon as a singular definitive data source.

The first three datasets look at pupil enrolments by sex, with autism identified as the primary SEN. The total numbers of autistic pupils, whose diagnosis of autism was identified as the primary need, at state-funded primary and secondary schools in England each year is shown in Table 4.1 (DfE, 2018). The number of males in primary school with a primary diagnosis of autism increased by 84% from 2009/10 to 2016/17, compared to an increase of 143% in the numbers of autistic females. The figures for secondary schools show a similar pattern: the number of autistic males increased by 76% from 2009/10 whilst the number of autistic females increased by 153.6%. This establishes a trend of rapid growth in the school population of both diagnosed autistic males and females, with a particularly large increase in the number of diagnosed autistic females.

Table 4.1

Pupil Enrolments at State-Funded Primary and Secondary Schools in England, with Autism as Primary SEN

	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
Primary								
Male	16525	17365	17400	18485	20465	24460	27995	30330
Female	2610	2880	2895	3195	3700	4600	5485	6355
Secondary								
Male	14975	16695	17245	18335	18975	21795	24785	26185
Female	2295	2650	2925	3185	3500	4290	5195	5820

The data shows that the ratio of autistic males to females at state-funded schools in England has changed year-on-year since 2009 (Table 4.2), indicating a steady trend of autistic girls making up more of the autistic school population each year (DfE, personal communication, November 20, 2018). Interestingly, from 2011/12 diagnosed autistic females made up a greater percentage of the autistic population at secondary schools than they did at primary schools.

Table 4.2

Percentage of Diagnosed Autistic Females Compared to Diagnosed Autistic Males at Schools in England

	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
Primary								
Male	86.4%	85.8%	85.7%	85.3%	84.7%	84.2%	83.6%	82.7%
Female	13.6%	14.2%	14.3%	14.7%	15.3%	15.8%	16.4%	17.3%
Secondary								
Male	86.7%	86.3%	85.5%	85.2%	84.4%	83.6%	82.7%	81.8%
Female	13.3%	13.7%	14.5%	14.8%	15.6%	16.4%	17.3%	18.2%

The numbers of female pupil enrolments were retrieved (DfE, 2018c) to identify whether the increase in autistic female numbers was reflected in the general population (Table 4.3). The number of female enrolments at state-funded Secondary schools fell by 2.71% from Jan 2010 to Jan 2017. However, the proportion of female pupils with autism as the primary identified SEN increased by 154%. This demonstrates a continuous increase in the numbers of autistic girls in secondary schools and therefore a heightened requirement on schools to make provision for the needs of autistic females at Secondary school.

Table 4.3

Female Enrolments at State-funded Secondary Schools, Aged 11-15

Census date	Total female enrolments	Autistic females (autism as primary SEN)	Autistic females as a percentage of total female enrolments (autism as primary SEN)
Jan 2010	1,378,870	2295	0.17%
Jan 2011	1,371,725	2650	0.19%
Jan 2012	1,358,955	2925	0.22%
Jan 2013	1,343,700	3185	0.24%
Jan 2014	1,322,485	3500	0.26%
Jan 2015	1,318,140	4290	0.33%
Jan 2016	1,324,874	5195	0.39%
Jan 2017	1,341,549	5820	0.43%

The next datasets consider patterns in persistent absenteeism from school, by sex and by autism as the primary SEN. It is noteworthy that the way persistent absence has been measured has changed since 2009/10. Figures from 2009/10 to 2011/12 are calculated over five half terms, and over six terms from 2012/13. The definition of persistent absentee has also changed, from pupils who miss about 20% or more of all sessions in 2009/10, to 15% or more from September 2015, to 10% or more in 2015/16 (DfE, 2018a). However, the data provided in the FOI response were ‘produced using the same methodology [as 2015/16] in order to allow users to make comparisons on a consistent basis over time’ (DfE, personal communication, November 20, 2018). These changes reflect increasing DfE attention on attendance.

The dataset in Table 4.4 shows a clear trend of increasing numbers of autistic pupils classified as persistent absentees at state-funded secondary schools in England. It is striking that whilst the number of autistic males has increased by 43% since 2009/10, the number of persistently absent autistic females has risen more sharply by 126%.

Table 4.4

Number of Pupil Enrolments at State-Funded Secondary Schools in England, with Autism as Primary SEN, who are Persistent Absentees

	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
Male	3140	3400	3140	3285	3130	3700	4130	4510
Female	590	685	655	745	755	965	1115	1335

Looking at this data in terms of proportions of autistic females classified as persistent absentees, compared to autistic males (Table 4.5), what stands out is the progressive change in the ratio over the eight-year period. Autistic females made up a far larger proportion of the number of persistently absent autistic pupils in 2016/17 than they did in 2009/10.

Table 4.5

Percentage of Autistic Females, Compared to Autistic Males, who are Persistent Absentees at State-Funded Secondary Schools in England

	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
Male	84.2%	83.2%	82.7%	81.5%	80.6%	79.3%	78.7%	77.2%
Female	15.8%	16.8%	17.3%	18.5%	19.4%	20.7%	21.3%	22.8%

Pupil absence statistics for England, collected and published by the government (DfE, 2011, 2012, 2013a, 2014a, 2015a, 2016d, 2017, 2018b) were retrieved to compare proportions of autistic and non-autistic males and females at primary school (Table 4.6) and at secondary school (Table 4.7).

Autistic females were only slightly more likely than autistic males to be persistent absentees in primary school by the year 2016/17, though both groups were much more likely to be so than non-autistic males or females. At secondary school, however, autistic females were much more likely to be persistent absentees than non-autistic males and females *and* autistic males, which was unexpected. The differences between settings may indicate that autistic females find secondary schools to be a more challenging environment than autistic males, or that they are less likely to receive support, perhaps due to a lack of awareness of the issues facing this group. It may also be a reflection of autistic females typically receiving a diagnosis later than males, which is considered later (see section 4.3.1.5).

In addition, both scenarios suggest suitable support for these girls may be lacking or insufficient at secondary school. Whilst both the number of autistic females and the proportion of them who are persistent absentees are increasing, the rate of growth in numbers of autistic females is much steeper than the rise in the percentage of them who are persistent absentees.

Table 4.6

The Number of Persistent Absentee Enrolments Expressed as a Percentage of the Total Number of Enrolments with same Characteristics at Primary School

Pupil enrolments	Autistic females	Autistic males	Total females	Total males
2009-10[21]	20.4%	18.7%	14.1%	14.1%
2010-11	19.5%	18.6%	13.2%	13.2%
2011-12	17.1%	15.9%	10.4%	10.5%
2012-13[22]	18.1%	16.8%	10.8%	11.1%
2013-14	15.1%	13.7%	7.9%	8.2%
2014-15[23]	16.0%	14.5%	8.2%	8.6%
2015-16	15.6%	14.5%	8.0%	8.5%
2016-17	15.4%	15.2%	8.1%	8.6%

Table 4.7

The Number of Persistent Absentee Enrolments Expressed as a Percentage of the Total Number of Enrolments with same Characteristics at Secondary School

Pupil enrolments	Autistic females	Autistic males	Total females	Total males
2009-10	25.7%	21.0%	21.8%	20.1%
2010-11	25.8%	20.4%	20.2%	18.7%
2011-12	22.4%	18.2%	17.5%	16.1%
2012-13	23.4%	17.9%	17.2%	15.9%
2013-14	21.6%	16.5%	14.2%	13.0%
2014-15	22.5%	17.0%	14.3%	13.4%
2015-16	21.5%	16.7%	13.4%	12.8%
2016-17	22.9%	17.2%	13.7%	13.4%

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[21] 20% or more sessions of absence (authorised and unauthorised) during the academic year.

[22] Data shown uses the 10% definition from this year forward, although the threshold introduced from the year 2012/13 was 15% and the 10% threshold was not introduced until the year 2015/16. This consistent use of the data enables comparisons between years.

4.2.1 Section summary

1. The number of autistic males and females is increasing at mainstream primary and secondary schools in England. The number of diagnosed autistic females is increasing more rapidly than that of autistic males.
2. The proportion of diagnosed autistic females at primary and secondary schools in England, compared to autistic males, is increasing. The M:F ratio is closest at secondary school.
3. At secondary school, autistic females are more likely to be persistent absentees (as a proportion of their group) than autistic males, and more likely than both non-autistic females, and males.

These points are important to this research as they demonstrate a growing number of autistic girls in school, and therefore a need to increase suitable educational provision. The most interesting finding was that the proportion of adolescent autistic girls who become persistent absentees is greater than that for the other groups identified, which underscores the importance of this research.

4.3 Autism referral and assessment pathway

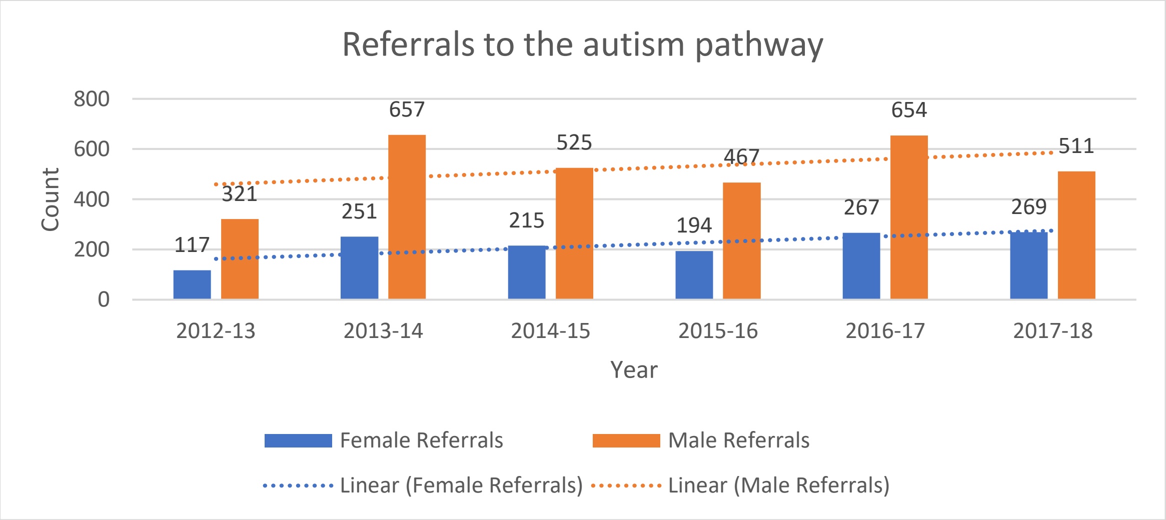
4.3.1 Referrals dataset

The dataset provided information on the number of referrals and the numbers of CYP diagnosed as autistic by sex, ethnicity, year, and CCG. It was hoped that an analysis of ethnicity could be included here, and data retrieved on ethnicity are provided in the Appendix 4.1. However, 28% of female records and 26% of male records did not state an ethnic group. The scale of this missing data, which could be through parental choice or input error for example, meant few conclusions could be drawn.

Total numbers of referrals to the autism pathway of this Trust fluctuated over the period (see Fig 4.1).

Figure 4.1

Referrals Over Six Years



The surge in referrals in 2013-14 may be due in part to service reconfiguration, as a joint pathway opened in this Trust in April 2013. More male than female CYP were referred each year (Figure 4.1), with the highest number of referrals for male CYP occurring in 2013-14. The highest number of referrals of female CYP was in 2017-18, with annual figures for female referrals rising since 2015.

What is striking about this data is the steady change in the proportion of male to female CYP being referred over this time (Table 4.8), from approximately 4:1 males to females in 2012/13 to almost 3:1 in 2017/18. This reflects the literature on male to female ratios of diagnosed autistic people (Dworzynski et al., 2012; Loomes et al., 2017). The change reflects an increase in the number of females being referred, plus a decrease in the number of males from a peak in 2013/14.

Table 4.8

Percentage of Females Aged 5-18, Compared to Males, who were Referred to the Autism Pathway at the NHS Trust from 2012-2018

	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18
Male	73.3%	72.4%	70.9%	70.7%	71.0%	65.5%
Female	26.7%	27.6%	29.1%	29.3%	29.0%	34.4%

4.3.1.1 Referrals as a percentage of population.

The Office for National Statistics population estimates (ONS, 2020) for each Local Authority (LA) within the Trust were used to calculate referrals as a percentage of the total population and for each CCG[24] (see Appendix 4.2). CCG's C and E are part of the same LA and so referrals from these two CCGs were combined in this table, hence it being a much larger group. There are no years in any CCG where the number of female referrals is equal to or more than the number of male referrals. This pattern is maintained after removing population variation.

There are interesting differences between CCGs. CCG C&E had the highest proportion of male and female referrals every year, based on LA population percentages, when compared to other CCGs and when based on mean averages over six years (see Figure 4.2). Big variations in referrals by sex within CCGs were evident, with the greatest difference seen in CCG C&E in almost every year. This is interesting as these CCGs also received the most referrals for females as a proportion of their population. The smallest differences were consistently seen in referrals to CCG F.

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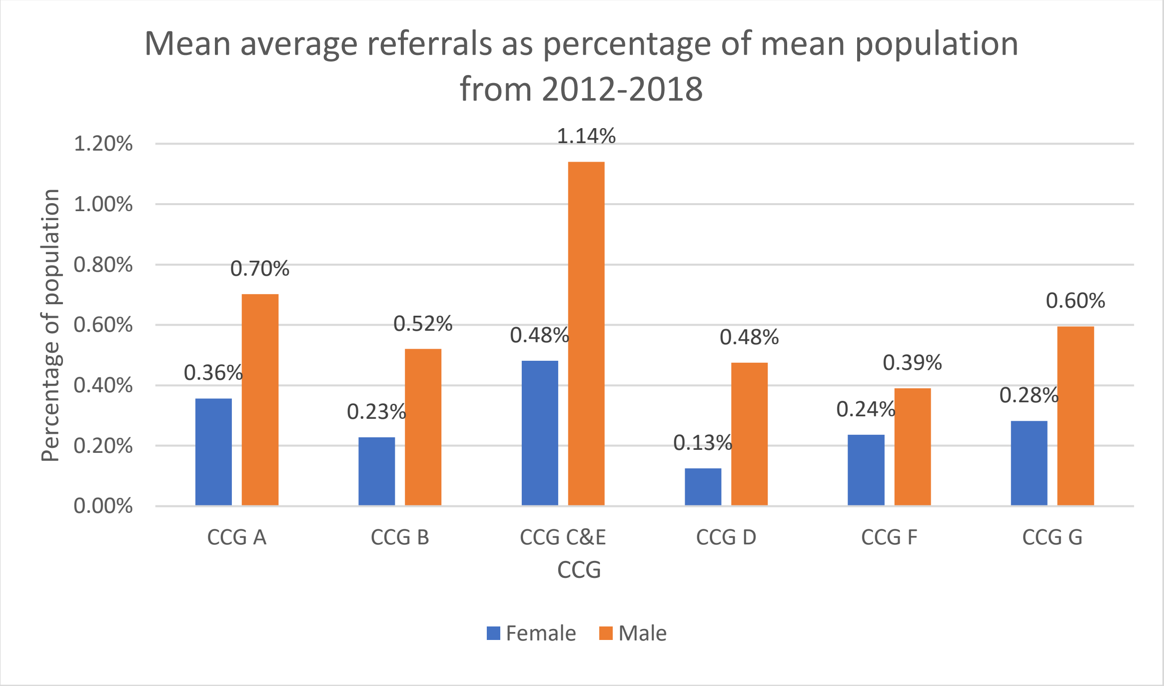
[24] Clinical Commissioning Group

Figure 4.2

Mean Average of Female and Male Referrals aged 5-18 Years by CCG, as a Percentage of the Mean Average of the Population with the same Characteristic in each CCG from 2012-2018



These variations may be the result of several factors, all of which would require further investigation. There are cultural and socio-economic differences between the LAs in this county which may impact referral rates (DfE, 2020d). CCGs C&E cover urban areas with the highest percentage of CYP eligible for free school meals (FSM) whilst CCG G is a rural area with the lowest percentage of FSM eligibility. CCG D has a population with the highest percentage of CYP for whom English is not their first language; CCG B has the lowest. CCG D is also ranked as one of the most deprived in the region, followed by CCGs C&E, whilst all other CCGs are approximately twice as affluent. It is also possible that greater numbers of referrals are due to a genuinely higher density of autistic CYP living in the area covered by CCG C&E, may reflect a greater understanding of autism within that community or, conversely, indicate an over-referral in this area.

4.3.1.2 Age at referral.

Descriptive statistics indicate that over the six-year period females in this county were, on average, a year older than males when they were referred (see Table 4.9). Except for 2015/16, when the mean age at referral was almost the same for males and females, the mean age at referral when considered by year (see Figure 4.3 and Appendix 4.3) shows a similar pattern of males being referred at a younger age on average than females.

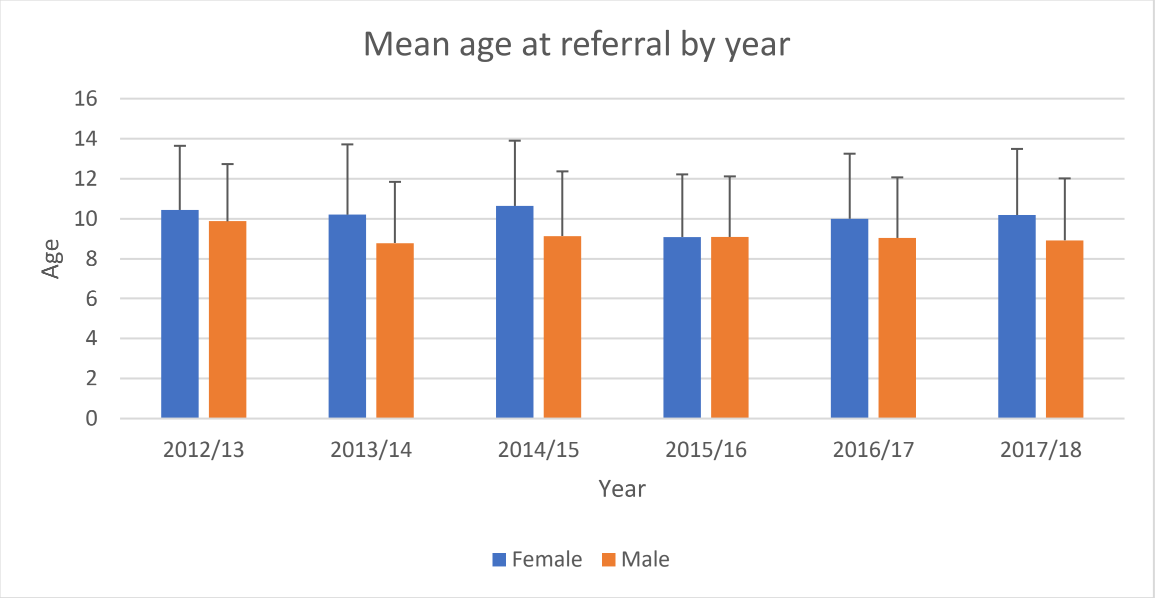
Table 4.9

Descriptive Statistics of the Age (in Years) at Referral over Six Years, by Sex

Sex	*n*	Mean	SD	Min	Max	Range
Female	1313	10.08	3.32	5	18	13
Male	3135	9.07	3.08	5	18	13

Figure 4.3

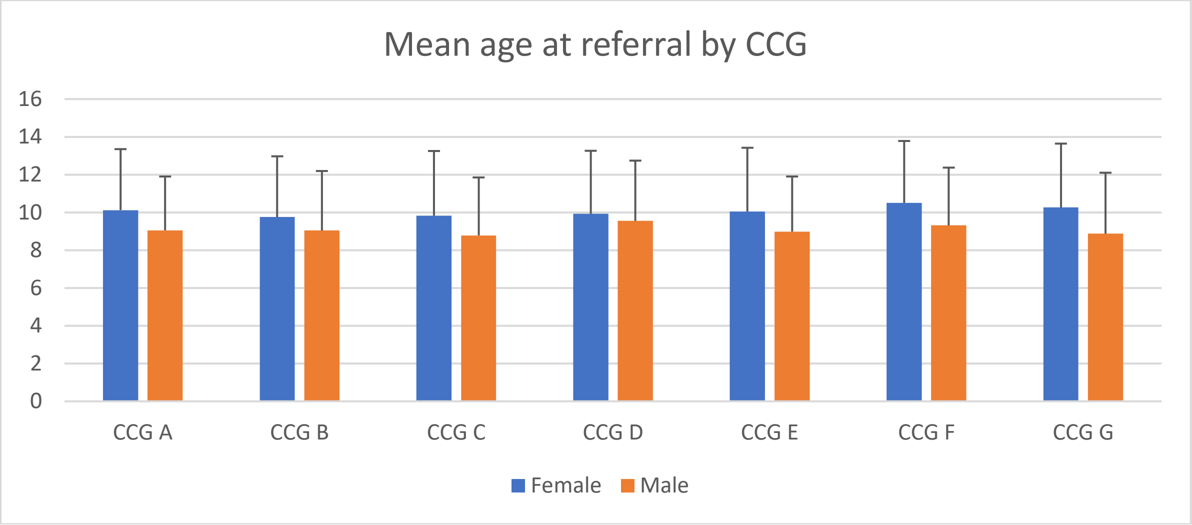
Mean Age at Referral by Sex and Year. Error Bars show Standard Deviation.



The mean age at referral from 2012-18 within each CCG (see Figure 4.4) reveals some interesting differences. The mean average age of referral for males was lowest in CCGs C & E, the CCGs which also had the highest number of male referrals, whilst the highest mean average age for males was in CCG D. All three CCGs are in areas ranked as being the most deprived in the county, suggesting that SES may be an influencing factor in referral age (Begeer et al., 2013). By contrast, the mean average age of referral for females was lowest in CCG B and highest in CCG G, which are amongst the least deprived areas, suggesting that factors influencing referrals are not simply economic. Whilst these are interesting data, it is beyond the scope of this thesis to speculate on the impact of socio-economic factors on referral statistics or to confirm correlations. However, this is recommended as an area for future research (see section 7.5).

Figure 4.4

Mean Age at Referral by Sex and CCG

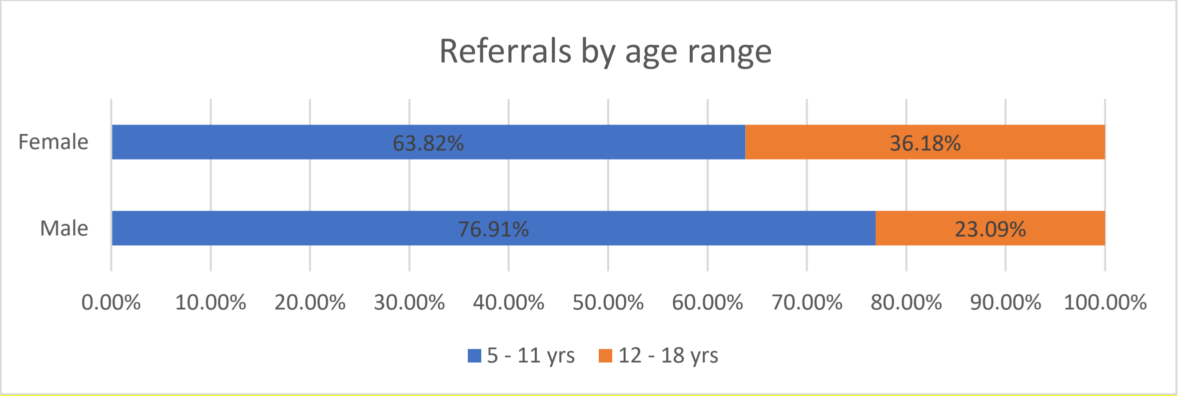


Note: Error bars show Standard Deviation.

Finally, it is noteworthy that the proportions of males and females referred aged 5-11 years, compared to those aged 12-18 years, show that males were more likely than females to be referred whilst still at primary school. Whilst some caution is needed over these figures, as some children in the age 11 category (included in the primary, blue band in Figure 4.5) will have been referred once at secondary school, it is clear that at least 36% of autistic girls referred are not diagnosed until they were at secondary school.

Figure 4.5

Percentage of Referrals by Age Range and Sex



This is a concern, given that the move to secondary school involves increased social and organisational demands, that successful transitions may relate to ‘school- and system-level factors’ such as ‘lack of primary preparation and communication between schools’ (Makin, Hill, & Pellicano, 2017, p. 1), and that ‘autistic children are particularly vulnerable to negative transition experiences’ (Hoy et al., 2018, p. 184).

4.3.1.3 Waiting time between referral and diagnosis.

The data was then analysed to look for patterns in CYP who were referred to the autism pathway[25] and were assessed during this period. The records of CYP referred between 2012-18 who were still waiting to be seen (n=1424) or whose case had been closed without being seen (n=631) were excluded, leaving a dataset of 2393. Table 4.10 reveals that a percentage of referrals from 2015/16 were still waiting to be assessed, giving an initial indication of lengthy wait times to be seen and assessed. Whilst there are some variations between females and males in these figures, the differences are small. The average yearly number of referrals were 111 females and 287 males, which equates to 28% and 72% proportionately.

The dataset does not include CYP who were diagnosed between 2012-18 but who were referred before April 2012. The value of the dataset for understanding patterns or trends in wait times and diagnosis may be limited by these factors.

Table 4.10

Status of all Referrals from 2012-18

	Females						Males					
Year	Seen		Waiting		Closed Not Seen		Seen		Waiting		Closed Not Seen	
2012 - 13	97	83%	0	0%	20	17%	268	83%	0%	0%	53	17%
2013 - 14	202	80%	0	0%	49	20%	537	82%	0%	0%	120	18%
2014 - 15	165	77%	0	0%	50	23%	374	71%	0%	0%	151	29%
2015 - 16	122	63%	39	20%	33	17%	303	65%	87	19%	77	16%
2016 - 17	65	24%	180	67%	22	8%	195	30%	412	63%	47	7%
2017 - 18	18	7%	248	92%	3	1%	47	9%	458	90%	6	1%

As the mean wait times between referral and diagnosis would be greatly impacted by the number of referrals still waiting to be seen in 2016-18, an analysis was made of mean wait times (in days) across the CCGs over the six-year period (see Table 4.11), rather than by year. Several things stand out in this table. Firstly, the wait times for males and females in all CCGs vary enormously, as shown by the range.

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[25] Referrals made to the Common Point of Entry that are put on the waiting list for an assessment of autism, and relevant paperwork sent out to capture school and parental views of the child.

Next, there is a difference of 192 days between the mean wait time of females in CCG E, compared to CCG D. By contrast, the difference between the highest and lowest mean wait times for males is just 60 days. It is also noteworthy that whilst wait times for females were considerably longer than for males in CCGs C, D and G, the pattern was reversed in CCG E. Males and females all waited a minimum of 14 months to be seen; at least two females waited over five years.

Table 4.11

Mean Number of Days Wait Between Referral and Diagnosis, by CCG

		CCG A	CCG B	CCG C	CCG D	CCG E	CCG F	CCG G
Female	Mean	477[26]	496	552	627	435	560	565
	Range	1031	1551	1961	2006	1376	1189	1636
Male	Mean	491	522	490	550	505	547	496
	Range	1416	1095	1310	1399	1662	1342	1439

A final analysis of the data confirmed that from 2012-18, the mean wait time to be seen was 11 days longer for females compared to males (see Table 4.12). Given the large variability and long waiting times in general, this small difference is unlikely to be clinically significant. However, given that females are referred at an average age of 10.08 years, the length of the wait to be assessed again suggests that females are more likely than males to transition to secondary school before they are seen in clinic.

Table 4.12

Mean Number of Days Wait Between Referral and Diagnosis, From 2012-18

	n	mean	SD	min	max	range
Female	289	523.38	318.03	0	2070	2020
Male	794	511.93	283.32	1	1663	1662

It is worth noting that the data do not enable an understanding of any potential differences in waiting times to be referred to the autism pathway. This will be addressed in the case studies in section 4.4.1.

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[26] Rounded down to the nearest whole day.

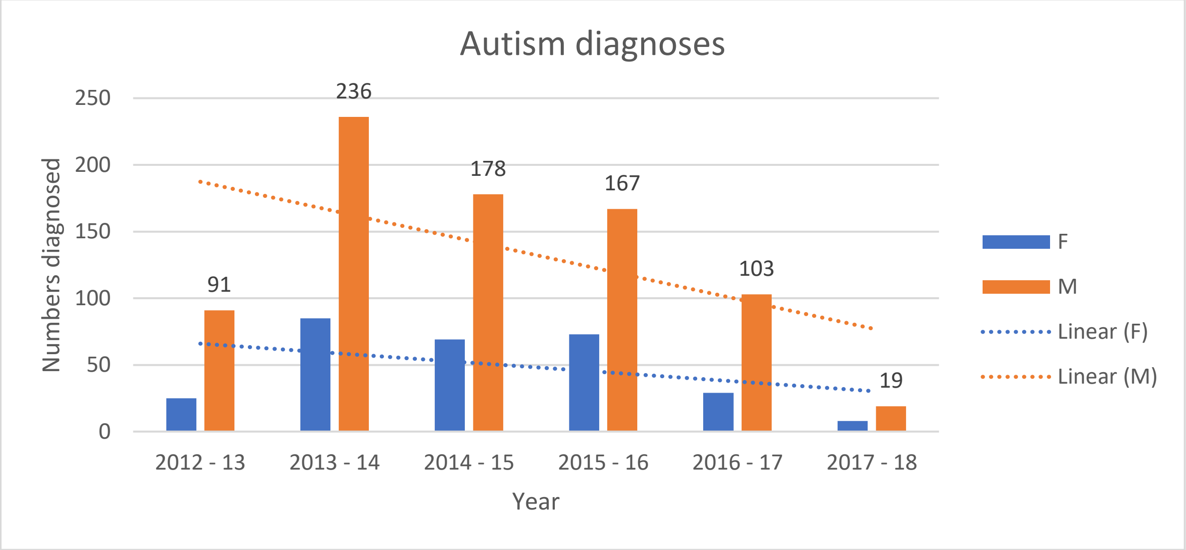
4.3.1.4 Diagnosis.

More males than females were diagnosed as autistic, which was predictable based on the referral figures and is consistent with published research studies. Numbers diagnosed in 2012-13 were low, as expected given the limitations of the dataset. However, the data did reveal some surprises.

Figure 4.6 shows that after a peak in 2013/14, the number of autism diagnoses of males in this Trust showed a steep decline. The number of females diagnosed as autistic was relatively stable from 2013-15 but then decreased. It is possible that the years 2017 and 2018 contain some incomplete assessments due to waiting for school observations or feedback and assessments where the code was not added properly.

Figure 4.6

Numbers of CYP Diagnosed as Autistic from 2012-18



In addition, however, Table 4.13 shows that the number of assessments conducted each year also declined substantially since a peak in 2013/14, when the diagnostic criteria changed in DSM-5. This could be due to a change in practice at the Trust or influences from external factors, but it was beyond the scope of this research to explore this further. Table 4.13 also indicates that the proportion of females who were seen and diagnosed as autistic increased more considerably than that for males from 2012-2016. This showed a trend for a reduction in the difference between the proportion of females and males being diagnosed. However, the figures for 2016-18 show a break with this pattern.

Table 4.13

Proportion of Males and Females Diagnosed, as Percentage of those Seen (in-group)

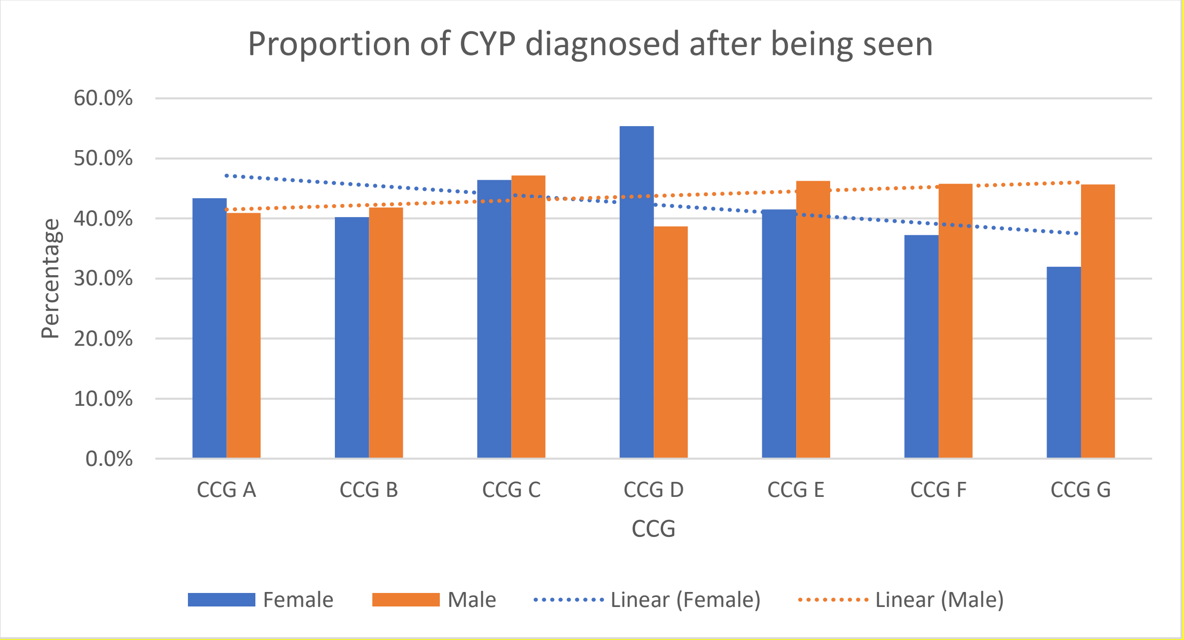
	Females			Males			
Year	Seen	Diagnosed	Proportion	Seen	Diagnosed	Proportion	Diff
2012 - 13	97	23	23.7%	268	88	32.8%	9.10%
2013 - 14	202	81	40.1%	537	232	43.2%	3.10%
2014 - 15	165	66	40.0%	374	157	42.0%	2.00%
2015 - 16	122	70	57.4%	303	160	52.8%	-4.60%
2016 - 17	65	27	41.5%	195	100	51.3%	9.70%
2017 - 18	18	8	44.4%	47	18	38.3%	-6.10%

The numbers of female diagnoses as a proportion of their total population for each CCG, compared to males, were considered for the years 2012-17 (see Appendix 4.4). The year 2017/18 was discounted for this analysis due to insufficient data. Results were as expected from the analysis of referral data. CCG D had the lowest proportion of females diagnosed as a proportion of females in that CCG, whilst CCG C&E had the highest. CCG C&E had the largest difference in proportion of males to females diagnosed and CCG F had the smallest.

Finally, the numbers of CYP from 2012-18 who were diagnosed after being assessed were calculated for each CCG (Figure 4.7).

Figure 4.7

Proportion of CYP Diagnosed as Autistic after being Seen, from 2012-18



This showed interesting variations between CCGs, particularly for females. Once referred, females assessed in CCG D were more likely to be diagnosed than females in any other CCG, which is interesting given how comparatively few females were referred in this CCG, whilst those in CCG G were the least likely. This supports earlier findings that where an autistic young person lives may affect their likelihood of accessing the assessment pathway and of subsequently being diagnosed. Variations between CCGs for males are present but appear less striking.

4.3.1.5 Age at diagnosis.

The referrals dataset was then reduced again, removing all records where a diagnosis was not given. This left a dataset of 1083 records.

The mean age at diagnosis was calculated for males and females over the six years for each CCG, to enable comparisons between areas (see Table 4.14). Interesting variations were found, particularly in CCG C where the difference in mean age at diagnosis between males and females was greatest. The mean age for females in CCG C was the highest across the CCGs, whilst that for males was the lowest.

Table 4.14

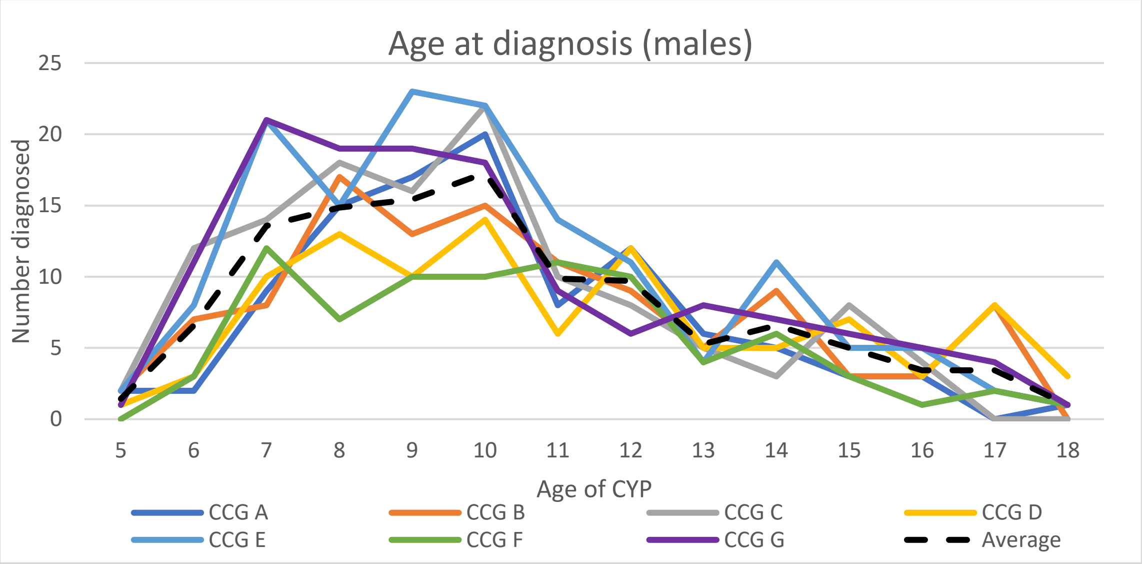
Mean Age at Diagnosis by Sex and CCG over Six Years

Sex		CCG A	CCG B	CCG C	CCG D	CCG E	CCG F	CCG G
Female	n	50	44	42	32	46	32	43
	Mean	10.96	10.3	11.43	11.34	10.78	12	10.74
	SD	3.27	3.22	3.46	3	3.61	3.46	2.5
Male	n	103	110	122	100	144	80	135
	Mean	10.18	10.55	9.71	11.15	10.08	10.47	10
	SD	3.17	3.17	2.76	3.39	2.88	2.83	3.11

The age at diagnosis for males (see Figure 4.8) and females (see Figure 4.9) in each CCG was plotted to look for patterns.

Figure 4.8

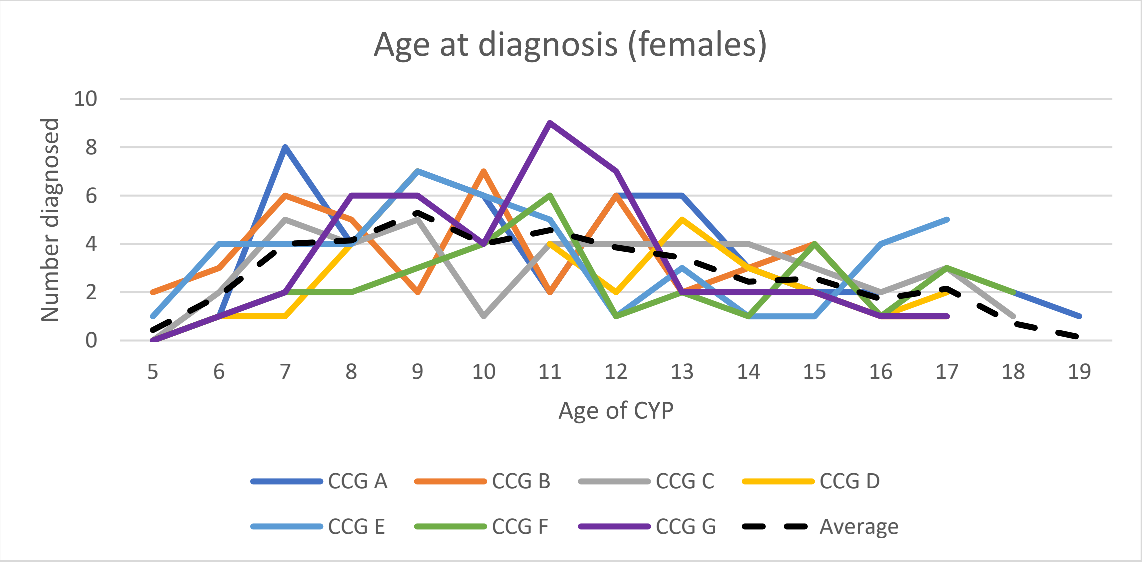
Age at Diagnosis for Males in each CCG, from 2012-18



It is apparent from Figure 4.8 that males were diagnosed most frequently at the age when they would have attended primary school. The picture for females (see Figure 4.9) shows a much greater dispersal over the age range, with no discernible pattern across the CCGs, and a clear indication that many females were not diagnosed until they reached secondary school age.

Figure 4.9

Age at Diagnosis for Females in each CCG, From 2012-18



Note: y axis scales are different for Figure 4.8 and 4.9.

4.3.1.6 Section summary.

1. Fewer females were referred and diagnosed than males.
2. There was wide variation between each CCG in the numbers of females referred and a similar disparity in the numbers diagnosed. This may reflect socio-economic and cultural differences between regions.
3. The mean age of females at referral and at diagnosis has been decreasing. However, males were still more likely to be referred and diagnosed at a younger age than females.
4. The sex ratio was wider between females and males diagnosed, than it was for females and males who were referred, suggesting that females were less likely than males to be diagnosed after referral.

4.3.2 Assessment dataset

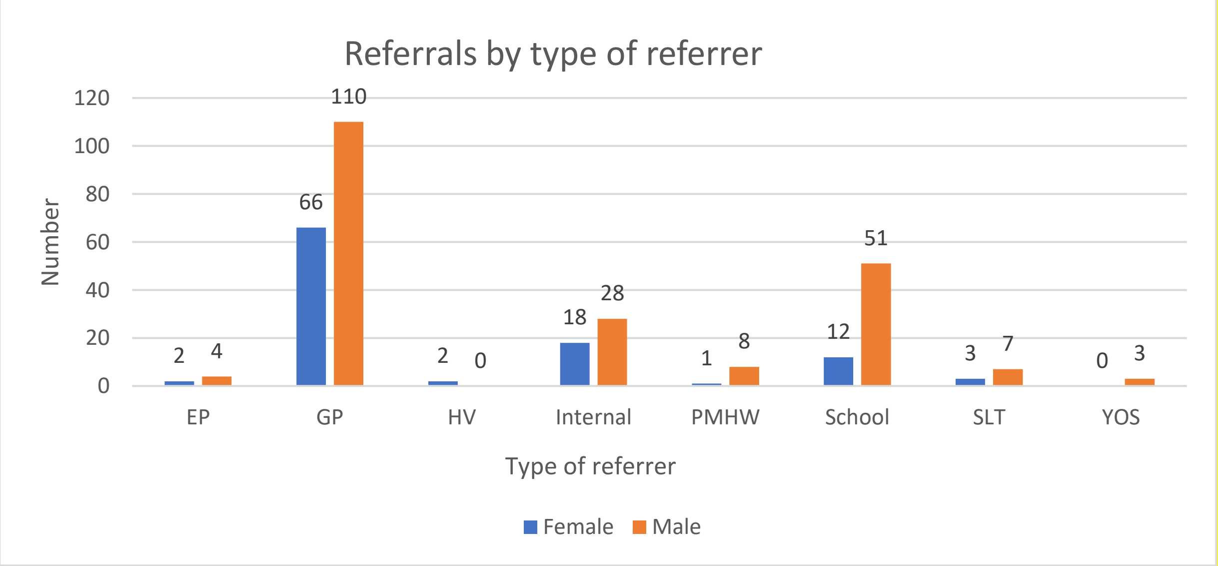
A breakdown of the assessment dataset is provided in Appendix 4.5.

4.3.2.1 Referrer.

Consistent with published literature, all types of referrers made more referrals of male than female CYP (see Table 4.15) except for Health Visitors who only made two referrals, both of which were for females. Most referrals for both males and females were made by a GP. Of the 66 referrals of females made by GPs, seven were at the request of community paediatricians. Further research would be required to understand whether the remaining female referrals were driven by parents or the GP.

Table 4.15

Type of Referrer for Males and Females Assessed in 2016



Note: Types of referrers are EP (Educational Psychologist), GP (General Practitioner), Internal (within the CAMHS service), HV (Health Visitor), PMHW (Primary Mental Health Worker), School, SLT (Speech and Language Therapist) and YOS (Youth Offending Scheme).

Five categories of referrer made less than five female referrals each: EP (n=2), HV (n=2), PMHW (n=1), SLT (n=3) and YOS (n=0), and so it is not possible to draw any conclusions from this data. The remaining records (n=285) from three types of referrer were examined to identify the proportion of females referred for assessment by each, compared to males (see Table 4.16). These were Schools, GPs and Internal[27] referrals. Half of the Internal referrals for females were made by mental health practitioners (psychologists; anxiety and depression team; specialist CAMHS).

Table 4.16

Proportion of Males and Females Referred by Three Main Types of Referrer

Sex	School	GP	Internal
Female	19.0%	37.5%	39.1%
Male	81.0%	62.5%	60.9%

It is interesting that schools referred fewer females compared to males, in comparison to GPs and referrals from within the NHS. A Chi-squared analysis of the data in R Studio showed there was a significant association between the type of referrer and the sex of the CYP referred $\chi^2(2) = 7.8$, $p < .05$. The standardised residuals were significant at $p < .05$ for females referred by schools, with significantly fewer females referred than expected (see Appendix 4.6 for contingency table). This is a small but interesting finding that merits further investigation.

It links with the research literature on autistic girls who mask and camouflage (Hull, Petrides, & Mandy, 2020) and whose challenges may not therefore be recognised in school (Moyse & Porter, 2014) or who may be perceived as experiencing insufficient impact to warrant a referral. It may also reflect a lack of expertise about autism in schools, relative to GPs and CAMHS, meaning potentially autistic females are overlooked unless difficulties evident to parents are also witnessed in school.

The age of the CYP at referral, based on the three main types of referrer, was also examined (see Table 4.17). It is logical that the mean age of the Internal referrals is higher than that for GPs or Schools, as they have already been referred once (albeit on a different pathway).

Table 4.17 also reveals that the mean age of females referred by Schools is lower than for those females referred by GPs, by 11 months. Males referred by GPs had the lowest mean age on referral, 17 months younger than that for females referred by GPs. A Levene's test of equality of error variances (see Appendix 4.7) was not significant, so equal variances were cautiously assumed.

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[27] Internal referrals are those made by NHS practitioners for CYP already being seen by a Tier 2 or 3 service.

Separate univariate ANOVAs on the outcome variables revealed significant main effects of sex, *F*(1, 279) = 5.73, *p*= .017, and referrer, *F*(2, 279) = 6.51, *p* = .002. There was no interaction between the variables, *F*(2, 279) = .81, *p*=.446.

Table 4.17

Mean Age (in Months) of Males and Females Referred by Three main Types of Referrer

Sex		GP	Internal	School
Female	n	66	18	12
	Mean	114.5	137.39	103.75
	SD	37.78	40.15	33.3
Male	n	110	28	51
	Mean	97.16	116.36	101.37
	SD	35.82	39.6	33.34

These findings showing the later referral for females across referrers are interesting, though the very uneven groups for the referrer category could be limiting. Further research using a larger dataset and more even groups would be beneficial to consider whether there is a meaningful inter-relationship between sex, the type of referrer and the age of the child on referral.

4.3.2.2 Other variables.

The other variables in the dataset were considered next. There was a striking difference between females, compared to males, who were referred for an autism assessment and received a diagnosis of autism whilst also on another assessment pathway[28] (see Table 4.18). A Chi-squared analysis showed this was a significant association between variables $\chi^2(1) = 7.3$, $p < .01$. Based on the odds ratio, this suggests that the odds of females being on another pathway at the same time were 0.49 (0.28 – 0.85) times higher than for males (see Appendix 4.8 for contingency table). This is a unique contribution to knowledge and further understanding could be gained from future research.

Table 4.18

Proportion of CYP Diagnosed who were also Currently on a Different Pathway

	Diagnosis whilst currently on another pathway			
Diagnosed CYP	Yes	n	No	n
Female	42%	28	58%	38
Male	26%	38	74%	109

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[28] The other pathways were A&D (n=3), ADHD (n=7) and Specialist (n=16). An additional two girls were on both the Specialist *and* ADHD pathways.

The underdiagnosis of autistic females is well established (see section 1.2.3) and this result may indicate some of the reasons for this apparent lack of recognition of the ways autism presents in females.

No differences were found between males and females in relation to CYP who were observed at school as part of an autism assessment; those who were diagnosed as a second opinion; and those who had previously been on a different pathway (see Appendix 4.9).

4.3.2.3 Section summary.

1. Females were most likely to be referred by a GP.
2. Schools referred the smallest proportion of females in comparison with other types of referrers.
3. The mean age of referral was lowest for females referred by schools.
4. Females who were also on another pathway were more likely to receive an autism diagnosis than males.

Findings from the DoE pupil data and from the two NHS datasets suggest some important differences between females and males, and the implications of these will be discussed further in Chapter 6. The next section will build on these results by examining eight individual patient records.

4.4 NHS Case Studies

A small number of individual patient records from the same NHS autism assessment pathway were then analysed (see Appendix 4.10 for example data), looking for patterns and any emerging issues that might inform the primary life history data collection and for the identification of factors that may contribute to a lack of support for autistic girls in school (see Appendix 4.11 for themes arising from an analysis of the case study data). All documents preceding the diagnosis of each girl as autistic were analysed (see Section 3.4.2.1 for further details) and three areas of interest emerged.

4.4.1 Delays in the referral process

The eight records examined indicated that most girls experienced significant delays between parents noticing challenges or differences and a referral being made to assess for autism (see Table 4.19). There was no delay to a referral for one of the girls (Katie[29]), whose differences were detected by a Health Visitor as well as a parent and who was first assessed at 21 months old. However, she was not diagnosed as autistic until a second referral nine years later. Five, possibly six, girls waited a minimum of four years for an autism referral, whilst two of these girls waited eight years or more. One of these, Emma, was also diagnosed after a later, second referral.

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[29] All names are pseudonyms to protect the identity of individuals.

Table 4.19

The Referral Process

Factor \ Case study pseudonym	Molly	Cayla	Lauren	Beth	Emma	Sofia	Katie	Gina
Earliest evidence of concern	Pre-school	Pre-school	Infant School	Infant School	Pre-school	Pre-school	Pre-school	Pre-school
Location of first concerns	Parent	Parent	Parent	Parent & School	Parent	Parent	Parent & Health Visitor	Parent
Time between first concerns and first referral to autism pathway	6 years	9-10[30] years	3-6 years	14 months	8 years / 10 years	5 years	No delay / 9 years	4+ years
Age diagnosed as autistic (yrs)	8	13	11	8	14	9	12	14
Requester of referral	Mum	SENCo	Head	Ed Psych	Mum	Paediatrician	Mum / Med	Asst HT
Referrer	GP	School	GP	School	Paediatrician	Paediatrician	GP	School
Previous referrals	Depression	Depression	Paediatrics, SaLT	Ed Psych, Behaviour Support Team	Podiatrist, Physio, OT, Paediatrics, Neurology	Audiology	Specific physical MC[31]	Paediatrics, Neurology, OT
Prior diagnoses	None	None	Reading & arithmetical disorders	None	None	None	Specific MC; astigmatism, mild DD	Epilepsy
Diagnosed after 1st or 2nd ADOS	1st	1st	1st	1st	2nd	1st	2nd	1st
Family history of autism	Yes	Yes	Not known	No	Yes	Not known	No	Not known
Family history of other conditions	No	No	Genetic disorder	No	ADHD; LD; anxiety; depression	No	ADHD; dyslexia	Not known
Parental circumstances	No evidence	No evidence	No evidence	Dad alcohol abuse; Grandma is p/t carer	Parents divorced	Parents not together; Dad abroad	Parents split then reunited	No evidence

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[30] Range is given where the data only shows a time period, such as ‘at Infant school’.

[31] Medical condition (MC) not named to prevent possible identification of the individual.

In half of the cases, referrals were ultimately requested by schools. Although this is a small sample, it is interesting to note the records for most of the girls showed a large amount of time between difficulties first being noted and a referral for assessment being made. Therefore, it is important to look at the reasons for delays in the referral process. Diagnostic overshadowing, where one overtly evident condition or illness effectively means autism is not considered (Miodovnik, Harstad, Sideridis, & Huntington, 2015), may have had an impact, as all the girls had previously been referred to at least one other service. For example, two of the girls (Emma and Katie) had physical conditions that required treatment, and these may have taken precedence over the exploration of neurological differences. In some cases, such as Molly, early observed differences were regarded as typical for the developmental age of the child, and thus not investigated further at that time. Family circumstances noted in the records included siblings with an additional need - Cayla's sister is described as 'very demanding' by the SENCO, for example – whilst Beth had a father with 'significant alcohol problems' according to a CAMHs psychologist. It is impossible to say whether these family circumstances affected the referral process for these girls. A family history of autism did not equate with an early referral in the three cases where this was relevant, which was unexpected. This may indicate that this was not established at the time first concerns were raised with professionals, or that a parental diagnosis came later.

4.4.2 Differing perspectives

The case studies demonstrate that parents and practitioners often did not share the same understanding of a girl's strengths and difficulties (see Table 4.20). Beth was 'affectionate' at home but 'defiant' at school; Katie was 'prone to temper tantrums' at home but 'fades into the background at school; Sofia had 'clear and fluent speech' according to a Paediatrician, yet 'did not engage' at school. Practitioners at the same school offered differing opinions in the case of Lauren: the school Inclusion Manager described her as an 'attention-seeker' who got 'angry very quickly', whilst the Play Therapist said, 'Through her work, Lauren has presented herself to be almost hidden'. There were also conflicting views between medical professionals in the cases of Lauren, Sofia and Katie, and between primary and secondary schools in the cases of Cayla and Emma.

School staff (class teachers, SENCO's, Inclusion Managers and Head teachers) descriptions of the girls, on assessment forms returned to CAMHS, formed two broad presentations. Most of the cases were of girls who fitted the first presentation, internalising or masking and camouflaging any difficulties. They were portrayed as 'shy', 'introvert', 'submissive', 'passive' or 'compliant'. This was expected, based on the research literature (Hull et al., 2020). The other girls were labelled as 'bossy', 'angry', 'resistant', concerned with 'injustice' or 'defiant'.

Table 4.20

Parent, School and Clinical Perspectives of each Girl

Girl	Parent view	School view	Paediatrician / Psychologist / GP View
Molly	‘Eccentric’, ‘ritualistic’, ‘always appeared young for her age’, ‘I’ve always found her a struggle.’	‘Craves attention’, ‘partners think she’s bossy.’	‘A mixed picture.’ (CP[32])
Cayla	Overweight, not sleeping well, bullied at school, tearful, depressed, no support. ‘Hard to help…is easily made angry’.	‘Hides in cupboards’, ‘anxious’, ‘only sees her point of view’, ‘aloof’, ‘unable to share friends’, ‘likes to be in control’, ‘tries to avoid/opt out’.	‘Very depressed, low and withdrawn, tearful, tired all the time’ (GP); 'clear concerns about her social ability’ (CP).
Lauren	‘Lauren says she feels different,’ ‘anxiety issues that lead to anger’, ‘disturbed sleep’, an ‘easy target’ at school.	‘Attention-seeker’, ‘angry very quickly’, ‘finds it hard to accept upsets and injustices’, ‘doesn't care about others if she has hurt them’.	'Does not present at least in the 1:1 situation as a child with significant social communication difficulties' (Paed[33]); ‘Profile of difficulties which meet criteria for a diagnosis of an ASD' (CP).
Beth	Very affectionate at home, becoming more aggressive, ‘doesn’t think she’s bad (bless her)’. Struggles to sleep.	‘Resistant’, ‘verbal refusal’, ‘physically distancing,’ ‘anxious and defiant’, ‘lacks empathy’, ‘over-attached and inappropriate’.	‘Energetic responses, periods of boredom, distracted.’ ‘ADOS score well above cut-off’ (CP).
Emma	‘She is a good child and not one of disruption’, ‘timid and v willing to please', anxious, ‘gets upset if directed towards sleep’, ‘came across as spoiled when she wasn’t’.	Works hard, 'seeks a lot of reassurance and support', 'anxious about failing with her work and in not being able to please’, ‘is a pleasure to teach and speak to’.	‘Presents with a complex pattern of difficulties… does not meet the criteria’ (CP); ‘some ADHD symptoms, but evidence inconsistent’ (2nd CP); ‘engaged well, eager to please’ (GP)
Sofia	‘Does not seem to have the need to interact’, ‘prefers to be on her own’, ‘often seems tired’.	‘Does not engage’, ‘extremely introvert’, ‘happy in 'her world', ‘obsessive playing with hair,’ ‘inappropriate talk’ and ‘behaviours’.	‘Fleeting' eye contact, 'clear and fluent speech', 'element of repetitive behaviour' (Paed); ‘score well above cut-off’ (CP).
Katie	'V passive and quite shy', 'will often say things which are rude or thoughtless without meaning to hurt or offend', 'prone to temper tantrums', ‘determined and independent', 'happy little girl'.	‘Quiet and inward’, ‘v shy’, ‘v submissive’, ‘doesn’t contribute unless prompted’, ‘tries to fade into the background’.	Good social reciprocity...hates getting into trouble...occasional outbursts of temper which she cannot control’ (Paed), ‘struggles socially’ (GP)
Gina	‘Lacks confidence; ‘feels that she is not good at most things’, ‘can shut down and refuse to do things’, ‘needs to be praised’.	‘Very compliant, usually (though can refuse when anxious)’, 'usually appears happy in school but reserves fears and reports at home. Can become v upset and tearful.'	Differences 'do not presently support the formal diagnosis of an ASD’ (CP); ‘made good eye contact’, ‘did not vocalise in any way’, ‘was quite sociable’ (Paed).

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[32] Clinical Psychologist

[33] Paediatrician

Beth and Lauren were both identified as externalisers of distress at school and it is interesting that these girls waited the shortest amount of time to be referred after concerns were initially raised. Lauren was also the girl, out of six without a Statement/EHCP, who received the most support in school. Support pre diagnosis ranged from deficit model interventions such as social skills groups and anger management classes; 1:1 support for academic lessons; fidget tools; speech and language therapy. One girl received support if she requested it.

While these girls are not a representative sample and findings cannot be generalised, these outcomes support earlier research (Moyse, 2013) that action is taken more quickly when the impact of an autistic child's unmet needs is felt by the teacher and school peers, rather than just by the child or her family. An unexpected finding was the language around power, raised by the descriptions of the girls, and this point will be discussed further in Chapter 6.2.2.2.

The impact of the girls' behaviours on home life had been described by half of the mums[34] (and a SENCO) as an issue. This ranged from 'quite a lot' (Molly and Gina's mums) to 'a great deal of strain on family life' (SENCO at Cayla's at Secondary school), and included worries about the future ('How will she cope?' Katie's mum). Most of the girls' current schools described them as having an impact on the school. Beth was described as putting 'a great deal of burden on the class teacher and the class as a whole', as was Gina. Sofia was 'inappropriate'. Lauren 'lashes out' and 'doesn't care about others if she has hurt them'. This was surprising, given that some of these girls were described by school staff as quiet and compliant. Some of the language used by teachers when describing these girls was unexpectedly judgemental and negative, such as the use of the word 'burden'. The implications of these types of descriptions will be discussed further in Chapter 6.2.2.

It is striking that, apart from Katie whose voice was reported as part of the annual review of her Statement, none of the girls' voices were recorded in the documents dated from before their ADOS assessments for autism. This was unexpected, given the recommendation by the Lamb Inquiry for the child's voice 'to be strengthened within the system' (Lamb, 2009, p.6). The direction in the SEND Code of Practice (DfE, 2014b) for Local Authorities to ensure CYP were supported 'to participate in discussions and decisions about their support' (p.21) is also relevant to Emma and Katie, who were assessed in 2016 and 2017 respectively. The lack of evidence of the girls' active involvement in discussions about their needs and decisions about their support was disappointing, though it is possible that this was happening but not recorded.

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[34] Forms were completed by mothers and appointments were attended by mothers. One father became involved at the end of one girl's pathway.

Some of the ADOS assessments recorded the girls' views about school. Molly had wanted to '*stay away from school*[35]*'* when she was bullied; Cayla said, *'people don't listen or they ignore me'* at school, whilst Beth said, '*I don't love to go to school'*. Gina's mum said she had 'taken a dislike to school' for the first time and came home 'saying she has no friends and she is very lonely'. Emma said school was '*difficult'* and '*upset'* her. Only two records noted school attendance figures, which were just for Y7 for Cayla (96%) and Gina (97%). These comments provide brief insights into their experiences of school, indicating issues that impacted on their wellbeing that were also noted by the girls who participated in the interview stage of the study (see Chapter five). Whilst no conclusions can be drawn about attendance for most of the girls, the remarks nevertheless demonstrate the importance of providing early and on-going opportunities for autistic CYP to communicate their views about school, so that arising issues can be swiftly addressed.

4.4.3 Alternative flags of concern

Consistent with the clinical presentation of autism, most of the girls were referred for an assessment over concerns around social communication or interaction differences. Some of these were specifically about peer relationships, such as keeping friends or 'getting on with partners (Molly). Two of the referrals were on the grounds of behaviour reported as 'violent' (Lauren) or inclined to 'provoke or strike' a peer (Beth), or because they were 'resistant to normal task expectations' (Beth). Academic underachievement was mentioned in two cases, though all the girls were either underachieving academically or had a spiky profile. One referral raised the issue of school attendance:

> Cayla has a history of suffering from high levels of anxiety and her friendships are volatile. She is beginning not to want to come to school, and although her parents are managing to do so, they are finding that she is becoming more difficult at home (SENCO, Secondary school).

However, the analysis of the girls' records pre-referral revealed three other factors that are often present in autistic CYP. Half of the girls were reported to have difficulties sleeping, in line with expectations from the research (Dimitriou & Pavlopoulou, 2019). Secondly, most of the girls were described as having sensory sensitivities, such as a dislike of bright lights, loud noises or of being touched, reflecting another common co-existing difference for autistic people (Bogdashina, 2003). Finally, all the girls except one had a history of anxiety (Simonoff et al., 2008). The implication of this information is that factors other than social communication and interaction can potentially indicate autism. This knowledge could be useful in providing support or adjustments to girls who may not otherwise be referred for assessment until they are older, such as those who mask or who do not have

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[35] The voices of the girls in the case studies, and of the girls who participated in the interviews (see Chapter 5), are presented in italics for emphasis.

Learning Difficulties (Hosozawa et al., 2020), or gathering further information that could result in an earlier referral.

It was surprising in such a small sample, however, to find evidence that three of the girls had self-harmed before their diagnosis of autism (all of whom were diagnosed aged 11 years+) and that three of them had exhibited suicidal ideation. Whilst correlations cannot be drawn on this evidence between the deterioration in the mental health of these girls and a late referral for an autism assessment, the findings are nevertheless concerning and worth highlighting. In addition, whilst generalisations cannot be made from these findings about the mental health of autistic girls who receive their diagnosis at secondary school, it is notable that the issue of poor mental health is also prominent in the life histories presented in Chapter five (see section 5.3.3). The subject is discussed in more detail in Chapter six.

4.4.4 Summary

The case studies looked for patterns in the NHS data to better inform the next half of the study. On paper there are three key issues emerging:

- All cases showed delays in the referral process, with implications for the provision of suitable support and the quality of educational outcomes.
- Perspectives were limited, highlighting the absence of the girls' voices until the point of assessment and the attitudes and language of power expressed by professionals.
- Referrals were made based predominantly on communication and interaction differences that were regarded as disordered and which impacted on others.
- Factors that negatively impacted the autistic YP, such as the environment, lack of sleep and high levels of anxiety were overlooked or underestimated.
- Some girls had reached crisis point before access to assessment for autism and the provision of appropriate support.

4.5 Chapter summary

Chapter 4 has presented findings from the analysis of a range of secondary data to provide scale and context for this study. Together the results provide valuable insights into the experiences of autistic girls during their 'diagnostic odyssey' (Lappé et al., 2018, S273), revealing differences in the referral and diagnostic process between female and male CYP, and diverging perspectives and potential flags of concern that impact support.

Informed by these findings, the following chapter moves on to consider individual pathways to absence from school by presenting the personal constructs and lived histories of ten adolescent autistic girls. The voices of the girls are central to understanding why they are not currently in school and provide a counterbalance to the views of parents and professionals documented in their NHS records.

Chapter 5: Narratives

5.1 Introduction

The previous chapter sought to place the research in context, by exploring national education and NHS data using descriptive statistics to look for trends and consider the scale of the issue in one county in SE England. The eight case studies from NHS records were analysed to look for patterns and emerging issues that could inform the primary data collection. Chapter 5 will present findings that address the second and third research questions:

- What can be learnt from the personal narratives of some autistic[36] adolescent girls about why they stopped attending mainstream secondary schools?
- How can the experiences of the young people in this study inform educational policy and provision?

Ten adolescent autistic girls, each with a clinical diagnosis, participated in the interview phase of the project. The number and location of each interview is presented in Table 5.1.

Table 5.1

Details and Locations of each Interview with each Participant

			Interview location			
Participant[37]	Age on date of first interview	Total number of interviews	At home	At UoR	Skype	Email
Alex	15	4	1, 2, 2b, 2c, 3			
Daisy	15	3	1, 2, 3			
Emily	15	1		1		
Erin	15	3			1, 2, 3	2b
Jane	15	3	1, 2, 3			
Lizza	13	3	1, 2	3		
Ming	12	3	1, 2, 3			
Robyn	15	3	3	1, 2		
Rosie	15	4	2b, 3		1, 2	
Sally	12	1		1		

Personal narratives of the ten participants are presented first. Key areas of focus for each girl are then be highlighted, based on the themes they identified in their final interviews or, in the case of Sally and Emily, on their one interview about their ideal school (see Appendix 5.1 for example coding of data).

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[36] Of the eight girls who completed life history interviews, the six older girls said they preferred to use the term 'autistic' and the two younger girls said they didn't talk about autism to other people so didn't have a term of choice.

[37] All participant names are pseudonyms chosen by the young people.

Additional written data from life charts are included in these sections and placed in brackets to indicate this source. Information on participant characteristics follows, to provide additional context. Finally, key themes emerging from the data about the sort of school the girls would not like to attend and their ideal school, plus the positive and negative events and experiences on their life charts, are presented.

5.2 Personal narratives

A key aim of this research was to prioritise the voices of the ten participants; to provide them with a platform from which to tell their stories and express their views (Lundy, 2007), and to consider whether their voices had previously been acted upon, as per UNCRC Article 12 (see Section 1.2.1). Brief personal narratives, using the girls' own voices (Goodley, 1996; Lewis & Porter, 2007), are therefore positioned first, with the aim of providing '*a fuller insight into their lives*' (Seal, 2014, p. 118). Key individual themes are noted at the end of each narrative and these will be discussed further in Chapter 6.

5.2.1 Alex (aged 15)

> *I want to go to university to study science, engineering, something like that, you know, STEM subjects…so if I can get, if I could get support I needed to do 5, 6, 7 GCSE's, like I'd be really happy.*
>
> *I've always been really academically bright, um, it's just, I've always felt pressure on me, and even from Y7 I felt like I couldn't, like I wasn't going to be able to keep up what I was doing, um, because I would always try 110% on everything and yet I had no kind of break, I had no like, let my hair down kind of time because break times and lunchtimes were just unpleasant for me as well…I used to not get lunch, because I, you almost had to have someone who is popular with you to go into the lunch hall or you would just get like basically trampled on. You have to be in a group or yeah. And so, just something as simple as like trying to get lunch becomes really difficult…So, it was really stressful. And I felt like it was a ticking time bomb which I now know it definitely was, because now I'm not in school.*
>
> *I was like, 'oh yeah secondary school, new friends, I'll make new friends and it'll be all good'. And 'yeah I can go to' …so I was really excited about doing science at secondary school and um lots of things, but then I kind of, and then I kind of realised quite, yeah, quite quickly, that I didn't really have any friends.*
>
> *Friendships never really last very long with me... it kind of shows why I don't really like to trust people, or rely on them or feel like I can like, like I can lean on people, because I don't know when they'll just disappear and I'll just fall over…In secondary school I got along well with the librarian, it was kind of, I kind of spent my break and lunches in the library able to avoid every, the world and stuff, um…until I fell out with a large group of friends I had in the library, and then I felt it was horrible to be in there because I felt judged the entire time…when I stopped being able to go there I, there was nowhere I felt I could be.*
>
> *I was acting in year seven and I wanted to just go back with the, go back and just be myself* [but] *when like I came out to people, I started being treated like specifically horribly, by a group of people, um specifically a group in my year group …I never admitted it at the time and so it*

> *was never dealt with…I basically lost all my friends from secondary school and spent breaks like outside my next lesson and I just didn't feel like I could be anywhere…*[I] *didn't feel like I belonged to a group or was important to anyone.*
>
> *I was self-harming…I got referred* [to CAMHS], *waited ages to actually have my appointment* [and then the clinician] *didn't believe that I had any mental health issues. He thought I was a normal, happy teenager um. He, er, he basically blamed it all on my mum, he thought it was all my mum's fault, or she was making it all up, whatever was most convenient for the time.*
>
> *I felt like I tried so hard academically, to the point where I, I knew that wasn't sustainable and I knew like, you know, I can't keep doing this…I wanted to put 110% into every single subject…*[but] *subjects that I'm not interested in like, it just feels like, why am I even here? And teachers don't like to hear, why am I doing this? Because it sounds like you are, you are just not bothering, it's not that I'm not bothering, I just want clarification as to why I'm doing something. Like, I want to know what the aim is…I need to know, and I need to ask and I need to check, um, which then means I, as someone who is academically able, I end up taking up more of the teacher's attention than someone who probably needs help with it.*
>
> *There's a lot of things I'm kind of like angry about, like, shouldn't have happened that way, you know?...It took the school a long time before they actually provided me some, something, because I think from the point of me going onto reduced hours they were kind of like, you know, you're smart, you'll come back, you know, and it will all be good. There's always, all through this, has been this kind of like, you're smart, it's fine…if I'd have struggled academically beforehand they may have had more of a problem with me not being at school, and they may have wanted to do more to help me be in school… It's relieving to not be at school, but it's also created, it's created different stresses and worries. I feel let down that, you know, I've put so much into my education and yet…everywhere is either, is either gives you the support you need, but won't actually provide the thing, like all of the lessons you need, you know, you do like three lessons, or they provide the lessons you need, but there's no support in place, and so neither of them are applicable for me.*

5.2.1.1 Key areas of focus.

Alex described themself[38] as academically bright and had been excited to start secondary school, with high aspirations for the future. They discussed the enormous effort they made daily at school; effort they said felt unsustainable and without respite. Alex identified anger and frustration as two of the key themes within their narrative (see Appendix 5.2 for participant theme analysis), about things they felt should have been different. They said they felt pressure was often unnecessary, that peers controlled spaces and were abusive, and that teachers failed to understand them or provide appropriate support (*'I had a teacher who disliked me being inquisitive or correcting her'*). Alex also talked about experiencing significant loss, not just of friends and their safe space at school, but also loss of family, support workers and the family home (shown on their life chart). These losses were linked to a serious decline in their physical and mental health (*'I don't know when* [people will] *just*

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1. Alex identified as gender fluid and used gender-neutral pronouns of they/them/their.

disappear and I'll just fall over'). They named isolation, through rejection and marginalisation, as a fourth theme.

Alex was extremely apologetic and self-deprecating throughout the interviews, including about their *'torrential mode of speaking'*. They framed their requirement for on-going clarification of expectations and explanations as a bother, describing themselves as a burden in the classroom with less entitlement to support compared with their peers. By contrast, events in the positive area of their life chart focused on recognition and identity. These events included their autism diagnosis, coming out as a non-binary person, and relationships based on empathy, responsiveness and belonging (peers who *'got me'*; *'a great teacher who would always answer my questions'; 'started going to LGBT+ youth group'*).

5.2.2 Daisy (aged 15)

> *My hope for the future is I get to be a government adviser on education to stop this happening to other people. I need my A levels, a degree and life experience. I think I've already got the life experience bit under the belt, to be honest.*
>
> *My biggest pet peeve in education is teachers treating me like I'm stupid, because that happens so much and it's just horrible…I'm not trying to be big-headed but I'm very academically able, they say my IQ is the same as Albert Einstein, or one above, but they'd give me simplified worksheets when I needed harder worksheets. The second they found out I was autistic…They're like, 'Daisy, you don't need to worry about this bit', but I'm doing the same GCSE as everybody else, and in the mock exams I got fairly decent grades, I got all A's and B's and A*s, and they're sitting there going, 'Oh you don't need to worry about all that, just do your colouring in'. I don't need to colour in, I need to learn geography…For me, it's very important that I'm treated like everyone else. The feeling it gives me* [otherwise], *it makes me feel so small and it's horrible. And it just doesn't help me make friends either.*
>
> *In Y4, I started learning the flute, and as you can probably tell, looking around my room, I'm quite musical, um and it just became something that I was absolutely <u>obsessed</u> with, and still today I am in <u>love</u> with music, and through learning the flute I got into like classical music and I just became completely <u>obsessed</u>, yeah! It gets me so excited. I <u>love</u> music, so much, like, so learning the flute it was the start of something to me, I always look back on that, at the time I didn't realise how significant it was…*[but at secondary school] *they said, because I was autistic, autistic people don't like noise so you can't take music. I mean, I love music so much. And they wouldn't let me take it, 'you won't handle it'.*
>
> *When I joined this new school they really thought, they finally realised I was like, I'm not trying to blow my own trumpet but I am quite smart, and they finally took notice of that, and then I felt so much pressure, because everyone was like, 'you're going to pass the 11+', yeah, but I didn't even want to go to grammar school because it was all girls, and I don't get on with girls, and, but I didn't want to go to the same school as everybody else from my primary school. There was just a lot of pressure.*
>
> *I used to eat lunch with Miss* [name deleted] *every single day. I used to go up at break and lunch to like the SEN department…we just sat and we just talked and I ate my lunch, because I was eating my lunch in the toilet and then I stopped eating lunch, and she was like, 'you know*

> *what? Just come and eat up here, you need to eat'. And then, it wasn't the Head teacher but I don't know what her job role was, she was like the Safeguarding Lead person, and she said it was damaging my social skills and I had to eat lunch outside with everyone else. Which, consequently, when she made me do that, I got my lunch thrown in the bin.*
>
> [In Y9] *I got attacked by a girl at school. She put my head through a wall. I had to get medical attention, because obviously I had a concussion. And they put me in isolation for my safety, but she was allowed to roam around the school. She got a detention, but she put my head through a wall…I was put in isolation quite a lot, and I just put that as one big thing. And another reason I was put in isolation in that year was because the girl who started the rumour* [about me], *she made my life a living hell. Um, one day, in the school library, she turned round and said 'no-one loves you, not even your mum, because you're an autistic retard', and I lost it, and I launched myself at her. So, I got put in isolation for that, which was fair enough. I shouldn't have launched myself at her. But the school didn't do anything about all the stuff leading up to that, her constant bullying me, making me feel bad about myself, socially excluding me, literally calling me a whole bombardment of names. Any time anyone came up to talk to me, she'd go up to them and say, 'You can't talk to her or I will make your life hell'.*
>
> [The school told] *me that I was either misperceiving* [the bullying] *because I was autistic, wasn't understanding it - it was a social joke - because I'm autistic, when it really wasn't, because Miss* [name deleted] *saw it and she was like, 'No, that's not a joke!' So, having her with me, to tell me what was a joke and what wasn't a joke, was quite reassuring. Because the whole time the school was basically saying I was crazy. It was a joke. Or they were like, 'Oh you just need to be more resilient'. I can't be resilient. When I'm getting physically attacked.*
>
> *I was off school for quite a while around that period… It was just bullying, and the fact school just didn't take it into account, they just didn't care. And I just felt so lonely because no-one at school really talked to me… I became very introverted, so my way of managing it was literally becoming like some sort of human tortoise. I just went into school and literally shut myself off...That helped me feel safe. I thought if I didn't talk and I just didn't really re-engage with anything or get involved in anything, that helped me manage it…In lessons I was not concerned about learning at all, I was just concerned that I wasn't going to get, like, attacked. You know, it made it very hard for me to go to school, and if I went to school it made it very hard to go to the lessons.*
>
> *Leaving school generally I would say, it's saved my life. I know that sounds a bit extreme, but if I'd stayed in school, I'd have carried on deteriorating and I don't know how, because obviously I wasn't, I was not happy, but it wouldn't have stopped. Being at the school was really detrimental to me.*

5.2.2.1 Key areas of focus.

A thread of injustice and abuse runs through Daisy's life chart, which included the most events and covered five pages. She spoke quickly, seeming to need little time to consider her answers during interview. Daisy described herself as very bright and expressed frustration that her autism diagnosis led to teachers treating her as though she was '*stupid*'. She remarked that she particularly disliked being treated differently to everyone else and said she was frequently isolated or marginalised by peers who didn't want to be with her and by staff who excluded her from lessons and school trips, which left her feeling very lonely. Bullying was a major theme for Daisy. She described years of harassment, intimidation, and attacks from peers, at different schools, incidents that she said were disregarded by staff until she was physically violent in response. She stated that some teachers lacked an understanding of autism, which she said meant support could be inappropriate and sometimes placed her welfare at risk. Unexpected change was another of Daisy's themes, and she gave the example of not being allowed to take music as a GCSE at school, despite her love of the subject, after she said teachers told her she wouldn't be able to cope with the noise. She labelled many school events as overwhelming, mainly due to pressure. Daisy also described how her mental health deteriorated significantly in Y8 and Y9 (*'stopped eating'; 'month off school due to S-H*[39]*'; '6 suicide attempts'*), which she linked directly to the constant and unchecked bullying. Poor mental health is an emerging theme that will be returned to in Chapter 6.

Despite the extent of the negative experiences she described, Daisy also identified lots of events that were positive for her at school. Starting flute lessons were particularly noteworthy, as she said they led to her falling in love with music. Relationships were also key, and she described the impact of teachers who understood and believed in her and gave her a safe space to be herself, as well as the value of occasional friendships (*'made a friend – year 5'*). She said that getting a diagnosis of autism in Y6 was a high point, despite the difficulties this also brought her at school, as was leaving school, which she described as *'life-saving'*.

5.2.3 Emily (aged 15)

> *I think* [in the ideal school] *they'd want their students to have skills to be able to go out and do, like to have skills to get over being anxious. And like to have the skills to be able to do work.*
>
> [I wouldn't like it if teachers] *didn't understand why I had difficulty with like something. Erm, well if they, if I'd expressed, if I'd said like I didn't like where I was sitting and they didn't do anything, or if they didn't try, or if the class was really loud and they didn't try and stop them being so loud… I don't mind talking and I don't mind a little bit of noise, but I don't like it when it's, like particularly when I'm already stressed, then I don't like a lot of noise.* [I don't like teachers] *talking quite quickly and doing a lot of things quite quickly without me being able to get the chance to like take a step back and like look at it and understand it, to process information...They wouldn't like explain or they wouldn't try erm help me understand. They'd just sort of explain it the same way they did without expanding on it…Erm, they'd treat me like some, like I didn't have any difficulties around certain things…They'd give like the same advice to everyone, without like thinking individually.*
>
> [My peers would] *be quite loud and they wouldn't really think about the fact that they're being loud, or, yeah. Like as if I was, I don't know. Like if I was like struggling with certain things, like if I was doing something, to help myself calm down, they were treating me like that was weird…I'd be quite stress, stressed. Yeah. And I'd be, I'd be really anxious and quite uncomfortable. I'd just be trying to keep out of everyone's way, trying to be on my own…I don't like being touched, without. Yeah, I don't like being lightly touched at all and I don't like being touched without knowing I'm going to be touched.*

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[39] Self-harm (S-H)

> [In the ideal school] *I'd want to be able to be in lessons and to be able to be working.* [Teachers] *erm they'd either, if they were teaching us as a class they'd go, they'd go sort of slowly and they'd go over everything quite thoroughly, and make sure that everyone knew what was going on…and then if I said I'm not totally sure then they'd come over and explain it to me. Yeah. Just making sure that I, cos everyone else has got it and I just need it explaining in a different way…If I was having a problem with something I'd like it if, if they sort of were able to give me like personal advice. I'd quite like it if they knew what, if they had like a particular plan that they had for each pupil, so for example if this pupil gets stressed then they take them out of the classroom for five minutes. Or if this pupil gets stressed then they have to, they go somewhere else and they have something to eat or something.*
>
> [The ideal school] *would probably care about its students and how, erm, how they work, how they, yeah. Like care less about what grades they get and more about how they get them. So, like they'd want to help with giving them strategies to deal with certain things…I'd want to be able to be in lessons and to be able to be working.*

5.2.3.1. Key areas of focus.

Emily participated in the first interview about the sort of school she would not like to attend, and her ideal school. There were consistently lengthy pauses, silences, and sighs (see section 3.4.2.2 for an explanation of the treatment of silences), which didn't occur to the same extent in interviews with the other participants. It is not clear whether any of her responses were based on personal experiences as she did not proceed to the life history interview stage, which could have provided evidence.

Emily commented that the environment and the behaviour of peers had an impact on her. She said she wouldn't like school to be particularly noisy or crowded, as she didn't like being touched unexpectedly. In addition, she didn't want peers to be loud or treat her like she was '*weird'* when she self-regulated.

Emily described key attitudes and behaviours of teachers that she thought were important. These aspects, and the ethos of the school, were shown during the ranking exercise as key for her (see section 5.4.1). She said teachers in her ideal school would be accepting of difference and responsive to her needs, would personalise help and provide strategies for managing anxiety, and would help students like her develop the life skills they needed to be able to work when they left school. She stated that her ideal school would care more for their pupils' wellbeing than the grades they achieved and would be a place where she could be in classes, learning.

5.2.4 Erin (aged 15)

> *Positive educational outcomes for me are getting the best grades I can and being happy. Going on to college and studying subjects I love. Then going to university and doing well.*
>
> *My difficulties got flagged up when I was 7, my first ADOS was when I was 10. After the original flag in Y3, school preceded to decide I had no problems and mum made it all up…The school changed from private to academy around this time and the class sizes increased with this. There were originally classes of 15-20 but this went up to 20-25. In order to accommodate*

more pupils, the school expanded and went through a remodel. We were in portacabins for Y3 and some of Y4 with frequent fire alarms being set off by the builders. I felt more anxious and was unable to settle in class properly.

My year 4 teacher was very cold and didn't accept my differences. She told me to pursue a solitary career such as a librarian because that was all I would be able to do. She often told me off for things I didn't know were wrong and dismissed my stimming...In year 5, my teacher was compassionate and loved all of her students. She treated us like we were her children. She was accepting of differences.

I didn't really have any proper friendships in primary school, so I struggled with that too…They said "we don't have bullying in our school" and acted like it was my fault and there was nothing they could do. It was overlooked by all the teachers. I was never believed and it made me angry…[In Y5] *I was under a woman from* [name deleted] *and my anxiety was awful. She described me as "not comfortable in her own skin" and I was lonely.*

[In Y7] *the initial excitement of a new building and new people took over my anxiety and I managed to function for the first year. After that though I massively crashed…In Y8 I began refusing to attend…My anxiety got really bad, I began feeling sick because the environment was so overloading. The school offered me no support whatsoever. When I was absent, they would get annoyed and try to get me in more. They didn't like that I brought their average attendance down…Before I stopped attending, I would cry before going to school and feel sick. I gradually struggled more and more after this and my attendance fell year on year.*

[In Y9] I made friends with someone new. Let's call her A. She was nice to me and everything. Then I began having more and more difficulties. We joined gymnastics together and she began ignoring me and made friends with other girls. They did not like me and would blank me. This caused a decline in my mental health even further…A told everyone in school that I had nothing wrong with me and I just wanted attention and that her mum thinks that too…In Y9, I spent about half of the year off and in Y10, I did a week before I was unable to cope at all. In the space between Y7 and Y10, I had a mental breakdown and developed anorexia.

I tried to mask my difficulties for 4 years and broke in the process… My behaviour at school was perfect. I followed all the rules so I didn't stick out and I pretended to have friends by loitering near people. I was shut down and quiet. In contrast, at home I would either be happy and chatty, or recovering from school and a crying mess…I would describe my experience at school as awful. I now have a fear of mainstream and suffer almost PTSD-like symptoms. It was horrific.

Not being in school was not fun. I wanted to learn but didn't cope with the environment…I think I struggled with teachers, friendships, too many people and not enough support. I could cope academically…I used to always get top marks in my exams despite having low attendance...but school would tell me I was doing badly to try to make me do better, this negatively affected my mental health. I would get unnecessarily punished all the time and struggled with the injustice. I often didn't understand why people would not be nice.

Since not attending mainstream school, my mental health has improved gradually. I have, however, lost my friends as they have moved on in their lives…[The hospital school I'm in now] *is a much smaller environment. There are* [less than 100] *pupils in the whole school with very small classes. Everyone there has been through a similar situation so can empathise. I am more able to learn now that my depression has gone and my anxiety is more under control. I have*

> *always loved learning and wanted to learn but being unable to attend school made this hard… I am currently achieving well in my hospital school and I am only doing 5 hours a week…I am studying maths, English, history and triple science (biology, chemistry and physics)…I was mute for the first few months of my new school, but now I have begun to speak to people (a bit) and my life is so much better now. I was extremely isolated before and had no one to talk to and I didn't see people ever. Now I have a more normal life and it makes me feel more human.*

5.2.4.1 Key areas of focus.

Erin's responses were articulate and concise, which may have been a benefit of communicating via the Skype text messaging service. She identified four themes in her narrative, with two being an aspect of every event on her life chart. The first was anxiety, and Erin said this was exacerbated for her by, for example, building work at school and problems with friends. Other people's perceptions of her was her second constant theme, and one to which I will return in the next chapter. She described her treatment by individual teachers and how this impacted whether she felt accepted. However, whilst she said her Y5 teacher was warm and caring, she indicated on her chart that attending school that year was still a struggle (*'not coping'*).

Injustice was another important theme for her. This included her experience of bullying by peers and of not having her concerns or needs believed by school or mental health staff. She noted that it was her school (rather than a clinician) that decided she did not require assessment or support, despite her Y3 teacher suspecting autism, and school that blamed her mother for difficulties she experienced. These arising issues of attribution of culpability and the impact of disbelief will be discussed further in Chapter 6. Her fourth theme was of being overloaded by the environment and the lack of support. Erin reported feeling overwhelmed from Y6, though she continued to attend school until Y10. During this period, she said she was struggling to manage ('*not coping*') and her attendance dropped. She said that she developed an eating disorder and described an incident with another girl that she said contributed to a further deterioration in her mental health. She stated that she stopped attending school in Y10 ('*MEGA CRASH').*

Erin said she wanted to be engaged in learning and did not enjoy being out of school. This is another emerging theme in the girls' narratives, and a point to which I will return in Chapter 6. The only positive event she recorded on her life chart was moving to a hospital school in Y10, where she said she was able to continue with her education. She said she still experienced some anxiety, overload and difficulties around other people's perceptions there, but was no longer mute and valued the empathy expressed by her peers. Erin stated she felt less lonely and more '*human'*.

5.2.5 Jane (aged 15)

I want to go to [name deleted] *College obviously and finish. It's a two-year course* [in] *art. And then I want to, I'm feeling pretty confident about wanting to go to University, I don't know what kind of University, or where, but I want to go to University. I've got very good academic abilities, but you know I still have to put the effort in.*

[At secondary school] *I kind of thought I wasn't worth anybody's time. Felt a bit like worthless, like no one should really have to be my friend because I'm clearly not fun to be around and that's what kind of, that's what made it kind of hard to make, that's why I spent a lot of Year 7 alone… I didn't really tell the school* [about being bullied] *because I was so used to it…so I just didn't report it… there's something that I've completely forgotten about, there was, I didn't report this again, just because I didn't, because I'd seen it like before, and I just didn't think they'd care enough. It was this one kid…he'd like create and bring up really like really, really, sexual scenarios that he'd made in his head, and describe them in quite graphic detail to me and my friend as we were talking and it just got really, really, uncomfortable. And like I didn't, I mean obviously at that point, I didn't feel safe at all.*

I had my attendances start to drop a little bit and they were like 'what's wrong?' And I was like I don't like being in the classroom, so they were like 'oh well we'll give you this card which you can use to get out'…which enabled me to leave lessons and take my work and do it separately in something in pastoral care. Whenever I wanted. I didn't use it at first, it actually took me a very long time to use it for the first time but after that, you know, after using it and realising how much more I liked it than sitting in a classroom, that's when I kinda started using it more. I didn't want, one thing I didn't really want to feel like a burden, I didn't want to be like oh I'm inconveniencing everyone, I'm inconveniencing my teachers, I'm inconveniencing the person in pastoral care to take care of me, so I was like I'll just stay in class, even if I don't want to. I think it started in Spanish... a couple of boys in the class who just gave [the teacher] *the hardest time, like legit throwing things at her just not, just disrespecting her completely. Not listening to a single word she says. And like and so eventually I think I was like, I don't want to be here.*

I made it very clear from the start that my problem was the school, that I didn't like the school environment, I was depressed around like other students and they didn't make me feel any better…I don't need everyone to like me, but I would like everyone to actually show me a little bit of respect…and this whole time [the school counsellor] *got really obsessed with the fact that my parents separated…she just assumed and not just assumed but was completely confident in herself that that was what was bothering me, and so I think it was kind of, I think that's what it represented, a feeling of like, 'oh I don't care if you think it's something different, I have the experience, so I know exactly what it's like to be in your head' and it's not, it's not true.*

I think they could have been like less authoritative because like they were trying to help but at the same time, they were always just like 'if you don't get your attendance up, there's gonna be some consequences'. And I was like that isn't really the best incentive for me to want to come back. And I always felt like threatened, and I made that very clear to people and they were like 'we're not threatening you', and it's like yeah but I feel threatened.

I have kind of like two versions of myself I'd say, they're still, both of them are still me and no one is less fake than the other, but it's kind of like I have my home version which is, I let myself say what I want, no like, no filters, stuff like that and like if I need to, if I have a twitch or if I feel frustrated by something, I just let it out. But then you know I kind of have like my in-public version of myself, which is very much more polite, and she stays quiet and she does this and

> *that, and she always says her pleases and thank you's. Erm because it's polite, I guess. Listen, I'm not doing it because I'm trying to trick anyone, I'm just trying to be polite and be considerate of other people because I'm aware that not everyone would particularly enjoy it if I just completely let myself go, well not really let myself go, but like, let myself – I don't really know how to describe it – but I know not everyone would appreciate it if they perhaps knew that I had ASD.*

5.2.5.1 Key areas of focus.

Jane described herself as academically able and stated that her negative experiences of school did not begin until Y7. She said a lack of respect from her peers, both towards her and towards teachers, was one of the causes. She stated that she was bullied in Y7 *('abusive best friend'*), which she said made her unwell (*'gave me depression*') and experienced sexual harassment from a male pupil. She also referred to the '*disrespecting'* behaviour of peers during some lessons, such as Spanish, which caused her to leave those classes.

Her second theme related to teaching staff. She said that some teachers lacked knowledge, understanding and emotional empathy. She described how some made assumptions about what she was thinking and the causes of her unhappiness at school, rather than believing what she told them. Not being listened to is another emerging theme to which I will return in Chapter 6. Jane said she sometimes felt unsafe at school and threatened by school, but that she perceived the school wouldn't '*care enough*' to take action to stop this. In addition, she stated did not want to be a burden or an inconvenience to staff and said this sometimes impacted on whether or not she stayed in an uncomfortable or hostile environment.

Positive experiences for Jane were based around a sense of belonging: the teachers and peers, with whom she developed good relationships, and participating as part of a group (*'I took part in a fashion show* Y3'*; 'I'm one of the main characters* Y10').

5.2.6 Lizza (aged 13)

> *I just want to get a job and I want to have my own money and I want to be able to buy a ticket to visit my best friend out in America, that's all I want from a job. If I can do that, I'm happy.*
>
> *I started seeing CAMHS* [in Y3] *because I was starting to have anxiety…I think it might have been my strict teacher, technically she wasn't my teacher, she was my phonics teacher and the classroom next door's teacher. But um she was very scary. Shouting, like staring, and blunt, just like, I don't know. Just like, evil, to be honest…I think I did have too much* [anxiety] *before Y3, but I didn't realise and I didn't know why, and in Y3 I realised the reason I'm scared is because of this person, maybe this is not a normal feeling, even though it's normal for me, but because I'm scared of this person.*
>
> *The first time I like properly got told off, um, well basically it was in maths class and I had a really strict maths teacher…she starts screaming at me, and she keeps saying things like, 'You think you're so much better than everyone else! You believe that the rules don't apply to <u>you</u>, and <u>you</u> think that <u>you</u> are different, you're <u>special</u>, and you're <u>not</u>. You think that nothing*

> *applies to you, that you are the best, that you can do whatever you like, but you can't'…I was devastated because I'd always been like the goody two-shoes and I hadn't done anything wrong…*[but my Y6 teachers], *they were just like, they felt more like friends than teachers, they had nicknames, they were really cool, they were young, trendy, kind, funny, not too formal. They were just like really relaxed.*
>
> *Most people say I'm quite bright and I did quite well on my 11+, but I don't want to sound big-headed, but I guess I am sort of bright? I don't know if that's big-headed…*[but] *there was so much pressure* [in school], *you had to get the right scores, everyone was very clever there, the teachers were all really strict, they all wanted you to get like really good grades, cos they were all like 'oh yeah, we're in the top 5% of the schools in the UK', whatever. They were just very strict and pressurising and they want everything to be perfect and not everyone is perfect.*
>
> *It was difficult making new friends* [in Y7]*, but it was also exciting, you know, it was exciting to have a clean slate, it was exciting to start again, to choose your friends, choose who you wanted to be, like that was scary and exciting. And then once I had new friends, it was good getting to know them. And then again I put it down a bit because I didn't know if they liked me and that was scary... It was over a certain amount of time that I feel those things, so maybe, like one day I'd be like oh, yeah I'm really excited to see my friends and then later that day they would have said something that they thought was like normal and I would have freaked out and gone oh my god, they don't like me anymore…it was just general uncertainty, it wasn't things that they said, well I mean it might have been things that I over-analysed, but most of the time it's just tiny things that don't even make sense.*
>
> [The school] *tried to give me like counselling, they tried to give me places to go, put things in place that would try to relieve my stress, like, having a thing that we called an orange which meant on request you could leave the classroom without being, asking why…The orange card helped slightly because I had a freedom. But it didn't help because when you got to student support it was where all the sick people were, but I liked the staff there which is why I didn't want to go anywhere else. And also at student support, everyone would just be looking at you and people would be coming in all the time, often I wouldn't sit directly in the place I was supposed to sit, I'd sit where the desks were, where the teachers worked.*
>
> *At home I was bored. School refused to send me any work because they said that if I was home then I'd be having too much fun and they didn't want me to get settled working at home… Sometimes I feel sad because I miss my friends and it's quite, I, I wanted it to work… And it's difficult because I did really want to go there and I really wanted it to work out. And I was trying my hardest, but I couldn't, and it makes me sad that I couldn't go there because I really was enjoying myself at times, but not mostly, and I felt very sad that I couldn't go.*

5.2.6.1 Key areas of focus.

Lizza said pressure was the major theme for her, with exams and tests being flash points despite her academic abilities. She said she disliked schools exerting high pressure to achieve top grades and that this was for the benefit of the school rather than the pupil. She also said she disliked staff who were strict and described being so frightened of a teacher who shouted that she developed clinical levels of anxiety. Lizza stated that one of her worst memories at school was of an occurrence with another teacher who she felt treated her unreasonably. She said that the teacher shouted at her, made assumptions about an incident, assigned blame, discriminated against her, and wouldn't listen to her point of view. This feeling of injustice and the lack of agency are themes that run through a few of the girls' narratives and will be discussed in greater detail in Chapter 6. Her second theme was social anxiety, which encompassed other people's perceptions of her. She described a general feeling of uncertainty at starting secondary school, of being excited but also unsure of new friendships (*'not sure if liked me Y7'*), and of over-analysing conversations.

Lizza identified more positive than negative events on her life chart. She said that good relationships and having fun were important to her. She regarded Y6 as a particularly good year due to kind, relaxed teachers and interesting, enjoyable work (*'WW2 project & mini enterprise'; 'fun times'*).

Finally, it is again striking that Lizza stated several times that she wanted to be in school. She described the effort she made in trying to make her placement succeed and her sadness at being unable to keep attending. This rejection, not of the value of learning but of the school environment, will be discussed further in the next chapter.

5.2.7 Ming (aged 12)

> *I think you should be able to choose your subjects earlier. Because like some people may totally not want to do anything, like not want to do history, and will be unlikely to ever be an archaeologist or do anything about history, so they don't really need to learn history, but another person might be going to be an archaeologist.*
>
> [At school] *I was always getting told off for being in a corridor, especially in Y8, mainly because year sevens aren't really allowed in the corridor. Although all my friends were, it was just me they were telling off. And then when I was in Y8 they still thought I was Y7… I get really bad chilblains in winter so I try to keep really dry and warm…When I'm cold I don't feel happy. And I get annoyed…one of the main things was there were a couple of benches, but there weren't enough, so everyone would, there'd be groups on benches, and then everyone else wouldn't be able to sit down.*
>
> [Becoming a school librarian] *was really great because I got to sort all the books and stuff, and yeah I got some, my favourite books, Warrior Cats, ordered in…I made some friends…we'd just go and do stuff in the library…I liked the library…it's like nice and comfy. And it's got all my favourite things in it – books.*
>
> *Every time I got a friend, really soon afterwards they would just not be my friend. Just start being mean…Like on my like, day, when you went to see and met everyone in your tutor and stuff, there were some people who were really nice and I made friends with them, and then when I started school, they were just mean… Didn't have very many friends* [in Y7]. *People were just mean, mean, mean, mean, mean…I sort of wanted to* [move tutor group in Y8]*, but I didn't know if I'd get told off, and one of my friends was going to go and ask, so I went with them as well. But then afterwards, when we had changed tutor groups, she kept being mean to me and saying like that I had copied her and I was always following her around, copying her…And all those people in the new tutor, well not all of them, but some of them, it did mean I was in lessons with more of my friends, but also, basically I just made another load of people being mean to me.*

> [The most difficult about being in school was] *erm. Well. Just learning with people… I don't know* [who it was hardest to get along with]*. Everyone. Just everyone. All of them (sighs).* [I felt least comfortable] *just like in between classes, and in classes. Like going to classes, and standing outside, and then in the classes when I'm sat next to people, and stuff like that. Umm. When we had to go in groups, because like no-one picked me, and then when I was assigned to a group, no one would listen to me. There was this one time in science where I was like going, we're supposed to add it to the water, and they were like 'no, we're doing it this way' (mocking voice), and then they got told, and then we all got told off. It's like, I was telling you not to do that, and they were like just excluding me.*
>
> *We also had to keep having supply teachers because the, our history teacher just quit, yeah, in the middle of the year. She quit early and they just didn't get a proper teacher the whole year. We just had supplies. Every time they wouldn't know why. Every time they got a new supply teacher they'd be like, starting from the beginning.*
>
> *There was one thing where I went out of a lesson* ['*too many people/noise*']*, but that didn't really help. I didn't find it helped. I just found it made people go 'oh you're special, having to go out'* (mocking voice). *I just tried* [to manage]*. I spent my days in the library…Quite often I used to come home crying. And then my mum just decided to take me out of school.*
>
> [Home education] *means I can go to lots of in-the-week things. Like I now go riding on Fridays…I love horses. I love all animals, but horses, like, yeah…I get to do a lot more textiles…I just sort of do my own history, so like one of my history projects is, could be my Roman city. I used to go to a place called* [name deleted] *with my science, oh, and I do history there. And I'm doing classical civilisations GCSE there, in September. Roman daily life and Greek mythology, both of which, I'm pretty good…You should be able to like, do things above your level, like, above the level you should be at, like so I could go and do history with people who know a lot more about history (laughs).*

5.2.7.1 Key areas of focus.

Ming's interviews were punctuated by her talking about all the things she loved. These were her preferred topics of conversation and so words from her life chart are used more extensively here to illuminate the meanings in her experiences. Her interests focused on specific periods in history and on animals, and she showed many photos of her and others dressed in historically accurate costumes (Roman or Victorian), as well as textile items she had made. She also enjoyed pointing out animals outside her window and talking to her cat (a new addition to the family, who she described as the '*best thing ever*'). Ming stated that leaving school to be home educated had enabled her to learn more about the things she was particularly interested in, and work at her own pace.

Her positive memories of school (see Appendix 5.3 for an example section of her life chart) related to these interests, which she said provided fun and a sense of achievement. She identified getting good SAT's results and having her abilities recognised as positive events *('Y6 one of best SAT's results for reading'*; 'Y7 *put in gifted and talented group*'), whilst she stated having her abilities underestimated *('not being given a chance to show what I can do'*) was a theme in her negative experiences of school.

She remarked on the impact of the school environment. She said she disliked too much noise, too many people and having to be outside in the cold. She said she often had nowhere to be at lunchtime *(‘canteen is loud and dirty’*). She also said that she was reprimanded for being somewhere she shouldn’t have been, although peers were not. Becoming a librarian at school in Y7 was helpful, she said, because it gave her somewhere to be, as well as something to do that she enjoyed.

Ming linked all her worst experiences of school, as indicated by their position on her life chart, under the theme of being bullied. She reported peers being unkind and turning other children against her (*‘made everyone be mean to me’)*. She also described being excluded from conversations in class and of not being picked for activities but did not want to talk more about this during interview. Her chart showed that the unpleasantness continued until she said she was leaving school (‘*when I told people they all said “Yay, finally”,’* Y8).

5.2.8 Robyn (aged 15)

> *I would like to go to University, whether it's a brick building or the OU, and eventually get a doctorate in theoretical physics, preferably astronomy. But any theory is cool.*
>
> *I have a vague* [first] *memory of crying right outside my bedroom, because I was told I had to go to school or something, and it was a few days after the summer, before going back to school after the summer. I can’t remember how old I was, but I remember that.* [whispers] *It was traumatic…The only things in experience I’ve learnt from bad schools is how to have a breakdown, how to mask, and how to hate school. Pretty much ticks the boxes for that. I can’t see any other things really. Oh, and the other people are weird. I’m sorry, I’ll never understand them for the life of me.*
>
> *It was, you <u>must</u> talk, you <u>must</u> communicate with the world and these <u>horrible</u> teachers. They made me write a Mother’s Day card. Yeah. I just remember crying. Thinking back, it’s just like, yeah, I’m sure my mum would <u>love</u> a Mother’s Day card that was made from me <u>crying</u> with sadness. Such logic…You <u>must</u>.*
>
> *You know, it’s that kind of thing without an option…it’s the way it originated from a factory, so schools were designed for factory workers, well, to develop them into factory workers. It’s that kind of sit in lines, you have to conform to that, you cannot speak or really have any ideas of your own. You can’t do what you want to. You can’t speak in class to people around you, you have to put your hand up. There’s a lack of respect, both ways. Well, one way, actually, because you have to call your teacher Mr and Mrs, Sir, Miss, you know, all of that. And, if the teachers do that, then they should do it to the students. It should have a two-way respect, which it lacks. In the real world especially.*
>
> *They tried to force me to go into* [primary] *school, like hold me, and quite literally, physically…Touch. Force. No option. And it’s also, I guess, discrimination, age discrimination. You have no choice as a child. I remember, it was one of the days I totally flipped out and got quite physical with the people who were trying to make me go in. I can’t remember. I, I was, very desperate to get home. Um. And very disruptive. Well, not disruptive, but I made my point, let’s just say.* [At secondary school] *it was a very simple, less physical obviously because you’d*

> *just get bullied for whatever, and it was more of, I would get out of the car or I wouldn't. There was no in-between. It was a simple yes or no.*
>
> [My fight with the Head teacher] *was one of my proudest moments to this day. All the special needs parents were like, 'yes!' Come on!* [to mum] *She was abusive, we both know that. What did she threaten? She threatened to lock a Down's Syndrome child in the cupboard…I picked a fight with her…So, highlights. It was theatre. Was it the theatre day? I can't remember. I just remember picking a fight* (small laugh). *Freaking out. Being held down…I think that was the only time* [I was restrained]*, the one main time. But I made my point come across.*
>
> *In Y7 I really didn't have any friends, in school. Mainly because they were lunatics and immature and really weird…The ARP*[40] *was quite nice because only a few people could go in, which was nice to get rid of people, but then they were coming too, it's a long story but it got really annoying when more people came in. I enjoyed it just being a few of us.*
>
> *Normally, for break, I would read a book in silence, or try and find somewhere silent. I was slightly annoyed* [when I was given] *a detention but, you know, I held it together, went into the detention, and I was allowed to sit down and read!* (laughs) *In perfect silence. It was, brilliant!*
>
> *It was, yeah, it was, supposedly education that you had to attend, that you must go to every day in the week. You had to sit there for hours on end, in a classroom, confined by kids that weren't so much, by 30 kids, actually it was more for me, every year, like 33, who were also forced to be there, but didn't enjoy it and didn't want to learn, so they messed about, reduction of time learning, not that you really learned anything whatsoever…*[The EHCP] *supposedly gave me, um, LSA for maths, English and science, but that was a total lie because they had no idea where the money went.*
>
> *I'm happy with* [the term] *school refuser* (laughs). *Because it, again, people associate education with schools, as the same thing, schools should provide education, but it's not, 100%. Yeah. Because, it turns out, I absolutely love education. I just didn't know it.*
>
> *I'm happy to be autistic, but I hate the way I can't do things. Now, I was always comparing myself to the rest of the world, because they were going, 'Well, you can't do this, you can't do that,' you know, and the main reasons I couldn't do it was because of them. And once I'd learnt that, then it was actually, well, I <u>can</u> do it, just don't get in my way!*

5.2.8.1 Key areas of focus.

Robyn identified 'force' as one of her key themes, a term she used to encompass pressure, rigidity, abuse and discrimination. She linked the issues of conformity and uniformity that she said she experienced in schools back to the training of the working classes to be compliant factory workers in the Industrial Revolution. This was an approach she found damaging. Robyn gave descriptions of being '*made*' or '*pressured*' to do things she didn't want to do at school, although she also said she stood up to authorities (*'Y4 fight with the Headteacher')* when she saw others being treated unjustly. Her account raises issues of power and agency which will be developed further in the following chapter.

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[40] Autism Resourced Provision (ARP)

She said she wanted to learn but was unable to due to the actions of peers and the impact on her of an overwhelming environment. She described experiencing sensory overload at school every day, identifying the theme of '*sensory'* as a dotted line across her whole chart as well as underpinning single events.

Robyn identified being diagnosed as autistic (Y4) and leaving mainstream education as two of the most positive events on her life chart (see Appendix 5.4 for an excerpt from her life chart), though the latter was also '*scary'*. She said that getting an EHCP (Y7) was useful in terms of enabling choice, as it later helped her secure funding for a place with an online education provider, but that it did not provide her with promised support in school. She stated that there had been a lack of honesty and transparency about the allocation of her funding, something that was also raised by Daisy. Robyn also described a national achievement with her online education provider *('winning STEM competition'*) as an exciting and positive event for her, despite feeling her entry was under scored by ('*mainstream'*) judges.

Some of the events she said she found enjoyable were unexpected, such as being in detention. This highlights the value of the personal narrative in understanding appropriate support for the individual.

5.2.9 Rosie (aged 15)

> *I want to get good GCSEs. I want to get good A levels. I want to go to Uni and study veterinary. And then I want to become a large animal vet…I would like to specialise in animal psychology.*
>
> *I don't have to worry when I'm talking to animals. You know, they're not going to, they're not going to argue, really. They're not going to say unkind things. They're not going to bend or say things to other people, manipulate your words…they're not going to just randomly take something the wrong way, and then hate you for the rest of your life……Most of the time I don't let people get close enough to me to be important, because I've had so many experiences where I've trusted someone and then they've gone and stabbed me in the back.*
>
> [Reception] *was scary because it was big and loud and I didn't know what to do or where to go or anything. I just wanted to go home. The school didn't do anything to help me. I hated it. I was stressed all the time and I couldn't cope with anything and that really confused me… Everything there was the worst thing ever. Because mom would leave and I really didn't want her to leave and I just felt that there was nowhere I could turn for comfort or help…* [In Y1] *Mrs* [name deleted], *the teacher, told us all off because too much paper towel was being used when people washed their hands. When she demonstrated that you just use one piece of paper towel she faked washing her hands and lied about it. She was telling a lie to make her point. I felt like I couldn't trust anyone after that… Mrs* [name deleted] *the* [Y2] *teacher always blamed me for everything. It felt like that. I hadn't ever done the things she blamed me for. This really upset me because I was always really scared about getting into trouble and paranoid about doing things I wasn't meant to.*
>
> [Name deleted] *School had a base…It was meant to help that I had people around me who understood autism but being around other children with problems wasn't helpful because I*

would constantly be worried that they might kick off. I was always in the base so I would be in the way of them kicking off… The other kids made fun of me. They made fun of me. They were mean to me. [Name deleted] *kicked off and hurt everyone. He really stressed me out. There was just one other girl. About 8 or 9 boys…It was the only place I could withdraw to, but it wasn't actually safe.*

[My next school] *was meant to be good because they had animals on site…smaller classes and I was going to have a one to one TA…*[But] *they wouldn't let me go and see the animals when I needed them. My TA turned out to have no experience with children, didn't know anything about autism. She stuck her fingers in my mouth when I yawned. And she lied about me…There were multiple incidents when she lied about my behaviour to try and get me in trouble. If I made jokes, she said you were being serious. She exaggerated what I'd said to make it look like I was being mean. I was told off by the SENCo. She used to try to twist my words to make it look like I was lying about my pain. Because she couldn't see my pain, so she didn't believe it.*

[My next school] *was the only specialist school that said they didn't have pupils who were physically aggressive, and they said they could teach me 10 GCSE's… It was really good for the first year. They kept me safe and they helped me a lot emotionally. They helped me to communicate better and get some independence back. They didn't make me try to do things I wasn't ready for. They let me lead my own progress, so I didn't feel pressured. I felt safe around the staff because I felt listened to and understood.* [But] *they weren't teaching me enough academic material for me to get my GCSE's and they started to treat their staff really badly so all the staff who understood me and listened to me and made me feel safe left. Then we had agency staff a lot of the time who didn't know what they were doing…The kids were kicking off all the time because they weren't being looked after properly. The staff were forgetting to feed us and give us medication.*

I didn't really start worrying about my education until the end of [name of school deleted]*…Um, yeah, that was when I really started worrying about what's going to happen in my future if I don't get a proper education…*[But] *no-one wanted to understand. No-one really wanted to know why or help with it. I mean the occasional person would kind of crop up and attempt to help. And they would mean well, but there just wasn't support for them to do that. Like the people who were nice and tried to do the things that were actually helpful, wouldn't get support from whoever they were working for.*

I've had two different sorts [of home education]. *One of them was tutors that were being funded by* [name of school deleted], *but we found the private tutors. Um, quite a few of them were new. And that teaching was <u>amazing</u>. I loved all of it, I was achieving really well, um, my anxiety was much lower. Everything was amazing. Erm. But then when* [name of school deleted] *refused to carry on paying for that, I got the ones that the local authority provided…They were absolutely awful. They didn't, I felt like they were learning more than I was, when they were supposedly teaching me. And they would teach, if they <u>were</u> teaching me, it was to a very low level. It wasn't going to be to a level I would achieve GCSE's from.*

Erm, I'd say, erm, absolutely higher academically than normal people…If I'm out of education, I'm generally just very depressed, and down, because I know I'm not getting an education and I know that I <u>need</u> an education. And, generally if I'm out of school, there's a reason, like someone's done something really bad to be in that situation.

5.2.9.1 Key areas of focus.

Rosie identified two key themes that ran across her life chart. The first was staff attitudes. She said that some teachers blamed her without reason, whilst '*nice*' staff didn't get the support to help her. Rosie said that after one particular incident in Y1 she felt she could not trust anyone. She described the treatment she received from one support staff member as abusive, which she said contributed to her feeling anxious, vulnerable and unsafe. Her second theme was her struggle with peers. She described some of the young people at school as the '*enemy'* and said they made her feel *'upset'* and *'scared'*. She said a base, one of the places she should have felt safest and most understood, was the most frightening due to the actions of a male peer who also attended. The importance and impact of relationships will be returned to in the following chapter.

Rosie also identified worrying about her education as a significant theme from Y7 to the end of Y10 when another placement ended ('*life officially re-fucked up').* She said she had left a placement due to staff cuts, which she said made her feel unsafe. She stated she had then engaged well with private tutors, but that this provision was removed. Her mental health deteriorated over this period ('*suicide attempt'*).

All her negative memories are in roughly the same position on the chart, so it is not clear visually whether one was worse for her than others. However, she identified one period at one school ('*staff cuts start,'* Y9) as including all her themes of concern. This was a time and place when she described feeling particularly unsafe.

5.2.10 Sally (aged 12)

> *I just sort of learned to not mind anything really. I mean I do mind, but it doesn't really matter. Some things that I don't like about schools can't really be changed, can they...Busyness. People…And not the nice kind of people either. The kind that makes you want to just punch them in the face…Everyone around me all throwing pencils…There have been a few rubber bands pinged at me, when I clearly wasn't joining in this little game that they had.*
>
> *I guess peer work is not the best but it's necessary…you know, working with the class and having to get into groups. Yeah, and if the teachers aren't the nicest either then that's bad…Erm, you know, those kinds of teachers that hate you for seemingly no reason…You can tell that I hate people, can't you? I hate people…* [The teachers treat me] *like I'm a mosquito, I guess. And treating me with pure hatred…Sort of snap at* [pupils who need help] *and tell them that they weren't listening or they need to do better or that they should just suck it in…*[I'd] *probably* [be] *in the corner trying to keep the stress in.* [The school cares about] *possibly just getting good grades and seemingly they only really care about trashing students' dreams. Only the unpopular ones though, they love the popular ones. And they hate me. Leaves me wanting to punch them in the face.*
>
> [I'd want] *probably mainly a place with people who don't make me want to punch them in the face. There's a lot of punching in the face going on in this interview…I tend not to pay much attention to my feelings*. [I'd want] *as little people as possible. Then again, that won't be too*

> *effective if they are the horrible kind…*[I'd sit] *probably near the front, where I can keep an eye on the others, possibly...Corners or by the window can help as well. I wasn't really a fan of the cafeteria…*[I'd sit] *maybe outside, more naturistic, or somewhere I could keep an eye on everyone else*…[I'd want corridors to be] *neat, not noisy and er not so crowded that there is inevitable pushing and when someone does push you, you don't feel like your neck's going to snap against the wall. Holy sugar, that got violent.*
>
> [A teacher] *that's helpful and nice and just…Somebody that's willing to help me with things I don't understand and doesn't just snap my head off straight away. Holy sugar, I'm making school sound terrifying. And somebody who's actually good at their job...They have all the qualifications…They'd be patient and understanding, I guess…I'd be willing, I'd be willing to do group work if the group were actually nice people. That didn't make me want to give them a nice little hug with my arm around their neck…They'd be helpful and not prejudiced… And if, if I've had a bit of a spat with someone who is perhaps more popular than me, which is probably going to be everyone, then they wouldn't really side with the popular person just because they're popular.*
>
> [Peers would be] *probably helping anyone who sort of needed it. And not pushing others around mentally and physically. And not trying to be friends with someone just so they can push them down… I'd be more popular for being the kind of person I thought I should be…I was sort of told to be kind to everyone, and there was a time I did do that but then that's how I got false friends and unpopular erm and so I, so I abandoned that tactic.*
>
> [The ideal school cares most about] *students' wellbeing…that's what schools should look out for. They all say they're looking out for them, and mum says it's the law that they say that. To be honest all they do is just put it on a piece of paper, they don't actively enforce them and I want to kick them in the face.*

5.2.10.1 Key areas of focus.

Sally's powerful narrative is based entirely on one interview about her ideal school. She described the sort of school she would not like to attend as violent and dangerous, with teachers who hated her and peers who threw objects at her. Sally showed the amber card when asked how peers would behave at the school she did not want to attend. She said she would be vigilant and watch others or hide and try to contain her '*stress*'. She stated that this school would not care about her '*dreams*' or wellbeing and described it as '*terrifying*'.

She struggled to provide answers to the questions about her ideal school and referred to negative scenarios instead. She said that a school that prioritised pupils' mental health was most important for her but noted that some schools state this is their ethos whilst not implementing such an approach.

Although this personal construct of the ideal school exercise was designed for the young people to talk about imaginary schools, it is possible from the emotional responses within Sally's narrative that she drew upon her own experiences. Whilst she did not overtly analyse her responses, themes of bullying, fear, anger, and injustice emerged from her descriptions.

At the end of this interview, once the microphone was switched off and preparation for the next interview was being described, Sally said she did not wish to continue if she had to complete a life chart as she had '*tried to forget a lot about school*'.

5.2.11 Summary

During their last interview, the eight participants who completed the life charts identified key themes from the events and experiences they regarded as negative (see Appendix 5.2) and evidence has been provided to support these themes. Figure 5.1 provides a summary of the issues raised and illustrates the frequency of each theme, ranked by word size. A lack of understanding by peers and school staff emerged as the primary theme. Additional key themes were bullying, pressure, sensory overload, change, discrimination, social isolation, and anxiety. These will be explored further in Chapter 6. Sally and Emily did not do this exercise. The only theme evident from Sally's personal construct interview that is not already captured here is fear. Adding an analysis of Emily and Sally's themes would result in an increase in the ranking of bullying, injustice, attitudes, and anger.

Figure 5.1

Themes Identified by the Girls from their Life Charts during their Final Interview

5.3 Participant characteristics

The voices above form a powerful narrative about the experiences of 10 autistic young people. Given the uniqueness of this sample, it is important to recognise that the participants are an opportunity sample, and their experiences are therefore not necessarily representative of all autistic adolescent girls absent from school. The ten participants had all begun mainstream secondary schools aged 11 (Y7), were all female at birth and had been clinically diagnosed as autistic. They came from a range of backgrounds and shared a wide variety of personal histories and experiences. Of the eight participants in life history interviews, three were living with a single parent and one had been in a new family unit with a parent and stepparent for most of her life. Two had always lived in the same home; one had moved five times. One of the participants (Alex) identified as gender-fluid whilst another volunteered that she was gay. Two of the participants, Emily and Sally, elected not to continue past the first interview and information that was to be collected in later sessions is therefore not known about these girls.

Similarities and differences identified between the participants during this research are now presented to provide further context. These sections cover their autism diagnosis (see Table 5.2), clinically diagnosed co-occurring conditions (see Table 5.3), self-reported descriptions of mental health (see Table 5.4), the type of school they previously attended (see Table 5.5) and school-recorded attendance figures (see Table 5.6).

5.3.1 Age when diagnosed as autistic

Variation in age at referral, diagnosis and wait times are shown in Table 5.2. The youngest a girl was referred was 2-3 years and the oldest participant was 12-13 years. Five girls waited less than a year from first referral to being diagnosed as autistic, whilst three waited over four years.

Table 5.2

Age at Interview, First Referral for Assessment of Autism and at Diagnosis, Plus the Potential Time in Months Between the Two Dates

Pseudonym	Age on date of first interview	Age at first referral (yrs)[41]	Age at autism diagnosis (yrs)	Wait between referral and diagnosis (months)
Alex	15	12-13	15	6-7
Daisy	15	4-5	9	52-63
Emily	15	12	13	8
Erin	15	7	14	95
Jane	15	13	14	7-11
Lizza	13	10	10	8
Ming	12	8	9	16
Robyn	15	2-3	9	79-90
Rosie	15	7	8	12
Sally	12	4	Not known	Not known

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[41] A range is given to represent the minimum and maximum possible figure where exact dates of referral and diagnosis were not provided.

One of these three was diagnosed after almost eight years from the age at first referral. Five were diagnosed in primary school whilst four were of secondary school age. The youngest a girl was diagnosed was at the age of eight, whilst the oldest was 15. The shortest waits from referral to diagnosis were for participants aged 10 years or older. Data for Sally was not provided.

5.3.2 Co-occurring clinically diagnosed conditions

All the girls had at least one clinically diagnosed co-occurring condition or illness (see Table 5.3), as reported by a parent. These preceded the diagnosis of autism in some cases, but not in others. In addition, during interview Alex reported being diagnosed with chronic pain syndrome and believed that the cause was EDS[42].

Table 5.3

Clinically Diagnosed Co-Existing Conditions, as Reported by Parents of Participants

	Additional clinically diagnosed conditions or disorders								
Pseudonym	Eating disorder	OCD	ADHD	PDA	Chronic pain syndrome	Tic disorder	ME[43]	Anxiety	Depression
Alex					Y	Y		Y	Y
Daisy			Y					Y	Y
Emily								Y	Y
Erin	Y						Y	Y	
Jane								Y	Y
Lizza					Y			Y	
Ming		Y							
Robyn								Y	
Rosie				Y				Y	Y
Sally								Y	

It is interesting that clinical levels of anxiety had been diagnosed in every participant except Ming, and that half of the girls had also been diagnosed with depression. This could indicate a correlation between poor experiences in school and mental health, which is discussed in Chapter 6 (see section 6.2.3.2) Further data provided by the girls on their mental health is given next.

5.3.3 Mental health

A clear pattern emerged from most of the narratives showing what the girls viewed as a lack of appropriate support or provision at the same time as a decline in mental health. Over half of the

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[42] Ehler's Danlos Syndrome (EDS)

[43] Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome.

participants in life history interviews reported developing mental distress whilst at school (see Table 5.4). Three of the girls said they had experienced a breakdown. Two of the eight said they had developed an eating disorder, resulting in a hospital admission for one (Erin). Alex, Daisy and Rosie all said they had been hospitalised at least once due to self-harm, suicidal thoughts or attempts at suicide. Rosie stated that she had PTSD as a result of her experiences at school. Daisy said she had made a total of seven suicide attempts before the age of 16.

Table 5.4

Participant-Reported Evidence of Mental Distress

	Participant reported evidence of distress						
Pseudonym	Breakdown	Eating disorder	PTSD	Self-harm	Suicidal thoughts	Suicide attempt(s)	Hospital admission
Alex				Y	Y	?[44]	Y
Daisy		Y		Y	Y	Y	Y
Erin	Y	Y					Y
Jane	Y						
Lizza							
Ming							
Robyn	Y						
Rosie			Y	Y	Y	Y	Y

Note: Emily and Sally did not participant in the life history interviews.

It is beyond the scope of this thesis to determine a causal link, though this is clearly suggested by some of the participants. Listening to the girls was a priority for this thesis, as was reporting the evidence they provided and presenting the meanings they found. The proposition from seven of the eight participants that the decline in their mental health was correlated at least in part with their experiences in school, leading to their absence from it, is compelling and warrants further exploration in the next chapter (see section 6.2.3.2).

5.3.4 Type of school previously attended

All participants had been attending state schools (see Table 5.5). The number of schools each girl attended ranged from two to four. Over half of the girls had gone to just one primary school and one secondary school before they stopped attending, which was unexpected given recent literature on off rolling and managed moves.

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[44] Alex's narrative hints at this but it is not clear from their narrative exactly why they were hospitalised.

Table 5.5

Background Information Provided by Participants on Age, Homes, Schools and Current Attendance Status

								School attendance at time of consent to participate	
Participant	Age on date of first interview	Number of homes	Number of primary and secondary schools attended[45]	Type of last school attended	Sex	Ofsted rating of last school when left	Capacity of last school	Out of school F/T	Out of school P/T
Alex	15	2	2	Secondary	Mixed	Requires Improvement	450 *	Y	
Daisy	15	6	3	Academy	Mixed	Not available ~	1000		Y
Emily	15	NK	NK	Academy	Mixed	Good	1000	Y	
Erin	15	4	2	Academy	Girls	Outstanding	1100 **	Y	
Jane	15	2	2	Academy	Mixed	Good	1300	Y	
Lizza	13	2	2	Academy	Girls	Outstanding	1300		Y
Ming	12	2	3	Academy	Mixed	Good	1300	Y	
Robyn	15	1	2	Academy	Mixed	Not available ~	1000	Y	
Rosie	15	1	4	Secondary	Mixed	Outstanding	500		Y
Sally	12	NK	NK	Academy	Mixed	Good	1300	Y	

Notes:
NK = Not known
* under capacity by 100+
** over capacity by 100+
~ Converted to academy status since girl left

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[45] All schools attended were mainstream provision.

Almost all the last schools the girls attended were rated by Ofsted as good or outstanding, one of which was heavily oversubscribed. One participant had been at a school that Ofsted rated as 'Requires improvement', with an enrolment well under capacity. Erin and Rosie, who had previously attended schools graded by Ofsted as 'Outstanding', both said a school with a good to outstanding Ofsted grade was the sort of school they did not want to attend, due to perceived pressure to achieve at the expense of pupil wellbeing. This was an interesting finding, given the academic aspirations of the girls.

Most of the girls had been at mixed schools. Two had most recently attended girls' schools, one of which was a grammar school. Most of the girls were at Academies, two of whom last attended a school that converted to Academy status after they had left.

Almost all of the girls had previously attended large secondary schools with 1000+ pupils on the roll. However, all the participants stated a preference for smaller schools and smaller class sizes, with Lizza, for example, being one of just 12 on the school roll of her new placement.

5.3.5 Attendance

Participants were asked for their annual attendance statistics as reported by their previous schools (see Table 5.6). This enabled comparison of these figures with instances of absence in the narratives provided by each girl during the second and third interviews. Daisy and Erin didn't have access to their primary school attendance figures.

Table 5.6

Attendance Statistics on School Reports

Name	Y1	Y2	Y3	Y4	Y5	Y6	Y7	Y8	Y9	Y10	Y11
Alex*[46]	95%	95%	95%	95%	95%	95%	95%	95%	50%	0%	0%
Daisy	-[47]	-	-	-	-	-	80%	65%	34%	17%	40%
Erin	-	-	-	-	-	-	97%	93%	76%	12%	N/A
Jane	99%	99%	99%	99%	99%	99%	99%	99%	99%	70-> 0%	0%
Lizza*	95%	95%	95%	95%	95%	95%	80%	60 -> 45%	N/A	N/A	N/A
Ming	-	-	98%	96%	96%	90%	89%	80 -> 0%	N/A	N/A	N/A
Robyn	92%	90%	91%	89%	68%	76%	34%	0%	N/A	N/A	N/A
Rosie*	100%	100%	90%	90%	60%	50%	40%	0%	80%	0%	N/A

Note: Emily and Sally did not participate in interview three, when this information was collected.

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[46] * Denotes estimates by participant and parent.

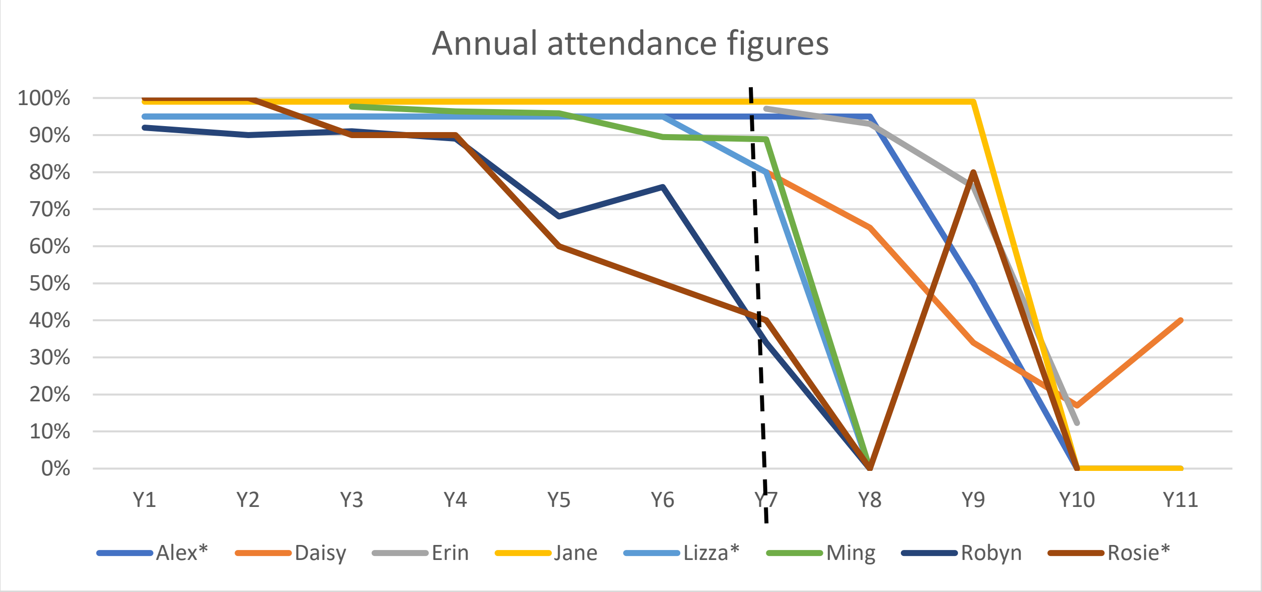
[47] - Denotes no figure provided.

These statistics suggest that absence did not become an issue for most participants until secondary school (see Figure 5.2). This is in line with the trend seen in DfE statistics on persistent absence (DfE, personal communication, November 20, 2018), which were discussed in Chapter 4 (see section 4.2). Attendance dropped severely in years 8 or 10 for the girls in this study. For some (Jane and Ming), attendance to complete non-attendance appeared to happen very quickly:

> *It was on a Wednesday, it was this Wednesday when I just woke up, I don't think I had much sleep that night but that's because I think I was thinking about like school and stuff, and I woke up and my brain was just like why are we going to school? I feel horrible. I feel like this is the most pointless thing on the planet* (Jane).

Figure 5.2

Annual Official Attendance Figures for Participants



Note: The dashed line shows attendance after the first year at Secondary school, other than for Rosie, who attended a Middle school.

For others it was over a couple of years (Alex, Erin and Lizza). Alex, for example, stated they were put on reduced hours by school before they stopped attending: '*obviously there was a gradualness with that'*. Daisy, Robyn and Rosie's figures show a more gradual decline in official attendance:

> Robyn*: It was always there. I mean, I always refused.*
>
> RM*: Was it a build-up, a gradual thing?*
>
> Robyn*: It was a build-up. It was like, every week, when I was about to totally refuse, it would be like, I went in three times a week, and then it was just a simple no, and that was that.*

It is interesting that Daisy and Rosie also increased their attendance for a year at some point, after their attendance had started to fall. This correlated with a change in provision (Rosie) and being present for GCSE examinations (Daisy). Robyn and Rosie were the only girls who gave low attendance figures from primary school.

The life charts and narratives, however, revealed that difficulties were apparent for most of the girls from much earlier in their school careers. Half of the girls reported wanting to stop attending school from the first day or within the first year (*'It never was a certain time where I just went 'I don't want to go'. I never really wanted to go,'* Lizza). These girls all persevered at school for 8-9 years before they stopped attending. Continued attendance was a key issue that most of the participants reported negatively impacted their health and wellbeing:

> *Before I stopped attending, I would cry before going to school and feel sick. I gradually struggled more and more after this and my attendance fell year on year* (Rosie).

In addition, multiple examples of informal absences that do not show up in official statistics were reported by the girls. These included being told not to participate in a lesson, not being listened to and being put in isolation, or removing themselves from class for respite. In some cases, the girls were almost entirely absent from lessons despite being recorded as present in school. Rosie, for example, said that she was only in class approximately 20% of her Y5 attendance figure, which would give an actual attendance of approximately 12%, and only 10% of the official figure in Y6, giving an approximate in-class figure of 4%.

Lack of attendance did not always or initially correlate with obvious underachievement, with some participants describing meeting targets and maintaining high academic levels even when they were rarely in school:

> *My teachers describe me as "very capable" and I used to always get top marks in my exams despite having low attendance* (Erin).

Meeting academic and attendance targets are both standard measures that operate as indicators of concern if either are not met. Conversely, meeting these targets may mean that difficulties and barriers to learning are missed. This knowledge has implications for the identification of needs and provision of suitable support in school.

These findings regarding presence compared to official attendance, achievement despite absence, and quiet perseverance in the face of unnoticed challenges are small but important contributions to knowledge on the barriers to support for some adolescent autistic girls, and may help to explain why some ultimately stop attending school. These ideas will be discussed further in the next chapter.

Finally, it was notable that some of the girls referenced staff absences as issues in some schools. Alex said, '*loads of them just stopped coming in, saying they were ill, until there were like barely any teachers*', suggesting that this may also indicate issues within a particular school's ethos or structure. One of Rosie's comments about what could have been done differently was that a school '*could have treated their staff better'* and taken action earlier when staff cuts led to unsafe situations:

> Rosie: *Because like, when something starts to go wrong, you're meant to go, 'This thing has just started to go wrong, let's see what we can do to stop it, and see what we can do to make it go right again.*
>
> RM: *Yeah.*
>
> Rosie: *You're not meant to just sit with it and let it go more and more wrong until it's just completely fell apart.*

Although it is beyond the scope of this thesis to speculate further on staff absences, the personal narratives in this chapter have illustrated that Rosie's observation is highly applicable to the experiences of the girls, and to the lack of action which led to their absences.

5.4 Lived experience: reframing the narrative

The methods used to generate interview data enabled the capture of ideas about participants' ideal schools and of their memories of significant events at school (see section 3.2.2 for further details). Final interview sessions were used to identify and explore the themes and meanings participants attributed to their experiences, thereby challenging the narrative about pupil absence from school.

5.4.1 Personal construct of the ideal school

All ten participants completed this activity, which was developed from the model used by Williams and Hanke (2007). Participants were asked to give three responses to nine briefly described aspects of school (e.g., 'the classroom'), for the sort of school they did not want to attend and for their ideal school. Three set questions per aspect were available for those girls who struggled to answer the open questions (see Appendix 3.13). Alex, Daisy and Robyn all had the most ideas to share, only needing the subject heading to prompt them. Emily and Sally took the longest to provide answers and required the most structured questioning.

The responses provided for the sort of school participants said they would not like to attend contrasted considerably with those for their ideal school (see Figures 5.3 and 5.4). However, '*people'* emerged as the most frequently discussed theme in both types of schools. This is interesting as it suggests the attitudes and approaches from teachers and peers are fundamental to understanding the difficulties experienced by these girls, and that they are key to solutions.

Figure 5.3

All responses about the Sort of School Girls did not Want to Attend

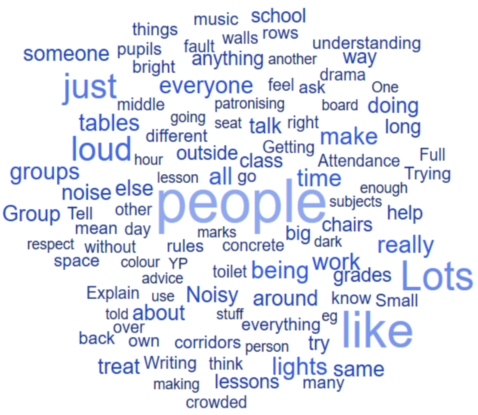


Figure 5.4

All Responses about their Ideal School

Difficulties with peers are exemplified by the amount of bullying described in the personal narratives (see Appendix 5.5), and also in the responses to how teachers structured classroom tasks. Most of the girls said that, in the sort of school they did not want to attend, teachers would ask them to work in groups (see Table 5.7). Whilst there was a recognition that working with others was important (*'peer work is not the best but it's necessary'*, Sally), the attitude of peers made completion of group work difficult. The impact of this was that some girls said they would not be able to do any work (*'I can't focus because I'm focusing on the other people instead of my own work'*, Jane), whereas other participants said they would do the task alone:

> *I end up being over controlling and, um, and yeah taking over really badly and doing all of the work because no one else wants to and end up having to complete the whole task myself* (Alex).

Table 5.7

Difficulties of Group Work and Example Evidence

Reason	Evidence
Peers don't want to participate in group work	• *'Group work's extremely difficult for me unless I'm in a, in a specific group of people who know how I work and are willing to work too and actually want to do stuff.'* (Alex) • *'Sometimes people don't do their work.'* (Jane)
Peers are more disruptive during group work	• *'Neurotypical kids, they quite like all the group work, because it's a chance to mess around'* (Daisy) • *'The other students would also be badly behaved and disruptive to classes.'* (Erin)
Peers are unkind during group work	• *'Are actually consciously unpleasant to me.'* (Alex) • *'I'd be willing, I'd be willing to do group work if the group were actually nice people.'* (Sally)

In both cases, the collaborative benefits of group work would not be achieved. In addition, the noise of people chatting, the difficulties of managing interactions (‘*I want to say something and I don't get to say it, or like if someone's saying something that I don’t get’,* Lizza) and the confusion created by tasks that require moving around the classroom (‘*it just gets so confusing and everyone, it’s just like hectic’*, Daisy) made learning via group work more difficult.

The impact of teacher attitudes on learning and engagement in the classroom is illustrated by how the girls said teachers would respond in the non-ideal provision if they said they didn’t understand work (see Table 5.8). In these responses, teachers do not engage with the girls or seek to investigate why they don’t comprehend instructions or explanations. Instead, their actions suggest the lack of comprehension is the fault of the child. In addition, there is evidence of a perceived reluctance on the part of the teacher to spend further time assisting the girl, a theme returned to in section 6.2.3.1.

Table 5.8

Teacher Responses to Participants not Understanding Work and Example Evidence

Response	Example evidence
Repetition of explanation	• *‘Like repeat exactly the same back to me.’* (Alex) • *‘They’d just sort of explain it the same way they did without expanding on it.’* (Emily)
Dismissive of need to understand	• *‘Tell me not to worry about it, ‘don’t worry if you don’t understand it’, but I need to know it!* (Daisy)
Blame pupil	• *‘They would get annoyed and assume that you just weren’t listening and either get another pupil to explain or just skim over the instructions again.’’* (Erin) • *‘They sort of like roll your eyes or they sigh, and they think you don't see but you do.’* (Lizza) • *‘They’d just, would say that ‘you can do it, you’re just not trying hard enough, like, you’re just trying not to.’* (Ming) • *‘They would respond to, mostly, um, “you weren’t listening” or “it was your fault for not understanding because you weren’t paying attention to how it was explained”.’* (Robyn)
Punish pupil	• *‘Detention. Shout at me.’* (Rosie)

Differences between the two types of schools were particularly apparent in comments about the likely ethos of each (see Figures 5.5 and 5.6) and in how the girls thought they might feel as a pupil at each (see Figure 5.7). All the participants said they would least like to attend schools they perceived cared most about grades (see Appendix 5.6 for example data). This was unexpected as all eight who took part in the life history interviews described themselves as academically able, and the six older participants needed good exam results to achieve their ambition of going to University.

Instead the girls said their ideal school would prioritise the welfare of the students the most. They talked about wanting to go to a school that cared most about the ‘*wellbeing’* of its pupils and treated them with ‘*kindness’*, where they could be ‘*happy’*.

Figure 5.5

Responses about the Ethos of the sort of School Girls did not Want to Attend

Figure 5.6

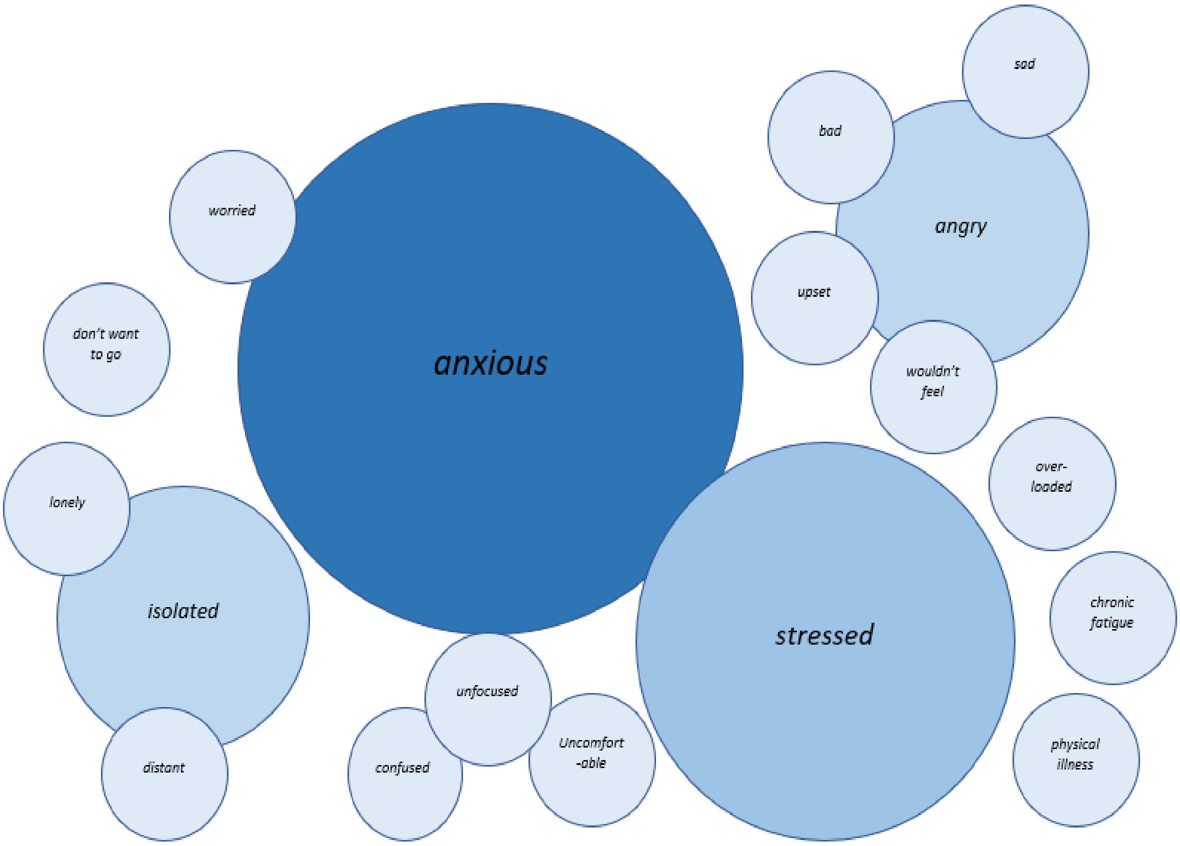
Responses about the Ethos of their Ideal School

The importance of mental health to these girls is further evident from their responses to how they might feel at each school (see Appendix 5.5 for example data). Figure 5.7 illustrates feelings about the sort of school they would not like to attend, with the more frequent the response, the larger the size of the shape. Similar feelings are grouped together.

This pictorial representation of the data shows that anxiety and stress were the predominant responses, with Emily for example saying she would feel ‘*really anxious and quite uncomfortable’.* By contrast, the most common answers for how they would feel at their ideal school were ‘*happy’* and *‘comfortable’*. Girls listed feelings such as ‘*happy and respected’* (Robyn) and ‘*accepted and safe’* (Jane) in their ideal school. This recurring theme of pupil wellbeing will be considered further in the following chapter (see section 6.2.2).

Figure 5.7

How Participants said they Might Feel in the Sort of School they would not Like to Attend



Most of the girls said they idealised schools with more space and less sensory input. Half of the participants reported finding inconsistent classroom lighting, flickering lights or bright, fluorescent lights distressing. Over half of the girls were hyper-sensitive to smell *('My mum calls me a sniffer dog because I can smell things from like miles away,'* Daisy) and stated that in their ideal school no one would wear strong perfume or aftershave as it impacted their ability to work ('*It makes me feel physically sick,'* Alex; *'I can't function if there are strong smells I don't like,'* Rosie). Several mentioned the loudness of the school bell, or the inconsistency of the length it rang, and most highlighted the noise created by their peers as problematic. One (Rosie) raised the difficulty of concentrating in an uncomfortable school uniform. All the girls except one reflected that in the worst schools there was not enough space to move about. Classrooms, corridors, and the canteen were too confined or too crowded and the girls felt at risk of being pushed or touched unexpectedly, which made them feel anxious and vulnerable:

> *I don’t like being, I get quite stressed if I’m worried that people are going to like knock into me or, er, touch me. Erm. I wouldn’t like to be sitting sort of in the middle. So, I’d have, I wouldn’t want to have people all around me.’* (Emily)

Greater volumes of people, such as at times of transition or in the canteen, also led to queueing, which Ming said gave people the chance to be mean or to throw things.

There were also anticipated differences between the girls’ preferences, such as Lizza preferring brightly lit spaces (‘*I quite like the lights to be bright because if it's quite dark and warm you feel very tired, I feel very tired and I can't concentrate’*) whilst others like Robyn wanted low lighting (‘*I have blackout blinds to block out the sun from glaring at me. The light in my room, the bulb is eco-friendly, so it’s really dull*’), reflecting an individual’s hyper- or hypo- responsiveness to sensory input and the importance of understanding personal needs. Having personal control over sensory input was important for some of the girls, which could affect the suitability and success of a placement.

Robyn, for example, preferred working from home with an online education provider as:

> *I can, you know, I have the choice of the type of mouse that I like, the computer mouse. You know, how it feels, which one I have. You know, I can choose the cushions behind me, water, eating. I’ve got that control* (Robyn).

Prioritising answers in the diamond ranking activity that followed was difficult for most participants and for Alex in particular. They expressed that it was hard to select their most important answers (‘*I wouldn't have written them if they weren’t important!’*) and then to rank them:

> *Yeah, I think it depends a lot on, on, on what's happened around that time because if you’ve had someone be really unpleasant to you recently, then that’s gonna, then people being nice and understanding is going to go higher up um, than like other things* (Alex).

Their ranking was done in an extra session between interviews 1 and 2. Perfectionism and a lack of concrete context were significant factors in why participants struggled with this task. Rosie, working from a distance, did not present her top nine answers as instructed and in the same way as the others. She said she positioned them in the form of a rectangle because they formed the foundation for everything else that she needed (see Appendix 5.7). Her work is presented in this way to honour her voice. The results of the ranking exercise are presented in Table 5.10 (see Table 5.9 for a key to colour-coded themes).

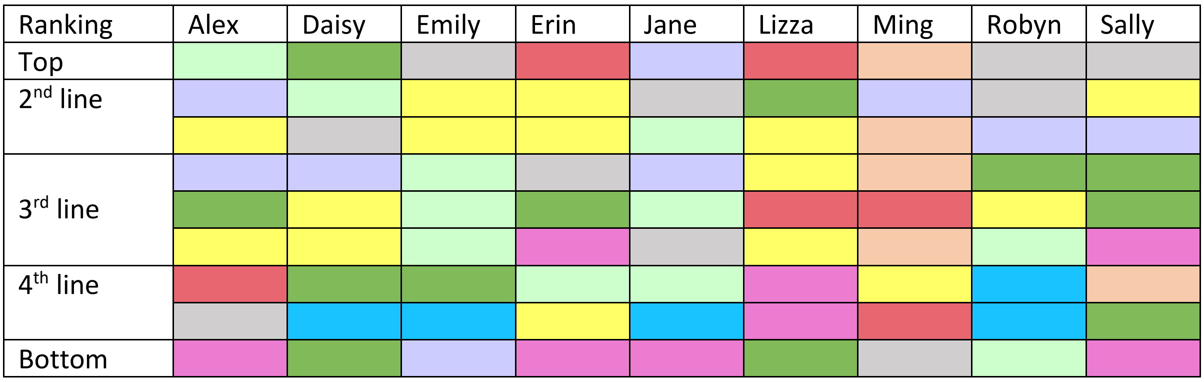
Table 5.9

Themes used in the ideal school exercise, by colour

Theme		
The classroom	Adults	Teaching
Other space	Peers	Learning
Sensory issues	Me	School ethos

Table 5.10

Ranking of each participants' top nine responses, as identified by them



Ranking	Alex	Daisy	Emily	Erin	Jane	Lizza	Ming	Robyn	Sally
Top									
2nd line									
3rd line									
4th line									
Bottom									

Whilst just over half the girls included responses about their sensory experience of school, most participants placed these elements low down in their rankings. Robyn, who talked about the huge value to her of being able to make her own environmental adjustments by online learning at home, didn't include sensory items at all. Looking at the literature, it was unexpected that the sensory experience of the environment did not rank more highly in the girls' prioritisations, and reasons for this are discussed further in the next chapter (see section 6.2.2).

'Adults' was the theme placed in the rankings most frequently. Responses from this theme were placed in the top two lines of ranking by half of the girls and half of them selected 'adults' more than once in their top nine. It was also the most mentioned theme amongst all chosen responses in the ranking exercise. Participants explained this by stating that the right approach from staff would mean all necessary adjustments would be made, and requirements met (including those of the environment). This is explained well by Rosie:

> *Adults would know everything they need to know about me and would understand me, because if they don't know why they are doing things and agree with the reasons behind it, they just won't do it.*

Only Jane did not select an item from this area. Participants wanted '*supportive, understanding teachers who check in with you emotionally'* (Alex), who would '*understand situations that might make* *something difficult'* (Ming), and who would '*give personal advice*' (Emily). In their ideal schools, adults would '*care about* you' (Ming) and have '*a personal plan'* (Emily) for each pupil. They would provide help that was '*discreet'* (Alex) or '*subtle'* (Daisy) when it was needed and '*go out of their way to make sure you understand'* (Ming). They would also treat you fairly ('*be just and not prejudiced*,' Robyn).

The significance of peers is likewise noticeable from the ranking exercise which was expected from the literature on friendships (Sedgewick et al., 2016) and is in line with the bullying reported by most of the girls in their narratives. Alex, for example, stated that peers should, '*Be understanding and not discriminatory and not shout abuse at me!'* In their ideal school, they would have '*a group of friends who would miss me* – [I'd be] part *of it'* whilst Sally said peers would be '*genuine friends'*. The attitude of peers towards others and about work emerged as important. Robyn said they would be '*very mature and respectful'*, whilst Emily said they'd be '*considerate',* and Daisy stated they would '*see me as a person not as a diagnosis'*. Peers would have a '*willingness to learn*' (Jane) and be '*likeminded people interested in learning'* (Alex). Only Lizza did not rank peers in her diamond of top answers.

The ethos of the school also emerged as an important theme. It was ranked top by a third of the participants, on the top or second line of ranking by two thirds of the girls, and in the top nine by all participants except Lizza. Prioritising '*student wellbeing'* was included by Daisy, Erin, Jane and Sally (for whom it was most important aspect of her ideal school). Ming, Robyn and Rosie said their ideal school would want pupils to be '*happy'*, plus '*feel safe'* (Rosie), *'independent and yourself'* (Robyn). School would teach them to '*have the skills to do work and manage anxiety*' (Emily), enable them to '*reach their goals*' (Alex) and '*achieve their dreams*' (Rosie), whilst still giving them time for themselves ('*the choice of a life*', Robyn).

The category of 'me' also had interesting results. All the older girls had at least one response from this theme in their ranking, with Emily, Jane and Robyn selecting more than one. Meanwhile, Lizza, Ming and Sally, the three youngest participants, did not include any responses about themselves. Statements reflected a desire to feel '*safe'*, '*accepted'* (Jane), '*relaxed'* (Erin) and '*comfortable to be myself'* (Alex). Daisy said in her ideal school she'd be '*blending in – a part of it all*'. Girls also said they would be '*working,'* '*in lessons*' (Emily and Lizza) and '*learning*!' (Jane).

Finally, some themes were particularly important to one individual but not others. 'Teaching' was included most often for Daisy, who said she wanted teachers to '*treat me and give me the same challenge as NT child'* and be '*very direct and blunt* [about] *expectations and* [when giving] *explanations'*. Ming included 'other space' four times in her ranking, with her ideal school having '*gardens you can help with'*, '*library, farm* [and outside] *equipment*' and a '*clean canteen with wooden tables and tablecloths*'.

The personal construct exercise showed that the ethos of the school, plus the behaviour of adults and peers, impacted on how the girls felt about themselves and about school. Whilst this exercise asked the girls to imagine the sort of school they would and would not like to attend, it is possible that the participants' comments were based on personal perceptions of real experiences. The implications of this for their attendance at school will be considered in Chapter 6 (see section 6.2.2).

5.4.2 Life charts

All of the life charts (see appendix 5.2 and 5.3 for two example sections) showed that participants remembered positive as well as negative experiences and events; with most presenting a history that meandered above and below the neutral line of the chart. There was variation between individuals in terms of the number of events added to each life chart (ranging from 7 to 47). Daisy and Robyn had the highest numbers of negative and positive events. Erin and Jane had the lowest numbers. The earliest memories ranged between starting at nursery/pre-school to Y3. Just over half had more negative than positive experiences. Half the participants also identified a few events as neutral. This illustrates in part the extent of the individual variation in the completed charts.

In the final interview participants were asked to choose three negatively remembered events, explain why they hadn't gone well and consider what might have helped on that occasion. They were then asked to select three positive events from their life chart, explain why it had been good and describe what had been helpful. Evidence of what helped the girls at school is as valuable in making recommendations about provision as the negative experiences, as it leads to a deeper understanding of why some support strategies were effective for some individuals, and not for others. Reasons given for which events were chosen included that they were most important for the individual (*'I feel like it was more significant',* Alex), or that they were selected using a pattern (*'Year 3, year 6, and year 9'*, Erin, 3).

5.4.2.1 Negatively experienced events.

The type of event or experiences chosen are listed in Table 5.11, which also indicates which participants selected them. 12 types of events or experiences were chosen, of which six were chosen by three or more of the girls.

Table 5.11

Type of Negative Event Selected by Participants from their Life Charts

Event or experience	Alex	Daisy	Erin	Jane	Lizza	Ming	Robyn	Rosie
Struggled to communicate	Y							
Tests and exams (pressure/anxiety)	Y			Y		Y		
Bullying (by adults or peers)	Y	Y	Y	Y		Y		Y
Friendships (making/losing)	Y			Y	Y			
Loss of safe space	Y	Y						Y
Excluded		Y						
Disruption and change			Y					
The environment (sensory impact)			Y			Y	Y	
Injustice					Y		Y	Y
Homework					Y			
Not being given a chance / overlooked						Y		
Force / discrimination							Y	

Bullying by peers and adults in school was the most frequently selected type of negative experience (see Appendix 5.5 for the types of bullying the girls said they had experienced). These incidents were particularly concerning in Rosie’s case, who reported in her narrative that the TA responsible for her 1:1 support abused her, and for Daisy, who (for example) stated another pupil violently assaulted her to the extent she needed medical treatment, and who mentioned bullying more than twice as much as anyone else. Some events concerned loss, such as the loss of a safe space at school or the loss of friendships. The sensory impact of the environment was another common issue, as were the pressure and anxiety created by tests and exams. Injustice was the final theme, encompassing being blamed, overlooked, discriminated against, and forced to comply with others’ expectations.

Participants were then asked to suggest what the school could have done differently to prevent or reduce the impact of the negative event or experience (see Table 5.12 for example data). Suggestions were made for staff knowledge and attitudes, for the structure and ethos of the school, and for the treatment of pupils as individuals.

Table 5.12

Example Data of Negative Events Selected

Name	Event	Reason chosen	What might have helped?
Daisy	*All bullying events / attacks at school*[48]	*They all made me feel sad and scared to go to school.*	*Addressed the issues and listened to my concerns, investigated the issues and dealt with them appropriately.*
	Being excluded from school (informally) for a week (2018)	*It highlights and perfectly captures the injust*[49] *and segregatory treatment I have received from the system.*	*Actually used their EHCP funding correctly, offered alternative solutions and try to understand how my diagnosis effects my behaviour.*
	Banned from eating lunch / staying inside with LSA at lunch (2017)	*This forced me to go into an unsafe and overwhelming situation as senior staff with no ASC experience tried to get me to be 'more social'.*	*Asked me why I wanted to eat inside and aimed to understand my difficulties and threat from peers or offered me an alternative safe space to eat and spend my break/lunch.*
Erin	*Building at school, disruption and random fire bells* (Y3)	*I felt more anxious and was unable to settle in class properly.*	*I think they could have allowed me to wear ear defenders for fire bells and given us a more structured environment. I don't think there was much they could've done as most things were focused on the bigger picture of the school, and not current pupil wellbeing.*
	Friend problems (Y6)	*I got bullied by someone…who masqueraded as my friend.* [The school] *said, "We don't have bullying in our school" and acted like it was my fault and there was nothing they could do. It was overlooked by all the teachers. I was never believed, and it made me angry.*	*They could have encouraged friendships better and structured school better.*
	Barely in, no friends, bullying (Y9)	*I just didn't cope in the mainstream environment. I think because my autism wasn't supported throughout I reached breaking point. I was feeling sick all the time, my best friend was telling lies about me and school did nothing.*	*I think school could have made adjustments to accommodate my extreme anxiety at the time. They made small changes like a timeout pass, to leave class if I was overwhelmed. But none of these helped…* *Maybe creating a nurture environment where there were less pupils or having a teaching assistant. Having written prompts to aid me in my work. And also having things explained in a way I understood.*

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[48] Daisy identified 14 occasions of bullying on her life chart, from specific incidents (e.g., '*had my head put through a wall 2016*') to long periods of time (e.g. *'bullying 2011'*).

[49] The spelling of Daisy's words in this section is taken from her original data, which in this case was provided in written format.

All eight of the girls who completed life charts said they thought being autistic was part of the reason they were no longer in school. Some of the girls connected this with teachers needing more knowledge about autism. Alex said, '*I don't think it's my autism that's caused it, I think it's the lack of understanding of other people that's caused it,'* whilst Rosie said of her primary school and her Y2 teacher, '*I would think the school should have helped her understand better'.* Alex also said they wished that staff '*had actually identified I was autistic'* when they were in the early years of primary school, as this may have been beneficial. The term 'autism' was used by some peers as an insult, either as a general term ('*Now if someone does something stupid, people say, "What, are you autistic?"'* Jane), or as a personal attack. All of the girls described the challenges they experienced as autistic young people in school, which ranged from struggling to communicate (Rosie) to a lack of '*the right support'* and no '*resources or training'* (Daisy) to being overwhelmed by '*anxiety and social difficulties'* (Erin). As Ming said, *'It just made things harder'.*

Some girls stated that if staff had been more curious about what they did, then problems could have been averted. Daisy said if teachers '*had asked me why I wanted to eat inside'* with a trusted adult they would have realised why insisting she went out on the playground was so threatening for her. Rosie linked a lack of understanding to a lack of will from school to recognise issues and make changes:

> *If the school had wanted to understand and made an effort to learn how they could have made it easier, then that would have been a huge help.*

Most of the girls said they thought that poor experiences could have been improved if schools had '*listened, when we were telling them things'* (Rosie) and taken action to resolve problems rather than making assumptions or offering '*empty reassurances*' (Ming). This involved doing more to stop bullying by making it '*clear that there are consequences and…you won't just get away with it'* (Jane).

Daisy said her school could have 'a*ddressed the issues and listened to my concerns, investigated the issues and dealt with them appropriately'.* This was also mentioned by Lizza, who said she thought teachers should do more to '*investigate'* situations before blaming pupils and not *'just straight away shout at them, that's not fair'*, revealing a strong sense of injustice that was echoed in Robyn and Rosie's narratives. This was amplified by some girls saying that the removal of threats about attendance from schools ('*they were like 'we're not threatening you', and it's like yeah but I feel threatened',* Jane) and about abuse from peers, plus the fear generated by being shouted at, would both have had a positive impact on them.

The next group of suggestions relate to the school environment. Several girls said that adjustments that accommodated their sensory experience of school would have been extremely beneficial. Jane expressed the difficulty of trying to learn in a classroom whilst being hyper-sensitive to sound:

> *I could hear people shuffling around and playing with pens, and like l could hear the very distant whispering over in the corner, and it was just like I couldn't handle it because I couldn't focus on my own work.*

For Robyn, meeting her sensory needs was a constant consideration and underpinned everything. She suggested:

> *Either noise-cancelling headphones, or something to do with the ears…Get the ones* [lights] *that don't flash or are too bright…Like have sections for the food, so like a vegetarian room, for those who only are vegetarians.*

Some of the girls suggested '*maybe creating a nurture environment where there were less pupils*' (Erin). They made comments about the provision of safe spaces for unstructured, unmonitored periods, with half the girls naming the library as their preferred space. This option had been removed for two of the girls. Alex said they had '*lost library as a safe space'* and Daisy said she was '*banned from using the library'*. This resulted in them feeling less safe, more isolated and, in Daisy's case, unable to eat. She said it would have helped her if school had '*offered me an alternative safe space to eat and spend my break/lunch'.*

Finally, the girls suggested that schools and staff providing personalised support would have a positive impact. Alex reflected that this should be pre-emptive, not reactive, and led by the school. This would mean support was already in place or planned for when they needed it, so they wouldn't feel like a burden when they asked for help. The girls had different ideas of the sort of support that would be meaningful and helpful for them. Jane and Rosie wanted teachers to listen to their views and voices so that plans were individualised, and they weren't '*just lumped in with the rest of the class'* (Rosie). Ming said that teachers could have given her things to do '*based on my ability rather than them thinking I couldn't do it'.* Rosie and Erin wanted to have the aid of a TA (whilst Daisy did not), with Erin also expressing a preference for '*having written prompts to aid me in my work'.* Ming wanted a room on her own for exams whilst Alex felt removing unnecessary pressure from tests would have helped. This desire for individualised support was connected to their wellbeing. The girls wanted to know that schools cared enough about them; that they would be '*seen'* as individuals, valued, '*listened to'* and supported.

The importance of relationships to these girls is noteworthy, and the impact of positive or negative encounters on their attendance will be discussed further in Chapter 6 (see section 6.2.2.2).

5.4.2.2 The meaning of positive events.

The type of event or experiences chosen are listed in Table 5.13, which also indicates which participants selected them. 13 types of events or experiences were identified, of which three were chosen by three or more of the girls. Being able to access education outside the mainstream system was one of these.

Table 5.13

Type of Positive Event Selected by Participants from their Life Charts

Event or experience	Alex	Daisy	Erin	Jane	Lizza	Ming	Robyn	Rosie
Supportive teachers who believed in me	Y	Y						Y
Working at my own pace / teachers guided by me	Y							Y
Fun activities / school play	Y			Y	YY[50]			
Joining a team	Y							
Learning music – discovering a new passion		Y						
Dropping subjects that were stressful		Y						
Accessing alternative form of education			Y			Y		Y
Making a good friend				Y		Y		
Personal academic achievement					Y		Y	
Being a school librarian						Y		
Diagnosed autistic							Y	
Leaving mainstream education							Y	
Quiet environment; space to be alone								Y

One participant, Erin, only had one positive event on her chart. Some of the girls chose positive events that happened after they had left mainstream. Emerging themes intertwine with and reflect some of the meanings revealed from the analysis of negative events.

Participants were asked to suggest what the school did that was so helpful in these cases (see Table 5.14 for example data). As per the negative events, being understood by other people was influential

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[50] Mentioned twice.

Table 5.14

Example Data of Positive Events Selected

Name	Event chosen	Reason chosen	What worked well
Lizza	*Free reading list* (Y4)	[It] *was important to me because I was the first person and I'm competitive, so that's why, and also I like reading.*	*I'm just really competitive and I like to be first. I like to say I was the first on the free reading list in Y4 and no one else was. Because you automatically go on the free reading list in Y5, but no one else was on the free reading list in Y4.*
	We hatched chicks (Y5)	*I just really like animals, they're so cute. So adorable, I love them.*	*Just because I like animals, that's why, they make me happy… I had a special one that I liked, and it was the only one, um, it was just like, it was like the odd one out, they were all fluffy and yellow but that one was black.*
	WW2 project (Y6)	*I'm interested in it.*	*I like projects, putting stuff together and being focussed on one thing, because I can be very good at that one thing. Whereas when we're constantly switching from topic to topic, then um, it just gets confusing and um I can't learn it thoroughly.*
Ming	[Name deleted] *moved to my school* (Y6)	*Because she is one of my best friends, even though we are not at school together now.*	*She's a very good friend. She's nice, she likes Minecraft, history and reading like me.*
	Being a school librarian (Y7)	*I love books and I made friends there.*	*Librarian was nice. Somewhere to go at lunch not outside. I liked the jobs we did.*
	Home Ed. Doing my own projects like Iron Age house (Y8)	*I can learn about things I'm interested in.*	*I can do more stuff on the stuff I'm really interested in. Don't have to do the same as everyone else. I like it because I get to do more textiles / horse riding and history.*
Robyn	*Diagnosed autistic* (Y4)	*It just helped me to understand myself.*	*Understanding myself. I mean, yes, I have so many more things to be discriminated against I guess, but it's illegal.*
	Leaving mainstream (Y7)	*I could begin to de-stress. And de-sensory.*	*It was mainly let myself de-stress after the horror of year seven, and the (name of school deleted), the way they treated me…So like ground myself from the sensory input I had had for years, which took ages. Help get my anxiety, well I didn't really get it under control, but it reduced anxiety.*
	Finals of STEM competition (Y9)	*Everyone was concerned that I wasn't attending a proper school um, and yet I'd just beaten all mainstream people.*	Worked with her best friend. Got to make something using their own design. *We had great fun…I got to go and think about all the people in my life who thought I was stupid and useless, and go, 'Ha! I came second in a national competition, beat that!' kind of thing.*

in the girls having positive experiences. They valued adults who they perceived as supportive, who answered questions (‘*someone there I could ask stuff to and wanted to help me’,* Alex*)* and ‘*understood my difficulties but didn’t ignore my strengths’.* Feeling that they were cared about was important, with Daisy describing a teacher who provided *‘a safe space to hide and express my feelings’* and Jane responding best to ‘*teachers who actually liked me and respected me’.* Rosie stated that teachers who trusted her to control the pace of her learning, who listened to her and were guided by what she said worked best:

> *I knew how much I could deal with, like how much, like what things I couldn’t cope with, what things I could cope with, how much support I would need to be able to cope with those things, and they just went by what I was saying. And because of that I was able to achieve really well.*

Having a friend or someone to share things with was mentioned by most of the girls in their explanations of why events were positive, in contrast to the amount of bullying most described experiencing at school. Someone being ‘*nice to you*’ was seen as a ‘*big break’* (Jane) from their normal experience. They valued occasions when they felt ‘*part of the group’* (Alex) instead of ‘*being judged’* (Erin). Ming and Robyn commented on the pleasure of being with someone who shared their interests (‘*she likes Minecraft, history and reading like me’,* Ming) and Alex liked being with people on the ‘*same wavelength’.* Having opportunities to develop a mutual understanding - overcoming the ‘double empathy problem’ (Milton, 2012) – was important to these girls.

The girls noted when the impact of the physical, pedagogical, and social environment was positive. For Erin and Robyn, this was after they had left mainstream school. Robyn talked about needing time at home to ‘*ground myself from the sensory input I had had for years’* and letting herself ‘*de-stress after the horror of Y7, and the* (name of school deleted), *the way they treated me’.* Erin described why the hospital school she attended next was a much better setting for her:

> *The small environment of the hospital school meant that I was no longer overwhelmed. There were less pupils and they had all been in the same place as me so would not judge me as easily. I also began to make friends a few weeks ago and that has improved my mood.* (Erin)

Most of the girls chose an event that they said was fun. Jane enjoyed participating in a school play (*‘the people who were there wanted to be there and, you know, there was no disruption’).* Ming, Lizza and Rosie all talked about the pleasure of spending time with animals. Lizza described hatching chicks at school and connected this to a feeling of wellbeing: ‘*I like animals, that’s why, they make me happy’.* For other girls, being able to spend more time with animals was a benefit of no longer attending school. Ming said she got to do more horse riding, whilst Rosie said *'I was at home, so I was having lots of animal time with the dogs. Erm and getting some horsey time for a bit.'*

The girls described other advantages of not being in mainstream school. These included having more time to pursue subjects that appealed (*'I can do more stuff on the stuff I'm really interested in,'* Ming) and being able to focus on individual projects (*'I like projects, putting stuff together and being focussed on one thing,'* Lizza). These preferences were expected, given the concept of monotropism (Murray, 2018). Some of the girls felt leaving mainstream school gave them the opportunity to start achieving their academic potential, which was unexpected. Robyn described feeling vindicated when she was placed second in a national STEM competition:

> I *got to go and think about all the people in my life who thought I was stupid and useless, and go, "Ha! I came second in a national competition, beat that!" kind of thing.*

Rosie had private tutors for a short period of time, during which she said she made academic progress and also noticed an improvement in her mental health (*'I was feeling really happy academically, I was achieving, I was being told that I was achieving. I didn't feel worried about my future'*).

These findings point to connections for these girls between agency, interest, wellbeing, and learning, which will be discussed further in Chapter 6 (see section 6.3).

5.4.3 Strengths and Difficulties Questionnaire

The eight girls who took part in the third interview concluded by filling in the YP (self-report) section of the SDQ[51] (Goodman, 1997, 2012). Although Lizza said she enjoyed doing it, the other girls found it very difficult to complete. Some statements were felt to be impossible to answer, such as '*Other people my age generally like me*'. Lizza responded to that item by ticking every box (meaning that statement wasn't scored) and said, *'I don't know, I'm not a mind-reader!'* They queried the meaning of statements and struggled with the lack of context, with the self-awareness that their response would vary depending on the situation and their skills. Alex gave particularly detailed explanations of their thought process for each statement. For the item '*I'm helpful if someone is hurt, upset or feeling ill',* for example, they said:

> *I feel very empathetic for people and like if someone is upset, um, I will feel really bad for them, but at same time I have zero clue what to do about it. So, like I try, but I'm probably not that helpful.*

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[51] Strengths and Difficulties Questionnaire.

The results of the SDQ (see Table 5.15) are included here as they demonstrate the mutual misunderstandings that can occur through imprecise language and indicate the need for unambiguous tools that provide context (see section 6.2.1.2 for further discussion). This scored item on the SDQ questionnaire could, without incorporating the voice of the young person during completion, suggest that the YP is unhelpful (and may lack empathy) whereas the reality is that the YP is very empathetic (but unsure how to act). These points are highly relevant for teachers in how they speak to and support autistic YP and emphasise the importance of enabling these YP to give their views: *'If they just <u>spoke</u> to me and <u>asked</u> me what things I think I'm, I'm dealing with,'* (Alex).

Table 5.15

Individual scores on the SDQ

Scale	Alex	Daisy	Erin	Jane	Lizza	Ming	Robyn	Rosie	Sally	Emily
Prosocial behaviour	8	8	4	9	8	9	7	8		
Emotional symptoms	10	7	10	6	10	3	3	8		
Conduct problems	1	3	1	1	6	4	3	3		
Hyperactivity	5	8	4	5	7	3	5	3		
Peer problems	6	6	6	6	1	6	3	7		
Total difficulties[52]	22	24	21	18	24	16	14	21		
Externalising[53]	6	11	5	6	13	7	8	6		
Internalising[54]	16	13	16	12	11	9	6	15		

4 band categorisation of scales:

All scales except prosocial scale

Close to average
Slightly raised
High
Very high

Prosocial scale

Close to average
Slightly lowered
Low
Very low

The individual scores for each scale on the SDQ (see Table 5.15) are also interesting. Robyn's total difficulties score was the only one close to average. Only Lizza's responses on the Conduct scale scored as very high (top 5% of population), with the rest of the girls scoring close to average or slightly raised. In addition, most of the girls had higher internalising than externalising scores, suggesting 'difficulties'

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[52] Sum of all scales except the prosocial scale

[53] Sum of Conduct Problems and Hyperactivity scales

[54] Sum of Emotional Symptoms and Peer Problems scales

with peers and emotions. These findings are consistent with the literature on masking by many autistic girls (Hull et al., 2020) and have implications for how other people may perceive the extent of their needs.

Finally, all the girls except Erin scored close to average on the prosocial behaviour scale, which was unexpected as the literature suggests ‘Autism Spectrum Disorder (ASD) and reduced prosocial behaviour are strongly intertwined’ (Oerlemans, Rommelse, Buitelaar, & Hartman, 2018p. 1033). The literature furthermore says that prosocial behaviour, described as ‘voluntary behavior intended to benefit another’ (Eisenberg, Fabes, & Spinrad, 2006, p. 646), is motivated by empathy (van der Graaff, Carlo, Crocetti, Koot, & Branje, 2018); a quality some studies have also suggested is lacking in autistic people. The responses of the girls in this study suggest otherwise.

5.5 Summary

The girls’ thematic analysis of their own charts together with their personal narratives revealed many reoccurring themes. The girls reported overwhelming environments, unmanageable group tasks and a lack of individualised support. Whilst these issues could have been resolved, the girls said that further difficulties arose when teachers did not appear to listen to or believe them, were seemingly unresponsive to their needs or prevented them from accessing the personal adjustments they had developed to cope. Some of the girls described force being used against them, either physically or by being expected to conform. Eight of the girls recalled (often multiple) incidences of bullying and abuse by teachers and peers, which were linked to them feeling unsafe, frightened, and anxious.

The feeling of injustice about their experiences was highlighted by most of the participants, and they exhibited anger and frustration about this to varying degrees. These aspects were all associated with absence and a sense of loss (of education, of friends, of trust and of health). Rejection, exclusion, and isolation were also prominent in their accounts, as were descriptions of not being understood. These outcomes are noteworthy due to their recurring nature through the other participants’ narratives.

An examination of the three key positive and negative events identified by each participant, together with the ideal school exercise, suggested that prioritising pupil wellbeing was the most important protective factor for these girls in being able to attend school. They reported that to learn they needed to feel safe, cared about and understood; to be recognised and listened to, not overlooked. The type of positive and negative events that were significant for each girl, as well as the presence of good memories, the meaning they ascribe to them and the recommendations to improve practice that emerged, all make small but important contributions to an understanding of the phenomenon under investigation.

The next chapter draws together the findings presented in chapters four and five, arranging them under the overarching theme of tensions and contradictions. The possible meanings of the findings are discussed and the implications of each are considered, with reference to Paulo Freire and the influence of power in education, and to Albert Bandura and the importance of agency.

Chapter 6: Discussion

6.1 Introduction

This research set out to understand why a seemingly growing number of autistic adolescent girls stop attending mainstream secondary schools, and to provide some scale of the issue. A mixed methods approach was taken, prioritising the voices of a sample of autistic girls in a series of life history interviews, and also utilising secondary data retrieved from the DfE and NHS. Analysis of secondary NHS data showed that the proportion of female CYP referred for an autism assessment compared to males was increasing, though males were still more likely to be referred than females. The data shows that the mean age at referral and diagnosis was decreasing for females, but was a year older than that for males, who were diagnosed most frequently at primary school. Interesting between-group differences by type of referrer were revealed (see Sections 4.2 and 4.3 for additional detail).

DoE data showed the number of diagnosed autistic females in primary and secondary schools in England is increasing, with a later diagnosis of autistic females reflected in the proportion of autistic males to females being closest at secondary school. These results all supported the notions that understanding and providing for the needs of autistic female pupils were growing requirements. In addition, DoE data showed that autistic females were more likely than their autistic male or non-autistic male and female peers to be persistent absentees at secondary school, providing some context and indicating that absenteeism was an important area of investigation.

Results from the analysis of case studies suggested delays in the referral process, which appeared to overlook or underestimate the impact of factors experienced by the YP, such as the environment, lack of sleep or anxiety. Some of the girls reached crisis point with their mental health before receiving an autism assessment and the possibility of the right support. Participants in the life history interviews also suggested a correlation between lack of suitable provision - this time in school - and a deterioration in their mental health, leading to absences within and from school. Positive and negative experiences and events provided insights into why the research sample of autistic girls stop attending mainstream secondary schools, which was a gradual withdrawal for most.

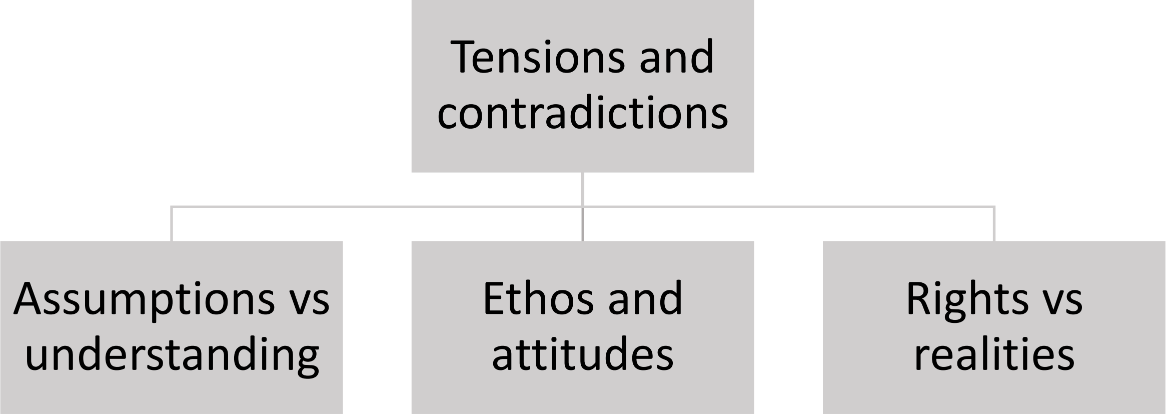
This chapter will now focus on interpretations and possible implications of these findings. It will explore the multiple tensions and contradictions reflected in the results, and then situate the interpretations within an understanding of current educational policies and school practices.

6.2 Tensions and contradictions

Tensions and contradictions were evident throughout the results chapters. These included statistical data that suggested difficulties leading to absence began in secondary school, in contrast to life chart data that reflected problems from as early as first days at primary school; support plans that were based on assumptions rather than understanding individual needs; and the right to an education but the reality of a lack of suitable provision. Three areas were identified for discussion (see Figure 6.1).

Figure 6.1

Themes within Tensions and Contradictions



The discussion will begin with a consideration of assumptions about autism and girls, how their needs are assessed, the use and meaning of absences, and the relevance of typical flags of concern. The second strand will reflect on the tensions created by a school's ethos and the impact of the attitudes of professionals and peers towards the autistic girls in this study. The final section will revisit the rights discussed in section 1.2.1 and compare them with the realities reported in chapters 4 and 5.

6.2.1 Assumptions vs understanding

A good knowledge of autism and a genuine understanding of individual needs are required for appropriate provision for autistic girls in school. However, the findings of this study noted that the actions of professionals were often based on assumptions. This section discusses the implications of this for the assessment and support of autistic girls.

6.2.1.1 Referral and diagnosis of autistic females.

The analysis of NHS data showed that, whilst more male CYP are still referred and diagnosed as autistic than females, the proportions are changing at both primary and secondary schools in England. The number of females diagnosed is increasing more rapidly than that of autistic males, implying that the incidence of autistic females is rising (or males are declining), or more likely that referrers and clinicians are becoming more aware of and better at identifying them. However, the wide variation between each CCG in the numbers of females referred and diagnosed suggests that some may still be missed or else picked up much later than others in neighbouring areas. It may be that females in some CCGs are over-referred, whilst they are under-referred in others. Diagnostic bias (Loomes et al., 2017) may account for some of the variation though not all, as assessing clinicians work in more than one

CCG. It is interesting that the highest proportion of females who were diagnosed after assessment lived in the most deprived areas covered by this NHS Trust, whilst the mean age at referral was highest for females living in the most ethnically diverse CCG and suggest that variables other than sex contribute to variations between areas in referral and diagnostic rates. This would support the findings of some previous studies (Brett et al., 2016; A. M. Daniels & Mandell, 2013; G. Russell et al., 2011). However, it was beyond the scope of this thesis to investigate possible causal links with socioeconomic or cultural factors.

It is interesting that the mean age of females at referral and at diagnosis decreased over the period, and that the comparable means for males were still a year younger. Whilst most males were diagnosed at primary school, there was no discernible pattern for females, with a greater dispersal across the age range in the raw data. The mean age at referral of 10 years for females (per the large NHS dataset analysis), plus a wait time to be seen of 14 months or longer, means that many autistic females in the Trust would not have received a diagnosis until they reached secondary school. This is supported by the NHS case studies, which revealed all the girls experienced extended pathways to diagnosis, with striking delays in the referral process, and the life history interviews which found the shortest delays from referral to diagnosis occurred when participants were aged 10 years or older. These findings all help explain why the male to female ratio of autistic pupils is closer at secondary school than at primary.

Possible explanations for the later diagnosis of females (see section 1.2.3) include bias by clinicians and within the assessment tools (Loomes et al., 2017). However, the analysis of NHS data in this study (see section 4.3) suggests it is disparities in the referral process that lead to sex differences in the age at diagnosis. An important group of findings in this study related to this process concern the interactions between types of referrers and the sex of CYP. The mean age of referral was lowest for females referred by schools, suggesting that they are better than GPs at recognising potentially autistic girls. However, they also referred the smallest proportion of females compared to males than the other two main types of referrer. Females (and males) were most likely to be referred by a GP. Tentative interpretations of these results follow.

It is possible that teachers referred girls who *they* observed had the most difficulties, those whose needs perhaps had the most impact on the teacher or on their peers. It may be that primary teachers had a male-centric understanding of autism, so that they more readily recognised autistic traits in males compared to females per the research by Whitlock et al. (2020). The referral of girls who internalised difficulties at school (Hull et al., 2020; Mandy, 2019), like most of the girls in the life history interviews, and released frustrations at home (E. Davidson & Moyse, 2020), may have been more dependent on different parties sharing perspectives and agreeing a plan of action. As the literature suggests that parents and professionals do not always agree on the needs of an autistic child (Bargiela et al., 2016), with the views of parents sometimes underestimated or not believed, this is problematic. This was seen within the case studies in this thesis, which also highlighted the absence of the girls' voices in the records until the point of assessment. A request for assessment from a parent to a GP may have taken further time and evidence to action than via a school that could make an application directly to the assessment team. Interestingly, a family history of autism did not equate with an early referral in the case studies, nor in all the life histories. In addition, whilst parents in this NHS Trust are now able to make referrals for their child to be assessed for autism themselves[55], autism assessment teams may still prefer to receive requests from schools:

> We often find a school referral helpful though because we then get the additional information from the educational setting at the point of referral…In terms of who can make referrals, we tend to think that the best referrals come from those who know the child (so not typically the GP) – i.e. school (if school aged) (Autism Lead, personal communication, June 16, 2020).

NHS statistical data showed that females who were also on another assessment pathway were more likely to receive an autism diagnosis than males, though being on another pathway may have impacted on the time to receiving the diagnosis. All the girls in the case studies had previously been referred to another service. It may be that these girls were all unusual, complex cases, and were certainly not a representative sample. However, it is also possible that a lack of knowledge on autism and females meant referrers sometimes ascribed conditions other than autism to autistic girls, or that poor mental health (perhaps as the result of unmet autistic needs) was the more obvious concern. Of the girls in the life history interviews, all had at least one other clinically diagnosed condition or disorder, and all bar one had clinical levels of anxiety.

The evidence of delays to referrals and then diagnosis is consistent with the research literature (Zwaigenbaum et al., 2015) and there are a number of implications that are relevant to this thesis. Firstly, research has found that autistic CYP had better outcomes and 'required less ongoing support' when they received an early diagnosis (M. L. E. Clark, Vinen, Barbaro, & Dissanayake, 2018, p. 92). More recent research suggests 'parents can help their children develop neurodiversity-aligned perspectives about autism by mindfully discussing autism with them early in their development' (Riccio, Kapp, Jordan, Dorelien, & Gillespie-Lynch, 2020, p. 1), which an early diagnosis would facilitate. Schools that do not have a clear understanding of autism and how it may present differently in females, and thus don't refer, may not be providing the optimum support for such pupils even with a

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[55] This changed in 2018, when it became possible for parents to refer directly to a Common Point of Entry.

diagnosis (Moyse, 2013). Not including the voice of the child from the beginning of the referral process means their views on their needs are not directly captured and cannot be used to inform support from the point of initial concerns.

Wait times to be assessed increased over the six-year period covered by this study, with prolonged waits for a diagnosis of 11 years in two cases. This suggests that demand now far exceeds capacity to assess, because referrals have increased, the number of assessing clinicians has decreased, or both. There are clear implications for the funding and resourcing of diagnostic services, but also for the provision of pre-assessment services to support the needs of potentially autistic children at home and in school during the time between referral and assessment, and for ensuring that schools and GPs refer to the correct pathway.

Many referrals of girls happened around the time of transition or at Secondary schools. It is possible that these girls experienced more overt challenges in the last year of primary school or on arrival at secondary school, which would explain the delay. It is also possible that some primary teachers did not believe the CYP required a diagnosis or ‘label’ of autism at primary school, but that they would at secondary school, hence referring in later years. However, extended wait times meant children referred in Y5 or Y6 were unlikely to receive a diagnosis before they moved to secondary school. This means they may not have benefitted from an extended transition programme to secondary school or have support measures organised for entry into Y7. Undiagnosed autistic girls may have found moving to secondary school particularly challenging, and yet have been expected to be more independent at a time they most needed scaffolding. This may have impacted on how successfully they were able to adjust to their new environment, with implications for their later attendance. This has implications for secondary schools to be alert to and prepared for autistic CYP entering their institutions without a diagnosis.

In summary, the process of acquiring a diagnosis has been described as a ‘diagnostic odyssey’; a ‘long and eventful journey’ (Lappé et al., 2018, S273) influenced by ‘individual, social and structural conditions’, and this is supported by the findings of this thesis. The difficulties in getting a girl referred and then diagnosed may then be repeated in efforts to get autistic needs met in school, as evidenced by the personal narratives in section 5.2. These issues will be discussed next.

6.2.1.2 Assessment of need and provision of support.

> They say that if you walk into a room filled with people with autism, the first thing you notice is how similar everyone is; the second is how different they are from each other (Grinker, 2008, pp. 75-76).

There is now arguably a widespread awareness of the term ‘autism’, and many people have met an autistic person. The familiarity of the term, yet minimal knowledge of the heterogenous nature of the condition, perhaps makes it easier for assumptions to be made about how to support autistic girls in school. The previous section considered how assumptions about girls and about autism may impact on referral and diagnostic rates. These assumptions and ‘the ways in which autism is conceptualised’ (Wood, 2017, p. 309) also inform decisions about when and why a CYP may need additional or different support, and what that support might look like. The autistic girls in this study identified a lack of understanding by peers and school staff as a primary theme, which sometimes led to their needs being incorrectly assessed. This meant support, when provided, was often inappropriate. The lack of knowledge about autism was a concern consistent with the literature (Pellicano et al., 2014).

The reasons for referral identified in the case studies were social and/or academic difficulties. All the girls in the case studies were described by others as underachieving academically, which suggests academic support could be made available for them, whilst the life history participants all described themselves as underachieving at times but *also* as academically able. This is important as the research suggests some underachievement may have been conflated with inability in some cases, resulting in unsuitable support. Daisy, for example, who was soon to start ‘A’ levels, talked about how assumptions about her ability meant she was *‘treated like I was absolutely stupid and had no intelligence whatsoever’* at one school had a negative effect upon her and her attendance. This changed when a teacher *‘finally took the time to read what I’d done, rather than disregard it and just cast me off before they’d even looked at it’,* and meant she took more interest in school:

> *It just made me like more happy to go to school because like they don’t think I’m stupid any more. Which just made me happy. And that meant, because I'd never really engaged in lessons because, you know what, they think I’m stupid, what’s the point?* (Daisy)

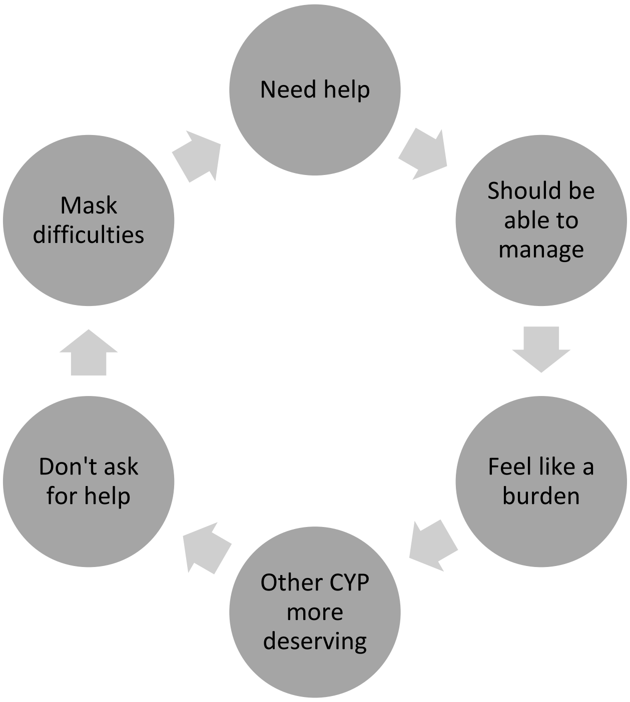
The samples for the case studies and the life histories may appear to be different, but it is noteworthy that the evidence of ability in the second sample is from the autistic girls, whilst that of the first sample is from others and based on achievement. The impact on understanding of how information is gathered is illustrated by how the girls were asked about school. Comments in the ADOS assessments from the girls in the case studies stated they said they didn’t like school, and similar statements were made by the life history participants during interview. However, the methods used during interviews for this research also demonstrated that this second group of girls had positive as well as negative experiences at school, that they valued education and wanted to learn. It is possible that the girls in the case studies may have described themselves similarly, if asked.

Self-awareness of ability, however, created the first example of tensions within the young people. Alex, for example, believed they should be able to complete work without assistance because they were '*smart'*. They described other children in the class as more deserving of support, as though there were a hierarchy of needs. Their own requirement to have objectives and instructions clarified made them feel like they were a burden. This reduced the likelihood that they would accept or request help whilst, at the same time, they recognised that a lack of support based on teacher assumptions about their academic ability meant they were less likely to offered help (see Figure 6.2). Academic ability overshadowed their requirements for support:

> *No-one at school had actually gone "right, let's actually connect you to people to help you", because they didn't really acknowledge I had issues, because I was smart* (Alex).

Figure 6.2

Cycle Leading to Increased Withdrawal and Reduced Likelihood of Asking for Help



All the girls in the case studies were referred for assessment based on social communication and interaction differences, per the criteria for the diagnosis, as well as underachievement, and it was correctly anticipated that most of the participants in the ideal school exercise would say working in a group was their least favourite way of working. However, these girls did not have an objection to group work per se, but because peers used it as an opportunity to be unkind, to be disruptive, and to do nothing. The girls described not being picked to be on a team, being ignored during group work, having to do all the work for the group because other peers would not engage, or being told to work alone. Group work was difficult for these girls not because they were autistic, but because the conduct of peers made learning harder. Some peers negatively impacted some girls' ability to concentrate on the task, made them feel vulnerable, and marginalised rather than included them, meaning the purpose of working as a group rather than as individuals was lost.

Some girls therefore chose to work alone when they could. Jane described doing this in science, despite the teacher emphasising work had to be done in groups, because she '*enjoyed doing it on my own'* and also because when she worked alone, she '*always finished*'. The importance of being able to complete tasks was stated by several of the girls. However, the strategy of working alone in these cases (by teacher instigation, peer rejection or own choice) was not seen as helpful by some of the girls, who recognised the importance of being able to work with others:

> *Working with people is a key life skill, you kind of need to learn that, so just sitting me in the corner wasn't going to do much long term* (Daisy).

Based on this research, the expectation that autistic girls would be supported in the completion of tasks requiring collaborative working in school is an assumption predicated on a misunderstanding. Whilst their diagnosis meant the girls may have found interacting with non-autistic peers difficult (Crompton & Fletcher-Watson, 2019), their peers equally lacked the skills to engage constructively with them, as per Milton's (2012) double empathy problem. Rather than assuming competency from everyone else, or that autism prevented cooperation, all pupils would have benefitted from being taught how to work in partnership effectively with each other before being expected to do so, and in ways that utilised each other's talents.

Making an assessment of the strengths and needs of an autistic YP using checklists, rather than seeking pupil voice, was found to be problematic. Administering the Strengths and Difficulties Questionnaire (Goodman, 2012) at the end of the life history interviews, after the girls had provided such rich detail about their experiences at school, enabled the demonstration of the limitations of the tool for understanding these girls and their needs. Alex, for example, remarked that answers would depend on their most recent experiences, whilst others noted responses would vary depending on the situation.

This emphasised the importance of providing context and of asking the girls to provide their own answers and explanations to avoid assumptions and mutual misunderstandings:

RM: *Okay. Erm, what else might have helped?*

Rosie: *Um. People wanting to learn, really. People wanting to know things. Not making assumptions. That would have made it so much easier. If people didn't just assume, like, things about me-*

RM: *Yeah.*

Rosie: *-it would just have made it so much easier. If people didn't assume things about my needs-*

RM: *Yeah.*

Rosie: *-and what they should do to help me, it would have made the whole experience so much easier. If they'd just asked, and then listened to the answer.*

This was particularly the case with prosocial scores and highlights the risk of over-reliance on questionnaires that rely on the subjective experience of other people, and their motivations, rather than those of the individual. Differences in perspectives on needs seen in case studies further reinforced the importance of involving autistic CYP in an assessment of their needs and talents at an early age.

The provision of support was a further area where assumptions based on poor knowledge of autism or of the individual needs and preferences of each girl, made school more difficult. Some of the girls felt a 1:1 LSA[56] would have been helpful, for example, whereas others *'hated it'* (Daisy) and did not want one as it meant you were *'laughed at'* (Alex) or isolated. There were tensions with strategies that both teachers and the girls valued, such as seating plans, but which had differing motivations and outcomes in practice. A further example was given by several of the girls who said teachers did not answer questions or restricted how many questions they could ask. It is assumed this was to enable the completion of the delivery of a lesson, but left the girls confused about what they were to do, perhaps frustrated by the illogicality of such techniques in a place of learning, and less likely to ask for help.

There were also tensions that arose from preferences to internalise and fit in. However, the apparent contradiction of not wanting to be treated differently from their peers, yet also wanting to have their individual needs recognised and met, was the result of being bullied and abused for being treated as less than and 'other' (Wood & Milton, 2018, p. 162). The recommendations they made were based on

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[56] Learning Support Assistant

equity, fairness and respect. They required support that was subtle and discreet, yet they also had a desire for recognition, which appears to conflict with concurrent known strategies of masking and withdrawal. The girls were hidden but wanted to be seen. This is a small but significant contribution to understanding. Recognition came in the form of parts in plays; of winning competitions and being first; of making excellent academic progress. For some it was about being given respect or the same opportunities as peers, of having strengths recognised by others or of having a teacher who believed in them. It encompassed knowing that they were noticed and cared about. They wanted teachers to check they understood, to show that they were '*a part of it all'* and that they belonged.

In summary, the challenges of a mainstream setting should not be underestimated for autistic girls, regardless of academic ability, but assumptions about what constitutes appropriate support are not helpful. The girls in this study wanted teachers to be more curious. They wanted to be understood and valued as individuals and as equals, for teachers to question why the girls did what they did, and for schools to be both proactive and responsive to their needs. This is important in terms of teachers getting better at identifying and referring potentially autistic girls at school, but also in providing the most effective support for them pre- and post-diagnosis.

6.2.1.3 Withdrawal and absence.

The type of support provided for the sample girls highlights a further tension, as the strategies employed by teachers frequently involved the removal of the girl from the activity or from the space, thus leading to absence from the classroom and access to learning. This was seen in girls being told they did not need to participate in lessons, the supply of exit passes, and the use of part-time timetables. The exit pass, for example, was described by Erin as enabling her *'to leave class if I was overwhelmed'*. These strategies were useful in providing short-term relief from problematic situations. However, they were unhelpful in returning the girls to the classroom ('*None of these helped'*, Erin), as the underlying reason for them needing to leave was unaddressed. In addition, such measures may have encouraged the girls to feel they didn't belong in class, and to see absence as an acceptable or preferred solution when encountering problems.

This was seen in the utilisation of these strategies by some of the girls, when they were in lessons or elsewhere in school, and were finding staying in place too difficult or unsafe. Jane said she was given a card that would let her leave lessons and go to pastoral care, which then motivated her to be absent:

> *I didn't use it at first, it actually took me a very long time to use it for the first time but after that, you know, after using it and realising how much more I liked it than sitting in a classroom, that's when I kinda started using it more.*

Rosie said she '*would avoid things'*:

> *If there was something really difficult at school, I wouldn't go to school. If there was something particularly difficult about one lesson, I wouldn't go into that lesson.*

Alex wrote on their life chart that they '*went onto reduced hours at school'* as school was '*really unpleasant'*, although 't*hat wasn't really the school doing anything, that was me not turning up'*. Daisy was *'off school for quite a while'* after she was bullied so severely that she made multiple attempts to end her life. Others described avoiding certain spaces at school, such as the assembly hall, lunch canteen or the playground; places where they reported having negative experiences or feeling particularly vulnerable. This meant some girls did not eat all day, for example.

However, the use of absence as a strategy involved a contradiction. Some school staff were happy to use it themselves but did not want the girls to use it. One interpretation of this is that teachers recognised absence was not a useful problem-solving strategy. This supports the notion that strategies involving absence used by teachers were not to support the child, but perhaps to support the teacher, school rules or the rest of the class. The girls, meanwhile, used the same strategy as a coping mechanism to support themselves. This theme is discussed further in section 6.3.3. Lizza described being challenged by teachers about whether she really needed to use the exit pass. Daisy's English teacher let her eat lunch with her in her classroom after finding out Daisy had been eating her lunch in the toilet or not at all, to avoid bullying. However, the Safeguarding Lead had subsequently told her she needed to be on the playground:

> *She said it was damaging my social skills and I had to eat lunch <u>outside</u> with <u>everyone else</u>. Which, consequently, when she made me do that, I got my lunch thrown in the bin.*

Daisy's example demonstrates the difference between a teacher who sought to understand the reason for the autistic girl's absence and find an appropriate solution, and one who made assumptions about needs, and whose actions returned the girl to a place where she felt unsafe. This type of intervention with autistic YP, that focuses on social compliance (Evans, 2017), has major implications for schools in terms of ensuring the welfare of CYP.

Interestingly, the places the girls were allowed to withdraw to often did not provide support either ('*it was where all the sick people were…everyone would just be looking at you and coming in all the time,'* Lizza) and sometimes involved more risk ('*the Base…It was the only place I could withdraw to, but it wasn't actually safe'*, Rosie). The places they chose themselves, however, frequently the library, were again often removed as safe places by teachers, or by peers who controlled access to spaces during unstructured periods.

It may be assumed that being out of school was negative for these girls, whereas for some it was positive. Ming said it enabled her to focus on projects she enjoyed and spend time with people and animals she cared about or found interesting. Rosie made better academic progress. Robyn discovered she loved learning once out of a mainstream school ('I*t turns out, I absolutely love education. I just didn't know it'*). They became 'agents of their own learning' (Bandura, 2006, p. 176). However, there was a tension here as being out of school was both a relief and a worry for most of the girls. They recognised their own abilities and were aspirational, and knew they needed to pass certain subjects and achieve good grades to progress to the course and University of their choice. These plans were jeopardised by the lack of support in school, the absence of work when withdrawn from a lesson, and the lack of suitable alternative provision when they stopped attending school. Non-attendance at school was not a rejection of learning, but of a toxic environment. In addition, all eight of the girls who participated in the life history interviews thought being autistic was part of the reason they were not currently in mainstream schools. Whilst the girls who talked about it saw their diagnosis as a positive event, they described challenges they experienced as due to a lack of understanding about autism and how to connect with autistic YP. Some said they wanted to be seen as a person (Daisy), as a human being (Jane), suggesting that they were othered and thought less of by peers and staff due to their condition. This stigmatizing conceptualisation of autism as a deficit may partly explain the reluctance of some teachers and GPs to refer a child for an autism assessment, who see a diagnosis as a negative label rather than a route to understanding and support.

It might also be assumed that going to mainstream schools were completely negative experiences for these girls, but their life charts illustrated that this wasn't the case. There were an unexpected number of positive events on most charts, which may have helped to maintain the girls' attendance and mitigate for the more difficult encounters until their mental health deteriorated too far. The inclusion of these positive experiences provides a more nuanced presentation of their feelings and recollections of school and present a method of reducing or removing negative aspects by learning what made other events so successful.

In summary, withdrawal strategies used by some schools served to reduce problems in the classroom at that moment, by displacing them instead of resolving them. This meant that the need for an exit pass or a part-time timetable never went away, as the barrier remained. However, the use of the strategy at times of difficulty led to the girls also viewing absence as a solution when they were in distress, leading to additional informal and unrecorded absence whilst they were present in school but not learning. Conversely, schools tried to prevent the girls withdrawing themselves, and this became a particular issue once absences translated to non-attendances at school that appeared in registers and official statistics. There is therefore a further contradiction between the strong emphasis on attendance from government and thus schools, as seen by monitoring requirements, and the actions of some teachers who actively encouraged absence from classrooms.

6.2.1.4 Flags of concern.

Data on pupil achievement, attendance, and conduct are used as partial methods of school performance and may trigger internal concerns about a child if required standards are not being met. However, early concerns about the autistic girls in this study would not have been raised by these measures. Although negative comments about conduct were made by practitioners about two of the girls in the case studies (see section 4.2.2), none of the girls in either the case studies or the life history interviews were formally excluded.

Attendance figures were mentioned in two of the case studies, and for one year only. DfE statistics on persistent absenteeism (see section 4.2) suggest the problems begin for autistic girls in secondary school. However, most of the participants in the life history interviews exhibited a gradual withdrawal from school that began much earlier than this with the type of informal absences noted in section 6.2.1.3. As such, difficulties may have been overlooked or underestimated until non-attendance had become frequent and ingrained.

Lack of attendance did not always or immediately impact on achievement, which was another reason why initial absences did not cause concern (‘*I used to always get top marks in my exams despite having low attendance’*, Erin). Academic achievement, despite other challenges, also meant the difficulties these girls *did* experience were often overlooked or not viewed with the same merit:

> *If I’d have struggled academically beforehand they may have had more of a problem with me not being at school, and they may have wanted to do more to help me be in school, but because it was kind of like “oh well, it's not like you're, you're falling behind”, because you’re, you know, you’re way in front* (Alex).

The implications of these findings were that the needs of autistic girls in this research were missed or underestimated until their withdrawal from school had greatly progressed and remedial action therefore less likely to be effective. The narratives suggest that attendance and mental health can decrease even whilst academic achievement remains as expected if you are a bright, intelligent pupil. This suggests that different warning signs need to be established for autistic girls who are of average intelligence or above, per the finding by the Lamb Inquiry, which says ‘parents should not have to wait until their child fails or falls further behind before help is available’ (Lamb, 2009, p. 4).

In summary, the findings of this study show that the use of strategies that involve the absence of a CYP whilst at school should in themselves serve as flags of concern. Teachers should be addressing known needs proactively, so techniques such as the provision of exit passes, that provide immediate relief for some autistic girls, should be for unforeseen or unexpectedly difficult situations. However, they also require action to uncover what drives the need for the absence. This requires working with the YP to understand the problem from their perspective, and to formulate the appropriate solution (see section 6.3). Otherwise, continued absences (either teacher or YP initiated) may lead to the failure of a placement, which may also involve a mental health crisis and missing the personal academic targets (Ashburner, Ziviani, & Rodger, 2008) required for the girls' chosen pathways of progression.

6.2.2 Ethos and attitudes

The findings of the personal construct exercise indicated that the ethos of the school and the attitudes of adults were of the greatest importance to the autistic girls in this study. This section considers the implications of these aspects for the girls, their education, and their presence in school.

6.2.2.1 Grades vs wellbeing.

It has already been established that the autistic girls who participated in the life history interviews identified as academically able, and the six older YP aspired of attending University. It may appear contradictory then, that the girls prioritised wellbeing over grades in the ideal school exercise. However, it became clear that they believed good mental health was important if they were *to* learn, and that this was a protective factor. Eight of the ten girls said the ethos of the sort of school they did not want to attend would value grades most, whilst the other two girls mentioned reputation and acting like robots. Pressure to achieve had a negative impact:

> *I could cope academically, but school would tell me I was doing badly to try to make me do better, this negatively affected my mental health* (Erin).

Conversely, they all said their ideal school would prioritise wellbeing, with four specifying happiness, which would in turn enable academic success:

> *I would be learning and achieving and enjoying it. I would be calm inside as well as outside* (Rosie).

This is consistent with Maslow's hierarchy of needs (1981), which states physiological, safety, belonging and self-esteem needs (motivated by 'deficiency') must be met before and higher level learning (motivated by 'growth') can occur (p. 162). It also supports the findings of Williams and Hanke (2007), who found 'some pupils gave graphic details about the adverse impact on their well-being and mental health that attending a non-ideal provision would bring' whilst, conversely, most YP also described the 'educational benefits' of an ideal school (p. 134). It is particularly striking that all participants reported valuing education and wishing they had access to a school that met their academic *and* support needs.

The current climate of accountability through academic performance not only adds pressure to teachers and their pupils, but also infers a value on exam success that is not necessarily expressed for mental health. Whilst academic progress is measured and tested, the lack of such measurement or apparent focus on wellbeing may lead some CYP to consider that it is not regarded as of equal merit. This may explain why some of the girls in this study felt like a burden, as they didn't need help academically and didn't want to ask for help that would take a teacher's time away from peers who *did* require academic support.

The perception in these autistic girls of being a burden is of great concern and has implications for their welfare and safety. A recent study by Pelton and Cassidy (2017) found that autistic traits predicted 'perceived burdensomeness' (p. 1891), which was associated with an increased likelihood of suicidal ideation and attempts in autistic people. This is not an uncommon or insignificant issue for autistic girls. Recent studies have suggested 70% of autistic CYP could have a mental health issue (Iemmi et al., 2017), and that autistic CYP are 28 times more likely to think about or attempt suicide than non-autistic CYP per maternal report (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013). The strategy used by some autistic girls of camouflaging has also been found to be associated with higher self-reported anxiety and depression (Cage, Di Monaco, & Newell, 2017; Hull et al., 2018) and itself 'significantly predicted suicidality' (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018, p. 1). This does not automatically mean that autistic CYP have mental health difficulties because they are autistic per se, but because of the difficulties they experience interacting with a frequently hostile environment.

Given the levels of poor mental health expressed within some of the case studies and most of the life history interviews, it is essential that urgent attention is given in schools to finding ways to foster and monitor the wellbeing of their autistic female pupils. Such an approach is likely to also benefit autistic males and non-autistic CYP.

6.2.2.2 Relationships.

> Unconditionality and commitment by practitioners are likely to be critical ingredients in approaches that succeed in moving young people back from the margins (Sanders & Munford, 2007, p. 195).

The previous section noted that a perceived singular focus on grades led some girls to experience unnecessary amounts of pressure that led to anxiety. This is not specific to autistic YP. A worldwide study by Rees and Main in 2015 (cited by Reay, 2016) found that the wellbeing of CYP in school in England 'was lower than all but one other country' and that 'the adverse impact of testing' was one contributing factor. However, 'equally important was the poor quality of relationships between teachers and students' (p. 326). Amongst the findings of Chapter 5, it was clear that people – and relationships – were also major factors in making attendance at school possible or unbearable for the autistic girls in this study. ‘People’ were both the worst thing about non-ideal provision, and the most positive aspect of their ideal schools, and relationships were prominent in all their life charts.

Tensions in relationships were illustrated by the language used to describe some of the girls, either in the case studies (see section 4.4.2) or in the way the girls in the life history interviews said the word ‘autism’ and ‘autistic’ were used to insult them (‘*an excuse to just be horrible and discriminatory*’, Alex). The case studies evidenced differences in understanding a girl and her needs. These were present between some mothers and teachers; between primary and secondary teachers; and between medical professionals. Such differences again highlight the need to include the voices of the girls from the time concerns are first raised by parent or professional (or child) and for respectful and equal communication between parties. The descriptions of some of the girls in the case studies by some school staff were particularly problematic: Molly ‘*craves attention*’; Cayla is ‘*aloof*’; Lauren ‘*doesn’t care about others*’; Beth is ‘*defiant*’. Such language is judgemental and unprofessional. Its presence on inter-agency forms suggests both that the staff in question felt it was acceptable to use such terminology about these pupils and that they perceived others would not find their language inappropriate. This may mean such ways of speaking about pupils are common practice. However, the language is value-laden and invites the reader to infer a deficit understanding of these girls, with comments that perhaps better reflect adult attitudes than child competencies.

A major tension expressed by some girls in the study was that some teachers were perceived as not *wanting* to understand what they needed to thrive in school, and therefore actions were based on assumptions made about them. This is illustrated in a piece of dialogue with Rosie during her thematic analysis of the events on her chart during interview 3:

Rosie: *Staff. Problems with staff. Um, and the way that staff would, um, like, the way that staff would like treat my autism and anxiety. Like how they would behave because of that, how they would, how they would decide how I needed to be treated because of it-*

RM: *Okay.*

Rosie: *-because some staff would decide that I was just misbehaving.*

RM: *So, what do you think that is? What theme would you call that? What is that about?*

Rosie: *Staff not understanding.*

RM: *So, it’s not understanding?*

Rosie: *Not wanting to understand.*

RM: *So, it’s more like staff attitudes, [perhaps?]*

Rosie: *[Yes] staff attitudes, yes.* (15 seconds) *That one’s a huge one.*

Some of the girls perceived that teachers expected them to work hard, but that this was not reciprocal. Their favourite teachers, conversely, were perceived as making an effort with them by checking their understanding in a lesson, asking after their wellbeing, or standing up for them.

In addition, all the participants described relationships with some peers or school staff that made them feel bullied or undermined (See Chapter 5). This ranged from being shouted at, blamed, abused, and physically assaulted. Importantly, it also sometimes meant they were not believed, or their needs were underestimated when they sought help from adults in school. This had implications for their safety and wellbeing, and for their ability to function. It also contributed to a breakdown in trust and to feelings of self-doubt. Respect, which most of the girls raised and felt should be bi-directional, was expected by teachers but not shown to the pupils. Robyn stated this was also true for peers towards those with *'special needs'*. This impacted on their self-esteem and on their likelihood of developing trusting relationships with adults and peers (John, 1996).

Relationships with peers could also be oppressive and hold tensions. Some research suggests that some autistic girls without learning disabilities may be protected or mothered by non-autistic girls at primary school (Attwood, 2006). However, this did not appear to have been the case for most of the girls in the life history interviews. Moving to secondary school resulted in further difficulties ('*Every time I got a friend, really soon afterwards they would just not be my friend. Just start being mean.*' Ming). Sometimes coping strategies such as masking used by autistic girls were also used by non-autistic girls, but for different purposes. Eri, for example, noted that one child '*masqueraded as my friend'*, but was '*emotionally abusive'*. Ming said that some girls appeared friendly but then bullied her using personal information she had shared in their conversations. Jane stated one girl '*kind of just hang out with me'* whilst thinking of her '*as like this person who was like less than her while she was doing it'.* In addition, there was evidence from Daisy that a poor relationship with a more powerful peer could mean isolation from the rest of her classmates, who were told not to speak with her. These attitudes served to further increase rejection and marginalisation (Wittemeyer et al., 2011).

By contrast, relationships were also seen to help maintain attendance, and these demonstrated attitudinal differences. The girls wanted friendships (Sedgewick et al., 2016; Tierney et al., 2016) and valued *'having someone who would just, you know, was nice to you'* (Jane) or shared a common outlook or ability. Of the six key themes identified from the positive events on life charts, all but one of the participants in the exercise mentioned individual teachers or other adults as the reason why one or more of their experiences of school were good. Teachers were nurturing and caring (Noddings, 2012), treated a class like their own family ('*like we were her children'*, Erin), and kept them safe. The girls said this meant they enjoyed their lessons. These teachers also gave the girls time. This was exemplified by giving them time to ask questions and time to be helped. One teacher '*was very patient and she didn't you know get angry or frustrated at people if they didn't do what she said immediately'* (Jane). This finding accords with work by Milton and Sims (2016) about supporting autistic adults and CYP, who found that, 'Fundamental to positive narratives of wellbeing, were feelings of connection and recognition from others and positive accepting relationships,' (p. 520).

There were tensions in the provision of support by individual teachers. Some helpful teachers were perceived as acting alone and without '*support from whoever they were working* for' (Rosie), suggesting not all staff shared the same ethos. Some teachers provided clarity – a literal sanity check - on the intentions of peers and the meaning of their actions (see Daisy's narrative in section 5.2.2). Some assistance was covert:

> Daisy: *She* [Safeguarding Lead] *was just like 'no, it's damaging your social skills, go outside!'*
> RM: *And how did Miss Smith*[57] *respond to that?*
> Daisy: *She snuck me up. Yeah, she like, she'd make sure no-one else was around, she snuck me up the back stairs.*
> RM: *Right. So that you would eat?*
> Daisy: *Yeah. So that I was safe.*

Whilst Daisy said Miss Smith '*was doing what she knew was best for me'*, it is concerning that the actions of both this teacher and of the Safeguarding Lead put Daisy in potentially unsafe positions. Following the direction of the Safeguarding Lead would have put her with peers who severely bullied her, whilst Miss Smith's actions to hide Daisy could be interpreted as a safeguarding risk. Furthermore, the contradiction of the Safeguarding Lead acting in a way that made Daisy unsafe, whilst a potentially unsafe action made her feel safe, is noteworthy. Having one strong relationship with one member of staff emerged as being particularly valuable. This is supported by the literature, with a study by Ekstrand (2015) stating the need for pupils 'to bond with adults who care for, listen to, respect, and engage them' (p. 473). The implications of these findings for teachers are firstly to highlight the importance of endeavouring to build strong connections with their autistic pupils. Whilst this should be a quality first teaching technique for use with all pupils, it is possible that autistic girls have a stronger requirement for this relationship if they have experienced feeling rejected, isolated and unsafe in school. In addition, it is also clear that the girls found their own trusted adults, which was often not the person assigned to care for them. Schools need to consider this when constructing support plans.

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[57] All names are pseudonyms.

The attitudes of staff as experienced by the autistic girls in the study are important considerations, not least because they had the power to shape how the girls felt about themselves and about their sense of belonging at school. Furthermore, this research showed that this power could influence, knowingly or not, how a YP felt for many years. This was exemplified by a Y1 event described by Rosie, when she said the teacher berated the class for using too many paper towels, but did not wet her hands when demonstrating how to use just one:

> *She faked washing her hands and lied about it. She was telling a lie to make her point. I felt like I couldn't trust anyone after that.*

6.2.3 Rights vs realities

Education is a right and therefore non-attendance is a rights issue (see section 1.2.1). This research found that the legislation in place to protect these rights did not serve to enforce them. The following section discusses three key areas that emerged from the study that created a tension between rights and reality.

6.2.3.1 Action vs inaction.

> *The point at which someone is having issues is too late. You need to have fixed it beforehand, you need to have set, set things up to be there* (Alex).

The girls in the life history interviews identified several rights violations in school that they said teachers had failed to address. One of the most evident was the bullying and abuse of them by some peers and school staff. Harassment and victimisation were evidently not in the best interests of the child (Article 3, UNICEF, 1989) and discrimination based on autism (Article 23, UNICEF, 1989) was in contravention of the Equality Act 2010. The apparent lack of action to resolve these issues was therefore a surprise, given schools have a duty under the Equality Act to eliminate these practices and to 'foster good relations between people who share a protected characteristic and people who do not share it' (DfE, 2015b, p. 9).

Some of the girls stated that nothing was done to stop bullying, despite them telling teachers, which they interpreted as a lack of concern for them. One implication was they did not report further instances ('*I just didn't think they'd care enough',* Jane), which created a further tension between staff not appearing to respond to and stop bullying, and not being in a position to stop bullying because they weren't being made aware. Longer-term bullying seemed to result from an initial or on-going lack of action, or unsuccessful resolution, and led to a belief that nothing would change. The girls went into school every day expecting to be bullied *and* that nothing would be done to stop it if they were. This may have acted to encourage the abusers, thus making the school appear complicit in this behaviour. An implication of this for the girls is that they felt almost constantly unsafe or vulnerable, even when they were not being abused, which they reported increased anxiety, caused exhaustion, and reduced their capacity to engage with their education:

> *In lessons I was not concerned about learning at all, I was just concerned that I wasn't going to get, like, attacked* (Daisy).

Continuing to go to school without hope of positive change undoubtedly impacted their mental health, which in turned reduced their ability to attend, with lack of action to protect the girls at school therefore impacting on their right to education (Article 28, UNCRC) and to good health (Article 24, UNCRC). Their perseverance in attending is a subject that is discussed further in section 6.3.4.

A further issue was the apparent failure in many of the schools described by the girls in this sample to ask for their views on how they needed to be supported. This was aggravated by not listening to or believing them when they expressed fears or concerns, which again meant no action was taken to resolve difficulties or remove barriers. This practice is in contravention of Article 12 of the UNCRC, which is the right for a child to be heard and for their views to be taken account of (see section 1.2.1).

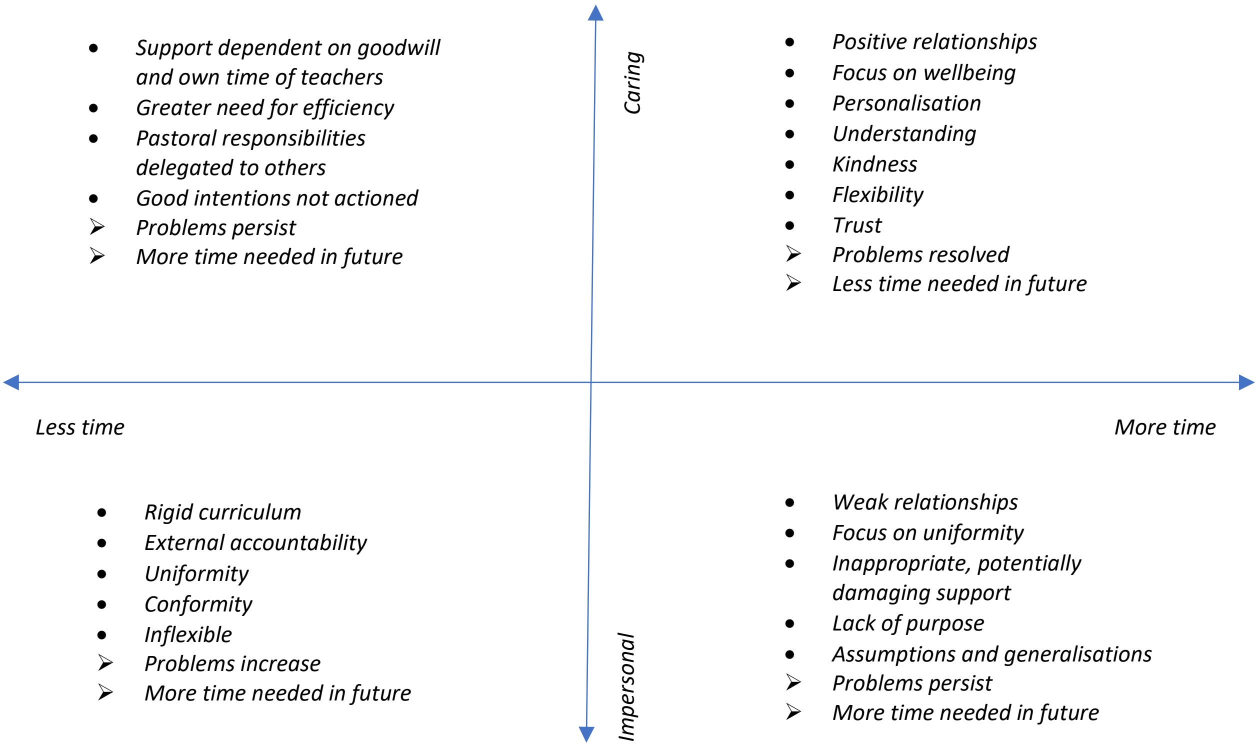
Whilst some girls believed that a lack of action by staff was deliberate (*'some teachers I would say it was absolutely intentional that they didn't do what they were meant to',* Rosie), perhaps because they didn't want to get involved in managing certain incidents (*'there'd be…like a physical fight going on and they'd walk over straight up to my friends and just go 'you're not supposed to have phones in the café',* Jane), it is likely that other factors played a part. One interesting dynamic found in the previously discussed tension between conformity and flexibility was the concept of time, which was both a director of action and a reason for inaction. The case studies and life history interviews showed that some girls had to wait years before being referred and diagnosed as autistic, by which time some were in mental health crises. Professionals with limited time may perhaps have acted fastest for CYP who had the most observable impact on others or themselves, whilst delaying action for those who seemed outwardly to be managing.

The pressure of time was problematic. In the classroom teachers are under pressure to deliver the curriculum, whilst YP are under similar pressure to learn. However, the girls in this study described a variety of reasons why this was not helpful for them, despite wanting to achieve. They wanted to learn at their own pace and complete work before moving on; they found it difficult to transition from one lesson and then settle into the next; they needed rationales and alternative explanations which they felt took time from the teacher and peers who they felt merited support more than they did. Some were perfectionists; some needed to feel engaged with the lesson within ten minutes or they gave up; some needed an hour to plan and then had no time left to complete a task. The pressure to achieve high grades therefore conflicted with having the time and support needed to reach them. This meant the girls often had to work longer outside lessons (*'you'd have to stay behind, do extra homework, practice more'*, Lizza), increasing pressure on them and leaving them more exhausted.

Time could be given or denied; used to positively impact on the girls or to undermine, suggesting an interaction between staff attitudes, school ethos and time as a resource. Some of the girls perceived that teachers did not have time for them, whilst some teachers may have felt that supporting autistic pupils required time they did not have. Given one of the findings of this research was the influence of people and relationships (see section 6.2.2.2) on the autistic girls in this study, it is interesting to consider the implications of such an interaction (see Figure 6.3).

Figure 6.3

Teacher Approach Mediated by Time and Attitude



The contents of each quadrant may be fluid, depending on different teachers and circumstances. In addition, small amounts of time spent building relationships can have a much bigger impact than more time with a less nurturing member of staff. Spending more time on building connections early in the academic year could have helped the girls feel more secure and better able to ask for help in lessons, resulting in greater attendance, and less time being required to work on solutions thereafter.

6.2.3.2 Equity vs injustice.

> The history of education has been a history of valorising elitism, and privileging the already privileged (Reay, 2016, p. 329).

The English legislative landscape requires that a 'reasonable adjustments' duty is activated in schools where it is necessary to prevent 'substantial disadvantage' to disabled pupils, such as the autistic girls in this study (Equality and Human Rights Commission, 2015, p. 4). The Commission further states that this duty means acting to 'provide the best possible education' for them (p. 6) and 'if an adjustment costs little or nothing to implement, it is likely to be reasonable to do' (p. 9). These points are important because they indicate a further tension. The life history interviews revealed it was the girls in this study who generally made personal modifications to manage challenging environments, although it was the schools that should have been making the adjustments. Small, cost-free and easily arranged adjustments, such as being able to sit in a particular place in a classroom ('*my massive thing is, something that always triggers me, is when someone sits in my seat'*, Daisy), could have been made but were not. Some simple changes, such as allowing the wearing of noise-cancelling headphones, would have been reasonable. Strategies that were used by some schools, such as facilitating the removal of a girl from a classroom, did not deliver education that was optimal for them but often conversely removed them from the opportunity to learn.

Leaving lessons appeared to mean the girls lost access to work completely ('*they weren't really giving me proper work if I wasn't in the lesson',* Rosie) or were not given the instructions or support to finish a task. This was clear from one of Daisy's recommendations:

> *Make sure they can actually do the work. Don't just go 'okay well just do some colouring in'. I mean, I love colouring in, but I should be doing algebra.*

The contradiction of a school support strategy resulting in a girl not being able to work was replicated with the lack of work provided to be done at home when the girls were persistently absent. The girls believed that this was to stop them *'having too much fun'* (Lizza) and about *'pressuring me to go back'* (Erin), with some of the girls reporting feeling threatened. This reinforces an understanding that schools felt the girls needed to be in the classroom to learn, whilst highlighting the absence of change or support for them to be there. School did not appear to be a safe place to which they could return, and the girls were further disempowered and disadvantaged.

It may be that the reason these changes were not made, and that offered provision was sometimes inappropriate or ineffective, was because needs and supports were based on assumptions and misunderstandings. One of the key recommendations made by the girls in the life history interviews, when they considered what the schools could have done differently, was simply to involve them. They wanted teachers to be more curious (*'Ask me why I wanted to eat inside'*, Daisy), to listen to their answers (*'to the specific of what was being said'*, Jane) and to act on their words (*'Less empty reassurances from teachers. Actually do something',* Ming). The very reasonableness of these requests is a powerful message to schools and underlines the contradiction between the girls' rights to have the best education provided for them, and the injustice of the reality of their experiences in school. The barriers and challenges described by the girls in the life history interviews, however, also reflect that it was not a deficit within themselves that meant they were unable to attend, 'but rather the attitudes and environments around them that put them at a disadvantage' (Child Rights International Network, 2020).

A feeling of unfairness was highlighted by most of the participants, and they exhibited anger and frustration about this to varying degrees. The implications for the sample girls of not being listened to, or perceived as unheard, were the increased likelihood of absence as the girls' actions removed themselves, and their disassociation from school as a place where they felt seen, valued and as though they belonged. It is not within the scope of this thesis to speculate about why the girls' voices were not heard in school, though it is concerning. Children's rights organisations argue that disabled CYP may be 'at disproportionate risk of other rights violations because of their dependence on others and the barriers they face in reporting abuse' (Child Rights International Network, 2020). This was evidenced within the life history interviews by the level of bullying and abuse reported by the girls, indicating that enabling their voice to be heard and for their concerns to be acted upon, per the legislation (see section 1.2.1), should be mandatory, not just to ensure their education but also to protect their mental health.

Despite legislative provision for the right of autistic girls to an education, this research found tensions within school-based support strategies that sometimes served to remove them from opportunities to learn. Lack of action from school staff, either to listen to the views of the girls, or to act to keep them safe, led to further injustice. Whilst it is the legal duty of a Local Authority to arrange 'suitable full-time education' for CYP absent from school 'who – because of illness or other reasons – would not receive suitable education without such provision' (DfE, 2013b, p. 3), per section 19 of the Education Act 1996, persistent absence did not lead to changes in school or to the provision of work at home. This is even though Local Authorities should make such provision once it is known that 'the child will be away from school for 15 days or more, whether consecutive or cumulative' (DfE, 2013b, p. 4). In addition, where provision was made, the girls in this study reported that it was neither full-time nor of good quality. As such the girls had either to struggle with an unsupportive but academically appropriate mainstream setting or stop attending and accept part-time provision of a lower academic standard. This has implications for Local Authorities to provide settings that meet both emotional and academic needs.

Both the case studies and the life history interviews indicated showed that lots of the girls suffered with poor mental health. This was evidenced by reports of anxiety, self-harm, not eating and suicide attempts. For the girls who were interviewed, it seemed that their right to an education and their right to good health had become competing entitlements. Daisy's life chart, for example, showed '*Stopped eating referred back to CAMHS'* (Y8), '*Month off school due to S.H*[58]*.'* (Y9), '*Suicide attempt no.1'* (Y9), followed by a further '*6 suicide attempts'* (Y10) which were listed as one event, and when she was absent from school for an extended period. A correlation between attending school and deteriorating mental health was made by all the girls who participated in the life history interviews except Ming, although it was notable that she described coming home from school in tears every day.

There are several implications to these findings. First, schools that believe an autistic girl's absence to be health-related may decide it is not appropriate to provide work whilst they are absent (deeming them to be unwell), thus further excluding them from education. It may also mean that schools are less likely to perceive or accept that there are within-school problems that need to be addressed before she can return. An example of this is the use of a part-time timetable to facilitate a graduated return to school, which reduces time in school but places the burden of improvement on the YP rather than the school. Next, schools may state they are prioritising wellbeing but not implement the ethos in practice (as per Sally's narrative in section 5.2.10) or else not realise that well-meaning measures are ineffective. Finally, the girls in this research described a commitment to education and desire to learn that they said resulted in profound damage to their mental health whilst they persevered in attending school. The apparent lack of care for them by some staff contributed to this deterioration and the beliefs of some autistic girls that they were a burden and did not belong.

6.3 Power and agency

> Conscientização refers to learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality (Freire, 2005, p. 35).

An analysis of the tensions and contradictions described earlier in this chapter reveal much that appears to flow from the structure and aims of state secondary schools in England, under government guidance. The climate of accountability in England (see section 1.2.4) based on performance, conduct and attendance appeared to encourage conformity and uniformity in schools, perhaps resulting from the pressures to achieve. This has implications for the recognition of, and response to the individual

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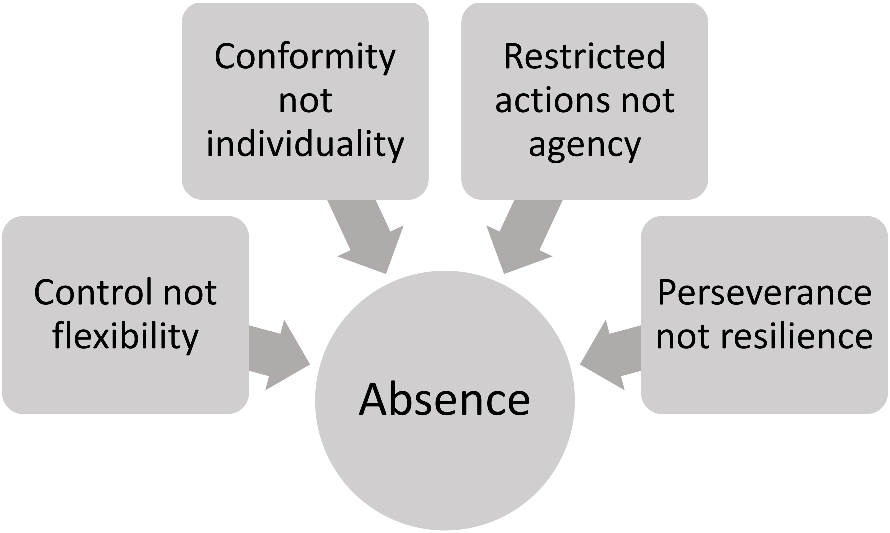
[58] S.H. is self-harm.

needs of the autistic girls in this study. The imbalance of power and oppression of the girls within the school system makes the work of Paulo Freire particularly relevant, whilst the impact on the resilience of the girls by restricting their agency is considered with reference to Albert Bandura. This section discusses these aspects and their effects (see Figure 6.4) in more detail.

Figure 6.4

Impact of Power Imbalances on Attendance



6.3.1 Power as control

> The good student is not one who is restless or intractable, or one who reveals one's doubts or wants to know the reason behind facts…on the contrary, the so-called good student is one who repeats, who renounces critical thinking, who adjusts (Freire, 1985, p. 117).

Autistic people can be seen as 'the oppressed in Freireian terms' in taking the role as 'passive participants' in much research about them (Parsons et al., 2020, p. 224). This lens can be used to help understand the choice of methodology for this study (with the use of personal narratives to enable active engagement contrasting with the use of the SDQ), and the treatment in school of the participants. Freire said the oppressed were 'regarded as the pathology of the healthy society,' (2005, p. 74), and that 'the interests of the oppressors lay in "changing the consciousness of the oppressed, not the situation which oppresses them"' (Freire, 2005, p. 74, cites de Beauvoir, 1963). In this scenario difference is a deficit, whilst conformity and uniformity are desirable. Autism becomes a disorder to be corrected (see section 1.2.2), with the young person to be changed rather than the environment. The purpose of education is seen as the transfer of knowledge and negation of consciousness, as it is essential to prevent people from seeing themselves as 'reflective, active beings, as creators and transformers of the world' (Freire, 1985, p. 115).

A requirement to conform in school was evident from both the case studies and the life history interviews, and examples have been provided in earlier sections of this chapter on relationships, grades, and attendance. It is seen in the language used *about* the girls in the case studies, with the girls variously described as '*resistant'* (Beth), '*very submissive'* (Katie) or '*very compliant'* Gina), and in that used by a teacher to criticise Lizza for thinking she is '*special'*(see section 5.2.6). It is apparent in the use of physical force used *against* the girls in the life history interviews, such as the use of restraint (Robyn), abuse from a member of staff (Rosie) or assault by another pupil (Daisy), all of which put their welfare at risk. Robyn talked about there being a culture of *having* to - '*you <u>must</u>'* (see section 5.2.8) – which she regarded as discrimination and an '*abuse of power'*. Some teachers acted in ways that emphasised power over understanding, leading to some enforcement practices that could be painful for autistic YP ('*We had this teacher who wouldn't let us in the class unless we made eye contact and said good morning'*, Daisy; Ming wanted to eat inside due to her chilblains and was '*told off'* for being in a corridor instead of outside). The importance of conforming is also noticeable in references some of the girls made to being constantly blamed and unnecessarily punished, which made them feel '*paranoid about doing things I wasn't meant to'* (Rosie).

The perception of most of the girls that they needed to conform was further evidenced by Rosie's answers in the personal construct exercise. When asked about herself in her non-ideal provision, she said:

> *I would be smiling and acting like I was fine. I would be getting on with my work and doing everything I could to pretend to fit in. Inside I would be worried and upset and angry and anxious. I would be planning how to escape. I would tell anyone that asked me anything whatever they wanted to hear.*

This illustrates the tension between a pupil who observers may consider to be 'good', and the hidden, painful reality of the experience for the autistic YP. Behaviour that conforms, in this case behaviour that may also be seen as stereotypically female, such as *'revising or maybe reading or just sitting quietly'* (Erin), may be regarded as 'more highly valued than conduct that fails to meet such expectations' (Campbell, 2009, pp. 413-414). It is possible that behaviour that fits such expectations is equated with that of the ideal pupil who, by definition, would not have additional needs. This is further supported by Erin, who stated that in a non-ideal setting one of the three things teachers would do is '*scrutinise appearance'*, emphasizing expectations of obedience and uniformity. This also potentially suggests provision of support was based on observable behaviours, rather than by internally-experienced needs, and that the allocation of these resources was at least partially driven by requirements for conformity:

> Education has always been a means of pacifying and controlling the masses rather than educating them (Smith, 1982, cited by Reay, 2016, p. 329).

Freire's conception of an education of the oppressed was as a banking system, where 'education thus becomes an act of depositing, in which the students are the depositories and the teacher is the depositor' (Freire, 2005, p. 72). Pupils are regarded as empty vessels 'to be filled' (Freire, 1985, p. 114). This is seen to a certain extent within the life history interviews (see section 5.2): Robyn said, '*you cannot speak or really have any ideas of your own'*; Lizza was restricted from asking questions; Alex did not just accept but wanted clarification; Emily needed a slower pace. The assumed role of the teacher as deliverer, with the pupil as recipient, may also partly explain why no instruction and no work were provided for the girls when they were absent from the classroom. Teaching and learning appeared to be activities and processes that had to be located in the classroom. Teachers therefore controlled access to education at the same time as they [perhaps benevolently] encouraged these girls to remove themselves from it.

The positioning of the teacher as 'the one who knows' (Freire, 1985, p. 114), and the girls as those who do not, was seen in the incorrect assumptions (see section 6.2.1) teachers sometimes made about their autistic pupils. Daisy, for example, wanted to study GCSE music (*'I love music so much'*) but was told she couldn't (*'they said, because I was autistic, autistic people don't like noise so you can't take music'*). The certainty of the teacher that his/her own knowledge and beliefs about the situation held a greater validity than those of Daisy is remarkable and demonstrates an apparent unwillingness to value the perspective of the YP, to the detriment of her education. The use of autism to not allow Daisy to do something she wished to do indicates a negativity and lack of understanding about the condition, and its use as a tool to exert power over her.

The impact of being believed or not by professionals was also seen in the referral process for an autism assessment. The case studies (see section 4.4.2) illustrate the sometimes-conflicting views of the mothers, teachers, and clinicians. These differences may have contributed to prolonged wait times for referral, particularly where observed behaviour in school did not match that at home, with the belief of the professional overriding that of the parent. In addition, the disbelief of clinicians in some of the girls' narratives appeared to prevent or restrict required access to CAMHS support (*'I did not receive the correct CAMHS help because they believed we were making it up (again 🙄)'* Erin). It is interesting that both Erin and Alex said their mothers were accused of '*making it all up'*, that it was mothers who were the parental voice throughout most of the case studies, and mothers who were described by their daughters as supporters during interview. However, whilst it is possible that their female sex and role as mother were factors in not being believed, it is beyond the remit of this thesis to seek a correlation or explore this further. Nevertheless, it is apparent that some stories become more dominant, such as the idea of a weak or untrustworthy mother, and this may have contributed to the girls being further marginalised (R. G. Dean & Rhodes, 1998).

It is noteworthy that, whilst access to the autism assessment pathway was held by professionals, and that to knowledge was directed by teachers, access to other areas of school was sometimes controlled by more powerful peers. Whilst these YP could be benevolent, enabling access to the canteen, for example, they could also be threatening. This 'horizontal violence' (Freire, 2005, p. 62) is described as 'that which peers inflict on each other to gain a modicum of power within an oppressive system' (Carlile, 2009, p. 35). Almost all the girls described some peers as verbally and physically abusive; they are the '*enemy'* (Rosie) and '*you want to just punch them in the face'* (Sally). Given the power held by schools and the requirement for conformity, the apparent lack of action to prevent or end the bullying of these autistic girls is concerning. At its most extreme conclusion, schools may be perceived as complicit in their abuse, with the girls' stories overlooked or disregarded:

> School culture functioned not only to confirm and privilege the dominant classes but also through exclusion and insult to discredit the histories, experiences, and dreams of subordinate groups (Giroux, 1985, p. xv).

Outcomes of power that sees education as 'a dominating task' (Freire, 1985, p. 114) are seen to lead to exclusion and absence: from places; from friendships and the wider community of peers; from conversation through relational aggression; from learning and from other school-based opportunities. An insistence on compliance sometimes made the girls more vulnerable by pushing them into unsafe spaces; non-compliance meant they risked being punished. The SEND Code of Practice (DfE & DoH, 2014) requires a shift of power to CYP and their families in decisions about their education, from those who currently control it, yet it is apparent from this research that such a shift has yet to happen. Under such circumstances, 'schools are destined to legitimate inequality' (Bowles & Gintis, 1976, p. 266).

It has been argued above that secondary schools demand a degree of conformity and uniformity from their pupils, in part to meet the accountability targets arising from government-driven measures. If this holds true, then there must also be implications for needs that fall outside of this framework, as what follows is that school structures are therefore not designed for individuality. This research found that requirements different to those provided for the whole class were not necessarily met within the classroom, but instead by removing the girl from the classroom. This is evidenced by the strategy frequently described by the girls in this study of the 'exit pass', by which a pupil in distress is enabled to leave a lesson and return when they feel able to cope with being in the classroom again. Whilst a uniformity of approach may be to encourage a sense of community and belonging, the result may be a perceived lack of acceptance of difference. The lack of flexibility in the system therefore creates a tension in meeting any distinctive needs of autistic girls, despite legal requirements to do so. Furthermore, divergence may be seen as deviance, per the negative language already noted.

This may help to explain why adjustments required by the girls in the life history interviews had not been made, despite some being relatively simple to resolve, and led some girls to perceive that lack of action was due to lack of will (though this may also have been the case). The results of the personal construct exercise revealed that the girls believed sensory accommodations would be made with the right school ethos and attitudes of staff, because they would be listened to and believed. There was therefore a recognition that support would not happen unless the adults understood the need for the provision and wanted to provide it, but the school structure may also have served to restrict the actions of willing teachers or of teachers who may have offered different levels of support within another school structure and prevailing ethos.

It may also potentially account for the absence of the girls' voices in much of the NHS documentation and reports of school in the life histories. Voices were not present in referral information and seemingly not always encouraged in class, as seen by limits being set on questions or requests. This may have progressed to a failure to ask the girls for their views or provide opportunities for them to discuss their needs and appropriate support. The girls who participated in the interviews were able to clearly describe their experiences and express what actions had been helpful or unhelpful in school. The ostensible absence of their voices in school was not therefore because they did not have anything to say or were unable to communicate. The failure of some schools to gather these views is contrary to the recommendation of the Lamb Inquiry (2009) and the statutory guidance in the SEND Code of Practice (DfE & DoH, 2014) (see section 1.2.1). The failure to act on the girls' views served to further marginalise them (Milton et al., 2014, p. 2650).

6.3.2 Agency

> Problem-posing education does not and cannot serve the interests of the oppressor. No oppressive order could permit the oppressed to begin to question: Why? (Freire, 2005, p. 86).

Action within school is not wholly within the control of the teachers, however, as 'human influence…is a two-way process' (Bandura, 1995, p. 38). This next section of the discussion focuses on the ability of the autistic girls in this study to partially address the imbalance of power by using their individual agency, by 'intentionally [influencing] one's functioning and life circumstances' (Bandura, 2006, p. 164) to meet their own needs at school, with particular reference to the work of Bandura.

Bandura states that most people do not act as 'autonomous agents' as they do not have complete control over their lives, but use 'socially mediated, or proxy agency' (2006) to influence others 'and secure the outcomes they desire' (p. 165). The functioning of individuals is the result of this 'interplay of intrapersonal, behavioral, and environmental determinants' (p. 165). Belief in personal efficacy underpins agency, as it is this belief that 'affects people's goals and aspirations, how well they motivate themselves, and their perseverance in the face of difficulties and adversity' (Bandura, 2006, pp. 170-1). Reflecting on the autistic girls in this research as agents, they described differing levels of self-efficacy, varying amounts of influence over their situation and different degrees of success in achieving their aims.

There are four aspects to Bandura's theory of agency: intentionality, forethought, self-regulation and reflectiveness (Bandura, 2006). These all help in a consideration of the influence of agency on the autistic girls in this research. All the girls in the life history interviews said they were academically able and described high aspirations. The six older girls demonstrated both intention and forethought, through the description of clear goals that included progressing to University study, and an understanding of what they needed to do to do to attain them. However, despite many schools' focus being on the accomplishment of exam success, and this being an aim shared by the girls, this was not sufficient to keep the girls in school. It is though, perhaps, an explanation for why the girls persevered in attending for so long before stopping completely.

The support plans devised by the schools may also have reflected an intention to aid the girls. However, by not engaging with the YP they were sometimes ineffective. The use of the exit card (see section 6.3.2) resulted in some of the girls being asked to do non-educational activities such as colouring in, which they resented, or in them being sent to a place where they felt more vulnerable or unsafe. A lack of the girls' ability to execute self-regulation, and of teachers' forethought and understanding, was exemplified by the amount of time Alex could leave the classroom using the exit pass being controlled by staff, rather than by them[59]. Instead of facilitating an understanding of individual need, the exit pass strategy neither identified the reason why the girl had to leave the lesson, nor sought to understand what in-class adjustments could be made to enable her to attend in future. In this scenario, the YP would almost inevitably be forced to repeat the withdrawal from the lesson again, but with less belief in her ability to manage or return, and less confidence in her teacher to help.

It is interesting, then, to note that most of the girls in the interviews demonstrated agency in response to their needs not being met by staff. They self-regulated by devising and implementing strategies of their own to manage the difficulties they encountered at school, in areas over which they had some control (Bandura, 1995, 2006). They withdrew from classes, avoided the canteen or playground, and

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[59] Alex used the pronouns they / them / their.

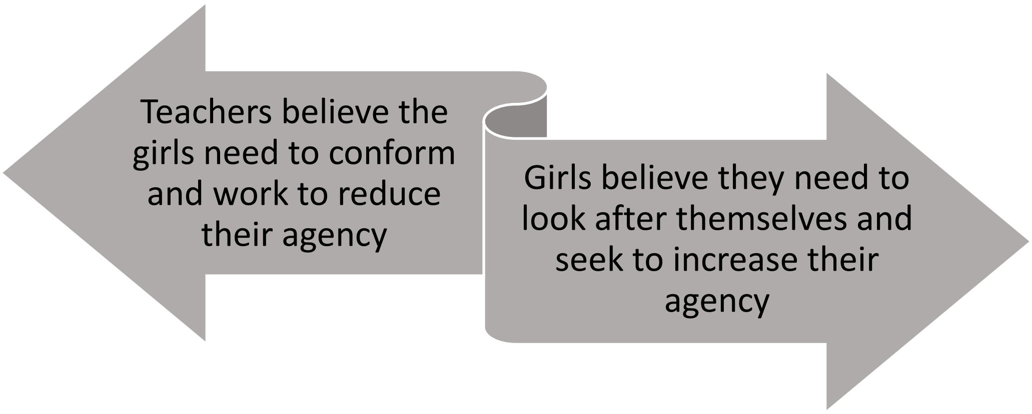
worked on their own. This is not to say that strategies employed by the girls removed barriers or solved all problems. They often came at a cost to them. Alex spent breaks sitting outside the classroom of their next lesson and Ming spent days in the library to avoid peers, which compounded feelings of loneliness and isolation; Erin masked her difficulties but '*broke in the process'*; Rosie avoided lessons and missed work as a result. They wanted to learn but had to leave.

In addition, personal approaches were sometimes in conflict with the instructions of school staff who prevented them. Some were stopped from accessing the library or being in a corridor over lunch, for example. Daisy, meanwhile, used her influence with her English teacher to stay inside a classroom at lunchtime to avoid being bullied, only to be told by the Safeguarding Lead that not being on the playground was damaging her social skills. Her diagnosis of autism was again used as a reason to attempt to enforce conformity. It is also noteworthy that, in this example, the teacher's support for Daisy's strategy was covert, despite it appearing to be in her best interests.

A tension was created when teachers attempted to reduce the girls' agency, as this served in some cases to encourage them to devise and implement their own survival techniques. The teachers not accepting or supporting the girls' individuality may have increased the girls' own recognition of their difference, emphasised their aloneness, and increased their belief that they had to look after themselves without help from others (see Figure 6.5). Furthermore, schools that restricted the girls' ability to act, whilst not meeting their needs, may have strengthened feelings of hopelessness in them and reduced their belief in themselves to affect change.

Figure 6.5

Tension Created by Teachers Reducing Girls' Agency

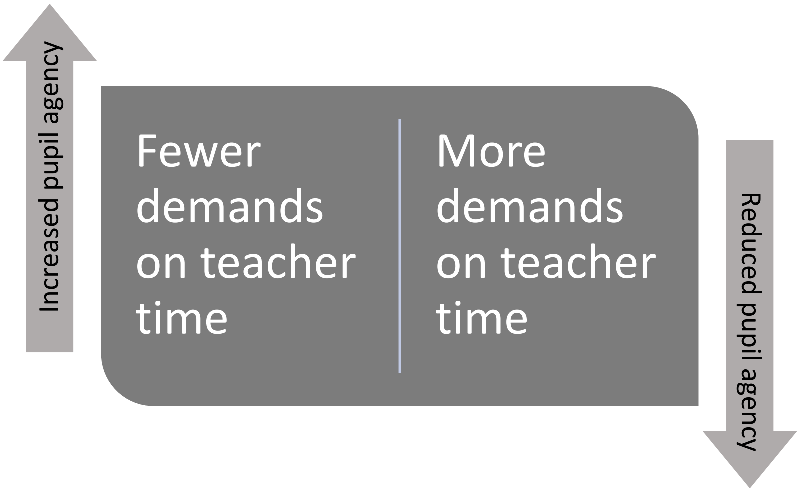


In addition, reducing the girls' agency could also be counter-productive in terms of the teacher's time (see section 6.2.3.1). Alex said they required what they perceived as excessive reassurance ('*I constantly want clarification…I need to ask and I need to check'*). In a school that valued individuality, increasing pupil agency in a nurturing environment could reduce demands on the teacher and on their time.

By contrast, reducing agency would, through an increased requirement for conformity, increase demands on the teacher and therefore take more of their time (see Figure 6.6).

Figure 6.6

Relationship Between Pupil Agency and Teacher Time



The girls in this study reported that some teachers underestimated or discounted negative events and the impact they had on them, and this may have been true. It may be that they disengaged from their role in such outcomes in order to accomplish the attainment results they required, by 'minimizing, distorting or even disputing the harm', or by 'blaming the recipients (Bandura, 2006, p. 171). This latter aspect was seen in several of the narratives. Teachers may not have been aware of the harm they caused to these girls through their actions or lack of action. Nevertheless, 'because they play a part in the course of events, they are at least partially accountable for their contributions to those happenings' (p. 172). This has implications for how they manage and resolve pupil concerns. It was also interesting that some of the girls described teachers behaving in ways that indicated conformity, suggesting they lacked agency and the power to influence events, whilst other staff were able to provide support as long as it was hidden. This inversion of expectations mirrors that of the camouflaging portrayed by the girls and the subtle adjustments they made to meet their own needs.

6.3.3 Resilience

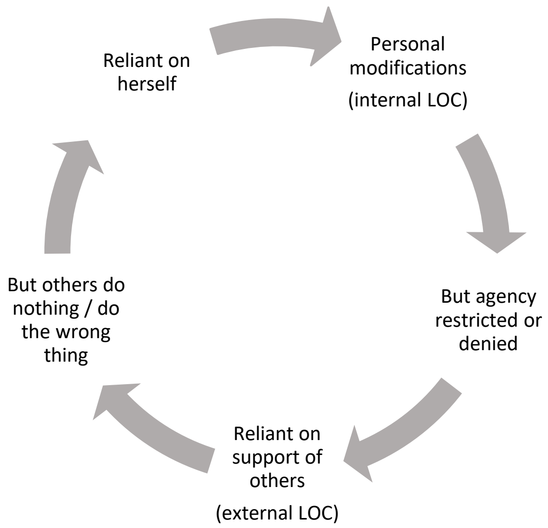
> Inability to exert influence over things that adversely affect one's life breeds apprehension, apathy, or despair (Bandura, 1995, p. 1).

Despite the reported negative impact of being in school on their mental health, the life charts demonstrated that (with the exception of Jane, whose departure was more rapid) the girls kept attending, in some cases for many years. This was surprising. It is possible that it took some of the girls to reach adolescence before they felt sufficiently influential to stop attending, or that it took that amount of time for their mental health to deteriorate to the extent that they were no longer able to keep going. It may be that their aspirations of achieving good exams and progressing to higher level study motivated them to continue, or that negative experiences were sufficiently mitigated by positive events until that point. Nevertheless, their continued attendance appeared to be in the absence of support and despite contradictory messaging (see section 6.2), with some of the girls told to '*be more resilient'* (Daisy) in order to manage any problems that they encountered. This implies it was within the girls' power to affect the changes required for them to remain at school, although it wasn't, or to accept the circumstances in which they found themselves without expectation of change.

Schwartzman (2020) talks about resilience as the 'complex interplay between active subject vs object of external forces', with agency mediated by the locus of control (LOC) which may be external or internal. This description highlights some of the difficulties with expecting resilience from these young people (see Figure 6.7), which required them to 'bounce back' (Earvolino-Ramirez, 2007, p. 73) and successfully adjust 'in the face of adversity' (M. Rutter, 1985, p. 598).

Figure 6.7

Cycle Illustrating the Tensions and Contradictions in Asking an Autistic YP to be more Resilient

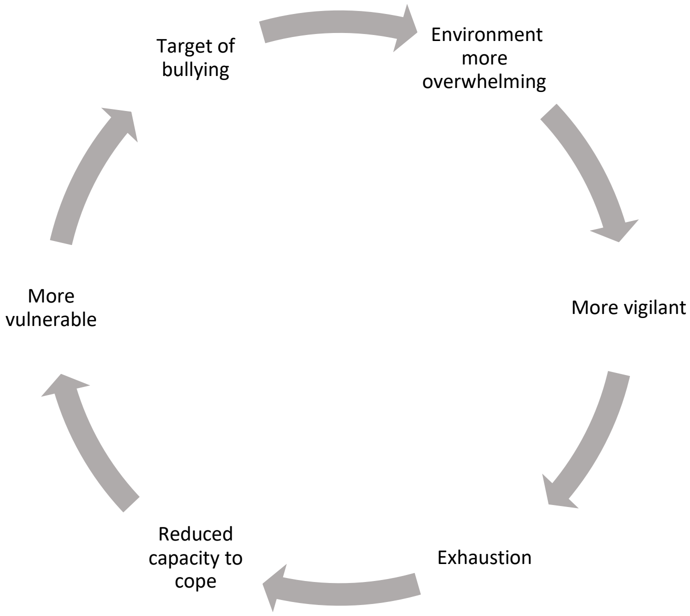


Bandura (1995) argues that facing problems can be helpful ‘in teaching that success usually requires sustained effort’ (p. 3), and that on succeeding people therefore understand achievement requires effort and are more likely to persevere in difficult circumstances: ‘they emerge stronger through adversity’ (p. 3). Some of the autistic girls in this study did not experience success in finding ways to manage in school though, which impacted on their sense of self-efficacy, and their restricted agency (see section 6.3.3) prevented the use or development of self-regulatory skills, regardless of their efforts. In addition, they were aware of the injustice of their situation.

Resilience in this instance did not involve the cause of the adversity to be addressed by the school, or necessarily prevented or removed it once it had been identified, nor allow the girls to exercise their own agency. Instead it appeared that the girls were expected to endure the challenges they experienced, and with little apparent hope of change. As such, the girls’ persistence in attending for so long more resembled perseverance. Some of the girls talked about the exhaustion this caused, as they had no space or opportunity to decompress and recover before the cycle repeated the next day (E. Davidson & Moyse, 2020). Rosie and Erin commented on the energy it took to try to manage in school. Alex talked about being constantly tired. Robyn said it left her with ‘*chronic fatigue’.* A combination of such factors appeared influential in decreasing attendance (see Figure 6.8).

Figure 6.8

Factors Influential in Decreasing Attendance



Rutter (2000) questioned whether it is ‘more useful to focus on the risks that render children vulnerable…or on the protective factors that provide for resilience in the face of adversity’ (p. 651). Elements that contributed to positive experiences for the girls in this study, and potentially to ‘optimistic self-efficacy’ (Bandura, 1996, p. 7), were identified as ‘feeling safe, validated or recognised; feeling understood; enjoying learning; pursuing passions and interests’ (personal research journal, August 22, 2019). Girls referred to nurturing classrooms, with fewer pupils, trusted adults, and safe spaces.

In addition, some described the importance of feeling safe to be themself:

> *Feeling safe in school means not being anxious or depressed and feeling free to be myself without worrying about what people are going to say to me or how I’m going to get bullied* (Erin).

In summary, the term ‘resilience’ is a misnomer when used in relation to the girls in this study. Risks to them were not addressed nor protective factors sufficiently enabled. Their voices and therefore needs and solutions, were overlooked or ignored over extended periods of time, which led eventually to breaking point. Whilst it is noted that the views of the schools and staff are [deliberately] not captured here, it is important to note the tremendous efforts the autistic girls in this study made, sometimes over years, to continue attending school for as long as they did.

6.3.4 Non-attendance

> One cannot expect positive results from an educational or political action program which fails to respect the particular view of the world held by the people (Freire, 2005, p. 95).

It can be argued that neither the issues that made these girls more vulnerable, nor the protective factors that aided them, were sufficiently addressed by the schools the girls had previously attended. The girls reported that their differences were not always accepted or accommodated, nor voices heard, meaning their perspectives and experiences were overlooked or underestimated at times. They stated they were unable to prevent negative events from happening to them at school, and the personal adjustments they made were not always permitted or sufficiently mitigating. The apparent lack of understanding in some schools, coupled with a perceived lack of will or influence of some teachers to affect change on their behalf, appeared to gradually erode the girls’ self-efficacy. This was associated with exhaustion, anxiety and depression, which further reduced their ability to persevere. These factors all pushed the girls towards absenteeism (see Figure 6.9).

Figure 6.9

Changes to Self-efficacy Beliefs and the Impact on Attendance

Stopping attending school could therefore be seen as a strong act of self-preservation. Their agency could be seen not in continuing to push back against the forces they described as harmful to them, but in withdrawing from spaces and people. For one participant, Robyn, absence from school was an act of resistance. Non-attendance had a positive impact for most of the girls, predominantly in terms of their mental health (‘*my mental health has improved gradually*’ Erin; ‘*leaving school generally I would say, it's saved my life’*, Daisy; ‘*I feel a lot safer and you know, I’m just more myself’*, Jane; ‘*I just overall seem a lot happier’*, Lizza). This was partly due to non-attendance but also from being ‘agents of their own learning, not just recipients of information’ (Bandura, 2006, p. 176). They benefitted from having greater influence over their studies, which enabled them to follow their interests (‘*I get to go riding on Fridays, I get to do a lot more textiles, I’ve even gone on an actual archaeological dig,’* Ming), work at their own pace and level, in an environment that they controlled.

However, some of the girls found being out of school extremely difficult. Whilst some were able to find alternative settings to continue their education (via an online provider, tutors, or small private schools, all of which had financial costs) others struggled to find suitable provision, which also impacted on their mental health. Rosie, for example, said, ‘*If I’m out of education, I’m generally just very depressed, and down, because I know I’m not getting an education and I know that I need an education’*. Alex, meanwhile, talked about the difficulty of finding suitable provision that provided them with the support they needed *and* with the teaching in academic subjects that would enable them to achieve the number and level of GCSE grades they wanted. Mainstream schools did not provide the support, whilst special schools did not offer the level of academic teaching that they needed to progress. There are implications here for Local Authorities (LAs), who are legally obliged under the Education Act 1996 to provide appropriate education for all pupils (see section 1.2.1). The experiences of the girls in this study suggest that the provision currently available is insufficient, as it does not meet the needs of CYP, autistic or not, who are academically able with individual support requirements. Furthermore, available alternative provision that was suitable was not always an option, for example if the girl did not have an EHCP, or if the LA elected to fight the request. In addition, it should be noted that some of the girls reported that being granted an EHCP was not straightforward, even though they met the two legal tests (IPSEA, 2019) and they were not able to access education in mainstream provision. It may be that some schools and LAs were not aware of the legal reasons why an EHCP may be given, as illustrated by Daisy:

> *I didn't have an EHCP because basically the school said I was too smart to warrant one…they said no, you won't get an EHCP for autism unless it affects your academic ability. So we had to get one for mental health*.

The sobering implication of this, however, is that most of the autistic girls in this study had to wait until they had developed serious mental health difficulties before they were deemed to meet criteria for support.

6.4 Summary

A discussion of the findings presented in Chapter 5 identified a range of tensions and contradictions that help explain why some adolescent girls stop attending school. The case studies and interviews revealed that assumptions about autism contributed to girls typically being referred for an autism assessment when they were older than boys, and to teachers being less likely to refer girls than GPs. This lack of understanding in part explains why support for the autistic girls in this study, *with* a diagnosis of autism, was absent, insufficient, or inappropriate. Unsuitable support strategies included those which encouraged or enabled withdrawal, which removed the girl from the situation but failed to address the problem and made some schools complicit in seeing absence as a solution to an unsafe or overwhelming environment. Unregistered absences, rather than concern about conduct or underachievement, were identified as better flags of concern. In this research, recorded persistent absenteeism tended to be associated with YP whose needs had been unmet for years not weeks.

The findings from the life history interviews illuminated some apparent contradictions in terms of school ethos and teacher attitudes. Whilst all the girls in this part of the study described themselves as academically able, they defined ideal schools as those that would prioritise their wellbeing over the grades they achieved. The attitudes of people in school, be they staff or peers, were influential in contributing to absence or to enabling attendance. The language used by some professionals about some autistic girls reflected a deficit understanding of autism that was highly problematic, some school staff were perceived as unwilling to help the girls, and having a friend was seen as uncommon luck. By contrast, positive relationships kept girls connected to school, kept them safe and influenced their ability to learn.

Tensions were also evident in the lack of action to support the autistic girls in this study or keep them safe, contrary to UK legislation. Bullying and abuse was prolific in the girls' accounts and yet school staff appeared unable or unwilling to stop it. Some of the girls said they stopped reporting harassment because they stopped believing anything would be done. The failure of schools to listen to the girls and to take their views into account per their rights (see section 1.2.1) was particularly striking, as was their dereliction in not making the reasonable adjustments required by law. Current legislation was not sufficient to ensure the right of these girls to an education. A further injustice to the girls was the sometimes-catastrophic impact on their mental health, resulting from the failure of others to act as they should.

The discussion with reference to Freire (Freire, 1985, 2005) highlighted that a school system that conceptualises education as a system of knowledge transfer is fundamentally at odds with meeting the needs of the individual. Such a system requires conformity, meaning there is little space for difference. The structure seems little able to flex to meet individual needs but instead removes those pupils (in this study, the autistic girls) who do not or cannot fit within such narrowly defined parameters. The life history interviews established that the girls were sometimes prevented from exercising their own agency yet, without support, were expected to be resilient. Lack of change, a reduction in self-efficacy and increasing exhaustion all contributed to a final withdrawal from school, which was a rejection of the environment, not a rejection of learning.

The final chapter reviews the findings presented in chapters four and five and considers how well they have answered the research questions. It further reflects on how these results may inform practice in schools and makes recommendations for policy makers at Local Authority and national levels. The chapter concludes by identifying the methodological limitations of this study and makes suggestions for future research.

Chapter 7: Conclusion

7.1 Introduction

This thesis set out to investigate a concern raised by a Principal Educational Psychologist about a seemingly growing number of autistic girls who stopped attending mainstream secondary school. The previous chapters presented the research questions and identified gaps in the literature; established the focus on a constructivist paradigm and the participatory methodology chosen to explore the phenomenon; and presented the findings and discussed the results with reference to disability theory, rights legislation, and the works of Freire and of Bandura. This concluding chapter summarises how the research questions were answered and aims met, highlights contributions to knowledge made by this study, and makes recommendations to inform policy and improve practice in schools. It evaluates the chosen methodology for its suitability as an approach and includes limitations of the design and process. Finally, suggestions for future research are made, based on questions which arose as a result of this study.

7.2 Key findings

It is important to first restate that many of the findings of this research support those in earlier literature of autistic pupils' perspectives of school, as noted in earlier chapters. These include the negative impact on the mental health of autistic CYP of 'often-harrowing' school experiences (Brede et al., 2016, p. 4), of misunderstandings by teachers about the nature of autism (APPGA, 2017) and of a lack of emotional and learning support (Wittemeyer et al., 2011).

This thesis adds to this existing body of knowledge because it takes a feminist standpoint to present the school experiences specifically of autistic *females* absent from school. The methods employed for the interview stages enabled the sampled girls to share their perspectives and co-construct knowledge based on the meanings they found in their experiences. Whilst the narratives presented here are not intended to be representative of all adolescent autistic girls, they nevertheless form part of the story for this particularly marginalised group of YP. The diversity within their accounts indicates no claims are made for a universal female experience of autistic girls at school, but instead presents their narratives in response to the historical absence of females from stories about autism and exclusion, and in recognition of their frequently overlooked voices. The absence of autistic girls from school cannot be understood *without* these female voices.

The first aim of the research was to understand the scale of the issue and provide some context for the study. This was completed using a combination of statistical data retrieved from the DfE and an NHS Trust, and the NHS records of eight autistic girls.

Patterns were explored in DfE school attendance records, and in the NHS autism referral and diagnostic data, looking specifically for differences in the data between school-aged females compared to males. This analysis resulted in two key findings. Firstly, the research established that **the absence of adolescent autistic girls from secondary school is a growing issue** (see section 4.2). The DfE data revealed the number of autistic pupils at schools in England rose during the period examined (2009-2017), and that the proportion of female autistic pupils compared to males increased, meaning the number of female autistic pupils increased disproportionately. The male to female ratio was closest at secondary school. Additional data showed that over this period autistic females were significantly more likely (as a proportion of their group) to be persistent absentees than autistic males or NT females or males. This is a contribution to knowledge.

Secondly, the analysis of NHS data revealed **schools were less likely to refer girls for an assessment of autism** than other main types of referrer. Whilst the literature has previously shown that girls are referred and diagnosed when they are older than boys (see section 2.2), this research established differences in the proportion of girls referred by different groups of referrers. In comparison to GPs, schools referred proportionately fewer girls than boys. However, those girls referred by schools were younger on average than those referred by GPs. This suggests that schools refer girls who are perceived to be more observably autistic, and perhaps who have more of an impact on the classroom. Whilst this earlier referral is positive for those girls, it also suggests that autistic girls who internalise difficulties may miss out on an early referral. The case studies suggested that teachers sometimes had explanations other than autism for the way autistic girls presented in class (see section 4.4.2), which were not always helpful. This has implications for whether girls are referred for assessment by schools. Although teachers are not clinicians, and do not have (nor need to have) the expertise to diagnose autistic pupils, they are an important link to various referral agencies and thus to a potential diagnosis. Therefore, the apparent lack of awareness that girls can be autistic is significant. A further implication is that teachers may not, as a result, support a parental request for their child to be assessed. In addition, they may not provide the appropriate support for a potentially autistic girl pre-diagnosis or, as evidenced by this research, not accept an autism diagnosis as valid nor understand that a pupil with a neurological condition may not visibly demonstrate their needs in class. Furthermore, the research found that many girls were referred around the time of the move from Y6 to secondary school, meaning a diagnosis was not already in place by Y7 and which potentially impacted on the success of the transition.

The second aim was to understand why some adolescent autistic girls stop attending school, by engaging a group in the production of individual life charts and personal narratives, and by referring to the NHS case studies. A third key finding was the **absence of the girls' voices** in the NHS records until the point of assessment, and from decisions about their needs in school. This research found that the sample girls were often not asked to contribute to conversations about their needs, were not listened to, were not believed, or their words were not acted upon. This is contrary to the SEND Code of Practice (see section 1.2.1) which requires LAs to ensure CYP are involved in 'discussions and decisions about their support' (DfE & DoH, 2014, p. 21). As such, the girls felt they were frequently supported inappropriately or not at all, there was no clear, accurate understanding of their strengths and needs, and they were sometimes placed in situations that made them more vulnerable. The implications of this were profound. The girls experienced bullying and abuse, unrelenting pressure, overwhelming environments, isolation, and loneliness, almost all of which were unnecessary and avoidable. In addition, almost all the girls interviewed had clinically diagnosed levels of anxiety and most reported additional mental health concerns (echoed in some of the case studies) such as self-harm, eating disorders and suicide attempts.

This leads on to the fourth key finding of the research, which is that **these girls were not rejecting learning**, but an environment and ethos that were damaging them. This is a unique contribution to knowledge. Most of the girls stated they believed there was a correlation between the lack of appropriate support for them in school and the deterioration in their mental health. An emphasis in school on conformity and uniformity appeared to mean that teachers were not able or prepared to respond to individual needs. At times difference was seen as deviance, as demonstrated by the negative language about CYP identified in the case studies, and led to some of the girls feeling like a burden and like they did not belong. For them, a school that cared first for their wellbeing, that made them feel safe, seen, and respected, was preferable to one that prioritised academic achievement. They were aspirational and continued to seek education even when they were no longer attending their mainstream school, but some struggled to find alternative provision that provided both a nurturing environment and met their academic needs. This has implications for Local Authorities, who have a legal duty under the Education Act 1996 to provide suitable education for all CYP. In light of this research, some LAs appeared to be failing some autistic girls, which had serious consequences for the health and educational outcomes in the sample girls.

The fifth key finding was that government accountability measures that may have served to identify typically struggling pupils were not useful with the girls who completed life history interviews, as they didn't highlight problems until the girls had already experienced excessive negative experiences. At that point, support strategies seemed less likely to be effective. The girls had maintained high academic standards and had official attendance figures that belied growing periods of informal and unrecorded absences, some of which were encouraged by the schools. This research demonstrated that **alternative flags of concern were required to identify autistic girls who needed different or additional support**. Central to this are the inclusion of the YP in conversations about their needs and for attention to be given to early informal absences which indicate an issue that the school should endeavour to resolve. Disengagement was a long, gradual process for most of the girls in this study, the findings of which illustrated the possibility of resolving issues much earlier in each YPs educational career. In addition, it is deeply disappointing that existing legislation does not appear to have been sufficient for some schools and LAs to meet the needs of the autistic girls, some of whom were made increasingly vulnerable and harmed by their lack of action. It is striking that, whilst the sample was small, all the girls reported it to be the case in their own experiences. As such, it may indicate that this issue is far wider than this research had the scope to show.

The third and final aim was to consider what could be learnt from the personal narratives of the autistic girls who were no longer attending school, which could inform educational policy and practice in schools. The key recommendations are presented in the next section.

7.3 Recommendations

Five key recommendations are made based on this research. All of these align with one or more of the principles of good autism practice identified by the Autism Education Trust (Guldberg et al., 2019).

1) ***'Just <u>listen</u>. It's not rocket science, just listen'*** (Daisy). As recommended by the Lamb inquiry (2009) and in the statutory guidance relating to the Children and Families Act 2014, as noted in the SEND Code of Practice (DfE & DoH, 2014), making the voice of the child central to understanding their individual needs and requirements is crucial (Crane & Pellicano, 2017). This research has shown that too often school provision was based on assumptions, contradictions, and stereotypical notions of autism. Engaging the girls in respectful dialogue, meanwhile, revealed simple explanations for their concerns and often equally simple adjustments and solutions. The findings showed the impact of particular teachers who encouraged and believed in the girls, and the development of strong relationships is therefore crucial, and key to communication. Schools should recognise the value to autistic YP of an adult they can trust to be their ally and understand that this adult must be chosen by the YP, not the school. Therefore, any appointment of a mentor or one-to-one should be with the input and consent of the YP. Evidence of pupil voice should be present in all school or medical records about a child from the first time concerns are raised, by a parent, professional or the YP, partly because the law requires it, but also because it is an indicator of them being valued by teachers and clinicians as individuals with views and rights. In addition, listening to their

voices is essential to understand and resolve problems as they are experienced by the YP. This evidence should form part of any referral documentation.

2) **‘Be curious’** (Robyn). Given the propensity of many autistic CYP to mask and camouflage difficulties they encounter (see section 1.2.3), and the evidence from this study that neither conduct nor achievement may be issues for autistic girls in school, seeking to understand *why* a YP is behaving in a particular way is important. The girls in this study revealed differences between how they may have appeared at school and how they behaved at home, and differing perspectives could alert professionals to real issues that may not be evident to them. Some of the girls were not where they were expected to be during the day. They sat outside a classroom door or in a corridor during break, ate lunch in the toilets or made frequent use of an exit pass to leave a lesson. Patterns in absence highlight issues that need to be addressed. Furthermore, strategies used by teachers that involve absence are not appropriate unless they are followed up and underlying issues resolved, otherwise the message the girls may receive is that they are not welcome in that space and that they are the problem. Being more curious about a YP also means positives are identified. Strengths can be celebrated and developed. Particular interests, such as Ming’s passion for the Romans, can be fostered. Relationships can be nurtured.

3) The ***‘ideal school would prioritise pupil wellbeing’*** (Erin). This research found that the girls in this study most wanted to attend a school that cared for their wellbeing more than the grades they may achieve. This is perhaps unsurprising given the impact of their negative school experiences on their mental health. Being happy and feeling accepted were not unreasonable wishes of the girls. Wanting to be taught, to feel safe and to have reduced sensory input from their environment are not unreasonable requests. Mainstream secondary schools may believe they are prioritising pupil wellbeing, but this research suggests they are either being ineffective in this or that their messages are contradictory. If current accountability measures lead to an unhealthy preoccupation with grades, then more accountability needs to be put in place to ensure a successful focus on the mental health and wellbeing of the pupils in school. In addition, some of the girls were clear that, once they had left mainstream school it was not possible to return and that there was no alternative provision that met their academic needs. They were ‘betwixt and between’ (Grinker, 2008, p. 22). Whilst noting that autistic girls should never be in a position where absence is the only solution to continued unmet needs, mainstream provision was not suitable for some of the girls in this study. This means Local

Authorities (LAs) need to provide schools that offer the broad curriculum and high academic teaching expected of a mainstream with the nurturing and low arousal environment that these girls said they needed, and which is not currently available. This requires the collection of better data by LAs on the needs of their autistic pupils in order to commission the appropriate services and provision, per the recommendation of the All Party Parliamentary Group on Autism (APPGA, 2017).

4) ***'Take action'*** (Jane). Chapter 6 discussed the power imbalances in schools and the emphasis on conformity, and the expectation that problems were met with resilience. Whilst the girls in this study showed great perseverance and the ability to be creative and seek their own solutions, their lack of agency and absence of [appropriate] support meant resilience was challenging. Given this structure, it is essential that individual teachers lead change and act to resolve damaging situations, such as the extensive bullying identified by this research. The requirement for LAs to make alternative educational provision for these girls is urgent and compelling. It is noteworthy that the current Covid-19 pandemic has meant that practices that could have benefitted autistic pupils but were not previously offered in mainstream schools, such as recorded lessons or remote web-based learning, are now more widely available. Education has continued without staff or pupils being physically present in a classroom. This provokes thought about why such measures were not previously put in place for absentee pupils, with the inference that such decisions were politically based and resource-driven rather than unachievable or pupil-centred.

5) Be ***'more informed about being autistic, and what autism was'*** (Alex). It was apparent from the case studies and from the interviews that some school staff did not understand what it meant to be autistic. This contributed to autistic girls being referred for assessment later than necessary, and to a lack of suitable support for those with a diagnosis. Training is therefore a key recommendation, in line with that made by the All Party Parliamentary Group on Autism, as is greater accountability in how schools abide by the requirements of the Children and Families Act 2014 and the SEND Code of Practice (APPGA, 2017). This must be for all school staff, not just the SENCo or the class teacher; autistic girls should be able to access spaces during breaks and lunchtimes that are supervised by other staff, who therefore also need to receive training to ensure they are safe and supported when necessary.

> To avoid further assumptions and misunderstandings about the nature of autism, it is important that training is led by an autistic practitioner. Autistic people's perspectives are crucial in order to convey different perspectives, challenge assumptions and myths about autism, and help to change attitudes and mindsets.

In summary, mainstream secondary schools have the potential to meet the needs of many academically able autistic girls. To do this, they must prioritise wellbeing, book autistic-led training for all staff, become more curious about why some autistic pupils take the actions they do and take action to protect and support them. Alternative provision that meets academic needs in a smaller nurturing environment must be made available for those autistic CYP for whom mainstream will not adapt to care for. Underpinning all these recommendations is the need to truly listen to the voice of the autistic YP.

7.4 Evaluation of methodology

The mixed methods approach of this study (see section 3.2.1) proved effective in providing valuable context as well as the richness of data required for a nuanced understanding of the phenomenon. Together the analysis of statistical and qualitative data, from a range of sources and of methods of retrieval or collection, combined to give a deeper and more extensive understanding (Creswell & Plano Clark, 2011).

7.4.1 Successes

The participatory approach taken was an ethical priority for this research, based on the marginalisation of autistic girls and the imbalance of power experienced by them at school. It was also in recognition that education is a right, and that being out of school may have been partly due to that right being overlooked. It appeared to be successful in helping to address power differentials between the YP and the researcher, particularly through the use of research tools that enabled them to be in control of the memories they shared and how they positioned them.

Adjustments to methods as suggested by the Autism Advisory Group, such as how and where the girls were interviewed, ways in which answers could be recorded, and how to reduce anxiety pre-interview, were all helpful. Providing questions in advance gave them the opportunity to process the information beforehand and consider their answers without the pressure of time. The personal construct exercise enabled the girls to prioritise their answers and, as such, provided new knowledge that avoided potential researcher assumptions. The use of life charts provided a scaffold for them to identify key experiences that were important to them, whilst the final interview involving their thematic analysis of events enabled the participant-led co-production of knowledge whilst discussing the meaning of individual realities.

These tools were also chosen to support an emancipatory approach. They aided a rebalance of power by encouraging the girls to liberate themselves from a past over which they had no control; to decide themselves what they shared and how they interpreted potentially traumatic memories of school; and to consider their aspirations and pathways to a more positive future. The research process was transformative for some of the girls, who gained strength from transforming the pain of negative experiences into key recommendations for change and best practice using their own words. The case studies demonstrated the absence of the girls' voices in conversations about them and their experiences; the life history interviews gave the autistic girls in that sample the opportunity to speak and have their voice heard; they were validated.

7.4.2 Limitations

There were, however, a number of limitations to this study. Firstly, the data obtained from the NHS Trust was incomplete. Data from the autism assessment pathway for all CYP aged from 1 to 18 years had initially been requested. However, it was later discovered that, due to the structure of this particular Trust and the way it collected data, a large section of the data for children under the age of five was not available. As a result, all the data for children under the age of five were removed from the database. In addition, there were systemic problems with the way data had been recorded in the past. An example of this was the date of the diagnosis of a child was sometimes recorded as earlier than the date of their referral to the autism assessment pathway, making it impossible to make a logical assessment of this data. Furthermore, 27% of the records provided lacked information on ethnicity, meaning this was either not provided to the Trust, or not entered onto the RiO database. It was therefore not possible to investigate possible interactions between ethnicity, sex and autism referral and diagnosis.

The detailed review of eight individual records provided further instances of errors or omissions. Lauren's record had two entries (13/09/11; 27/01/2012) with a note against each stating 'delete this', although neither of the entries or documents had been deleted, whilst two other documents with different dates were identical. Mia's record was missing part of the Educational Psychologist's report, and additional diagnoses of ODD and ADHD were noted on a letter from CAMHS to her GP but were not listed as diagnoses on the relevant part of her records on RiO. In addition, some documents were not precise. This was seen in the time when difficulties were first noted being reported as covering a few years, such as 'at infant school'.

Over and above these issues, a further limitation was that data from only one Trust was requested. As such, it is possible that different results would be found by analysing referral and diagnostic data from the autism assessment pathways of other Trusts.

There were also limitations to the interview stages of the study. Firstly, the self-selecting opportunity sample of participants could have been more diverse. All ten participants from the sample were white and, as research with BAME autistic CYP is scant and much needed, this was a particularly notable issue. Next, two girls only completed the first interview. The interview with Sally suggested her non-continuance was due to the trauma she was still experiencing from her time at school, which made the timing inappropriate for her. It may be that Emily, the second girl who chose not to continue, would have done so if the process had been different.

Next, all eight girls who participated in the life history interviews self-identified as academically able. Since the nature of qualitative research is that results cannot be generalised, interviewing a different ten girls could have produced different findings. Those who participated could have had very different experiences from those who chose not to (Gregory & Purcell, 2014). Potential participants who were non-verbal may have decided not to take part, for example. Whilst the possibilities of being interviewed by text messenger or email were offered, it is recognised that the research tools used could have been limiting.

The use of the SDQ may, initially, appear to have been an odd choice given the prioritisation of the autistic girls' voices. However, by completing the questionnaire the girls were able to explain why answering contextless statements was so problematic and to highlight how answers could be misinterpreted. This demonstration of the limitations of this tool for them has implications for how it is used in clinical practice as well as in research with autistic CYP.

Finally, it is accepted that other people in the girls' narratives may remember the events recounted very differently. However, Freire's approach was for the marginalised to challenge oppression from within their own stories and experiences (Giroux, 1985), and the absence of triangulating perspectives of others was a decision made to prioritise previously absent or overwhelmed voices; those of the girls. This feminist standpoint also explains why autistic boys were not included in the interview stages of the research.

7.5 Future research

Whilst this study answered the three research questions presented, nevertheless additional questions arose during the process which provide scope for future research. Firstly, this research identified wide variations and unexplained differences in age at referral and diagnosis for females and males between different areas of the NHS Trust studied. As diagnostic clinicians worked across CCGs and wait times between referral and assessment were not significantly different, the variation arguably lay in the referral process. Further research could be conducted into the role of cultural, socioeconomic and ethnicity variables on referrals to the autism assessment pathway, of both the referrer and the referred (CYP *and* their parents). It would also be beneficial to consider multi-Trust comparisons to provide a broader understanding of the issues across the country.

Secondly, the life chart research tool used for the life history interviews was instrumental both in engaging the YP in the research and their own narrative as well as in aiding the co-creation of knowledge. It enabled positive and negative events in the girls' school experiences to be plotted and discussed, which in turn enabled the identification of successful or desirable support strategies. It would be interesting to understand how this tool could be used *in school* with autistic YP, to facilitate pupil voice and help monitor wellbeing. A project that employed a shorter version of this technique could be used with Y7 pupils towards the end of their first year of secondary school, with learning arising used to inform support for the following year, during which and at the end of which progress (wellbeing, attainment, and absence) could be evaluated.

The focus on autistic females who were non-attenders meant that no comparisons could be made with autistic males who were non-attenders. It is possible that it is the process of internalising challenges experienced in school that makes autistic CYP more likely to become non-attenders, rather than sex, and a study that explores this issue could be of interest. Given existing research that suggests autistic people may be more likely than people with the PNT to relate to non-binary gender identities (Strang et al., 2020), studies that are informed by both sex and gender may also be of value.

Finally, this research has produced some interesting findings on why some autistic adolescent girls stop attending mainstream secondary schools. The girls identified aspects of school that were positive and negative, and reasons for their absence, and it would be interesting to research whether autistic girls who *are* attending school full time would produce similar results from their life charts. There may be additional factors not uncovered in this study that have contributed to their continued attendance. This is not to preclude male CYP from such studies, which may lead to similar or contrasting findings, but to continue to elevate the voices of those female autistic CYP who have been absent from research about them for so long.

7.6 Concluding remarks

This thesis began with an awareness that adolescent autistic girls were frequently missing from stories about autism and exclusion from school, a silencing of an already marginalised group. A comment from a Lead Educational Psychologist and anecdotal evidence from national groups on social media, together with work locally with the families of autistic girls, suggested their absence was a growing, overlooked issue. This study took a feminist standpoint to draw attention to this apparent phenomenon of autistic females absent from school and chose a participatory framework to give voice to some of their stories and co-create meaning from their words. In recognition of the trauma and lack of control experienced in school by some of the girls in the study, the approach taken was emancipatory, with efforts made to shift the balance of power between researcher and participants. The resulting data provide a range of findings that both support and add to the existing body of knowledge about autistic CYP and schools. The subsequent discussion draws on these elements to present an understanding of the issue that is more nuanced and multi-faceted than initially considered.

In conclusion, this study is one of the first in the literature that has worked exclusively with autistic adolescent girls absent from school through non-attendance as opposed to formal exclusion. It has identified that absence from school is a significant issue for many of these girls, and their narratives challenge the dominant view of 'school refusal'. In contrast to much of the literature on school non-attendance, this research found that these girls wanted to be in a school, learning. They were not rejecting education, but an ethos and an environment that were profoundly damaging. The lack of support and understanding they experienced were the result of their voice being undermined or overlooked, contrary to UK legislation and the UNCRC rights of a child. Had they been encouraged to share their thoughts, incorrect assumptions about them and their needs could have been corrected. Had appropriate action been taken, or care and protection been in place, then perhaps the deterioration they described in their mental health could have been avoided. This is a rights issue, and it is hoped that this research will alert schools and LAs to these outstanding needs, as well as shine a light on examples of best educational practice as experienced by these girls.

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Appendix

Appendix 1.1 Number of Male and Female Autistic Pupils in England

Numbers of Pupils in England with a Primary Diagnosis of Autism, by Sex

	Pupils with SEN at School Action Plus (2010-14) or Pupils with SEN support or School Action Plus (2015-16)			Pupils with statements of SEN (2010-14) or with statement or EHC plan (2015-16)			Total identified as SEN		TOTAL males and females	Change	Change
	Male	Female	Total[60]	Male	Female	Total	Male	Female	All	males	females
Year	Number	Number	Number	Number	Number	Number	Number	Number	Number	%	%
2016	34,680	8,121	42,801	48,315	8,896	57,211	82,995	17,017	100,012	83.0	17.0
2015	29,830	6,700	36,530	46,030	8,215	54,245	75,860	14,915	90,775	83.6	16.4
2014	21,500	4,545	26,040	42,485	7,490	49,975	63,985	12,035	76,020	84.2	15.8
2013	19,640	3,920	23,560	40,240	6,985	47,225	59,880	10,905	70,785	84.6	15.4
2012	18,300	3,540	21,840	37,870	6,490	44,355	56,170	10,030	66,200	84.8	15.2
2011	16,530	2,940	19,470	35,995	6,105	42,105	52,525	9,045	61,570	85.3	14.7
2010	14,450	2,480	16,930	33,710	5,620	39,320	48,160	8,100	56,260	85.6	14.4

---

[60] The totals in years 2010, 2011, 2012 and 2014 vary, dependant on whether the totals of males and females are summed, or the totals of pupils with SEN support/School Action Plus and Statements/EHCP's are summed. Variance is between 10 less and 5 more of the totals shown for males and females.

Appendix 2.1: Search Terms used in Initial Literature Review

No.	Terms
1	(autis* or Asperge* or ASD or ASC or AS or HFA)
2	(child or children or teen* or adolescen* or young people or young person or youth)
3	(girl or girls or female or females or young women or young woman)
4	(education or school or mainstream or secondary or primary)
5	(exclud* or exclusion or self-exclusion or missing or absent or absence or truan*)
6	(experienc* or view or views)
7	(missing education)
8	(school absence)
9	(missing school)
10	absent
11	exclusion
12	missing
13	school
14	non-attenders or truants or absenteeism or refusal or exclusion
15	autism
16	girls

Appendix 2.2 Initial Searches

	Autism	Children	Girls	Education	Missing	Experience	All found	Possible relevance: author and year
All Education Databases, run 23.03.17					5		0	
					5		2	
							35	Peters, 2016 (parental perspectives); Jarman, 2015 (adult autistic females and parental perspectives); Cridland, 2014 (experiences; mothers and daughters)
					5		4	
					5		410	Carlile, 2009 (exclusion and gender); Olafson, 2006 (truancy and girls); Osler, 2006 (exclusion and girls); Russell, 2011 (exclusion and girls); Sanders, 2007 (exclusion and marginalisation)
					5		15	Harrington et al, 2014 (autism and research methodology)
					7		0	
					8		0	
					9		0	
					10		1	
					11		2	
					12		3	
Google Scholar, run 01.06.17				13	14		11	Osler, 2003 (exclusion and girls); Smith, 2014 (absenteeism); Murray, 2012 (SEND and challenge of mainstream)
EThOS, run 13.02.17	15		16		10		0	
	15		16		11		0	
	15		16		12		0	
	15		16				12	Tierney, 2014 (autistic girls and masking)
	15				11		10	Bennett-Warne, 2015 (autistic CYP and transition to Y7)
			16		11		37	Alexis, 2015; Douglas, 2013 (girls and exclusion); Rouse, 2011 (girls and exclusion); Loizidou, 2009 (exclusion and CYP); Connolly, 2008 (girls and exclusion); Padfield, 2001 (exclusion and CYP)

Appendix 2.3 Final Searches

Search number	University library, Education Databases: Search terms		Searched by: a. Contains ANY of these words in the title b. Subject terms
1		school OR education	Rouse 2011; Carlile 2008; Abuya 2014; Dhilion 2011; Teofilo de Brito 2015
	AND	exclude* OR exclusion	
	AND	girl* OR female	
2		autis* OR ASD OR Asperger OR HFA	Brede 2017; Gray 2018; Sproston 2017; Osler and Osler 2002; Goodall 2018; Hatton 2018; Humphrey 2008; Dean 2013
	AND	school OR education	
	AND	exclude* OR exclusion	
3		autis* OR ASD OR Asperger OR HFA	Goodall 2019; Myles 2019; Myles 2017
	AND	school OR education	
	AND	exclude* OR exclusion	
	AND	girl* OR female	
4		autis* OR ASD OR Asperger OR HFA	Ochi 2020; Munkhaugen 2017a; Munkhaugen 2017b
	AND	school OR education	
	AND	refuse OR refusal OR SRB	
5		autis* OR ASD OR Asperger OR HFA	Ochi 2020; Munkhaugen 2019 (revised article)
	AND	school OR education	
	AND	refuse OR refusal OR SRB	
	AND	girl* OR female	
6		autis* OR ASD OR Asperger OR HFA	*No results*
	AND	school OR education	
	AND	absent OR absence OR absentee*	
7		autis* OR ASD OR Asperger OR HFA	Totsika 2020
	AND	school OR education	
	AND	non-attendance	
8		autis* OR ASD OR Asperger OR HFA	*No results*
	AND	school OR education	
	AND	withdraw* OR truant* OR truancy	
9		autis* OR ASD OR Asperger OR HFA	Moyse and Porter 2015; Goodall 2019; Tomlinson 2020; Land 2015; Myles 2017; Sedgewick 2015; Bottema-Beutel 2016; Williams 2017; Neal 2016
	AND	school OR education	
	AND	girl* OR female	
	AND	experience OR narrative	

Appendix 3.1 Freedom of Information request

FOI request from the author to the Department for Education on 29/10/2018 via email:

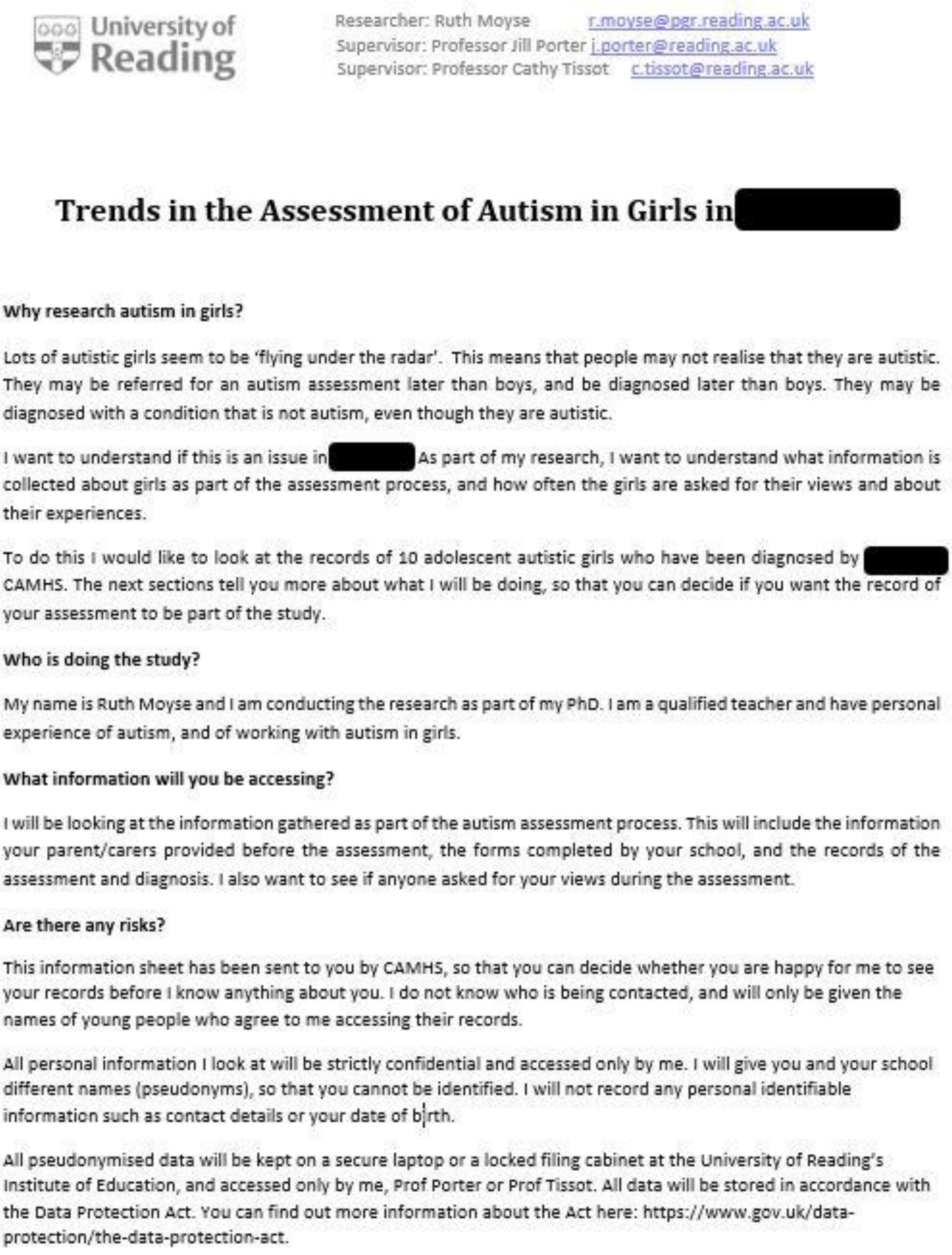
> I would like to make a Freedom of Information request, please.
>
> What proportion (%) and number of girls (compared with boys) with an autism spectrum disorder (ASD) have been persistently absent from state-funded primary schools and secondary schools for each of the academic years: 2009-10, 2010-11, 2011-12, 2012-13, 2013-14, 2014-15, 2015-16, 2016-17?
>
> I would like the data for primary schools and secondary schools to be separate, rather than shown as a total.

FOI response from the school absence and exclusions data team, Department for Education, on 20/11/2018 via email:

> Dear Ms Moyse,
>
> Thank you for your request for information, which was received on 29 October 2018.
>
> You requested:
>
> *'What proportion (%) and number of girls (compared with boys) with an autism spectrum disorder (ASD) have been persistently absent from state-funded primary schools and secondary schools for each of the academic years: 2009-10, 2010-11, 2011-12, 2012-13, 2013-14, 2014-15, 2015-16, 2016-17? I would like the data for primary schools and secondary schools to be separate, rather than shown as a total.'*
>
> I have dealt with your request under the Freedom of Information Act 2000.
>
> A copy of the information is enclosed. Please note that the definition of persistent absence changed from the 2015/16 academic year. Pupil enrolments missing 10 per cent or more of their own possible sessions (due to authorised or unauthorised absence) are classified as persistent absentees. The information presented for years prior to 2015/16 has been produced using the same methodology in order to allow comparisons on a consistent basis over time.
>
> The department publishes National Statistics releases on absence in schools, and the most recent full year release may be found at: https://www.gov.uk/government/statistics/pupil-absence-in-schools-in-england-2016-to-2017. Underlying data accompanies the publication and includes data at school level.
>
> You may also find it useful to refer to our guide on absence statistics, which may be found at: https://www.gov.uk/government/publications/absence-statistics-guide

Data provided by this FOI request are presented in Tables 4.1 and 4.4.

Appendix 3.2 NHS Participant Information



University of Reading

Researcher: Ruth Moyse r.moyse@pgr.reading.ac.uk
Supervisor: Professor Jill Porter j.porter@reading.ac.uk
Supervisor: Professor Cathy Tissot c.tissot@reading.ac.uk

Trends in the Assessment of Autism in Girls in [redacted]

Why research autism in girls?

Lots of autistic girls seem to be 'flying under the radar'. This means that people may not realise that they are autistic. They may be referred for an autism assessment later than boys, and be diagnosed later than boys. They may be diagnosed with a condition that is not autism, even though they are autistic.

I want to understand if this is an issue in [redacted] As part of my research, I want to understand what information is collected about girls as part of the assessment process, and how often the girls are asked for their views and about their experiences.

To do this I would like to look at the records of 10 adolescent autistic girls who have been diagnosed by [redacted] CAMHS. The next sections tell you more about what I will be doing, so that you can decide if you want the record of your assessment to be part of the study.

Who is doing the study?

My name is Ruth Moyse and I am conducting the research as part of my PhD. I am a qualified teacher and have personal experience of autism, and of working with autism in girls.

What information will you be accessing?

I will be looking at the information gathered as part of the autism assessment process. This will include the information your parent/carers provided before the assessment, the forms completed by your school, and the records of the assessment and diagnosis. I also want to see if anyone asked for your views during the assessment.

Are there any risks?

This information sheet has been sent to you by CAMHS, so that you can decide whether you are happy for me to see your records before I know anything about you. I do not know who is being contacted, and will only be given the names of young people who agree to me accessing their records.

All personal information I look at will be strictly confidential and accessed only by me. I will give you and your school different names (pseudonyms), so that you cannot be identified. I will not record any personal identifiable information such as contact details or your date of birth.

All pseudonymised data will be kept on a secure laptop or a locked filing cabinet at the University of Reading's Institute of Education, and accessed only by me, Prof Porter or Prof Tissot. All data will be stored in accordance with the Data Protection Act. You can find out more information about the Act here: https://www.gov.uk/data-protection/the-data-protection-act.

Are there any benefits to taking part?

No participation is required for this part of my study, so there are no direct benefits. However, I hope that the findings from looking at records like yours will help to improve support for autistic girls like you, and your information will have contributed to this change.

What happens if I change my mind?

You may withdraw your consent to participate at any stage by emailing me to let me know. No reason needs to be given, and there any no penalties for changing your mind. Any data I had already collected about you would be destroyed.

Can I see the results of the research?

Yes. I will email a copy of the summary to all participants once the project has been completed.

What will happen to the data?

The results of my study will be written up as part of my PhD thesis, and may be presented at national and international conferences, and in written reports and articles. I can send you electronic copies of these publications if you wish.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you can contact Professor Jill Porter, University of Reading, at j.porter@reading.ac.uk or on 0118 378 2772.

What should I do next?

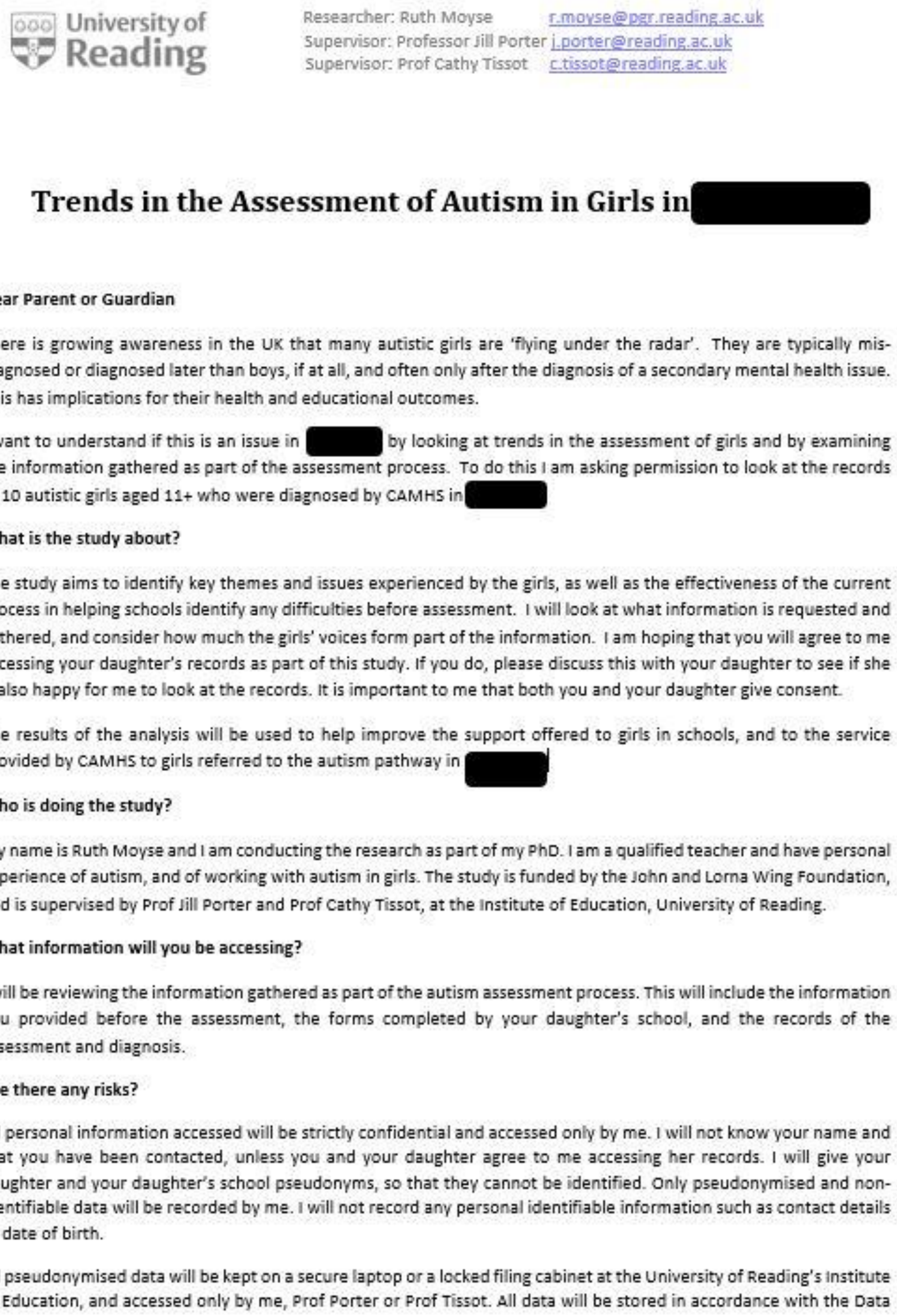
If you have any further questions, please contact me at r.moyse@pgr.reading.ac.uk. I do hope you will feel able to support this project. If you and your parent/carer agree, they will email me to let me know. I will then send you a consent form for you to sign and return to me in a pre-paid envelope.

This Project has been reviewed by the University Research Ethics Committee and the NHS Confidentiality Advisory Group, and has been given a favourable ethical opinion for conduct. The University has the appropriate insurances in place. Full details are available on request.

Thank you for your time

Ruth Moyse
Doctoral Researcher

Appendix 3.3 NHS Parent or Guardian Information



University of Reading

Researcher: Ruth Moyse r.moyse@pgr.reading.ac.uk
Supervisor: Professor Jill Porter j.porter@reading.ac.uk
Supervisor: Prof Cathy Tissot c.tissot@reading.ac.uk

Trends in the Assessment of Autism in Girls in [redacted]

Dear Parent or Guardian

There is growing awareness in the UK that many autistic girls are 'flying under the radar'. They are typically mis-diagnosed or diagnosed later than boys, if at all, and often only after the diagnosis of a secondary mental health issue. This has implications for their health and educational outcomes.

I want to understand if this is an issue in [redacted] by looking at trends in the assessment of girls and by examining the information gathered as part of the assessment process. To do this I am asking permission to look at the records of 10 autistic girls aged 11+ who were diagnosed by CAMHS in [redacted]

What is the study about?

The study aims to identify key themes and issues experienced by the girls, as well as the effectiveness of the current process in helping schools identify any difficulties before assessment. I will look at what information is requested and gathered, and consider how much the girls' voices form part of the information. I am hoping that you will agree to me accessing your daughter's records as part of this study. If you do, please discuss this with your daughter to see if she is also happy for me to look at the records. It is important to me that both you and your daughter give consent.

The results of the analysis will be used to help improve the support offered to girls in schools, and to the service provided by CAMHS to girls referred to the autism pathway in [redacted]

Who is doing the study?

My name is Ruth Moyse and I am conducting the research as part of my PhD. I am a qualified teacher and have personal experience of autism, and of working with autism in girls. The study is funded by the John and Lorna Wing Foundation, and is supervised by Prof Jill Porter and Prof Cathy Tissot, at the Institute of Education, University of Reading.

What information will you be accessing?

I will be reviewing the information gathered as part of the autism assessment process. This will include the information you provided before the assessment, the forms completed by your daughter's school, and the records of the assessment and diagnosis.

Are there any risks?

All personal information accessed will be strictly confidential and accessed only by me. I will not know your name and that you have been contacted, unless you and your daughter agree to me accessing her records. I will give your daughter and your daughter's school pseudonyms, so that they cannot be identified. Only pseudonymised and non-identifiable data will be recorded by me. I will not record any personal identifiable information such as contact details or date of birth.

All pseudonymised data will be kept on a secure laptop or a locked filing cabinet at the University of Reading's Institute of Education, and accessed only by me, Prof Porter or Prof Tissot. All data will be stored in accordance with the Data

Protection Act. You can find out more information about the Act here: https://www.gov.uk/data-protection/the-data-protection-act.

Are there any benefits to taking part?

It is hoped that findings from looking at the records of your daughter's assessment, and those of other girls, may help to improve the referral process and the assessment of autism in girls like her. Whilst your daughter will not be directly involved, your daughter's records will therefore contribute to benefitting autistic girls like your daughter, who are yet to be diagnosed.

What happens if I change our mind?

You may withdraw your consent to participate at any stage by emailing me to let me know. No reason needs to be given, and there any no penalties for changing your mind. Any data I had already collected about your daughter would be destroyed.

Can I see the results of the research?

Yes. I will email a copy of the summary to all participants once the project has been completed.

What will happen to the data?

The results of my study will be written up as part of my PhD thesis, and may be presented at national and international conferences, and in written reports and articles. I can send you electronic copies of these publications if you wish.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you can contact Professor Jill Porter, University of Reading, at j.porter@reading.ac.uk or on 0118 378 2772.

What should I do next?

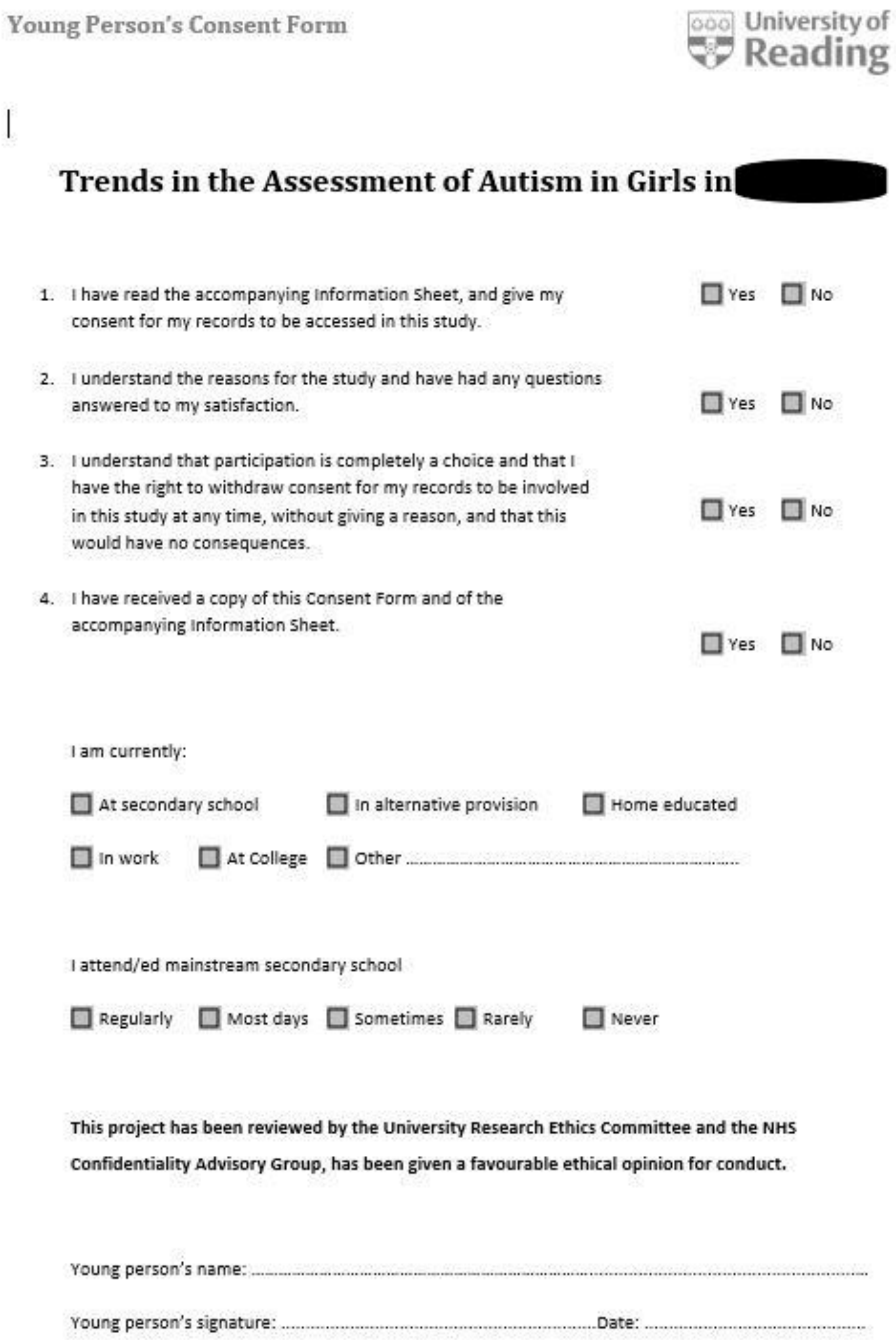
If you have any further questions, you can contact me by email at r.moyse@pgr.reading.ac.uk. I do hope you will feel able to support this project. If you do, please email me to let me know, and I will post consent forms for you and your daughter to sign and return to me, in a pre-paid envelope.

This Project has been reviewed by the University Research Ethics Committee and the NHS Confidentiality Advisory Group, and has been given a favourable ethical opinion for conduct. The University has the appropriate insurances in place. Full details are available on request.

Thank you for your time

Ruth Moyse
Doctoral Researcher

Appendix 3.4 NHS Participant Consent Form



Young Person's Consent Form

University of Reading

Trends in the Assessment of Autism in Girls in [redacted]

1. I have read the accompanying Information Sheet, and give my consent for my records to be accessed in this study. ☐ Yes ☐ No

2. I understand the reasons for the study and have had any questions answered to my satisfaction. ☐ Yes ☐ No

3. I understand that participation is completely a choice and that I have the right to withdraw consent for my records to be involved in this study at any time, without giving a reason, and that this would have no consequences. ☐ Yes ☐ No

4. I have received a copy of this Consent Form and of the accompanying Information Sheet. ☐ Yes ☐ No

I am currently:

☐ At secondary school ☐ In alternative provision ☐ Home educated

☐ In work ☐ At College ☐ Other ……………………………………………………………

I attend/ed mainstream secondary school

☐ Regularly ☐ Most days ☐ Sometimes ☐ Rarely ☐ Never

This project has been reviewed by the University Research Ethics Committee and the NHS Confidentiality Advisory Group, has been given a favourable ethical opinion for conduct.

Young person's name: ……………………………………………………………………………………

Young person's signature: ……………………………………………Date: ……………………………

Appendix 3.5 NHS Parent or Guardian Consent Form

Parental Consent Form

University of Reading

Trends in the Assessment of Autism in Girls in [redacted]

1. I have read and had explained to me by Ruth Moyse the accompanying Information Sheet, and give my consent for my daughter's records to be accessed in this study. ☐ Yes ☐ No
2. I have had the reasons for the study explained to me and have had any questions answered to my satisfaction. ☐ Yes ☐ No
3. I understand that participation is entirely voluntary and that I have the right to withdraw consent for my daughter's records to be involved in this study at any time, without giving a reason, and that this would have no consequences. ☐ Yes ☐ No
4. I have received a copy of this Consent Form and of the accompanying Information Sheet. ☐ Yes ☐ No

Does your daughter/did your daughter attend secondary school:

☐ Regularly ☐ Most days ☐ Sometimes ☐ Rarely ☐ Never

This project has been reviewed by the University Research Ethics Committee and the NHS Confidentiality Advisory Group, has been given a favourable ethical opinion for conduct.

Parent's name: ....

Parent's signature: ....Date: ....

Appendix 3.6 Visitors to London Road

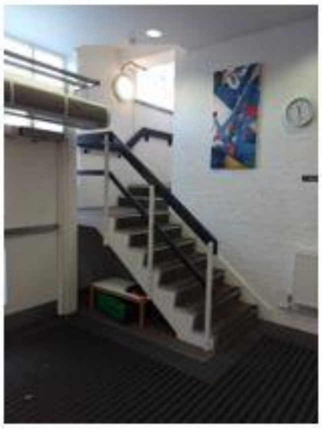
University of Reading

1.Welcome to the London Road campus!

This is the entrance to Reception, building 16.

2. This is the Reception desk, where I will meet you. Caroline is the receptionist, and she will give you your car permit (if you need one).

3. The room we will be using in on the first floor. The stairs are in the Reception area.



4. If you prefer you can use the lift. This is also in Reception.

Campus Map: Institute of Education, University of Reading, London Road, RG1 5EY

http://www.reading.ac.uk/web/files/University-of-Reading-London-Road-COLOUR-NUMERIC.pdf

5. At the top of the stairs you will see the door to some toilets.

6. Turn right just before the toilets, then immediately left. Or, turn right out of the lift. We will be using room GD102, which is straight ahead. It's also called the rest room.

7. This is the room. I've taken the photo standing in the doorway. You can see it has a window, an 'L' shaped desk and three chairs. You and I will sit near the desk. Your friend or parent/carer can sit on the third chair, either inside or outside the room.

Thank you for taking part in this research. Your ideas and experiences will contribute to real change for autistic girls in schools.

Ruth

Campus Map: Institute of Education, University of Reading, London Road, RG1 5EY

http://www.reading.ac.uk/web/files/University-of-Reading-London-Road-COLOUR-NUMERIC.pdf

Appendix 3.7 Amendments as a Result of Pilot studies

Amendments were made to the primary data collection methods after pilot studies with the autistic advisory group (AAG).

1. *Personal construct of the ideal school*

No.	Issue	Solution
1	One participant needed the information sheet reading, although she had been involved in the design.	Make the information sheet shorter, clearer, and more visual.
2	One participant, communicating via skype text, struggled to provide answers initially. She became more expressive as the interview progressed.	Begin interviews with a warm-up conversation (non-formal questions that required straightforward answers).
3	None of the girls chose to draw answers.	Provide the option to write responses.
4	One participant needed the answers written for her. The risk was that the researcher decided what the key points were whilst listening, rather than the participant.	Offer to be the scribe during main data collection but amend process to ask for just three words/sentences for each section to capture participants' key points.
5	The microphone picked up the researcher's voice more clearly than the participants.	Place the microphone closer to the participant, rather than centrally.
6	Review of the audio post interviews showed that the participants were not all asked the same questions, and that some questions were over-explained or confusing.	Re-write the interview schedule. During main data collection, repeat back the girls' answers to them for confirmation or so they can make corrections.
7	One of the participants remarked the questioning style was too formal.	Advised to be friendly and smile more.
8	One participant said if the green consent card stated on top, she would feel uncomfortable moving it or changing the colour.	Don't put the colour cards in a pile. Ask participants to show the green card when they are ready to begin.
9	One participant said writing '3-minute break' (on the key for the cards) as the explanation for the clock card made her anxious.	Re-write this to say '…until you are ready to start again, or decide you want to stop for today.'
10	One participant suggested moving 'ethos of the school' to the end of the interview, as a summary.	Move it to the end.

2. Life histories

No.	Issue	Solution
1	Paper provided for the life chart (A4) was too small.	Tell participants they can use the A4 provided or larger paper if they require, stick paper together, or complete using a computer.
2	Events were marked on life charts but not dates.	Change instructions for constructing life chart to say: 'add month and calendar year, as well as school year if possible'.
3	Adding events to Tiki Toki was very time-consuming. This meant the interview schedule was not completed. In addition, one participant became bored with the process, which impacted further on data collection.	Do not use Tiki Toki in the main data collection. It is not necessary as the life charts constructed by the girls are the data.
4	Asking general questions about barriers to school at the beginning became repetitive.	Ask questions about the events on the life charts to reveal the barriers and enablers particular to each girl.
5	Participants suggested moving questions about autism to later in the interview schedule.	Move general autism questions to the end of the third interview.
6	Using third interview to review answers from second interview was too unstructured.	Use third interview to conduct thematic analysis with the girls on their life charts, and base recommendations on three positive and negative events identified by them.

Appendix 3.8 Example Advert for Life History Participants

Missing: The Autistic Girls Absent from Mainstream Secondary Schools

This is a call for participants for a research project being run by a member of the PSC team, Ruth Moyse. Ruth is studying for a PhD at the University of Reading and we would be grateful if you are able to support this important study.

Education is a basic human right, yet we know that a growing number of autistic girls seem to stop attending school at some point during their time at mainstream Secondary schools. My study involves working with adolescent autistic girls, who are not currently or only occasionally attending school, for their views on why this happens and what needs to change to ensure they get the education to which they are entitled.

To take part the girls should:

- Be aged 11-16 and without intellectual disability
- Have a clinical diagnosis of autism
- Have begun at a mainstream Secondary school but are now absent for significant periods, or all the time:
    - Not currently attending
    - Only attending part-time or occasionally
    - Have been withdrawn from school and are now being home-educated
    - Not currently receiving any education at all

Participation will involve three informal interviews of up to an hour each time, initially at the University of Reading or at the girl's home. Later interviews can be done online by Skype text. I will ask them about their experiences and the significant events that led to them being out of school, and they will construct timelines. Together we will make some recommendations based on what they think would make a more successful experience for autistic girls at school.

For further information about the project please contact Ruth Moyse, Doctoral Researcher, at MissingOut@reading.ac.uk

Appendix 3.9 Young Person's Information Sheet

Researcher: Ruth Moyse r.moyse@pgr.reading.ac.uk
Supervisor: Professor Jill Porter j.porter@reading.ac.uk
Supervisor: Professor Cathy Tissot c.tissot@reading.ac.uk

Young person's information sheet

My name is **Ruth Moyse** and this information sheet tells you about some research I'm doing for a PhD at the University of Reading. I am a qualified teacher and have personal experience of autism, and of working with autism in girls.

What is the research about?

A growing number of autistic girls seem to stop attending mainstream secondary school. I want to understand why this is happening, and what needs to change. I think that the best way to do this is by listening to the views and experiences of autistic girls like you.

To take part in the research you should:

- Be aged ***11-16 years***
- Have ***started*** your Secondary education in a mainstream school but ***not currently be attending or not attending very often***
- Have a ***clinical diagnosis*** of autism

What will I be asked to do if I take part?

We will have three sessions together, with each session lasting 40 – 60 minutes. We can meet in person, either at the University or at your home. You can bring your mum or dad, or a trusted friend, to these meetings. If you don't live close to the University, we can do all the interviews online and by post.

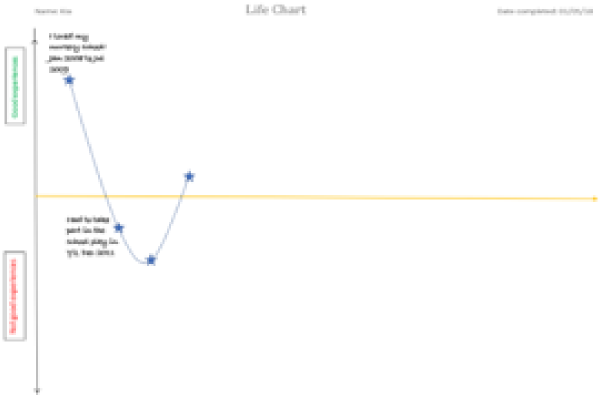
Session 1

This can be with me at the University of Reading, *or* I can come to your house. I will ask you questions to find out what your ideal school might be like and ask you to rank your answers.

Sessions 2 & 3

These can be *in person* again (at your home or at the University) ***or*** you can choose to do the interviews ***online*** by **text** over Skype, if you prefer.

I will ask you to draw a chart to show your memories of school. Some might be positive; some might not.



- This is an example of the chart.
- You will draw your own life chart.
- Your stories will be different.

I will ask you questions about what you write on your chart. I will also ask you a few questions about your family and about autism. Each interview will be recorded in full, with your permission. I will use my laptop to record talking. Our conversation will automatically be recorded if you use Skype text.

Lots of people find it hard to think of answers when they are first asked a question. If you have any thoughts or ideas after each interview, you can record these using a method of your choice (for example: as a journal, as a voice recording, or through a piece of artwork). You can email these to me at MissingOut@reading.ac.uk or post them to me at Missing Out, c/o Ruth Moyse and Professor Jill Porter, Institute of Education, University of Reading, London Road, Reading, RG1 5EY.

Will my name and any information I provide be kept confidential?

Yes. I will ask you to choose different names for you and anywhere you talk about, so that no one else can identify you or your school. All information will be confidential. This includes all personal details plus whatever you say during the research process. The only time this would change is if you told me something that made me believe you were not safe.

Are there any benefits to me?

I hope that you will find it interesting and helpful to think about and share your experiences, and to be involved in helping to improve provision for autistic girls in mainstream schools.

What happens if I change my mind about taking part?

You can change your mind at any time. Just email me to let me know. You do not have to give a reason, and there are no consequences for changing your mind. Any information I had already collected from you would be deleted.

Can I see the results of the research?

Yes. I will email a copy of the summary to you and your parent/guardian(s) once the project has been completed.

What will happen to the information you collect?

The information you give me will be kept on a secure laptop or in a locked filing cabinet at the University of Reading's Institute of Education. The results of my study will be written up as part of my PhD thesis, and may be presented at national and international conferences, and in written reports and articles. I can send you electronic copies of these publications if you wish.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you or your parent/guardian can contact Professor Jill Porter, University of Reading, at j.porter@reading.ac.uk or on 0118 378 2772.

What should I do next?

If you would like more information, or have any questions, please contact me at MissingOut@reading.ac.uk. If you would like to participate in this project, and your parent/guardian agrees, please ask them to email me to let me know. I will then contact you both to arrange the first meeting.

This Project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The University has the appropriate insurances in place. Full details are available on request.

Thank you for reading! I do hope you will choose to take part.

Ruth Moyse

Doctoral Researcher

Appendix 3.10 Parent or Guardian's Information Sheet

University of Reading

Researcher: Ruth Moyse r.moyse@pgr.reading.ac.uk
Supervisor: Professor Jill Porter j.porter@reading.ac.uk
Supervisor: Professor Cathy Tissot c.tissot@reading.ac.uk

Dear Parent or Guardian

I would like to invite your daughter to take part in a research project about the experiences of adolescent girls at mainstream secondary schools. Please read this information sheet and then discuss the project with your daughter to see if she would like to participate. You and your daughter will both need to give consent for her to take part.

What is the research about?

Every child has the right to education. However, there are a growing number of autistic girls who stop attending mainstream secondary schools. This research seeks to understand why this is happening, and what needs to change, by listening to their views and experiences. To participate in this project girls should:

1. Be aged 11-16 years
2. Have begun mainstream secondary school but are now absent for significant periods, or not currently attending mainstream at all
3. Have a clinical diagnosis of autism

Who is doing the research?

My name is Ruth Moyse and I am conducting the research as part of my PhD. I am a qualified teacher and have personal experience of autism, and of working with autism in girls. The study is funded by the John and Lorna Wing Foundation and is supervised by Professor Jill Porter and Professor Cathy Tissot, at the Institute of Education, University of Reading.

What will my daughter do if she participates?

Your daughter will work with me to create a mini life history, over three meetings. Each session will last for 40 – 60 minutes.

- The first session will either be at the University of Reading, with a trusted friend, or at your home if she prefers. I will ask her questions to find out about her ideal school and ask her to draw a timeline.
- The second and third sessions can either be in person again (at the University or at home) or your daughter can choose to be interviewed online by text, using Skype. I will be asking general questions about different stages in her life, about autism, and about her experiences of school. I will use this information to add detail to her timeline.
- At the end of the third session I will ask her to complete a Skills and Difficulties Questionnaire (SDQ)

All sessions can be conducted over the internet (using the text function of Skype and emails) and by post if you and your daughter live a distance from the University.

A full record of each interview and focus group will be captured, either as an audio file on my laptop or by Skype, as written communication is automatically recorded.

All participants will be given a project email address and postal address so that they can share any thoughts or ideas they have later, as for example, a journal, voice file, photograph or drawing.

Are there any risks?

All personal details plus whatever your daughter says during the research process will be kept confidential. The only time this would change is if your daughter told me something that made me believe she was not safe.

Are there any benefits to taking part?

Participants in research like this often find it interesting and helpful to reflect on their experiences, and to be involved in helping to suggest changes. It is hoped that the findings will help to improve school provision for girls like your daughter.

What happens if my daughter or I change our minds?

You or your daughter may withdraw your consent to participate at any stage by emailing me to let me know. No reason needs to be given, and there any no penalties for changing your mind. Any data already collected about your daughter would be discarded, unless she consented for it to be kept.

Can I see the results of the research?

Yes. I will email a copy of the summary to all participants once the project has been completed.

What will happen to the data?

All data (personal and that collected during the study) will be kept on a secure laptop or a locked filing cabinet at the University of Reading's Institute of Education, and accessed only by Ruth Moyse, Professor Porter or Professor Tissot. All data will be stored in accordance with the Data Protection Act. You can find out more information about the Act here: https://www.gov.uk/data-protection/the-data-protection-act.

In line with the University's policy on the management of research data, anonymised data gathered in this research may be preserved and made publicly available for others to consult and re-use. The results of my study will be written up as part of my PhD thesis, and may be presented at national and international conferences, and in written reports and articles. I can send you electronic copies of these publications if you wish.

What happens if something goes wrong?

In the unlikely case of concern or complaint, you can contact Professor Jill Porter, University of Reading, at j.porter@reading.ac.uk or on 0118 378 2772.

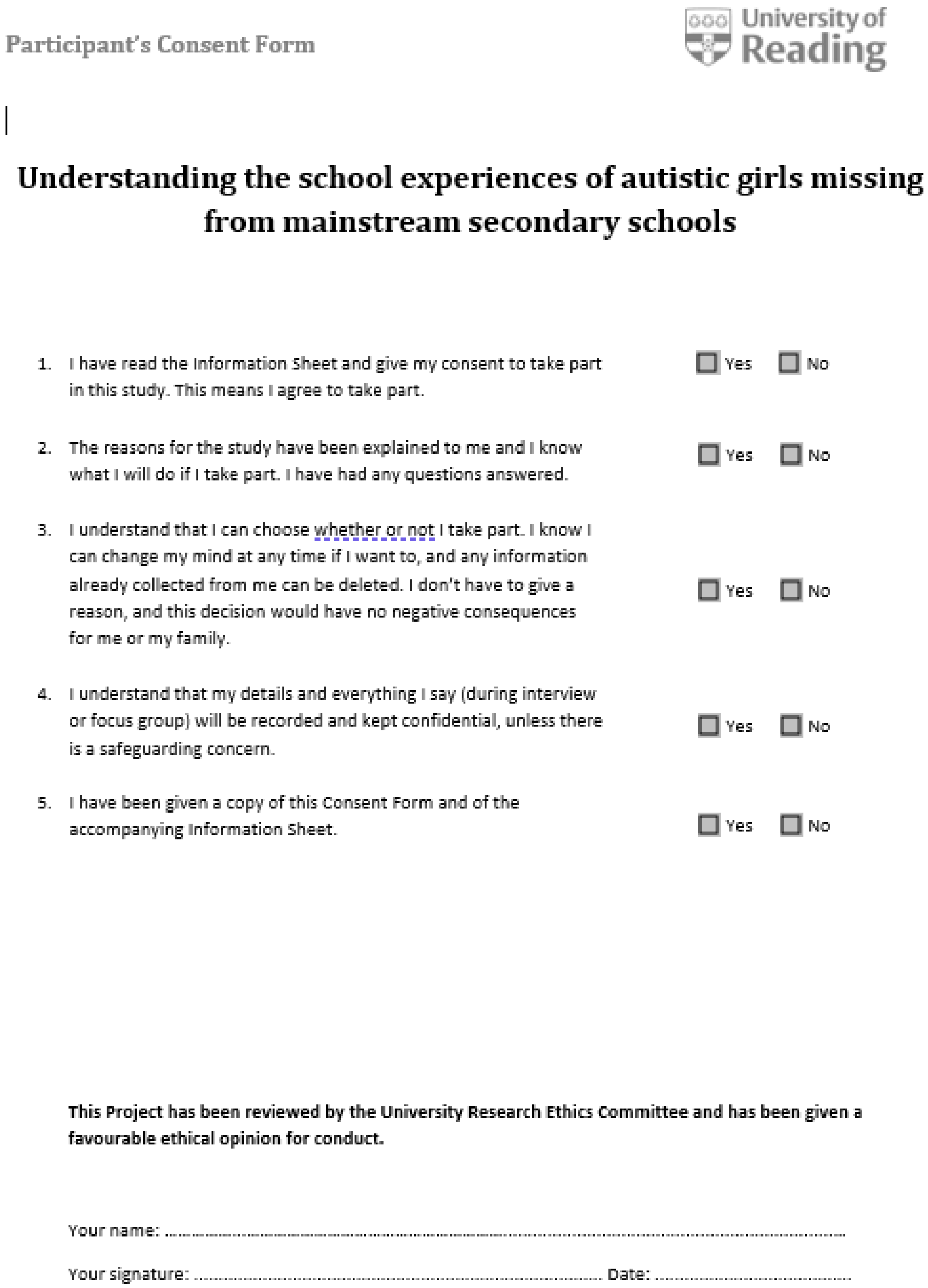
What should I do next?

If you have any further questions, or would like to proceed, please contact me at MissingOut@reading.ac.uk. I do hope that you will support your daughter's participation in this project.

This Project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The University has the appropriate insurances in place. Full details are available on request.

Thank you for your time

Appendix 3.11 Young Person's Consent Form



Participant's Consent Form

University of Reading

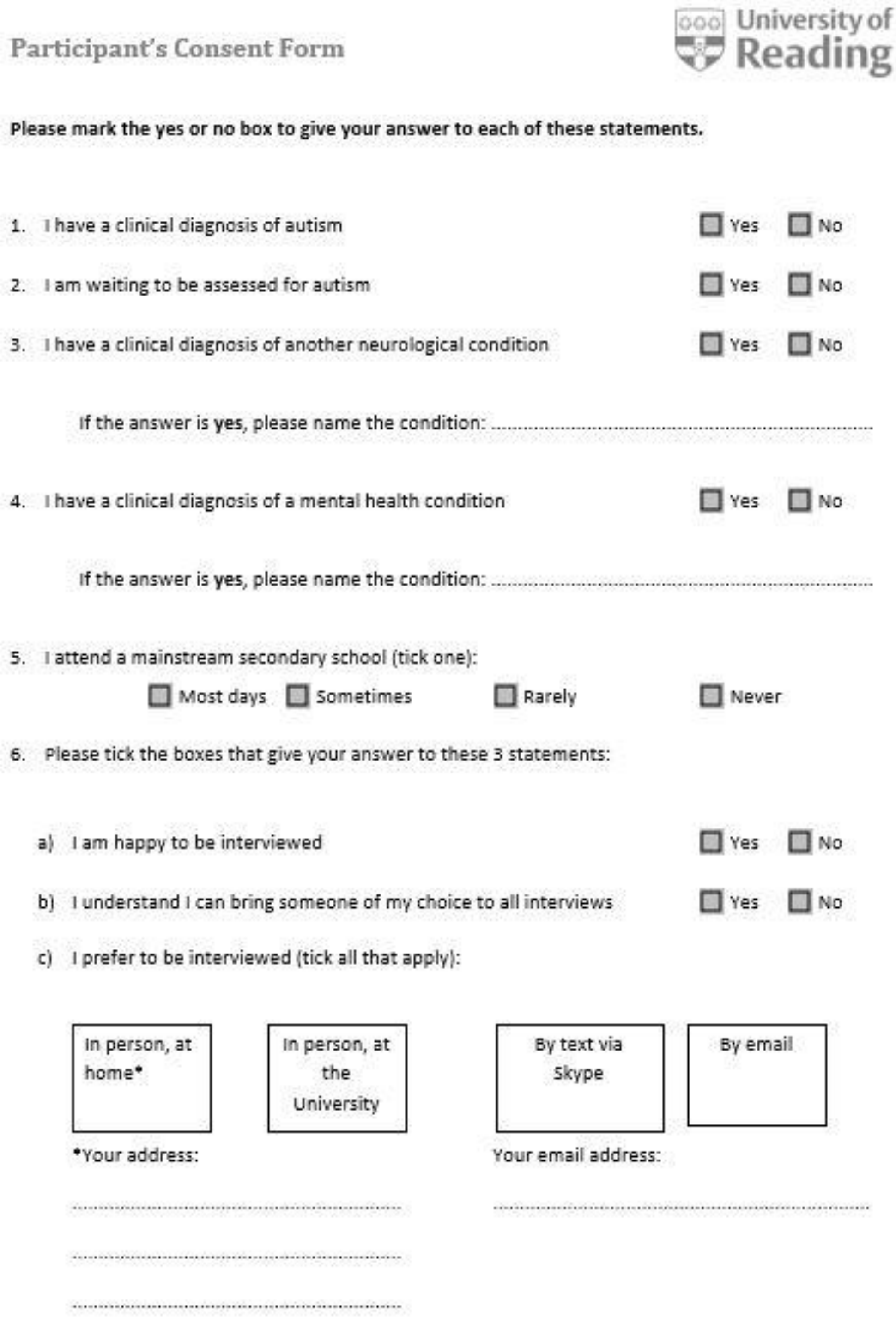
Understanding the school experiences of autistic girls missing from mainstream secondary schools

1. I have read the Information Sheet and give my consent to take part in this study. This means I agree to take part. ☐ Yes ☐ No
2. The reasons for the study have been explained to me and I know what I will do if I take part. I have had any questions answered. ☐ Yes ☐ No
3. I understand that I can choose whether or not I take part. I know I can change my mind at any time if I want to, and any information already collected from me can be deleted. I don't have to give a reason, and this decision would have no negative consequences for me or my family. ☐ Yes ☐ No
4. I understand that my details and everything I say (during interview or focus group) will be recorded and kept confidential, unless there is a safeguarding concern. ☐ Yes ☐ No
5. I have been given a copy of this Consent Form and of the accompanying Information Sheet. ☐ Yes ☐ No

This Project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Your name: ………

Your signature: ………………………………………………………… Date: ……………………………



Participant's Consent Form

University of Reading

Please mark the yes or no box to give your answer to each of these statements.

1. I have a clinical diagnosis of autism ☐ Yes ☐ No
2. I am waiting to be assessed for autism ☐ Yes ☐ No
3. I have a clinical diagnosis of another neurological condition ☐ Yes ☐ No

   If the answer is **yes**, please name the condition: ……………………………………………………………

4. I have a clinical diagnosis of a mental health condition ☐ Yes ☐ No

   If the answer is **yes**, please name the condition: ……………………………………………………………

5. I attend a mainstream secondary school (tick one):

   ☐ Most days ☐ Sometimes ☐ Rarely ☐ Never

6. Please tick the boxes that give your answer to these 3 statements:

   a) I am happy to be interviewed ☐ Yes ☐ No

   b) I understand I can bring someone of my choice to all interviews ☐ Yes ☐ No

   c) I prefer to be interviewed (tick all that apply):

In person, at home*	In person, at the University	By text via Skype	By email

*Your address:

……………………………………………………………

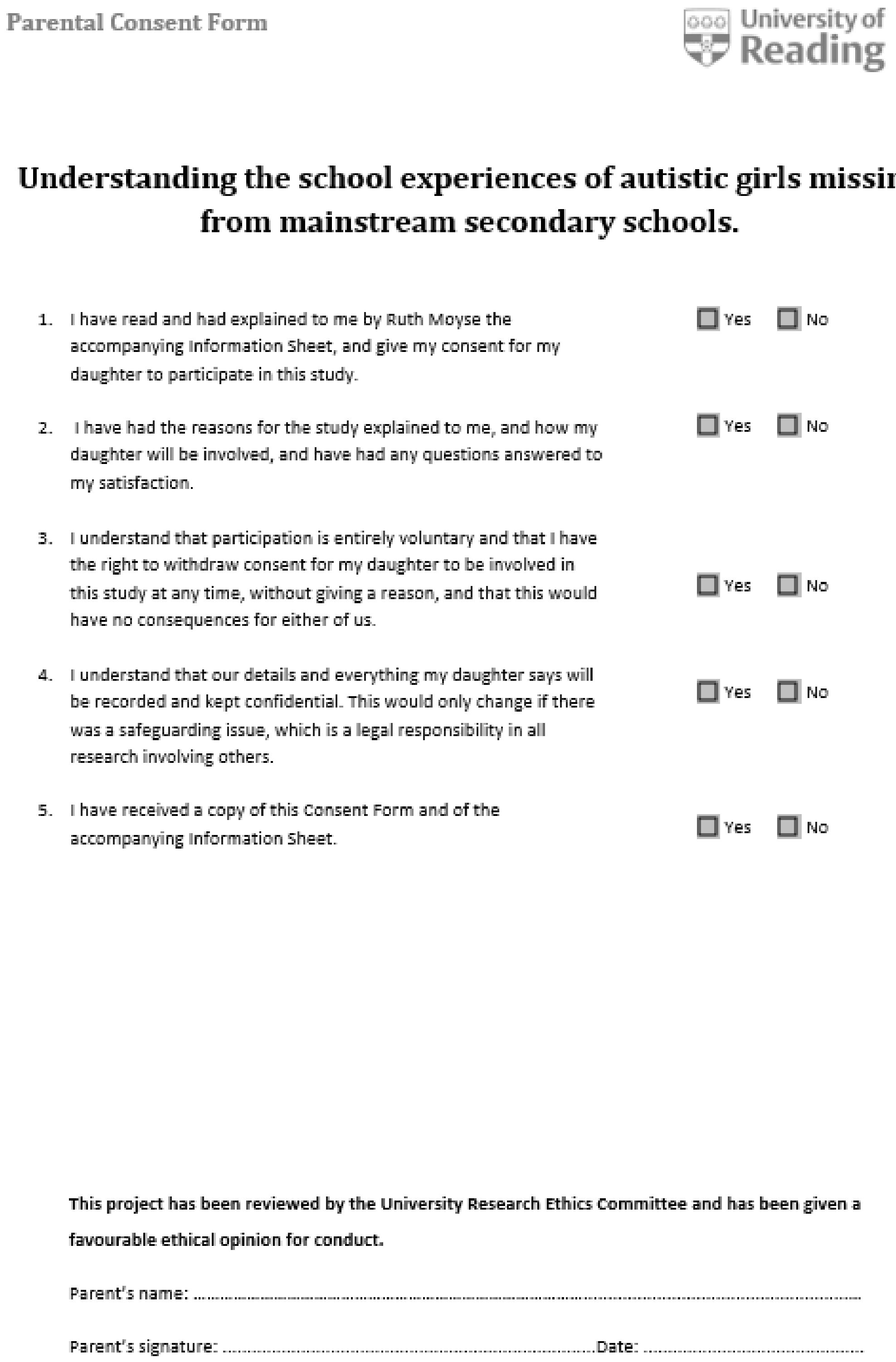
……………………………………………………………

……………………………………………………………

Your email address:

……………………………………………………………………

Appendix 3.12 Parent or Guardian Consent Form



Parental Consent Form

University of Reading

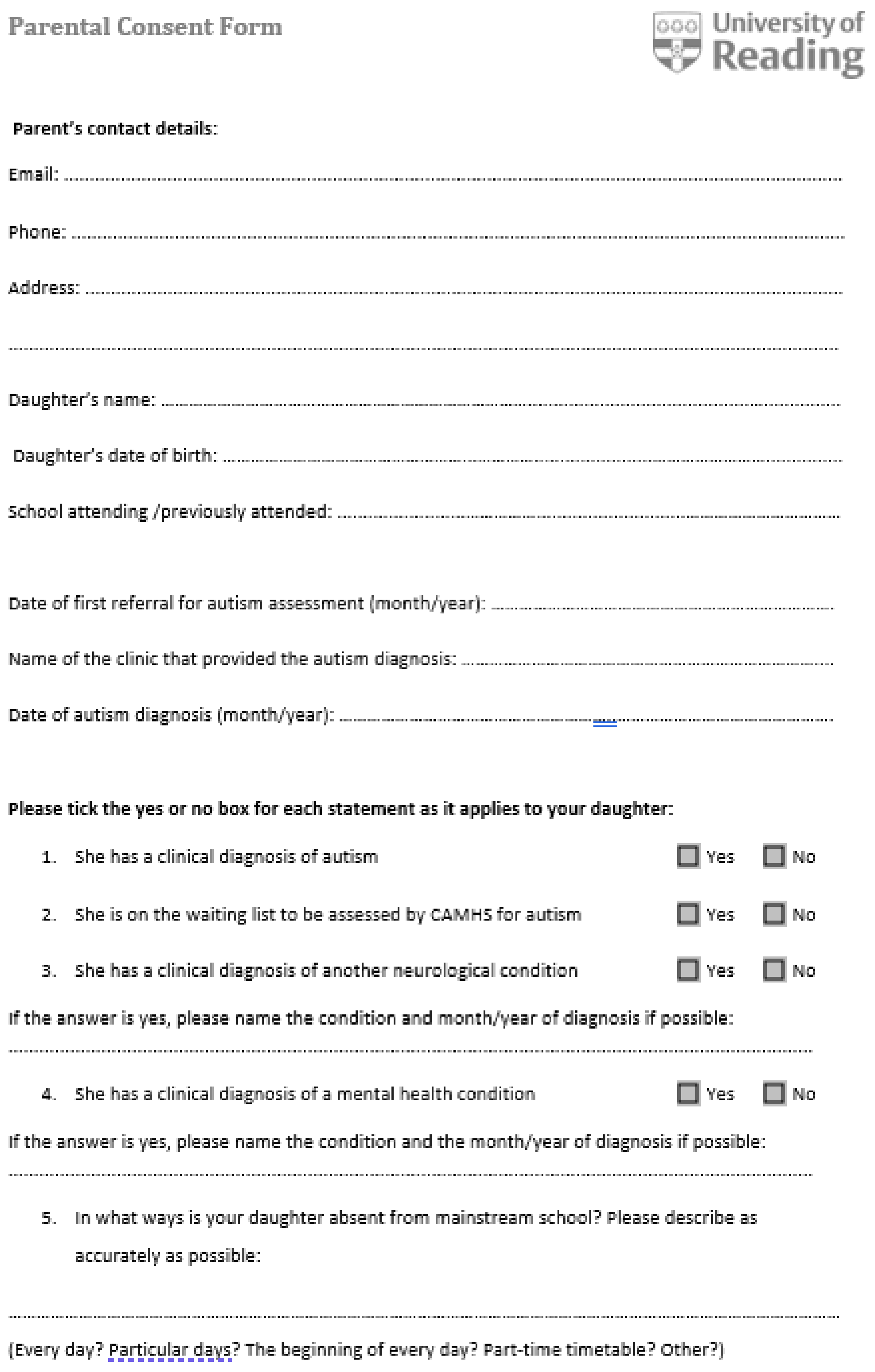
Understanding the school experiences of autistic girls missing from mainstream secondary schools.

1. I have read and had explained to me by Ruth Moyse the accompanying Information Sheet, and give my consent for my daughter to participate in this study. ☐ Yes ☐ No
2. I have had the reasons for the study explained to me, and how my daughter will be involved, and have had any questions answered to my satisfaction. ☐ Yes ☐ No
3. I understand that participation is entirely voluntary and that I have the right to withdraw consent for my daughter to be involved in this study at any time, without giving a reason, and that this would have no consequences for either of us. ☐ Yes ☐ No
4. I understand that our details and everything my daughter says will be recorded and kept confidential. This would only change if there was a safeguarding issue, which is a legal responsibility in all research involving others. ☐ Yes ☐ No
5. I have received a copy of this Consent Form and of the accompanying Information Sheet. ☐ Yes ☐ No

This project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Parent's name: ……

Parent's signature: ………………………………………………………………………Date: ………………………………………



Parental Consent Form

University of Reading

Parent's contact details:

Email: ………

Phone: ………

Address: ………

………

Daughter's name: ……………………………………………………………………………………………

Daughter's date of birth: ……………………………………………………………………………………

School attending /previously attended: ……………………………………………………………………

Date of first referral for autism assessment (month/year): ………………………………………………

Name of the clinic that provided the autism diagnosis: ……………………………………………………

Date of autism diagnosis (month/year): ……………………………………………………………………

Please tick the yes or no box for each statement as it applies to your daughter:

1. She has a clinical diagnosis of autism ☐ Yes ☐ No
2. She is on the waiting list to be assessed by CAMHS for autism ☐ Yes ☐ No
3. She has a clinical diagnosis of another neurological condition ☐ Yes ☐ No

If the answer is yes, please name the condition and month/year of diagnosis if possible:

………

4. She has a clinical diagnosis of a mental health condition ☐ Yes ☐ No

If the answer is yes, please name the condition and the month/year of diagnosis if possible:

………

5. In what ways is your daughter absent from mainstream school? Please describe as accurately as possible:

………

(Every day? Particular days? The beginning of every day? Part-time timetable? Other?)

Appendix 3.13 Personal Construct of the Ideal School: Researcher Copy

I will be your scribe and write for you. There are paper and pencils in case you want to draw any of your answers, and colouring sheets if you'd like to do something else while we are talking.

Part 1: The kind of school you would *not* like to attend.

A) **The classroom**

1. Think about the sort of classroom you would not like to be in. The sort of place that might stop you from learning. You can draw this if you wish. Tell me three things. *For example:*
    a. What furniture is in the room?
    b. What is the layout?
    c. Where do you sit?

B) **Other space**

Think about the other places at this school, inside and outside. Tell me three things. *For example:*

  a. What are the corridors and walkways like?
  b. Where do you eat your lunch?
  c. What is the outside space like?

C) **Sensory issues**

What do you notice when you are at this school? (Perhaps when you are moving around this school.) Tell me three things. *For example:*

  a. What do you hear?
  b. What do you see?
  c. How many people are near you?

D) **Teaching**

Think about how the teachers would teach you at this school. Tell me three things. *For example:*

  a. How do they teach? (What happens in the lesson? For example: talk at you; ask you to copy down from a board; get you to do activities; have discussions; get you read from books)
  b. How do they ask you to work? (For example: in silence/interactive/working on your own/in random group/in group of people you know)
  c. What do they do if you don't understand?

E) **Learning**

Think about what you would learn at this school. Tell me three things. *For example:*

  a. Which subject would you least/most like to have?
  b. How long are the lessons, and how many are there in a day?
  c. How do you record your work / show your learning? (For example: write / type / record / scribe / draw / make / act)

F) The adults

Think about the adults at this school you wouldn't like to go to. What are they doing? Tell me three things. *For example*:

a. How do they behave around school? (For example: strict/firm/fair/unfair/friendly)
b. How do they treat you?
c. What do they do when a pupil needs help?

G) The other young people

Think about some of the other young people at this school. What are they doing? Tell me three things. *For example:*

a. How do they behave in school?
b. How do they treat you?
c. How many friends do you have?

H) Me

Thinking about the kind of school you would not want to go to. What would you be doing? Tell me three things. *For example:*

a. How would you feel?
b. What would you be doing?
c. Where would I find you if I came to visit you at this school?

I) School ethos

Tell me three things about this school. *For example:*

a. What does it care about the most? (For example: uniformity / creativity / individuality / flexibility / discipline / rules / grades / happiness etc)
b. What does it reward? (For example: good grades, doing homework, being kind)
c. What does it expect its pupils to be like when they are 16 (and may leave school)?

Part 2: The kind of school you would like to attend.

- Use the same instructions as above.
- Write answers on individual cards.

Part 3: Diamond Ranking

- Think about your **ideal** school.
- I want you to pick the **nine** things from your pile of cards that are the most important to you.
- It might help to go through all the cards to begin with, and sort them into three piles: ***definitely*** very important to you; ***possibly*** one of the most important things to you; ***not*** that important to me.
- If there is an important thing missing, write it/ask me to write it on another card.
- Look at your *definitely* pile. If there are *more* than nine things, look again and take some cards out. If there are *less* than nine, choose some more from the *possibly* pile.
- Put these nine cards in diamond ranked order (1-2-3-2-1), with the most important thing at the top of the diamond, and the least important of the nine at the bottom.
- Talk me through your ranking.

Appendix 3.14 Personal Construct Pre-interview Questions

Think about the sort of school you *would not* like to go to, and the sort you *would* like to attend.

The first thing I'll ask you about is the sort of school you would *not* like to attend. This is not a real school.

Part 1: The kind of school you would *not* like to attend.

A) The classroom
Think about the sort of classroom you would not like to be in. The sort of place that might stop you from learning. Tell me three things.

B) Other space
Think about the other places at this school, inside and outside. Tell me three things.

C) Sensory issues
What do you notice when you are at this school? (Perhaps when you are moving around this school.) Tell me three things.

D) Teaching
Think about how the teachers would teach you at this school. Tell me three things.

E) Learning
Think about what you would learn at this school. How? Tell me three things.

F) The adults
Think about the adults at this school. What are they doing? Tell me three things.

G) The other young people
Think about some of the other young people at this school. What are they doing? Tell me three things.

H) Me
Thinking about the kind of school you would not want to go to. What would you be doing? Tell me three things.

I) School ethos
What kind of school is it? Tell me three things about this school.

I will then ask you the same questions, but this time about the sort of school you *would* like to attend. This is not a real school either!

Part 2: The kind of school you *would* like to attend.

We will then put your ideas into a ranked order.

That's it 😊

Appendix 3.15 Personal Construct of the Ideal School Process: Researcher Copy

Instructions/Process

1. Hello, as you know, my name is Ruth. I'm really pleased that you chose to be part of this research, and I look forward to hearing about your experiences.
2. Thank you for signing the **consent** form to say you're happy to take part in this project. So that I can know you're happy to continue during the interview, I've given you five cards:
    a. The first three cards are green, amber and red.
        i. 🟢 The green card is on top of the other three cards. This is to show you are happy to begin the interview.
        ii. 🟠 If you are feeling uncomfortable about something, please show the amber card, and I will stop asking about that issue.
        iii. 🔴 If you want to stop the interview session today, please show the red card and I will stop immediately. You do not need to give a reason unless you want to.
        iv. If you are happy to carry on, please **leave the green card on top.**
    b. **?** If you don't understand something, please show this card / type the question mark symbol and I will explain in a different way.
    c. ⏱ If you need to take a break, please show the clock card / type a clock emoji, and we can take a 5-minute break.

3. Today we will be talking about schools that are not real: the sort of school you would ***not*** like to go to, and the sort of school that you ***might* like** to go to.
4. There are no right or wrong answers! I am only interested in what *you* think.
5. I will be **recording** the session today and will be your scribe. You don't need to write anything unless you want to.

    OR

    Skype automatically records all the text we type, so you can look back over our questions and answers.
6. Everything you share with me in these sessions will be **confidential**. This means that I won't tell anyone what you have said.

7. The only time this would change is if you said something that made me think that you were **not safe**.
8. So that no one reading my study can identify you, please can you choose a different **name** I can use when I am writing about this project? I will also change any other names you mention during our meetings.
9. Do you have any **questions** before we begin?...........(Personal Construct exercise).....
10. The last thing we're going to do today is look at how to make a basic **life chart**, so you can record the key events and your strongest memories of your times at school. I want to understand what things led to you being out of school.
11. I've sent you/Have a look at these two life charts: one is an example, and the other is for you to complete at home. If you look at the example, you can see that Kia has started to add events. Taking part in the school play in Y2 was not a positive experience for Kia, so she has marked it below the amber line. She then had a great teacher in Y4 so she has marked that high up above the amber line. She has marked 10 memories on her chart – you may have more, as this is just an example.
12. Please can you make your own life chart at home and post it back to me? You can use the blank chart I'm giving you/have sent you, or you can make your own if you prefer.
13. It is really important that you only put down things that were significant for **you** – you may remember things differently to your parents, or other people you know.
14. Put positive memories above the middle line, and negative ones below. Remember to label them, with a short description and a year. You should finish on the right-hand side of the paper. Join the dots in the order in which things happened, to create a line of memories.
15. Post it back to me in the envelope I'm giving you now/I've sent you. I'll use your chart to create some questions for our next interviews and then contact you to arrange our next meeting. I'll send you the questions before this next meeting, so that you can start thinking about how to answer them.
16. That's the end of the session for today. If you think of anything you would like to add after today – ideas, thoughts, drawings for example - you can:
    a. email me at the project address: MissingOut@reading.ac.uk
    b. or post them to me at: Missing Out Project, c/o Ruth Moyse and Professor Jill Porter, Institute of Education, University of Reading, 4 Redlands Road, Reading, RG1 5EX.
17. Finally, I'm going to give you a leaflet to take home with you. This has the contact details of organisations you can contact if you feel you need someone to talk to after these sessions.

Appendix 3.16 Life Chart FAQs

Life Chart FAQ's

1. Do I need to use the blank chart you have given me, or can I make my own?

   You can choose. You can use the blank chart I've given you or make your own on a different piece of paper, or perhaps make one on the computer. It's up to you.

2. Which name should I put on the chart, my real name or the one I chose for this project?

   Please use the name you have chosen for this project.

3. What sort of things should I put on the chart?

   I want you to use it to record your strongest memories of your time at school – the good times as well as the difficult times.

4. Do I need to put things in the order in which they happened?

   Yes please.

5. How much information do I need to put against each mark?

   Just write the school year you were in, and a short sentence to say what happened.

6. Do I have to add something for every year I was at school?

   No. You might not remember anything about some years, and that's fine.

7. Can I add more than one memory for some school years?

   Yes, add as many as are important to you about your time in school.

8. What about the times after I stopped attending school?

   Yes, please add memories and events to do with your education after you stopped attending school.

9. I don't like writing. Can I ask someone at home to help me?

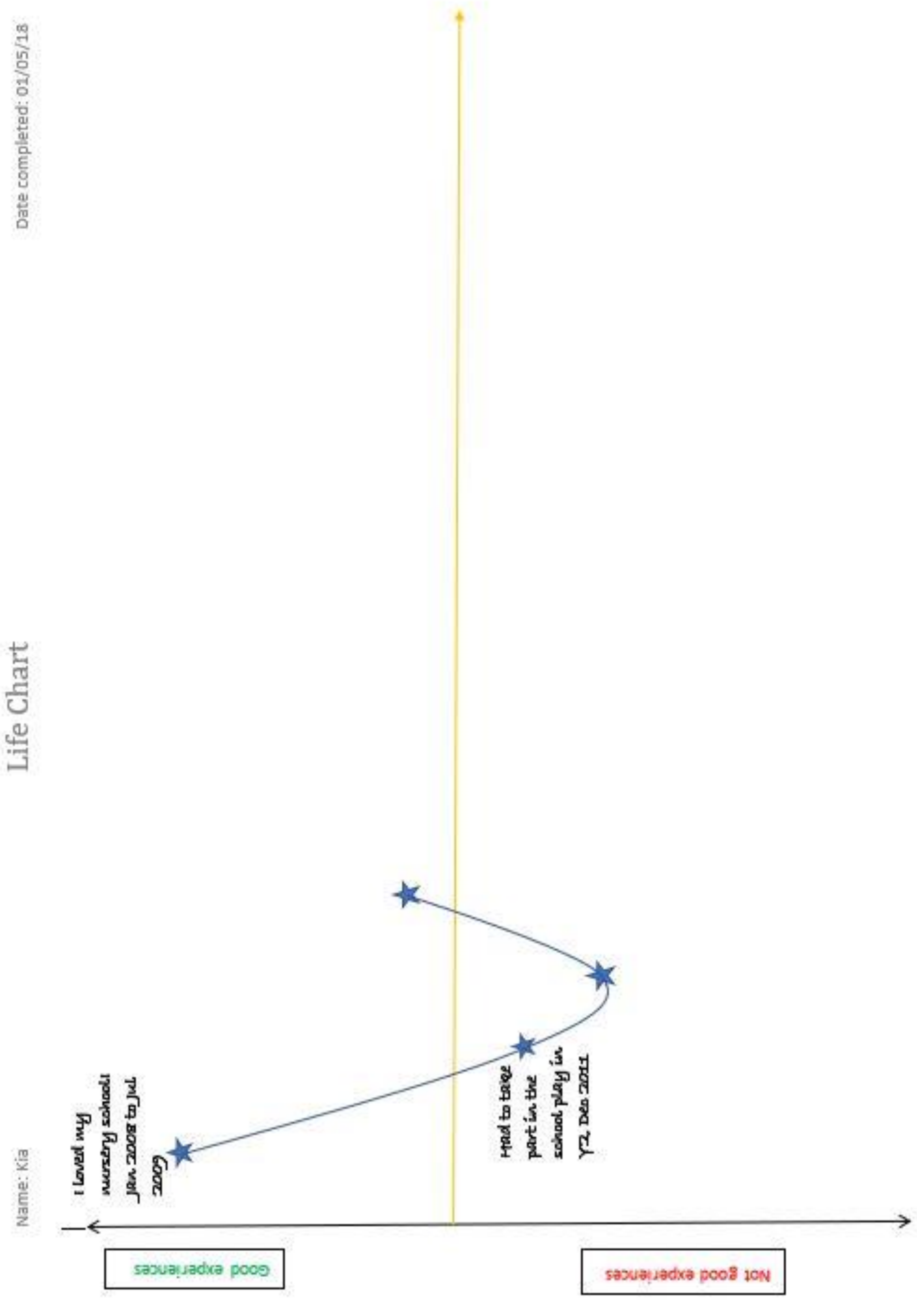
   Yes, you can ask someone to write or type for you.

10. My mum (or Dad) says I've forgotten something important – should I add it to the chart?

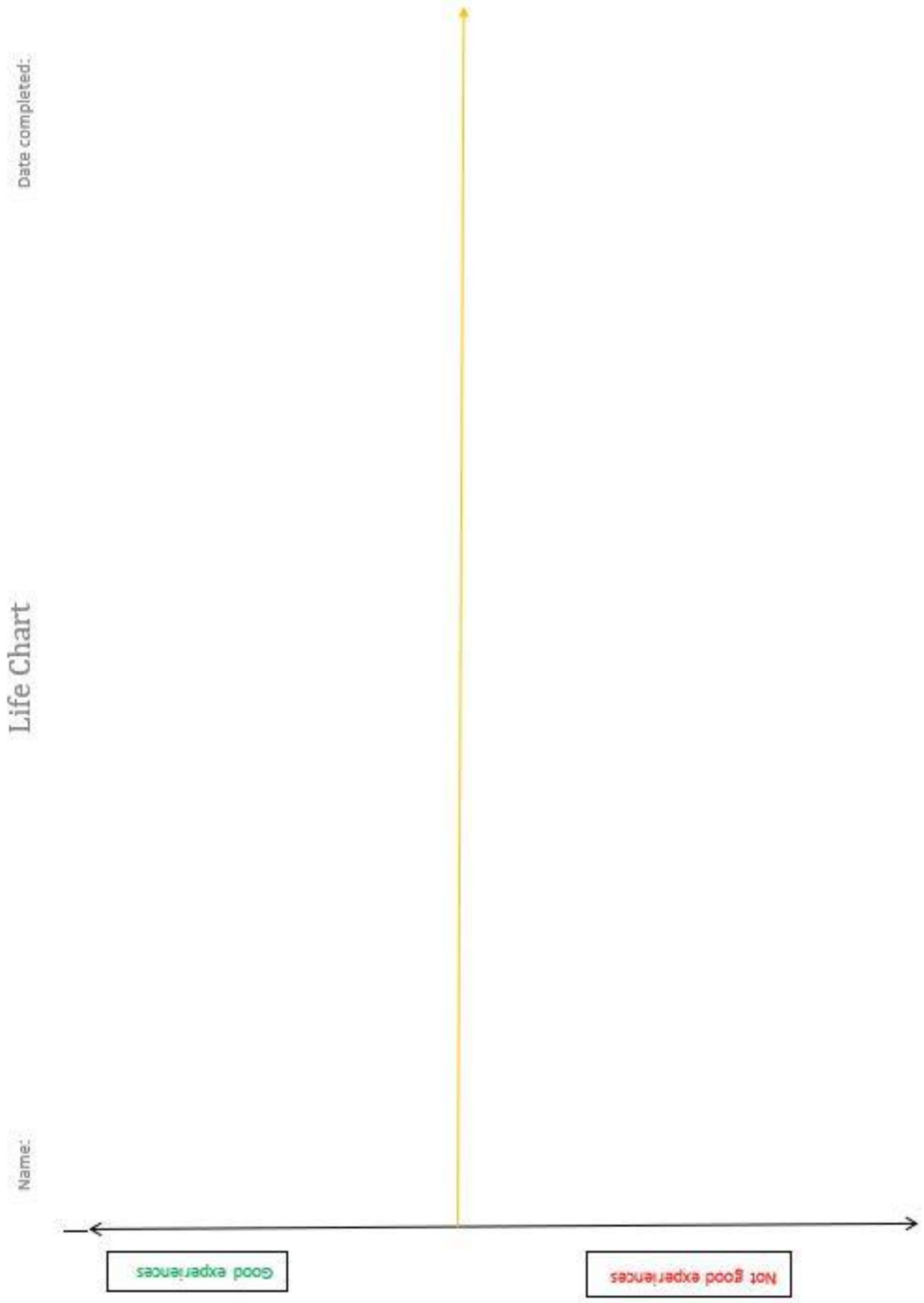
    No. People remember things differently, and I'm only interested in what is important to you.

Still stuck? Email me – or ask your parent to email me - for help: MissingOut@reading.ac.uk

Appendix 3.17 Life Chart Example



Appendix 3.18 Life Chart Template



Appendix 3.19 Interview Schedule

Interviews 2 & 3

I will be asking these questions during our second and third (last) interviews.

1. **Home life**
   I will ask you some questions about your family and home life, such as:
   i. Who lives at home?
   ii. What can you tell me about your family? (For example: How old is everyone? What do they do? What does everyone like doing?)
   iii. Does anyone else in the family have a diagnosis of autism or another diagnosis?
   iv. Have you always lived in the same place?

2. **Life Chart**
   I will ask you some questions about the events you have marked on your life chart. The sorts of questions I might ask you are:
   i. Can you tell me more about…?
      1. What were your thoughts and feelings?
   ii. What led up/contributed to…?
   iii. Can you give me an example?
   iv. What makes you say that?
   v. Who else was involved?
   vi. How/what/why?
   vii. What happened/what changed after that?
   viii. How did this affect your time in school?

3. **General**
   I will ask you some general questions about your experiences of school, after school, and your hopes for the future, for example:
   i. What did you enjoy the most about being in school?
      1. To whom were you the most connected? With whom did you feel most comfortable? Tell me about the people who were important to you at school.
      2. Where did you feel most comfortable?
      3. What did you like doing the most?
      4. What does feeling safe in school mean to you?
   ii. What did you find most difficult about being in school?
      1. Which people did you find it hardest to communicate and get along with?
      2. Where did you feel least comfortable?
      3. What did you like doing the least?
   iii. What help were you given?
      1. Did this/these things help?
      2. How? (Or why not?)
      3. What else might have helped?
      4. Did you have an EHCP or Statement?
   iv. What did you do to try to manage the things you found difficult?
   v. How was your secondary school chosen?

- vi. Can you describe any differences in your behaviour at home and at school? If I visited you in both places, what would I see?
- vii. When did you first experience not wanting to go to, or be, at school?
- viii. What was your secondary school's response to you being absent / out of school?
- ix. Were you given work to do at home?
- x. Tell me about the turning point, when you stopped going to school. Was this a gradual thing, or did you just stop?
- xi. What happened next? Did the school / LA do anything to help you reintegrate?
- xii. What words would you use to describe what happened, and your being out of school?
- xiii. How do you feel about not being in school? What does it mean for you?
- xiv. What positive and negative changes have occurred in your life since you stopped attending school?
- xv. What do positive educational outcomes look like to you?
- xvi. What are your hopes for the future?
    1. What do you need to get there?
- xvii. Is there anything else you think I need to know to help me understand why you no longer attend school?

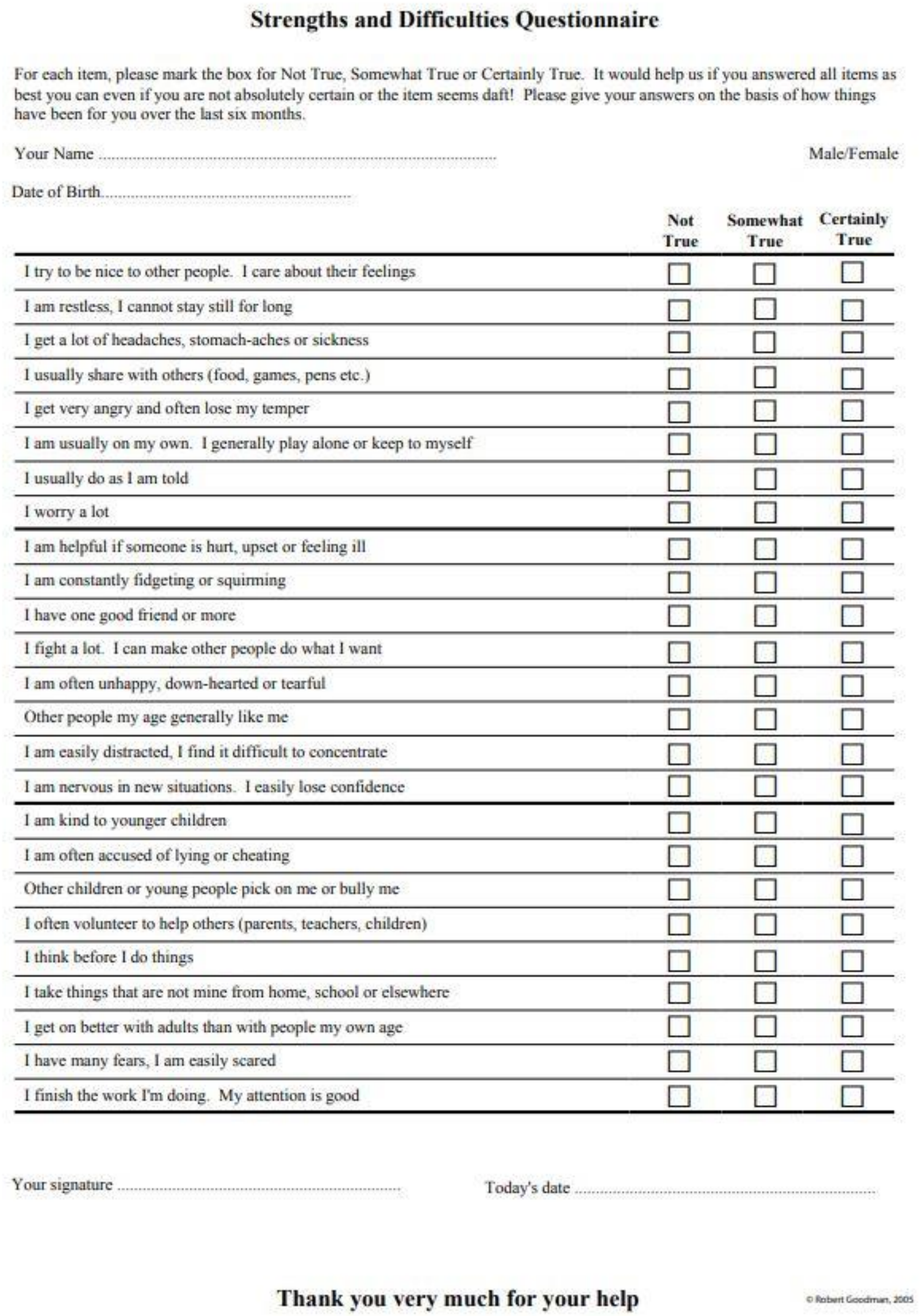
4. **Autism**
    - a. What does being autistic mean to you?
        - i. What language do you prefer to use - 'I am autistic' or 'I have autism' or either? Is there a reason for that?
        - ii. How do you feel about being autistic?
        - iii. Have these feelings changed since you were diagnosed?
        - iv. Do you think being autistic is part of the reason you are not currently in school?
            1. If so, why? In what ways? OR: If not, why not?
        - v. If you could teach the people at your last school one thing about autism and you, what would it be?
        - vi. Describe yourself in three words: a) at your last school, b) now.

If you think of anything you would like to add after either interview – ideas, thoughts, drawings for example - you can:

- *a.* ***email** me at the project address: MissingOut@reading.ac.uk*
    OR
- *b.* ***post** to me at: Missing Out Project, c/o Ruth Moyse and Professor Jill Porter, Institute of Education, University of Reading, 4 Redlands Road, Reading, RG1 5EX.*

During the third interview I will finish asking these questions. We will be looking back over your thoughts and descriptions of your experiences, to check I haven't missed anything and that I have understood you correctly. It will also be the time when we think about what schools could do differently to better support girls like you.

Appendix 3.20 Strengths and Difficulties Questionnaire (SDQ)



Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name .... Male/Female

Date of Birth..

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	☐	☐	☐
I am restless, I cannot stay still for long	☐	☐	☐
I get a lot of headaches, stomach-aches or sickness	☐	☐	☐
I usually share with others (food, games, pens etc.)	☐	☐	☐
I get very angry and often lose my temper	☐	☐	☐
I am usually on my own. I generally play alone or keep to myself	☐	☐	☐
I usually do as I am told	☐	☐	☐
I worry a lot	☐	☐	☐
I am helpful if someone is hurt, upset or feeling ill	☐	☐	☐
I am constantly fidgeting or squirming	☐	☐	☐
I have one good friend or more	☐	☐	☐
I fight a lot. I can make other people do what I want	☐	☐	☐
I am often unhappy, down-hearted or tearful	☐	☐	☐
Other people my age generally like me	☐	☐	☐
I am easily distracted, I find it difficult to concentrate	☐	☐	☐
I am nervous in new situations. I easily lose confidence	☐	☐	☐
I am kind to younger children	☐	☐	☐
I am often accused of lying or cheating	☐	☐	☐
Other children or young people pick on me or bully me	☐	☐	☐
I often volunteer to help others (parents, teachers, children)	☐	☐	☐
I think before I do things	☐	☐	☐
I take things that are not mine from home, school or elsewhere	☐	☐	☐
I get on better with adults than with people my own age	☐	☐	☐
I have many fears, I am easily scared	☐	☐	☐
I finish the work I'm doing. My attention is good	☐	☐	☐

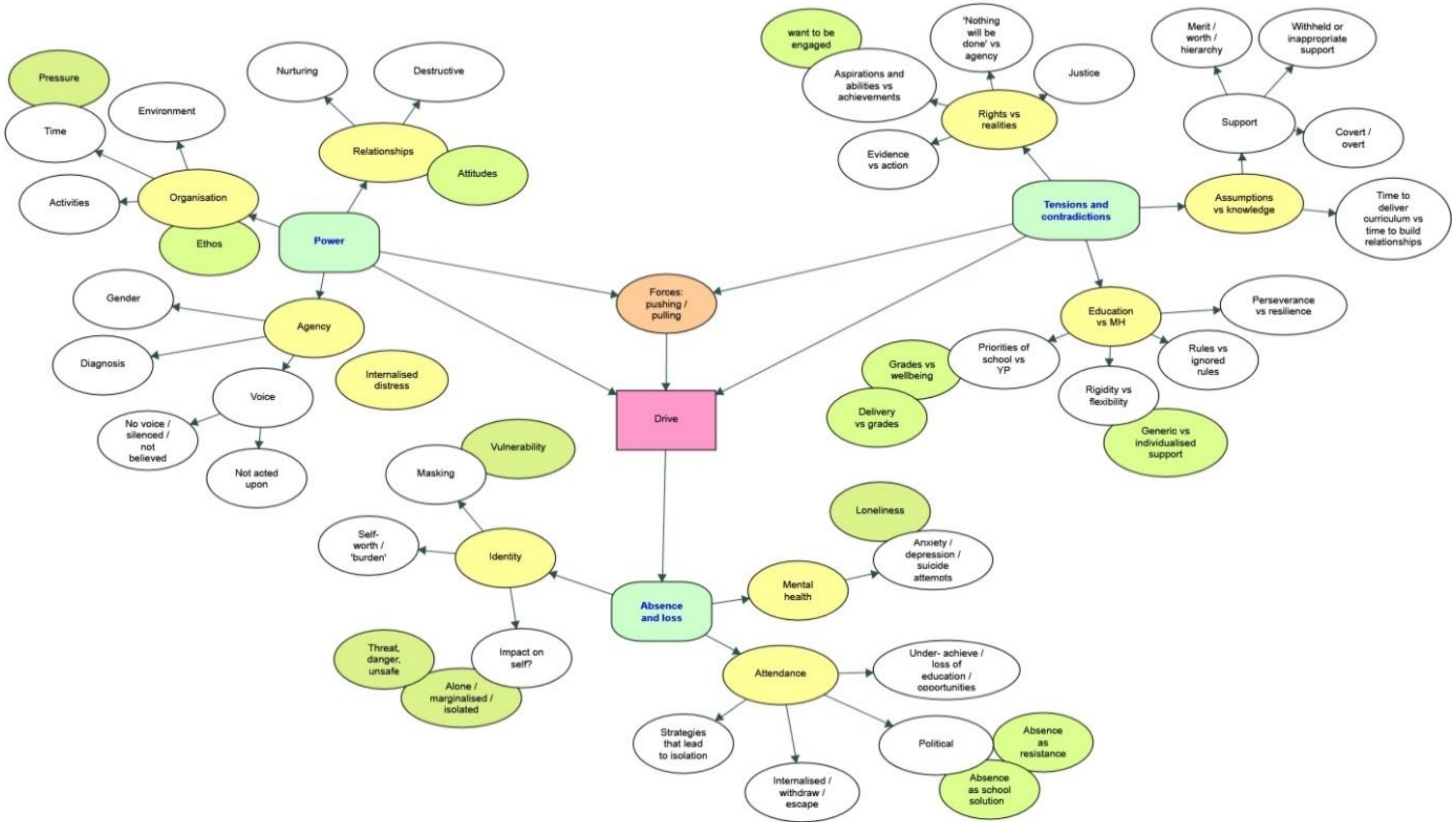
Your signature .... Today's date ....

Thank you very much for your help

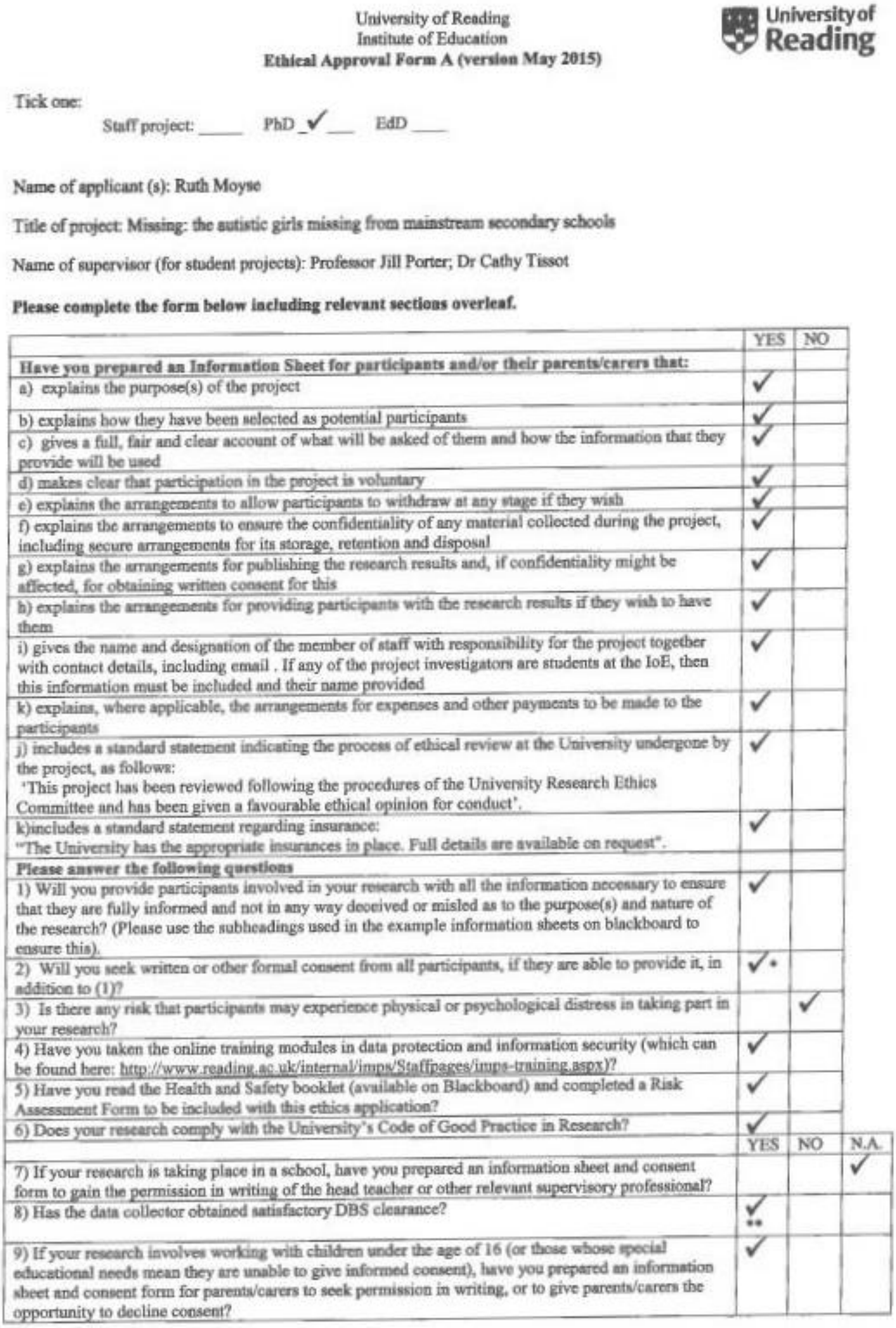
Appendix 3.21 Data Analysis Process: Pathways to Diagnosis

1. Pseudonymise to create a working record (pp), add to coding sheet (pp).
2. What documents are included in record? Identify and register all.
3. Read through each document.
4. Register all dates and events on the pathway to diagnosis.
5. When were concerns first raised?
6. How long between then and the referral being made?
7. What reasons can be inferred to explain this delay?
8. Whose voices are heard in the documentation? Is the girl’s voice present?
9. Is there evidence of the girl’s experiences of school and home life?
10. What barriers and challenges are identified?
11. What strengths are identified?
12. Does the girl contribute to identifying challenges and strengths?
13. What is missing from these documents that I would expect to see?

Appendix 3.22 Iterative Representation of Thinking Through the Analysis Process



Appendix 3.23 University Ethical Approval



University of Reading
Institute of Education
Ethical Approval Form A (version May 2015)

University of Reading

Tick one:

Staff project: ____ PhD ✓___ EdD ___

Name of applicant (s): Ruth Moyse

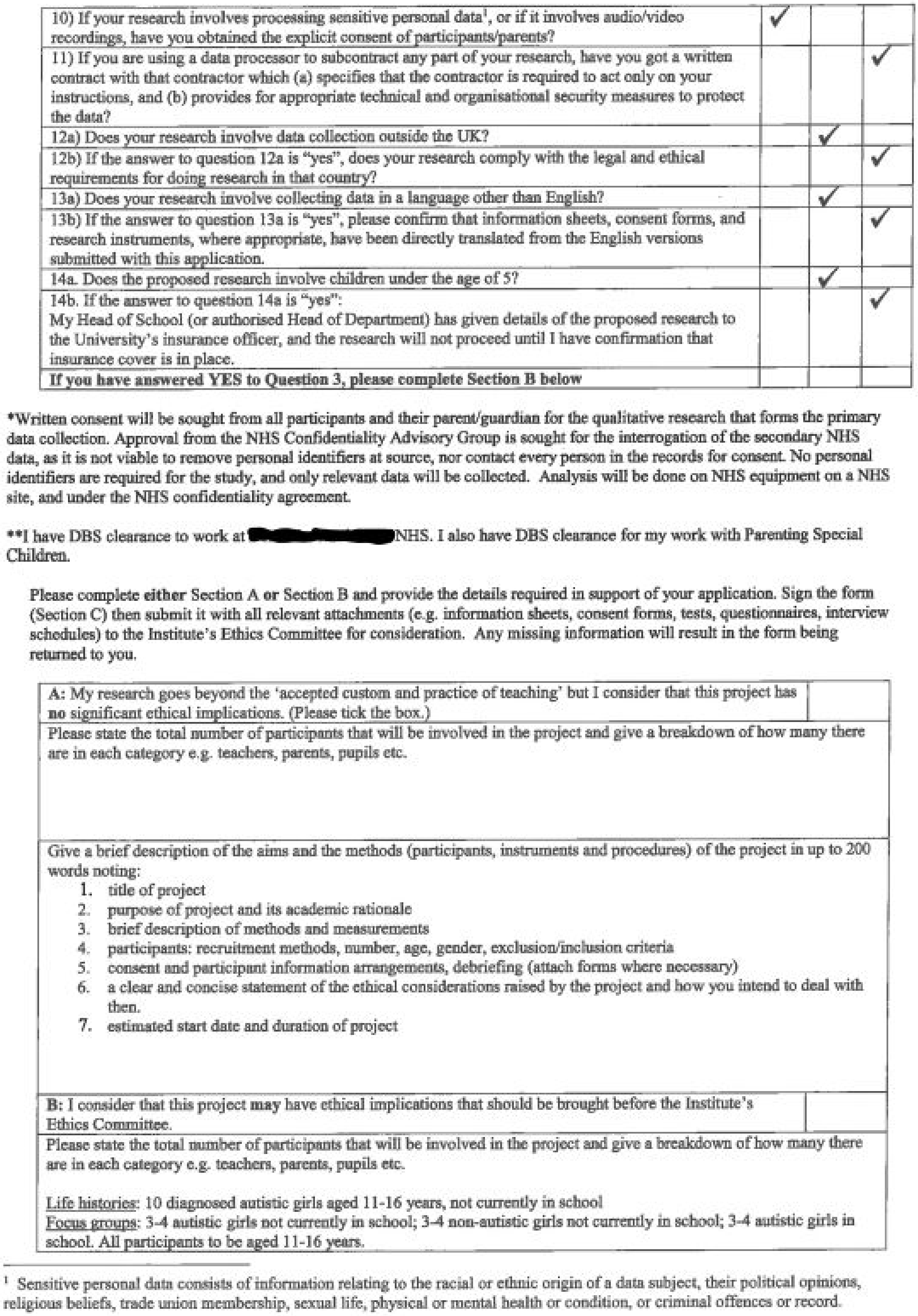
Title of project: Missing: the autistic girls missing from mainstream secondary schools

Name of supervisor (for student projects): Professor Jill Porter; Dr Cathy Tissot

Please complete the form below including relevant sections overleaf.

	YES	NO
Have you prepared an Information Sheet for participants and/or their parents/carers that:		
a) explains the purpose(s) of the project	✓	
b) explains how they have been selected as potential participants	✓	
c) gives a full, fair and clear account of what will be asked of them and how the information that they provide will be used	✓	
d) makes clear that participation in the project is voluntary	✓	
e) explains the arrangements to allow participants to withdraw at any stage if they wish	✓	
f) explains the arrangements to ensure the confidentiality of any material collected during the project, including secure arrangements for its storage, retention and disposal	✓	
g) explains the arrangements for publishing the research results and, if confidentiality might be affected, for obtaining written consent for this	✓	
h) explains the arrangements for providing participants with the research results if they wish to have them	✓	
i) gives the name and designation of the member of staff with responsibility for the project together with contact details, including email . If any of the project investigators are students at the IoE, then this information must be included and their name provided	✓	
k) explains, where applicable, the arrangements for expenses and other payments to be made to the participants	✓	
j) includes a standard statement indicating the process of ethical review at the University undergone by the project, as follows: 'This project has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct'.	✓	
k)includes a standard statement regarding insurance: "The University has the appropriate insurances in place. Full details are available on request".	✓	
Please answer the following questions		
1) Will you provide participants involved in your research with all the information necessary to ensure that they are fully informed and not in any way deceived or misled as to the purpose(s) and nature of the research? (Please use the subheadings used in the example information sheets on blackboard to ensure this).	✓	
2) Will you seek written or other formal consent from all participants, if they are able to provide it, in addition to (1)?	✓ •	
3) Is there any risk that participants may experience physical or psychological distress in taking part in your research?		✓
4) Have you taken the online training modules in data protection and information security (which can be found here: http://www.reading.ac.uk/internal/imps/Staffpages/imps-training.aspx)?	✓	
5) Have you read the Health and Safety booklet (available on Blackboard) and completed a Risk Assessment Form to be included with this ethics application?	✓	
6) Does your research comply with the University's Code of Good Practice in Research?	✓	

	YES	NO	N.A.
7) If your research is taking place in a school, have you prepared an information sheet and consent form to gain the permission in writing of the head teacher or other relevant supervisory professional?			✓
8) Has the data collector obtained satisfactory DBS clearance?	✓ ••		
9) If your research involves working with children under the age of 16 (or those whose special educational needs mean they are unable to give informed consent), have you prepared an information sheet and consent form for parents/carers to seek permission in writing, or to give parents/carers the opportunity to decline consent?	✓		



10) If your research involves processing sensitive personal data[1], or if it involves audio/video recordings, have you obtained the explicit consent of participants/parents?	✓		
11) If you are using a data processor to subcontract any part of your research, have you got a written contract with that contractor which (a) specifies that the contractor is required to act only on your instructions, and (b) provides for appropriate technical and organisational security measures to protect the data?			✓
12a) Does your research involve data collection outside the UK?		✓	
12b) If the answer to question 12a is "yes", does your research comply with the legal and ethical requirements for doing research in that country?			✓
13a) Does your research involve collecting data in a language other than English?		✓	
13b) If the answer to question 13a is "yes", please confirm that information sheets, consent forms, and research instruments, where appropriate, have been directly translated from the English versions submitted with this application.			✓
14a. Does the proposed research involve children under the age of 5?		✓	
14b. If the answer to question 14a is "yes": My Head of School (or authorised Head of Department) has given details of the proposed research to the University's insurance officer, and the research will not proceed until I have confirmation that insurance cover is in place.			✓
If you have answered YES to Question 3, please complete Section B below			

*Written consent will be sought from all participants and their parent/guardian for the qualitative research that forms the primary data collection. Approval from the NHS Confidentiality Advisory Group is sought for the interrogation of the secondary NHS data, as it is not viable to remove personal identifiers at source, nor contact every person in the records for consent. No personal identifiers are required for the study, and only relevant data will be collected. Analysis will be done on NHS equipment on a NHS site, and under the NHS confidentiality agreement.

**I have DBS clearance to work at [redacted] NHS. I also have DBS clearance for my work with Parenting Special Children.

Please complete **either** Section A **or** Section B and provide the details required in support of your application. Sign the form (Section C) then submit it with all relevant attachments (e.g. information sheets, consent forms, tests, questionnaires, interview schedules) to the Institute's Ethics Committee for consideration. Any missing information will result in the form being returned to you.

A: My research goes beyond the 'accepted custom and practice of teaching' but I consider that this project has **no** significant ethical implications. (Please tick the box.)	
Please state the total number of participants that will be involved in the project and give a breakdown of how many there are in each category e.g. teachers, parents, pupils etc.	
Give a brief description of the aims and the methods (participants, instruments and procedures) of the project in up to 200 words noting: 1. title of project 2. purpose of project and its academic rationale 3. brief description of methods and measurements 4. participants: recruitment methods, number, age, gender, exclusion/inclusion criteria 5. consent and participant information arrangements, debriefing (attach forms where necessary) 6. a clear and concise statement of the ethical considerations raised by the project and how you intend to deal with then. 7. estimated start date and duration of project	
B: I consider that this project **may** have ethical implications that should be brought before the Institute's Ethics Committee.	
Please state the total number of participants that will be involved in the project and give a breakdown of how many there are in each category e.g. teachers, parents, pupils etc. Life histories: 10 diagnosed autistic girls aged 11-16 years, not currently in school Focus groups: 3-4 autistic girls not currently in school; 3-4 non-autistic girls not currently in school; 3-4 autistic girls in school. All participants to be aged 11-16 years.	

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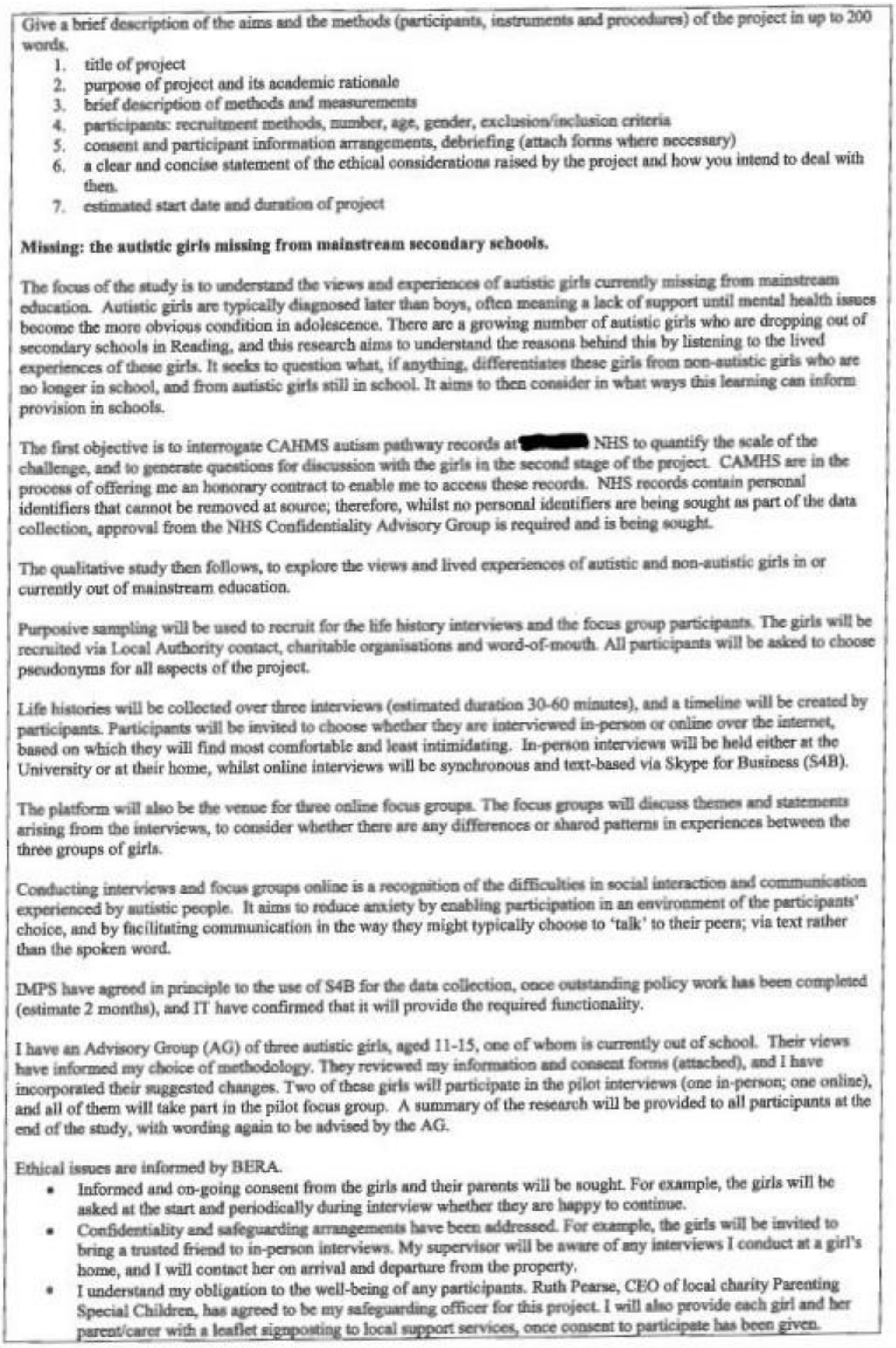
[1] Sensitive personal data consists of information relating to the racial or ethnic origin of a data subject, their political opinions, religious beliefs, trade union membership, sexual life, physical or mental health or condition, or criminal offences or record.



Give a brief description of the aims and the methods (participants, instruments and procedures) of the project in up to 200 words.

1. title of project
2. purpose of project and its academic rationale
3. brief description of methods and measurements
4. participants: recruitment methods, number, age, gender, exclusion/inclusion criteria
5. consent and participant information arrangements, debriefing (attach forms where necessary)
6. a clear and concise statement of the ethical considerations raised by the project and how you intend to deal with then.
7. estimated start date and duration of project

Missing: the autistic girls missing from mainstream secondary schools.

The focus of the study is to understand the views and experiences of autistic girls currently missing from mainstream education. Autistic girls are typically diagnosed later than boys, often meaning a lack of support until mental health issues become the more obvious condition in adolescence. There are a growing number of autistic girls who are dropping out of secondary schools in Reading, and this research aims to understand the reasons behind this by listening to the lived experiences of these girls. It seeks to question what, if anything, differentiates these girls from non-autistic girls who are no longer in school, and from autistic girls still in school. It aims to then consider in what ways this learning can inform provision in schools.

The first objective is to interrogate CAHMS autism pathway records at [redacted] NHS to quantify the scale of the challenge, and to generate questions for discussion with the girls in the second stage of the project. CAMHS are in the process of offering me an honorary contract to enable me to access these records. NHS records contain personal identifiers that cannot be removed at source; therefore, whilst no personal identifiers are being sought as part of the data collection, approval from the NHS Confidentiality Advisory Group is required and is being sought.

The qualitative study then follows, to explore the views and lived experiences of autistic and non-autistic girls in or currently out of mainstream education.

Purposive sampling will be used to recruit for the life history interviews and the focus group participants. The girls will be recruited via Local Authority contact, charitable organisations and word-of-mouth. All participants will be asked to choose pseudonyms for all aspects of the project.

Life histories will be collected over three interviews (estimated duration 30-60 minutes), and a timeline will be created by participants. Participants will be invited to choose whether they are interviewed in-person or online over the internet, based on which they will find most comfortable and least intimidating. In-person interviews will be held either at the University or at their home, whilst online interviews will be synchronous and text-based via Skype for Business (S4B).

The platform will also be the venue for three online focus groups. The focus groups will discuss themes and statements arising from the interviews, to consider whether there are any differences or shared patterns in experiences between the three groups of girls.

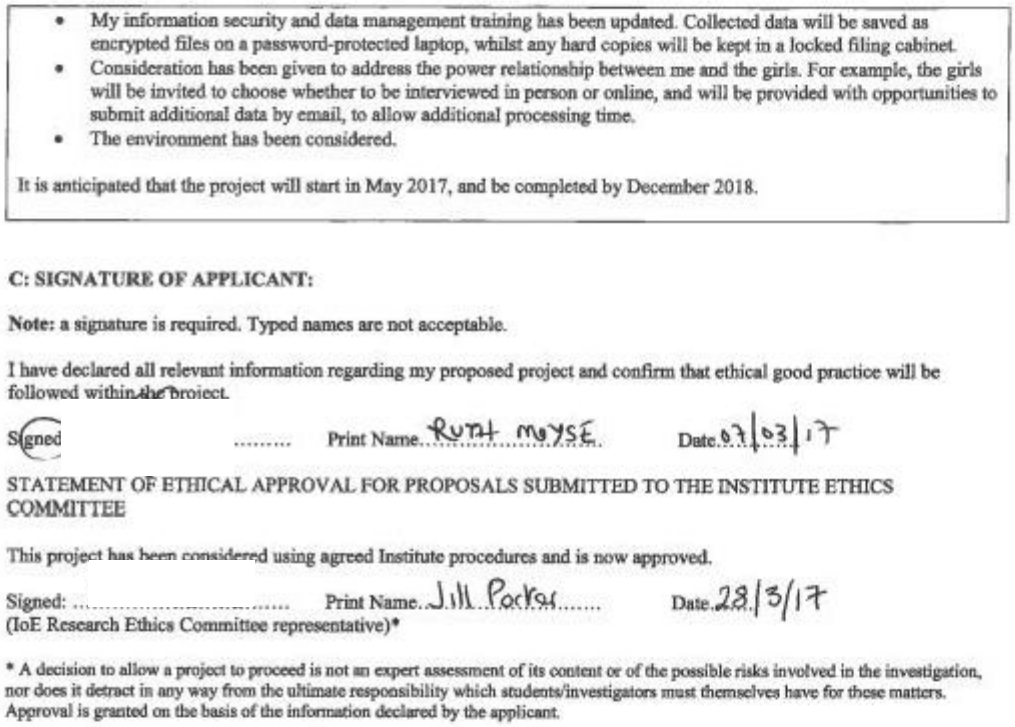
Conducting interviews and focus groups online is a recognition of the difficulties in social interaction and communication experienced by autistic people. It aims to reduce anxiety by enabling participation in an environment of the participants' choice, and by facilitating communication in the way they might typically choose to 'talk' to their peers; via text rather than the spoken word.

IMPS have agreed in principle to the use of S4B for the data collection, once outstanding policy work has been completed (estimate 2 months), and IT have confirmed that it will provide the required functionality.

I have an Advisory Group (AG) of three autistic girls, aged 11-15, one of whom is currently out of school. Their views have informed my choice of methodology. They reviewed my information and consent forms (attached), and I have incorporated their suggested changes. Two of these girls will participate in the pilot interviews (one in-person; one online), and all of them will take part in the pilot focus group. A summary of the research will be provided to all participants at the end of the study, with wording again to be advised by the AG.

Ethical issues are informed by BERA.

- Informed and on-going consent from the girls and their parents will be sought. For example, the girls will be asked at the start and periodically during interview whether they are happy to continue.
- Confidentiality and safeguarding arrangements have been addressed. For example, the girls will be invited to bring a trusted friend to in-person interviews. My supervisor will be aware of any interviews I conduct at a girl's home, and I will contact her on arrival and departure from the property.
- I understand my obligation to the well-being of any participants. Ruth Pearse, CEO of local charity Parenting Special Children, has agreed to be my safeguarding officer for this project. I will also provide each girl and her parent/carer with a leaflet signposting to local support services, once consent to participate has been given.



- My information security and data management training has been updated. Collected data will be saved as encrypted files on a password-protected laptop, whilst any hard copies will be kept in a locked filing cabinet.
- Consideration has been given to address the power relationship between me and the girls. For example, the girls will be invited to choose whether to be interviewed in person or online, and will be provided with opportunities to submit additional data by email, to allow additional processing time.
- The environment has been considered.

It is anticipated that the project will start in May 2017, and be completed by December 2018.

C: SIGNATURE OF APPLICANT:

Note: a signature is required. Typed names are not acceptable.

I have declared all relevant information regarding my proposed project and confirm that ethical good practice will be followed within the project.

Signed [redacted] .... Print Name RUTH MOYSE Date 07/03/17

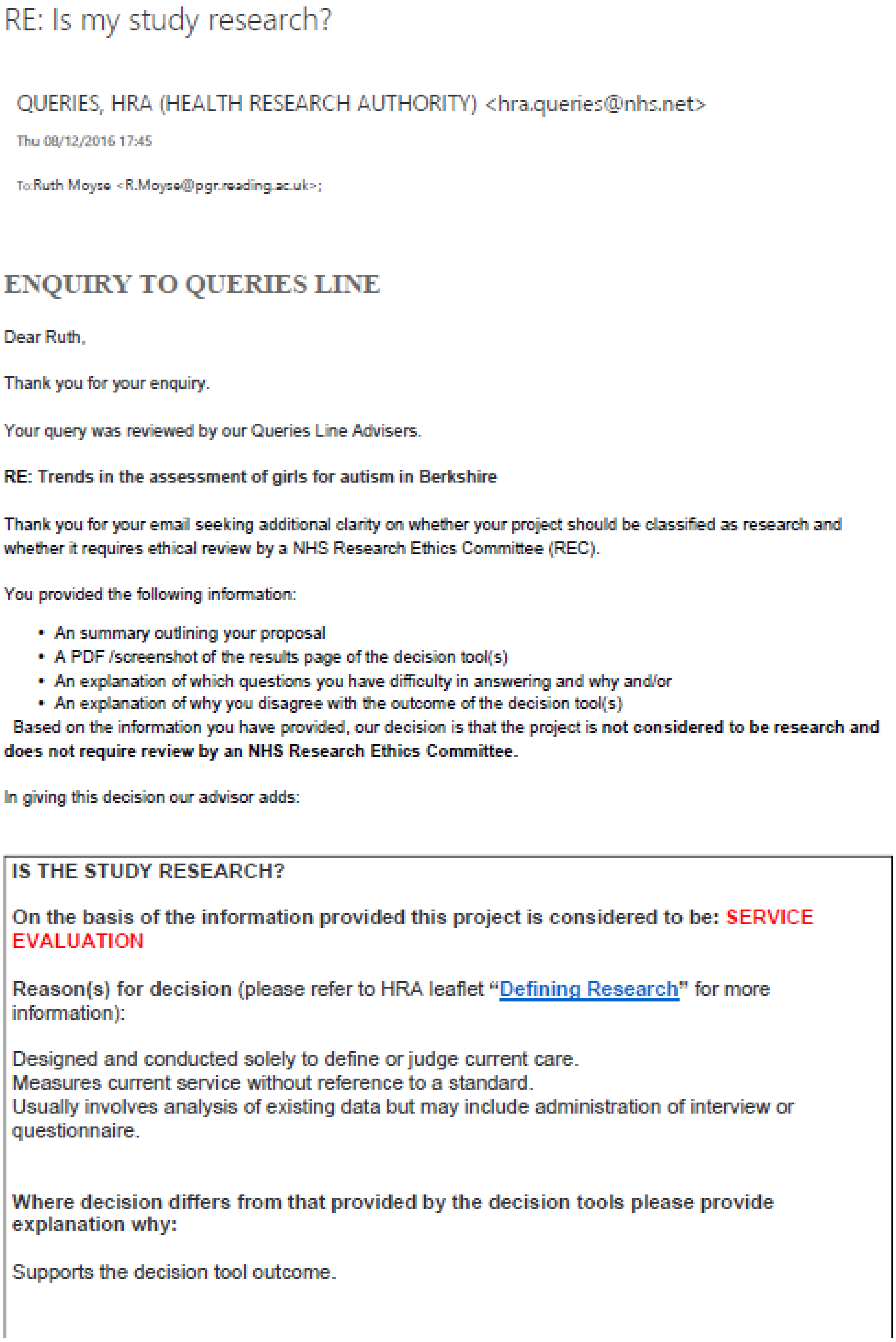
STATEMENT OF ETHICAL APPROVAL FOR PROPOSALS SUBMITTED TO THE INSTITUTE ETHICS COMMITTEE

This project has been considered using agreed Institute procedures and is now approved.

Signed: [redacted] .... Print Name Jill Porter...... Date 28/3/17
(IoE Research Ethics Committee representative)*

* A decision to allow a project to proceed is not an expert assessment of its content or of the possible risks involved in the investigation, nor does it detract in any way from the ultimate responsibility which students/investigators must themselves have for these matters. Approval is granted on the basis of the information declared by the applicant.

Appendix 3.24 Health Research Authority Project Classification Advice



RE: Is my study research?

QUERIES, HRA (HEALTH RESEARCH AUTHORITY) <hra.queries@nhs.net>
Thu 08/12/2016 17:45
To:Ruth Moyse <R.Moyse@pgr.reading.ac.uk>;

ENQUIRY TO QUERIES LINE

Dear Ruth,

Thank you for your enquiry.

Your query was reviewed by our Queries Line Advisers.

RE: Trends in the assessment of girls for autism in Berkshire

Thank you for your email seeking additional clarity on whether your project should be classified as research and whether it requires ethical review by a NHS Research Ethics Committee (REC).

You provided the following information:

- An summary outlining your proposal
- A PDF /screenshot of the results page of the decision tool(s)
- An explanation of which questions you have difficulty in answering and why and/or
- An explanation of why you disagree with the outcome of the decision tool(s)

Based on the information you have provided, our decision is that the project is **not considered to be research and does not require review by an NHS Research Ethics Committee.**

In giving this decision our advisor adds:

IS THE STUDY RESEARCH?

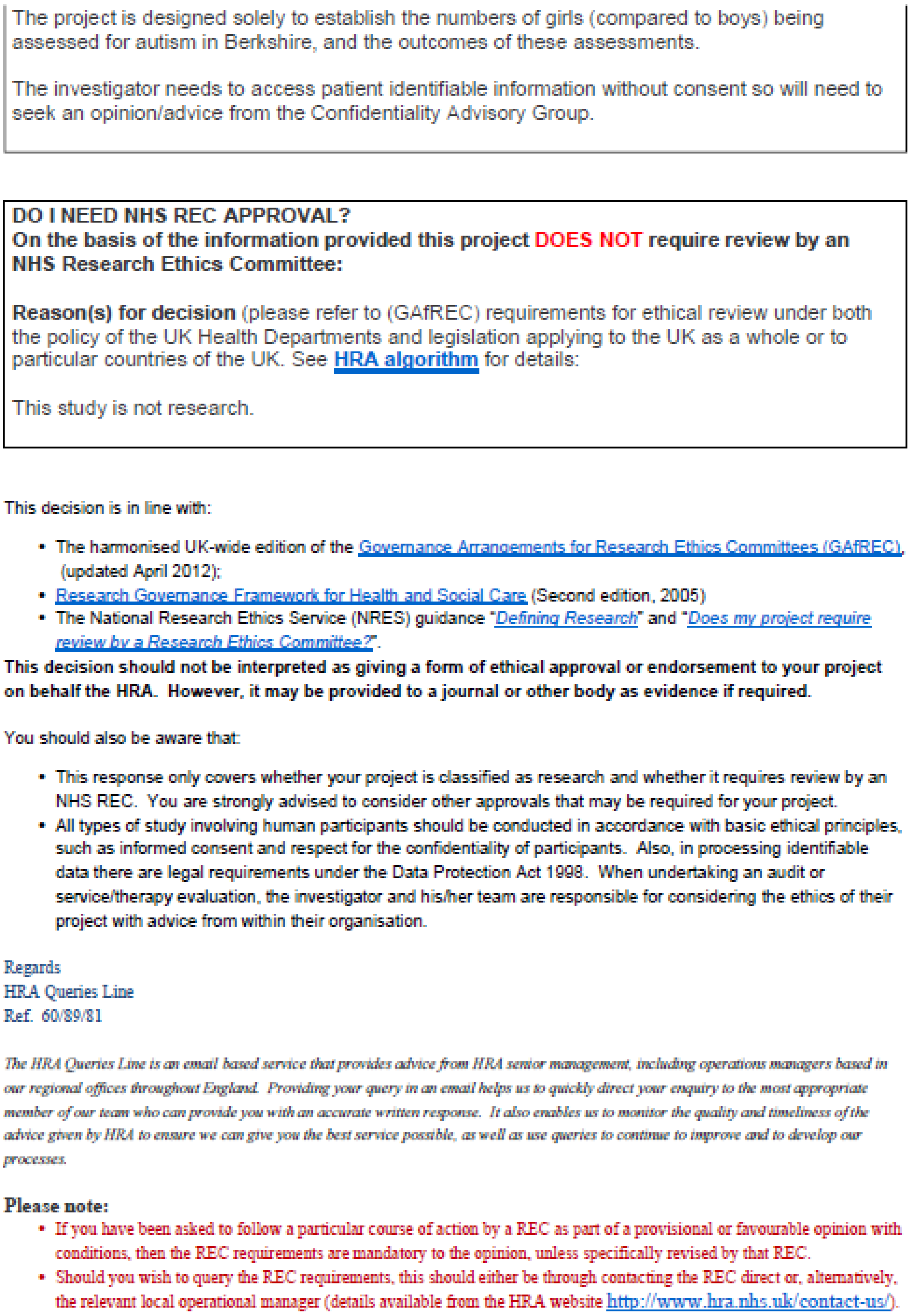
On the basis of the information provided this project is considered to be: SERVICE EVALUATION

Reason(s) for decision (please refer to HRA leaflet "Defining Research" for more information):

Designed and conducted solely to define or judge current care.
Measures current service without reference to a standard.
Usually involves analysis of existing data but may include administration of interview or questionnaire.

Where decision differs from that provided by the decision tools please provide explanation why:

Supports the decision tool outcome.



The project is designed solely to establish the numbers of girls (compared to boys) being assessed for autism in Berkshire, and the outcomes of these assessments.

The investigator needs to access patient identifiable information without consent so will need to seek an opinion/advice from the Confidentiality Advisory Group.

DO I NEED NHS REC APPROVAL?
On the basis of the information provided this project DOES NOT require review by an NHS Research Ethics Committee:

Reason(s) for decision (please refer to (GAfREC) requirements for ethical review under both the policy of the UK Health Departments and legislation applying to the UK as a whole or to particular countries of the UK. See **HRA algorithm** for details:

This study is not research.

This decision is in line with:

- The harmonised UK-wide edition of the Governance Arrangements for Research Ethics Committees (GAfREC), (updated April 2012);
- Research Governance Framework for Health and Social Care (Second edition, 2005)
- The National Research Ethics Service (NRES) guidance "*Defining Research*" and "*Does my project require review by a Research Ethics Committee?*".

This decision should not be interpreted as giving a form of ethical approval or endorsement to your project on behalf the HRA. However, it may be provided to a journal or other body as evidence if required.

You should also be aware that:

- This response only covers whether your project is classified as research and whether it requires review by an NHS REC. You are strongly advised to consider other approvals that may be required for your project.
- All types of study involving human participants should be conducted in accordance with basic ethical principles, such as informed consent and respect for the confidentiality of participants. Also, in processing identifiable data there are legal requirements under the Data Protection Act 1998. When undertaking an audit or service/therapy evaluation, the investigator and his/her team are responsible for considering the ethics of their project with advice from within their organisation.

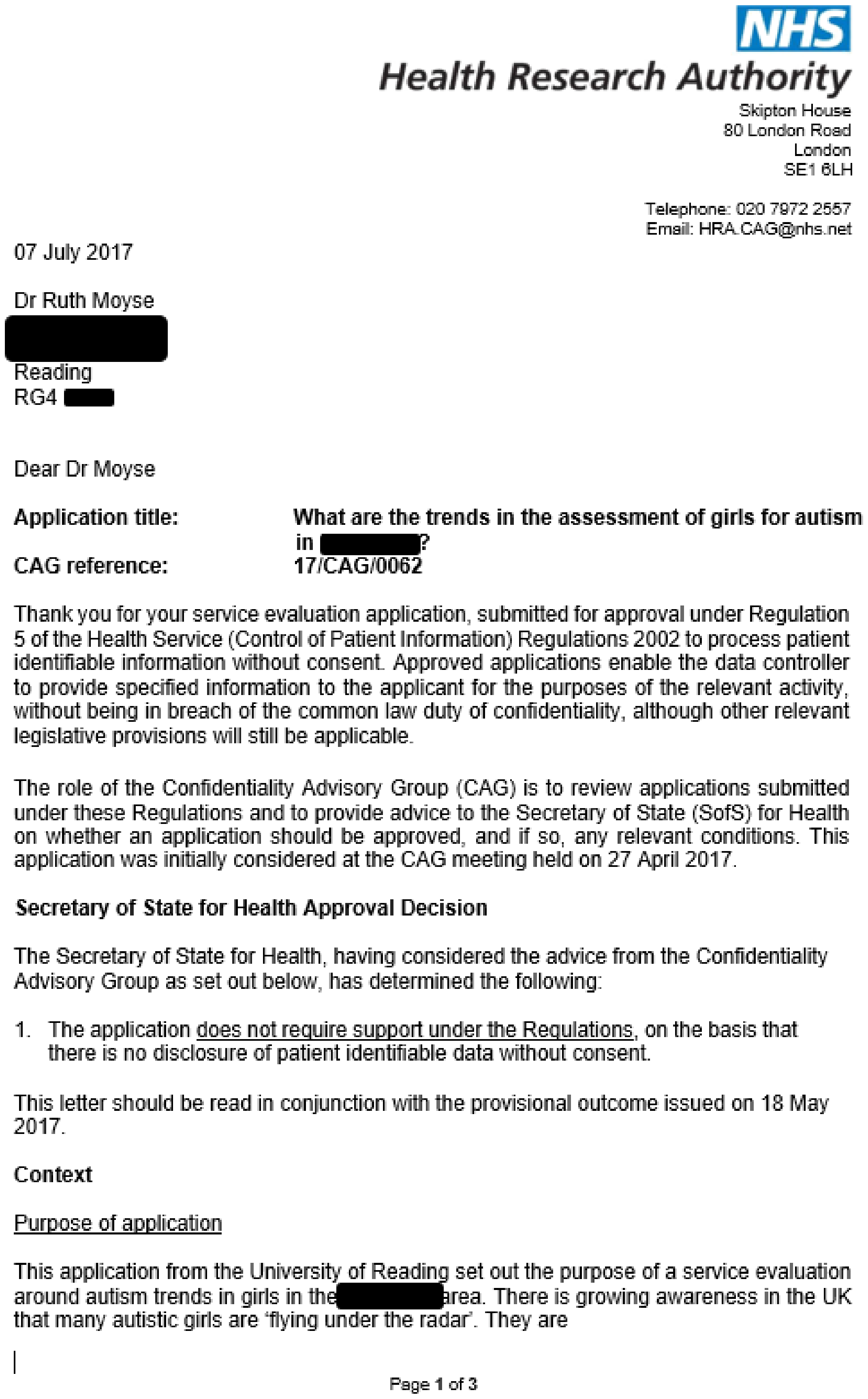
Regards
HRA Queries Line
Ref. 60/89/81

The HRA Queries Line is an email based service that provides advice from HRA senior management, including operations managers based in our regional offices throughout England. Providing your query in an email helps us to quickly direct your enquiry to the most appropriate member of our team who can provide you with an accurate written response. It also enables us to monitor the quality and timeliness of the advice given by HRA to ensure we can give you the best service possible, as well as use queries to continue to improve and to develop our processes.

Please note:

- If you have been asked to follow a particular course of action by a REC as part of a provisional or favourable opinion with conditions, then the REC requirements are mandatory to the opinion, unless specifically revised by that REC.
- Should you wish to query the REC requirements, this should either be through contacting the REC direct or, alternatively, the relevant local operational manager (details available from the HRA website http://www.hra.nhs.uk/contact-us/).

Appendix 3.25 Secretary of State for Health Approval Decision



NHS
Health Research Authority
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 7972 2557
Email: HRA.CAG@nhs.net

07 July 2017

Dr Ruth Moyse
[redacted]
Reading
RG4 [redacted]

Dear Dr Moyse

Application title: **What are the trends in the assessment of girls for autism in [redacted]?**
CAG reference: **17/CAG/0062**

Thank you for your service evaluation application, submitted for approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent. Approved applications enable the data controller to provide specified information to the applicant for the purposes of the relevant activity, without being in breach of the common law duty of confidentiality, although other relevant legislative provisions will still be applicable.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under these Regulations and to provide advice to the Secretary of State (SofS) for Health on whether an application should be approved, and if so, any relevant conditions. This application was initially considered at the CAG meeting held on 27 April 2017.

Secretary of State for Health Approval Decision

The Secretary of State for Health, having considered the advice from the Confidentiality Advisory Group as set out below, has determined the following:

1. The application does not require support under the Regulations, on the basis that there is no disclosure of patient identifiable data without consent.

This letter should be read in conjunction with the provisional outcome issued on 18 May 2017.

Context

Purpose of application

This application from the University of Reading set out the purpose of a service evaluation around autism trends in girls in the [redacted] area. There is growing awareness in the UK that many autistic girls are 'flying under the radar'. They are typically mis-diagnosed or diagnosed later than boys, if at all, and often only after the diagnosis of a secondary mental health issue. This has implications for their health and educational outcomes.

This project seeks to understand whether this is an issue in [redacted] The aim is to evaluate whether there are differences in the referral process and outcomes of girls assessed for autism, compared to boys, and to consider what factors may contribute to any variations.

The project will require accessing [redacted] Healthcare NHS data from the Children and Young Adults Mental Health Service (CAMHS) autism pathway, from 2011-2016. No participant involvement is required for the analysis. The results of the analysis will be used to provide a comprehensive picture of the assessment of girls for autism in [redacted], and to identify any points in the process where changes could be made to improve the service provided to girls on the autism pathway in [redacted].

This is part of a wider study into the experiences of autistic girls in mainstream secondary schools, and the findings will inform the (non-NHS) qualitative research that follows this initial analysis of secondary data.

Confidentiality Advisory Group Advice

Following the provisional outcome which was issued 18 May 2017 from review of the application at the CAG meeting held on 27 April 2017, the applicant submitted a formal review in writing to the queries raised by the CAG.

The following clarifications were provided:

1. Analysis of five years of data from the CAHMS autism pathway in [redacted] all data to be anonymised at source by a member of the NHS and containing no personal identifiers.
2. Further analysis of 200 of these patient records, with the required data extracted by a member of CAHMS, anonymised at source and containing no personal identifiers.
3. Analysis of a purposive sample of 10 patient records from this pathway, for which consent will be sought.

These clarifications confirmed that there was no access or processing of confidential patient identifiable information outside the direct care team without consent taking place during the project.

Confidentiality Advisory Group advice conclusion

The CAG recommended that support under the Regulations did not appear to be required as there is no disclosure of patient identifiable data without consent. The applicant was advised that this should not be considered as an endorsement of the approach or as legal advice.

Reviewed documents

The documents reviewed at the meeting were:

Document	*Version*	*Date*
CAG application from (signed/authorised) [Non-Research]	2.4	18 April 2017
Other [Data Flow Chart]		

Patient Information Materials		
Write recommendation from Caldicott Guardian (or equivalent) of applicant's organisation		
Email from Applicant Dr Ruth Moyse		24 May 2017

User Feedback

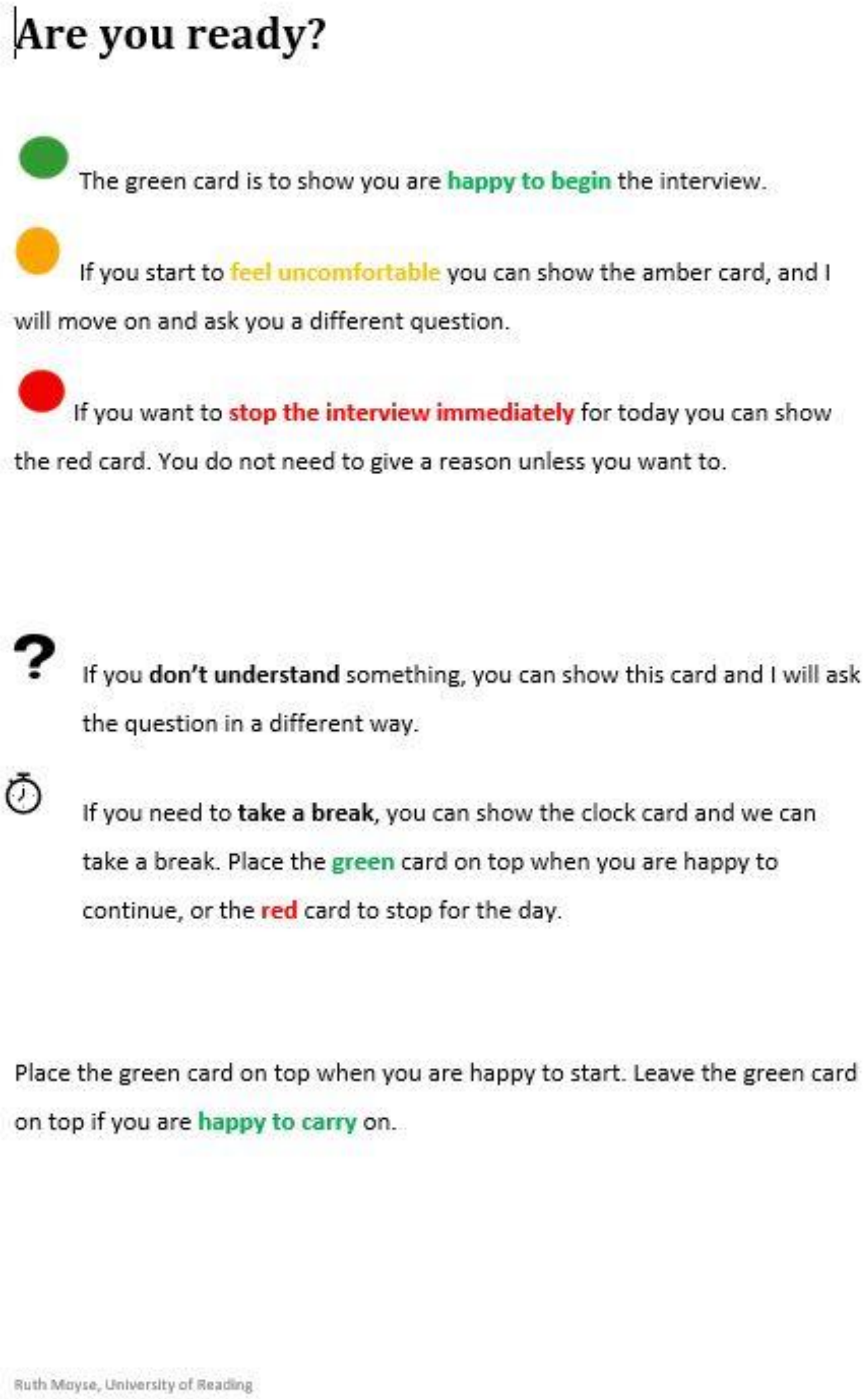
The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

Yours sincerely

Miss Kathryn Murray
Senior Confidentiality Advisor
On behalf of the Secretary of State for Health

Email: HRA.CAG@nhs.net

Appendix 3.26 Consent Card Instructions



Are you ready?

● The green card is to show you are **happy to begin** the interview.

● If you start to **feel uncomfortable** you can show the amber card, and I will move on and ask you a different question.

● If you want to **stop the interview immediately** for today you can show the red card. You do not need to give a reason unless you want to.

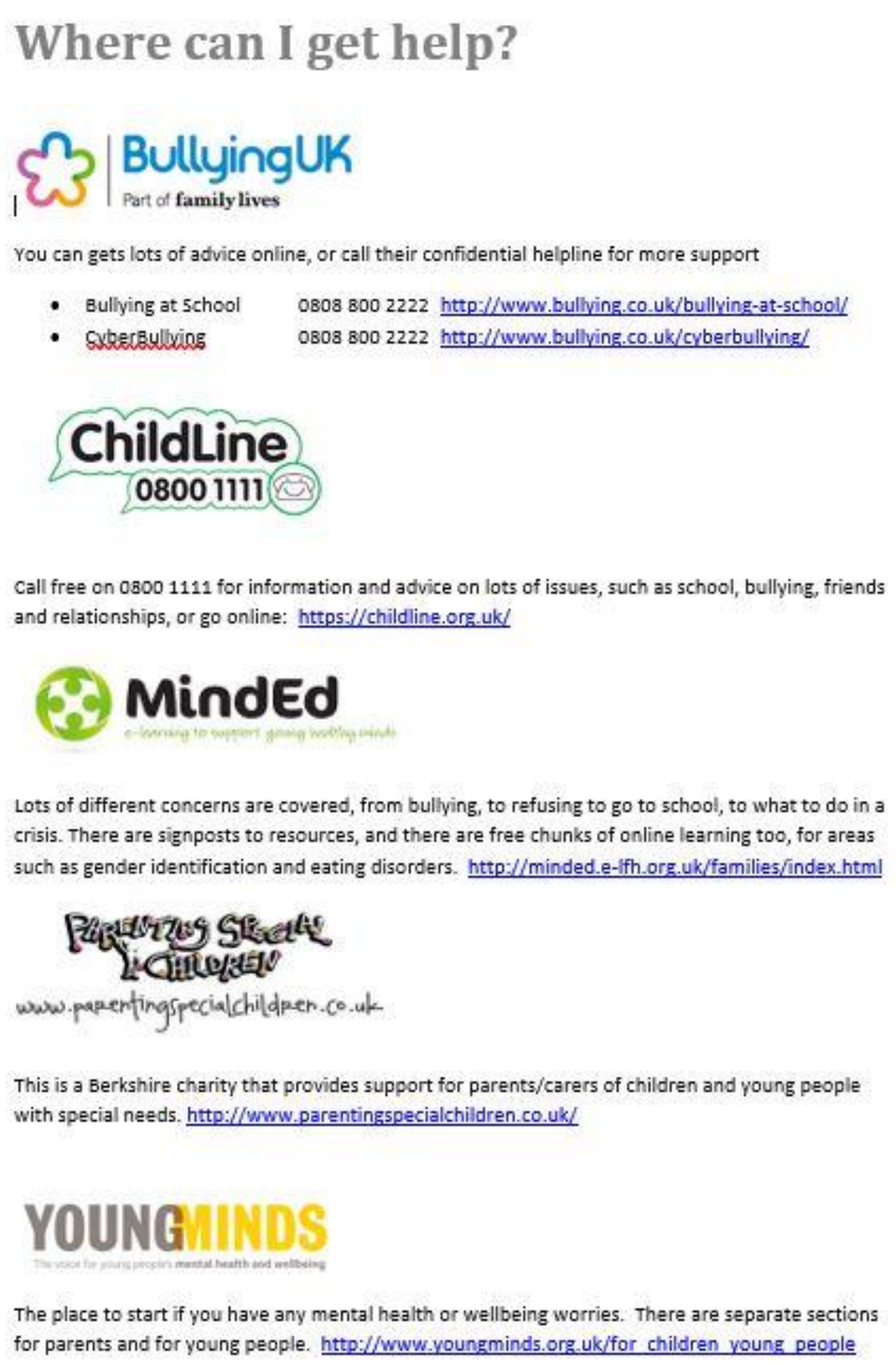
? If you **don't understand** something, you can show this card and I will ask the question in a different way.

⏱ If you need to **take a break**, you can show the clock card and we can take a break. Place the **green** card on top when you are happy to continue, or the **red** card to stop for the day.

Place the green card on top when you are happy to start. Leave the green card on top if you are **happy to carry** on.

Ruth Moyse, University of Reading

Appendix 3.27 Post-Interview Support



Where can I get help?

BullyingUK
Part of family lives

You can gets lots of advice online, or call their confidential helpline for more support

Bullying at School	0808 800 2222	http://www.bullying.co.uk/bullying-at-school/
CyberBullying	0808 800 2222	http://www.bullying.co.uk/cyberbullying/

ChildLine
0800 1111

Call free on 0800 1111 for information and advice on lots of issues, such as school, bullying, friends and relationships, or go online: https://childline.org.uk/

MindEd
e-learning to support young healthy minds

Lots of different concerns are covered, from bullying, to refusing to go to school, to what to do in a crisis. There are signposts to resources, and there are free chunks of online learning too, for areas such as gender identification and eating disorders. http://minded.e-lfh.org.uk/families/index.html

Parenting Special Children
www.parentingspecialchildren.co.uk

This is a Berkshire charity that provides support for parents/carers of children and young people with special needs. http://www.parentingspecialchildren.co.uk/

YOUNGMINDS
The voice for young people's mental health and wellbeing

The place to start if you have any mental health or wellbeing worries. There are separate sections for parents and for young people. http://www.youngminds.org.uk/for_children_young_people

Appendix 4.1 Six-year Referral Dataset

Variable		Female	Male
Referrals		1313	3135
Year[61]	2012/13	117	321
	2013/14	251	657
	2014/15	215	525
	2015/16	194	467
	2016/17	267	654
	2017/18	269	511
CCG[62]	CCG A	225	469
	CCG B	189	451
	CCG C	168	411
	CCG D	109	431
	CCG E	199	495
	CCG F	179	331
	CCG G	244	547
Ethnicity	Asian or Asian British	25	114
	Black or Black British	15	40
	Mixed	41	114
	Not Stated	368	811
	Other Ethnic Groups	64	151
	White	800	1905
Diagnosis	No	1021	2324
	Yes	292	811

---

[61] Financial year used by NHS Trust in original data set

[62] CCG = Clinical Commissioning Group

Appendix 4.2 Descriptive Statistics for Referrals to Autism Pathway

		Referrals		Population		Percentage of popn		Difference
Year	**CCG**	**F**	**M**	**F**	**M**	**F**	**M**	
2012/13	CCG A	20	51	9989	10639	0.20%	0.48%	0.28%
	CCG B	18	45	13595	14154	0.13%	0.32%	0.19%
	CCG C&E	28	82	11971	12448	0.23%	0.66%	0.42%
	CCG D	11	56	13339	14168	0.08%	0.40%	0.31%
	CCG F	21	36	12121	13375	0.17%	0.27%	0.10%
	CCG G	19	51	13708	14524	0.14%	0.35%	0.21%
	Total	**117**	**321**	**74723**	**79308**			
2013/14	CCG A	40	81	10201	10915	0.39%	0.74%	0.35%
	CCG B	37	110	13576	14216	0.27%	0.77%	0.50%
	CCG C&E	71	211	12328	12821	0.58%	1.65%	1.07%
	CCG D	23	84	13804	14503	0.17%	0.58%	0.41%
	CCG F	28	61	12190	13666	0.23%	0.45%	0.22%
	CCG G	52	110	13748	14694	0.38%	0.75%	0.37%
	Total	**251**	**657**	**75847**	**80815**			
2014/15	CCG A	41	70	10515	11071	0.39%	0.63%	0.24%
	CCG B	29	81	13742	14362	0.21%	0.56%	0.35%
	CCG C&E	57	156	12642	13119	0.45%	1.19%	0.74%
	CCG D	20	70	14274	14895	0.14%	0.47%	0.33%
	CCG F	25	39	12494	14025	0.20%	0.28%	0.08%
	CCG G	43	109	14053	15033	0.31%	0.73%	0.42%
	Total	**215**	**525**	**77720**	**82505**			
2015/16	CCG A	35	75	10710	11269	0.33%	0.67%	0.34%
	CCG B	29	64	13949	14538	0.21%	0.44%	0.23%
	CCG C&E	70	136	12889	13348	0.54%	1.02%	0.48%
	CCG D	9	61	14651	15282	0.06%	0.40%	0.34%
	CCG F	21	57	12747	14438	0.16%	0.39%	0.23%
	CCG G	30	74	14497	15478	0.21%	0.48%	0.27%
	Total	**194**	**467**	**79443**	**84353**			
2016/17	CCG A	46	100	10777	11340	0.43%	0.88%	0.45%
	CCG B	31	88	13985	14634	0.22%	0.60%	0.38%
	CCG C&E	73	178	13083	13691	0.56%	1.30%	0.74%
	CCG D	26	96	15117	15738	0.17%	0.61%	0.44%
	CCG F	37	78	12938	14517	0.29%	0.54%	0.25%
	CCG G	54	114	14940	15860	0.36%	0.72%	0.36%
	Total	**267**	**654**	**80840**	**85780**			
2017/18	CCG A	43	92	10873	11557	0.40%	0.80%	0.40%
	CCG B	45	63	13924	14740	0.32%	0.43%	0.10%
	CCG C&E	68	143	13286	14042	0.51%	1.02%	0.51%
	CCG D	20	64	15525	16081	0.13%	0.40%	0.27%
	CCG F	47	60	13031	14727	0.36%	0.41%	0.05%
	CCG G	46	89	15401	16295	0.30%	0.55%	0.25%
	Total	**269**	**511**	**82040**	**87442**			

Appendix 4.3 Descriptive Statistics for Age at Referral by Financial Year, and by CCG

Descriptive statistics of the mean age at referral by FY

FY	Gender	n	Mean	SD	Min	Max	Range
2012-13	Female	117	10.43	3.21	5	17	12
	Male	321	9.86	2.86	5	17	12
2013-14	Female	251	10.2	3.51	5	17	12
	Male	657	8.77	3.07	5	17	12
2014-15	Female	215	10.64	3.26	5	17	12
	Male	525	9.12	3.24	5	17	12
2015-16	Female	194	9.07	3.14	5	16	11
	Male	467	9.08	3.03	5	17	12
2016-17	Female	267	10	3.25	5	18	13
	Male	654	9.04	3.02	5	18	13
2017-18	Female	269	10.17	3.31	5	17	12
	Male	511	8.91	3.1	5	18	13

Descriptive statistics of the mean age at referral by CCG

FY	Gender	n	Mean	SD	Min	Max	Range
CCG A	Female	225	10.12	3.23	5	18	13
	Male	469	9.05	2.85	5	18	13
CCG B	Female	189	9.75	3.22	5	16	11
	Male	451	9.04	3.15	5	17	12
CCG C	Female	168	9.82	3.43	5	17	12
	Male	411	8.78	3.07	5	17	12
CCG D	Female	109	9.92	3.34	5	17	12
	Male	431	9.55	3.19	5	18	13
CCG E	Female	199	10.05	3.37	5	17	12
	Male	495	8.98	2.92	5	17	12
CCG F	Female	179	10.5	3.28	5	17	12
	Male	331	9.31	3.06	5	17	13
CCG G	Female	244	10.26	3.38	5	17	12
	Male	547	8.87	3.23	5	17	12

Appendix 4.4 Descriptive Statistics for Autism Diagnosis

		Diagnosed		Population		Percentage of popn		Difference
Year	CCG	F	M	F	M	F	M	
2012/13	CCG A	2	18	9989	10639	0.02%	0.17%	0.15%
	CCG B	7	9	13595	14154	0.05%	0.06%	0.01%
	CCG C&E	6	24	11971	12448	0.05%	0.19%	0.14%
	CCG D	3	13	13339	14168	0.02%	0.09%	0.07%
	CCG F	3	9	12121	13375	0.02%	0.07%	0.04%
	CCG G	5	20	13708	14524	0.04%	0.14%	0.10%
	Total	**26**	**93**	**74723**	**79308**			
2013/14	CCG A	11	22	10201	10915	0.11%	0.20%	0.09%
	CCG B	12	35	13576	14216	0.09%	0.25%	0.16%
	CCG C&E	29	88	12328	12821	0.24%	0.69%	0.45%
	CCG D	11	32	13804	14503	0.08%	0.22%	0.14%
	CCG F	11	25	12190	13666	0.09%	0.18%	0.09%
	CCG G	11	38	13748	14694	0.08%	0.26%	0.18%
	Total	**85**	**240**	**75847**	**80815**			
2014/15	CCG A	18	21	10515	11071	0.17%	0.19%	0.02%
	CCG B	8	21	13742	14362	0.06%	0.15%	0.09%
	CCG C&E	18	57	12642	13119	0.14%	0.43%	0.29%
	CCG D	7	26	14274	14895	0.05%	0.17%	0.13%
	CCG F	8	17	12494	14025	0.06%	0.12%	0.06%
	CCG G	10	38	14053	15033	0.07%	0.25%	0.18%
	Total	**69**	**180**	**77720**	**82505**			
2015/16	CCG A	14	30	10710	11269	0.13%	0.27%	0.14%
	CCG B	12	29	13949	14538	0.09%	0.20%	0.11%
	CCG C&E	24	56	12889	13348	0.19%	0.42%	0.23%
	CCG D	4	16	14651	15282	0.03%	0.10%	0.08%
	CCG F	7	17	12747	14438	0.05%	0.12%	0.06%
	CCG G	12	22	14497	15478	0.08%	0.14%	0.06%
	Total	**73**	**170**	**79443**	**84353**			
2016/17	CCG A	4	13	10777	11340	0.04%	0.11%	0.08%
	CCG B	5	18	13985	14634	0.04%	0.12%	0.09%
	CCG C&E	7	38	13083	13691	0.05%	0.28%	0.22%
	CCG D	5	12	15117	15738	0.03%	0.08%	0.04%
	CCG F	4	11	12938	14517	0.03%	0.08%	0.04%
	CCG G	5	17	14940	15860	0.03%	0.11%	0.07%
	Total	**30**	**109**	**80840**	**85780**			
2017/18	CCG A	2	2	10873	11557	0.02%	0.02%	0.00%
	CCG B	1	2	13924	14740	0.01%	0.01%	0.01%
	CCG C&E	4	8	13286	14042	0.03%	0.06%	0.03%
	CCG D	2	2	15525	16081	0.01%	0.01%	0.00%
	CCG F	0	2	13031	14727	0.00%	0.01%	0.01%
	CCG G	0	6	15401	16295	0.00%	0.04%	0.04%
	Total	**9**	**22**	**82040**	**87442**			

Appendix 4.5 Assessment Dataset

2016 assessment dataset

Variable	Variable	Female	Male
Referrer	EP[63]	2	4
	GP	66	110
	HV[64]	2	0
	Internal	18	28
	PMHW[65]	1	8
	School	12	51
	SLT[66]	3	7
	YOS[67]	0	3
School Observation	No	92	172
	Yes	12	39
Diagnosis	No	38	64
	Yes	66	147
Second Opinion	No	96	192
	Yes	35	19
Other Pathway (Past)	No	69	136
	Yes	35	75
Other Pathway (Present)	No	63	158
	Yes	41	53

---

[63] Educational Psychologist
[64] Health Visitor
[65] Primary Mental Health Worker
[66] Speech and Language Therapist
[67] Youth Offending Scheme

Appendix 4.6 Contingency Table for Referrer and Sex

```
   Cell Contents
|-------------------------|
|                   Count |
|         Expected Values |
| Chi-square contribution |
|             Row Percent |
|          Column Percent |
|           Total Percent |
|            Std Residual |
|-------------------------|

Total Observations in Table:  285

             | RefPP$Referrer
RefPP$Sex |       GP  | Internal  |   School  | Row Total |
-------------|-----------|-----------|-----------|-----------|
      Female |       66  |       18  |       12  |       96  |
             |   59.284  |   15.495  |   21.221  |           |
             |    0.761  |    0.405  |    4.007  |           |
             |   68.750% |   18.750% |   12.500% |   33.684% |
             |   37.500% |   39.130% |   19.048% |           |
             |   23.158% |    6.316% |    4.211% |           |
             |    0.872  |    0.636  |   -2.002  |           |
-------------|-----------|-----------|-----------|-----------|
        Male |      110  |       28  |       51  |      189  |
             |  116.716  |   30.505  |   41.779  |           |
             |    0.386  |    0.206  |    2.035  |           |
             |   58.201% |   14.815% |   26.984% |   66.316% |
             |   62.500% |   60.870% |   80.952% |           |
             |   38.596% |    9.825% |   17.895% |           |
             |   -0.622  |   -0.454  |    1.427  |           |
-------------|-----------|-----------|-----------|-----------|
Column Total |      176  |       46  |       63  |      285  |
             |   61.754% |   16.140% |   22.105% |           |
-------------|-----------|-----------|-----------|-----------|


Statistics for All Table Factors


Pearson's Chi-squared test
------------------------------------------------------------
Chi^2 =  7.799957     d.f. =  2     p =  0.02024235



Fisher's Exact Test for Count Data
------------------------------------------------------------
Alternative hypothesis: two.sided
p =  0.01714247


       Minimum expected frequency: 15.49474
```

Appendix 4.7 Univariate Analysis of Variance by Sex, Referrer and Age (Months) at Referral

```
UNIANOVA Months BY Sex Referrer
  /METHOD=SSTYPE(3)
  /INTERCEPT=INCLUDE
  /PRINT HOMOGENEITY
  /CRITERIA=ALPHA(.05)
  /DESIGN=Sex Referrer Sex*Referrer.
```

Univariate Analysis of Variance

Notes

Output Created		28-JUN-2020 12:36:02
Comments		
Input	Data	C:\Users\Ruth Moyse\Documents\PhD\Data Retrieval CAMHS\20200607\RefSexM.csv
	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	285
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics are based on all cases with valid data for all variables in the model.

Syntax

```
UNIANOVA Months BY Sex Referrer
  /METHOD=SSTYPE(3)
  /INTERCEPT=INCLUDE
  /PRINT HOMOGENEITY
  /CRITERIA=ALPHA(.05)
  /DESIGN=Sex Referrer Sex*Referrer.
```

Resources	Processor Time	00:00:00.11
	Elapsed Time	00:00:00.38

Between-Subjects Factors

		N
Sex	1	96
	2	189
Referrer	1	176
	2	46
	3	63

Levene's Test of Equality of Error Variances[a,b]

		Levene Statistic	df1	df2	Sig.
Months	Based on Mean	.917	5	279	.471
	Based on Median	.830	5	279	.529
	Based on Median and with adjusted df	.830	5	277.522	.529
	Based on trimmed mean	.946	5	279	.451

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.[a,b]

a. Dependent variable: Months

b. Design: Intercept + Sex + Referrer + Sex * Referrer

Tests of Between-Subjects Effects

Dependent Variable: Months

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	35133.617[a]	5	7026.723	5.296	.000
Intercept	2058166.034	1	2058166.034	1551.220	.000
Sex	7599.792	1	7599.792	5.728	.017
Referrer	17266.652	2	8633.326	6.507	.002
Sex * Referrer	2145.915	2	1072.957	.809	.446
Error	370178.432	279	1326.804		
Total	3646059.000	285			
Corrected Total	405312.049	284			

a. R Squared = .087 (Adjusted R Squared = .070)

Appendix 4.8 Contingency Table for Sex and Other Pathway

```
Chi Other path now and sex

> CrossTable(RefPP$Gender, RefPP$Opnow, fisher = TRUE, chisq = TRUE, expec
ted = TRUE, sresid = TRUE, format = "SPSS")

   Cell Contents
|-------------------------|
|                   Count |
|         Expected Values |
| Chi-square contribution |
|             Row Percent |
|          Column Percent |
|           Total Percent |
|            Std Residual |
|-------------------------|

Total Observations in Table:  285

             | RefPP$Opnow
RefPP$Gender |        No  |       Yes  | Row Total |
-------------|-----------|-----------|-----------|
      Female |       56  |       40  |       96  |
             |   66.021  |   29.979  |           |
             |    1.521  |    3.350  |           |
             |   58.333% |   41.667% |   33.684% |
             |   28.571% |   44.944% |           |
             |   19.649% |   14.035% |           |
             |   -1.233  |    1.830  |           |
-------------|-----------|-----------|-----------|
        Male |      140  |       49  |      189  |
             |  129.979  |   59.021  |           |
             |    0.773  |    1.701  |           |
             |   74.074% |   25.926% |   66.316% |
             |   71.429% |   55.056% |           |
             |   49.123% |   17.193% |           |
             |    0.879  |   -1.304  |           |
-------------|-----------|-----------|-----------|
Column Total |      196  |       89  |      285  |
             |   68.772% |   31.228% |           |
-------------|-----------|-----------|-----------|


Statistics for All Table Factors


Pearson's Chi-squared test
------------------------------------------------------------
Chi^2 =  7.344837     d.f. =  1     p =  0.006725564

Pearson's Chi-squared test with Yates' continuity correction
------------------------------------------------------------
Chi^2 =  6.630181     d.f. =  1     p =  0.01002651


Fisher's Exact Test for Count Data
------------------------------------------------------------
Sample estimate odds ratio:  0.4912923

Alternative hypothesis: true odds ratio is not equal to 1
p =  0.009919603
95% confidence interval:  0.2823346 0.8541751

Alternative hypothesis: true odds ratio is less than 1
p =  0.005339868
95% confidence interval:  0 0.7857587
```

```
Alternative hypothesis: true odds ratio is greater than 1
p =  0.99759
95% confidence interval:  0.3070181 Inf


       Minimum expected frequency: 29.97895
```

Appendix 4.9 Comparison of Other Variables in the Assessment Dataset

Table 4.6.1 *Proportion of CYP diagnosed with and without a school observation element*

	School observation as part of assessment	
Diagnosed CYP	Yes	No
Female	11%	89%
Male	14%	86%

Table 4.6.2 *Proportion of CYP diagnosed after a second opinion*

	Diagnosis after a second opinion	
Diagnosed CYP	Yes	No
Female	11%	89%
Male	11%	89%

Table 4.6.3 *Proportion of CYP diagnosed who had previously been on a different pathway*

	Diagnosis after being on a different pathway	
Diagnosed CYP	Yes	No
Female	33%	67%
Male	37%	63%

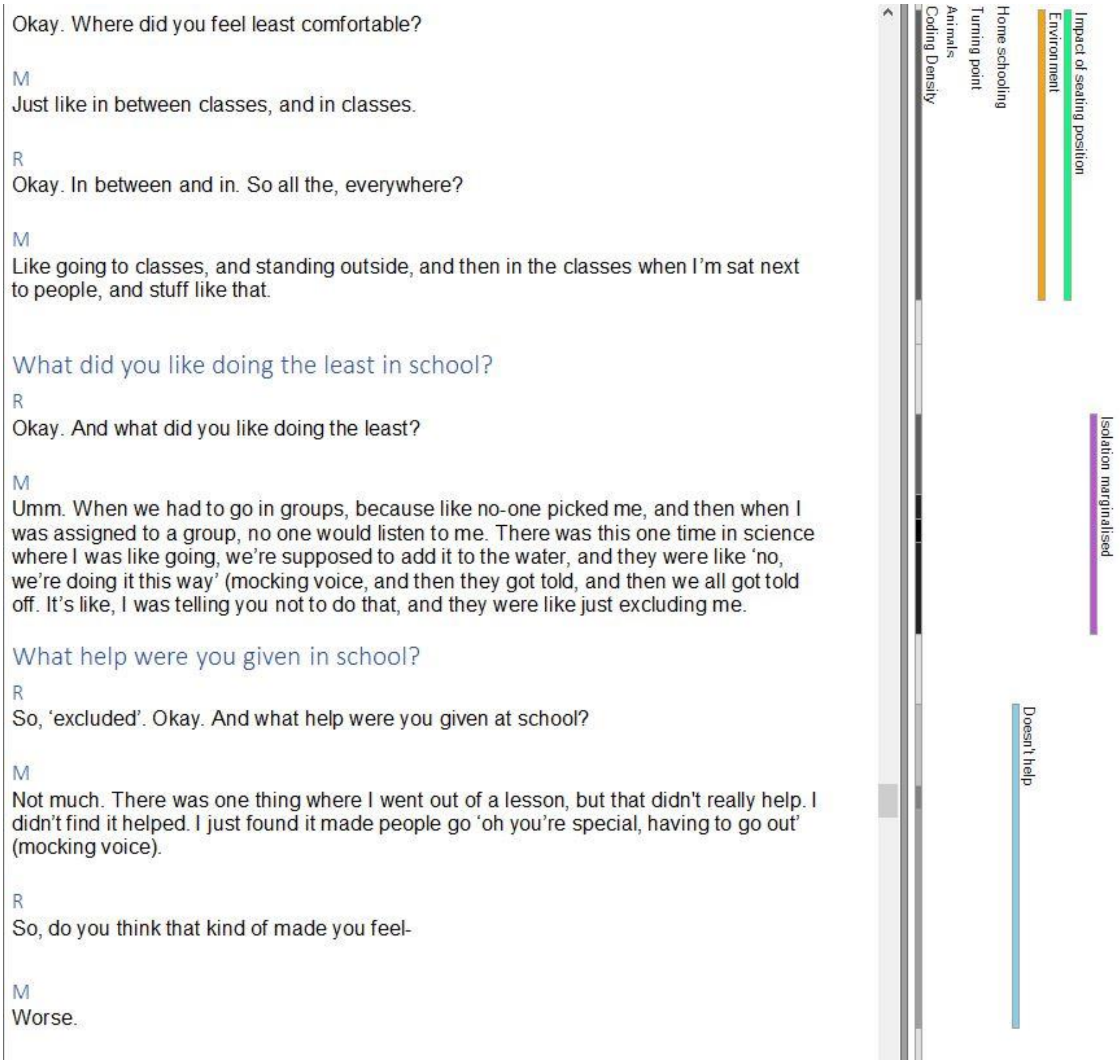
Appendix 4.10 Questions and Themes Arising from Case Studies

Name	**Theme**
Stage first concerns raised	Time
Who was first concerned?	Time
How long between then and first referral being made?	Time
Reasons inferred to explain delay?	Time
Referred by	Time
Request of	Time
Reason for referral	Time
Previous referrals	Time
Age at diagnosis	Time
Date of diagnosis	Time
Other diagnoses	Time
Later referrals / meets	Time
Impact on the child	Impact
Impact on the school	Impact
Impact on the family	Impact
Barriers and challenges	Impact
Existing support	Impact
Seen as a burden	Impact
Internaliser at schoool	Unmet needs
Physical symptoms	Unmet needs
History of anxiety	Unmet needs
Evidence of self-harm	Unmet needs
Evidence of suicidal ideation	Unmet needs
Withdraws	Unmet needs
First documentation of the girl's voice	Flags
Girl's words about school	Flags
Strengths & interests	Flags
Attendance	Flags
Academic progress	Flags

Appendix 4.11 Example Data from Case Studies, Highlighting Potential Themes

Question	Molly	Cayla	Beth	Katie
Impact on the child?	Bullied at school; resolved by teacher. Friendships. SDQ scores show mum and secondary school rate friendships difficulties v high	Both secondary school (not primary) and mum perceive high impact of difficulties on child. SENCo: 'Cayla has a history of suffering from high levels of anxiety and her friendships are volatile. She is beginning not to want to come to school'.	SDQ results high scores for overall stress and behavioural difficulties' 'Impact on Beth's ability to develop positive relationships with peers; impacts on her classroom learning	Mum: 'She does not communicate well even when she needs help.' Emotional responses. Peer relationships. Overly compliant - risk.
Impact on the school?	No evidence	Primary school said she was 'a lovely girl'. Secondary SENCo: 'It is not clear whether Cayla copying or competing, but her behaviour is becoming more controlling.' 'Hiding in cupboards'.	'School states Beth constantly requires adult support to engage in tasks', 'regularly leaves the classroom', 'tantrums', 'refuses to comply with requests from adults'. SDQ results high scores for overall stress and behavioural difficulties'...'puts a great deal of burden on the class teacher and the class as a whole'.	Quiet and inward. V shy. Found it difficult to make friends. V submissive. Doesn't contribute in lessons unless prompted.' 'V good at getting on with work. Takes pride in work. Wants to do well. Enjoys lessons'.
Impact on the family?	Mum: 'I have always found her a struggle' Dad - Mum says he's 'in denial' Molly: 'I'm in charge at home when Dad's not there'. SDQ parent scores stress (v high) and behavioural difficulties (high) at home	Secondary SENCo: 'puts great deal of strain on family life'; 'they are finding that she is becoming more difficult at home'.	Mum says Beth has social and behavioural difficulties at home. Mum says Beth has recently become more aggressive, possibly due to conflicting parenting styles (parents and grandparents).	Fits of temper', 'how will she cope?' More difficult to manage outdoors when she may run off without thought of her own safety.

Appendix 5.1 Example Coding of Life History Data



Okay. Where did you feel least comfortable?

M
Just like in between classes, and in classes.

R
Okay. In between and in. So all the, everywhere?

M
Like going to classes, and standing outside, and then in the classes when I'm sat next to people, and stuff like that.

What did you like doing the least in school?

R
Okay. And what did you like doing the least?

M
Umm. When we had to go in groups, because like no-one picked me, and then when I was assigned to a group, no one would listen to me. There was this one time in science where I was like going, we're supposed to add it to the water, and they were like 'no, we're doing it this way' (mocking voice, and then they got told, and then we all got told off. It's like, I was telling you not to do that, and they were like just excluding me.

What help were you given in school?

R
So, 'excluded'. Okay. And what help were you given at school?

M
Not much. There was one thing where I went out of a lesson, but that didn't really help. I didn't find it helped. I just found it made people go 'oh you're special, having to go out' (mocking voice).

R
So, do you think that kind of made you feel-

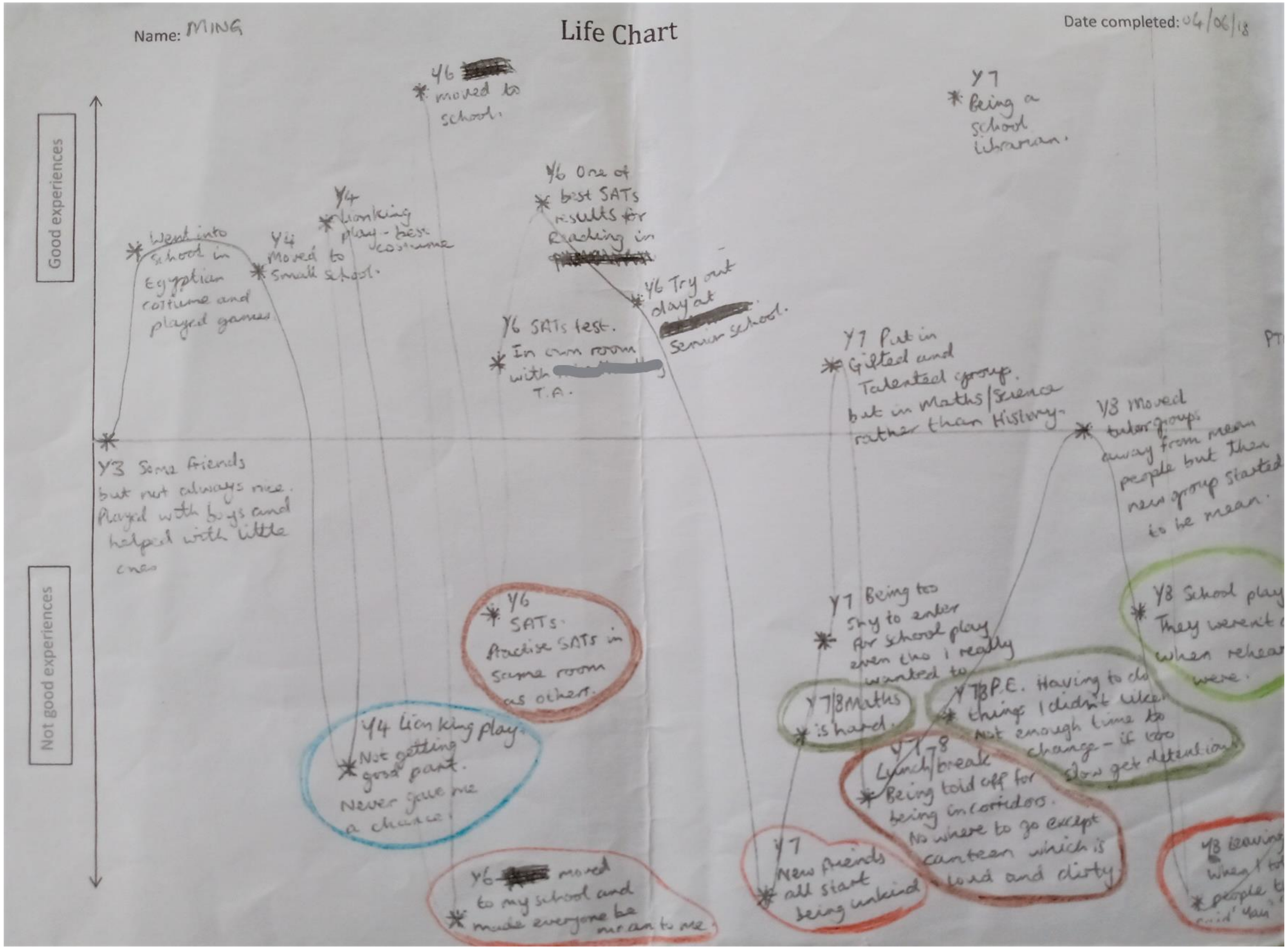
M
Worse.

Appendix 5.2 Thematic Analysis of Life Charts by Participants during Interview 3

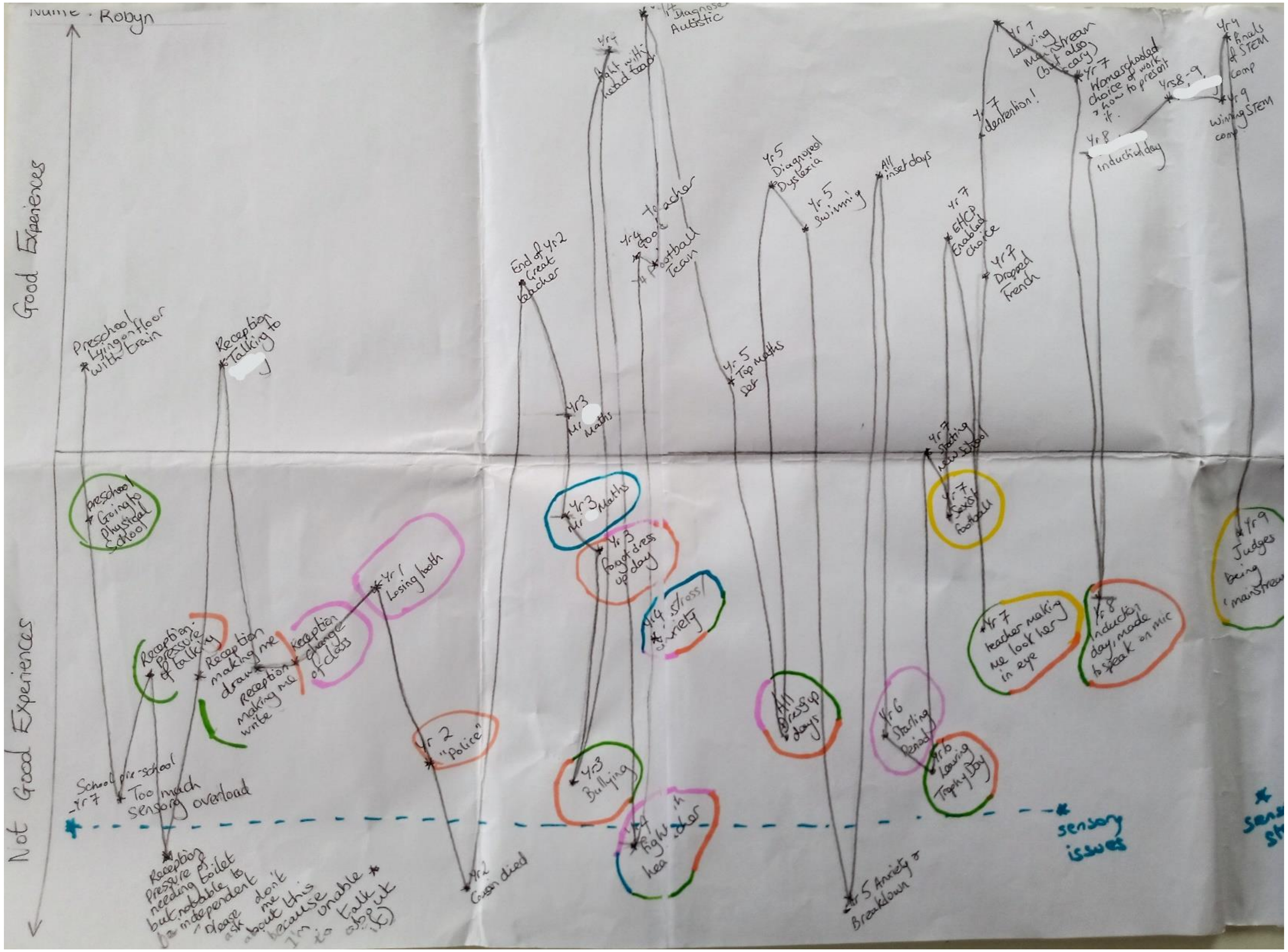
Theme	**Alex**	**Daisy**	**Erin**	**Jane**	**Lizza**	**Ming**	**Robyn**	**Rosie**
1	Not understanding autism	Bullying	Anxiety	Lack of respect (peers)	Pressure (strictness, deadlines)	Bullies and people being mean	Sensory overload	Staff attitudes
2	Loss	Isolation / loneliness / segregation	Overload	Lack of understanding, emotional empathy and knowledge (staff)	Social anxiety	Not being given a chance to show what I can do	Force (rigidity, discrimination, abuse of power)	Struggles with peers
3	Isolation	Unexpected change	Other people's perceptions			Wrong environment: hard to concentrate; too many people / noise	Change	Peers' behaviour
4	Anger / frustration	Overwhelming (sensory / pressure)	Injustice			Not enough information / not clear	Social expectations (understanding language)	Worry about education
5		Mental health				Difficult to learn in the way of teaching	Discrimination	
6		Lack of understanding / correct treatment by staff						

Note: Sally and Emily did not complete the life charts and therefore do not appear here.

Appendix 5.3 Excerpt from Ming's Life Chart Showing her Coloured Coding



Appendix 5.4 Excerpt from Robyn's Life Chart Showing her Coloured Coding



Appendix 5.5 Types of Bullying Reported by the Girls

Key:

Count	Colour
1-3	░
4-6	▒
7-9	▓
10+	█

Types of Bullying the Participants Reported Experiencing

Participant	Bullying (not otherwise defined)	Emotional abuse	Mean	Mistreated	Ostracised	Physical violence to her	Physical violence from her	Sexual assault	Sexual harassment	Theft	Verbal abuse
Alex	3										2
Daisy	13	1	1		2	8	1	2	1	4	3
Erin	9	1	2		1						1
Emily[a]											
Jane	1	1				1			1		7
Lizza			1								2
Ming		1	9								1
Robyn	3			1							1
Rosie	3		1	3		1					1
Sally[a]	3						8[b]				

Note: The count is not a measure of instances but of mentions, designed to reflect types of bullying they reported, plus the extent to which these memories formed part of their narratives.

[a] Whilst neither Emily nor Sally completed a life chart, Sally made it clear in her ideal school interview that it was part of hers. It is not possible to be certain whether bullying formed part of Emily's history.

[b] The count of physical violence in Sally's case refers to her thinking about hurting others, rather than actual violence, and appeared to be based on her experiences of being abused herself. Her response to the question about how peers would treat her (in the sort of school she didn't want to attend) was to show the amber card.

Appendix 5.6 Example Data from Personal Construct of Ideal School

The response of each participant to questions about school values and how they might feel in the sort of school they would and would not like to attend.

	Worst school		**Best school**	
Name	**What does this school value most?**	**How do you feel?**	**What does this school value most?**	**How do you feel?**
Alex	*Getting the best grades and working really hard, because if you just work hard, then you'll do amazingly and if you're not doing well then you're clearly just not trying hard enough.*	*I'd feel isolated and confused and stressed.*	*Pupils are, um, comfortable and happy and are able to fulfil their potential…helps you reach what's your best you…kindness… a nice, decent human being…and empathy.*	*Comfortable to be myself. Um and talk and not like think I had to like act a certain way to make other people happy.*
Daisy	*Grades or money.*	*Lonely. Angry. And isolated.*	*Cares about students. Well-being*[68]*. It rewards kindness and perseverance.*	*I'd be feeling fulfilled, so like, academically and socially, getting a good education and qualifications and my brain was stretched.*
Emily	*Only care about the results that students get rather than how they get them.*	*Really anxious and quite uncomfortable.*	*Care about its students and how, erm, how they work, how they, yeah.*	*Quite comfortable.*
Erin	*The school would prioritise good grades and statistics over pupils' wellbeing…be forceful with rules and regulations* [so they can] *have the best exam results and good attendance and a good ofsted rating…be overly critical of all of the students because they believe that it will make them do better.*	*Overloaded. Stressed and sad.*	*Prioritise pupil wellbeing over good grades and would encourage all students to do well but not place pressure or unrealistic expectations on them.*	*Quite relaxed.*

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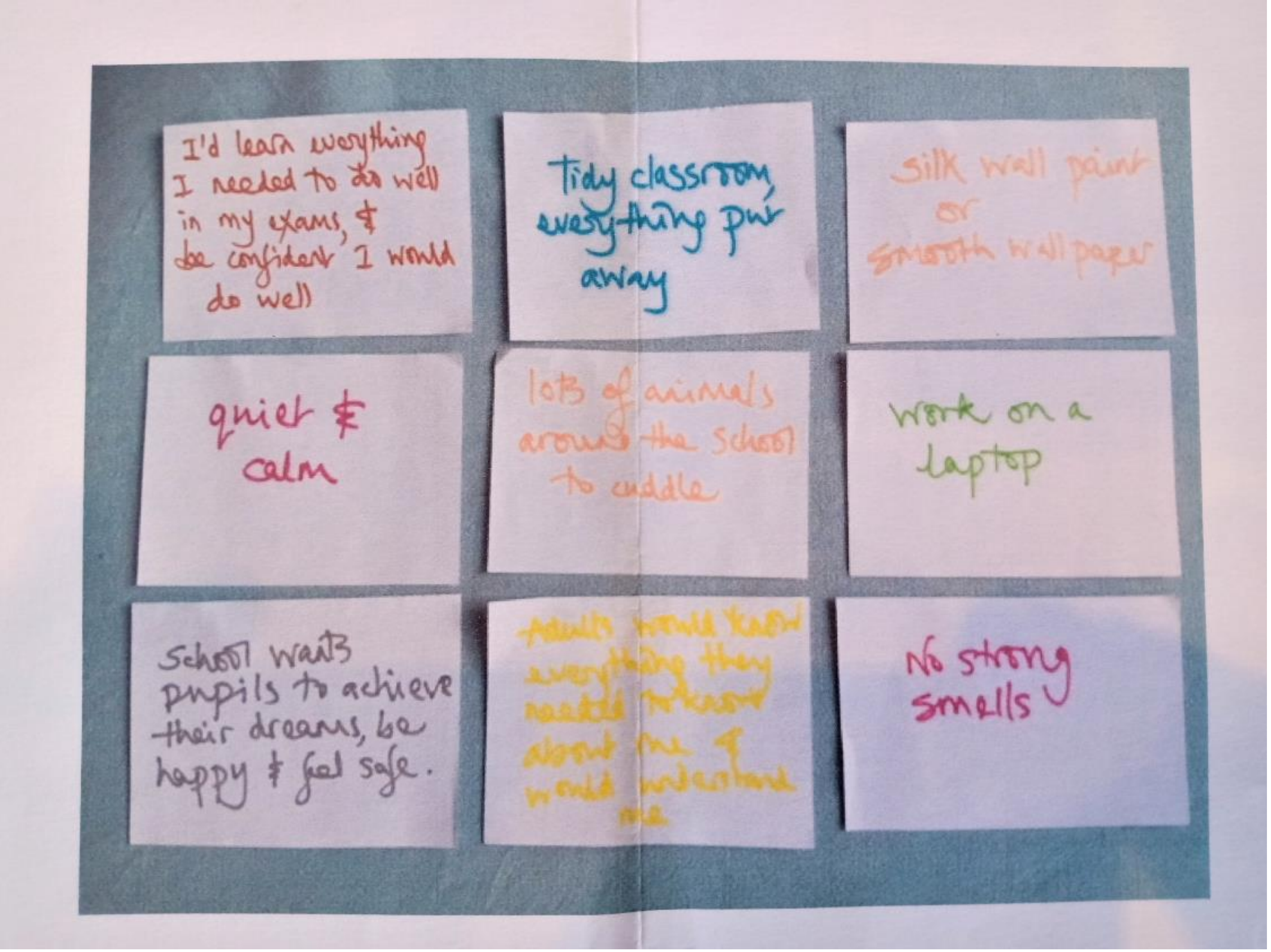
[68] The spelling of Daisy's words in this section is taken from her original data, which in this case was provided in written format.

Appendix 5.7 Rosie’s Presentation of her Top Nine Responses in the Ranking Activity for her Ideal School



I'd learn everything
I needed to do well
in my exams, &
be confident I would
do well

Tidy classroom,
everything put
away

Silk wall paint
or
smooth wallpaper

quiet &
calm

lots of animals
around the school
to cuddle

Work on a
laptop

School wants
pupils to achieve
their dreams, be
happy & feel safe.

Adults would know
everything they
needed to know
about me &
would understand
me

No strong
smells