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**Understanding How Autistic Pupils Experience Secondary School:
Autism Criteria, Theory and FAMe™**

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Abstract

Many autistic pupils experience difficulties associated with a mis-match between the explicit features of autism and the physical and psychosocial environment of secondary school, which leave them particularly vulnerable to a range of negative mental health outcomes, and which can create barriers to their academic success (Charman et al., 2011; Morewood, Humphrey and Symes, 2011). This situation is understood to be compounded by a lack of teacher training and understanding of autism in general, and of its specific impact on individual pupil's learning styles and support needs (Falkmer, Parsons and Granlund, 2012; Reed, Osborne and Waddington, 2012; Hebron and Humphrey, 2014). This project sought to investigate (1) the extent to which existing descriptions of autism were reflected in the general school experiences of a cohort of autistic pupils, and (2) the impact of a new pupil-to-teacher communication system, designed by the author, on the classroom experiences and psychological well-being of these pupils.

Situated within the paradigm of pragmatism, a mixed methods approach to this research project was adopted. Twenty-one autistic pupils shared their experiences of school during semi-structured interviews, whilst their teachers' experiences of teaching them were elicited via online surveys. Thematic analysis, using a specifically designed coding manual, was used to investigate the capacity of the diagnostic criteria descriptors and definitions of autism, and selected cognitive autism theories, to explain both the general school experiences described by autistic pupils, and the specific areas of difficulty they prioritised for additional support and/or teacher practice change. The efficacy of a new register-based pupil-to-teacher communication system (FAMe™), was evaluated using pre- and post-system implementation interviews and pupil self-report scales. The design of this project positioned participating pupils as experts in their own experiences, whilst the FAMe™ System enabled their voices to influence matters that affected them. The methods used, to facilitate engagement with and collect data from autistic pupils, have the potential to be considered a 'model example' for carrying out future research in this field.

Analysis evidenced the limited capacity of the diagnostic criteria and autism theory to inform understanding of the pupils' collective experiences. Positive impact of the FAMe™ System on pupils' classroom experiences and psychological well-being was demonstrated. Teachers reported improved confidence post-FAMe™ in their ability to teach autistic pupils, and to meet their pupils' self-reported classroom and/or learning support needs. Improved educational outcomes were also reported.

Findings contribute knowledge to the under-researched area of autistic pupils' lived experience. The apparent failure of current diagnostic criteria descriptors and definitions of autism to adequately reflect pupils' experiences led to the development of a new bio-psychosocial definition of autism. This has since been adopted by colleagues teaching students of autism (Beardon, 2017b) and by those engaged in independent autism research. If the demonstrated positive effect of FAMe™ System use, on teacher's autism-related practice and on pupil educational outcomes, is replicable in other schools, the impact of its continued implementation, for autistic individuals and wider society, could be significant.

Acknowledgements

I began this research project with a special interest in autism. I have finished it with an autism diagnosis of my own and a better understanding of what it is to be autistic, from the inside out as well as from the outside in. My thanks go to all the autistic pupils who engaged with me and shared their experiences (you taught me so much), and to the teachers who listened to and acted on their pupils' requests for change. Also, to Nick Williams of Sheffield City Council's IT department, for his time and advice during FAMe™ System development, and to Lucy Crawford from Capita SIMS, who responded so positively to the idea, and helped improve the system to optimise its ease of use. Without these people none of this would have been possible. Special thanks go to my supervisory team: Dr Luke Beardon, who has provided me with unwavering support from the beginning of my enrolment on the PGCert in Asperger Syndrome to the end of this PhD and, with genuine kindness and understanding of my autistic needs, never let me give up; and Dr Bronwen Maxwell, whose shared knowledge and critical advice has been an invaluable guide throughout this research process. I am also indebted to Dr Nicholas Chown, my colleague and mentor, who never lost faith in the value of what I was trying to achieve, and whose gentle words of wisdom and encouragement helped me to push through the hard times and get to the end. To my amazing children and husband who have shared every step of this journey with me and brought me a million cups of tea along the way, I am eternally grateful. Finally, to my wonderful friend Kate, and to my 'special' tribe, who celebrated the acceptance of my proposal and are still here with me to party at the finish line - you know who you are, and I love you all - thank you

xxx

Candidate's Statement

My objective when embarking on this research project was to continue to advance my understanding of autism, to make a contribution to knowledge in the field and, in doing so, to have a positive impact on the lives of the community of autistic pupils with whom I engaged and, with positive findings, potentially the wider autistic pupil community in the future.

I received FAMe™ System development support from Nick Williams (Information Systems Consultant, Management Information Systems (MIS) Team, Sheffield City Council). Nick enabled me to understand the schools' existing register software and worked with me to construct the best possible system within the technology currently available to schools.

All elements of this research, including the: design and development of original data collection material; field work; data analysis; and write up, are my own work.

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Glossary

Acronym/ Initialism	Full Name/Term
APPGA	**All Party Parliamentary Group on Autism** A cross-party group of MPs and Members of the House of Lords who work together to push autism up the agenda in Parliament.
AaA	**Ambitious about Autism** National UK charity for children and young people with autism. They provide services, raise awareness and understanding, and campaign for change.
APA	**American Psychiatric Association** Organisation of psychiatrists working together to 'ensure humane care and effective treatment for all persons with mental illness, including substance use disorders' (https://www.psychiatry.org/about-apa/vision-mission-values-goals)
AET	**Autism Education Trust** A partnership between Ambitious about Autism, the Autism Alliance and the National Autistic Society (NAS). It is funded and supported by the Department for Education (DfE) and hosted on behalf of the partnership by the NAS. Its purpose is to improve the education of children and young people with autism
ASPECT	**Autism Spectrum Australia** Australia's largest service provider for people on the autism spectrum. Their specialised, evidence informed schools program is the largest in the world. They share evidence-informed Aspect practice and applied research nationwide.

Acronym/ Initialism	Full Name/Term
BERA	**British Educational Research Association** BERA aims to inform the development of policy and practice by promoting the best quality evidence produced by educational research.
BYI-II	**Beck Youth Inventory- Second Edition** Battery of five self-report scales used to evaluate children's and adolescents' emotional and social well-being.
BYI-A	**Beck Youth Inventory - Anxiety Scale** One of the five BYI-II self-report scales, used to evaluate children's and adolescents' anxiety levels.
BYI-D	**Beck Youth Inventory- Depression Scale** One of the five BYI-II self-report scales, used to evaluate children's and adolescents' depression levels.
CC	**Central Coherence** The operation involved in processing information by extracting the overall meaning or gist. The theory of Weak Central Coherence is one of the three main cognitive theories which attempt to explain the underlying mechanisms behind the behavioural presentation of autism
CUP	**Community-University Partnership for the study of children, youth and families** A collaboration among the University of Alberta, community agencies, and organizations in and around Edmonton and across Alberta. CUP are committed to improving the development of children, youth, families and communities by creating or mobilising evidence-based knowledge that impacts programs and policies.

Acronym/ Initialism	Full Name/Term
DCSF	**Department for Children, Schools and Families** A department of the UK government, between 2007 and 2010, responsible for issues affecting people in England up to the age of 19, including child protection and education.
DfE	**Department for Education** A department of the UK government responsible for children's services and education, including higher and further education policy, apprenticeships and wider skills in England. They work to provide children's services and education that ensure opportunity is equal for all, no matter what their background or family circumstances. **Predecessor:** Department for Children, Schools and Families.
DoH	**Department of Health** A department of the UK government, responsible for government policy on health and adult social care matters in England.
DfES	**Department for Education and Skills** A department of the UK government, between 2001 and 2007, responsible for the education system as well as children's services in England.
DSM	**Diagnostic and Statistical Manual of Mental Disorders** An american volume that defines and classifies mental disorders in order to improve diagnoses, treatment, and research. Used by some UK diagnosticians to identify whether an individual is autistic. Contains the most recently updated medical definition of Autism.

Acronym/ Initialism	Full Name/Term
EADSEN	**European Agency for the Development of Special Needs Education** An independent organisation that acts as a platform for collaboration for the ministries of education in its member countries. Work focuses on improving all learners' achievement at all levels of inclusive lifelong learning. This enhances learners' life chances and opportunities for actively participating in society.
EF	**Executive Functioning** Executive functioning skills are abilities involved in preparing and engaging in complex organised behaviour. Executive (Dys)Functioning theory is one of the three main cognitive theories which attempt to explain the underlying mechanisms behind the behavioural presentation of autism.
EHCP	**Education, Health and Care Plan** A statutory document for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs. **Predecessor:** Statement of Special Educational Needs.
FAMe™	**Facts About Me** A newly developed computerised system designed to convey pupil-specific information to teachers through the lesson register.
GEO	**Government Equalities Office** Part of the Department for Education. The GEO has lead responsibility for gender equality within the UK government, together with a responsibility to provide advice on all other forms of equality (including age, race, sexual orientation and disability) to other UK government departments.

Acronym/ Initialism	Full Name/Term
HMT	**Her Majesty's Treasury** The UK government's economic and finance ministry, maintaining control over public spending, setting the direction of the UK's economic policy.
ICD	**International Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines** World Health Organisation produced. Provides clinical descriptions, diagnostic guidelines, and codes for all mental and behavioural disorders commonly encountered in clinical psychiatry. Used by some UK diagnosticians to identify whether an individual is autistic.
MALS	**Myself as A Learner Scale** A self-report scale focusing directly on school pupils' perceptions of their learning abilities. Suitable for use with children between the ages of 9-16 years.
NASEN	**National association for Special Educational Needs** A membership charity organisation supporting education professionals by providing resources and training to help meet and identify needs of individuals with special or additional learning needs.
NASUWT	**National Association of Schoolmasters and Union of Women Teachers** A trade union representing the interests of teachers, including headteachers, throughout the United Kingdom.
NAO	**National Audit Office** Scrutinises public spending for Parliament. It helps Parliament hold government to account and improve public services.

Acronym/ Initialism	Full Name/Term
NAP	**National Autism Project** A new initiative which aims to provide authoritative recommendations on autism research and practice which have demonstrable effectiveness in benefiting autistic people and their communities.
NAS	**National Autistic Society** A UK charity for autistic people and their families. The NAS provide information, support and services, and 'campaign for a world that works for autistic people'.
OfSTED	**Office for Standards in Education, Children's Services and Skills** Inspect and regulate services that care for children and young people, and services providing education and skills for learners of all ages.
POST	**Parliamentary Office of Science and Technology** The UK Parliament's in-house source of 'independent, balanced and accessible analysis' of public policy issues related to science and technology.
QoL	**Quality of Life** A term referring to the general well-being of individuals and societies. It includes physical and psycho-social health, family, education, employment, wealth, religious beliefs, finance and the environment.
SEN	**Special Educational Needs** (term used pre-2015) Learning problems or disabilities that make it harder for a child to learn than most children of the same age

Acronym/ Initialism	Full Name/Term
SEND	**Special Educational Needs and Disabilities** (term used post-2015) A significantly greater difficulty in learning than the majority of same-age children and/or a disability which prevents or hinders the use of educational facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions. **Predecessor** SEN
SENCO/SENDCO	**Special educational Needs Co-ordinator** (term used pre-2015)**/ Special educational Needs and Disabilities Co-ordinator** (term used post-2015) Responsible for the day-to-day operation of the school's SEND policy. All mainstream schools must appoint a teacher to be their SENDCO. The SENDCO will co-ordinate additional support for pupils with SEND and liaise with their parents, teachers and other professionals who are involved with them.
SENCOP/SENDCOP	**Special Educational Needs Code of Practice** (term used pre-2015)**/ Special Educational Needs and Disabilities Code of Practice** (term used post-2015) A statutory code which contains: Details of legal requirements that must be followed without exception Statutory guidance that must be followed by law unless there's a good reason not to. The SENDCOP explains the duties of local authorities, health bodies, schools and colleges to provide for those with special educational needs.
SIMS	**School Information Management System** A student information system, i.e. a school management information system, currently developed by Capita. It is the most widely used system of its kind in UK schools.

Acronym/ Initialism	Full Name/Term
TA	**Teaching Assistant** An individual who assists a teacher with instructional responsibilities and pupil support.
ToM	**Theory of Mind** Theory of mind refers to an individual's ability to attribute mental states to themselves and to others. Theory of Mind theory is one of the three main cognitive theories which attempt to explain the underlying mechanisms behind the behavioural presentation of autism
UN	**United Nations** A global organisation that brings together its member states to confront common challenges, manage shared responsibilities and exercise collective action in an enduring quest for a peaceful, inclusive and sustainably developing world, in conformity with the principles of justice and international law.
UNCRC	**United Nations Convention on the Rights of the Child** 54 articles that cover all aspects of a child's life and set out the civil, political, economic, social and cultural rights that all children everywhere are entitled to.
UNESCO	**United Nations Educational, Scientific and Cultural Organisation** Encourages international peace and universal respect for human rights by promoting collaboration among nations. Its mission is to contribute to the building of peace, the eradication of poverty, sustainable development and intercultural dialogue.
WHO	**World Health Organisation** A specialised agency of the United Nations that is concerned with international public health.

A Note about Terminology

Use of language is important because it represents underlying values (Shakespeare, 2014). Terminology use in the field of autism studies has been a contested area for decades (Brown, 2011a; 2011b; Kenny et al., 2016; Milton, 2012). As will be discussed in detail in the Literature Review Chapter of this thesis, negative and pejorative medical model language (Leatherland and Chown, 2015) still pervades autism criteria description and definitions (see for example, American Psychiatric Association (APA) 2013; World Health Organisation (WHO), 2011), whilst a move towards social model thinking and attitudes (Barnes, 2012; Oliver, 2004; Goodley 2014; Shakespeare, 2014) is reflected in some of the alternatives, e.g. the National Autistic Society (NAS) (2018). Changes to the diagnostic labelling system (DSM-5, 2013) have seen 'Autism Spectrum Disorder' (ASD) and 'autism' become the umbrella labels used to refer to all people considered to be on the autistic spectrum. As I do not conceptualise autistic persons as 'disordered' (Leatherland and Beardon, 2016; Leatherland and Chown, 2015), I use autistic/autism throughout this thesis to describe individuals identified as being on the autism spectrum, including the pupils who participated in this research, most of whom received a diagnosis of 'Asperger Syndrome' (DSM-4, 2000) prior to the revised edition of the criteria (DSM-5, 2013).

As with the diagnostic label itself, there is no single way of describing autism that is universally accepted. It is recognised that individual preferences vary widely, depending on a number of factors, including a person's relationship with/connection

to autism (Kenny et al., 2016), and the discipline/model of disability to which they subscribe (Leatherland and Chown, 2015; Leatherland and Beardon, 2016). An NAS survey (Kenny et al., 2016), explored the preferred terminology of 'individuals on the autism spectrum' when referring to themselves and/or being referred to. The majority endorsed the use of identity-first, rather than person-first, language, which is also my personal preference; i.e. if asked, I would refer to myself as an autistic individual, as I believe that autism is an essential part of who I am. I therefore use 'autistic' individual/pupil/population, throughout this thesis, rather than the person-first 'pupil with autism'. Pupils and their parents were made aware of my choice of terminology, and thus how they would be described, prior to consenting to participate, through the recruitment materials designed for the project. The non-autistic population is referred to as 'non-autistic' although I recognise that, outside of the autistic population, a wide range of neurodiversity also exists (Armstrong, 2010).

Chapter One: Introduction

This project is fundamentally concerned with attending to the experiences and perspectives of autistic pupils and responding to their individual and collective voice. Doing so is a matter of human dignity (Milton et al., 2014), and thus an essential requirement of researchers in the field of autism (Bolic-Baric et al., 2016; Milton, Mills and Pellicano, 2014; Parsons et al., 2009; 2014; Simpson et al., 2007), as well as being a condition of both national and international legislation and policy (e.g. Department for Education and Skills (DfES), 2002; 2004a; 2007; United Nations Educational Scientific and Cultural Organisation (UNESCO), 2006).

The FAMe™ Project investigations had two overarching goals: (1) to establish the applicability of current autism diagnostic criteria and descriptors, and mainstream cognitive autism theory, to autistic pupils' experiences of school and thus determine whether supplementary information might benefit practitioners working with and/or seeking a comprehensive understanding of this group of learners, and (2) through engagement with autistic pupils, to identify good autism-related teaching practice and autism friendly learning environments. Through the subsequent dissemination of this information to school staff, via a newly developed system, the overall ambition was to facilitate positive impact on the educational experiences and outcomes of autistic pupils.

Pupil and teacher information was provided, both pre- and post-system implementation, via: semi-structured interviews (pupils); self-report measures (pupils); and online surveys (teachers and Special Educational Needs and

Disabilities Coordinators (SENDCOs)). A combination of thematic coding and statistical analysis were used to generate qualitative and quantitative findings which were used to answer research questions relating to: the capacity of autism diagnostic criteria and theory to explain autism; autistic pupils' experiences of school and their ability to identify and articulate teaching practices and support strategies that would be of benefit to them in the classroom; teachers' understanding of, and confidence in their ability to meet, autistic pupils' individual support requirements; and the efficacy of the newly designed system to change teaching practice in-line with participating pupils' self-identified classroom/learning needs, and thus impact positively on autistic pupils' educational outcomes.

1. Background information - why this research?

Autistic pupils account for a quarter of all pupils with a statement of special educational need (SEN) or an Education, Health and Care Plan (EHCP) (Department for Education (DfE), 2015) in the United Kingdom (UK). They are considered to be more vulnerable than their non-autistic peers to a wide range of negative outcomes (Burgess and Gutstein, 2007; House of Commons Education and Skills Committee, 2006; Parliamentary Office of Science and Technology (Postnote), 2008) and their successful inclusion in mainstream education has been described as a unique challenge for teachers (Gibbons and Goins, 2008; Jones et al., 2008; Macbeath et al., 2006 et al., 2002; Robertson, Chamberlain and Kasari, 2003).

A range of factors are thought to contribute to the relatively high levels of poor psychological health outcomes and academic underachievement in the autistic pupil population (e.g. Ashburner et al., 2010; Barnes and Harrison, 2017; Bolic-Baric et al., 2016; Hebron and Humphrey, 2014; Keen et al., 2016; Parsons and Granlund, 2012; Ravet, 2011). These include a mismatch between the explicit features of autism, e.g. having: a different (from the non-autistic majority) social communication and interaction style (e.g. Knight et al., 2009; Osborne and Reed, 2011; Sprotson et al., 2017); a preference for sameness (e.g. Humphrey and Lewis, 2008; Myles and Simpson, 1998); difficulty switching attention (e.g. Gibbons and Goins, 2008); a tendency to perseverate (e.g. Jacobsen, 2005); and experiencing a hypo- or hyper-reactive response to sensory input (Ashburner et al., 2008; Bogdashina, 2016; Murray et al., 2005), and the typical physical and psychosocial environment of school, including the expectation to conform to a set of normative rules (Fleury et al., 2014; Mandy et al., 2016).

Compounding these issues is an insufficiency of autism-specific teacher training (Jones, 2006; NAS, 2016a; 2018a), and therefore in teacher knowledge, about how best to facilitate the successful inclusion of autistic pupils in mainstream classrooms (Emam and Farrell, 2009; Witmer and Ferreri, 2014; Sprotson et al., 2017), and a lack of teacher recognition and/or understanding of how autism impacts on the learning style and support needs of individual autistic pupils (Bevan-Brown, 2010; Charman et al., 2011; Falkmer, Parsons and Granlund, 2012; Hebron and Humphrey, 2014; Reed, Osborne and Waddington, 2012).

Non-autistic individuals, which will include the majority of teachers, who work with autistic populations, often rely on the application and/or interpretation of diagnostic descriptors (currently defined in psychiatric manuals) which form the basis of most online material relating to autism (Leatherland and Chown, 2015), and autism theories, which hypothesise the underlying mechanisms of autistic behaviours (Chown, 2017), to both make sense of the behavioural presentations they observe, and to design, select and implement particular 'autism' strategies/educational interventions (Jones, 2006; Sarrett, 2012). The accuracy of available autism descriptors and theories, and their capacity to facilitate understanding of autism and autistic experience, is therefore of paramount importance. However, their applicability to autistic school experiences remains ambiguous and contentious (Parsons et al., 2009). If autism descriptors and theory fail to adequately reflect and explain autistic experience, educational interventions and teaching practices constructed around them will inevitably fail to meet the spectrum of autistic pupils' school-related support needs.

To better understand the potential significance of this issue, the school experiences of a group of autistic pupils were explored. The aim was to ascertain the extent to which the autism diagnostic criteria definition and descriptors (American Psychiatric Association (APA), 2013; World Health Organisation (WHO), 2010), and 'mainstream' cognitive autism theories (Rajendran and Mitchell, 2007, p.247), can support non-autistic understanding of autism, sometimes described as the understanding of autism from the outside in (Williams, 1996). This aim is reflected in the first two research questions (see page 10).

Maintaining the focus on autistic pupils' school experiences, but with the aim of establishing whether it is possible to effect positive change on pupil outcomes through informing teachers of individual pupil's classroom support needs, a concurrent and related inquiry, originating from my personal experience, was also undertaken as part of this research project.

As the mother of five autistic children[1], I had witnessed many of the challenges involved in facilitating the successful educational inclusion of autistic pupils, and of the negative consequences, comprehensively documented throughout autism education research literature, that frequently result when this success is not achieved (e.g. Ashburner et al., 2008; 2010; Barnes and Harrison, 2017; Bolic-Baric et al., 2016; Fleury et al., 2014; Hebron and Humphrey, 2014; Keen et al., 2016; Mandy et al., 2016; Parsons and Granlund, 2012; Ravet, 2011). For example, teachers' misunderstanding of support needs and lack of autism knowledge (Bevan-Brown, 2010; Falkmer, Parsons and Granlund, 2012; Hebron and Humphrey, 2014; Reed, Osborne and Waddington, 2012); inappropriate sensory environments (Ashburner et al., 2008; Bogdashina, 2016; Murray, Lesser and Lawson, 2005); and scarce resources (Bolic-Baric et al., 2016; Iadarola et al., 2015), had all contributed negatively to my children's time at school and autism literature evidenced that their experiences were far from exceptional (Barnard et al., 2000; Charman et al., 2011).

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[1] All five of my children have received a clinical diagnosis of autism - identified as Asperger Syndrome as diagnosed prior to DSM-5 (2013).

Also documented in autism education literature is that teachers are not oblivious to the gaps in their autism-knowledge, nor of the negative impact this has, both on their own confidence and ability to teach autistic pupils, and on the pupils themselves (Ambitious about Autism (AaA), 2017; NAS, 2016a; National Association of Schoolmasters and Union of Women Teachers (NASUWT) 2013). Teachers have repeatedly requested more accurate information about the needs of their autistic learners (e.g. Miller, 2002; Wilkinson and Twist, 2010) and it has been recommended that future research focus on the development of methods to convey such information to them in a manner that is both accessible and useful (Cooper et al., 2015; Parsons et al., 2013; Weisz et al., 2005), in order that they can improve their evidence-based practice (Elsabbagh et al., 2014; Waltz, 2007).

I became aware of this specific issue during a conversation at parents' evening, in which a secondary school teacher apologised to my daughter for having criticised behaviours directly associated with her autistic learning and communication style. It was evident that, in her school, difficulties for teachers existed both in identifying which of their pupils were autistic (Frith, 2003; Myles and Simpson, 2002), and in retrieving and remembering pupil-specific information about each pupil's classroom and/or learning support needs (Sprotson et al., 2017; Wood and Gadow, 2010). A demonstration of the system in place to supposedly enable teachers to access my daughter's 'Pupil Passport'[2] (Morewood, 2014; National

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[2] A pupil passport is a short document detailing pupil-specific information. In the participating schools this document was also known as a 'Pupil Snapshot'

Association for Special Educational Needs (UK) (NASEN), 2014), demonstrated that it was both difficult and time-consuming to navigate.

Discussion of this issue, with colleagues, teacher friends, and my secondary-age autistic children, led me to conceive an easy-access notification system, designed to alert teachers to the presence of autistic pupils in their classrooms, with the facility to communicate to them, directly through the lesson register, concise information about the learning/classroom support needs of their individual autistic pupils. Collaboration with Sheffield City Council's IT department led to the development of 'Facts About Me' (FAMe™), from a concept into a new system ready to be introduced into local secondary schools.

Rather than relying on categorical descriptors of autism, and thus assuming the presence of a set of characteristics that may or may not be experienced as problematic by an individual pupil (Sarrett, 2012), the FAMe™ System was purposefully designed to reflect the heterogeneity of the autistic pupil population (Attwood, 2008; Beardon, 2012; Fleury et al., 2014; Rosqvist, 2012). It thus meets the researcher-recommended criteria for future investigation (Cooper et al., 2015; Parsons et al., 2013; Weisz et al., 2005), i.e. it is designed to provide a method to convey pupil-specific information to teachers in an accessible and useful manner.

Reflected in research questions three and four (see page 12) the second aim of this research project was to establish the FAMe™ System's potential, as a mechanism to effect pupil-recommended change in teachers' autism-related

practice, and to understand the impact of any such change on autistic pupils' school experiences and outcomes. It was therefore necessary to ascertain (1) whether by improving teachers' access to information, written by individual autistic pupils and outlining their unmet classroom support needs (termed 'FAMe™ Statements'), use of the FAMe™ System changed teachers' practice in line with the individual support requests of their autistic pupils, and (2) whether any such change in the classroom/learning support offered, had the expected positive impact on participating autistic pupils' psychological and academic outcomes.

2. Significance of the study

This research seeks to establish whether gaps exist, in the ability of current descriptors, definitions and/or theory to explain autism. The identification of explanatory deficiencies in these are likely to have implications for the quality of services provided by practitioners in education and elsewhere, who rely on autism descriptors and theories to conceptualise and understand the autistic individuals/populations they work with (Jones, 2006). This first element of this study has the potential to: determine what supplementary information, to that currently contained within the criteria descriptors, is required to fill existing gaps in the knowledge on which educational interventions are based (Charman et al., 2011; Parsons et al., 2009; Sarrett, 2012); identify which, if any, autism theories are best placed to explain autism and thus direct the focus of future autism theory promotion and development; and establish whether an alternative definition of autism, to those

based on diagnostic descriptors alone, would be beneficial to those seeking to understand autism.

Previous research focusing on the inclusion experiences of autistic pupils and the support they receive at school has predominantly involved survey studies of parents' perceptions of their children's education (Limbers, Heffer and Varni, 2009; NAS, 2010; Starr and Foy, 2012) which do not provide specific insight from the autistic individual's perspective (Milton, 2014; Milton, et al., 2014; Preece and Jordan, 2010). There exists only a limited body of qualitative research which specifically captures the views of autistic young people (Preece and Jordan, 2010; Bolte, 2014) and very little evidence is available about their educational experiences (Church et al., 2000), particularly in adolescence (Jang et al., 2014; Magiati et al., 2014). This study therefore has the potential to contribute new knowledge about how autistic pupils experience education in the current UK mainstream secondary system.

Despite increased efforts to improve teachers' autism knowledge and practice, and thus autistic pupils' inclusion experience (e.g. Autism Education Trust (AET), 2011; 2017; Department for Children, Schools and Families (DCSF), 2009), educational and psychosocial outcomes for this group of pupils are still generally reported to be poor (Autism Spectrum Australia (Aspect), 2012; Fleury et al., 2014; Howlin and Moss, 2012; Keen et al., 2016; Levy and Perry, 2011). The most recently released data relating to educational exclusion rates, reports that levels within the autistic population are more than twice the average for all pupils within state funded

schools in England (DfE, 2017), and that 60% of permanent exclusions involve secondary school pupils in the 12-14 years age group (DfE, 2015).

The ongoing cost of unsuccessful inclusion, to the autistic pupils (and thus, indirectly to their families, friends and carers), in terms of poor psychosocial health outcomes and diminished life/employment opportunities, and to wider society, in terms of lost potential and the increased need for financial support through the welfare system, is extensive (All Party Parliamentary Group on Autism (APPGA), 2015; National Autism Project (NAP), 2018). Any new system, such as FAMe™, that might improve the current situation, by facilitating the more successful educational inclusion of autistic pupils (Bolic-Baric et al., 2016; Emam and Farrell, 2009; Lindsay et al., 2013; Ravet, 2011; Reed et al., 2012), has the potential to achieve significant widespread positive impact, and is worthy of investigation.

3. Methodology and Methods

Situated within the pragmatist paradigm at the level of 'shared beliefs' (Denscombe, 2008, p.277; Morgan, 2007, p.74), where, with a focus on 'desired ends' (Johnson and Onwuegbuzie, 2004, p.16), methods are chosen in terms of their practical value for dealing with a specific research problem (Hall, 2013; Morgan, 2007), a mixed methods approach to data collection and analysis was employed throughout this research.

To investigate the capacity of the autism diagnostic criteria and cognitive autism theory, both individually and in synthesis, to explain/aid understanding of autistic school experiences, deductive thematic analysis (Boyatzis, 1998; Crabtree and Miller, 1999; Elo and Kyngas, 2008) of pupils' pre-FAMe™ interview transcripts was undertaken, using Nvivo11[3] software (qsrinternational, 2017) and following the rules outlined in a coding manual developed specifically for this project (Appendix 1). This investigation was designed to answer the following research questions:

1. *Are the explicit and implicit features of autism, specified in the diagnostic criteria of autism and autism literature, reflected in autistic pupils' descriptions of their lived experiences of school and, if so, to what extent?*

2. *To what extent can the school experiences of the autistic pupils participating in the FAMe™ Project be explained using cognitive autism theory?*

The percentage distribution of references to experiences of school which could be attributed to explicit and implicit features of autism (i.e. the pupils being autistic), or potentially explained by one or more of the cognitive autism theories selected, were calculated to establish the salience of these criteria/theory related factors to autistic school experiences. Pupils' school-related behaviours and/or experiences for which no explanation could be located, in either criteria or theory,

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[3] NVivo is designed to support qualitative and mixed-methods researchers to organise, analyse and find insights in unstructured, or qualitative data (qsrinternational, 2017).

were then inductively explored to highlight common themes and individual differences.

The extent of theory overlap, i.e. the ability of more than one autism theory to explain the same behaviour or experience, was also explored, and each theory was considered in relation to Rajendran and Mitchell's (2007) universality, uniqueness and specificity criteria (explained in detail in the Literature Review chapter), deemed necessary for good autism theory (ibid, p. 224). The aim of this inquiry was to understand which, if any, of the individual theories, chosen for investigation either because of their historical position as a 'mainstream' autism theory (ibid, p.247), or because of their more recent development and as yet unknown/under-researched status (Baron-Cohen, 2009; Murray et al., 2005), is best positioned to aid/supplement current understanding of autistic behaviour and/or lived school experience.

Understanding the potential value of the FAMe™ System as a mechanism of change, involved pre- and post-system engagement with the participating autistic pupils to explore and understand their: lived school-experiences; perceptions of desired (pre-FAMe™) and actual (post-FAMe™) teacher practice/behaviour change; and to evidence any change in their self-reported well-being and engagement with learning over the course of the project. In addition, teachers from the three participating schools took part in pre- and post-FAMe™ surveys, providing information about: their experiences of teaching autistic pupils; their level of autism-specific training and knowledge; their confidence in their ability to meet individual

pupils' needs; and the perceived (pre-FAMe™) and actual (post-FAMe™) benefits of using the FAMe™ System, including any changes to the support they offered pupils/their practice in relation to teaching autistic pupils following system implementation. This inquiry was designed to answer the following research questions:

3. *When engaging autistic pupils in research focusing on their experiences of school:*

   a) *What can be learned about autism/autistic pupils' school support needs from their descriptions of their school experiences?*

   b) *Are autistic pupils able to identify and communicate examples of positive and/or negative classroom experiences and, if so, how can these be used to inform teaching practice?*

4. *When information about individual autistic pupils is made easily accessible to their teachers:*

   a) *In what way does teacher behaviour/practice towards individual autistic pupils change?*

   b) *What impact is there on autistic pupils' educational experiences and quality of life related outcomes?*

4. Issues faced and limitations of this research

During the course of this project several problematic issues arose. Methodologically I began with a commitment to participatory inclusive research (Chown et al., 2017), understanding this to be an essential requirement if I were to make claims to 'ethical and epistemological integrity' (Milton, 2014, p.794; Milton et al., 2014). However, although the pupils involved were positioned as the true experts in their own experiences (Milton, 2014; Waltz, 2006), and their voices attended to during the project, there were a number of factors that precluded genuine participatory practice (Jivraj et al., 2014). These are discussed in detail in Chapter Three.

Disagreement between researchers about what constitutes an example of a criteria related behaviour or experience is possible because there are no behaviours that are exclusive to autistic individuals, i.e. no behaviour can be labelled 'autistic behaviour' (Beardon, 2012; 2017a), although there are those that are more often seen within the autistic population. Thus, what some researchers might consider evidence of an explicit feature of autism, others might believe to be a 'typical' behaviour/experience irrespective of an individual's neurology. In addition, explanations provided by autism theory are open to subjective interpretation. These issues were highlighted during the validation of coding process described in the Findings Chapter. In order to address this, and increase the reliability and future replication of findings, a manual containing strict criteria/rules to be applied throughout the coding process was developed (Appendix 1). This includes an

instruction to assume that *all* behaviours and/or experiences described by autistic pupils, that can *possibly* be associated with their being autistic, or has a potential explanation in one or more autism theory, be coded to the appropriate criteria and theory related node/s.

The generalisability of findings of any investigation involving autistic individuals is necessarily constrained by the heterogeneity of the sample population (e.g. Attwood, 2008; Beardon, 2012; Fleury et al., 2014; Rosqvist, 2012). In addition, it was accepted that the relatively small number of participants involved in this project would mean that the potential implications of any positive findings, at a group level, would be indicative but must not be over-stated. What would be possible to achieve however, was the identification of any positive impact on pupils at an individual level, which, if it existed, could potentially be replicated by introducing the FAMe™ System more widely thus benefitting other autistic individuals. In other words, the evaluative strand of this project was designed to establish an indication of the FAMe™ System's potential to effect positive change on autistic individuals' experiences of school and thus determine whether a larger-scale investigation/roll-out of the system is justified.

FAMe™ was designed specifically to address the needs of autistic pupils attending mainstream schools, who are understood to be a particularly vulnerable population (Charman et al., 2011; House of Commons Education and Skills Committee, 2006; Morewood, Humphrey and Symes, 2011), and with whom I feel a personal affiliation. I recognise that there are other autistic pupil populations who have been excluded from this thesis, and about whose needs I am not well educated.

In addition, the methods designed for this project do not provide for pupils who are unable or unwilling, for whatever reason, to identify and/or communicate their classroom support needs, and thus the utility of the FAMe™ System itself is limited in this respect. However, although some of the pupils I met could not continue to be involved in the research and/or had their data removed because it was not possible to establish their informed consent, *all* of those I engaged with *were* able to identify aspects of teachers' classroom behaviour that they found stressful and/or unhelpful and provide information about changes to teaching practice they felt would benefit them. Thus, *all* of the original 22 pupils generated information which was entered into the FAMe™ System and communicated to their teachers. Despite the heterogeneity of the autistic population, there is no reason to believe that this particular group of pupils differ from autistic pupils in other mainstream schools in relation to their ability to do this.

5. Thesis Overview

Throughout this thesis, two inter-related and concurrent investigations are documented. These explored (1) how well a group of autistic pupils' experiences of mainstream secondary school were reflected and or explained in autism diagnostic criteria descriptors and definitions, and by cognitive autism theory, and (2) the pupils' ability to identify and prioritise specific classroom difficulties and/or barriers to learning, and to advocate for the teacher practice change that they believed would benefit them. The impact of having this information communicated to their teachers was then investigated. The two concurrent investigations, which shared a qualitative

data source (i.e. pupils' pre-FAMe™ interview transcripts), are presented separately in each chapter for ease of reading.

The Literature Review Chapter provides a detailed overview of current understanding of the issues being investigated, and a rationale for the specific foci of each line of inquiry pursued in this project. It begins with a presentation of the current definitions of/criteria for diagnosing autism and a critical review of literature relating to cognitive autism theory. This is followed by a discussion of policy and practice pertaining to the current UK education system, and of research literature which documents the particular challenges faced by mainstreamed autistic pupils and their teachers. Limitations of existing research are highlighted and the potential of this study to contribute to the current research to practice gap (Charman et al., 2011; Kasari and Smith, 2013; Parsons et al., 2009; Sarrett, 2012), including the introduction of new methods to elicit and use autistic pupil voice to guide individualised teaching practice, are discussed.

In the Methodology, Methods and Ethics Chapter the different versions of the pragmatist paradigm are presented and an explanation for my situating this project at the level of 'shared beliefs' (Morgan, 2007, p.74) is provided. My research positionality and assumptions are outlined, and I provide justification for making use of the methods and method combinations that worked best in relation to the research goals (Goles and Hirschheim, 1999). Ethical considerations and the steps taken, to ensure that the methods used in this research were justifiable and sound (BERA, 2011) and that my responsibility as an autism researcher engaged in educational

research was prioritised (BERA, 2011; Hampton and Fletcher-Watson, 2016), are highlighted and addressed. The FAMe™ System concept, design and development are documented, and the methods used to recruit pupil and teacher participants detailed.

This section is followed by a description of the strategies and materials used to facilitate pupil and teacher participation and to accommodate pupils' preferred communication styles during interview. Information about the selection and administration of pupil self-report measures is provided. The chapter concludes with a description of the data analysis methods used to explore and understand the interview, self-report and survey material generated by pupils and teachers over the course of this project.

Due to the limited sample size, and qualitative nature of much of the data, the majority of the findings presented in the Findings Chapter are descriptive statistics/frequency figures. Findings are presented at an individual, between-group and whole sample level, in order to preserve the heterogeneity of the participant population data whilst ascertaining whether findings could be used to inform understanding of this pupil group as a whole. Whole pupil-group, pre- and post-FAMe™ System implementation quantitative self-report data was suitable for numerical analysis and are presented with reference to their statistical significance. Pupils' experiences of participating in the project were ascertained during the post-FAMe™ interviews and are also reported in this chapter. Teacher survey responses

are reported as frequency data with summaries of their written responses provided for context.

The Discussion chapter considers the findings of both inter-related investigations relating to the capacity of autism descriptors and theory to explain autism and the impact of FAMe™ System use on autistic pupils and their teachers. The potential benefits of continued FAMe™ System implementation to future autism policy and practice and the justification for continuing with further research in this area are also considered. Potential implications of both discrete and synthesised findings are discussed with specific reference to each of the four research questions. A new holistic definition of autism which, as a response to pupils' descriptions of their lived-experiences, moves away from medical model language and focus on deficit to include autistic strengths and skills, and to recognise the impact upon autistic individuals of their social and physical environment, is proposed. Feedback from pupils about the methodological process and my experience of this are considered, as are the limitations of this research and possible directions for future study.

This thesis concludes with a summary of the areas in which this research has made a contribution to knowledge in the field of autism and education studies. It is suggested that, as all of the participating pupils were able to identify, and articulate areas of unmet classroom support need and/or desired teacher change, in future autistic pupils should be encouraged and enabled to participate in evaluating their own educational environments. It is suggested that the methods and materials developed here could be used to facilitate this, and to engage with autistic pupils in

future education research. The project itself is considered in terms of its potential as an 'exemplar' of a research model (Morgan, 2007, p. 53) for future autism studies.

Chapter Summary

This chapter has provided the background to this research project and positioned the study in its context. It has acknowledged some of the main issues that arose and detailed how these were accepted and/or resolved. The next chapter outlines the autism diagnostic criteria and presents a critical synopsis of the cognitive autism theories selected for investigation. This is followed by a review of the literature relating to the educational inclusion of mainstreamed autistic pupils in the UK, including the difficulties faced, both by the pupils and by the teachers challenged to include them.

Chapter Two: Literature Review

1. Overview

This literature review is presented as a series of smaller reviews, or sections, examining literature pertaining to the four research questions. It begins with a discussion of the diagnostic criteria and existing clinical and non-clinical definitions of autism, through which autism is currently conceptualised and understood. This is followed by a review of the dominant cognitive autism theories, which hypothesise the underlying neurological mechanisms of autism in an attempt to explain its behavioural presentation. Other theories of autism, such as those hypothesising its genetic and biological determinants (Dawson, 2013; Newschaffer et al., 2007), are not included, as they do not contribute to the understanding of how it is to be autistic, or facilitate the development of strategies and/or interventions that have the potential to reduce barriers to success and/or enhance positive outcomes for autistic people (Chown, 2017; Milton and Bracher, 2013; Ne'eman, 2011; Pellicano et al., 2014), which is the focus of this thesis.

The purpose of the first section is to provide a rationale for the subsequent inquiry, in which the narrative accounts of autistic pupils describing their experiences of school were explored for evidence of the influence/impact of explicit and implicit features of autism (i.e. those specified in the diagnostic criteria and its exemplars), and in order to establish whether potential explanation for these experiences could be located in existing cognitive autism theory. This analysis is important because how autism is conceptualised and understood by practitioners, working with autistic individuals in any setting, has the potential to effect positive or negative impact on

the autistic individual and those who live with and/or support them (Brewin et al., 2008; Leatherland and Chown, 2015; Starr and Foy, 2012). Identification of gaps, in the capacity of the diagnostic criteria and/or existing cognitive theory, to enable understanding of autism and autistic need has implications for: future theory development; the provision of additional information to supplement that provided in the diagnostic manuals, on which many educational interventions are based (Sarrett, 2012); and the promotion of alternative definitions of autism.

This section is followed by a review of research literature concerned with the inclusion of autistic pupils in mainstream education settings and includes consideration of: the challenges faced by both the pupils and their teachers; limitations of existing research; and suggested future directions for methodologies and the development of interventions. This review informed the development of the FAMe™ System, the methods of data collection, and the decision to involve teachers in this project from the outset.

2. Defining Autism

Throughout this section the medical terms inherent in clinical/diagnostic definitions, which serve to perpetuate the notion that autism is necessarily a negative identity (Leatherland and Chown, 2015), are highlighted in the following way *'italics'*.

i. Diagnostic Criteria and Clinical Definitions of Autism

Autism Spectrum *'Disorder'* (ASD), is the diagnostic label, attached to a medical diagnosis, defined by criteria set out in the Diagnostic and Statistical Manual of *'Mental Disorders'* - Fifth edition (DSM-5, (APA), 2013), and the International Classifications of *'Mental and Behavioural Disorder'*: Clinical Descriptions and Diagnostic Guidelines - Tenth Revision (ICD-10, (WHO), 1994, last updated 2010).

In the revised DSM-5 (2013) criteria [4] the number of separate diagnostic labels in DSM-IV-TR (2000), i.e.: Autistic *'Disorder'* (Autism); Asperger's *'Disorder'* (AS); High Functioning Autism (HFA); and Pervasive Developmental *'Disorder'* Not Otherwise Specified (PDD-NOS), were reduced to one umbrella term, Autism Spectrum *'Disorder'*. In addition, diagnostic distinctions, in the form of severity levels (1, 2 or 3) have been created to reflect the amount of support an individual is deemed to need, as a result of their challenges with social communication, restricted interests and repetitive behaviours (APA, 2013; Reynolds and Kamphaus, 2013).

Based on the triad of behavioural *'impairments'* (Wing and Gould, 1979), the DSM-5 defines Autism Spectrum *Disorder* as: 'Persistent *'deficits'* in social communication and social interaction across multiple contexts', in addition to,

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[4] The DSM-5 (2013) and the ICD-10 (1994, last updated 2010) are both used by diagnosticians in the UK (NAS, 2017b). As the DSM-5 contains the most recently updated diagnostic criteria, which the ICD-10 is expected to adopt in its next revision in 2018 (NAS, 2017b, http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx), all references I make to diagnostic criteria are to the DSM-5 unless the ICD-10 is explicitly specified.

'restricted and repetitive patterns of behaviours, activities or interests', present since early childhood, to the extent that they currently 'limit and *'impair'* everyday functioning'. These *'disturbances'* are not better explained by intellectual disability or global developmental delay (APA, 2013). The ICD-10 also defines autism according to Wing and Gould's triad of *'impairments'* (1979), and describes it as: '*'Abnormal* or *impaired'* development*'* which is evident before the age of 3 years in at least one of the following areas: receptive or expressive language as used in social communication; the development of selective social attachments or of reciprocal social interaction; and functional or symbolic play (WHO, 2010).

Diagnosticians must identify evidence of *'symptoms'* of *'qualitative abnormalities/ deficits'*, in the following areas:

- social-emotional reciprocity
- nonverbal communicative behaviours used for social interaction
- developing, maintaining, and understanding relationships
- stereotyped or repetitive motor movements, use of objects, or speech
- insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour
- highly restricted, fixated interests that are abnormal in intensity or focus
- hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment

(DSM-5, 2013)

Various groupings of these *'symptoms'* must be present in specified minimum numbers for a definitive diagnosis of autism to be given.

The re-inclusion of sensory perceptual and/or processing differences within the updated DSM-5 criteria, following their omission from the DSM-IV-TR (2000), has been welcomed (Chown, 2017; Mandy et al., 2016; NAS, 2017b), as these are widely understood to be salient features of the autistic experience (Ashburner et al., 2013; Bogdashina, 2016; NAS, 2017b; Ozsivadjian et al., 2012).

In addition to the explicit criteria, the diagnostic manuals list some implicit features of autism which are referred to as, 'a range of other nonspecific problems'. These include: fears and phobias; sleeping and eating disturbances; temper tantrums; and aggression and self-injury (APA, 2013; WHO, 2010). Unlike the explicit features of autism, these problems [sic] do not have to be present for an autism diagnosis to be made.

According to the DSM-5, an individual must 'currently' be significantly limited and *'impaired'*, in order to be identified as autistic, whilst the level of support deemed necessary, to manage their autistic 'challenges', will determine their autism severity label (Happé, 2011; Mehling and Tassé, 2016).

Criteria Concerns

There is a lack of acknowledgment within the DSM-5 criteria of several implicit features of autism understood to have a profound negative impact on the lives of autistic individuals (Ashburner et al., 2010; Gibson and Kendall, 2010; Humphrey

and Lewis, 2008; Osborne and Reed, 2011). For example, masking behaviours (Beardon, 2014; 2017a), also referred to as camouflaging (Attwood, 2008; Gould and Ashton-Smith, 2011), are frequently associated with autism (Hull et al., 2017).

Masking has been described as effortful, and can create high levels of stress, anxiety and exhaustion (Gould and Ashton-Smith, 2011; Lai et al., 2015; Robinson et al., 2013) which contribute to negative well-being amongst autistic individuals (Holliday-Willey 2014; Hull et al., 2017). It is also suggested that engaging in masking behaviours is challenging to an autistic individual's identity (Bargiela et al., 2016) and sense of self (Beardon, 2017a; Hull et al., 2017). However, although the phenomenon of masking is acknowledged in the DSM-5, this is only in relation to the difficulties it can create for clinicians during the diagnostic process. It is not specified as an implicit feature of autism, and its potential impact on autistic individuals is not referred to. Other implicit features of autism frequently reported in autism literature, such as social anxiety (Carpenter, 2013; Freeth et al., 2013; Gadow et al, 2005; Preece, 2002) and general anxiety (Magiati et al., 2016; Wood and Gadow, 2010; Gibbons and Goins, 2008) are also absent from the diagnostic manuals.

My position is that the emphasis in the DSM-5 on the need for 'current' evidence of *'impairment'* to be identified at the point of diagnosis, can serve to limit the efficacy of the diagnostic process and has the potential to result in autistic individuals being refused appropriate identification. Such experiences are frequently described in autism literature, with reports of autistic individuals receiving relatively late diagnoses (i.e. after early childhood) at times of significant life-transition

(Beardon, 2017a; Wylie, 2014), when their self-developed coping strategies are no longer sufficient to mask their underlying autistic neurology (Attwood, 2008; Hull et al., 2017). As autism is a life-long developmental disability (NAS, 2017a), these individuals will have always been autistic and they and their families might have benefitted from earlier identification, through potential access to appropriate support services and information, had the criteria not stipulated the requirement for evidence of current *'impairment'*.

I have experienced this issue when providing support to an autistic individual going through the diagnostic process. In this case the environment and support in the months leading up to assessment had been such that the individual's 'current' level of *'impairment'* (i.e. the behavioural presentation of their autistic neurology) was not considered sufficiently significant to warrant a diagnosis. Although it was accepted that he had many 'autistic traits', he appeared to be managing his difficulties successfully at the time of the assessment and was therefore deemed not to be autistic. Within six months, following transition from junior to secondary school, this individual's autistic presentation was so altered that the same clinician agreed a diagnosis of autism was in fact appropriate. As autism is known to be present from birth (Baron-Cohen, 2008; Happé and Frith, 1996; NAS, 2017a), this individual could not have become autistic between assessments. However, at the time of the first assessment he was refused diagnosis because he did not present as 'currently' significantly *'impaired'*.

Concerns have also been raised regarding the addition of utilising autism severity levels to create diagnostic distinctions between individuals (e.g. Wietlauf et al., 2014). These were developed in order to, 'better capture the spectrum nature of the *'disorder'* and the inter-individual variations that differ less in quality than in quantity' (Ozonoff, 2012, p.1093). It is suggested that focusing on the support required emphasises a 'disability in context' (social) rather than the 'disability in person' (medical) model (Mehling and Tassé, 2016, p.2001), and provides more practical information for service providers regarding improving adaptive functioning and overall quality of life.

Whilst I do not contest that this shift in focus from medical to social model thinking is a positive move, unless the notion of autism severity level is well understood and articulated, this new way of classifying autism risks support-professionals, family members and autistic individuals themselves making assumptions about the likely level of functioning or disability they will experience across situations and the life-span. For example, giving an individual a label of 'Severity Level 1' at the point of diagnosis, does not take into account the often profound impact a change in environment can have on autistic experience (Beardon, 2017a), and/or the ability of an autistic individual to manage independently or to require support, at different times of their life, or even on the same day, depending on their circumstances (Attwood, 2008; NAS, 2017b). This is referred to in what Beardon describes as the 'Golden Equation', which states that 'Autism + Environment = Outcome' (Beardon, 2017a, p.11). This concept is illustrated perfectly in this text message, recently received from my fifteen-year-old autistic daughter:

Sometimes I feel I am so well looked after in terms of my needs that I only remember that I am autistic when I am in a difficult situation…if I go into town I am so anxious about things and incapable of knowing what is expected…that's when I remember. I shine out as autistic then. I don't know what to do and I freeze with anxiety. It's like I lose the ability to speak…

An individual's access to support services therefore needs to remain sufficiently flexible to accommodate such changing levels of need and should not be determined, as it potentially will be, by the severity label given at the point of diagnosis.

That the criteria for identifying autism is included in manuals of *'psychiatric disorders'* at all is a point of contention, as autism is not a mental ill-health condition (Chown, 2017; Chown and Leatherland, 2018). Whilst intellectual disabilities and mental health difficulties are frequently diagnosed in autistic individuals (NAS, 2017b) these occur concurrently, and autism in itself is neither.

The psychiatric manual definitions, presented as deficit-focused check lists of *'impairments'*, serve to perpetuate the 'myth' that autism is a singularly negative entity (Beardon, 2012) and risk denying those so diagnosed the benefit of a positive self-identity (Chown and Leatherland, 2018). In addition, the diagnostic criteria make no reference to how social and physical environments impact on the degree of disablement experienced by autistic individuals, or their capacity to flourish, which maintains the 'individual as problem' thinking so many in the neurodiversity movement are trying to shift (e.g. Beardon, 2017a; 2008a; 2007; Chown, 2017; Milton, 2014; O'Dell et al., 2015).

Regardless of the potential short-comings in the way the diagnostic criteria for autism are used in identification and classification, it remains the case that it is with reference to these prescribed definitions, and the explicit criteria set out in the DSM-5 and ICD-10, that a diagnosis of autism is currently made in the UK (referred to therein as Autism Spectrum *'Disorder'* or ASD). All the pupils participating in the FAMe™ Project had received this clinical diagnosis.

ii.   Non-Clinical Definitions of Autism

As autism is currently a medical diagnosis, all definitions of autism are necessarily based on its diagnostic criteria (DSM-5 and ICD-10) and refer to qualitative differences in particular areas of functioning relating to social communication and repetitive or ritualised behaviours (Wing and Gould, 1979). Variation exists however in the terminology adopted by the authors of non-clinical definitions of autism, which reflect distinct models of disability (Barnes, 2012; Mertens, 2010; Oliver, 1996) and typically denote the ontological position of the presenting author/s or organisation (Leatherland and Chown, 2015), which, in the case of the medical and social models, represent mutually exclusive dichotomies of attitude and thought (Goodley, 2014; Grue, 2009).

For example, the medical model terminology used by some researchers (e.g. Falkmer et al., 2012; Singh and Elsabbagh, 2014; Troyb et al., 2014), who refer to autistic *'symptoms'*, places emphasis on internal factors (*'impairments'*), and locates them as the cause of any difficulties encountered (Goodley, 1998; Samaha, 2007;

Snyder and Mitchell, 2006). Such language is rejected, in favour of 'autistic difference', in definitions provided by those who do not subscribe to the pathologising of autism (O'Dell et al., 2015), and who instead emphasise the external (social) factors which act to disable individuals. This distinction between *'impairment'* (i.e. individual) and disability (i.e. socially created difficulties imposed upon the individual) lies at the heart of the social model of disability (Barnes, 2012; Shakespeare, 2014; Solomon, 2014).

A third model, the bio-psychosocial model (Bickenbach, 2011), provides an alternative for people, such as myself, for whom the social model denial of *'impairment'* (Oliver, 2004) renders it too exclusive but who still choose to reject the medical model representation of autism as an individual defect (Mertens, 2010). This is not to say that I condone the use of the term *'impairment',* but rather I consider it possible for some degree of disablement to exist, as a result of an autistic individual's neurological functioning, regardless of any environmental adaptations made to reduce negative effects. The bio-psychosocial model employs an interactionist view of disability (Goodley, 2011; Bickenbach, 2011) to approach it holistically (Shakespeare, 2014), acknowledging biological, psychological, *and* social disabling/disadvantaging effects (Chown and Beardon, 2017). Through this model it is possible to recognise that autistic individuals sometimes continue to be disabled despite the provision of enabling environments (Leatherland and Chown, 2015). This position is incompatible with strict social model thinking (Oliver, 2004).

Non-clinical definitions of autism which reflect social or bio-psychosocial model affiliation and thinking (e.g. Beardon, 2017a; Chown, 2017; NAS, 2017b) typically acknowledge the preference of many autistic individuals to be referred to using identity-first language (Kenny et al., 2016). For example, the leading UK autism charity, whose website is the only one of the eight most commonly identified in an online search for 'What is autism?', that does not use medical model terminology (Leatherland and Chown, 2015) define autism thus:

> *Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them…Autistic people see, hear, and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity…Autism is a spectrum condition. All autistic people share certain difficulties but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support*
>
> (NAS, 2017b).

This definition avoids the intrinsically negative, pejorative language, inherent in the medical definitions of autism (Leatherland and Chown, 2015). However, this, like the clinical definitions on which it is based, still makes no reference to the potential impact of environmental factors, and the significance these can have on the disablement of autistic individuals (Beardon, 2017a). It is my belief that this absence of recognition of the potential for different physical and social environments, to cause, increase, or lessen the difficulties experienced by autistic individuals and therefore

to impact on the behavioural presentation of their autistic neurology, can serve to disable non-autistic individuals' ability to understand, and thus successfully support (if that is their role) members of the autistic population.

Also missing from the NAS (2017b) description of autism is any reference to the existence of positive attributes and skills in autism, echoing the *'deficit'*-based nature of its medical definition.

With this in mind, the first research question:

Are the explicit and implicit features of autism, specified in the diagnostic criteria of autism and autism literature, reflected in autistic pupils' descriptions of their lived experiences of school and, if so, to what extent?

was proposed, in order to identify the extent to which understanding autism, through its diagnostic definition and clinical descriptors, might enable (or not) members of the non-autistic population to make sense of the behaviours and experiences of autistic individuals - in this case secondary school pupils taught in mainstream settings. I determined to explore how well knowledge of the criteria, by which pupils have been diagnosed, might inform understanding of their lived experiences of school and the support they feel they require to enable them to be happy and/or successful in the classroom. Conversely, I was interested to establish whether any salient school experiences were left unexplained as this would evidence the potential

benefit that an alternative definition, which purports to capture a wider spectrum of autistic experience, might offer those seeking to understand autism.

3. Autism Theory

The following section provides a brief overview of cognitive autism theories and the rationale for my exploring their explanatory potential in relation to autistic pupils' experiences of school. Cognitive autism theory, or the 'psychology of autism' (Baron-Cohen, 2008, p.51), attempts to reduce the diverse presentation of autism down to one or two underlying mental processes in order to mediate between the neurobiological and behavioural levels of description (Baron-Cohen, 2009a) and enable the development of interventions designed to overcome the areas of supposed *'deficit'* (Rajendran and Mitchell, 2007).

Autism has been described variously by theorists as a condition associated with: a heterogeneity of possible 'neurological *abnormality*' (Bishop, 1993, p.279); a complex collection of 'cognitive *deficits*' (Baron-Cohen and Swettenham, 1997, p.20); a '*disorder* with no clear boundaries' (Green et al., 2002, p.666); and 'a collection of *symptoms*…leading to the same basic characteristics' (Rajendran and Mitchell, 2007, p.245). Whilst I oppose the use of such medical terminology in relation to autism and favour the non-pejorative 'autism spectrum' to describe the diversity of the autistic presentation, these descriptions serve to highlight the difficulty researchers face when attempting to evidence hypotheses about which

mental processes (Baron-Cohen, 2009a) underlie the heterogeneous entity that is autism (Rajendran and Mitchell, 2007).

Autism theory is important because of its potential capacity to contribute to a better understanding of the ways in which autistic individuals, 'process information and understand the world around them…and why certain behaviours are more evident in autism than in the non-autistic population' (Beardon, 2015, cited in Chown, 2017, p.8). Improved understanding of these areas should facilitate the development of more effective interventions and/or better-quality support for autistic individuals (Chown, 2017) which has the potential to enhance their 'life chances' (Pellicano et al., 2014, p.766). This has been highlighted as a research priority by the autistic population (ibid).

In order for any theory to be considered an 'autism theory' it must be universally applicable to the entire autistic population (Baron-Cohen, 2008; Chown, 2017; Rajendran and Mitchell, 2007), i.e. it should explain features common to 'all individuals on the spectrum, not just some of them' (Baron-Cohen, 2008, p.51). In addition, it is suggested that 'good' autism theory (Chown, 2017, p.16) should also be: 'unique' to autism (Rajendran and Mitchell, 2007, p.224), i.e. provide explanation for features that are only seen within the autistic population; and 'domain-specific' (ibid, p.224), i.e. provide explanation for the features of autism which implicates one particular underlying factor, rather than a combination of different factors. Baron-Cohen (2007) also states that an autism theory must explain 'all autistic traits' (p.51),

i.e. meet the specificity criteria, Rajendran and Mitchell, (2007), although his own influential theories do not do so (Baron-Cohen, 2008).

Unlike Rajendran and Mitchell, Chown (2017) considers that an accurate description of, 'some aspect or aspects of autism' (p.19) is sufficient, but suggests that, in order to be considered 'good' or 'useful', autism theory must reflect the 'uniqueness' of the autistic individual (p.19), i.e. it must be able to account for the difference in the presentation and experience of autism between individuals affected by the same factors. This concept of uniqueness 'within-autism' differs from the uniqueness 'to autism' criteria for 'good' autism theory defined by Rajendran and Mitchell (2007, p.224).

However, none of the current cognitive autism theories, with the possible exception of Monotropism (see p.52), offer explanation for the heterogeneity observed in the autistic population (Attwood, 2008; Beardon, 2012), or the potential cognitive and environmental mechanisms that might serve to protect some autistic individuals whilst others are significantly affected. Neither do they explain how the same individual's autistic presentation can be altered at different life stages and in different situations (Beardon, 2017a). In this respect it is possible that no current theory will meet Chown's (2017) uniqueness within-autism criteria for good autism theory and that a synthesis of theory might be needed (Chown, 2017), as proposed by Pellicano (2010a), who suggests that the adoption of a multiple-deficits model, in which it is accepted that there exist several core underlying atypicalities which

together cause autism, would provide a more realistic position and an explanation for the heterogeneity of the autistic population.

My own criteria for judging the usefulness of existing autism theory is concerned with its capacity to enable non-autistic individuals to develop a better understanding of autism, and/or enable autistic individuals to better understand themselves (e.g. Chown and Beardon, 2017; Chown, 2017), through the identification of, and explanation of how, the cognitive mechanisms which underlie presenting behaviours impact the way the world is experienced and interpreted by autistic people, both individually and as a population. Whether any of the current 'mainstream' autism theories (Rajendran and Mitchell, 2007, p.247) achieve this, in relation to this research project, is the subject of the second research question:

To what extent can the school experiences of the autistic pupils participating in the FAMe™ Project be explained by existing cognitive autism theory?

i.   The three main cognitive autism theories

Three cognitive theories have dominated psychological research into autism since the 1980s (Chown and Beardon, 2017; Chown, 2017; Milton, 2014; Rajendran and Mitchell, 2007). These are: Theory of Mind (ToM) theory (Baron-Cohen, Leslie and Frith, 1985); Executive (Dys)Functioning (EF) theory (Ozonoff, Pennington and Rogers, 1991); and (weak) Central Coherence (CC) theory (Frith, 1989, 2003; Frith and Happé, 1994; Happé, 1999). Each of these theories reflects an attempt to

explain autism through the identification of specific *'deficits'* in the cognitive mechanisms thought to be responsible for social interaction, communication and behaviour in typically developing [sic] (Rajendran and Mitchell, 2007) individuals.

Evidence of the explanatory power of these theories has been sought through an array of experimental research spanning three decades (e.g. Apperly, Samson, and Humphreys, 2005; Baron-Cohen 1989;1995; Booth et al., 2003; Charman and Swettenham, 2001; Frith, Happé and Siddons, 1994; Happé and Frith, 2006; Ozonoff and McEvoy, 1994; Pellicano et al., 2006), with mixed and often conflicting findings (Rajendran and Mitchell, 2007), which have resulted in all three theories being changed and/or more clearly specified, by its original authors (Chown, 2017; Rajendran and Mitchell, 2007) and to new theories being proposed to extend and/or subsume them (e.g. Baron-Cohen, 2002; 2007; Murray et al., 2005).

Whilst it is generally accepted that the cognitive functions involved in theory of mind, executive functioning, and central coherence play a major role in autism (Attwood, 1998; Baron-Cohen, 2008; Chown, 2017; Milton, 2012), it is no longer proposed that *'impairment'* in any one of these areas of functioning can explain autism in its entirety (Chown and Beardon, 2017; Chown, 2017; Pellicano, 2010a; 2010b; Rajendran and Mitchell, 2007). In combination, however, the explanatory power of these three 'mainstream' theories appears to increase (Rajendran and Mitchell, 2007, p.247) and they remain the framework(s) of choice for many researchers and clinicians (ibid). The following is a brief introduction to, and critique of the evidence base for Theory of Mind, Executive Functioning and Central

Coherence theory, for which evidence of their potential explanatory value was sought during the data analysis stage of this project.

a. *Theory of Mind theory*

Theory of mind, also known as the 'cognitive component of empathy' (Baron-Cohen, 2009, p.71), refers to an individual's ability to attribute mental states to themselves and to others (Frith and Happé, 1999). Much methodologically robust research has been conducted (Baron-Cohen, 1989; 1995; Happé, 1994; Luckett et al., 2002; Colle, Baron-Cohen and Hill, 2007), albeit with relatively small sample groups (n=16-34), which claims to support the idea of a connection between difficulties with theory of mind, more recently termed 'mind-reading' and/or 'mentalising' (Baron-Cohen, 2002; 2009), and the explicit features of autism which involve social interaction, communication and imagination (DSM-5, 2013). It is suggested that autistic 'mindblindness' (Baron-Cohen, 2009a) has been evidenced through a series of experimental techniques purporting to show that autistic individuals are less able, than non-autistics, to pass first and second order tests of 'mind-reading' and of its developmental precursors, e.g. tests of: joint attention (Swettenham et al., 1998); pretend play (Leslie, 1987); deception (Baron-Cohen, 1992; 2007); and reading the mind in the eyes (Baron-Cohen, Wheelwright, Hill, et al., 2001), at each point in the typical [sic] developmental trajectory (Baron-Cohen, 2009a).

It was originally hypothesised that theory of mind was absent in autism (Baron-Cohen, Leslie and Frith, 1985), however this position was modified following

criticism that, as some (intellectually-able) autistic individuals are able to succeed in theory of mind tasks, the theory could not claim universality (Happé, 1994), and therefore did not explain autism (Rajendran and Mitchell, 2007).

The revised ToM theory (Baron-Cohen, 1995), proposed that autistic children are 'delayed' in developing a theory of mind (rather than devoid of one) and that it is this delay, which in many cases is never fully resolved (Baron-Cohen, 2009a; Rajendran and Mitchell, 2007), that is the cause of autistic individuals being less able, than non-autistics, to understand the beliefs, desires and feelings that motivate the actions of others (Baron-Cohen, 2009a; Happé, 1995). It is suggested that one consequence of having difficulties in being able to predict other people's current and future behaviour, i.e. poor ToM (Baron-Cohen, 1995; Milton, 2012), is that social situations are experienced as confusing and even frightening (Baron-Cohen, 2009a). Such experiences are frequently reported by autistic individuals (NAS, 2017a).

The original ToM study has been replicated many times by many research teams (Tager-Flusberg, 2007), utilising variations of the false-belief task (Frith, 1989) and providing robust empirical evidence that the majority of autistic children do have difficulties passing these tasks (Tager-Flusberg, 2007). However, whether false-belief task-performance relates to ToM, as claimed by Baron-Cohen (1995), or instead reflects a lack of social insight, poor executive functioning skills, or linguistic ability, has been a contentious issue (Astington and Baird, 2005; Happé, 1995; Joseph and Tager-Flusberg, 2004; Tager-Flusberg and Joseph, 2005).

The revised theory's strengths, it is claimed (Baron-Cohen, 2009a), lie in its ability to explain the social and communication difficulties inherent to autism, and its universality across the autistic population (Baron-Cohen, 2009a; Chown, 2017; Rajendran and Mitchell, 2007) and across the life span (Baron-Cohen, 2009a). Identified limitations include its inability to provide explanation for the other domain specified in the diagnostic criteria as explicit to autism, i.e. restricted interests and repetitive behaviours (DSM-5, Category B, 2013) (Rajendran and Mitchell, 2007) and, therefore, to meet Baron-Cohen's own criteria, i.e. that cognitive theory should 'explain all autistic traits' (2008, p.51), which is reflected in Rajendran and Mitchell's criteria of specificity (2007, p.224).

Researchers from outside the field of autism have reported that populations with other disabilities, such as non-signing deaf children, also fail to pass ToM tasks (e.g. Peterson, Wellman and Liu, 2005), as do individuals diagnosed with schizophrenia and those with traumatic brain injury (Baron-Cohen, 2009b; Byom and Mutlu, 2013). This suggests theory of mind difficulties are not unique to autism (Rajendran and Mitchell, 2007). Other challenges to the notion that Theory of Mind theory explains a phenomenon unique to autism come from the Cross-Neurological ToM theory (Beardon, 2007; 2008a) and Milton's Double-Empathy Problem (2012). Both of these suggest that, contrary to being an autism specific *'deficit'* (Baron-Cohen, 2009a), members of the autistic and non-autistic populations each lack a well-developed theory of the other's minds. In other words, whilst 'it is true that autistic people often lack insight about [non-autistic] perceptions and culture…it is equally the case that [non-autistic] people lack insight into the minds and culture of

autistic people' (Milton, 2012, p.886). These models re-frame theory of mind as a question of reciprocity and mutuality across two qualitatively distinct neurological types (Beardon, 2008b; Milton, 2012). Since, as these authors suggest and Baron-Cohen himself accepts (2009b), ToM theory does not explain an autism-specific phenomenon, it cannot meet Rajendran and Mitchell's third autism theory criteria of 'uniqueness' (2007, p.224; Chown, 2017).

Baron-Cohen (2009) attempted to strengthen his theory with claims that functional neuroimaging studies provide biological confirmation of the psychological differences between the autistic and non-autistic populations that are addressed by ToM theory, as they have identified key areas of the 'social brain', specifically activated during mind-reading tasks in the typical [sic] brain (Baron-Cohen, 2009a, p.70), which are underactive in the autistic brain (Baron-Cohen et al., 1999; Castelli, Frith, Happé, et al. 2002; Frith and Frith, 2003). Other researchers have argued against these assertions and questioned both the ability of the various ToM and mindblindness tasks to actually measure what they purport to show (Bloom and German, 2000; Frith, Happé and Siddons, 1994; Wellman, Cross and Watson, 2001), and the reliability of the conclusions drawn from functional neuroimaging studies (Markram and Markram, 2010), disputing the role of the underlying neurobiological mechanisms at work (ibid).

Despite the criticisms of ToM theory, and the difficulties researchers have agreeing on its definition and theoretical underpinnings (Rajendran and Mitchell, 2007), the revised version of ToM theory is still the most enduring and influential

theory seeking to explain autism (Chown, 2017; Milton, 2012), with a legacy that has been described as 'both undeniable and irrepressible' (Rajendran and Mitchell, 2007, p.231). For the purposes of this research project it is of interest, therefore, to establish whether, and to what extent, ToM theory can offer explanation for the school experiences of autistic pupils.

b.   Executive (Dys)Functioning theory

There is no precise definition of executive functioning (Goldstein et al., 2014), but rather it is assumed to involve 'several abilities for preparing and engaging in complex organised behaviour' (Macintosh and Dissanayake, 2004, p.426), which enable an individual to adapt and thrive in complex psychosocial environments (Delis, 2012). These higher-level (executive) abilities are considered to include the formation of: abstract concepts; planning, focusing and/or shifting focus and sustaining attention; impulse control and inhibition of irrelevant responses; flexibility of thought and action; and working memory (Attwood, 1998; Macintosh and Dissanayake, 2004; Ozonoff et al., 1991), all of which are skills that require the individual to disengage from what they are doing in order to guide their actions (Chown, 2017), and are needed to work, in a motivated fashion, towards a future goal (Gillberg and Coleman, 2000; Milton, 2012). Collectively termed 'mental control processes' by Corbett et al. (2009, p.1), it is suggested that these executive functioning skills enable individuals to retain control over their physical, cognitive and emotional behaviour (Chown, 2017; Rajendran and Mitchell, 2007).

The theory of Executive (*Dys*)Function (EF) in autism began when researchers noted that some *symptoms* of autism were similar to those associated with specific brain injury (Rajendran and Mitchell, 2007). For example: the need for sameness; difficulty switching attention; tendency to perseverate; and lack of impulse control, all of which are included in the diagnostic criteria description of autism (DSM-5, 2013), are also displayed by individuals who have problems with executive functioning, usually, but not exclusively, due to frontal lobe damage (Hill, 2004). This observation led some researchers (e.g. Ozonoff et al., 1991) to suggest that autism could be explained as a *'deficit'* in executive functioning.

As with investigation of the ToM hypothesis, much research has been carried out to establish the credibility of EF theory as an explanation of autism (Rajendran and Mitchell, 2007). Whilst research exists to endorse the hypothesis (e.g. Fisher and Happé, 2005; Ozonoff and Jensen, 1999), there remain a number of criticisms, both of the theory and of the studies which support it (Chown, 2017). The lack of uniqueness to autism, i.e. other neuro-developmental *'disorders'* also involve executive functioning *'deficits'* (Rajendran and Mitchell, 2007), and the inability of researchers to evidence that there exists an autism explicit *'deficit'* in one executive function, or a distinct autism executive functioning profile (Hill, 2004), are cited as limitations of EF theory (Rajendran and Mitchell, 2007). In addition, there are researchers who propose a relationship between executive functioning and theory of mind (e.g. Zelazo et al., 2002; Zelazo, and Frye, 1997), with some suggesting that theory of mind is required for executive control (Perner, Lang, and Kloo, 2002; Pellicano et al., 2006), therefore making EF theory redundant, and others suggesting

the opposite, i.e. that the strength of early EF skills determine the developmental trajectory of ToM (Pellicano, 2010b). What is not in dispute amongst researchers however, is that autistic individuals do report/have difficulties in areas that require the use of executive functioning strategies and skills (Attwood, 1998; Chown, 2017; Milton, 2012), which contribute to their atypical [sic] cognitive profile (Rajendran and Mitchell, 2007).

As Executive (Dys) Functioning theory remains one of the three 'main' cognitive theories used to explain autism (Attwood, 1998; Chown, 2017; Rajendran and Mitchell, 2007), evidence of its explanatory potential was sought, in this study, through the analysis of autistic pupils' descriptions of their experiences of school.

c) Central Coherence theory

The essence of (weak) Central Coherence (CC) theory is the suggestion that, whilst typically developing individuals [sic] process information by extracting the overall meaning or gist (Rajendran and Mitchell, 2007), autistic individuals have a weak or absent drive for global coherence (Frith, 1989, 2003; Frith and Happé, 1994; Happé, 1999) and process information in a detail-focused or piecemeal way, processing the constituent parts, rather than the global whole (Chown, 2017; Rajendran and Mitchell, 2007). It is argued that autistic individuals tend to perform better than typically developing non-autistics on tasks that involve attending to detail (Attwood, 1998; Milton, 2012) because they lack a cognitive drive to attend to global form (Frith, 1989; 2003). That is, they have weak central coherence (Happé,1994).

Although suggesting a *'deficit'* in 'typical' functioning, i.e. weak central coherence, the development of CC theory was also an attempt to explain the existence of autistic strengths and talents in certain areas of processing (Rajendran and Mitchell, 2007; Milton, 2012). The validity of CC theory was called in question following investigations into visuospatial and verbal semantic abilities (Rajendran and Mitchell, 2007), with alternative hypotheses, for example reduced generalisation (Plaisted, 2001), and problems with hierarchical organisation of information (Mottron and Burack, 2001; Mottron et al., 2006), being proposed. Other researchers have reported that the construct of weak central coherence does not appear to be a unitary cognitive style, but instead one consisting of many components (Pellicano et al., 2006), and that it is not universal in the autistic population,but rather only evidenced in those with core linguistic difficulties (Norbury, 2005).

In response to such conflicting research findings, CC theory evolved and became better specified (Rajendran and Mitchell, 2007). 'Weak central coherence' has become known as, 'a preference for local processing' (Happé and Frith, 2006, p.15), with central coherence in autism now being regarded as an alternative information processing style (Chown, 2017; Happé and Frith, 2006), involving a bias towards detail but with the ability to extract overall meaning with effort (Happé and Frith, 2006). It is now suggested that this may be just one element of the autistic cognitive profile (ibid), and CC theory no longer seeks to explain all aspects of autism (Chown, 2017; Rajendran and Mitchell, 2007).

However, despite its original authors seemingly demoting CC theory to a description of autistic cognitive style (Happé and Frith, 2006), rather than a theory of autism per se, CC theory remains alongside ToM and EF theory as one of the 'big three' leading theories of autism (Chown and Beardon, 2017; Chown, 2017; Rajendran and Mitchell, 2007). Autistic pupils' qualitative interview data was therefore explored in this study for evidence of CC theory's potential value as a means of better understanding their school experiences.

ii.   Other theories

Two other more recently developed theories of autism were chosen for inclusion in this project. Empathising-Systemising (E-S) theory (Baron-Cohen, 2002; 2009) and Monotropism[5] theory (Murray et al., 2005) were included because they are purported to offer explanation not only of the social difficulties experienced by autistic individuals, but also of restricted interests and repetitive behaviours, understood to be an explicit feature of autism (DSM-5, Category B) but left largely ignored by earlier autism theory (Baron-Cohen, 2009a; b; Murray et al., 2005). Monotropism theory also hypothesises the origins of sensory perceptual differences, re-introduced into the updated diagnostic criteria (DSM-5, 2013) as an explicit feature of autism.

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[5] Also referred to as Single Attention/Monotropism theory (Chown, 2016)

The authors of both E-S and Monotropism theory claim to extend, or incorporate, earlier cognitive theories within their hypotheses so that, whilst the three dominant autism theories are no longer considered capable of, or continue to make claim to, explaining autism in its entirety (Chown and Beardon, 2017; Chown, 2017; Rajendran and Mitchell, 2007), it is suggested that these two more recent theories might achieve this (Baron-Cohen, 2009a; Murray et al., 2005) and thus meet Rajendran and Mitchell's 'specificity' criteria for 'good' autism theory (2007, p.224).

Both theories' authors also suggest that use of their hypotheses will improve understanding of autism and facilitate interventions and support that will enhance the lives of autistic individuals (Baron-Cohen, 2009a; Murray et al., 2005). These are important aspects of any new theory (Chown and Beardon, 2017) and were a key factor in my decision to include them in this investigation.

As potential alternatives, positioned to succeed the ToM, EF and CC theories of autism, it was of interest to determine whether and to what extent overlap exists, between these more recent theories and the three dominant ones, in their ability to explain the school experiences of the autistic pupils participating in this study, in addition to identifying the explanatory value of E-S and Monotropism theory in isolation.

d) Empathising-Systemising theory

According to E-S theory, autism is best explained, not just with reference to below average empathy (as in ToM theory), but also with reference to systemising, which is hypothesised to be either average or superior in autistic cognition (Baron-Cohen, 2009a; 2009b). In E-S theory, Baron-Cohen has extended his earlier definition of empathy, as understood in terms of theory of mind, i.e. the cognitive ability to identify someone else's (or your own) mental states (Baron-Cohen 1995; Baron-Cohen, Leslie and Frith, 1985), to include the response element of affective empathy (Baron-Cohen, 2002; 2009), i.e. understanding how to respond appropriately to another person once you have ascertained how they feel (Beardon, 2017a).

E-S theory constructs empathising as the drive to identify another person's emotions and thoughts, and to respond to these with an appropriate emotion (Baron-Cohen, 2009a; 2009b). Systemising, conceptualised as the 'opposite' trait (Baron-Cohen, 2002; 2009a; 2009b), describes the drive to analyse the variables in a system, to construct systems, and to derive the underlying rules that govern the behaviour of that system (ibid, 2006; 2009). Baron-Cohen argues in his new theory that, whilst empathy difficulties are not unique to autism, a criticism of ToM theory which hypothesised autism to be a *deficit* of empathy (Baron-Cohen 1995; 2002), 'only people on the autistic spectrum show the dissociation between this and their intact or even superior systemising drive' (2009, p.72). This means that, unlike ToM theory (Baron-Cohen, 2005), E-S theory potentially meets all the 'good' autism

theory criteria proposed by Rajendran and Mitchell (2007), of 'uniqueness', 'specificity'[6] and 'universality' (p.224).

Baron-Cohen suggests that empathy enables the prediction of the behaviour of another person and is what allows an individual to care about how others feel (Baron-Cohen, 2002), whilst systemising enables the prediction of the behaviour of a system (Baron-Cohen, 2006), through the identification of the rules that govern it (Baron-Cohen, 2009a). Empathising, he suggests, is the 'most powerful way of understanding and predicting the social world', whilst systemising is the 'most powerful way of understanding and predicting the law-governed inanimate universe' (Baron-Cohen et al., 2002, p.1).

It is proposed that the narrow interests, repetitive behaviour, and resistance to change/need for sameness, explicit to autism (DSM-5, Category B, 2013), derive from autistic individuals' tendency to systemise, while the explicit social and communication difficulties (DSM-5, Category A, 2013) are explained by a reduced ability to empathise (Baron-Cohen, 2009a). Baron-Cohen cites evidence from the earlier 'mindblindness' studies (Baron-Cohen et al., 1999; Castelli, Frith, Happé, et al. 2002; Frith and Frith, 2003) used to support his ToM hypothesis, together with results from research employing tests of systemising in members of the autistic population (Baron-Cohen, Richler, Bisarya, et al., 2003; Baron-Cohen, Wheelwright,

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[6] Hyper and hypo-reactivity to sensory stimuli were not included in the criteria at the time of E-S theory's conception

Scahill, et al. 2001) as evidence of the autistic cognitive profile which E-S theory purports to explain.

One study in particular (Baron-Cohen et al., 2002), in which 47 autistic adults were matched with a non-autistic control sample and their performance on the Empathising Quotient (Baron-Cohen and Wheelwright, 2004) and Systemising Quotient (Baron-Cohen, et al., 2003) were compared, provided what Baron-Cohen claimed to be a compelling argument in favour of the E-S theory of autism (Baron-Cohen et al., 2002), i.e. results supported the hypothesis that autistic individuals would perform significantly better on measures of systemising and less well on measures of empathising than their non-autistic counterparts. However, the underlying cognitive mechanisms that drive empathising and systemising are yet to be established (Rajendran and Mitchell, 2007).

E-S theory provides no explanation for the autistic sensory profile of hyper and hypo-reactivity to sensory stimuli (DSM-5, Category B (4), 2013), but claims to account for all the aspects of autism previously described in the earlier theories of ToM, EF, and CC (Baron-Cohen, 2009a). No reference is made in E-S theory to the difference between shared experience, learned, or intuitive empathy (Beardon, 2017a), nor does E-S theory account for the assertion of many autistic individuals that, rather than lacking empathy, they are overwhelmed by an excess of empathetic feeling (Beardon, 2017a; Markram and Markram, 2010), which can result in a decreased ability to respond in a typical non-autistic manner. The suggestion that autistic individuals are not impaired in their ability to empathise with other autistic

minds, any more than non-autistics are with each other (Beardon, 2008b; Edey et al., 2016; Chown, 2014; Milton, 2012) is also not explored/explained in E-S theory (Baron-Cohen, 2009a; 2009b).

In addition to the seemingly overly-simplistic definition of empathy utilised in E-S theory, no reference is made to the possibility that it might be alexithymia, an inability to identify and describe one's own emotional states, found to be co-morbidly associated with autism in 50% of cases (Brewer and Murphy, 2016), rather than a lack of empathy, that is responsible for the difficulties many autistic individuals experience recognising and responding to the emotions of others (Bird et al., 2010; Brewer and Murphy, 2016).

Baron-Cohen's continued assertion that autistic individuals lack empathy (Baron-Cohen 2002; 2006; 2009), in the face of more robust definitions of empathy, and alternative possibilities for autistic social difficulties (Beardon, 2017a; 2012; Brewer and Murphy, 2016; Chown, 2017; Milton, 2017), is a major concern for me. E-S theory might better stand up to criticism if its author gave it another name, based on the limited construct that is actually being described (rather than empathy), and that does not necessarily suggest that autistic individuals are inherently lacking in the ability to care about the feelings of others (Baron-Cohen, 2009a; 2009b).

Baron-Cohen presents a different perspective. He claims that by theorising autism based on individual differences in traits seen across the entire population, i.e. empathising and systemising, which exist to a greater or lesser extent in all human

beings (Baron-Cohen-2009; Lawson et al., 2004), E-S theory serves to 'destigmatise' autism, viewing it as a difference in cognitive style rather than a *'disorder'* (Baron-Cohen, 2009a, p.73). As an autistic individual myself, I do not accept that perpetuating the myth (Beardon, 2017a; 2012), that the autistic population lack empathy, does anything to reduce any potential stigma attached to the diagnostic label of autism.

As E-S theory claims to explain all the explicit features of autism (other than sensory perceptual differences, which were, at the time of the theory's development, not included in the diagnostic criteria), I intend to explore the extent to which the school experiences of the autistic pupils participating in this research can be explained according to their tendency to analyse or construct systems and to identify rules that govern these systems (Baron-Cohen 2006), and their use (or not) of empathic skills (as defined by Baron-Cohen, 2002; 2009), i.e. I aim to ascertain the extent to which E-S theory can enable understanding of autistic school experiences. Baron-Cohen himself noted that one criticism of E-S theory is that the evidence base for it is still quite limited (2009a). This analysis should go some small way towards addressing that.

e) Monotropism theory

In Monotropism theory it is proposed that there exists a limited amount of attention available to anyone at any given time that may either be broadly distributed over many interests or concentrated on a few interests, and that differences, in the

spread of attention available to individuals, follow a normal distribution pattern across the entire human population (Murray et al., 2005). Seen in this way 'Monotropism is not a model of autism as such…[but]…a theory about human beings, in which autism has a natural role' (Lesser, cited in Burne, 2005). Thus, according to Monotropism theory, the difference, between autistic and non-autistic, is in the strategies employed in the distribution of scarce attention, i.e. 'it is the difference between having few interests highly aroused, the *monotropic* tendency [autistic], and having many interests less highly aroused, the *polytropic* tendency [non-autistic]' (Murray et al., 2005, p.140). Monotropism theory therefore meets the 'unique' to autism criteria for 'good' theory proposed by Rajendran and Mitchell (2007, p.224).

The authors of Monotropism theory hypothesise that in autism, 'atypical strategies for the distribution of attention' (Murray et al., 2005, p.139) underlie both the social and non-social features made explicit in the diagnostic criteria (DSM-5, 2013 and ICD-10, 2010), and thus it is the 'restricted range of interests', outlined in the diagnostic manuals and termed 'monotropism' by Murray (1992), that is considered to be 'central to the autistic condition' (Murray et al., 2005, p.139). In other words, having a monotropic cognitive style results in the collection of behaviours and difficulties outlined in the diagnostic criteria for autism (DSM-5), because social interactions, the use of language and the shifting of attention all require broadly distributed attention (Chown and Beardon, 2017; Chown, 2017; Murray et al., 2005) rather than hyper-focus on a single stimulus (ibid). As in E-S theory, autism is viewed here as a profile of strengths and relative weaknesses, rather than purely a collection of *'deficits'*. When an individual has a tendency

towards monotropic focus they are likely to perform one task well, whilst simultaneously losing awareness of information relevant to all other tasks (ibid).

I am interested in the potential explanatory value of the Monotropism theory of autism, as it has been suggested that it 'may explain more characteristics of autism than any other theory' (Chown and Beardon, 2017, p.3). Its authors, two of whom identify themselves as autistic and the other as having 'a number of autistic characteristics' (Burne, 2005), suggest it forms 'a conceptual model that is capable of informing practice' (Murray et al., 2005, p.140). Unlike many theories, which appear (to me) to offer no practical real-life benefit to the autistic community, Monotropism theory is used to propose a heuristic guide to facilitate positive engagement with autistic individuals (ibid, p.153). In addition, distinct from all other cognitive theories, Monotropism theory places value on the input of autistic voices (Milton, 2012). The original article, (Murray et al., 2005), is rich with descriptive accounts of autistic experiences, for which theoretical explanations, of the cognitive mechanisms at work, are proposed.

The authors demonstrate how Monotropism theory provides potential explanation for all aspects of the diagnostic criteria (DSM-5, 2013), and offers an alternative, difference in autistic processing, account for the cognitive difficulties previously hypothesised to be affected by *deficits* in theory of mind (empathy), executive functioning and central coherence (Milton, 2011; 2012). These earlier theories made assumptions based upon interpretations of observed behavioural

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traits (ibid) with no reference to how it 'is' to be autistic 'from the inside according to how it is experienced' (Williams, 1996, p.14).

Monotropism is the first theory of autism to attempt to draw on subjective autistic experience (Milton, 2012). Furthermore, whilst '[n]one of the three dominant cognitive theories of autism seek to explain the sensory aspects of autism' (Chown, 2017, p. 235), also absent from E-S theory, Monotropism theory provides credible explanation for the sensory hyper- and hypo-sensitivities described by autistic authors (e.g. Blackburn, 2000; Grandin, 2006; Lawson, 2014), documented by Bogdashina (2016), and included in the revised diagnostic criteria (DSM-5, 2013). Thus Monotropism theory also potentially meets the 'specificity' and 'universality' criteria for 'good' autism theory (Rajendran and Mitchell, 2007, p.224), as well as that of 'uniqueness'.

In my opinion, including an explanation of the sensory differences experienced by autistic individuals is essential if the non-autistic population are going to be enabled to achieve a comprehensive understanding of autism and be better able to identify and offer appropriate forms of support. This view is supported by Chown and Beardon (2017) who suggest that 'good' autism theory must 'be capable of explaining the cognitive and sensory differences' (p.7). In Monotropism theory, it is suggested that, with monotropic hyper-focus comes a general lack of awareness of one's environment and thus a hypo-sensitivity to sensory stimuli outside the attention tunnel, because large areas of potential information are not registered (Murray et al., 2005). This, coupled with a lack of preparedness for interruption,

results in hyper-sensitivity to unexpected sensory stimuli. As an autistic individual who experiences both hyper and hypo-sensitivity to noise, particularly when task-focused, this explanation seems highly plausible to me.

On exploration of the literature pertaining to Monotropism theory in search of supporting evidence or criticism, there appears to be little of either. Notably the majority of the researchers who have written about its positive potential, including myself (Leatherland and Chown, 2015), are autistic (e.g. Chown, 2017; Milton, 2012; 2014). It has been reported that 'experts' in 'the mainstream' consider the promotion by autistic individuals of a theory that casts autism in a more positive light, to be an example of 'special pleading' (Burne, 2005). I accept that it is possible that I am drawn to this theory because it encourages me to consider myself, and many of those I care about, to be 'different' rather than '*defective*'. However, I believe it is more likely that a theory, written by autistic individuals, which attends to the subjective experiences of autistic others, appeals, not because it makes me feel better about myself, but because it appears to have the capacity to make sense of so many autistic lived experiences in a way the other main cognitive autism theories do not.

This might be an example of my experiencing 'a disjuncture in reciprocity' with theories proposed and written about by non-autistic authors, as described in Milton's conceptualisation of the double-empathy problem (Milton, 2012, p.884). Similarly, perhaps it is a consequence of my having difficulty with cross-neurological theory of

mind (Beardon, 2008b), and therefore being more attuned to the writing of other autistic individuals, than of non-autistic individuals.

With the possibility in mind, that I might be responding at an intuitive level to Murray et al.'s autistic thinking and communication style, rather than the quality of their theory, I am keen to investigate the extent to which the still relatively under-researched theory of Monotropism can provide explanation for the experiences of school described by the autistic pupils participating in this research, and to compare its capacity for doing so with the more widely recognised cognitive theories. Such investigation has the potential to provide much needed evidence to support or reject the hypothesis that autism is a difference in the distribution of scarce attention (Murray et al., 2005).

As detailed at the beginning of this section, the second research question was posed in order to identify the extent to which current autism theory might enable (or not) members of the non-autistic population (in this case teachers[7]) to make sense of the behaviours and school experiences of autistic individuals (in this case pupils). Conversely, I am also interested to establish whether any salient school experiences are left unexplained by current autism theory, as this would evidence the potential

[7] I do not suggest that none of the teachers in this study are autistic, but it can be assumed - in terms of the prevalence of autism in the general population (NAS, 2017a) - that the vast majority of them are not.

benefit that further theory development might offer those seeking to understand autism.

4. Autism and Education

This section outlines the current educational situation in the UK and the challenges faced by autistic pupils and their teachers in mainstream schools. Limitations of the research evidence are discussed, followed by recommendations for the direction of future investigations and the way in which the FAMe™ Project addresses some of these.

i. UK educational context

In the United Kingdom, the majority (71%) of an estimated 133,500 autistic children and young people (NAS, 2009) receive their education in mainstream school settings (Department for Education, (DfE) 2014a), rather than in specialist units and schools, reflecting a policy of inclusion in education, for pupils with special educational needs and disabilities (SEND), which began with the Salamanca statement (UNESCO, 1994) and has spanned the last two decades (e.g. European Agency for the Development of Special Needs Education (EADSEN), 2010; Office for Standards in Education (Ofsted), 2006; Scottish Executive Education Department (SEED), 2005; UNESCO, 2006; 2008). As a consequence, most schools will have autistic children on their rolls and most teachers can expect, at some point, to teach them (Ravet, 2011; Wilkinson and Twist, 2010). The vast majority of these mainstreamed pupils' intellectual ability will be in the average to above average

range (Chakrabarti and Fobonne, 2005; Estes et al., 2011) and they would previously have been identified as having Asperger Syndrome (DSM-IV-TR, 2000), or be described as [cognitively] 'high-functioning' (Baron-Cohen et al., 2001).

Following the publication of research carried out by the National Autistic Society (Barnard et al., 2000), which suggested that, in order to include autistic children successfully, teachers must have a working knowledge of the social, behavioural and emotional characteristics most directly related to and affecting pupils' school performance, the government produced specific information to guide service provision for autistic children which included information for schools (DfES, 2004; 2002). However, despite these new initiatives, researchers continued to report that teachers found autistic pupils more difficult to include (Humphrey and Symes, 2013; Jones et al., 2008; Robertson et al., 2003), and suggested that these pupils remained more vulnerable than their non-autistic peers to a wide range of negative outcomes (Burgess and Gutstein, 2007; House of Commons Education and Skills Committee, 2006; Postnote, 2008).

In recognition of these findings, 'Supporting pupils on the autism spectrum' was produced as part of the 'Inclusion Development Programme' (DCSF, 2009), and in 2011 the Autism Education Trust was commissioned to develop a set of 'National Autism Education Standards' for good practice in the education of children and young people with autism (AET, 2011). Nationwide 'schools training hubs' were created, which run ongoing professional development programmes for teaching staff such as 'Making Sense of Autism' and 'Good Autism Practice' (AET, 2017). Again,

despite the increased efforts to improve teachers' autism knowledge and practice, results of a survey carried out by the largest UK teachers' union (NASUWT, 2013), suggested that more than half of all participating teachers still reported lacking the knowledge to teach autistic pupils (60%[8]) with many (44%) lacking confidence in their ability to do so (NAS, 2016a; NASUWT, 2013; AaA, 2017).

A more recent follow-up survey (NASUWT, 2018), to which 1615 teachers responded, reported similar findings and concluded that, although 'teachers try to do the best for the learners they teach…,' '…they are not always equipped with the knowledge, skills and expertise to meet the needs of learners with SEN' (p.4). This claim is supported by findings from autism education research which cites teachers' anxiety over training, knowledge and provision as barriers to the successful inclusion of autistic pupils (Emam and Farrell, 2009; Jones, 2006; Witmer and Ferreri, 2014; Sprotson et al., 2017).

There is a growing set of findings (e.g. Ashburner, Ziviani and Roger, 2008; Waddington and Reed, 2017; Zingerevich and LaVesser, 2009) which suggest that a mainstream school placement might not always offer the best prospects for autistic pupils (Norwich and Lewis, 2005; Ravet, 2011; Reed et al., 2012). Many still find inclusive education stressful (Mackintosh, Goin-Kochel and Myers, 2012; Osborne and Reed, 2011; Starr and Foy, 2012), especially in the secondary school phase

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[8] Data identifying the number of teachers surveyed is not available

(Bolic-Baric et al., 2016; Cumming, 2012; Morewood et al., 2011; Osborne and Reed, 2011), and their educational and psychosocial outcomes, although variable, are still generally reported to be poor (Aspect, 2012; Fleury et al., 2014; Howlin and Moss, 2012; Keen et al., 2016; Levy and Perry, 2011).

As many as 84% of autistic children and adolescents are thought to have at least one co-occurring mental health problem (Magiati et al., 2016; White et al., 2009; Selles et al., 2015; Steensel, Bögels, and Perrin, 2011), such as depression, anxiety, and Obsessive Compulsive Disorder (OCD) (Howlin and Moss, 2012; Macintosh and Dissanayake, 2006), and high rates of academic under-achievement (54%) have been reported for this group (Ashburner, Ziviani and Roger, 2010; Estes et al., 2011; Keen et al., 2016). This compares to prevalence rates of around 10% and 8% respectively in non-autistic children (Ashburner et al., 2010; NAS, 2010).

Whilst the methodologies, participant numbers, and percentage of autistic young people reported to be affected by mental health issues vary considerably between studies (White et al., 2009), a systematic review of the autism mental [ill]health literature (Steensel et al., 2011) identified 31 studies, involving a total of 2,121 autistic young people (aged <18 years), where the presence of anxiety disorder had been assessed using standardised questionnaires and/or diagnostic interviews. It was found that, across studies, over one third (37%) of autistic young people had at least one comorbid anxiety disorder, the most frequent being specific phobia (30%) followed by OCD (17%) and social anxiety disorder (17%). I have been unable to locate any study, that set out to investigate the existence of mental health

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issues in the autistic population, that has concluded that this group do not have a considerably higher rate of mental ill-health than is reported for the non-autistic population.

This increased risk of mental ill-health, reported to exist in the autistic pupil population (Charman et al., 2011; Morewood et al., 2011; Osborne and Reed, 2011), is thought to develop in part through their experience in the education system (NAS, 2010) and is particularly salient in adolescence (Church et al. 2000) and in pupils at the less severe [sic] end of the spectrum (Gadow et al., 2005). Improving the understanding of how successful inclusion can be achieved for mainstream educated, secondary-aged autistic pupils should therefore be a research priority.

A recent large-scale study exploring links between SEND status and subjective and psychological wellbeing (Barnes and Harrison, 2017), which used data from a sample of 1600 secondary school children (299 of whom were identified as having SEND), found an independent association between SEND and being unhappy with school, with 19% of the SEND group reporting being unhappy with their school and their school work, compared to just 7% of children without SEND.

The Strengths and Difficulties Questionnaire (Goodman, 1997), which assesses young people's: emotional symptoms; behavioural problems; hyperactivity or inattention; peer relationship problems; and prosocial behaviour, and has been designed so that only a minority (10%) of children score in the 'high' or 'very high' range, was used by Barnes and Harrison (2017) to explore between-group

differences. Children/young people who score in the 'high' or 'very high' range are considered to be most at risk of mental health problems (Goodman, 1997). Barnes and Harrison's analysis of their pupil participants' scores found that between 18% and 27% of those with SEND scored in the 'high' or 'very high' psychological difficulties range, which was a significantly higher proportion than children without SEND (between 11% and 13%), and higher than the 10% that would be expected in a normally distributed population (Goodman, 1997).

Pupils' specific SEND was not reported in this study but, as autistic children have been identified as a particularly vulnerable group amongst all pupils with SEND (Burgess and Gutstein, 2007; House of Commons Education and Skills Committee, 2006), and make up at least 11% of the total SEND population (DfE, 2014a), it is reasonable to assume that the experiences of autistic pupils are represented in these findings, which support those of smaller studies examining levels of school related anxiety in the autistic pupil population (e.g. Ozsivadjian et al., 2012; Macintosh and Dissanayake, 2006; Simonoff et al., 2008).

In summary, it is apparent, from the findings of extensive autism education research, that inclusion in mainstream settings can create considerable difficulties for both autistic children (e.g. Humphrey and Lewis, 2008; Lindsay, 2007; Mandy et al., 2016; Morewood and Glew, 2011) and their teachers (e.g. Batten and Daly, 2006; Charman et al., 2011; Hebron and Humphrey, 2014; Macbeath et al., 2006), and that these difficulties are exacerbated in the secondary phase of education (Bolic-Baric et al., 2016; Morewood et al., 2011; Osborne and Reed, 2011). In order to better

understand these difficulties, and to provide a rationale for the development and evaluation of the FAMe™ System, it is important to consider the particular challenges of the secondary school environment in relation to autism.

ii. Challenges faced by autistic pupils in mainstream secondary school settings

Secondary schools demand greater academic and social independence and have a greater focus on academic assessment (Mandy et al., 2016) than will usually have been experienced by autistic pupils in their previous settings. State maintained secondary schools and academies are typically large buildings with high pupil numbers and so have an increased potential for sensory overwhelm (Ashburner et al., 2008; Bogdashina, 2016; Murray et al., 2005) and unpredictability (Humphrey and Lewis, 2008). Such factors are a common source of stress for autistic individuals (Ashburner et al., 2008; 2010).

Pupils are predominantly taught by different teachers in different rooms for each lesson, expected to move around the school site throughout the day, cope with mixed class groupings due to being put in sets (Fleury et al., 2014), and take on additional personal responsibilities for organising their own books, tools and food (Ashburner et al., 2010). These recurrent transitions throughout the school day, are thought to be particularly difficult for autistic pupils because of an innate tendency toward routine and stability (DSM-5, 2013; Gibbons and Goins, 2008; Myles and Simpson, 1998). In addition, a strong resistance to some subjects and refusal to do

work outside their own area of interest (Jacobsen, 2005), coupled with a preference to work on one task for long periods and/or until completion (Gibbons and Goins, 2008), is not a good fit with the typical timetable of secondary school.

An increased emphasis on note taking during lessons, which requires pupils to determine what information is important, and the simultaneous need to write it down, keep up and concentrate (Fleury et al., 2014; Jacobsen, 2005) can be problematic for autistic pupils who will, by definition, experience difficulties in some areas of their executive functioning (DSM-5, 2013). EF difficulties commonly involve poor planning and organisation skills and can impact on working memory (Attwood, 1998; Chown, 2017; Macintosh and Dissanayake, 2004) which creates problems for autistic pupils when they are required to focus on multiple tasks at once (Ashburner et al., 2008; Jones et al., 2011; Estes et al., 2011; Rosenthal et al., 2013).

Periods of unstructured social time, particularly stressful for autistic pupils (Ashburner et al., 2010; Humphrey and Lewis, 2008; Knight et al., 2009; Osborne and Reed, 2011), are frequent (Sprotson et al., 2017) and can pose a threat to those children who have difficulty with social interactions, particularly in understanding the nuances of social behaviour and those who display unusual behaviours and/or behavioural excesses which interfere with positive relationships (Robertson et al., 2003), as they can increase the potential for teasing and bullying (Barnes and Harrison, 2017; Hebron and Humphrey, 2014; Humphrey and Lewis, 2008; Jordan, 2005).

These many environmental challenges, and the inherent unpredictability of mainstream school life (Ashburner et al., 2008; 2010; Humphrey and Lewis, 2008; Myles and Simpson, 1998), are thought to contribute to the high levels of anxiety (Bolic-Baric et al., 2016; Charman et al., 2011; Keen et al., 2016; Osbourne and Reed, 2011; Ravet, 2011) and behavioural problems (Ashburner et al., 2010) reported for autistic children, and thus to the high exclusion rates experienced by this pupil population (Barnard et al., 2000; Frederickson, Osborne and Reed, 2004; NAS, 2018a), which is over twice the average for all pupils within state funded schools in England (DfE, 2017) and occurs most frequently (60% of all permanent exclusions) in the 12-14 years age group (DfE, 2015).

iii.   Challenges faced by teachers of autistic pupils in mainstream secondary school settings

Amongst pupils with a Statement of SEN or an EHCP, autism is the most common primary need, accounting for 25% of the total (DfE, 2014a). This Statement/EHCP rate evidences that autistic pupils' support needs typically extend beyond those of the majority of children and young people with SEND, who will/should have their needs met through 'high quality teaching that is differentiated and personalised' (DfE and DoH, 2015), and thus do not qualify for an EHCP (ibid).

However, as Ravet points out, 'there is no theoretical formula for 'doing' inclusion' and 'no 'recipe' for the inclusion of children on the autism spectrum' (2011, p.680) and, although teachers are frequently expected to be able to create inclusive

classrooms for autistic pupils (DfE, 2014b; DfE and DoH, 2015), they have few guidelines about how to do so (Emam and Farrell, 2009; Lindsay et al., 2013; Reed et al., 2012).

Including autistic pupils in mainstream classrooms has been described as a unique challenge for mainstream teachers (Gibbons and Goins, 2008; Jones et al., 2008; Macbeath et al., 2006 et al., 2002; Robertson et al., 2003), who are dealing with ever-increasing curriculum demands (Starr and Foy, 2012) within an education system that has a target-obsessed culture (Ball, 2010; Galton and Macbeath, 2008) and a dominant narrative of high-pressure, data-driven, punitive structures (Hutchings, 2015). Teachers are continually confronted by a mantra of progress, and statistics have become the effective arbiter of their value (Beckett, 2014). In this current system, where learning is viewed as the attainment of measurable skills by a set of normative criteria (Milton and Lyte, 2012), teachers continue to be tasked with finding ways to 'provide balanced support for individual needs' (Bolic-Baric et al., 2016, p.192) whilst financial conditions have deteriorated, resulting in larger classes and more students with special needs in each class (Bolic-Baric et al., 2016; Iadarola et al., 2015).

At secondary school, teachers typically teach multiple classes across several year groups and will often teach hundreds of pupils over the course of a week. It can therefore take much longer, than at primary level, to establish relationships, recognise learning styles and understand the motivation for individual pupil's

classroom behaviours. Unlike many other disabilities, autism is not immediately apparent to others (Frith, 2003; Myles and Simpson, 2002) and secondary school teachers, often limited to a few hours per class per week, can have difficulty remembering which of their many pupils is autistic (personal communication with my children's teachers). Furthermore, even when they are aware of a pupil's diagnosis, some teachers can find it hard to recognise, and in some cases difficult to believe, the extent of its associated difficulties, such as the extremes of anxiety that can be produced by everyday situations (Ghaziuddin, 2002; Powell and Jordan, 1991; Sprotson et al., 2017; Wood and Gadow, 2010).

Autistic children understand and respond to the world in a very different way to non-autistic children (Jacobsen, 2005), and it is very easy to attribute meaning to their behaviour that is wholly inaccurate (Jordan, 2008). Thus, autistic children have sometimes been labelled as lazy, difficult or defiant (Humphrey and Lewis, 2008) because their teachers fail to understand their autistic perspective (Jones et al., 2009; Sciutto et al., 2012; Tobias, 2009) and, by default, make normative assumptions about the reason for, and meaning of, the presenting behaviour (Ravet, 2011).

Some autistic children have obsessive or narrowly defined interests (Myles and Simpson, 2002) and lack motivation towards other-directed or socially-meaningful tasks (Jordan and Powell, 1995). The teacher cannot always use his/her own enthusiasm to motivate, as he/she might with a non-autistic child, especially if

the autistic child does not care about what the teacher cares about (ibid). Even with the motivation, some autistic children have fundamental difficulties which affect their capacity to become independent learners (Leatherland, 2014; Mandy et al., 2016; Myles and Simpson, 2002). For example, high levels of anxiety about whether their responses and actions are appropriate can prevent them from carrying out a task. This performance anxiety may bear no relationship to a pupil's actual abilities (Estes et al., 2011) making it even more difficult for a teacher to comprehend (Sprotson et al., 2017).

Autistic pupils might not engage with anything at school, physical or intellectual, without continual encouragement or approval, even when they are perfectly able to complete a task (Myles and Simpson, 2002), and more passive children might not ask for clarification during lessons or ask for help when information is not understood (Church et al., 2000). This dependency on their teacher is likely to increase when new activities are encountered, and the class teacher might simply not have the resources to devote to the autistic child when they need it (Jordan, 2008; Myles and Simpson, 2002). To compound this difficulty for teachers, what works to motivate and support an autistic child one week (or in one situation) may not work the next, and this will be influenced by many factors including the child's mood, pre-school stress, or changes in their sensory environment (Beardon, 2017a; Bogdashina, 2016; Leatherland, 2014).

Smells, sounds and other sensory stimuli can affect the autistic child and their ability to concentrate, stay seated, and remain calm (ibid), but may remain undetectable to the teacher. Such sensory stimulation is likely to have a profound effect on an autistic child and determine which learning environments are most effective and which are counter-productive, leading to withdrawal or distress (Jordan, 2005). To complicate this issue further for teachers, it might not be obvious when an autistic child is becoming distressed, as many autistic children do not reveal stress through voice tone or overt agitation, and they may escalate to the point of crisis before their teacher becomes aware of any difficulty (Myles and Simpson, 2002). The level of attentiveness necessary therefore, to monitor an autistic pupil's emotional state, is likely to be difficult for a class teacher who also has the diverse needs of approximately thirty other children to meet and even more so because it is not always easy to predict when the autistic child will cope and when they won't (Myles and Simpson, 2002; Leatherland, 2014).

Simply knowing *what* should be taught is likely to be insufficient for teachers of autistic pupils. They will need to not only be able to align their teaching to meet curriculum standards but must also be skilled at adapting their delivery to meet the unique needs of each individual autistic pupil (Fleury et al., 2014). The revised SEND Code of Practice (SENDCOP) states that: 'All teachers and support staff who work with the child should be made aware of their needs, the support provided, and any teaching strategies or approaches that are required' (DfE and DoH, 2015). However, unlike in primary education settings, there is a limited opportunity to spend time with

and get to know individual pupils, and so many teachers must rely on and access documents such as Pupil Passports (Morewood, 2014; NASEN, 2014) to gain information about their autistic pupils, adding another layer of demand on their time.

Compounding these difficulties, even when they do have knowledge of a pupil's diagnosis, many teachers possess only a limited understanding of autism (AaA, 2017; Iadarola et al., 2015; Jones et al., 2008; NAS, 2016a), both in general and of the way it can impact on individual pupils' experiences of their environments, inter-personal relationships, and/or their cognitive style and learning abilities (e.g. Charman et al., 2011; Falkmer et al., 2012; Hebron and Humphrey, 2014; Leatherland and Chown, 2015). Such understanding is essential (Ravet, 2011) to facilitate successful inclusion (Jordan, 2005).

In addition, it has been reported that there exists a general lack of awareness amongst teachers, of the pedagogical approaches and adaptations to teaching and the classroom environment, which can enable successful participation and learning for autistic pupils (Barnard et al., 2000; Charman et al., 2011; Humphrey and Lewis, 2008; Myles and Simpson, 2001; Ravet, 2007; 2011). The resulting situation for autistic pupils is exacerbated by teachers' general lack of confidence in their ability to implement autism-related strategies even when they are known (AaA, 2017; Macbeath et al., 2006; NAS, 2016a).

The complexity of providing autism-friendly learning experiences (Batten et al., 2006; Macbeath et al., 2006 et al., 2002: Singh and Elsabbagh, 2014), and the obstacles to understanding how best to meet pupils' individual needs, crucial if teachers are to appropriately differentiate the curriculum and tailor classroom strategies (Bevan-Brown, 2010; Falkmer et al., 2012; Hebron and Humphrey, 2014; Reed et al., 2012), is further compounded by the heterogeneity of the autistic population (Beardon, 2012; Beardon and Worton, 2011; Fleury et al., 2014; Rosqvist, 2012; Sarrett, 2012). It is suggested that 'teachers need to be able to take their student's perspective in a genuinely empathetic way and have a thorough understanding of that individual student, in order to create an inclusive school situation' (Falkmer et al., 2012, p.3), and yet the ability to intuitively empathise with those who are neurologically different is understood to be problematic (Beardon, 2008b; Milton, 2012).

iv.   Limitations of current autism inclusion research

Studies focusing on the inclusion experiences of autistic pupils and the support they receive at school, are predominantly survey studies of parents' perceptions of their children's education (Jordan, 2010; Limbers et al., 2009; NAS, 2010; Starr and Foy, 2012) which indicate that support is limited and inappropriate (Morrison, Sansoti and Hadley, 2009; Starr et al., 2006; Stoner et al., 2005; Vohra et al., 2014; Whitaker, 2007), but do not provide specific insight, from an autistic perspective (Milton, 2014; Milton et al., 2014; Jordan, 2010; Parsons et al., 2009), into how more successful inclusion could be facilitated (Bishton and Lindsay, 2011;

Bolic-Baric et al., 2016; Keen et al., 2016). Furthermore, studies that have ascertained the views of both parents and autistic children, in relation to quality of life issues, report low agreement (Coghill et al., 2009; Upton, Lawford and Eiser, 2008), suggesting that parental ratings are not a reliable proxy (Potvin et al., 2015).

Although it has been claimed that the involvement of autistic people in autism research has often added much to the work produced (Wittenmeyer et al., 2011; 2012; Milton, 2014), the scientific quality of much of the limited body of qualitative research designed to capture the views of autistic young people (Preece and Jordan, 2010; Bolte, 2014) has been called into question (Bolte, 2014; Milton, 2012; Waltz, 2007). As a consequence, very little reliable evidence is currently available about their experiences (Church et al., 2000), particularly in adolescence (Jang et al., 2014; Magiati et al., 2014) and the evidence base for many educational interventions continues to be ambiguous and contentious (Parsons et al., 2009), with many gaps in knowledge (Charman et al., 2011).

In reviewing previous autism research specifically for this project, several methodological issues were identified which could serve to limit the extent to which findings might usefully contribute to the understanding of autistic pupils' experiences of school. Limitations included the use of retrospective surveys by some researchers (e.g. Bolic-Baric et al., 2016; Church et al., 2000; Fisher and Taylor, 2016), in which autistic adults have been asked to recall their past school experiences. Not only are problems understood to exist with retrospective recall (Bradburn, Rips and Shevell, 1987; Maughan and Rutter, 1997), but, as the UK education system has been

through a period of significant change in relation to SEND legislation and practice (DfE, 2014b; DfE and DoH, 2015), retrospective accounts might not reliably inform understanding of how it is to be an autistic pupil in the current UK education system.

In other studies, rather than engaging pupils in interviews, which would have enabled their views and perspectives to be heard, researchers have relied exclusively on the use of self-report scales (e.g. Mandy et al., 2016). This necessarily restricted the data available for analysis and thus the scope of any research conclusions.

The conclusions of studies which have engaged single or few participants (e.g. Ashburner et al., 2013; Harrington et al., 2013; Kasari and Smith, 2013; Machalicek et al., 2008; Smith et al., 2007) are similarly restricted, as they report findings that cannot be considered to reflect the views and/or experiences of the wider autistic pupil population. Whilst the heterogeneity of the autistic population (Attwood, 2008; Beardon, 2012) will inevitably mean that findings from group studies must always be considered with caution, single case studies make extrapolation impossible.

Some methodological decisions about engagement with autistic pupils were found to have been guided by assumptions based on the categorical diagnostic features of autism (e.g. Harrington et al., 2013). This could have served to potentially limit participants' contributions, whilst collaboration with participants, around the methods of engagement best suited to their communicative style (e.g. Davis et al.,

2012; Hampton and Fletcher-Watson, 2016; Nicolaidis, 2015), might have elicited different results.

A lack of focus, in some studies, on external factors within the learning environment and the potential these have to impact on academic success (e.g. Keen et al., 2016), suggested that the researchers involved considered the explanation for academic failure to be situated within the pupil (i.e. attributable to internal factors) and that the aim of intervention is to change autistic pupils rather than the system within which they are taught (Waltz, 2007). Such research, that follows a normalising agenda (Milton and Lyte, 2012), fails to consider the external influence of the school environment and people within it and thus cannot provide the full picture of an autistic school experience (Beardon, 2017a). In other research, the focus has been on objective rather than subjective indicators of success (e.g. Burgess and Gutstein, 2007; Gibson and Kendall, 2010; Reed et al., 2012), which are not necessarily aligned with the priorities for intervention of autistic pupils and their families (Elsabbagh et al., 2014; Lewis and Norwich 2005; Pellicano et al., 2014).

Criticism from several researchers (e.g. Burgess and Gutstein, 2007; Howlin et al., 2007; Kasari and Smith, 2013; Weisz et al., 2005) has been levelled at autism research conducted outside the real-world school environment, as it is necessarily more difficult to establish the efficacy of the evaluated interventions in practice (Elsabbagh et al., 2014; Waltz, 2007).

Much autism education research has been carried out outside the UK within a different education system context (e.g. Ashburner et al., 2010; Falkmer et al., 2012; Magiati et al. 2016; Robertson et al., 2003). Whilst these studies contribute to an understanding of issues such as pupil-teacher relationships and environmental stressors, their findings might have little bearing on the day-to-day experiences of mainstreamed autistic pupils in this country and the changes that need to be implemented to improve their educational outcomes.

The combined effect of the methodological limitations and restricted foci of previous autism education studies, and the dearth of intervention-in-practice and participatory, participant voice-led research, means that, whilst it is generally understood that autistic pupils are more vulnerable to negative educational outcomes than their non-autistic peers (Charman et al., 2011; House of Commons Education and Skills Committee, 2006; Morewood, Humphrey and Symes, 2011), teaching practices which successfully address this inequality of outcome have yet to be established (Emam and Farrell, 2009; Witmer and Ferreri, 2014; Sprotson et al., 2017).

To date, few researchers (e.g. Moran, 1996; 2001; Williams and Hanke, 2007) report having utilised methods that facilitated genuine engagement with autistic pupils. Based in Personal Construct Psychology (Kelly, 1955, cited in Moran, 2006), and described as a process of assessment that can be used with autistic children who have sufficient verbal skills to have a conversation (ibid), the 'Draw your Ideal Self' (Moran, 1996; 2001) and 'Draw your Ideal School' (Williams and Hanke, 2007),

have been employed to enable autistic pupils to share their desires for their own personal development, and to advocate for types of intervention and/or provision that they might positively respond to. The reported success of these techniques (Moran, 2012), as methods of eliciting the autistic pupil voice, and thus the potential of using similar materials in this project to identify specific teaching practices that might better target individual pupil's priorities (Ravet, 2011; Sarrett, 2012), led me to develop an 'Ideal Teacher' pro-forma (described in more detail in the Methods section). This was used as a tool to facilitate the communication of pupils' personal constructions of the things their teachers do or do not do in the classroom that they do or do not like.

It is widely accepted that more information is needed to fill the gap in understanding how autistic learners actually experience school, and how barriers to their successful inclusion can be overcome (Dockrell and Lindsay 2011; Parsons et al., 2013; Pellicano, Dinsmore and Charman, 2014; Preece and Jordan, 2010; Sprotson et al., 2017). This is essentially what the FAMe™ Project research set out to achieve.

v. The FAMe™ Project - bridging the gaps

The purpose of the FAMe™ Project investigations was to gain a better understanding of autistic school experiences, and to identify good autism-related teaching practice and autism friendly learning environments. Through the easily accessible dissemination of this information to teachers via the FAMe™ System, the

overall project ambition was to facilitate positive impact on the educational experiences and outcomes of autistic pupils.

This goal is aligned with a key future priority for the Department of Health, identified by the National Autism Project (NAP). In their most recent report (NAP, 2018) it is suggested that 'generalist autism awareness courses do not provide the level of practical understanding required for meaningful impact' (p.2). They advocate for more effective training, which focuses on the practical, realistic elements of living with autism, to support and upskill professionals working with autistic people. The recommendation is that this training should have autistic people involved in its design, content and delivery (ibid).

The FAMe™ System (designed by an autistic person) to offer teachers easy access to specific information ('content') provided by individual autistic pupils about any desired adjustments to curricula, classroom environments and pedagogy (Ashburner et al., 2010; Bolic-Baric et al., 2016; Sarrett, 2012), has the potential to fulfil this NAP professional training recommendation and facilitate 'meaningful impact' on the lives of the autistic pupil population.

a) FAMe™ meeting the needs of autistic pupils

Many educational interventions put in place to support autistic pupils are related to the categorical diagnosis of autism, rather than the needs of the individual concerned, and thus assume the presence of a set of characteristics that may or

may not be experienced as problematic (Sarrett, 2012). This continues despite the suggestion that mainstreamed autistic pupils are fully capable of identifying and expressing their own accessibility concerns (Pivik, Mccomas and Laflamme, 2002) and should be allowed and encouraged to participate in evaluating their educational environments (Goode, 2007; Humphrey and Lewis, 2008; Mortier et al., 2011; Sciutto et al., 2012). These pupils should be enabled to articulate what needs to be provided that is currently not being offered (Bolic-Baric et al., 2016; Parsons et al., 2009; Seale, Nind and Parsons, 2014; Reed et al., 2012; Simpson et al., 2007) that will better enable them to meet their academic potential when taught in mainstream schools (Fleury et al., 2014; Keen et al., 2016), whilst at the same time protecting their mental health (Barnes and Harrison, 2017; Fleury et al., 2014; Pellicano et al., 2014; Sprotson et al., 2017) and self-esteem (Gibson and Kendall, 2010).

Informed by the materials used in previous research (Moran, 1996; 2001; Williams and Hanke, 2007), which enabled the articulation of autistic voice, and by attending to pupils' interaction and communication preferences, the FAMe™ Project methods are expected to facilitate a move beyond responding to what researchers/practitioners think these learners are experiencing, to establishing what is actually happening at school and how it impacts them (Fisher and Taylor, 2016). Allowing autistic pupils' day-to-day experiences, rather than researcher or practitioner ideology, to be the guide for intervention (Ravet, 2011; Sarrett, 2012) creates the potential to target the priorities of the pupils themselves and thus to reduce negative outcomes. The third research question was posed to guide my investigation of whether this could be achieved, i.e.:

When engaging autistic pupils in research focusing on their experiences of school:

a) *What can be learnt about autism/autistic pupils' school support needs from their descriptions of their school experiences?*

b) *Are autistic pupils able to identify and communicate examples of positive and/or negative classroom experiences and, if so, how can these be used to inform teaching practice?*

b) FAMe™ meeting the needs of teachers teaching autistic pupils

It has been reported that many teachers lack confidence in their ability to teach and meet the learning support needs of the autistic pupils in their classrooms (NASUWT, 2013), and have repeatedly requested more accurate and accessible information to help them to improve their autism-related practice (Miller, 2002; Wilkinson and Twist, 2010). However, despite various government training initiatives (AET, 2009; 2011; 2017; DCSF, 2009), teachers still report their autism knowledge to be inadequate and maintain that their training needs, in relation to good autism-related teaching practice, remain unmet (AaA, 2017; NAS, 2016a).

Due to the heterogeneity of the pupil population (Beardon, 2012; Beardon and Worton, 2011; Fleury et al., 2014; Rosqvist, 2012; Sarrett, 2012) it is suggested that continuing the attempt to identify a 'best treatment' for autism in education is 'ultimately futile' (Schreibman, 2007, p.251) and that the provision of generic autism information is unhelpful (Leatherland and Beardon, 2016; Ravet, 2011; Singh and Elsabbagh, 2014). Instead it has been suggested that future research efforts should focus on the development of methods to obtain accurate information about the needs of autistic learners and convey it to teachers in a manner that is accessible and useful (Cooper et al., 2015; Parsons et al., 2013; Weisz et al., 2005). This should better enable teachers to improve their evidence-based practice (Elsabbagh et al., 2014; Waltz, 2007), and thus have a positive impact on pupil outcomes (Batten et al., 2006; Charman et al., 2011; Brewin et al., 2008; Macbeath et al., 2006; Starr and Foy, 2012; Whitaker, 2007).

The FAMe™ System was specifically designed to provide teachers with the accessible, individualised, pupil-specific information they have been asking for (Miller, 2002; Wilkinson and Twist, 2010). The fourth research question was posed to establish whether, through doing so, the desired impact of the FAMe™ System, on teaching practice and pupil outcomes, was achieved.

When information about individual autistic pupils' support needs is made easily accessible to their teachers:

a) In what way does teacher behaviour/practice towards individual autistic pupils change?

b) What impact is there on autistic pupils' educational experiences and quality of life related outcomes?

Collaborative models of working, between teachers and researchers (Parsons and Kasari, 2013), which provide the opportunity for teachers to offer feedback (Parsons et al., 2013; Stahmer et al., 2012), including during the design phase of an educational intervention (Iadarola et al., 2015), have been shown to improve its subsequent effectiveness, adoption and sustainability compared to more researcher-led approaches (ibid; Kelleher et al., 2008).

With this in mind, teachers were consulted during the FAMe™ System design process, and their feedback used to ensure the best compatibility of fit with their working practices. For example, it was important to consider the ever-increasing curriculum demands made on teachers and the contexts within which they work (Parsons et al., 2013), to ensure that they did not simply regard the FAMe™ System as another competing burden (Starr and Foy, 2012). It was hoped that by evaluating the FAMe™ System in its 'real-world' context (school) from the beginning (Weisz, 2000, p.645), findings of this research will go some way towards lessening the gap which currently exists between research and its practical implementation (Kasari and Smith, 2013).

Chapter Summary

In this chapter I have presented a critical overview of the literature which informed my understanding of the research problem and the development of the four research questions. Current diagnostic criteria definitions and descriptors of autism have been outlined and problematic features of these discussed. A critical synopsis of the five cognitive autism theories identified for investigation, together with the justification for their selection, has been provided. Challenges faced by autistic pupils and by the teachers tasked with facilitating their successful inclusion within the current UK education system, were highlighted and explained.

Contributions to knowledge, in the under-researched area of autistic lived-experience, and in relation to the efficacy of the diagnostic criteria and autism theory to facilitate the understanding of autism, are expected and have been outlined in this review. The potential positive impact of FAMe™ System use, on the participating autistic pupils' educational experiences, and on their teachers' confidence in and ability to meet their pupils' classroom needs, was discussed with reference to those features of the current educational environment which are understood to increase this pupil groups' vulnerability to negative outcomes. Furthermore, I have suggested that, if successful, future adoption of the FAMe™ System in other schools could have a significant positive impact on the lives of the autistic pupil population, their families and wider society.

In the following chapter I present: my researcher positionality; methodological assumptions and decisions; the methods selected; and the project materials chosen and/or developed, in order that I might reliably answer the four research questions. FAMe™ System design and development are explained, and the different data analysis techniques used are specified and justified. Ethical issues, inherent to each stage of the project, are identified and the measures taken, to ensure that my responsibilities as a researcher working with a vulnerable population were met, are described.

Chapter Three: Methodology, Methods and Ethics

1. Overview

This research project aims to facilitate a better understanding of the school experiences of mainstreamed secondary-age autistic pupils and, by relating these to the diagnostic criteria for autism and cognitive autism theory, contribute to the understanding of autism itself.

The project involved three mainstream secondary schools into which a new system (FAMe™), designed to improve teachers' knowledge of their individual autistic pupils' learning and classroom-support needs, was introduced. A mixed methods research approach was taken, employing inductive and deductive thematic analysis (Boyatzis, 1998; Crabtree and Miller, 1999; Elo and Kyngas, 2008) to qualitatively explore autistic pupils' pre-FAMe™ interview data for evidence of how features of autism, the classroom environment, and teaching practice impacted on their school experiences. Analysis of quantitative and qualitative data, collected using: repeated-measures pupil self-report scales; pre- and post-FAMe™ pupil interviews; and teacher/SENDCO surveys, was undertaken to evaluate the effectiveness of the FAMe™ System at improving pupils' school experiences and reducing their negative outcomes, and to explore the different participant groups' perceptions of its efficacy.

It was essential, through engagement with research methodology literature, to ensure that a mixed methods approach to this project was justified, and that the philosophical assumptions which underpin it were understood (Carter and Little,

2007). As there exists a level of contention amongst researchers surrounding paradigm use/usefulness (Biesta, 2010; Cameron, 2011; Hall, 2013; Mertens, 2012; Morgan, 2007; Shannon-Baker, 2016), it was of paramount importance that the paradigm upon which this research proposal and design was based was 'fully understood and made explicit in the research itself' (Cameron, 2011, p.100). This section therefore details and substantiates the methodological decisions taken and includes a definition of my researcher positionality and how I came to identify myself as a pragmatist researcher.

2. Paradigms and Pragmatism

Within social science studies, the consensual set of beliefs and practices that guide a research field is typically referred to as a 'paradigm'. This term, used as a way to summarise researchers' beliefs about their efforts to create knowledge (Morgan, 2007), was made popular, by Thomas Kuhn in his work, 'The Structure of Scientific Revolutions' (1962; 1996) (Morgan, 2007, p.50).

Over the last 50 years, proponents of qualitative and quantitative research methodologies have been competing in what are known as the 'paradigm wars' (Clegg, 2005; Denscombe, 2008; Gage, 1989; Jones and Kennedy, 2011), the key issues of which concern epistemological and ontological assumptions about what constitutes knowledge and truth. These issues are fundamental to the arguments of 'incompatibilists', who remain critical of 'paradigm pluralism' (Tashakkori and Teddlie, 2012, p.779).

Set against the back-drop of these 'wars', the mixed methods approach emerged as a third methodological movement (Johnson and Onwuegbuzie, 2004; Teddlie and Tashakkori, 2003).

i. Mixed Methods

Although 'the precise definition of a mixed methods approach remains a contested area' (Cameron, 2011, p.96) with ongoing philosophical arguments regarding its justification (Hall, 2013; Morgan, 2007), it has evolved to the point where it is 'a separate methodological orientation with its own worldview, vocabulary, and techniques' (Tashakkori and Teddlie, 2003, cited in Denscombe, 2008, p.271), with research that shares the common characteristic of 'methodological eclecticism' (Tashakkori and Teddlie, 2012, p.777).

This approach has been described as a 'viable alternative' for social researchers (Denscombe, 2008, p.270) who employ a pluralist approach to thinking about research problems (Jones and Kennedy, 2011). It is frequently underpinned by the philosophical assumptions of pragmatism (Creswell and Plano Clark, 2011; Morgan, 2007) although other philosophical orientations are also represented, in what has been described as a 'big tent' of mixed methods research (Tashakkori and Teddlie, 2012, p.779), typically: transformative-emancipation; dialectics; and critical realism (Shannon-Baker, 2016, p.320). The latter has, however, also been described as a 'theoretical perspective' and is not often used in mixed methods (Creswell and Plano Clark, 2011, p.45; Hall, 2013).

A dialectic approach, which promotes the mixing of paradigms, in order to gain insights from multiple perspectives (Shannon-Baker, 2016), was initially considered for this project, as it was recognised that the research goals were reflected in elements of more than one paradigmatic perspective, i.e. it had potential to be understood through a transformative-emancipatory and/or pragmatist framework. However, as the dialectic approach has faced criticism for lacking clarity around which paradigms can be mixed and how their philosophical 'incompatibilities' can be overcome (Hall, 2013), I decided to focus my attention on the single paradigm options for combining qualitative and quantitative methods. I was keen to determine whether my epistemological and ontological beliefs connect me to the dominant philosophical partner for the mixed methods approach, i.e. pragmatism (Denscombe, 2008), or whether they are better reflected by one of the other 'big tent' mixed methods research orientations (Tashakkori and Teddlie, 2012, p.779), such as the transformative-emancipatory approach, often adopted by researchers working with marginalised populations (Hall, 2013; Mertens, 2010). The following section provides an overview of these two paradigmatic approaches and offers an explanation of how I came to understand my position as a pragmatist researcher.

a) The transformative-emancipatory paradigm

The transformative-emancipatory paradigm, proposed by Mertens (2003; 2010), focuses on social justice (Creswell, 2013a; Mertens, 2003) and places central importance on the lives and experiences of marginalised groups (Hall, 2013). It was therefore identified as a paradigm to which the aspirations of this

research were closely aligned (Creswell, 2013a; Mertens, 2007; 2010; 2012; Shannon-Baker, 2016), i.e. to attend to and use the voices of autistic individuals, who are traditionally excluded from the process of knowledge production (Beresford et al., 2004; Milton, 2014; Milton et al., 2014; Saggers, Yoon-Suk and Mercer, 2011), to effect positive change on their experiences (Mertens, 2007). In addition, other transformative concerns, such as the appropriate use of communication and adopting 'culturally sensitive' ways to collect data (Mertens, 2012; Shannon-Baker, 2016) are inherent to good autism and ethical practice (NAS, 2016b; British Educational Research Association (BERA), 2011), and had therefore been, and would continue to be, attended to during the design and data collection stages of this project.

Having ascertained a 'good fit' between my own values and transformative research principles, a practice apparently typical of researchers, who tend to locate themselves within their 'preferred paradigm', that best fits their 'personal history' (Denzin, 2008, p.322, cited in Tashakkori and Teddlie, 2012, p.779), it was important to establish whether my methodological decisions and assumptions, and the practicalities of the potential methods to be used in this research project, could also be justified in relation to transformative-emancipatory criteria.

As an autistic researcher, and therefore a member of my research participant 'community', it could be argued that this project met the transformative criteria for involving community members throughout the research process (Canales, 2013). However, as the participant population were autistic pupils, immersed in an

education system that has undergone many changes since I was at school, and because the autistic community itself is so diverse, it would be wrong for me to make claims of 'cultural competency' (Mertens, 2012). I might intuitively possess a greater degree of insight (than a non-autistic researcher) into what it is to be autistic, but I cannot claim to be able to represent the views and wishes of the heterogeneous population of autistic pupils (Attwood, 2008; Beardon, 2012; Beardon and Worton, 2011; Rosqvist, 2012), none of whom were to be afforded the opportunity to be actively involved (Shannon-Baker, 2016) in the research design, analysis or dissemination stages of this project.

In addition, this research study also explored the perspective of teachers, whose community I made no attempt to immerse myself in, and whose subjective realities were not expected to be accurately represented, other than with regard to their experiences of teaching autistic pupils and their use of the FAMe™ System, and, even then, only in relation to the particular questions asked of them.

Examination of power relationships and the historical and educational contexts into which the FAMe™ System was to be implemented would also be essential, if this research were to meet transformative-emancipatory requirements (Creswell, 2013a; Mertens, 2012), but this was outside the scope of the project. It was therefore accepted that, despite its goals being aligned with transformative-emancipatory ideology, the research methods to be used in the FAMe™ project, which would necessarily be constrained by its participant population and the context in which it was situated, would make transformative-emancipatory practice (Mertens,

2010; Shannon-Baker, 2016) unachievable. Nevertheless, transformative expectations of the FAMe™ Project research outcomes continued to be held and aspired to.

b.   *Pragmatism*

Pragmatism is positioned towards 'solving practical problems in the real world' (Feilzer, 2010, p.8) and, like transformative-emancipatory research, takes an explicitly value-oriented approach, in which there is 'agreement about the importance of many (culturally derived) values and desired ends' (Johnson and Onwuegbuzie, 2004, p.16). The aims of the FAMe™ project were naturally aligned with specific research goals cited by these authors as examples of 'desired ends' (p.17) which can be achieved through pragmatist research, i.e.: 'finding effective teaching techniques for different kinds of students'; 'helping to reduce discrimination in society'; and 'attempting to eliminate or reduce [the effects of] mental, learning, and other disabilities'.

However, having already established that, despite the goals of this project being reflected in the transformative agenda, the research approach did not fit transformative criteria, it was important to understand whether, having identified that the research aims were 'typical' of pragmatist work (Johnson and Onwuegbuzie, 2004, p.17), a methodological approach situated in pragmatist philosophy could effectively answer the research questions. To this end, literature relating to the concept of paradigm, and specifically to pragmatism, was explored in more detail.

ii.   Conceptualising a paradigm

Morgan (2007; 2014) suggests that different versions of 'paradigm' can be distinguished in terms of the generality of the underlying belief system which is shared, and, in his persuasive text, 'Paradigms Lost and Pragmatism Regained' (2007), calls for a move away from traditional 'epistemological stance' taking in the social sciences, in favour of the adoption of pragmatism as the dominant paradigm.

Using Kuhn's work (1962; 1970, p.176-183) as a foundation, Morgan described four versions of the paradigm concept, which he understood to be 'nested within one another' (Morgan, 2007, p.56), in what I visualise as a 'hierarchy of paradigm belief specificity' (see Fig.1 below). My hierarchy conveys no relative value or status to Morgan's different versions of the paradigm concept, but rather it represents the way the belief system referred to in each is narrower and more specifically defined than the one into which it is 'nested' (ibid, p.56). Creating this visual representation helped me to make sense of the abstract concepts involved in paradigm literature, and to locate where my own paradigmatic position fitted into the hierarchy. According to Morgan's argument, by identifying and clarifying the version/level of paradigm being adopted, a claim to pragmatism as the paradigm within which the FAMe™ Project was located could be justified.

Figure 1.

The hierarchy of paradigm belief specificity

Top-down thinking about methodology

All-encompassing Worldviews

'Our values and our politics are always a part of who we are and how we act' (Morgan, p.72)

Epistemological Stances

Shared Beliefs in a Research Field — Pragmatist Researchers

Exemplar of a Research Model

Bottom-up thinking about methodology
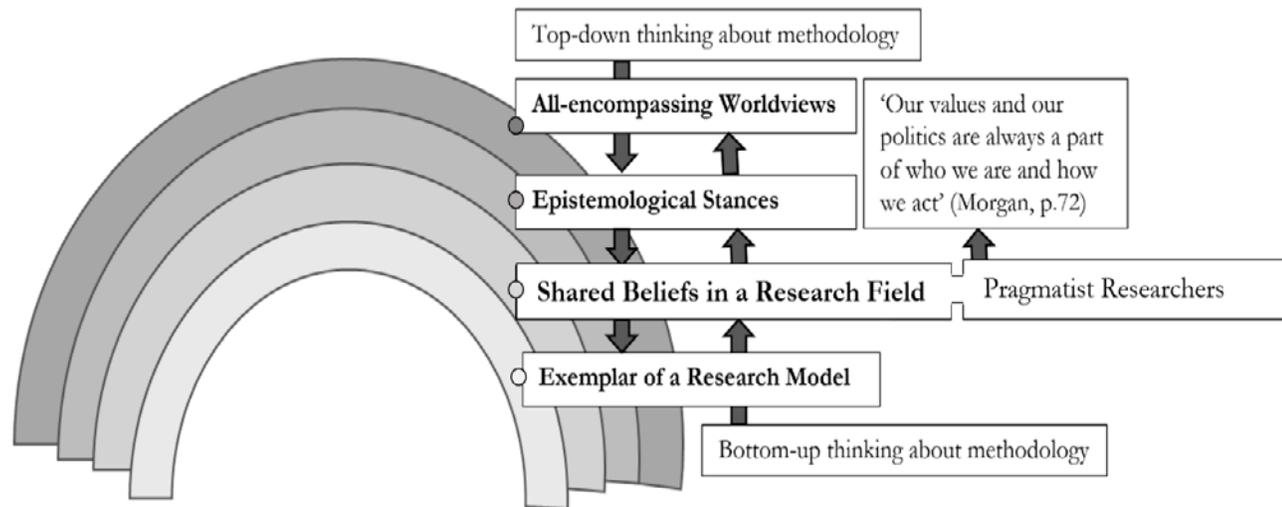
Adapted from Morgan's four versions of a paradigm concept (2007, p.56).

What follows is a brief summary of Morgan's four versions of paradigm. I have included my understanding of pragmatism, and how the FAMe™ project was aligned to its underlying philosophy, when describing the third version/level of specificity, adopting the position that, given certain beliefs about the world, a paradigm can be used as a 'guide' to ground research (Shannon-Baker, 2016, p.321). This enabled me to frame my approach to the research problem and determine how it should be addressed.

(i) An all-encompassing worldview

According to Morgan (2007)[9], in its broadest version the term 'paradigm' is used synonymously with 'worldview' and refers to: 'our all-encompassing ways of experiencing and thinking about the world, including beliefs about morals, values, and aesthetics' (p.51); shared understandings of reality (Rossman and Rallis, 2003); 'a worldview, together with the various philosophical assumptions associated with that point of view' (Teddlie and Tashakkori, 2009, p.84); and the basic set of assumptions that guide a researcher's inquiry (Creswell, 2013b; Lincoln, 1990).

It has been claimed (Lincoln, 1990) that worldviews have such pervasive effects that they permeate every aspect of research inquiry, influencing everything, including the topics researchers choose to study and how they choose to study them. According to these authors, worldviews consist of stances adopted on ontology, epistemology, axiology, and methodology (Hall, 2013). Teddlie and Tashakkori (2009) and Creswell and Plano Clark (2011) both identify pragmatism as a paradigm at the worldview level (Hall, 2013), unlike Morgan (2007) who locates pragmatism within his preferred definition of paradigm, i.e. shared beliefs amongst a community of researchers (Hall, 2013; Morgan, 2007; 2014).

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[9] Page numbers with no further reference details refer to this article

(ii) Epistemological stance

At the next level, the 'epistemological stance' version of paradigm, also termed the 'metaphysical paradigm' (p.59), concentrates on shared beliefs about the philosophy of knowledge, which includes the concepts of ontology (the nature of reality); epistemology (the justification and nature of knowledge); and methodology (the nature of generating knowledge). Distinct 'higher level belief systems' and assumptions (Denscombe, 2008, p.275), about the nature of knowledge and the appropriate ways of producing such knowledge, are understood to influence how research questions are asked and answered. A visual model, borrowed from Carter and Little (2007), is used here to illustrate the top-down interrelationship between epistemology, methodology and methods, central to paradigms at this level of the hierarchy (Fig. 2).

Figure 2.

The simple relationship between epistemology, methodology and method
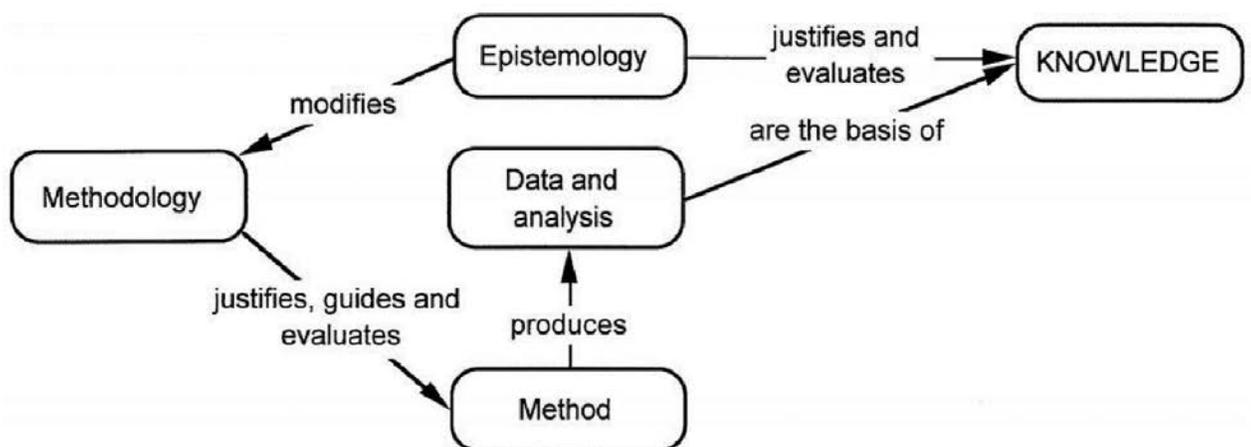
From Carter and Little (2007, p.1319)

This metaphysical version is generally accepted to be the most widely used definition of paradigm in social science methodology literature, within which post/positivism, a paradigm associated with the use of quantitative research methods, and constructivism/interpretivism, associated with qualitative research, are mutually exclusive concepts from an ontological perspective (Clegg, 2005; Denscombe, 2008; Morgan, 2007; 2014).

Adopting a firm 'epistemological stance' paradigm, makes the philosophical justification of mixed methods research problematic, as qualitative and quantitative methods are 'rooted in different paradigmatic assumptions' (p.65) understood to be incommensurable (p.60, citing Kuhn, 1962; 1996). I consider Hall (2013) to be locating pragmatism at this paradigmatic level when he suggests its philosophy is an inappropriate justification for mixed methods research.

(iii)   Shared beliefs

The next level of specificity is the version of paradigms as 'shared beliefs within a community of researchers who share a consensus about which questions are most meaningful and which procedures are most appropriate for answering those questions' (p.55), and is the version said to be favoured by Kuhn himself (p.74, citing Kuhn, 1970; 1974). This concept of a research paradigm described by Morgan is 'markedly different from the notion of paradigms linked to overarching grand epistemological paradigms' (Denscombe, 2008, p.277). It is mirrored by Denscombe's Communities of Practice paradigm (2008), proposed to accommodate

the variations and inconsistencies within mixed methods approaches and to be 'sufficiently flexible, permeable and multi-layered to reflect the reality of social research in the 21st century' (ibid., p.271).

Both Denscombe (2008) and Morgan (2007) suggest that at this level of understanding the paradigm concept, methodological choice is not constrained by metaphysical principles. Instead, methods can be chosen in terms of their practical value for dealing with a specific research problem. This is 'consistent with the pragmatist underpinnings of the mixed methods approach' (Denscombe, 2008, p.270), in which it is accepted, philosophically, that there are singular and multiple realities that are open to empirical inquiry and research is orientated toward solving practical problems in the 'real world' (Creswell and Plano Clark, 2011, p.20-28). The FAMe™ Project was located within this concept of paradigm with a methodological approach that was consistent with the philosophical foundations of pragmatism when identified at this level (see below).

The FAMe™ Project located in the pragmatist paradigm

'Pragmatism presents a coherent philosophy that goes well beyond "what works".' (Morgan, 2014, p.1051). Based on the work of John Dewey, pragmatism points to the importance of joining beliefs and actions in a process of inquiry that underlies any search for knowledge (Denzin, 2010). It adopts a pluralist attitude (Goles and Hirschheim, 1999) and uses the methods and method combinations that work best in relation to the research goals. With a focus on research questions and

research consequences (Creswell and Plano Clark, 2011; Miller, 2006; Tashakkori and Teddlie, 1998), rather than framing research around commitments to an abstract set of philosophical beliefs, pragmatism, when defined at this level, concentrates on such questions as: 'How do researchers make choices about the way they do research?'; 'Why do they make the choices they do?'; and, 'What is the impact of making one set of choices rather than another?' (Morgan, 2014, p.1051-52). These issues were considered when outlining my research position and are referred to throughout the ethics and methods sections.

Three important imperatives of pragmatism, taken from 'the philosophers who had the most influence' (p.68), are that: knowledge should make a difference in action (Dewey, 1931); data are generated through and used in both assessment and intervention (Mead, 1938); and research entails concrete inquiry into experience (James, 1907). My fundamental commitment, to engage in research: that has the potential to be of practical, real-time, real-world benefit to the population with whom I am researching; which, in this project, involved evaluating a system (not an intervention in psychosocial terms (Chown, 2017) but an intervention into the life path of the pupils involved); and concentrating on the lived-experiences of pupils, means that I, and therefore the FAMe™ Project, are aligned at a philosophical level, with these pragmatist requirements. Goldkuhl's description of pragmatist research states that:

> *Epistemologically, there is a general aim for prospective and prescriptive knowledge. Methodologically, exploration and experimentation in the world are applied in order to generate change and new knowledge. Ontologically, there is an empirical focus on actions, artefacts and actors.* (2012, p.15).

The FAMe™ Project met all three of these philosophical assumptions, as essentially the aim was to create knowledge to be used to bring about change through action, using an artefact (the FAMe™ System) to be experienced by actors (teachers and pupils).

It has been suggested (Goldkuhl, 2012; Hall, 2013; Morgan, 2007; Shannon-Baker, 2016) that pragmatist research should be both meaningful as a local improvement (i.e. the aim of the FAMe™ System in schools), and instrumental in creating knowledge that may be useful for more general practices (i.e. the potential extended use of FAMe™ System in further and higher education, and of the project to contribute to the understanding of autism and its impact on individuals). Goldkuhl states that the very idea of functional pragmatism (a term he uses for the type of pragmatism used in action research) is to 'be helpful to the world' (2012, p.10). If I were asked to articulate the one fundamental aspect of my overarching worldview, the very reason I want to do research, 'to be helpful to the world' would be an accurate summation.

Questions about the connection between ethics and epistemology were a long-standing concern for James, Dewey, and Mead (Morgan, 2007, p.72), and 'pragmatism has some important things to offer…in helping mixed methods researchers to ask better and more precise questions about the philosophical implications and justifications of their designs' (Biesta, 2010, p.114, cited in Cameron, 2011, p.102). Morgan argues that within the paradigm of pragmatism there exists a 'more direct connection to those [ethical] issues', than between

axiology and the core elements from the philosophy of knowledge, stating that, 'a pragmatic approach reminds us that our values and our politics are always a part of who we are and how we act' (2007, p.72). The relevance of epistemological issues, and other concepts from the philosophy of knowledge, are not ignored but, rather than privileging ontological assumptions in a 'top-down' approach, pragmatists attempt to connect abstract epistemological issues to the mechanics of their research methods using 'bottom-up' thinking (see Fig.1, p. 97, this chapter).

As the primary focus of pragmatism is on: the problem to be researched (rather than metaphysical principles); adopting the appropriate research methods to answer the research questions; and the consequences of the research (Feilzer, 2010), the abstract pursuit of knowledge through inquiry, central to the metaphysical approach (Denscombe, 2008), is superseded by an attempt to gain knowledge in the pursuit of desired ends (Morgan, 2014). This pragmatist position fits with that endorsed by authors concerned with ethical practices in research involving children, in which: the choice of appropriate methodology is deemed 'crucial' to ensure ethical rigour (Kellett, 2005); researchers should only ask questions which are worth asking (according to the participants); and only use research methods that answer the questions effectively (Thomas and O'Kane, 1998). It is also aligned with those who advocate that any research involving autistic participants must have 'desired ends' (Johnson and Onwuegbuzie, 2004, p.16; Morgan, 2014) that meet the priorities of the autistic population (Chown et al., 2017; Pellicano et al., 2014), members of which should be actively involved in the research process (Milton and Bracher, 2013).

Central to any pragmatic approach is an emphasis on processes of communication and shared meaning (Cameron, 2011; Morgan, 2007; Hall, 2013). Morgan argues that, as pragmatist researchers, 'we need to achieve a sufficient degree of mutual understanding with not only the people who participate in our research but also the colleagues who read and review the products of our research' (p.74). I found the neatness of fit, between this central aspect of pragmatism and the aims of the FAMe™ System, i.e. to promote 'shared meanings' and 'mutual understanding' between autistic pupils and their teachers, extremely satisfying.

Parallels were also identified between the emphasis on communication in pragmatism and the interview methods used in this project, in which attending to and accommodating different communication preferences and styles was key to establishing 'mutual understanding' between myself and the participating pupils. It also connects well with the double-empathy problem, proposed by Milton (2012), and also known as a shared difficulty in cross-neurological theory of mind between autistic and non-autistic individuals (Beardon, 2008b), in which potential exists for a mutual misunderstanding of how it is to be the other. A recommendation for the development of a greater level of 'shared meaning', between the autistic and non-autistic populations, is made by both authors. The discovery that a core tenet of my methodological approach was reflected in the project methods and aims, provided my first insight into what it might mean to locate one's methods and oneself within a paradigm.

The research approach, and bottom-up thinking style, used to connect the research methods to my philosophical position, was therefore justified by my identifying as a pragmatist researcher. Rather than focusing on abstract metaphysical concepts, by taking a pragmatic approach to this research it was appropriate to direct attention to investigating the factors that had the most impact (my position as a researcher; as an autistic individual; and as a parent of autistic children) on what I chose to study (autism) and how (i.e. the methods) I chose to do so (Morgan, 2007). These factors are outlined in my researcher positionality and methods sections. Ethical issues are discussed both within the methods section and separately.

(iv)   *Exemplar of a research model*

The most specific version of a paradigm discussed by Morgan (2007) is as a 'model example' for carrying out research in a given field. Here a research project is often used as a case study giving a 'paradigmatic example' (p.56). The paradigm is a framework for thinking about research design, measurement, analysis, and personal involvement.

An example of a paradigm at this most specific level is the Draft Framework for inclusive autism research (Chown et al., 2017), i.e. that which is both participatory and emancipatory (Chown and Beardon, 2017, p.6), which builds on an earlier 'structure' for framing research within which, 'the purpose of research and its potential links to practice can be explored' (ibid, p.6). The Draft Framework is based

on two sets of emancipatory research principles for disability research (Oliver, 1997, p.6 and Stone and Priestley, 1996, p.709-710). It is compatible with pragmatist research principles and consistent with the draft Code of Practice for Researchers, prepared by the Shaping Autism Research project (Hampton and Fletcher-Watson, 2016).

The following 'general' requirements' are outlined:

- The autism community and/or a researcher with autism identifies and defines the matter(s) requiring investigation or confirms the identification and definition of the problem by others

- The social model of disability is at the heart of the project ethos

- Projects are either owned or jointly owned by representatives of the autism community

- Research outcomes are focused on improving the lives of people with autism

(Chown et al., 2017, p.734).

The research undertaken within The FAMe™ Project reflects three of these four 'general' requirements and the methods were consistent with the draft Code of Practice (Hampton and Fletcher-Watson, 2016). However, the second proposed requirement of the draft framework, i.e. for the social model of disability to be 'at the

heart of the project ethos', was not met. This framework item was designed to ensure

that any project:

> *…is based on a belief that the main reasons for autistic people not being able to live a fulfilling life are the barriers placed in their way by a non-autistic society, and that it is a societal responsibility to remove these barriers, not put the blame for the difficulties faced by autistic people on them as individuals.*
>
> (Chown et al., 2017, p.727).

Although I do not subscribe to strict social model thinking, my affiliation to the

bio-psychosocial approach to disability does not preclude me from sharing these

beliefs. In the draft framework article, it is argued that 'there is little point in

researching autism unless the forces creating and sustaining the barriers to autistic

people living fulfilling lives are tackled' (ibid, p.729). The aim of the FAMe™ System

is to reduce the negative experiences of school and barriers to learning faced by

autistic pupils through the promotion of teacher understanding and pedagogical

change. Thus, whilst not explicitly fulfilling the framework requirement of being

located within the social model of disability, the social model ethos is nevertheless

represented. I was therefore satisfied, and Dr Chown agreed (personal

communication, 17.01.2018), that the FAMe™ project sat comfortably within the

general requirements of the Draft Framework, which provides a 'model example'

(Morgan, 2007, p.56) of 'best practice' for carrying out inclusive research in the field

of autism (Chown et al., 2017).

In addition to its general requirements, the Draft Framework also specifies

certain non-general requirements for inclusive research practice. Some of these are

relevant only to research groups, rather than individual researchers and, as such, this project does not meet them. Other requirements relate to funding bodies and applications for funding, which were not necessary in this case. All of the non-general requirements/principles of the Draft Framework, which relate to: design; methods; participants; and data, and that are relevant to single researcher projects, were met by the FAMe™ Project.

Another example of the 'exemplar of a research model' version of paradigm (Morgan, 2007), which provides a framework for thinking about research design, measurement, analysis, and personal involvement, is provided in a chapter contributed to the latest Encyclopedia of Autism Spectrum Disorders, (Volkmar (ed.) 2017). Here, Chown and Beardon identify a list of questions for researchers to consider, in order to ascertain the purpose and potential impact of their work. Whilst these authors do not claim that there are types of implicitly 'good' and 'bad' research, their questions have been devised to encourage researchers to reflect on whether their projects meet the priority criteria outlined by the autistic community (Pellicano et al., 2014), and/or are likely to inform autism practice. Their questions, with my brief responses reflecting the FAMe™ Project, are shown below:

1. ***Does the research engage directly with the autism community?***
   Yes

2. ***Does the research engage with autistic individuals as 'subjects' or as co-researchers?*** Participatory-styled practice is utilised when

possible and the pupils are positioned as 'experts' to be worked with (rather than 'subjects' of study).

3. ***What potential impact might the research have on autistic individuals?*** If the FAMe™ System is effective in achieving its aim, autistic pupils will receive individualised support from their teachers and/or teachers will stop doing the things in class which cause pupils difficulties/stress. It is anticipated that this will have a positive impact on the participating autistic pupils' experiences of school and on their psychological well-being.

4. ***What impact might the research have on those associated with autism (e.g., parents, carers, professionals)?*** Use of the FAMe™ System has the potential to increase teacher confidence in their ability to meet the needs of their autistic pupils. In addition, any improvement in school related quality of life for autistic pupils is likely to have a knock-on beneficial impact on their parents/carers.

5. ***Is the main purpose of the research to directly or indirectly influence quality of life for the autistic population?*** To have a direct positive impact.

6. ***Does the research intend to establish new knowledge that can influence practice that will have a positive influence within the autism community?*** Yes, a greater understanding of autistic pupils' experiences of school in general, and in particular of their priority areas for additional in-class support, will be identified and used to inform teaching practice.

7. ***How might the research enable practitioners to develop better practice?*** It has the potential to enable teachers to better understand

their autistic pupils and to offer individualised support according to pupils' self-prioritised areas of difficulty.

8. ***How involved are autistic people in the aims of the research and the project design?*** The project has been designed and every stage, including the development of data collection materials, carried out by an autistic researcher (me).

9. ***Does the research fulfil or acknowledge any criteria identified by the autism community as needing investigation?*** Yes, to identify an intervention that addresses the immediate real-world needs of autistic individuals with the potential to enhance quality of life (Pellicano et al., 2014).

Questions written by:

Chown and Beardon (2017, page number unobtainable).

I was able to identify that, as was the case for the non-general requirements/principles of the Draft Framework (Chown, et al., 2017), the goal and design of the FAMe™ project, and methods used throughout, had the potential to satisfy each of the nine questions posed (Chown and Beardon, 2017). Therefore, although the concept of paradigm used to frame this research was identified at the level above this one (i.e. that of 'shared beliefs), it is envisaged that the FAMe™ Project itself has the potential to become a 'model example' for carrying out research with autistic pupils (Chown, personal communication, 18/04/2018).

3. Researcher Positionality

Identifying myself as a pragmatist did not mean absolving myself of the responsibility to consider my research positionality. Although this research did not sit within the level of paradigm that privileges 'metaphysical' assumptions (Denscombe, 2008; Morgan, 2007), I was still required to reflect on how my own perspective essentially influenced the research issues I prioritised and the methods I employed to research them.

It was recognised that every choice I made, including, but by no means exclusive to, my: use of autism terminology (e.g. autistic vs with autism; difference vs disorder); the model-lens, through which I view autism (e.g. bio-psychosocial vs medical vs social); and the research-field/paradigm-lens (e.g. education studies vs disability studies), through which I locate issues of importance, are interrelated and connected to my underlying values and belief systems, which in turn are related to my experiences and understanding of the world (Takacs, 2002). It is important that these underlying assumptions be made explicit in order that inherent biases can be understood by those who wish to interpret my findings.

i.   Methodological assumptions

Methodological assumptions relate to the appropriate approach to systematic inquiry (Mertens, 2007). Methodologically, choices were made in this project - that went beyond the use of quantitative, qualitative, or mixed methods - about how to

collect data that would inform me about the reality of autistic pupils' school experiences in such a way that I could feel confident that I had captured their subjective reality. These ontological and epistemological choices were reflected throughout the research approach. For example, when developing the recruitment and interview materials, I took into account what other researchers have written about the needs of autistic participants (Hampton and Fletcher-Watson, 2016; Research Autism, 2015), and considered such issues as potential difficulties with communication (Allen and Lewis, 2014), and anxiety created by the unknown (Sinha et al., 2014), whilst making no assumptions about their preferred learning styles (Chown, 2017). This led me to: present all project information to pupils through a variety of media (Nicolaidis et al., 2015); introduce myself via email, photograph, and video prior to the initial meeting (Hampton and Fletcher-Watson, 2016; NAS, 2016b); and provide alternatives to face-to-face interviews (Davis et al., 2012). Further discussion of these strategies is included in the methods and ethics sections.

The impact of my ontological and epistemological position on the choice of methods is outlined below. A visual representation of how I understood interrelated influences to have come together to form my methodological position was created (Fig. 3). The funnel represents my methodological position, the contents of the funnel are what I understand to be the 'main basic ingredients', and the resulting 'output' is this research. Factors which contributed to/made up these 'ingredients' are attached where I believe they have had the most effect but, due to the interrelationships between the funnel contents: of personal identity; model-lens; and research

field/paradigm, all contributory factors can be understood to have had some influence on all of the main ingredients.

I recognise that the main ingredients themselves are subject to change, as I learn and develop my thinking and have different experiences, and also that there are many influencing factors missing, such as my gender, ethnicity, and social class, which other researchers might argue are essential components of who I am, and therefore of my research positionality. However, in line with pragmatist principles, I constrained my consideration to those issues I believe to have had the 'most impact' (Morgan, 2007) on what I have chosen to study and the way I have chosen to study it, whilst at the same time accepting that there will be 'higher-level' influences (Denscombe, 2008) which are not being attended to.

Figure 3.

The influences of my positionality on the research approach and methods.
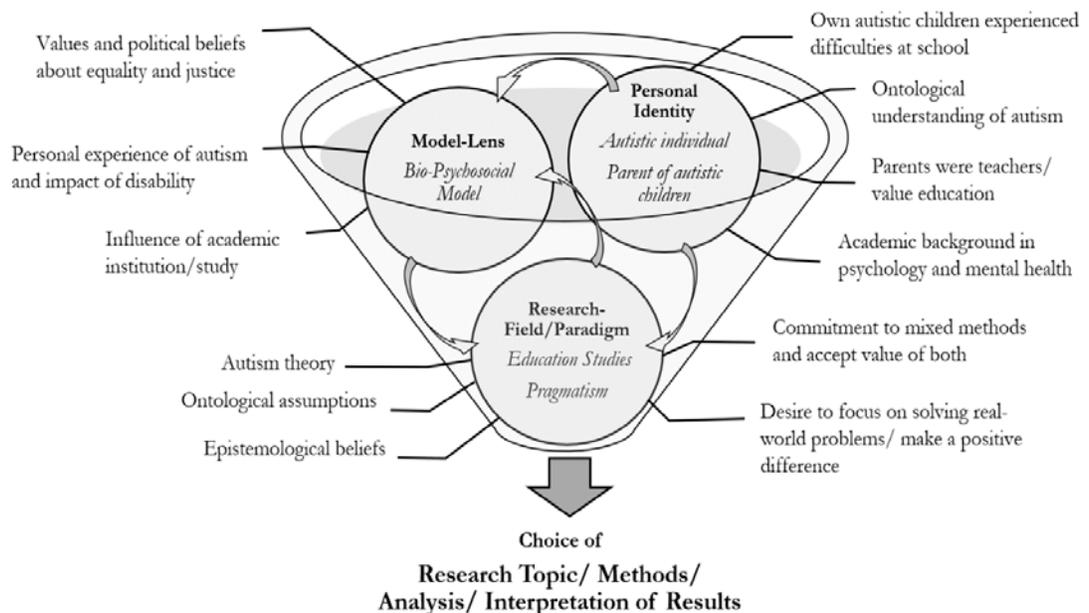
ii. Ontological assumptions

Ontology deals with realities that can only be known at a conceptual level (Mertens, 2007). Autism is conceptualised variously as, amongst other things: a psychiatric/mental disorder (classified in diagnostic manuals); a neurological condition with an entirely biological basis (medical model thinking); a disability created by societal attitudes and physical barriers (social model thinking); a set of cognitive, perceptual, and sensory differences which are impacted by an individual's environment (bio-psychosocial model thinking); and as a 'myth', or label given to a socially-constructed category, with no existence other than as a conglomeration of unconnected behaviours (a view described but not endorsed by Chown and Beardon, 2017, p.5).

Evidence sought to enable a better understanding of autism includes that from: psychological experimentation (e.g. tests exploring '*deficits'* in ToM, EF and CC); neurological investigation (e.g. functional brain imaging); genetic screening; behavioural observation; and qualitative investigations of parental and practitioner, and less frequently autistic individuals', experiences and views.

As previously discussed, only a scant body of research exists in which members of the autistic population have been engaged with to ascertain their views about how it actually is to be autistic (Milton, 2014; Milton and Bracher, 2013; Milton et al., 2014). In 2014, Pellicano et al. investigated the percentage of funding allocated to different types of UK autism research projects over a three-year period,

with the following results: biology, brain, and cognition (56%); treatment and interventions (18%); causes (15%); diagnosis, symptoms, and behaviours (5%); services (5%); societal issues (1%). The response of the autism community to this was almost entirely negative (Chown and Beardon, 2017), with autistic adults suggesting that the majority of autism research follows a non-autistic agenda, and parents reflecting that it 'fails to accurately reflect the reality of the lived experience of autistic individuals' (ibid, p.6).

My ontological understanding of autism, as a neurological difference affecting an individual's social, cognitive and sensory experience of the world, has been influenced by: my own and my children's diagnosis and experiences; my post-graduate study at an institution committed to the social model ethos; the writing of autistic academics and autistic authors; and an ideological rejection of deficit-based medical model thinking, in which the existence of societal effects on the autistic experience is not acknowledged (Chown and Beardon, 2017).

I maintain that autism can only truly be understood through the type of engagement with autistic individuals that enables their articulation of how it is to be autistic. This position has necessarily influenced my approach to autism research, which I believe should focus on meeting the priorities of the autistic population (Pellicano et al., 2014), and the theories of autism I have chosen to explore for their possible explanations of autistic experiences. I have no interest, for example, in theories that prioritise cause or cure, neither of which, in my opinion, can offer anything of use to autistic individuals and the difficulties they face day-to-day,

although I recognise that others do not agree (e.g. Barnes and McCabe, 2012). Instead I privilege those theories that aim to describe and promote the understanding of autism (Chown, 2017, p.7), with explanations that have the potential to inspire societal/environmental change.

For this research project, it was necessary for me to consider and justify what evidence I would accept to demonstrate the existence of such concepts as pupil mental [ill]health (e.g. anxiety, depression, stress, low self-esteem), and the notions of improvement and change. For example, I trusted that validated self-report measures, designed to capture the thoughts and feelings understood by researchers to be related to the concept of anxiety (e.g. Beck, Steer and Garbin, 1988; Kashani, Orvaschel, & Kashani, 1990; Leyfer, Ruberg, and Woodruff-Borden, 2006), that had previously been shown to provide reliable results within the autistic population (Ichikawa et al., 2013; Mandy et al., 2016), would actually provide a reliable measure of the anxiety levels of pupils participating in this research. I did not investigate the ontological assumptions made by the designers of these measures, but instead relied on the knowledge that they have been widely accepted, by other researchers in the field, to provide the information I was seeking at an acceptable level of accuracy (e.g. evidence of strong reliability, validity and internal consistency) and have been shown to retain their validity when used with autistic youth (Ichikawa et al., 2013; Mandy et al., 2016).

In terms of the identification of improvement and/or change, from pre- to post-FAMe™, in pupils' scores, I placed my confidence in statistical indicators. In other

words, if measurable differences in pupil self-report scores, taken at two points in time, were large enough to be considered unlikely to have occurred by chance, I accepted this as evidence of change. I defined improvement/positive change as a difference in scores in a desirable (fewer symptoms of a negative concept) direction.

Contacting parents, for their perceptions of change in their children's mental health over the course of the project, as a means of validating any alteration indicated by the self-report scales, was considered but rejected. There were several reasons for this. Firstly, as this project is essentially about facilitating and responding to pupil voice, I was concerned not to create a situation where pupils might feel that their own communication, regarding their symptomology, was being verified and/or considered not to be reliable. In addition, it has been suggested that parents are an unreliable proxy for their children's mental health status (Coghill et al., 2009; Potvin et al., 2015; Upton, Lawford and Eiser, 2008), thus I do not believe that engaging with parents would have meaningfully contributed to the validity of these findings.

Reflecting on ontological considerations made me conscious of just how much of a shared language relates to concepts which are accepted as reality (Mertens, 2007) without the speaker/writer needing to justify/explain the meaning being attributed (because of the acceptance of shared meanings). To have to do so would render the writing and reading of this thesis impossible. For example, I make the assumption that anxiety and depression are 'negative' concepts, and that there will be general agreement that any reduction of the symptoms of these constitutes

'positive' change. The possible ontological arguments around the concepts of positive and negative, whilst potentially interesting, are not discussed here. I rely on their 'shared meaning' to justify my decision to use decreased symptoms of negative well-being (supported by narrative accounts of positive change) as an outcome measure when evaluating the success of the FAMe™ System. What I did not assume, however, was that 'shared meanings' would necessarily exist in the language of the self-report measures and that of the autistic pupils completing them (and so I might need to support them to understand what was being asked), nor between the pupils and myself (although I believe our finding shared meanings to be more likely, than if I were not autistic, because we share the same neurology). This is discussed in the epistemology section.

iii.   Epistemological assumptions

Having considered what evidence would be accepted, to establish the reality/existence of the concepts being researched, it was important to decide how to gather this evidence in order that I could 'know' that it was a valid indication of the concept under investigation. If I were to be the 'knower', and the 'would-be-knowns' the autistic pupils (Mertens, 2007, p.215), I needed to remain cognisant of their potentially idiosyncratic and/or literal use of language (Allen and Lewis, 2014) and ensure that, before I interpreted their communication (verbal or self-reported/written), 'shared understanding/meaning' was established (Nicolaidis et al., 2011). This was reflected in my methodological approach, where a process of reflecting back and

checking out meaning, during each interview and afterwards via email, occurred (Leatherland and Beardon, 2016).

It was recognised that pupils' interpretation of and reactions to situations, people and communication might not reflect those typically perceived/experienced by non-autistic others. However as that is, by definition, a feature of autism (DSM-5; ICD-10), it was essential to capture such differences and to recognise pupils' descriptions of their school experiences as representations of their own truth. A carefully considered decision was made to accept that the pupils participating in this research would say what they meant and, once clarity and shared meaning was established, through the reflection and checking back process, interview and self-report responses were assumed to be an accurate representation of their beliefs, feelings and opinions, whilst acknowledging the possibility that factors beyond my comprehension/control might have influenced their responses. For example, if a pupil described/experienced a situation that the majority of non-autistic others would likely recognise as teasing/bullying, but the autistic pupil did not perceive it as such, their perception was accepted as 'truth'. The alternative, i.e.: to not accept the pupils' responses at face value; assume hidden meanings; or think that I somehow knew better than they what they were trying to say, would have been unethical and disrespectful.

Teachers' survey responses were provided anonymously online, and there was no reason to question their validity. However, although some potential

influencing factors, such as existing power relationships within school, or a desire to react positively to the FAMe™ System for my sake, which might otherwise have biased results, were assumed to have been negated through anonymity, it is important to acknowledge the possibility that these, and other factors, might still have influenced teachers' responses in ways that cannot be accounted for.

iv.   Identifying the research problem

In line with pragmatist principles, the research problem identified here, i.e. that autistic pupils attending mainstream secondary schools are vulnerable to a range of negative outcomes (Charman et al., 2011; House of Commons Education and Skills Committee, 2006; Morewood et al., 2011) which are contributed to by teachers' lack of understanding of autism in general, and of pupils' individual support needs in particular (Charman et al., 2011; Falkmer et al., 2012; Hebron and Humphrey, 2014; Leatherland and Chown, 2015), led to the development of research questions designed to produce prospective and prescriptive knowledge (Goldkuhl, 2012), with the potential to result in local improvement and be useful for more general practices (Goldkuhl, 2012; Hall, 2013; Morgan, 2007; Shannon-Baker, 2016).

In addition, research questions, about the relationship between autistic pupils' school experiences and the explicit features of autism specified in the diagnostic criteria, and factors that are explained by existing cognitive autism theory, were included. This was because determining the power of currently available information to provide explanation for and therefore understanding of autistic experiences, is an

important step in the identification of what information and theory should be attended to and/or developed in the future. The research questions for this project were as follows:

Research Questions

1. Are the explicit and implicit features of autism, specified in the diagnostic criteria of autism and autism literature, reflected in autistic pupils' descriptions of their lived experiences of school and, if so, to what extent?

2. To what extent can the school experiences of the autistic pupils participating in the FAMe™ Project be explained using cognitive autism theory?

3. When engaging autistic pupils in research focusing on their experiences of school:

    a) What can be learned about autism/autistic pupils' school support needs from their descriptions of their school experiences?

    b) Are autistic pupils able to identify and communicate positive and/or negative classroom experiences and, if so, how can these be used to inform teaching practice?

4. When information about individual autistic pupils is made easily accessible to their teachers:

    a) In what way does teacher behaviour/practice towards individual autistic pupils change?

    b) What impact is there on autistic pupils' educational experiences and quality of life related outcomes?

Research Questions were sequenced logically and in relation to the presentation of autism related information throughout the thesis. Their order does not indicate any priority within the investigation, or any relative importance in terms of the potential contribution to knowledge, and/or the positive impact on the lives of members of the autistic population answering them might have.

4. Ethical Considerations

Ethical research with children should, '. . . enable children to be heard without exploiting them, protect children without silencing and excluding them, and pursue rigorous inquiry without distressing them' (Alderson, Morrow and Clifton, 2005, p.12). This was my go-to statement when considering/reflecting on my actions at every stage of this research project.

Ethical approval from Sheffield Hallam University's ethics committee was sought and granted prior to project commencement (Appendix 2).

This section details the essential ethical considerations, and the necessary actions taken, to ensure that the methods used in this research were justifiable and sound (BERA, 2011), and to demonstrate that my responsibility, as an autism researcher engaged in educational research (BERA, 2011; Hampton and Fletcher-Watson, 2016), was prioritised at every stage of the research process. The steps

taken to attempt to reduce/eliminate potential risks to participants are described in full within the methods section.

Embedded throughout, the principle of ensuring that participants were fully supported and protected from risk of harm was continuously reflected in practice. Taking into consideration the particular vulnerabilities of autistic youth (Ashburner et al., 2013; Sarrett, 2012; Vasa et al., 2013), possible risks were identified from the outset. These included, but were not exclusive to, the potential for: increased stress due to social interaction (de Bruin et al., 2007); difficulties with communication (Allen and Lewis, 2014); power dynamics (Harcourt et al., 2011; Stone and Priestly, 1996); and heightened anxiety as a result of change to routine (Gillott and Standen, 2007; Humphrey and Lewis, 2008).

Research ethics literature, from the fields of both childhood and autism studies, report concerns around the issues of participation, agency, and voice (e.g. Powell and Smith, 2009; Smith in Harcourt, Perry and Waller (eds), 2011; Thomas and O'Kane, 1998; Milton et al., 2014), with many of the criticisms relating to the research of/with children being mirrored in autism research literature. Both groups have traditionally had their voices excluded from the process of knowledge production (Beresford et al., 2004; Gray and Winter, in Harcourt, Perry and Waller (eds), 2011; Milton, 2014; Milton and Bracher, 2013; Milton et al., 2014), and researchers from both fields have been accused of 'tokenistic' participatory practices (Kellet, 2005; Milton, 2012) that either have no long-term impact on children's lives (Gray and Winter, in Harcourt, Perry and Waller (eds), 2011), or do not concentrate

on the everyday needs of autistic people (Nicolaidis et al., 2015; Pellicano and Stears, 2011).

In 1989, the United Nations Convention on the Rights of the Child (UNCRC) introduced an internationally accepted standard of basic human rights for children (Smith in Harcourt, Perry and Waller (eds), 2011), which was ratified in the UK in 1999, and has implications for all research involving children. BERA ethical guidelines (2011, paragraphs 9 and 10) require researchers to comply with Articles 3 and 12 of the UNCRC and for research such as this, which involves children with additional needs, Article 7 and 8 must also be upheld. In combination these UNCRC Articles require researchers to ensure the best interests of the child/ren are their primary consideration, and to guarantee all children the opportunity to participate and express their views freely on matters that affect them (Kellet, 2005).

Legislation and policy, both national, for example the Children Act (DfES, 2004b) and Aiming High for Disabled Children: Better Support for Families (Her Majesty's (HM) Treasury/DfES, 2007), and international, for example, the Convention on the Rights of Persons with Disabilities (UN, 2006), has enshrined these rights for disabled children, making it a requirement that their views, both about 'their experience of daily life and about the services in place to support them', be obtained (Preece and Jordan, 2010, p11). It has been claimed that research with children can only be seen as 'high quality' when it is rooted in respect for human dignity and ethical practice (Groundwater-Smith and Mockler, 2007, p.359).

As a result of the shift in research approach, brought about by the UNCRC (1989), a considerable body of literature now exists on children's participation, arguing for greater involvement of children and young people in decisions that affect them (Alderson, 2000; Hill et al., 2004; Sinclair, 2004). Such research is thought to have the potential to enhance participants' skills and self-esteem, to support better decision-making and protection, and to improve policies for children (Mayall, 1999; Sinclair, 2004, cited in Powell and Smith, 2009) as well as overcoming the ethical problems involved when research involves direct child contact (Thomas and O'Kane, 1998). Similarly, autism researchers have argued for the inclusion of autistic individuals in autism research, claiming that it 'enriches' the process and strengthens its epistemological validity (Milton, 2014; Milton and Bracher, 2013, p.66), whilst often adding much to the work produced (Wittenmeyer et al., 2011; 2012). This project involved both of these participant groups simultaneously, i.e. the participants were autistic and children, and it therefore required the maintenance of a constant level of reflection on the ethical issues involved at every stage (Leatherland and Beardon, 2016).

It has been suggested that the involvement of autistic individuals in research, and improvements in participatory methods, are essential requirements 'if social research in the field of autism is to claim ethical and epistemological integrity' (Milton, 2014, p.794), and some propose that participatory practice involving autistic individuals, is 'the only ethically acceptable way forward' (Milton et al., 2014, p.2651). However, genuine participatory practice (Jivraj et al., 2014) involves empowerment, partnership, and equality of input for participants at every stage of the research

process, including the design, analysis, and dissemination of findings (e.g. Chown et al., 2017; Waltz, 2006). Participation at this level was not offered in this project, where the majority of the research processes were carried out independently of the participants, although they were afforded some opportunity to contribute to the FAMe™ System design and were given choices regarding aspects of the interview methods. In addition, according to the Draft Framework for inclusive autism research (Chown et al., 2017), 'an autism research project undertaken by one autistic researcher working alone cannot be classified as participatory, even if it otherwise meets all the requirements…'[10] (p.17).

It could not therefore be claimed that the FAMe™ Project was an example of participatory research, although, as previously discussed in the methodology section, it did meet all of the requirements of the Draft Framework (Chown et al., 2017) that could be applied to it, and fulfilled many criteria of 'good practice' (ibid; Hampton and Fletcher-Watson, 2016). For example, my own autistic voice was embedded in every stage, and the research aims met the priority criteria for future research identified by: members of the UK autism community, i.e. it responds to the needs of autistic individuals and has the potential to effect immediate positive change (Pellicano et al., 2014); and the founder of the Autism Self-Advocacy Network, i.e. it focuses on an intervention aimed towards an improved quality of life and a quality of opportunity agenda for autistic individuals (Ne'eman, 2011). There was a commitment, from the

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[10] …even if, as in this case, 'the autistic researcher is committed to participatory styles of working and adopts a participatory approach'

beginning, to attend to the voices of the autistic pupil participants and to position them as the true experts (Milton, 2014; Waltz, 2006) in what secondary school is like for them, and to thus elucidate what support is required (both individually and as a group) to enhance their chances of educational success. This satisfies Thomas and O'Kane's ethical position that, 'researchers should only ask questions [of child participants] which are worth asking' and 'which are relevant to [their] own concerns' (1998, p.341).

Boyden and Ennew's definition of participation, i.e. 'taking part and the sense of knowing that one's actions are taken note of and may be acted upon' (1997, cited in Morrow, 1999, p.298) was also met, through the collaborative process of FAMe™ statement generation. Pupils understood that the very function of the FAMe™ System was to make these statements available to their teachers, to be attended to and acted upon. The facilitation of this process offered a level of empowerment and inclusion (participatory working) to those who took part, and I believe that, although 'genuine' participatory practice (Chown et al., 2017; Jirav et al., 2014) was not achieved, it is justifiable to frame this research as a 'participatory-styled' project, which offers more than a *tokenistic* effort at inclusionary practice (Milton, 2014; Charman et al., 2011).

Attending to the rights of the child provided the ethical basis for this research and the following examples provide evidence of how this was achieved. Smith (in Harcourt, Perry and Waller (eds), 2011) has suggested that: the relationships children have with the researcher/s; the settings in which the research takes place;

how they are viewed as participants; and how they are assessed, hold the key to advancing authentic knowledge regarding their experiences. The autistic children participating in this project were positioned as 'knowers' (as well as 'would-be-knowns', (Mertens, 2007, p.215)) to be researched with, rather than objects to be researched on (Woodhead, 2005); in a project where their active participation was crucial (Hill et al., 2004; Sinclair, 2004); attending to their voices was central to the process (Powell and Smith, 2009; Smith in Harcourt, Perry and Waller (eds), 2011; Thomas and O'Kane, 1998); and their involvement had the potential to enhance their own well-being (Munford and Saunders, 2001; Pellicano and Stears, 2011).

Standard ethical practices (BERA, 2011) relating to: gaining informed consent, from both participants and their parents (paragraph 3); being open about the aims and purpose of the study (paragraph 4); ensuring pupils understood their right to withdraw (paragraph 8); protecting their right to privacy (paragraph 18); and notifying pupils of the duty to disclose behaviour and/or intentions deemed likely to be harmful to themselves or to others (paragraph 22), were all attended to in the recruitment materials (Appendices 5 and 6) and were reiterated immediately prior to the commencement of each interview.

As autistic individuals necessarily have differences (from those who are non-autistic) and/or difficulties with aspects of their communication and language (Martin and McDonald, 2004; Mitchell, Saltmarsh and Russell, 1997; NAS, 2017b), and it is thought that providing choice about communication methods can set up opportunities for children to express themselves in a manner that makes them feel

empowered and capable (Dockett, Einarsdottir and Perry, in Harcourt, Perry and Waller (eds), 2011), special consideration was given to the methods used to communicate project information to pupil participants and to the preferences they might have for expressing themselves during their interviews. For example, project information was provided in different formats, i.e. in long and short written form with illustrations (Appendix 5) and via a narrated video (Appendix 6), to accommodate potential variance in information-processing styles, and pupils were offered the choice to be interviewed: face-to-face or via email (Davis et al., 2012); at home or at school; with or without additional support from a parent/carer or other trusted adult; and were given the opportunity to communicate their interview responses through a variety of media (NAS, 2016b; Research Autism, 2015) according to their needs and/or preference (Nicolaidis et al., 2011).

It has been reported that children are more likely to respond openly and honestly if they feel respected and safe (Gollop, 2000), and this usually relies on: the skill of the researcher in putting them at ease; minimising the distance between adult and child (whilst still respecting personal space preferences); establishing shared interests and a dialogue; and putting the child in the position of the expert. The pupils in this study were most certainly positioned as 'experts', whose knowledge about themselves and their experiences of school was something they understood only they could share and was central to the whole research process.

My position, as the parent of autistic children (although not as an autistic researcher as I had not been identified as autistic at that time), was made known to

participants at the recruitment stage and, although no prior assumptions were made about individual's communication preferences, I believe my own experience of talking to autistic young people (and of being autistic) enabled me to be flexible and adapt my communicative style to meet their needs in situ (Owen, Hayett and Roulstone, 2004).

In terms of distance between myself and the participants, we sat at right angles to each other at a large school desk and the pupils were asked if they were comfortable with me sitting in this position and offered alternatives. This positioning reduced the need for eye contact, known to be uncomfortable for some autistic individuals (NAS, 2017b), and enabled me to share project materials with and read answers to pupils who wanted my support in that way. It also acted as a means to lessen the power disparities (Harcourt et al., 2011; Morrow and Richards, 1996; Stone and Priestley, 1996) that might have been more likely to be assumed/inferred from my adult status in school, had I sat opposite participants in a manner more typical of a teacher/pupil interaction.

I remained alert to the possibility of 'detriment rising from participation in research' (BERA, 2011, paragraph 16), and the behaviour of participants during interview was continually monitored for signs of distress (Alderson and Morrow, 2011; Harkema and Coffee, 2014). As a result, one pupil was withdrawn from the research process, two were offered the opportunity to stop their interview but chose to continue (one took a break and then returned), and another pupil decided not to

complete the self-report measures because of the focus on issues relating to mental health.

All pupils were reminded that a familiar member of school support staff was available throughout should they wish to access them at any point. None of the pupils indicated the desire for additional support, which was taken as an indication that their participation needs were met throughout the interview and quantitative data collection process.

Pupils were asked to provide feedback about their experiences as participants (Hampton and Fletcher-Watson, 2016) as part of the post-FAMe™ interview. Their responses were generally positive and are reported in the Findings Chapter (Section 7).

In terms of the teachers who participated in this research, I recognised, and sought to minimise, the impact of the project on their normal working and workloads (BERA, 2011, paragraph 14) by using online surveys to collect their data. These surveys could be completed at a time convenient to each teacher, in as little as 5 minutes, with the option for teachers to take longer and elaborate their responses should they wish to. During the design of the FAMe™ System, consideration of teachers' existing workloads was a priority issue, and one which the System itself seeks to address, in terms of providing teachers with easy access to pupil information.

5. The FAMe™ System

i. Concept

The FAMe™ System concept was born from my experience as the parent of autistic children attending mainstream secondary schools. My experience reflected what has been frequently reported in the autism education literature (discussed in the Literature Review Chapter), i.e. teachers often misunderstood my children's needs as autistic learners (Batten et al., 2006; Brewin et al., 2008; Starr et al., 2006; Whitaker, 2007), and my children received criticism for academic failures that were inherently linked to their autistic processing style (Chown, 2017), and behaviours related to their difficulties understanding social communication (NAS, 2017b), such as their literal interpretation of language (Hobson, 2012; NAS, 2017b) and misinterpretation of non-verbal cues (NAS, 2017b; DSM-5, 2013).

As my children moved through secondary school, they experienced increasing levels of mental health difficulties and school refusal, both common phenomena amongst autistic children and adolescents (Magiati et al., 2016; White et al., 2009; Selles et al., 2015; Steensel, et al., 2011), thought to develop in part through their experiences within the education system (Morewood and Glew, 2011; NAS, 2010).

Communication with my children's teachers suggested that, although various SEND teacher-information systems existed in their schools, e.g. Pupil

Passports/Snapshots and register-linked SEND files (Morewood, 2014; NASEN, 2014), these were relatively difficult and/or time consuming for teachers to access, and often remained unread. When information had been read by teachers, this tended to have been at the beginning of an academic year, when SENDCOs typically contacted teachers about all pupils on the SEND register, and much of the detail, and sometimes their diagnosis itself, had since been forgotten.

On reading my children's 'Snapshots', I learned that the majority of the information contained was generic, e.g. 'Pupils with autism often have an inflexible thinking style', and, 'Pupils with autism can find it difficult to cope with change', and teachers were being required to translate this non-specific information into individualised classroom support plans. The expectation, that teachers should simply be able to 'intuit' the wide and complex array of subtle difficulties experienced by individual autistic pupils, is unrealistic (Leatherland and Beardon, 2016; Ravet, 2011; Singh and Elsabbagh, 2014), given that the majority of teachers possess only a limited understanding of autism (Charman et al., 2011; Falkmer et al., 2012; Hebron and Humphrey, 2014; Leatherland and Chown, 2015; Leatherland and Beardon, 2016) and many lack confidence in their autism pedagogy (AaA, 2016; NAS, 2016a; NASUWT, 2013).

In addition to the generic nature of my children's 'Snapshot' contents, I found they had been written on entry to Y7, using information passed from junior school during transition, had not been updated (for 4 years in my daughter's case), and did

not reflect my children's perceptions of what would actually be most helpful to them in the secondary school environment.

Motivated by my frustration with the present system, and the need for better understanding of autism in schools and for evidence based educational practice (Parsons et al., 2009; Parsons et al., 2013; Pellicano et al., 2014), I set out to design and develop a method to more easily communicate individual pupil's specific classroom support needs to their teachers. The aim was/is to provide teachers with quick, one-click access to key facts about each autistic pupil they teach at the beginning of every lesson they attend. Thus, teachers would/will no longer be expected/required to remember each pupil's information, or 'intuit' their needs from generic statements, but rather to access key details about their support needs every time they have an autistic pupil in their class, the presence of whom would/will be highlighted through the computerised class register. It was/is my hope that, instead of attempting to teach teachers what autism is (Milton, 2012), by facilitating their understanding of the individual autistic pupils they teach, this new system will begin to bridge the gap between teacher knowledge and pupil need (Kasari and Smith, 2013; Parsons et al., 2013; Parsons and Kasari, 2013).

An acronym for 'Facts About Me', i.e. FAMe™, was chosen as the name for the new system, to highlight the personal involvement of pupils which is essential to its efficacy. The information (FAMe™ Statements), to be communicated to teachers, must be generated by each individual autistic pupil, in order that it reflects the specific classroom/learning support they believe will make the most positive

difference to them. As autistic pupils should all now be encouraged to participate in termly pupil SEND review meetings (DfE and DoH, 2015), it is anticipated that, if schools adopt FAMe™, these will provide an appropriate opportunity for staff and pupils to work together to generate and regularly update FAMe™ System information.

ii. Design and Development

a) Considerations

It was important, not only ethically but practically, that I recognised the context into which I wanted to launch the FAMe™ System and pay attention to the needs or perspectives of the teachers (Parsons et al., 2013), whose engagement with the system would be essential for its success (Starr and Foy, 2012). I had to ensure teachers would not simply regard using the system as 'another competing burden' adding to their existing workload (Starr and Foy, 2012, p.214), which was described as 'unmanageable' by 82% of 4450 teachers in response to a recent survey (The Guardian, 2016a). In addition, education researchers have reported that teachers have concerns about both the feasibility of implementation, and the 'best fit' of educational interventions with pupils' needs (Parsons et al., 2013, p.270), and have suggested that a mismatch often exists between the intervention and the school context (Kasari and Smith, 2013). It was important, therefore, that I include teaching professionals from the beginning (Parsons et al., 2013) and consult them about the potential benefits of, and barriers to their use of, the FAMe™ System.

Another design consideration was the current 'funding crisis' affecting UK schools (Coughlan, 2017; National Audit Office, 2016; The Guardian, 2016b; The Telegraph, 2016), in which budgets are 'being pushed beyond breaking point' (Hobby, 2016). The ability of school management to invest in new initiatives will necessarily be limited in such a financial climate, and therefore ensuring low system implementation costs was a priority.

b) Stages of development

(i) Concept

- Formulation of the basic concept, i.e. a register-linked, easy-access system that could provide key facts about individual autistic pupil's classroom/ learning support needs to their teachers

- Informal discussion with teachers and teacher trainers at conference events to establish their perceptions of the FAMe™ System concept

- Consultation with a member of Sheffield City Council IT department, regarding the feasibility of using secondary schools' existing Capita SIMS (SIMS) register software[11], so that FAMe™ System implementation would come at no financial cost to participating schools

- Collaboration with participating school's IT departments to work through the logistics of implementing the FAMe™ System in individual settings

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[11] Capita SIMS software is the management information system used by council-maintained schools throughout the city in which this research took place.

- Online survey of teachers from participating schools to ascertain perceptions of the FAMe™ System concept and perceived barriers to its use

- Ensuring system design met any criteria for maximum engagement that were articulated by teachers

(ii) System design - as implemented in this project

- FAMe™ utilised an existing column within SIMS - this enabled participating schools' IT departments to activate the FAMe™ System without having to make any changes to their software. The system remained visible to all teachers as part of their lesson register screen throughout the course of the project

- When a participating autistic pupil attended a lesson, teachers were alerted to their presence by a marker in whichever SIMS column had been adopted for the FAMe™ System

- This marker acted as a prompt to teachers to access the three[12] FAMe™ Statements (by hovering their cursor over the marker) which had been provided by the individual autistic pupil, informing teachers how to best support them in the classroom

- Teachers were simultaneously alerted to the presence of more in-depth information about individual pupils, and told it was contained in the SEND section of SIMS

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[12] 'The rule of three' or 'power of three' is a writing principle which suggests that things that come in threes are inherently more effective than other numbers of things (Clark, 2007) and therefore presenting ideas in threes helps make them more memorable (Rule of Three, 2015).

At the time of initial FAMe™ System development, several issues were identified which could not be resolved prior to the commencement of this project (outlined below). It was accepted that a 'best fit' with existing school software, rather than the optimal design (which would involve an exclusive FAMe™ System register column) would have to be adopted, until evidence of potential system efficacy could be established and used to justify a request for change to the SIMS software programme. This has to be made through Capita and typically takes 18 months to be implemented once agreed.

(iii) Drawbacks of implemented FAMe™ System design identified and accepted before implementation

- Schools had to use an existing column of SIMS not necessarily exclusive to the FAMe™ System – potentially making FAMe™ information more difficult to identify quickly

- One school had to use the 'on report' function of SIMS, as other columns were already in use. Whilst this had the added benefit of highlighting FAMe™ pupils' names in red on the register, making them easy for teachers to attend to, pupils reported not liking this feature as they associated it with being in trouble at school (see findings)

- Although access to pupil information was improved, teachers were still required to perform one step (hovering their cursor over a marker) to view key facts

(iv) Post-project system development

Following the findings of this research, which suggested that teachers' use of the FAMe™ System had a positive impact on their autism-related practice and autistic pupils' outcomes, the system was further developed, in collaboration with Lucy Crawford, Product Manager for the SEND area at Capita SIMS. This updated version of the FAMe™ System utilises the Marksheet tab of SIMS which remains open above class registers at all times (see Figures 4 and 5). This improved the functionality of the FAMe™ System and removed the need for schools to utilise other columns within SIMS, which caused some difficulties for pupils and teachers during the system trial (see Findings Chapter, Section 5).

Figure 4.

Teachers' register view when FAMe™ System is fully operational
(i.e. prior to Sept 2018 when an additional column will be introduced into the main SIMS register screen)

Marksheet tab as it appears in register

Teachers must click this to access FAMe™ System information

Figure 5.

Example contents of SEND and FAMe™ Marksheet Tab

Students	Age	Gender	Reg Group	SEN Status	SEN Need	Gifted/Talented	Pupil Premium	FAMe
ABBOT, Ben	16/0	M	11A				Y	
ABRAHAMS, Jacqui	16/10	F	11B	N				
BRIANCON, Linda	16/8	F	11B					
CANDY, Milly	16/9	F	11A				Y	

Hold cursor over cell to expand

1. Please **break down my instructions for me** - I can't take in a lot of information at one time

2. Please **come to me to check that I have understood the learning task** - I find it hard to ask for help and often need clarification

3. Please **write my homework in my planner for me**/check I have taken it down correctly/ provide it on a homework sheet

6. Methods

According to the British Educational Research Association: 'Researchers must employ methods that are fit for the purpose of the research they are undertaking' (BERA, 2011, paragraph 30). The following section outlines and provides justification for the choice of qualitative and quantitative methods which were employed to answer the research questions. Methods included: semi-structured pre- and post-FAMe™ pupil interviews; pupil self-report measures, designed to establish levels of psychological well-being; pre- and post-FAMe™ online teacher surveys; and post-FAMe™ online SENDCO surveys. Recruitment methods and materials are described, and examples of pupil communication/participation aids, are provided.

i.   Preliminary decisions and implications - how many participants?

The number of people required to make an adequate sample for qualitative research can vary, and the question of 'how many?' has no reasonable answer (Becker, 2014). When searching research methodology literature, to determine how many participants were needed for the qualitative element of this mixed-methods project, the answer most often found was, 'it depends' (Baker and Edwards, 2012). Some researchers aim for saturation, i.e. the point at which additional interviews offer no further insight into the research question, to define their sample size (Bryman, 2012b), but this was not an appropriate sampling strategy for this study, as each

pupil's narrative accounts were to be used to generate individualised information for inclusion in the FAMe™ System, and every individual pupil had the potential to make a unique contribution to the collective knowledge of how it is to be autistic in a mainstream secondary school. In addition, the prospective benefit to each participant of taking part meant it would be unethical (Kellet, 2005) to end or refuse their participation on the assumption that their data would contribute nothing more to the narrative analysis.

In order to determine the ideal sample size then, it was necessary to approach the issue pragmatically and: consider carefully and critically the best options in relation to this specific project; scale the plans and expectations to the realities of the time and resources available; and ensure there was enough time to make the best use of the data generated (Mason, 2014).

As recruitment was from a heterogeneous population (Attwood, 2008; Beardon, 2012; Beardon and Worton, 2011; Rosqvist, 2012), a large enough sample to capture the breadth of subjective experience was needed (Charmaz, 2012). However, because of the intention to transcribe and qualitatively analyse interview material, using deductive and inductive content coding techniques (Boyatzis, 1998; Crabtree and Miller, 1999; Elo and Kyngas, 2008), it was essential to ensure the sample was not so large as to be unmanageable (Mason, 2014). Adler and Adler (2014) advise that somewhere between 12-60 interviewees is typical of qualitative studies, with 30 being the mean, whilst Bryman suggests that between 20-30 participants are needed for 'an interview-based qualitative study to be published'

(2012a, p.425). As these numbers are characteristic of the few existing qualitative studies where interviews with autistic individuals have been used (e.g. Harrington et al. 2013; Ozsivadjian et al., 2012; Preece and Jordan, 2010) they should be enough to satisfy my 'epistemic community' (Doucet, 2014, p.25). It was therefore decided to attempt to recruit between 20-30 participants, with a view to having interview data from 40-60 interviews (each pupil was to be interviewed both pre- and post-FAMe™ System implementation). The subsequent implications, for data analysis and the generalisability of the consequent results, were recognised and accepted.

In this project, each pupil's data was treated as both an individual case and as part of the whole participant group to: establish the extent to which their school experiences were related to features of autism defined in the diagnostic criteria and/or explained by cognitive autism theory; compare pre- and post-FAMe™ experiences and self-reported levels of mental [ill]health; and to evaluate the FAMe™ System's capacity to effect change in teachers' autism pedagogy.

The quantitative data collected using pre- and post-FAMe™ self-report scores was suitable for paired-sample t-test analyses. However, limiting the sample size to one that was manageable from a qualitative perspective meant it was uncharacteristic of single-method quantitative studies (Ragin, 2014). Recognising that, due to the relatively small sample size, the quantitative results could be criticised in relation to the validity of any significant differences identified, it was determined that any implications of the findings for the wider autistic population

would not be overstated in the conclusion. Quantitative findings were corroborated with evidence from the qualitative data where possible through the process of triangulation.

Descriptive statistics were used to evidence the frequency of themes identified from the narrative data. The overall aim was to 'offer sound qualitative insights, rather than try to mimic a quantitative 'representative' logic' (Mason, 2014, p.30). It was anticipated that analysis of the data, at the level suggested, would be sufficient to provide an indication of whether further evaluation of the FAMe™ System with a larger data set was warranted, whilst contributing something meaningful to the current understanding of the school experiences of mainstreamed autistic pupils.

ii. Recruitment and Participants

a) Pupils

In order to retain as much homogeneity within the data set (in terms of school placement) as possible, Sheffield secondary schools with specialist/integrated autism provision (n=4) were excluded from the recruitment drive as it was assumed that the classroom experiences of/support available to autistic pupils attending these schools was likely to be qualitatively different from those attending mainstream schools without such specialist resources.

FAMe™ Project information packs for schools (Appendix 4) were emailed to the SENDCO of all council maintained mainstream secondary schools in Sheffield (n=22). SENDCOs were invited to contact me for more information and, of those who did so (n=5), 3 agreed to trial the FAMe™ System in their school and subsequently facilitated pupil recruitment. The total number of autistic pupils in years 7-10 (Pupils in year 11 were due to be out of school, on GCSE study leave, during the term the FAMe™ System was to be implemented, and so would not be invited to take part in the project) at these 3 schools was 30 (matching the maximum desired sample size), and therefore no attempt was made to re-contact the schools who had not responded to the first wave of recruitment information.

To protect pupil anonymity, family FAMe™ Project information packs and consent forms (Appendix 5a-f) were posted via school to the homes of pupils with a known (by school and by the pupil) diagnosis of autism in years 7-10. Contact between myself and parents/participants was only established once parent and pupil consent forms (which provided details of parental email addresses) had been returned to school.

To take account of preferred communication style (NAS, 2017b) and the susceptibility of autistic individuals to experiencing social anxiety, especially in unfamiliar situations (Humphrey, 2008; Jones et al., 2009; Powell and Jordan, 1991), pupils were offered the choice of taking part in a face-to-face interview at school or home, either alone or with a familiar adult (Teaching Assistant (TA)/parent/carer) present, or being interviewed via an email exchange. All elected to attend interviews

in school without additional support.

In total, 25 autistic pupils were recruited from the possible 30. All 25 had an autism diagnosis and, as the majority of the pupils had received their diagnosis prior to the latest revision of the DSM (DSM-5, 2013) they had the diagnostic label 'Asperger Syndrome'. The most likely diagnostic label these pupils would now acquire is 'ASD - Severity Level 1'. None of the pupils received full-time in-class support from an additional adult/Teaching Assistant (TA). Two pupils had a dyslexia diagnosis in addition to their diagnosis of autism. No other comorbid diagnoses amongst the participant group were disclosed, although two were understood by their school to have below average cognitive abilities.

Of the 25, 1 pupil was sent home ill on the day of interviewing and did not return to school for some time. One pupil subsequently withdrew consent immediately prior to the first interview, telling his TA that he was too anxious to take part and did not want to meet me. The decision was made to withdraw another pupil during the first interview, when evidence of informed consent could not be established (the pupil did not seem aware of the project, or her prospective involvement in it, and did not remember completing the consent form. She presented with signs of anxiety at being in an unfamiliar situation, e.g. asked the same questions repeatedly/stated information repeatedly whilst pacing the room, and so the session was brought to an end).

The data from one pupil, who chose to attend both interviews and completed the pre- and post-FAMe™ self-report scales was withdrawn from all stages of analysis, except that pertaining to the production of his FAMe™ Statements which were used and found helpful by his teachers. This pupil was unable to reflect on or discuss his experiences of school, making comments such as, *"I like everything about my life".* His literal interpretation of language led to him discussing his bus journey when asked how he felt about 'coming to school' and, when the question was rephrased to be more specific, he said, *"I feel good",* but was unable to articulate more about this. When completing the self-report measures he indicated the most positive response to each statement and questioned the statements themselves, e.g. *"Why would I feel like crying? My life is a good life".* He was, however, able, during his pre-FAMe™ interview, to construct FAMe™ Statements with my support, e.g. *'I like it when you tell me you are pleased with me'*, and these were made available to and used by his teachers throughout the project. It wasn't decided until his post-FAMe™ interview, when he demonstrated a lack of recognition that he had been involved in a research project, i.e. *"What is this thing? FAMe™?"* that his research data should be withdrawn. This was done on ethical grounds as I could not ascertain that he understood the process of, or could reliably provide informed consent, despite his having completed the pre-FAMe™ consent form.

One pupil took part in the pre-FAMe™ interview but chose not to complete the self-report measures. This pupil was out of school, attending a work experience placement, during the post-FAMe™ interview period, and did not respond to an invitation to attend.

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During the term in which the project took place, one pupil moved into specialist provision and one began attending twilight sessions only (individual teaching after normal school hours). This change in provision was as a direct result of information that became known during her initial interview which was communicated, with her consent, to her school's SENDCO. These pupils gave consent, prior to their initial interviews, and did not respond to an offer to withdraw their consent for their pre-FAMe™ data to be retained, and it was therefore included in the thematic content analysis. However, their pre-FAMe™ self-report data was not included in the FAMe™ System evaluation analysis, which relied on the comparison of individual and whole group pre- and post-FAMe™ scores. This was because of the potential these pupils' pre-FAMe™ self-report scores had to shift the pre-FAMe™ group mean scores in a negative direction (both these pupils scored in the extremely elevated range for anxiety and depressive symptoms). This would have resulted in the appearance of a greater FAMe™ System impact than would otherwise have been observed from the whole-group analysis.

Participant distribution data is shown in Table 1. The pre- and post-FAMe™ data available for analysis is shown in Table 2.

Table 1.

Participant distribution data by school site, gender and year group

	School 1				School 2				School 3				Year Group Total				Total
	Y7	Y8	Y9	Y10	Y7	Y8	Y9	Y10	Y7	Y8	Y9	Y10	Y7	Y8	Y9	Y10	
Male	0	3	1	2	0	0	2	0	3	3	1	0	3	7	4	2	**15**
Female	1	1	1	0	2	0	0	0	0	0	0	1	3	1	1	1	**6**

Table 2.

Pre- and post-FAMe™ data available for analysis

	Pre-FAMe™ System implementation in school	Post-FAMe™ System implementation in school
Interview data	21	18
Self-report data	18	18

Participation and interview communication aids

Respecting that autistic individuals often process information differently to the non-autistic population (Ashburner et al., 2013; Minshew et al., 1997; Preece and

Jordan, 2010; Williams and Hanke, 2007) and that visual presentation can sometimes aid comprehension (Arthur-Kelly et al., 2009; Dettmer et al., 2000; Dockrell and Lindsay, 2011; Rao and Gagie, 2006), all information packs were provided in both long (detailed) and short (essential points) formats and included images as well as text wherever possible (Appendix 5b-e). I had made examples of pupil information sheets available to a community parenting group during an MA pilot project and received responses from 9 autistic child volunteers (age 7-17 years) who had agreed to read it and offered their feedback regarding their comprehension of its contents. The information they provided was used to inform the development of the FAMe™ Project Pupil Packs to ensure clarity and ease of reading.

Information packs contained a link to an online animated video (https://youtu.be/IWZSaTZrO8U) which introduced the FAMe™ Project and myself as the principal researcher. This video was designed to accommodate the variety of processing styles and preferences, recognised to exist within the autistic population (Chown, 2017; Eldeson, 2016), of which autistic individuals are understood to often rely on one preferred primary learning style (McCabe, 2015) that cannot be assumed from diagnosis alone. The use of multiple media, to communicate project information was therefore employed, to ensure the process of understanding the project, and thus enabling informed consent, was as accessible as possible to potential participants.

Recognising that meeting new people can be a source of stress for autistic individuals (Gillott and Standen, 2007; Humphrey, 2008; Jones et al., 2009; NAS, 2016b), the FAMe™ Project video included photographs of my face and I narrated the script (Hampton and Fletcher-Watson, 2016) to make prospective participants as familiar as possible with what I look and sound like (see Appendix 6 for slides of full video content, or follow the link above). The video also provided a step-by-step account of the interview and data collection process to reduce any anxieties participants may experience due to the difficulties with social imagination and prediction, understood to be inherent in this population (DSM-5; Humphrey and Lewis, 2008; ICD-10; Jacobsen, 2005; Jordan, 2008; NAS, 2017b).

SENDCOs at participating schools were asked to provide feedback on the video contents before it was finalised. Amendments were made to the information provided around issues of confidentiality and child protection/safe guarding, Limits to confidentiality were made explicit (Fig. 6), in line with school policy (i.e. that I had a responsibility to disclose any information that suggested a pupil might be at risk of harm to self or others) and in accordance with BERA guidelines for ethical educational research (BERA, 2011, paragraph 22). SENDCOs were also given access to the information video for those pupils who did not have home internet access (n=1). In addition to introducing myself via video, all pupils and their parents were given the opportunity to email, telephone or meet me in person prior to the first interview, however none chose to do this.

Understanding that pupils might experience increased anxiety, due to the unfamiliarity and changes to their routine participating in this project would necessarily involve (Gillott and Standen, 2007; Humphrey and Lewis, 2008; Jacobsen, 2005; Jordan, 2008), additional steps were taken to prepare pupils in advance. For example, pupil interview information (Fig. 7), which included pictures to aid comprehension (Harrington et al. 2013), outlining the structure of the interview were emailed to pupils' parents two days before the interview was due to take place, together with the interview date and details of the room in school where the interview would be held. Parents were sent another email the day before the interviews and asked to remind their child that they would be meeting me the following day.

Figure 6.

Consecutive slides taken from the recruitment video regarding confidentiality
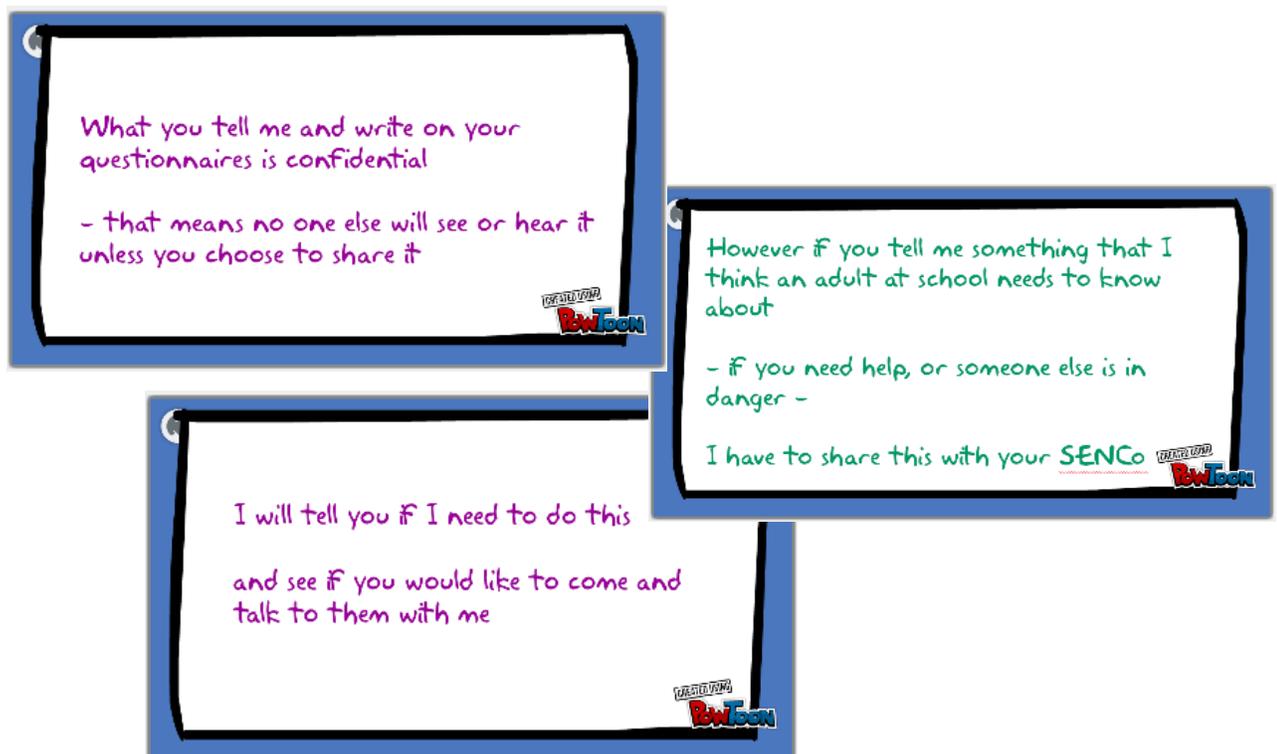
The Interviews

I was introduced to each pupil by a member of school staff. Who this was depended on the individual school (e.g. Learning Base Support Worker, TA, SENDCO), but each was an adult familiar to the pupil and with knowledge of the project. Each interview was begun by establishing that the pupil still agreed to participate in the project. The interview information (Fig. 7) was provided and pupils were advised that they could refer to it at any time should they wish to.

Pupils were told that they could ask to stop the interview at any point and that a member of school staff was available should they wish to access support from a familiar adult. No pupil requested bringing the interview to an end before it's natural conclusion. One pupil said he was *"bored"* and didn't like talking. I asked if he would like to end the interview, but he said we could carry on, as long as I made it as short as possible, which I did. This pupil chose to use the drawing materials provided and drew himself sitting at the back of a classroom. He indicated that he would like his teachers to know this was where he preferred to sit.

Figure 7.

Interview information (provided to pupils in advance via email and available during interview)

We will use these things to help us write the FAMe™ information that your teachers are going to see.

Every pupil's FAMe™ information will be different

Remember - Teachers won't see anything that you don't want them to and I won't tell them what we talk about.

We will have a short break - I will bring biscuits

The next job is to complete 3 questionnaires

You can do these on your own or I can read them to you

They all ask you to tick a box or make a circle round the answers that best describe you - they are not tests - there is nothing to get right or wrong

A scripted introduction sheet was read to all pupils before beginning each interview (Appendix 7) ensuring they were all given the same information.

Verbal consent was established for me to make an audio recording of each interview, and pupils were assured that no one else would have access to this other than myself and my academic supervisor. One pupil commented that he would feel more comfortable if he couldn't see the recording equipment and made the suggestion that recordings should be made secretly so as not to raise feelings of self-consciousness. The ethical problems involved in secret recording were discussed with him and it was established that he was happy for the recording of his interview to continue, as long as the recorder was placed where he couldn't see it.

The aim of the pre-FAMe™ interview was to elicit information about the pupils' experiences of school, in order to answer Research Question 3. This initial meeting was also used to discuss and develop pupils' FAMe™ Statements (to be shared with teachers through the FAMe™ System). To ensure all pupils were given the opportunity to share information about the same issues, a semi-structured interview guide was followed (Appendix 8). The pre-FAMe™ interview focused on pupils' feelings about: attending school; sensory aspects of the classroom environment; common scenarios that happen in lessons (e.g. pupils being asked to put their hand up); pupils' perceptions of their teachers' understanding of their needs; pupils' perceived barriers to their learning; and what they would like to be different. The

interview questions were directive, in terms of their focus, but designed to be open enough to encourage pupils to talk about what was most relevant to them in relation to each area of research interest. Each question was followed up with a prompt, encouraging pupils to explain their response further, e.g.: "What makes you think that?"; "What could be different?"; "How do you think that would make you feel?"

Reflecting the fourth research question, the post-FAMe™ interview was pupils' opportunity to share their experiences of teachers' use of the FAMe™ Statements to inform their classroom practice. The interview guide for this (Appendix 10) focused on: pupils' perceptions of whether teachers had read and used their FAMe™ information; the difference it had made to them if teachers had changed their classroom behaviour and/or support practice in line with the pupil's FAMe™ information, and how it made them feel if they perceived that teachers had not changed; whether their expectations of what the FAMe™ System would achieve had been met; and, in line with the draft Code of Practice for researchers (Hampton and Fletcher-Watson, 2016), their experiences of taking part in the interview process and whether there was anything they would have liked me to have done differently.

The interview guide supported the use of flexible strategies, such as probes and clarification of answers, and I remained attuned to individual pupil's vocabulary and conversation style, in order to adapt the interview situation to match their communication preferences when this felt necessary (Harrington et al., 2013).

During the course of all interviews, visual supports (Ashburner et al. 2012; Beresford et al. 2004; Preece 2002; Preece and Jordan 2010) and a variety of art materials were made available to pupils, to aid communication, promote relaxation (several children commented that doodling helped them to think) and, in the case of the pre-FAMe™ interviews, enable the completion of blank answer templates (Fig. 8). Pupils were encouraged to write or draw (if they wanted to), as well as talk, when communicating their thoughts to me (Beresford et al. 2004; Harrington et al. 2013; Williams and Hanke, 2007). For example, adapted from the 'Draw your Ideal Self' (Moran, 1996; 2001) and the 'Draw your Ideal School' (Williams and Hanke, 2007) techniques, I used an 'Ideal Teacher' template (Fig. 8) to facilitate discussion of how pupils would like their teachers to support them in the classroom. Pupils were encouraged to think about and communicate, either orally (for me to scribe) or in their own writing, what their teachers do that they 'like' and 'don't like'. Example sheets were provided to illustrate the concept, however it was made clear to pupils that they could write/tell me to write whatever they wanted on these sheets. These templates proved to be extremely useful in the subsequent development of pupils' FAMe™ Statements, which detailed pupils' top three prioritised support requirements/specific areas where teacher practice change was desired, as pupils could refer back to them and highlight the issues of most importance to them.

Figure 8.

Example sheets - liked/not liked teacher classroom behaviours

Blank Template Sheets:

During the interviews, some pupils chose only to communicate verbally and requested that their information be written down for them, others wrote a lot and communicated orally only minimally. One pupil drew a person at the back of the classroom and then pointed at it. When asked whether it was him or someone else in his drawing, he answered that it was him and that he only liked to sit at the back. He chose this to be included in his FAMe™ statement information.

Powell and Jordan (1992) suggest that photographs can serve as useful 'aides-memoire' to children with autism and photographs were used in research by Preece and Jordan, (2010), which examined autistic children's views about their daily lives. Thus, as a way of facilitating pupil engagement (Ashburner et al. 2012; Beresford et al. 2004; Preece 2002; Preece and Jordan 2010), prompt sheets containing photographic images (Appendix 9) of common classroom scenarios were developed. These were shared with pupils during interview and they were invited to talk about whether they had experience of each scenario and, if so, how it made them feel (see Fig. 9 for some examples of these).

The information provided during the discussion of these materials was used at the end of the interview to aid the development of each pupil's individual FAMe™ Statements, the three 'most important' (to the pupil in terms of wanting their teacher to be aware of them) of which were written into the FAMe™ statement template (Fig. 10).

Figure 9.

Examples of photo prompt sheets shown to pupils during interview

Some pupils like working as part of a group

Some pupils do not mind when people lean over them

Some pupils like to put their hand up in lessons

Some pupils enjoy demonstrating their work to the class

Figure 10.

FAMe™ Statement Example and Template Sheet

Template

Where necessary, pupils' FAMe™ Statements were rewritten by me, to be as concise and easy for teachers to understand as possible, and then sent via parental email to pupils for confirmation that they retained the intended meaning. Any requests for amendments were actioned prior to making the information available to teachers through the school register system for one school term (April-July 2016).

Self-report measures were administered once all questions/topics from the interview schedule (Appendix 8) had been discussed and pupils' three FAMe™ Statements had been written. Pupils were offered a break between the two elements of the session and drinks and snacks were made available. Pupils were given the choice of completing the measures independently or having the items read to them. They were encouraged to ask for clarification of any questions that they were unsure how to interpret. It was explained that the questionnaires focused on their thoughts and feelings and assurances were given that there were no right or wrong answers.

The decision was made to order the interview in this way for several reasons:

1. The qualitative data collection and generation of the FAMe™ Statements was crucial to the main goals of better understanding pupil experiences of school and establishing the FAMe™ System. The quantitative data, whilst necessary for triangulation and the evaluation of FAMe™, was not essential to achieve these goals. If pupils were to tire, and want to end the interview early, my priority was to have collected their qualitative information. The quantitative data could then have been collected at a further meeting, if necessary and agreed to by participants. In addition, if pupils decided they did not want to

complete the self-report measures, I believed they would feel more confident to say so at the end rather than the beginning of the interview;

2. It was important to develop a rapport with pupils and establish their preferred method of working, and any difficulties, for example with reading, before presenting them with the self-report measures. I anticipated that pupils would feel more comfortable asking me to read or scribe for them once they had had the chance to get to know me;

3. The self-report measures focused on issues related to mental health and well-being that required pupils to disclose personal information that they might not have considered or shared with anyone before. I wanted to ensure they felt comfortable enough with me to ask for clarification of items, refuse to answer items or share their distress should they need to.

It was explained to pupils that, should their answers to the self-report measures indicate high levels of distress, I would be obliged to alert their school SENDCO for safe-guarding reasons. Only one pupil chose not to complete the measures.

One pupil became visibly distressed during completion of the questionnaires and requested a break. He left the room and went to the dining hall, choosing not to access a member of school staff. On his return, he was offered the choice of ending the meeting without completing the questionnaires, or leaving out the items he found difficult to answer. He was determined to answer all items and asked for my support

to help him do so. This pupil chose to stay with me for a further 15 minutes once the interview was complete. He said he needed time to regain himself before returning to class because he had been doing some *"intense thinking"*. He drew a maze for me to attempt to solve and recited the Periodic Table, both of which he said were things he did to relax. His questionnaire scores suggested that he was suffering from anxiety and depression levels in the 'extremely elevated' range, and he disclosed that he was feeling suicidal. We discussed my duty to share concerns about his welfare with an adult in school, which he had been informed of at the beginning of our meeting. He gave permission for me to share his information with his school SENDCO, which resulted in a referral to an outside agency for therapeutic support.

Self-report measures

The measures selected focus on issues relating to quality of life, i.e. anxiety, depression, and self-esteem, which are widely understood to be negatively impacted by school experiences (Ashburner et al., 2010; Charman et al., 2011; Morewood et al., 2011; NAS, 2016a; Osborne and Reed, 2011). The choice of measures took into account evidence of: their reliability, validity, and internal consistency; their suitability for use with autistic youth; sensitivity to change over time; the time taken for completion (they needed to be short so as not to overburden pupils who had already taken part in a lengthy interview); ease of reading; and suitability for administrator reading/scribing if pupils preferred. Cost and availability to me as a PhD research student (rather than a registered clinician) were also factors in the selection process.

The Beck Youth Inventories™ (BYI-II-revised, Beck, Beck and Jolly, 2005), is a widely used measure of adolescent mental health, comprising a collection of self-report scales that may be used, separately or in combination, to assess a child's experience of depression, anxiety, anger, disruptive behaviour, and self-concept (Beck et al., 2005). The inventories are intended for use with children and adolescents between the ages of 7 and 18 years and produce age and gender-standardised t-scores (Pearson Clinical, 2016a), which can be grouped according to their clinical significance: average <55; mildly elevated =55-59; moderately elevated =60-70; extremely elevated >70 (Beck et al., 2005), and can be used to discriminate between sub-groups of adolescents with high and low levels of distress (Community University Partnership, (CUP) 2016).

Each component of the BYI-II has good test–retest reliability (correlation coefficients of 0.83-0.94 in the 11-14 age group) and has been shown to be sensitive to changes over a relatively short time period, making them appropriate intervention evaluation tools (PearsonClinical, 2016a). During development, internal consistency analysis yielded a Cronbach's alpha coefficient that ranged from 0.86-0.92 in the 11-14 age group (CUP, 2016) and criterion validity was demonstrated (Beck et al., 2005). A systematic review of measures of child and parent reported mental health and wellbeing outcomes in children (Deighton et al., 2014) identified the BYI-II as having met key psychometric standards. These authors concluded that the BYI-II has been well validated through 'a range of modern psychometric and statistical modelling approaches' (ibid, p.5), and can be used for both assessment of intervention impact and individual assessment at treatment outset (ibid, p.12). In addition, the BYI-II, has

been used in previous research with autistic youth (e.g. Ichikawa et al., 2013; Mandy et al., 2016), and the assessment publishers advertise its suitability for use in the identification of mental health issues in autistic individuals (Pearson Clinical, 2016b). One identified limitation of the BYI-II is the lack of evidence of cultural sensitivity (Deighton et al., 2014). This was not relevant in this study, as all pupils were of white British heritage.

For this project the depression and anxiety subscales of the BYI-II were selected, to measure existing levels of these constructs in the pupil sample pre-FAMe™, and to establish whether significant change in pupils' depression and anxiety levels occurred over the course of the project. The depression inventory subscale (BYI-D) includes items that reflect the respondent's negative thoughts about: him or herself; his or her life, and future; feelings of sadness; and physiological indications of depression. The anxiety inventory subscale (BYI-A) includes items reflecting: fears (e.g. about school, getting hurt, and health); worrying; and physiological symptoms associated with anxiety. These 20 item self-report scales are easy and quick to administer and score and can be completed independently (requiring a reading age of 7 years) or read out-loud by the administrator.

The Myself As a Learner Scale (MALS, Burden, 1998) was developed as a means of focusing directly on school pupils' perceptions of their learning abilities and is suitable for use with children between the ages of 9-16 years. Containing 20 items,

participants are asked to rate how applicable each statement is to them on a scale of 1-5, from 'Definitely true of me' to 'Definitely not true of me at all'.

Burden (2005) suggests that a pupil's self-confidence to succeed, and the explanations that they give themselves for successes and failures, play a vital part in the learning process. He proposes that, in order to better understand why children do well at school or sometimes fail to live up to expectations, it would be helpful to gain some insight into their views of themselves as learners.

As many autistic pupils are known to achieve poor academic outcomes, relative to their intellectual/cognitive profile (e.g. Ashburner et al., 2010; Charman et al., 2011; Morewood et al., 2011; Osborne and Reed, 2011), it was decided to include the MALS to identify pupils' perception of themselves as learners and assess whether these views were impacted by teachers use of the FAMe™ System. This measure has been used by other researchers to establish whether pupils' general self-perceptions about their learning capabilities are open to the influence of teaching style or other contextual factors (Armstrong and Humphrey, 2009; Burden, 2005; Burke and Williams, 2012; Kaufman and Burden, 2004).

As with the BYI-II, items can be completed independently or read by the administrator. Burden (1998) reports that in his standardisation study in the UK, MALS yielded encouraging reliability figures (Cronbach's alpha coefficient of 0.85). Standardised scores enable researchers to compare participants with a normative population sample to establish whether individuals and/or groups demonstrate a

high/low or average academic self-concept. A test-retest reliability analysis, with a group of 22 mixed ability 12-year-old children, generated strong correlations between two occasions of measurement (r (22) = 0.96), indicating good figures of reliability (Erten, 2015).

Designed specifically by me for this project, the **How I feel at School Questionnaire** asks pupils to consider their experiences at school over the past week and rate their level of in-class anxiety, interest in lessons, and understanding of the work presented to them, on a sliding scale with emoticons illustrating each rating to accommodate potential visual learner preference (Beresford et al., 2004; Dettmer et al., 2000; Preece, 2002). A small group of 5 autistic children (age range 7-17) completed the questionnaire and provided feedback relating to their comprehension of the instructions and the questions, which were reworded when misinterpretation occurred.

In order to gain insight into pupils' expectations of the FAMe™ System, and whether the expected impact was achieved, the pre-FAMe™ version of the How I feel at School Questionnaire included an item asking pupils to rate how they thought they would feel if teachers used their FAMe™ information. This question was replaced, post-FAMe™, with an item relating to their perception of change in teacher behaviour/practice since the FAMe™ system was introduced. An example item was provided on the questionnaire cover sheet (Fig. 11) and this was discussed, prior to questionnaire completion, to ensure pupils understood what was expected of them.

Figure 11.

How I feel at School Questionnaire

Example question

a). How anxious or worried have you felt in class over the last week?

If you had been feeling completely OK you would circle the number 1 like this…

I have felt completely OK not at all anxious or worried	I have felt a bit anxious and worried	I have not felt OK at all - I have felt very anxious and worried
(1) 😃	2 😐	3 🙁

and if you had been feeling very anxious or worried you would circle the number 3 like this…

I have felt completely OK not at all anxious or worried	I have felt a bit anxious and worried	I have not felt OK at all - I have felt very anxious and worried
1 😃	2 😐	(3) 🙁

Eighteen pupils in this study completed the: BYI-D; BYI-A; MALS; and the How I Feel at School Questionnaire, at both pre- and post-FAMe™ data collection points. All but one pupil chose to read the items to themselves, although most read them out-loud and asked for clarification of at least one item. Discussion of the questionnaire items elicited additional qualitative information which was included in the interview transcripts and thematic content analysis. A summary of the data collection methods is provided in Table 3, which follows the description of teacher recruitment and participation.

b) Teachers

Pre-FAMe™

All teachers in the 3 participating schools were emailed a FAMe™ Project information document via their school SENDCO (Appendix 11). This included: a description of the aims of the project; an explanation of what trialing the FAMe™ system involved; and an invitation to participate in a pre-FAMe™ online survey (Appendix 12).

The survey was designed to establish whether teachers in the participating schools were representative of those described in autism education research literature, who have reported having only a limited understanding of the way autism can impact on individual pupil's experiences of their environments, relationships, and/or their cognitive style and learning abilities (Charman et al., 2011; Falkmer et al., 2012; Hebron and Humphrey, 2014; Leatherland and Chown, 2015). It was important that the participating teachers' current experiences of teaching autistic pupils, and their opinion of the FAMe™ system concept, including any perceived barriers to its use, were understood, in order to maximise the usability of FAMe™ before implementation, and to have a baseline against which to compare post-FAMe™ responses.

Survey questions focused on teachers': level of autism training; awareness of which of their pupils are autistic; frequency of use and current ease of access to pupil's individual SEND information; confidence in their understanding of and ability

to support autistic pupils' classroom needs; perceptions of the FAMe™ System concept; and perceived barriers to prospective FAMe™ System use. Teachers were also provided with space to describe their experiences of teaching autistic pupils. Fifty-three teachers completed the pre-FAMe™ online survey.

At the point of FAMe™ System implementation, SENDCOs emailed a FAMe™ flyer (Appendix 13) to alert teachers to the start of the project, and teachers were provided with in-house technical support to activate the FAMe™ System on their class registers. The precise method of delivery of the FAMe™ System to teachers differed between schools, according to how they were currently using the Capita SIMS software system, and the FAMe™ flyers distributed in each school reflected this.

All schools made use of an empty/little used register column that, once activated, remained open next the class lists for the duration of the project. In one school the Quicknote column was adopted for FAMe™, another used the Gifted and Talented column, and one the report system (which highlighted pupils' names in red on the register as well as providing a link to their FAMe™ statement information). Essentially, each of these methods required the same of teachers, i.e. to click on the highlighted column and hover the cursor over a dot to activate a pop-up box containing a pupil's three FAMe™ Statements. Teachers were asked by their SENDCO to read and take account of pupils' FAMe™ Statements during lessons. They were reminded again to do this after returning from the half-term holiday. Pros and cons to each of these methods of delivery existed, which were identified by

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pupils and teachers. These are outlined in the findings and considered in more detail in the Discussion chapter.

Post-FAMe™

Teachers were again contacted via their school SENDCO and sent an email link to the post-FAMe™ online survey (Appendix 14), designed, with reference to the second research question, to collect data about their experience of using the FAMe™ System. Teachers were asked whether the FAMe™ System had: alerted them to the presence of autistic pupils in lessons; provided easy access to pupil's FAMe™ Statements; provided information about individual autistic pupils that was not already known to them; informed their classroom practice and/or changed the way they supported individual autistic pupils; and changed their confidence in their ability to meet the learning and/or support needs of participating FAMe™ pupils.

Teachers were also asked whether they perceived any change in FAMe™ pupils' engagement, behaviour, learning and/or academic outcomes since the FAMe™ project began, and whether they would welcome future updates to Capita SIMs software to optimise the functioning of the FAMe™ System. Space was provided so that teachers could expand/explain their answers to all questions, and they were given the opportunity to offer suggestions for future improvements/developments of the FAMe™ System. Sixty-five teachers completed the online post-FAMe™ feedback survey.

c) SENDCOs

SENDCOs were asked to complete an online post-FAMe™ survey (Appendix 15). This focused on how pupil pre-FAMe™ interview information, provided (with pupils' consent) for inclusion in pupils' SEND files had been used, and their experience/perception of the impact both the FAMe™ System, and the project as a whole, had had in their school.

Table 3.

Data collection methods and timings

Pre-FAMe™	Pupils in Years 7-10 attending mainstream secondary schools (n=22)
March 2016 Data collected used to address: **RQ** 1, 2 and 3a & b	**Meeting 1. (in school)** – approximately 1 hour **Semi-Structured Interview (Appendix 8)** With a focus on experiences of school, the physical learning environment, and what teachers do that is helpful/unhelpful in the classroom. Also included: Completing 'The Ideal Teacher' template (Figure 8) Discussion of the photograph prompt sheets (Appendix 9) **Development of FAMe™ Statements** (using the FAMe™ Statement template sheet – Figure 10) The 3 'Facts About Me' prioritised by pupils – i.e. what they most wanted their teachers to do differently an/or know about them (to be communicated to teachers via the FAMe™ System) **Completion of Self-Report Measures** • The Beck Youth Inventory Anxiety Scale (BYI-A) • The Beck Youth Inventory Depression Scale (BYI-D) • The Myself As a Learner Scale (MALS) • The How I feel at School Questionnaire – developed for this project

Post FAMe™	Pupils in Years 7-10 attending mainstream secondary schools (n=18)
July 2016 Data collected used to address: **RQ** 3a & b and 4b	**Meeting 2. (in school)** – approximately 1 hour **Semi-Structured Interview (Appendix 10)** With a focus on experiences of teachers' FAMe™ System use and the impact on/difference made to pupils when teachers used their FAMe™ Statements to change their classroom practice/behaviour in line with their prioritised support needs. **Updating of FAMe™ Statements where required** for ongoing FAMe™ System use. **Completion of self-report measures –** repeat of measures used in pre-FAMe™ interview.
Pre-FAMe™	**Teachers - self-selected from 3 mainstream secondary schools (n=53)**
March 2016 Data collected used to inform: **RQ** 4a	**Online Survey (Appendix 12) distributed via email by SENDCO** With a focus on: • Autism training received • Experiences of teaching autistic pupils • Confidence in ability to understand and meet autistic pupils' support needs • Experience of accessing pupils' individual SEND information • Potential/perceived usefulness of easy access to pupil specific information (FAMe™ System)
Post-FAMe™	**Teachers - self-selected from 3 mainstream secondary schools (n=65)** **n.b. surveys were completed anonymously and therefore responses could not be linked to specific individuals from pre- to post-FAMe**
July 2016 Data collected used to address: **RQ** 4a & b	**Online Survey (Appendix 14) distributed via email by SENDCO** With a focus on experience of teaching autistic pupils with access to the FAMe™ System, including: • Whether FAMe™ Statements provided new information • The frequency FAMe™ information was accessed • Change in classroom practice • Impact on confidence in ability to understand and meet individual autistic pupil's support needs • Ease of use of the FAMe™ System • Suggestions for further system development

Post-FAMe™	SENDCOs (n=3)
July 2016	**Online Survey (Appendix 15) – distributed via email** With a focus on: • Impact of the FAMe™ Project on their understanding of their autistic pupils' support needs • Usefulness of the information gathered during administration of the pre-FAMe™ pupil self-report measures (passed on when pupils were identified to be 'at risk'/had clinically significant levels of anxiety and/or depression) • Changes in SEND provision offered to pupils since beginning of project • Desire to continue with FAMe™ System use within school following end of project

iii.   Analysis of Data

Pupils' interview recordings were transcribed verbatim and entered into the Nvivo11 software programme (qsrinternational, 2017) as individual case nodes. Demographic and self-report data was then attached to each case node in order that within-group, e.g. according to gender or anxiety level, analyses could be performed.

A series of deductive nodes were developed from: the diagnostic criteria (DSM-5, 2013; ICD-10, 2010); criteria exemplars (Carpenter, 2013); autism research literature; the five cognitive autism theories selected for this investigation; and whether pupils' perception of the experience described was positive/neutral or negative. Catch-all nodes of: 'Other'; 'Past'; 'Unrelated to school'; and 'Clarification of a point already made', were included to enable all pupil transcripts to be coded in their entirety. Units of coding (UoC) (defined in detail in Appendix 1A) taken from

pupils' interview transcripts were then coded to these deductive nodes according to hierarchical coding strategies (Appendix 1D & G). Further development of inductive nodes, relating to pupils' school experiences and their perceptions of factors impacting on these, was carried out in response to the findings of the first rounds of coding and transcripts were then coded accordingly.

Analysis of pupils' coded qualitative data involved identifying the number of UoC relating to each node/group of nodes. Percentage distributions, of individual within- and whole group references coded to nodes, were calculated and are reported in the findings section.

Pupils' quantitative data, resulting from their self-report measure responses (converted to standardised t-scores where appropriate) was collated in Microsoft Excel. The number of pupils with scores falling within the boundaries of each clinical sub-group category (determined from the diagnostic manuals for each measure) was calculated and the findings are presented as descriptive statistics. Whole sample group pre- and post-FAMe™ mean scores from each self-report measure were compared in IBM SPSS Statistics using paired-sample t-test analyses.

Teacher and SENDCO qualitative and quantitative data was collated using the report function of the Qualtrics software through which the surveys were developed and distributed. Descriptive statistics in the form of percentage distributions, supported by summaries of the qualitative data, are reported in the

Findings Chapter (Section 5). Further examples of teachers written responses are provided in Appendices 16 and 17.

Chapter Summary

In this chapter I have defined my methodological approach to this study. Having established that, despite its transformative goals, this project did not meet the paradigmatic criteria for transformative research, I came to recognise myself as a pragmatist researcher, positioned at the 'level' of paradigm 'defined by the 'shared beliefs' of a research community (Denscombe, 2008, p.277; Morgan, 2007, p.74). I subsequently identified that my methodological, epistemological and ontological assumptions were appropriate within this framework.

Pragmatist philosophy advocates the use of whichever methods have the most practical value for dealing with a specific research problem (Hall, 2013; Morgan, 2007), and therefore supports my decision to take a mixed methods approach and collect both qualitative (to understand the participants' experiences) and quantitative (to establish whether measurable change had occurred) data, using pupil interviews and self-report scales, and online teacher and SENDCO surveys.

The FAMe™ System itself was designed to provide the type of individualised information about autistic pupils that teachers have been requesting, in such a way that it would not be experienced as an additional burden competing with their existing workloads.

Methods used, and materials developed, to facilitate pupils' engagement with their pre- and post-FAMe™ interviews and generate FAMe™ Statement information, took account the variety of communication styles and preferences recognised to exist within the autistic population. Self-report scales were selected for their focus on those areas of pupil well-being understood to be negatively impacted by school experiences, and because their validity for use with autistic youth had previously been established.

The inherent ethical considerations, involved in any research involving vulnerable populations, were considered and how these issues were attended to, throughout each stage of this research process, has been described.

The techniques used to analyse and present the narrative and numerical data, generated by pupils and teachers, were selected for their suitability of use with the individual data sets and have been described here. The next chapter reports the findings of these analyses, in both descriptive and statistical formats, as appropriate.

Chapter Four: Findings

1. Overview

This chapter reports findings from the data analysis and is split into seven sections:

i. Section 1 Part A details findings from the pre-FAMe™ self-report measures which were used to identify two distinct pupil groups for the subsequent comparative analysis, i.e. those with average and those with above average levels of anxiety. Further analysis of the self-report measure scores is reported in Section 4, Part A.

ii. Section 1 Part B relates to Research Question 1 and, following an explanation of the data validation process, details findings from the analysis of Coding Round 1a, in which the capacity of the diagnostic criteria for autism (DSM-5, 2013) and its exemplars (Carpenter, 2013) to explain, or aid understanding of, autistic pupils' experiences of school was explored. A second level of coding this data, used to invesigate pupils' attribution of impact to internal or external factors (both negative and positive/neutral), and any overlap of these attributions with round 1a coding, is also reported here.

iii. In Section 1 Part C, the findings of Coding Round 1b, in which pupils' interview data was coded to a series of deductive nodes pertaining to the five cognitive autism theories, in order to invesitgate their potential to explain the autistic pupils' school experiences (Research Question 2), are presented. Level 2 coding of this data, i.e. according to pupils' internal and external attribution of impact (as detailed above), was also performed and the findings reported here.

iv.   Following this, in Section 2, overlap between Coding Rounds 1a (Diagnostic Criteria) and 1b (Autism Theory) is explored, in order to ascertain the capacity of cognitive autism theory to explain the school experiences of autistic pupils that relate to the explicit features of autism, and to establish whether autism theory can explain any experiences that criteria cannot.

v.   In Section 3 findings from analysis of the references made by pupils, which specifically related to the impact of teachers' behaviour and/or practice on their classroom experiences (pre-FAMe™), and the types of support they identified as desirable through the writing of their FAMe™ Statements, are reported (Research Question 3).

vi.   Section 4 Part A relates to Research Question 4, and details findings from the comparative analysis of pupils' pre- and post-FAMe™ self-report scores, used to evaluate the impact of the FAMe™ system on pupils' self-reported levels of depression, anxiety and academic self-esteem together with pupils' pre- and post- FAMe™ responses to the 'How I feel at School Questionnaire'. Findings from the analysis of the qualitative data collected during the post-FAMe™ pupil interviews are also included (Section 4 Part B).

vii.   In Sections 5 and 6, findings from participating teachers' pre- and post-FAMe™ online surveys and the post-FAMe™ SENDCO survey are presented, including details of their experiences of using the FAMe™ System and suggestions for its future development.

viii.   Section 7 reports pupils' descriptions of the interview process and their
thoughts about the FAMe™ Project, as a concept and in practice.

ix.   This is followed by a summary of the key findings.

Section 1.

Part A.

Pupils' Pre-FAMe™ Quantitative Data

In this section pupils' pre-FAMe™ self-report scores, from a range of Quality of Life (QoL) related questionnaires, are reported. These scores provided a baseline measure of the participating pupils' anxiety and depression levels, and a context for the analysis of the narrative data which follows in Parts B and C. Three widely used and validated self-report measures were used: the Beck Youth Inventory Anxiety Scale (BYI-A, Beck et al., 2005); the Beck Youth Inventory Depression Scale (BYI-D, Beck et al., 2005); and the Myself as a Learner Scale (MALS, Burden, 1998).

Using the BYI-II administration and assessment manual (Beck et al., 2005), pupils' raw scores from the BYI sub-scales were converted into T-scores, according to age and gender, and grouped into one of the following 4 categories:

- Average (T-score <55)
- Mildly elevated (T-score 55-59)
- Moderately elevated (T-score 60-69)
- Extremely elevated (T-score >69

Whilst not a diagnostic tool, the BYI-II is considered to be a reliable assessment of symptom severity, and discriminates between groups with differing levels of psychological distress (Beck et al., 2005).

MALS scores can range from 0-100 and fall into one of 3 categories:

- Above average (score >80)
- Average (score 60-80)
- Below average (score <60)

It is important to note that whilst above average scores on the BYI-II inventories are associated with negative psychological well-being, the opposite is true of the MALS, where an above average score signifies higher than average academic self-esteem (i.e. is positive).

Table 4 shows the percentage of the total sample (n=20[13]) whose scores fell into each category. Forty five percent of pupils (n=9) reported levels of anxiety, and

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[13] One pupil chose not to complete the self-report measures following his pre-FAMe™ interview

55% levels of depression (n=11), that were in the above average range, with 40% (n=8) and 25% (n=5) having 'extremely elevated' pre-FAMe™ anxiety and depression levels respectively. Such scores are considered to be clinically significant and signifies a child or adolesent might be in need of further assessment or intervention (Beck et al., 2005). The majority (n=13) of pupils had average levels of academic self-esteem pre-FAMe™ (65%) and almost a third (30%) reported above average (i.e. positive) levels of academic self-esteem. Only one pupil had an academic self-esteem score that was below average.

Although distributed slightly differently, in terms of the severity level, it was the same pupils who scored in both the above average depression and above average anxiety level range (except for one pupil whose scores indicated that he had mildly elevated depression levels but average levels of anxiety). For this reason, and because it was expected that the FAMe™ System was more likely to impact positively on pupils' anxiety rather than depression, BYI-A scores were used to determine the two comparison groups for later analyses, i.e. average anxiety levels (Group 1) and above average anxiety levels (i.e. all pupils with either mild, moderate or extremely elevated levels of anxiety) (Group 2).

Table 4.

The percentage of pupils (n=20) whose pre-FAMe™ self-report scores fell into each category

Self-Report Category	% of pupil sample (n=20) in each category	% of pupil sample (n=20) with either average or above average BYI scores
Average Anxiety Levels	55% (n=11)	**55%** (n=11)
Mildly Elevated Anxiety Levels	0%	**45%** (n=9)
Moderately Elevated Anxiety Levels	5% (n=1)	
Extremely Elevated Anxiety Levels	40% (n=8)	
Average Depression Levels	50% (n=10)	**50%** (n=10)
Mildly Elevated Depression Levels	10% (n=2)	**50%** (n=10)
Moderately Elevated Depression Levels	15% (n=3)	
Extremely Elevated Depression Levels	25% (n=5)	
Above Average MALS Score	**30%** (n=6)	
Average MALS Score	**65%** (n=13)	
Below Average MALS Score	**5%** (n=1)	

Key:

Green indicates positive well-being scores

Red indicates negative well-being scores

In addition to the validated self-report measures, pupils completed a questionnaire, designed specifically for the FAMe™ project, that asked them to think about the previous week in school and rate: how anxious/worried they had felt in

class; how interested/bored they had felt in class; and how easy it had been to understand the work in class. The percentage of pupils rating 1 (not at all), 2 (a bit/quite), or 3 (very), for each question is shown in Figure 12.

As 'very' and 'not at all' could be either positive or negative responses (depending on the question) the value labels are not always presented in the same order in the chart. Instead the bars have been stacked to read from positive (left) to negative (right). The majority (85%) of pupils (n=17) indicated that they had felt at least a bit anxious in class during the week prior to the pre-FAMe™ interview; 90% (n=18) had only been a bit (n=13), or had not been at all interested (n= 5), in their classwork; and 20% (n=4) had not found their classwork at all easy.

Figure 12.

Percentage of pupils (n=20) reporting either 'very', 'a bit/quite' or 'not at all' to three questions relating to their in-class feelings during the week before their pre-FAMe™ interview
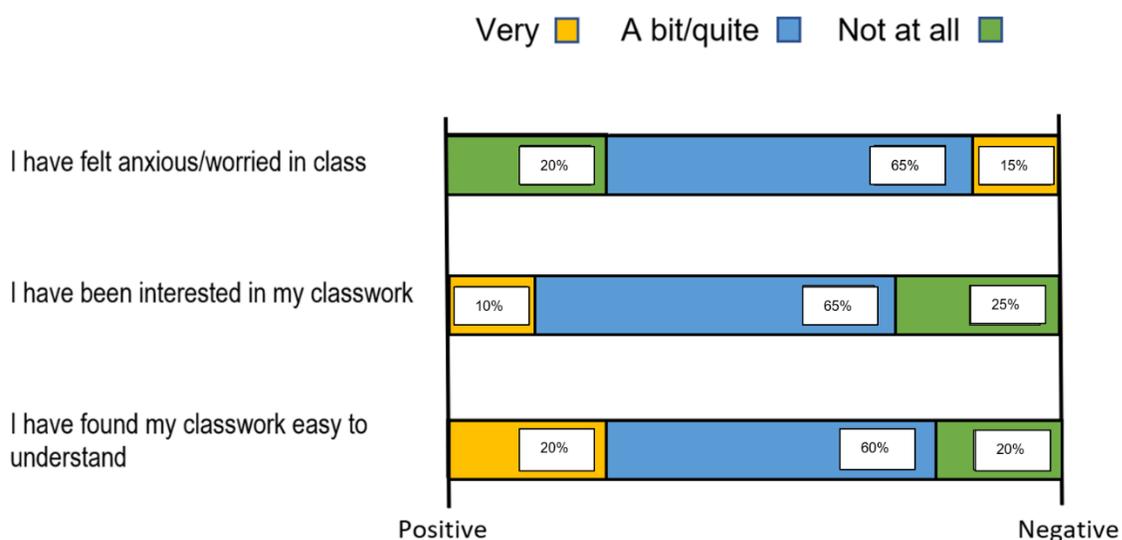
A comparison of pupils' pre-FAMe™ scores from each of these questionnaires with their repeat-measures post-FAMe™ scores is reported in Section 4 (Part A) of this chapter as part of the FAMe™ System evaluation.

Part B.

Pupils' Pre-FAMe™ Qualitative Data:
Diagnostic Criteria for Autism

This section begins with a description of the validation process undertaken to achieve confidence in the relibility of the findings obtained from the narrative data analysis. This is followed by a report of the descriptive statistics resulting from Coding Round 1a, a thematic analysis of pupils' pre-FAMe™ interview transcripts in which the narrative data was coded to a deductive scheme of nodes developed from: the diagnostic criteria (DSM-5, 2013; ICD-10, 2010); the Guidelines and Criteria exemplars, developed during a Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring (CDC ADDM) project (Rice et al., 2013) and adapted by Carpenter (2013); and autism research literature. Coding followed a hierarchical coding strategy (Appendix 1D).

Coding results are provided at both an individual and group level throughout. The extent to which the diagnostic criteria can provide explanation for, or can inform

understanding of, autistic pupils' in-school behaviours and school experiences was explored.

A further inquiry into the data was conducted, to investigate the extent to which participating pupils attributed positive and negative experiences of school to external factors, such as their teachers' behaviour/practice or the physical environment, or to internal features (of themselves), such as their academic strengths or weaknesses or their coping strategies. This was important to ascertain, as the diagnostic criteria seeks to describe or explain inherently internal features of autistic individuals. Any attribution by participating pupils to external factors impacting on their school experiences could potentially influence the results and subsequent interpretation of the coding analysis. It was therefore necessary to establish whether this was the case. The aim of this first stage of the analysis was to answer the following research question:

Research Question 1:

Are the explicit and implicit features of autism, specified in the diagnostic criteria of autism and autism literature, reflected in autistic pupils' descriptions of their lived experiences of school and, if so, to what extent?

The goal was to gain insight into the capacity of the explicit and implicit features of autism (taken from the diagnostic criteria, criteria exemplars, and autism literature)

to provide an explanation for and/or aid understanding of the experiences of school described by autistic pupils.

Validation of Coding

In order to ensure that my coding of the qualitative data was methodologically robust and reliable, I used two different methods of validation. In the first instance my Director of Studies (Dr Luke Beardon - EdD Autism), and a research colleague who is an independent autism researcher with a particular interest in autism theory, and with whom I have collaborated on other autism related projects (Dr Nick Chown - PhD Autism), read all the references provided as examples throughout the coding scheme (Appendix 1) and confirmed their agreement that each reference was coded correctly, i.e. was an example of the node it had been coded to. This process returned an agreement rate of 100% without any need for alteration/modification.

In the second stage of data validation Dr Chown coded one complete pre-FAMe™ interview transcript[14] following the coding rules (Appendix 1C) and returned the coded transcript to me for comparison. During this stage, email correspondence highlighted that certain areas of the coding scheme required further explicit clarification to prevent any potential miscoding of pupils' references should a repeat/follow-up study be conducted. This was particularly true in relation to the

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[14] Dr Chown signed a confidentiality document in which he agreed not to disclose any details of the anonymised pupil interview transcript (Appendix 16)

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autism theory nodes (the analysis of which is presented in Part C). Deciding whether or not a behaviour and/or experience described by an autistic individual can be explained by a particular autism theory is vulnerable to subjective interpretation based on an individual coder's understanding/interpretation of the theory itself. In order to ensure maximum reliability the coding rules were revised and made more explicit in relation to each node, with additional examples provided where there had been evidence of potential disagreement and/or confusion.

It was also made explicit that coders (n.b. for this study I was the only coder) are required to follow the coding rules regardless of their own understanding of autism theory. It was decided during this process that there should be a requirement to assume that *all* of the experiences/perceptions/feelings, described by participating pupils, were autism related/impacted by their being autistic, i.e. the coder must not distinguish between experiences that might be thought 'typical' of adolescents regardless of their neurology, e.g. arguing with friends, or being stressed, and those that are more obviously explicit to autism, e.g. not understanding sarcasm or body language. This reduces the potential for a coder's subjective opinion to impact on coding and the subsequent analysis. Following Dr Chown's communications, the coding rules were updated to ensure it was made explicit that *all* references to experiences/thoughts/feelings that had the potential to result from autism (i.e. a feature listed in the diagnostic criteria), or that could possibly be explained by autism theory/ies, were to be coded to the appropriate node/s.

I accepted that this strategy might lead to some over-coding of references to autism criteria and theory nodes but decided that this was preferable, in an exploration of the capacity of these to explain the experiences of autistic individuals, than to risk introducing subjective views about what was and wasn't an autism related experience, or was an experience that could be explained by a particular autism theory.

The revised strategy and a description of the method used to develop individual nodes for coding, with examples of the interview material coded to each node, is provided in Appendix 1. Following these modifications to the coding strategy/rules, the inter-rater reliability, between myself and Dr Chown, of the complete pupil trancript was 98% and 94% respectively for coding rounds 1a (diagnostic criteria) and 1b (autism theory).

Coding round 1a.

Pupils' Pre-FAMe™ Interviews Coded to Explicit and Implicit Features of Autism as Defined in the Diagnostic Criteria

The autistic population is a heterogeneous group of individuals, who inherently share difficulties in specific areas, relating to social communication and interaction, and restricted, repetitive patterns of behaviour, interests, or activities (DSM-5, 2013), but for whom the particular manifestation of these difficulties is unique (Attwood, 2008; Beardon, 2012; Rosqvist, 2012). Thus, in order that any individual differences in the accounts given by pupils about their current experiences

of school were not lost from view, through the process of displaying group coding only, the following pie charts present the coding of pupil transcripts at an individual (Figs.13 and 14); gender group (Figs.15 and 16), anxiety group (Figs.17 and 18); and whole sample group (Figs.19 and 20) level.

Of the deductive nodes created from the list of implicit features of autism, set out in the DSM-5 (2013), ICD-10 (2010) and the criteria exemplars, i.e.: sleeping and eating disturbances; meltdowns/behavioural difficulties and temper tantrums; shyness/social anxiety; fears/phobias; self-directed aggression/self-injury; lacking spontaneity, initiative and creativity in the organisation of their leisure time; difficulty applying conceptualisations in decision-making in work (even when the tasks themselves are well within their capacity); problems with play/imagination; language and developmental delays; and poor imitation skills, only two had references coded to them. These were 'Shyness/Social Anxiety' (n=70) and 'Behavioural Difficulties' (n=8). Other nodes were represented in the pupils' narrative data but did not related to current school experiences (e.g. they were experiences that had happened in the past or at home) and so were omitted from the analysis (see coding strategy, Appendix 1C). Only one pupil (Site 3, Pupil 02) made references coded at 'behavioural difficulties', all of which related to his engaging in aggressive behaviour which was directed at others (rather than at himself). As the majority (90%) of the references coded to these nodes were associated with shyness and social anxiety, these two implicit features were collapsed into one category ('Criteria Implicit') for reporting purposes throughout Figures 13-20.

References relating to: general anxiety/worry and masking behaviours - i.e. not specifically attributed to the social environment/socialising/having attention drawn to them (which were coded to Criteria Implicit, 'Shyness/Social anxiety'), or perfectionistic tendencies (coded to DSM-5, B3, 'Highly restricted, fixated interests) - were coded to deductive nodes developed in response to the wide reporting of these features in academic autism literature. As the majority, 80 of the 89 references (90%) coded to this node, were associated with general anxiety/worry these two implicit features have been collapsed into one category ('Literature Implicit') for reporting purposes throughout Figures 13-20.

Findings are reported as percentages of the total units of coding made by individuals and/or groups, rather than the number of units of coding made, to eliminate the potential for data from the more/less verbose pupils to impact on distribution figures. Using percentages in this way enabled a more accurate comparison of individual and group data.

i. Coding comparison by individual pupil

The distribution of coding to nodes of the school experiences described varied widely between individual pupils (Fig.13). For example, over half (54%) of the individual units of coding made by Site 3, Pupil 07 were coded to the 'Criteria Explicit' nodes, i.e. it was possible to infer that these experiences were affected by/resulted from an explicit feature of autism as defined in the DSM-5 (2013) diagnostic criteria. In contrast, only 8% of the units of coding made by Site 2, Pupils 02 and 03 were

coded to one of these nodes. Difficulties relating to social communication and social interaction (i.e. DSM-5, A1; A2; and A3), accounted for over a quarter of the individual units of coding made by Site 1, Pupil 04 (26%), but only for 2% of the units of coding made by Site 3, Pupil 02. For some pupils, the percentage of units of coding coded to shyness and social anxiety (Criteria Implicit) was greater than those relating to general anxiety and worry (Literature Implicit). For other pupils the opposite was true.

Figure 13.

The percentage of references (UoC) relating to current experiences of school made by individual pupils in their pre-FAMe™ interview which were coded to each criteria related node
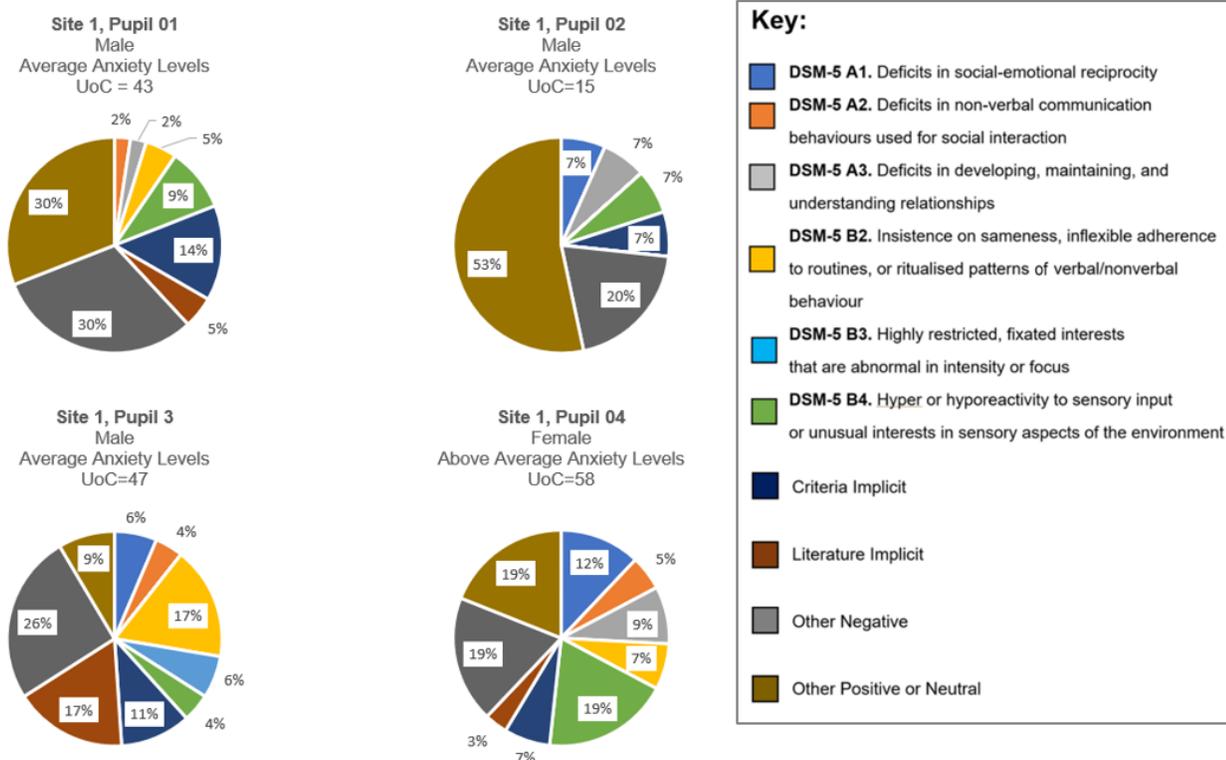
Site 1, Pupil 5
Female
Above Average Anxiety Levels
UoC=101
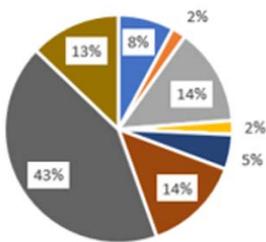
Site 1, Pupil 06
Female
Above Average Anxiety Levels
UoC=46
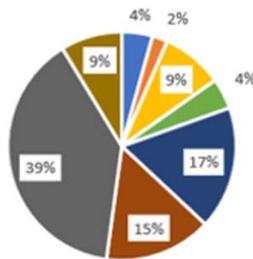
Site 1, Pupil 07
Male
Average Anxiety Levels
UoC=38
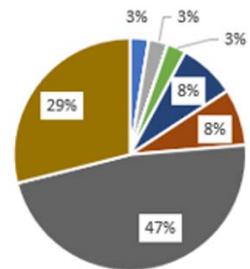
Site 1, Pupil 08
Male
Above Average Anxiety Levels
UoC=24
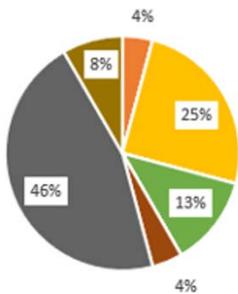
Site 1, Pupil 09
Male
No Self-Report Scores
UoC=43

Key:

DSM-5 A1. Deficits in social-emotional reciprocity

DSM-5 A2. Deficits in non-verbal communication behaviours used for social interaction

DSM-5 A3. Deficits in developing, maintaining, and understanding relationships

DSM-5 B2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour

DSM-5 B3. Highly restricted, fixated interests that are abnormal in intensity or focus

DSM-5 B4. Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

Criteria Implicit

Literature Implicit

Other Negative

Other Positive or Neutral

Site 2, Pupil 01
Female
Average Anxiety Levels
UoC=39

Site 2, Pupil 02
Female
Average Anxiety Levels
UoC=48
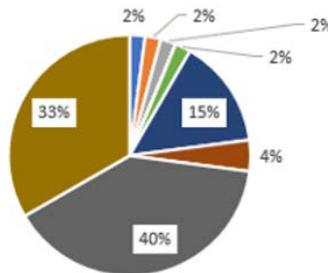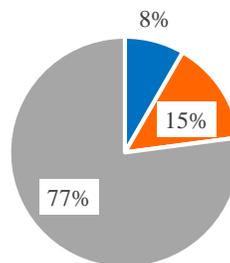
Site 2, Pupil 03
Male
Average Anxiety levels
UoC=41
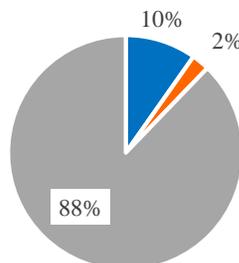
Site 2, Pupil 4
Male
Above Average Anxiety Levels
Uoc=64

Site 3, Pupil 01
Male
Average Anxiety Levels
UoC=32

197
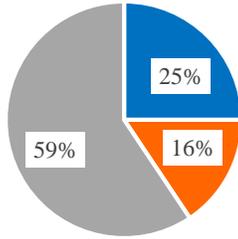
Site 3, Pupil 02
Male
Above Average Anxiety levels
UoC=66

Site 3, Pupil 03
Male
Above Average Anxiety Levels
UoC=32

Site 3, Pupil 04
Male
Average Anxiety Levels
UoC=59

Site 3, Pupil 05
Male
Average Anxiety levels
UoC=47

Site 3, Pupil 06
Male
Average Anxiety levels
UoC=41

Key:

DSM-5 A1. Deficits in social-emotional reciprocity

DSM-5 A2. Deficits in non-verbal communication behaviours used for social interaction

DSM-5 A3. Deficits in developing, maintaining, and understanding relationships

DSM-5 B2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour

DSM-5 B3. Highly restricted, fixated interests that are abnormal in intensity or focus

DSM-5 B4. Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

Criteria Implicit

Literature Implicit

Other Negative

Other Positive or Neutral

Site 3, Pupil 07
Male
Above Average Anxiety levels
UoC=28

Site 3, Pupil 08
Female
Above Average Anxiety Levels
UoC=73

The following summary table (Table 5) is provided to show the percentage distribution range of references coded to each 'Criteria Explicit' node amongst individual pupils, and the number of pupils making at least one reference coded to each node.

Table 5.

The percentage distribution range, amongst individual pupils (n=21) of references coded to each of the nodes in coding round 1a

Node	% Distribution Range Amongst Individual Pupils (n=21)	Number of pupils making at least one reference coded to this node
A1. Deficits in social-emotional reciprocity	0-12%	12 (57%)
A2. Deficits in non-verbal communication behaviours used for social interaction	0-13%	16 (76%)
A3. Deficits in developing, maintaining, and understanding relationships	0-14%	15 (71%)
B1. Stereotyped or repetitive motor movements, use of objects, or speech	No references coded to this node	0
B2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour	0-25%	16 (76%)
B3. Highly restricted, fixated interests that are abnormal in intensity or focus	0-8%	4 (19%)
B4. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment	0-36%	18 (86%)
Criteria Implicit i.e. Social anxiety/shyness	0-18%	20 (95%)
Literature Implicit i.e. general anxiety and masking	0-17%	19 (90%)
Other Negative	16-72%	21 (100%)
Other positive/neutral Including references to skills or the absence of an autism specific *deficit*	4-53%	21 (100%)

None of the explicit features of autism were universally referred to. Hyper- or hypo-reactivity to sensory input was the explicit feature of autism to which the highest proportion of references was attributed by any one pupil (36%) and was also referred to by the highest number of pupils (n=18).

The pie charts in Figure 13 were simplified (Figure 14) to show the distribution of coding to three distinct compound categories: Criteria Explicit (all 8 criteria nodes combined); Criteria Implicit; and unrelated to the DSM-5 criteria for autism (i.e. all other coding). This is followed by a summary table which provides details of the percentage distribution range between individual pupils, and the number of pupils who made at least one reference coded to each of the compound nodes (Table 6).

Figure 14.

The percentage of references (UoC) relating to current experiences of school made by individual pupils during their pre-FAMe™ interview coded to 'Criteria Explicit' 'Criteria Implicit' and 'Unrelated to Criteria'.

Site 1, Pupil 03
Male
Average Anxiety Levels
UoC=47

38%
11%
51%

Site 1, Pupil 04
Female
Above Average Anxiety
Levels
UoC=58

41%
52%
7%

Key:

Criteria Explicit

Criteria Implicit

Unrelated to the DSM-5
Criteria for Autism

Site 1, Pupil 05
Female
Above Average Anxiety
Levels
UoC=101

26%
5%
69%

Site 1, Pupil 06
Female
Above Average Anxiety
Levels
UoC=46

20%
17%
63%

Site 1, Pupil 07
Male
Average Anxiety levels
UoC=38

8%
8%
84%

Site 1, Pupil 08
Male
Above Average Anxiety Levels
UoC=24

42%
58%

Site 1, Pupil 09
Male
No Self-Report Scores
UoC=43

21%
9%
70%

Site 2, Pupil 01
Female
Average Anxiety Levels
UoC=39

26%
74%

Site 2, Pupil 02
Female
Average Anxiety Levels
UoC=48

8%
15%
77%

Site 2, Pupil 03
Male
Average Anxiety Levels
UoC=41

10%
2%
88%

Site 2, Pupil 04
Male
Above Average Anxiety
Levels
UoC=64

16%
17%
67%

201

Site 3, Pupil 01
Male
Average Anxiety Levels
UoC=32

25%
16%
59%

Site 3, Pupil 02
Male
bove Average Anxiety Levels
UoC=66

21%
18%
61%

Key:

Criteria Explicit

Criteria Implicit

Unrelated to the DSM-5
Criteria for Autism

Site 3, Pupil 03
Male
Above Average Anxiety Levels
UoC=32

13%
3%
84%

Site 3, Pupil 04
Male
Average Anxiety Levels
UoC=59

24%
2%
75%

Site 3, Pupil 05
Male
Average Anxiety Levels
UoC=47

26%
6%
68%

Site 3, Pupil 06
Male
Average Anxiety Levels
UoC=41

17%
10%
73%

Site 3, Pupil 07
Male
Above Average Anxiety
levels
UoC=28

43%
54%
4%

Site 3, Pupil 08
Female
Above Average Anxiety
levels
UoC=73

27%
1%
71%

202

Table 6.

The percentage distribution range, amongst individual pupils, of references coded to the compound nodes Criteria Explicit, Criteria Implicit and Unrelated to the DSM-5 Criteria for Autism (i.e. all other coding)

Node	% Distribution Range Amongst Individual Pupils (n=21)	Number of pupils making at least one reference coded to this node
Criteria Explicit	8-54%	21 (100%)
Criteria Implicit	0-17%	19 (90%)
Unrelated to the DSM-5 Criteria for Autism	41-88%	21 (100%)

It is evident from Figure 14 that, for the majority of pupils (90%), a greater proportion of their references relating to current experiences of school were not related to the diagnostic criteria (explicit or implicit) than were. The between-pupil percentage distribution range, of the total number of references each made that were coded to the combined criteria explicit node, was 8-54%, with a mean of 24% and a median of 21%. The distribution of coding to the criteria implicit node, which relates almost exclusively to shyness and social anxiety, ranged from 0-17% of the total number of references made per pupil, with an average of 8.2% and a median of 7%. The majority of pupils (90%) made references which were coded to this node, with 38% (n=8) having ≥10% of their total coded references coded here. This suggests that social anxiety is a salient feature of their school experiences.

i. Coding comparison by gender

Interview data was next separated into two groups according to the pupils'
gender. One pupil told me he is *"gender fluid"* and, at the time of the pre-FAMe™
interview, identified as male (which he is, biologically). The percentage distribution
of coding of the two groups' interview data relating to current experiences of school
is shown in Figure 15.

Figure 15.

**The percentage of the total number of references relating to current school
experiences made by male and female pupils
that were coded to each criteria related node**
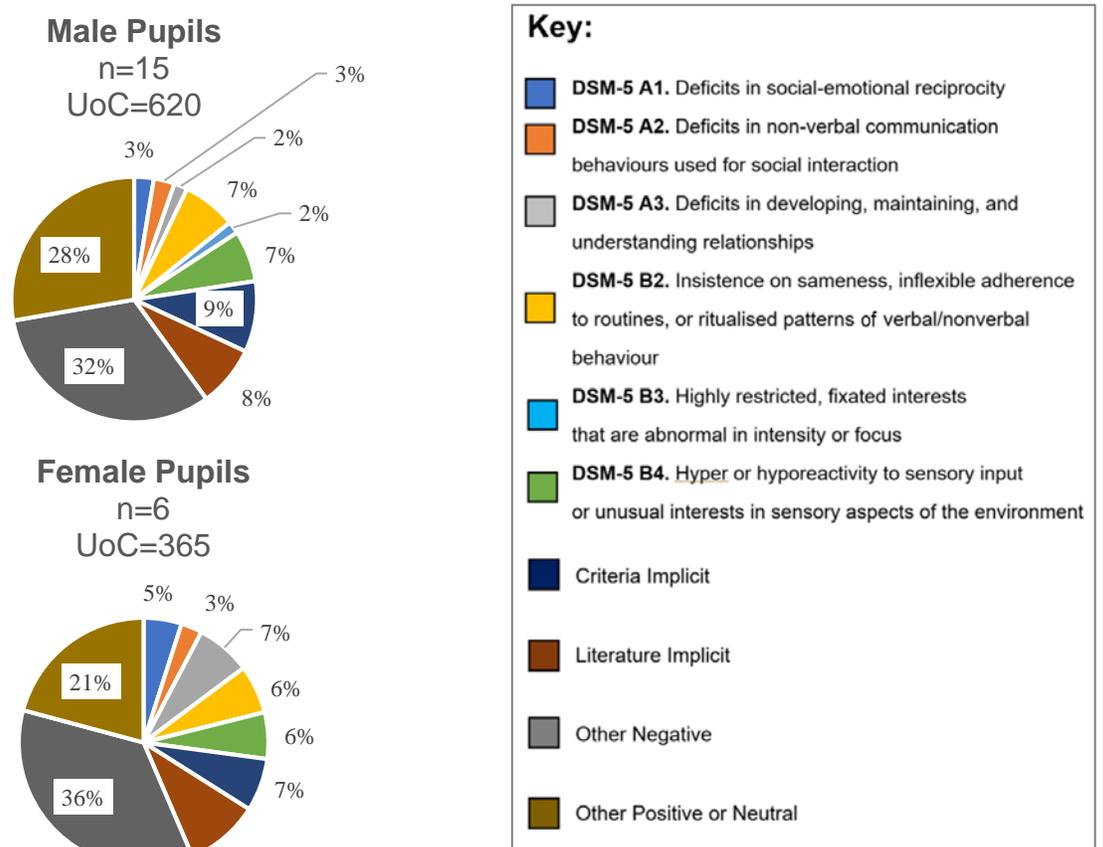
Between gender-group differences were observed, in relation to the percentage of references coded to the explicit features of autism. A higher proportion of the total number of references made by female pupils (14%) were coded to nodes relating to social communication and interaction (DSM-5, Category A), than of those made by the male pupils (8%). The percentage of references coded to DSM-3, A3., i.e. 'deficits in developing, maintaining, and understanding relationships', made by girls, whilst relatively small (7% of their total references) was more than three times that of the boys (2%). In contrast, a higher percentage of the units of coding made by male pupils (16%) than female pupils (9%) were related to restricted, repetitive patterns of behaviour, interests, or activities (DSM-5, Category 4).

The pie charts in Figure 15 were simplified (Figure 16) to show the distribution of coding to the three distinct categories that were developed during analysis of individual pupil's data (Fig. 14), i.e.: Criteria Explicit; Criteria Implicit; and unrelated to the DSM-5 criteria for autism (i.e. all other coding).

It can be seen that just under a quarter (23%) of the male pupils' individual units of coding, and just over a quarter (27%) of those made by female pupils, were coded to 'Criteria Explicit' nodes, i.e. it was possible to infer that the behaviours and/or school experiences being described were affected by/related to an explicit feature of autism (DSM-5). These percentages rose to 32% and 34% when the 'Criteria Implicit' (social anxiety/shyness) node was included in this total, with male pupils having a slightly higher percentage of their references coded to this node (9%), than female pupils (7%).

Figure 16.

The percentage of the total number of units of coding made by male
and female pupils that were coded to
'Criteria Explicit' 'Criteria Implicit' and 'Unrelated to Criteria'
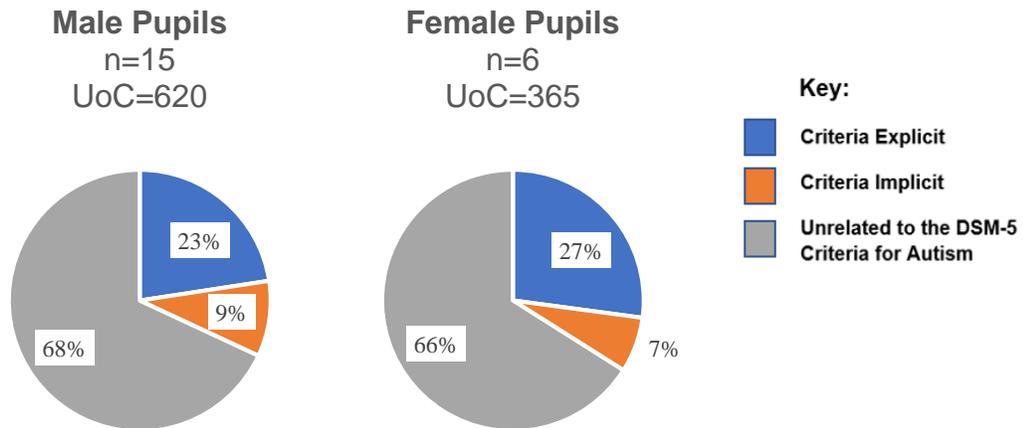
ii.　Coding comparison by anxiety group

Pupils' data was grouped according to the pupils' pre-FAMe™ anxiety level, as measured on the BYI-A self-report scale (i.e. those pupils with average levels of anxiety and those with above average anxiety levels). The distribution of coding, of each groups' references relating to current school-related experiences, to the explicit features of autism (Round 1a nodes) is shown in Figure 17 and simplified in the same manner as before (i.e. Figs.14 & 16) in Figure 18.

Although the overall percentages of references coded to each explicit feature of autism were relatively low, between anxiety-group differences were observed. For example, the percentage of the units of coding made by those in the above average

anxiety group, which related to difficulties in developing, maintaining and understanding relationships (6%), was 3 times that of the average anxiety level group (2%), and the percentage of the total number of units of coding made which related to difficulties resulting from changes to routine was double (9% and 4% respectively).

Figure 17.

The percentage of the total number of units of coding made by pupils with average or above average levels of anxiety coded to each criteria related node

Average Anxiety Level Group
n=11
UoC=450

Above Average Anxiety Level Group
n=9
UoC=492

Key:

DSM-5 A1. Deficits in social-emotional reciprocity

DSM-5 A2. Deficits in non-verbal communication behaviours used for social interaction

DSM-5 A3. Deficits in developing, maintaining, and understanding relationships

DSM-5 B2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour

DSM-5 B3. Highly restricted, fixated interests that are abnormal in intensity or focus

DSM-5 B4. Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

Criteria Implicit

Literature Implicit

Other Negative

Other Positive or Neutral

The most significant difference in the coding of the two groups' references was observed at the 'Other Positive/Neutral Experiences' node. Far fewer of the references made by pupils with above average levels of anxiety made references that were coded to this node (18%) than were those made by the pupils with average levels of anxiety (32%). This node includes references to personal skills and enjoyment of school or the specific absence of autism related '*deficits*' (criteria explicit features). The two anxiety groups had very similar percentages of their units of coding coded to the criteria implicit and literature implicit nodes, which relate almost exclusively to experiences of anxiety and stress (social and general), which is surprising considering that the groups were defined by their clinical anxiety levels.

Figure 18.

The percentage of the total number of units of coding made by pupils with average or above average levels of anxiety coded to,
'Criteria Explicit' 'Criteria Implicit' and 'Unrelated to Criteria'
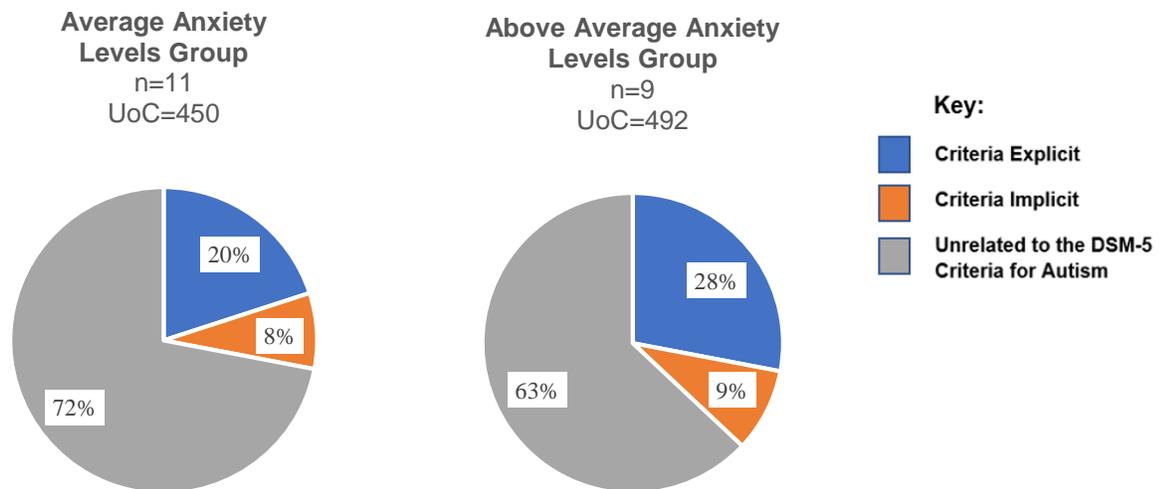
It is evident from Figure 18 that the majority of references made by the pupils, which related to current experiences of school, in both the average and above average anxiety groups (72% and 63% respectively) were not related to either the explicit or implicit criteria nodes, i.e. the in-school behaviour and/or school experiences being described could not be related to any feature of autism specified in the DSM-5 or its criteria exemplars (Carpenter, 2013). However, a higher proportion of the references made by pupils with above average levels of anxiety were attributed to explicit features of autism (28%) than of those made by pupils with average anxiety levels (20%).

iii.   Whole Sample Coding

The percentage distribution of the references, made by the whole pupil sample which related to current experiences of school, coded to the deductive nodes developed from the diagnostic criteria, its exemplars, and autism literature, is shown in Figure 19 and simplified in 20 (to the same three compound categories defined in Figs. 14, 16 & 18). The percentage of pupils making at least one reference that was coded to each node is also provided.

The diagnostic criteria (DSM-5) related 'explicit' nodes with the highest percentages of pupils' references coded to them were: B2., 'Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour' (7%, n=69); and B4., 'Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment' (6%, n=59).

The 'Criteria Implicit' node, which is almost exclusively related to experiences of social anxiety and shyness, accounted for 8% of the references (n=78) made by the whole pupil sample. Nine percent of the total number of units of coding made were coded to the 'Literature Implicit' node, i.e. were related to general anxiety and masking behaviours (n=89). Overall, these two anxiety related nodes made up 17% (n=167) of the total number of school related references, evidencing anxiety as a salient issue for this group of pupils. Pupils made a higher proportion of references to 'other negative' experiences (34%) than to 'other positive/neutral ones' (25%).

Figure 19.

The percentage of the total number of units of coding (n=985) made by pupils (n=21) in their pre-FAMe™ interviews which were coded to each criteria related node


Whole Pupil Sample
n=21
UoC=985

Key:
DSM-5 A1. Deficits in social-emotional reciprocity
DSM-5 A2. Deficits in non-verbal communication behaviours used for social interaction
DSM-5 A3. Deficits in developing, maintaining, and understanding relationships
DSM-5 B2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour
DSM-5 B3. Highly restricted, fixated interests that are abnormal in intensity or focus
DSM-5 B4. Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment
Criteria Implicit
Literature Implicit
Other Negative
Other Positive or Neutral

Of the total number of references made by the whole pupil sample during their pre-FAMe™ interviews which were related to their current experiences of school (n=985), one third were coded to either an explicit (DSM-5) (n=236) or implicit (Carpenter, 2013) (n=78) feature of autism. This means that it was not possible to infer any relationship between the diagnostic criteria for autism, nor the criteria exemplars, for the majority (68%) of the references pupils made which related to their in-school behaviour and/or the experiences of school they described.

Figure 20.

The percentage of the total number of units of coding (n=985) made by pupils (n=21) in their pre-FAMe™ interviews which were coded to 'Criteria Explicit' 'Criteria Implicit' and 'Unrelated to Criteria'

Compound Node	% of sample making at least one reference coded to this compound node
Criteria Explicit	95%
Criteria Implicit	86%
Unrelated to diagnostic criteria for autism	100%

211
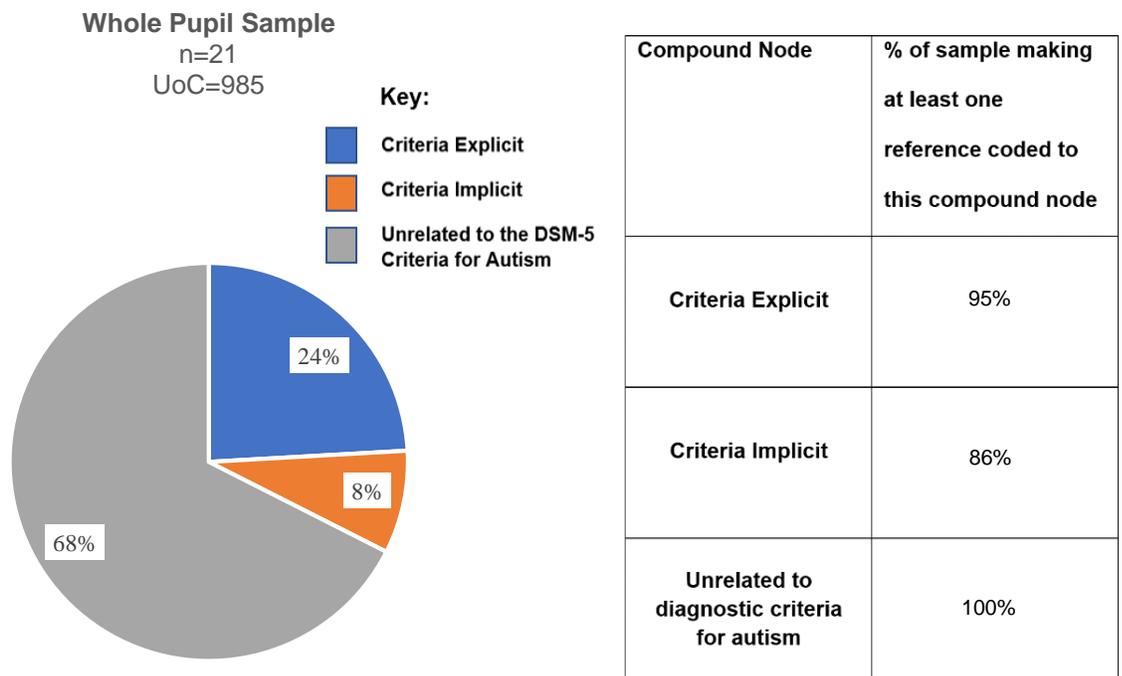
iv. Overview of criteria explicit nodes

In order to obtain a clear picture of the distribution of the coding, of the whole pupil sample's school related references, to the nodes that represent the autism diagnostic criteria (DSM-5, 2013), Figure 21 dislays the percentage distribution of the total number of references coded to a Criteria Explicit node (n=246) represented at each node.

Figure 21.

The percentage distribution of all references coded to explicit features of autism (n=246) which were coded to each individual feature

Total number of references coded to each of the
Criteria Explicit Nodes
n=236

Key:

DSM-5 A1. Deficits in social-emotional reciprocity

DSM-5 A2. Deficits in non-verbal communication behaviours used for social interaction

DSM-5 A3. Deficits in developing, maintaining, and understanding relationships

DSM-5 B2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour

DSM-5 B3. Highly restricted, fixated interests that are abnormal in intensity or focus

DSM-5 B4. Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

As discussed in relation to Figure 19, Figure 21 evidences that the DSM-5 criteria categories B2 and B4 define the two most frequently identified explicit features of autism impacting on participating pupils' current experiences of school. These two nodes, relating to insistence on sameness/adherence to routines, and

hyper/hypo-reactivity to sensory input, each had over a quarter of the total number of references that were coded to an explicit feature of autism node (n=236) coded to them. This is perhaps unsurprising, considering the typical secondary school environment and the unpredictable nature of the school day.

Although references to problematic sensory experiences made up only 6% of the total number of units of coding made (n=985), the causes of these experiences are potentially amenable to environmental change, and so it was important to explore these further.

Figure 22 displays the number of pupils who made at least one reference, and the average number of references made per pupil, to the following inductive sub-nodes, developed through thematic examination of pupils' interview data which had been coded to the DSM-5 B4 node: a) classroom environment problematic/disrupts concentration for pupil, e.g. too noisy/hot/bright; b) teachers leaning over pupil/getting too close upsets or distresses pupil/makes them uncomfortable, e.g. when teacher is looking at pupil's work; c) pupil helped to concentrate or listen in class through use of a fiddle toy/ fiddling with something; d) pupils not liking it when teachers shout/ raise their voice in class; and e) other.

It can be seen that the physical environment of the classroom, e.g. the noise, temperature, and lighting, was referred to as problematic by more than half of the pupils (57%) and this was also referred to most often on average (2.7 times/pupil). The same number of pupils (n=12) reported that they felt uncomfortable when

teachers got close to them to look at their work. Nine of these (43% of the sample) commented independently (i.e. without suggestion from me) that they would prefer to hand teachers their books instead of having them come and read over their shoulder. One third (n=7) of the pupils found that having something to fiddle with helped them to stay calm, concentrate and listen in class. This was only problematic if teachers drew attention to it or asked them to stop. The implications of these findings are considered in the Discussion chapter.

Figure 22.

Number of pupils making at least one reference to an inductive sub-node of DSM-5, B4. 'Hyper- and hypo-reactivity to sensory input' and the average number of times each aspect was referred to per pupil
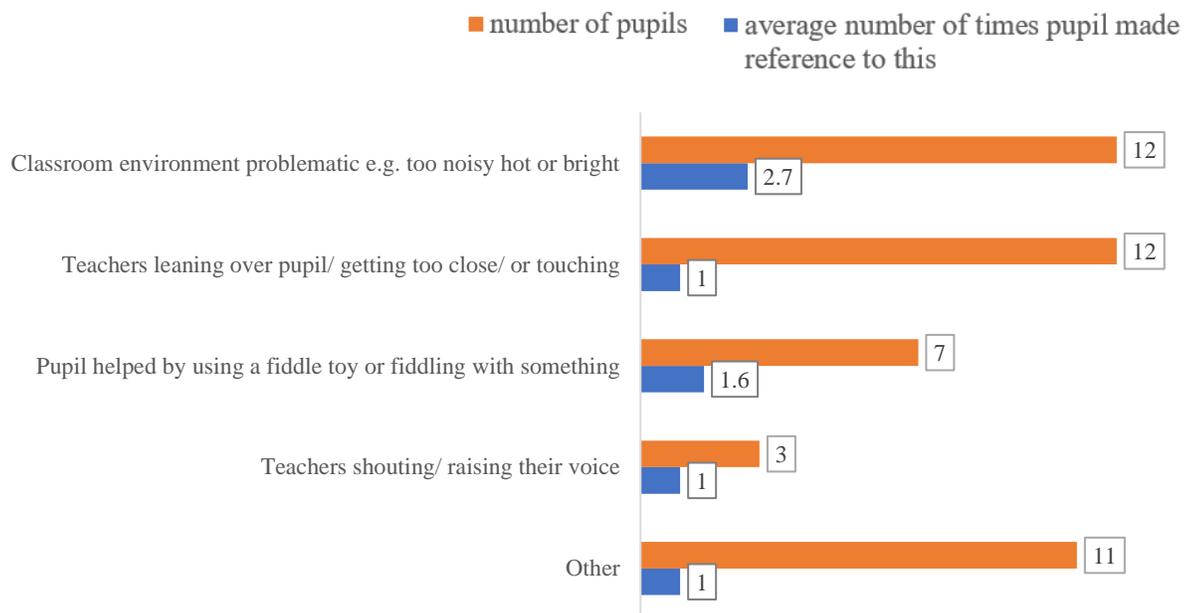
It became evident during Coding Round 1a that, within the units of coding coded at the 'Other Negative' and 'Other Positive/Neutral' nodes, multiple references were made to particular areas of difficulty ('Other Negative), or enjoyment of school, skills and strengths ('Other Positive') and/or the absence of a specific autism related *'deficit'* ('Other Neutral') by multiple pupils.

In order to better understand the interview material that was coded at the 'Other' nodes, an additional layer of coding was undertaken (Coding Round 1a Extension).

Coding Round 1a Extension

i. Exploring References Coded to the 'Other Negative' and 'Other Positive/Neutral' Nodes

In order to capture and better understand the pupil interview data which had been coded to 'Other Negative' or 'Other Positive/Neutral' in Coding Round 1a, these two nodes were inductively split into the following sub-nodes, identified when the number of pupils referring to experiencing difficulty (negative) or not experiencing difficulty (positive/neutral) in a particular area numbered five or more (i.e. ≥ 25% of total sample):

Inductive sub-nodes

From the Original 'Other Negative' Node in Coding Round 1a:

a) *Other (Negative)* i.e. any references that could not be coded to sub-nodes b-e (defined below)

b) *Difficulties with or caused by poor concentration/daydreaming/zoning out*

Examples of units of coding at this sub-node are:

- **Site 1, Pupil 03:** *Sometimes I may have moments where I just stop take a daydream, stop focusing and then suddenly a teacher says something, and the class starts to get lively again, and I come back* [from daydream] *and I'm like, 'What are we doing?'*

- **Site 1, Pupil 05:** *I think if I'm having a stressful time I daydream - or if I'm bored because some of the lessons I can't understand some of the words they are saying - especially in physics it sounds like a lot of nonsense to me and I just daydream, and I don't even really know what I daydream about*

- **Site 2, Pupil 02:** *I find concentrating difficult*

c) *Difficulties with or caused by memory difficulties*

Examples of units of coding at this sub-node are:

- **Site 1, Pupil 01:** *I struggle in tests like in science when you have to remember equations – I struggle with them*

- **Site 1, Pupil 09:** *My memory is terrible*

- **Site 1, Pupil 03:** *'I need them to give me concrete examples because I may forget* [what teachers want from homework task] *maybe give out sheets of what they want, cos I may just put 'Complete this', but when it comes to it I'm like, I can't remember'*

d) Peers' behaviour has a negative impact on pupil

Examples of units of coding at this sub-node are:

- **Site 1, Pupil 03:** *Our class in general when we are all together, it can be like disruptive if you know…just constantly talking and the teacher just stops the lesson it just stops my learning, so I don't like that*

- **Site 1, Pupil 04:** *Other pupils…they know I keep everything neat, so my friends sometimes write on it to mess it up and I hate that*

- **Site 1, Pupil 05:** *A lot of people spread rumours around classrooms which is quite difficult to deal with when it's about me in particular*

- **Site 1, Pupil 04:** *It's a bit difficult for me working with him because lots of people don't like him and lots of people struggle working with him because he has autism …they kind of ignore his ideas and boss him about*

- **Site 2, Pupil 03:** *Yeah that's one thing that I don't like it's just that – you know in English and like we are sitting down and everyone talks over the teacher all the time and everyone shouts out and I'm like, 'God shut up everyone', and they just keep talking and talking and it's annoying*

e) Teachers' behaviour/practice has negative impact on pupil

Examples of references coded to this sub-node are:

- **Site 1, Pupil 06:** *She goes over everything really briefly and she always says, 'Don't worry if you haven't got it', at the beginning of the new topic then she goes, 'Don't worry if you've not got it, everyone will have got this by the end', and then, if you've not got it then she just like makes you ask and keeps asking you why you can't get it*

- **Site 1, Pupil 04:** *I just feel like she really doesn't like me because she's always – she never like smiles at me or anything and she never says anything nice she just shouts at me she tells me off quite a lot more* [than other people get told off]

- **Site 2, Pupil 03:** *Some of my teachers ask me questions without me putting my hand up and ask for answers and I don't like that*

- **Site 3, Pupil 02:** *My teachers ask me to put it* [fiddle toy] *away*

<u>From the Original 'Other Positive/Neutral' Node in Coding Round 1a:</u>

    a) ***Other (Positive/Neutral),*** i.e. any references that could not be coded at sub-nodes b-d (defined below)

    b) ***Academic skills, enjoying school and learning***

       Examples of units of coding at this sub-node are:

- **Site 1, Pupil 02:** *I like it when we do practical activities I also like to get my brain working – I don't really like the writing that much – I like thinking and doing* (positive)

- **Site 1, Pupil 05:** *I feel good that I am learning things and becoming more confident that's it really* (positive)

- **Site 2, Pupil 02:** *It doesn't really bother me* [if teachers lean over her work] *because I know they are just checking my work and I don't mind them writing on it because at least I know what I'm doing* (neutral)

- **Site 3, Pupil 03:** *I like this school very much, yes, the teachers are nice they give you support and help if you need anything – it's just a really nice school* (positive)

    c) ***Self-help skills/seeking help***

       Examples of units of coding at this sub-node are:

- **Site 1, Pupil 06:** *If I'm really like stressed, I'll probably come up here* (student support) *and talk to someone* (neutral)

- **Site 1, Pupil 05:** *I was fine after thinking that I could go for a minute - I just breathed and told myself that I could go if I was not calm after one minute - and I was so I thought OK I won't go, so I didn't go* [to student support] (neutral)

- **Site 1, Pupil 07:** *If something like that happens I usually just find somewhere alone at break or lunch and just listen to music or something* (neutral)

d) Teachers' behaviour or practice having a positive impact on pupil

Examples of units of coding at this sub-node are:

- **Site 1, Pupil 09:** *In my chemistry lessons, what is really useful is that they have a sheet of the power point slides and he's missed out a few words, so you have to read it and fill in the gaps and that really helps me* (positive)

- **Site 3, Pupil 02:** *A couple of teachers usually do written homework instructions, which is quite helpful to help you remember* (positive)

- **Site 3, Pupil 05:** *In maths that doesn't happen* [whole class punishments] *people who are talking get a warning, people who are talking again red slip, talking again - detention - talking again - another detention - it's a simple as that* (neutral)

- **Site 3, Pupil 08:** *It's a really laid-back lesson and, as long as you get everything done, then you are fine, and I really enjoy lessons like that, that are calm and laid back* [rather than when teachers shout] (positive)

Figure 23 displays the sub-node coding of references to current negative school experiences that were identified during Coding Round 1a and originally coded at 'Other Negative'. Percentages shown are as a proportion of the total number of units of coding coded to the 'Other Negative' node (UoC=330).

Figure 23.

Sub-node coding of the original 'Other Negative' node

219
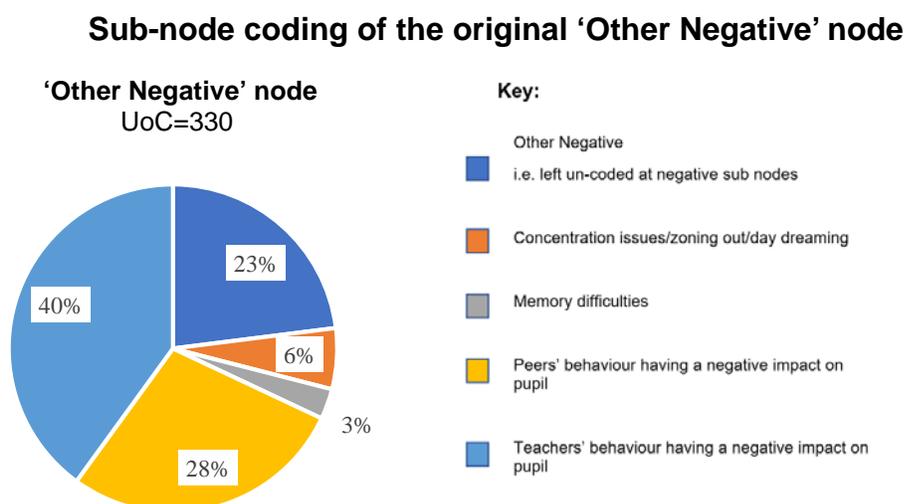
More than one quarter (28%) of the references, originally coded to the 'Other Negative' node in Coding Round 1a, related to the behaviour of other pupils in the classroom or at unstructured times in school. Over a third (40%, n=132) referred to aspects of teachers' behaviour/practice having a negative impact on the participating pupils. This represents 13% of the total number of references made in pupils' pre-FAMe™ interviews (n=985) and accounts for more references than were coded to any of the individual nodes relating to the DSM-5 criteria (Fig. 19).

It is important to note that the references coded here are in addition to any that were coded to the two nodes relating to anxiety ('Criteria Implicit' and 'Literature Implicit') which may also have contained reference to teachers' behaviour. The aim of the FAMe™ System is to change teachers' classroom behaviour/practice in line with their autistic pupils' support needs. This result would appear to substantiate the need for such a system.

Figure 24 displays the sub-node coding of references to positive or neutral school experiences that were identified during coding for explicit and implicit features of autism and originally coded at 'Other Positive/Neutral' during Coding Round 1a. Percentages shown are as a proportion of the total number of units of coding coded to the 'Other Positive or Neutral' node (UoC=248).

Figure 24.

Sub-node coding of the original 'Other Positive/Neutral' node

'Other Positive/Neutral' Node
UoC=248

40%
38%
8%
14%

Key:

Other Positive/Neutral
i.e. left un-coded at positive sub nodes

Academic Skills/enjoying school and learning

Self-help skills and seeking help

Teachers' behaviour/practice has a positive impact on pupil
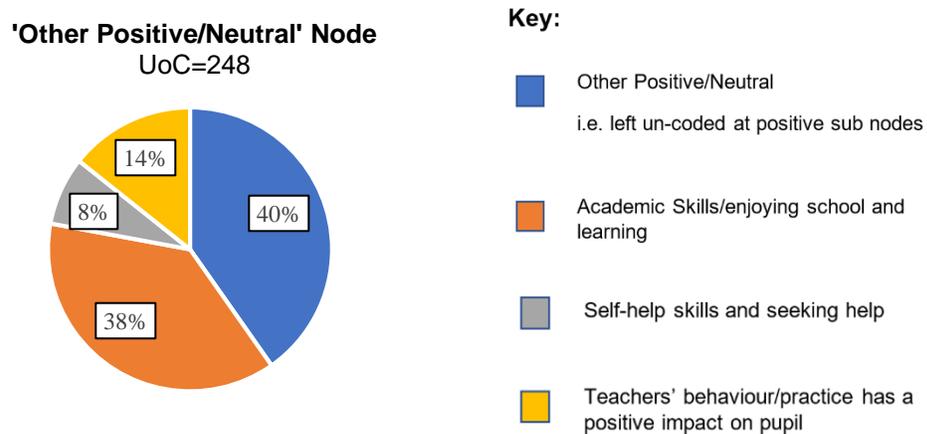
More than one third (38%) of the references, coded at the original 'Other Positive/Neutral' node, referred to the pupils' enjoyment of school and learning and their academic skills (n=94). Fourteen percent (n=35) were coded to the sub-node that related to teachers' behaviour and practice, evidencing that some pupils' experienced positive (as well as negative) experiences which they attributed to their teachers. In order to gain more insight into both the positive and negative impact of teaching practice on this group of pupils, interview data went through a further round of coding (Level 2 Coding) which is reported later in this chapter (Section 3).

The largest percentage of units of coding originally coded to the 'Other Positive/Neutral' node remained coded as 'Other' (40%). This demonstrates the extent of the individual differences in what pupils referred to during their pre-FAMe™ interview, i.e. fewer than 5 pupils referred to the same skills, lack of a specific autism

related 'deficit' (DSM-5, 'Criteria Explicit'), or other type of positive/neutral experience and therefore a separate sub-node was not created to capture this data).

Examples of the units of coding which remained coded at 'Other Positive/ Neutral' are:

- **Site 1, Pupil 04:** *We had an assembly on it [autism] yesterday and it was good because it kind of explained what it was and how it affects you and that kind of thing and what to do with people who are [autistic] and it also said the good sides so that made it look ok…*(positive)

- **Site 02. Pupil 02:** *Sometimes I like personal space but I'm not always pushy about it usually when I need help I will want to have someone near, but I like to do it by myself sometimes and I suppose it's peace and quiet I guess but …it doesn't really bother me so much – I don't need to get out really* (neutral)

- **Site 2, Pupil 05:** *I don't mind putting my hand up, but I will only put my hand up if I'm 100% sure and that's not a lot of the time but I still put my hand up - I'm not one of those really quiet people* (neutral)

ii. Exploring Pupils' Attributions to Internal and External Factors Impacting on Current School Experiences (Level 2 Coding)

In order to understand whether pupils attributed their positive and negative school experiences to internal (i.e. a feature of themselves) or external (e.g. other people or the school environment) factors, further (Level 2) analysis of the Round 1a data was performed. This stage of the investigation was important in order to ascertain:

a. whether the relatively low overall percentage of references (32%) coded to explicit/implicit features of autism in Coding Round 1a might be explained by pupils' discussion of external factors unrelated to their being autistic

b. whether any references coded to the explicit/implicit features of autism in Coding Round 1a overlap with externally attributed impact, which might suggest an interaction between autism and the environment

c. which, and to what extent, pupils' school experiences might be amenable to change through environmental intervention (e.g. a change in teaching practice).

Four new deductive nodes: 'external negative'; 'external positive/neutral'; 'internal 'negative'; and 'internal positive/neutral' were therefore introduced. Round 1a coding remained in place in order that overlap between the two levels of coding could be explored.

Level 2 Deductive Nodes

a. **Internal (negative or positive/neutral)**

Locus of impact/cause of a difficuly (or absence of a difficulty) experienced is attributed to a factor *internal* to the pupil,

   e.g.:

- because they tend to worry (negative) / not worry (positive/neutral)

- because they find instructions hard (negative) / easy (positive/neutral) to follow

- because they find it difficult (negative) / easy (positive/neutral) to approach people, interact and socialise

b. **External**

Locus of impact/cause of a difficulty, or absence of a difficulty experienced, is attributed to a factor *external* to the pupil,

e.g.:

- other people's behaviour causes (negative) / does not cause (positive/neutral) them stress

- teachers provide (positive/neutral) / do not provide (negative) clear instructions

- other people: do (positive/neutral) / do not (negative) understand them; do (positive/neutral) /do not (negative) attempt to engage them; do (positive/neutral) /do not (negative) want to be their friend

References/Units of Coding

Units of coding differed in length and were separated/defined when: a pupil finished speaking; if they changed what they were speaking about during a sentence/answer; or if the locus of impact (attributed cause) described in their sentence/answer changed. A unit of coding can span an interruption/question from the interviewer. For example, these references were split in the following way:

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a. *"I need slow instructions – like if there's lots of instructions I just prefer to take it step by step…because there's like classes where they may say, "Do this and this and this…", and I'd like them to sort of explain it in slow steady progress of what to do instead of just like, "Do this this and this", and you have to do it. I'd rather it was like, "do this…" done it, "do this", done it – do you know what I mean?"* **- coded to 'external to the pupil'**, **i.e. cause of difficulty attributed to teaching practice (overlapping with 'Criteria Explicit' DSM-5, B2)**

b. *"It's too much information in one go. I might remember the last five minutes of what they have said but the first five I won't remember that…* **- split here and coded to 'internal to pupil', i.e. cause attributed to difficulties with memory -** *…that's why I quite like art because it's a lot easier cos they get you all around a table and actually show you how to do it and it's not like going on for 20 minutes it's quick like 10 minutes at the most demonstration and in my chemistry lessons, what is really useful is that they have a sheet of the power point slides and he's missed out a few words so you have to read it and fill in the gaps and that really helps me"* **- coded to 'external' to the pupil, i.e. cause of positive experience attributed to teaching practice (overlapping with 'Other Negative')**

c. *"…in geography a few weeks ago she was like, "I want you to finish this as homework' and 'this test, I want you to do it as homework" and then she went through it and everyone else was writing the answers down as we go and she shouted at me and I was like but you told me to do it for homework I'm going to do it for homework and she was like, "Get out" and I was like "I've not done anything wrong you told me to do it for homework"…* **- split here and coded to 'external to pupil', i.e. cause of negative experience attributed to teacher behaviour (overlapping with 'Criteria Explicit' DSM-5, B2)** *…because I can't read between the lines, I need them to tell me literally what they want me to do"* **- coded to 'internal to the pupil' (DSM-5, B2).**

In coding rounds 1a these same extracts were split differently, as units of coding were determined according to whether an explicit or implicit feature of autism was identified as fundamental to the pupils' experiences. This accounts for the difference in the total number of units of coding taken from the same transcripts during the different levels of coding.

The percentage of units of coding coded at 'Internal' to the pupil ('Negative' or 'Positive/Neutral') and 'External' to the pupil ('Negative' or 'Positive/Neutral') and the relationship between these and the diagnostic criteria for autism ('Criteria Explicit' and 'Criteria Implicit') and to general anxiety and masking behaviours ('Literature Implicit'), to which transcripts were coded during coding round 1a, were calculated and are shown in Table 7.

Of the 812 individual references identified during Level 2 coding, in which pupils attributed the locus of impact/cause of their experience to an internal or external factor, 449 (55%) were attributed to internal factors (i.e. the cause was located within the pupil, e.g. to a thought or feeling, or to an action of the pupil) of which 184 (41%) were positive, i.e. related to skills, enjoyment of school, or lack of an autism specific difficulty. None of these positive internally attributed references overlapped with any of the Criteria Explicit/Implicit nodes coded in Round 1a.

Table 7.

Overlap between negative and positive/neutral impact attributed by pupils to internal or external factors and explicit and implicit features of autism (Round 1a Coding)

Round 1a Node coded to		% of UoC where attributed impact is **Internal to the pupil** (n=449)		% of UoC where attributed impact is **External to the pupil** (n=363)		% of total units of coding in Round 1a Level 2 (n=812)
		% of Internal Negative experience (n=265)	**% of Internal Positive /Neutral experience (n=184)**	**Negative experience (n=281)**	**Positive /Neutral experience (n=82)**	
DSM-5 1.	A1.	7%	0%	2%	4%	4% (n=29)
	A2.	6%	0%	2%	0%	2% (n=21)
	A3.	3%	0%	6%	0%	3% (n=26)
DSM-5 2.	B2.	10%	0%	9%	3%	7% (n=53)
	B3.	2%	0%	1%	0%	1% (n=8)
	B4.	0%	0%	17%	3%	6% (n=50)
Total Criteria Explicit		27% (n=72)	0%	37% (n=105)	12% (n=10)	23% (n=187)
Criteria Implicit		17% (n= 44)	0%	7% (n=21)	1% (n=1)	8% (n=66)
Literature Implicit		19% (n=50)	0%	7% (n=20)	4% (n=3)	9% (n=73)
Other Negative		37% (n=98)	0	49% (n=136)	6% (n=5)	29% (n=236)
Other Positive/Neutral		0%	100% (n=184)	0%	77% (n=63)	30% (n=247)
% of UoC coded to internal or external		59% (n=265)	41% (n=184)	77% (n=281)	23% (n=82)	Overall:
% of total UoC coded n=812		33%	22%	35%	10%	Negative = 67% Positive/Neutral = 33%
% of total UoC coded n=812		Internal 55% (n=449)		External 45% (n=363)		

Key:

□ (blue) **DSM-5 A1.** Deficits in social-emotional reciprocity

□ (orange) **DSM-5 A2.** Deficits in non-verbal communication behaviours used for social interaction

□ (grey) **DSM-5 A3.** Deficits in developing, maintaining, and understanding relationships

□ (yellow) **DSM-5 B2.** Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour

□ (blue) **DSM-5 B3.** Highly restricted, fixated interests that are abnormal in intensity or focus

□ (green) **DSM-5 B4.** Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

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Of the references made by pupils where the cause of their school experience was attributed to an external factor, such as the behaviour of teachers or peers, or the physical/sensory environment (UoC=363), over three quarters (77%) referred to negative experiences. A higher percentage (37%) of these overlapped with 'Criteria Explicit' nodes than did internally attributed negative experiences (27%), which was unexpected, considering that the diagnostic criteria, from which these deductive nodes were taken, relates specifically to the autistic individual.

For these externally attributed references which overlap with the 'Criteria Explicit' nodes, it appears that, despite the primary difficulty being inherently internal (i.e. a feature of their being autistic), the participating pupils considered that someone or something else was responsible for the negative impact/ experience of school they felt as a result. Examples of this were: a pupil describing finding it hard to concentrate in a noisy classroom (DSM-5, B4) but attributing their difficulty to their teacher's inability to control the noise of the other pupils (external); a pupil needing task instructions to be presented in specific non-ambiguous language to enable them understand the information (DSM-5, B3) and attributing the difficulty experienced in school to a teacher using metaphor and abstract language (external); and a pupil needing a fiddle toy in order to concentrate (DSM-5, B4) but the cause of the associated difficulty being attributed to the teacher who asked them to put it away (external).

A lower percentage of the externally attributed references were coded to 'Positive/Neutral' (23%) than were the internally attributed ones (41%). However,

there was some overlap (12%) between these and the references coded to 'Criteria Explicit', suggesting that it *is possible* for external factors to have a positive impact on the difficulties explicitly related to features of autism.

This is important in the context of developing a system with the aim of impacting positively on autistic pupils by changing external factors (i.e. teachers' practice). Also important, in the context of identifying potential future change that could improve pupils' school experiences, was the relationship between the explicit criteria node related to DSM-5 B4 (i.e. hyper/hypo-reactivity to sensory input) and externally attributed negative experiences of school. Forty-eight individual UoC were identified at this overlap, which represents 17% of all the references coded to 'External Negative'. The implication of these findings will be considered in the Discussion chapter.

Part C.

Pupils' Pre-FAMe™ Qualitative Data:
Autism Theory

This section presents the descriptive statistics resulting from thematic analysis of pupils' pre-FAMe™ interview transcripts in which the narrative data was coded to a deductive scheme of nodes, developed from literature pertaining to the five cognitive autism theories selected for investigation, i.e.: Theory of Mind theory;

Executive (Dys)Functioning theory; Central Coherence theory; Empathising-Systemising theory; and Monotropism theory (Coding Round 1b). Coding followed a hierarchical coding strategy (Appendix 1G).

The identification of the extent of overlap between the autism theories, i.e. when potential explanation for a pupil's experience could be located in more than one theory is displayed first. This is followed by the Round 1b coding results, in which the extent that cognitive autism theories can provide explanation for, or can inform understanding of, autistic pupils' in-school behaviours and school experiences was explored. These findings are provided at an individual and group level throughout.

A further inquiry into the data was conducted (following the same procedure as in Coding Round 1a, Level 2), to investigate the extent to which the coding of positive and negative experiences of school, attributed to either internal or external factors, overlapped with the coding to autism theory nodes. The findings of this analysis are reported.

The aim of this analysis was to answer Research Question Two:

To what extent can the school experiences of the autistic pupils participating in the FAMe™ Project be explained by cognitive autism theory?

The goal was to gain insight into the capacity of cognitive autism theory (which hypothesise the underlying mechanisms of autistic experience) to provide an explanation for, and/or aid understanding of, the experiences of school described by

the autistic pupils participating in this study. Findings have the potential to validate existing autism theory or to highlight the need for future theory development.

Pupil Pre-FAMe™ Interviews Coded to Cognitive Autism Theory

Autism Theory Overlap

In order for the reader to better make sense of the findings reported throughout this section, findings which relate to overlap between the 5 cognitive autism theories being explored, i.e. where more than one theory provides explanation for the same experience, are presented first.

Units of coding were coded to an autism theory node when *any* potential explanation for the experience being described by a pupil could be identified in: Theory of Mind theory; Executive (Dys)Functioning theory; Central Coherence theory; Empathising-Systemising theory; and/or Monotropism theory (Appendix 1E).

When coding references that evidenced/could potentially be explained using the systemising element of E-S theory, only those references associated with systemising which were made by pupils whose pre-FAMe™ interview transcript also evidenced a difficulty with ToM skills were retained for the analysis (i.e. contribute to the percentages shown at the E-S node throughout this chapter), as specified in Appendix 1E (p.27-28). This is because a pupil's tendency to systemise per se, without evidence of a weakness in the ability to empathise (according to Baron-

Cohen's ToM definition of empathy (2009)), cannot be considered evidence of E-S theory and thus of this theory's value as an explanation of the underlying cognitive mechanism responsible for autism.

As it was also important to evidence the strength of ToM theory in isolation, references coded to ToM theory (empathising) and E-S theory (i.e. references which demonstrated systemising in isolation that were made by pupils who also evidenced ToM difficulties, and/or those which evidenced both weak empathising and strong systemising in the same reference) are shown separately. However, as E-S theory incorporates ToM difficulties, i.e. difficulties with ToM must be present in tandem with the tendency to systemise for E-S theory to be evidenced, the overall percentage of references coded at the ToM and E-S nodes were combined in each stage of the analysis, when calculating the potential explanatory value of E-S theory.

It is important to recognise that absolute certainty, about whether any theory actually explains the cognitive mechanisms underlying autistic experiences, is not possible. In order to be coded to a theory node, a pupil's account had to contain enough information to determine that the experience being described was one that a particular theory attempts to explain/offers a potential explanation for. The coding rules (Appendix 1F) stipulate that individual units of coding be coded to multiple autism theory nodes if potential explanations were available from different theories.

There were no units of coding for which Central Coherence theory offered any potential explanation. This theory is not referred to again until the discussion section.

Figure 25 shows the distribution of the total number of units of coding (n=851[15]) identified in Coding Round 1b which related to pupils' current experiences of school that were coded to an autism theory node (n=237). The extent of theory overlap is demonstrated.

Figure 25.

Distribution of the individual UoC (n=237) coded to autism theory
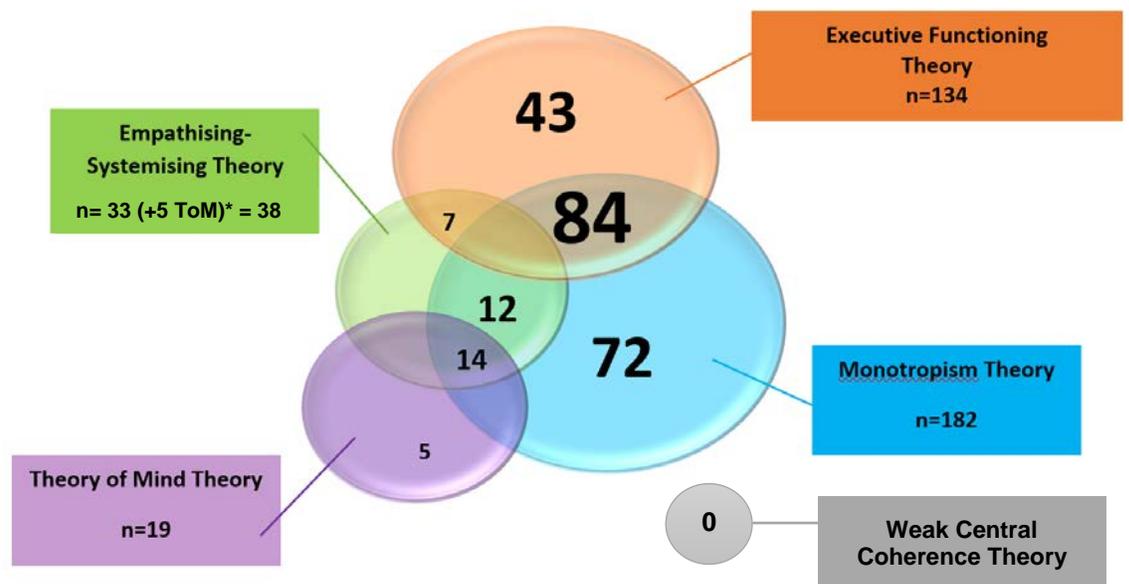
*As E-S theory subsumes ToM theory, the number of references evidencing ToM which did not overlap with the E-S theory node (i.e. those that did not evidence both a tendency to systemise and a weak capacity for empathy in the same reference (n=5)) are also include in the distribution figures for E-S theory.

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[15] The total number of UoC in this round differs from coding round 1a because of the way UoC were identified, i.e. according to either criteria or theory (see Appendix 1A)

Two thirds (66%) of all the units of coding coded to other autism theories (n=165) were also coded to Monotropism theory (n=110), which was the node with the highest percentage (77%) of the total units of coding that were coded to theory (n=237) coded to it (n=182). Monotropism theory also offered explanation for the highest number of pupil experiences that were left unexplained by other theories (n=72). Theory of mind theory was the least well represented theory of those still being investigated (following the removal of CC theory from the analysis). It provided potential explanation for only 8% of the references that were coded to an autism theory node (n=237), which is 2% of the total units of coding made in Round 1b (n=851).

Coding Round 1b.

As with the findings section of coding round 1a, in order that any individual differences in the accounts given by pupils about their current experiences of school are not lost from view through the process of displaying group coding only, coding of pupil transcripts are presented at an: individual (Fig. 26); gender group (Fig. 27); anxiety group (Fig. 28); and whole sample group (Fig. 29) level. The existence of coding overlap, across autism theories, made it necessary to present the descriptive data in two ways to avoid distortion. Therefore, in Figures 26-29:

- pie charts display the percentage of units of coding coded to: 1. all four autism theories as one collective node, i.e. 'Autism Theory' (in general); 2. 'Different Sensory Processing'; 3. 'Other Negative'; and 4. 'Other Positive/Neutral'

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- adjacent bar charts show the relative percentage breakdown of the distribution of units of coding to each individual theory node. Theory overlap dictates that the cumulative total of the percentages coded to individual autism theory nodes can be >100

i. Coding comparison by individual pupil

Figure 26 illustrates the distribution of the total number of units of coding relating to current experiences of school made by each pupil during pre-FAMe™ interview that were coded to 'Autism Theory' (as a collective node), and the relative percentage of these that were coded to each individual autism theory node.

Figure 26.

The percentage of references (UoC) made by individual pupils during pre-FAMe™ interview which were coded to 'Autism Theory' in general and the percentage of these that were coded to individual autism theory nodes

Key:
- ■ Difficulties potentially explained by Autism Theories
- ■ Difficulties potentially explained by Sensory Differences (For which potential explanation could not be found in Monotropism theory)
- ■ Other Negative
- ■ Other Positive or Neutral
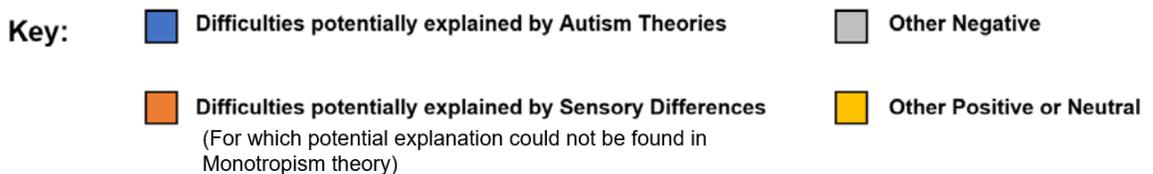
Site 1. Pupil 01
Male - Average anxiety level group
UoC = 33
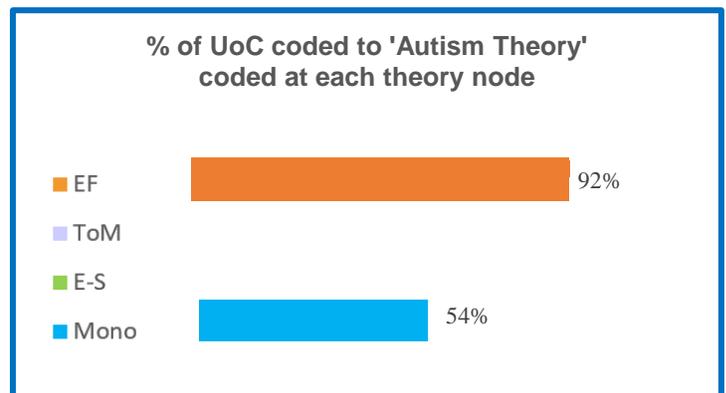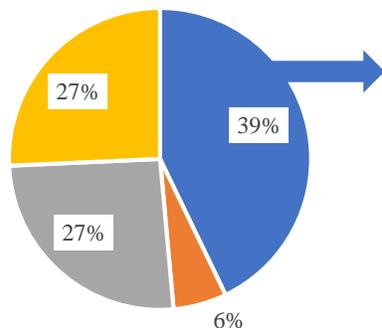
% of UoC coded to 'Autism Theory' coded at each theory node

- EF: 92%
- ToM:
- E-S:
- Mono: 54%

Key:

- ■ Difficulties potentially explained by Autism Theories
- ■ Difficulties potentially explained by Sensory Differences (For which potential explanation could not be found in Monotropism theory)
- ■ Other Negative
- ■ Other Positive or Neutral

Site 1. Pupil 02
Male - Average anxiety level group
UoC = 15

7% 7%
60% 27%

% of UoC coded to 'Autism Theory' coded at each theory node

- ■ EF
- ■ ToM
- ■ E-S
- ■ Mono — 100%

Site 1. Pupil 03
Male - Average anxiety level group
UoC = 37

14%
32% 54%

% of UoC coded to 'Autism Theory' coded at each theory node

- ■ EF — 65%
- ■ ToM
- ■ E-S
- ■ Mono — 50%

Site 1. Pupil 04
Female - Above average anxiety level group
UoC = 53

23% 38%
36% 4%

% of UoC coded to 'Autism Theory'

- ■ EF — 50%
- ■ ToM — 5%
- ■ E-S — 25% } 27%
- ■ Mono — 70%

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Key:

- ■ Difficulties potentially explained by Autism Theories
- ■ Difficulties potentially explained by Sensory Differences
  (For which potential explanation could not be found in Monotropism theory)
- ■ Other Negative
- ■ Other Positive or Neutral

Site 1. Pupil 05
Female - Above average anxiety level group
UoC = 92

Pie chart: 22%, 1%, 58%, 20%

% of UoC coded to 'Autism Theory' coded at each theory node

- ■ EF — 35%
- ■ ToM — 5%
- ■ E-S — 5% } 10%
- ■ Mono — 75%

Site 1. Pupil 06
Female - Above average anxiety level group
UoC = 34

Pie chart: 21%, 6%, 59%, 15%

% of UoC coded to 'Autism Theory' coded at each theory node

- ■ EF — 100%
- ■ ToM
- ■ E-S
- ■ Mono — 100%

Site 1. Pupil 07
Male - Average anxiety level group
UoC = 30

Pie chart: 27%, 3%, 37%, 33%

% of UoC coded to 'Autism Theory' coded at each theory node

- ■ EF — 75%
- ■ ToM — 13%
- ■ E-S — 0%
- ■ Mono — 75%

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Key:

Difficulties potentially explained by Autism Theories

Other Negative

Difficulties potentially explained by Sensory Differences
(For which potential explanation could not be found in Monotropism theory)

Other Positive or Neutral

Site 1. Pupil 08
Male - Above average anxiety level group
UoC = 19

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 62%
- ToM — 8%
- E-S — 38%
- Mono — 77%

46%

Site 1. Pupil 09
Male - No self-report scores
UoC = 30

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 50%
- ToM
- E-S
- Mono — 100%

Site 2, Pupil 01
Female - Average anxiety level group
UoC = 37

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 50%
- ToM — 5%
- E-S — 15%
- Mono — 75%

20%

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Key:
- ■ (blue) Difficulties potentially explained by Autism Theories
- ■ (orange) Difficulties potentially explained by Sensory Differences (For which potential explanation could not be found in Monotropism theory)
- ■ (grey) Other Negative
- ■ (yellow) Other Positive or Neutral

Site 2, Pupil 02
Female - Average anxiety level group
UoC = 46

% of UoC coded to 'Autism Theory' coded at each theory node

EF — 10%
ToM — 10%
E-S — 20% } 30%
Mono — 70%

Site 2, Pupil 03
Male - Average anxiety level group
UoC = 35

% of UoC coded to 'Autism Theory' coded at each theory node

EF — 100%
ToM
E-S
Mono — 33%

Site 2, Pupil 04
Male - Above average anxiety level group
UoC = 56

% of UoC coded to 'Autism Theory' coded at each theory node

EF — 60%
ToM — 7%
E-S — 20% } 27%
Mono — 80%

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Site 3, Pupil 01
Male - Average anxiety level group
UoC = 27

% of UoC coded to 'Autism Theory' coded at each theory node

- EF
- ToM — 40%
- E-S
- Mono — 100%

Pie chart: 19%, 44%, 37%

Site 3, Pupil 02
Male - Above average anxiety level group
UoC = 57

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 52%
- ToM — 10%
- E-S — 43% } 53%
- Mono — 24%

Pie chart: 37%, 7%, 28%, 28%

Site 3, Pupil 03
Male - Above average anxiety level group
UoC = 22

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 71%
- ToM
- E-S
- Mono — 100%

Pie chart: 32%, 9%, 50%, 9%

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Key:

■ Difficulties potentially explained by Autism Theories

■ Other Negative

■ Difficulties potentially explained by Sensory Differences
(For which potential explanation could not be found in Monotropism theory)

■ Other Positive or Neutral

Site 3, Pupil 04
Male - Average anxiety level group
UoC = 52

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 63%
- ToM
- E-S
- Mono — 74%

Pie: 37%, 10%, 13%, 40%

Site 3, Pupil 05
Male - Average anxiety level group
UoC = 50

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 58%
- ToM — 17%
- E-S
- Mono — 75%

Pie: 24%, 6%, 32%, 38%

Site 3, Pupil 06
Male - Average anxiety level group
UoC = 39

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 42%
- ToM — 25%
- E-S — 8%
- Mono — 83%

33%

Pie: 31%, 3%, 13%, 54%

Key:

- Difficulties potentially explained by Autism Theories
- Other Negative
- Difficulties potentially explained by Sensory Differences
  (For which potential explanation could not be found in Monotropism theory)
- Other Positive or Neutral

Site 3, Pupil 07
Male - Above average anxiety level group
UoC = 20

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 50%
- ToM
- E-S
- Mono — 100%

Site 3, Pupil 08
Female - Above average anxiety level group
UoC = 67

% of UoC coded to 'Autism Theory' coded at each theory node

- EF — 29%
- ToM — 18%
- E-S — 24%
- Mono — 65%

42%

Individual (between-pupil) differences, both in the proportion of units of coding made which were coded to 'Autism Theory', range 7% (Site 1, Pupil 02) to 68% (Site 1, Pupil 09), and to each of the specific autism theories providing potential explanation for pupils' experiences, are evidenced.

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At least 24% of all 21 pupils' references that were coded to an autism theory were coded to Monotropism theory. This suggests that it meets the universality criteria for good theory (Rajendran and Mitchell, 2007) in relation to the participating pupils. None of the other theories were universally represented in the pre-FAMe™ interview data across the whole sample. In addition, for the majority of pupils (81%), Monotropism theory provided potential explanation for between 70-100% of the references they made which were coded to the collective 'Autism Theory' node.

Over three quarters (81%) of all participating pupils described experiences that were coded to the node relating to difficulties caused by sensory differences for which no explanation was offered by Monotropism theory (n.b. Monotropism is the only one of the four cognitive theories still under investigation that provides any explanation for autistic differences in sensory processing/experience). Any difficulties caused by a pupil's sensory processing style that *did* have a potential explanation located in Monotropism theory were coded accordingly, with no overlap between these two nodes permitted (see coding rules Appendix 1G).

The coding of some sensory related difficulties to Monotropism accounts for the typically lower percentage of pupils' references coded to the 'Sensory' node in this round (1b) than the earlier round of coding (1a), i.e. the between-pupil range in the percentage distribution of references to the 'Sensory Differences' node was 0-30% in this round of coding compared to 0-37% in Round 1a, and the percentage of the total number of references coded here was 4% compared to 7% in Round 1a.

The following summary table (Table 8) is provided to show the percentage distribution range of references, coded to each Round 1b node, amongst individual pupils, and the number of pupils making at least one reference coded to each node.

Table 8.

The percentage distribution range, amongst individual pupils, of references coded to each of the nodes in coding round 1b and the number of pupils making at least one reference coded at each node

Node	% Distribution Range Amongst Individual Pupils (n=21)	Number of pupils making at least one reference coded to this node
Autism Theory (Compound Node)	7-68%	21 (100%)
EF Theory	0-100%	19 (90%)
ToM Theory	0-40%	12 (57%)
E-S Theory	0-53%	9 (43%)
Mono Theory	24-100%	21 (100%)
Sensory Experiences (not explained by Mono Theory)	0-30%	17 (81%)
Other Negative	13-59%	21 (100%)
Other positive/neutral Including references to skills or the absence of an autism specific *deficit*	10-60%	21 (100%)

Blue = as a % of the references coded to the compound 'Autism Theory' node

ii.   Coding comparison by gender

The percentage distribution of the total number of references coded in Coding Round 1b (n=851) made by male and female pupils, which related to current

experiences of school, that were coded to 'Autism Theory' and to each individual

theory node was calculated (Fig. 27).

Figure 27.

The percentage of references (UoC) relating to current experiences of school made by male (UoC=537) and female pupils (UoC=334) during their pre-FAMe™ interviews which were coded to 'Autism Theory' in general and the individual autism theory nodes
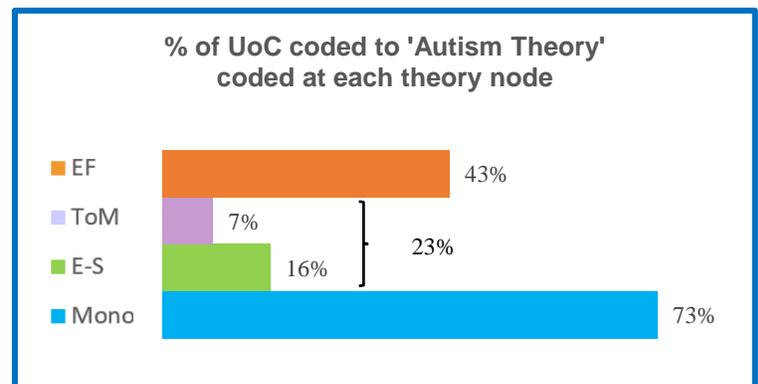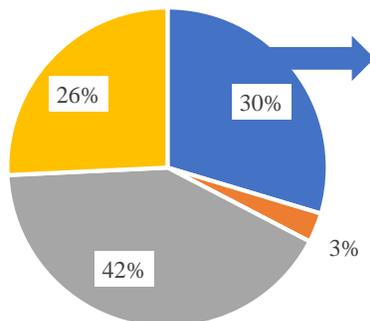
The coding distribution to 'Autism Theory', as a collective node, across the two groups was identical, with less than one third of the total units of coding made by both groups (30%) being coded to an autism theory node.

There were, however, differences between the two gender groups in terms of the distribution of coding to individual autism theory nodes. For example, a larger percentage of the total units of coding coded to autism theory, made by male pupils (61%) than female pupils (43%) were coded to the EF node. This theory offers explanation for individuals experiencing difficulty when, for example: there is a lack of structure in the task given; they need to make a choice; they are trying to concentrate; they are processing information; or there is a need to transition between tasks. There is considerable overlap in explanatory potential between EF theory and the systemising element of E-S theory. This is likely to account for there also being a higher number of boys' than girls' references coded to the E-S theory node (36% and 23% respectively).

Monotropism theory provided explanation for nearly three-quarters (73%) of the references made by both gender groups which were coded to theory and was the most well represented theory overall.

The most sizeable between gender-group difference in coding to the four main nodes of: 'Autism Theory'; 'Sensory Processing Difficulties'; 'Other Negative'; and Other Positive/Neutral', was observed at the node 'Other Negative'. Over a third

(42%) of female pupils' units of coding were coded to this node compared to 31% of those made by the male pupils.

iii. Coding comparison by anxiety group

The distribution of the total number of units of coding, referring to current experiences of school, made by pupils with average levels of anxiety (i.e. BYI-A T score ≤55) and those with above average levels of anxiety (i.e. BYI-A T score >55), which were coded to autism theory in general and to each specific theory node was calculated (Fig. 28). Data from the transcript of the pupil who did not complete the self-report measures was removed from this analysis (UoC=36).

The percentage distribution of units of coding coded to autism theory, as a collective node, was very similar across the two anxiety groups (31% and 29%). The largest between-group difference in the distribution of references to the four nodes of 'Autism Theory', Sensory Differences', 'Other Negative' and 'Other 'Positive/Neutral' was again observed between those coded at 'Other Negative'. More of the references (42%) made by the pupils with above average levels of anxiety were related to pupils' negative experiences and/or difficulties at school. This compared with 28% of those made by pupils with average levels of anxiety.

Examination of the coding to individual autism theory nodes revealed that between-group differences existed in the distribution of units of coding at this level. The most obvious of these was the higher percentage of the references made by

pupils with above average anxiety levels (29%) which were coded to Empathising-Systemising theory than were those made by pupils with average levels of anxiety (13%). This theory offers explanation for individuals experiencing difficulty when they are faced with, for example: an unexpected change; unclear instructions/ explanations; they experience someone not doing what they say they will and/or breaking rules; or they find it difficult to interpret another person's intentions/meaning.

Figure 28.

The percentage of the total number of units of coding made by pupils with average (n=404) or above average anxiety levels (n=431) which were coded to 'Autism Theory' in general and the individual autism theory nodes
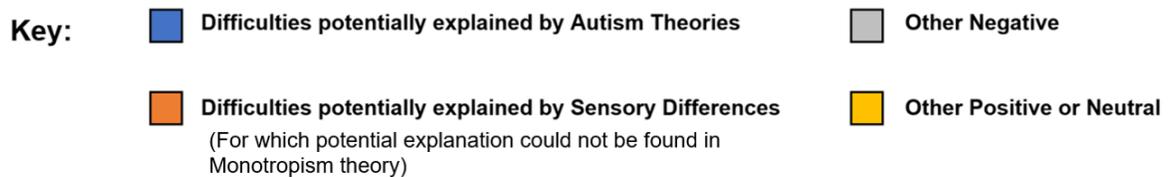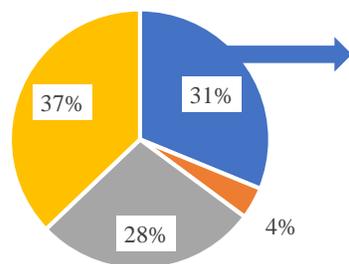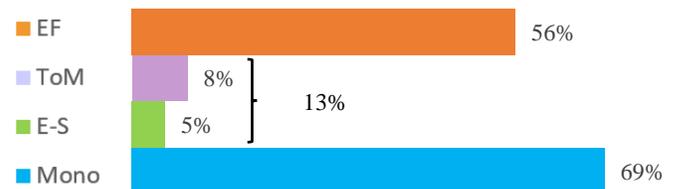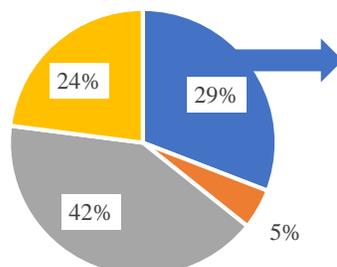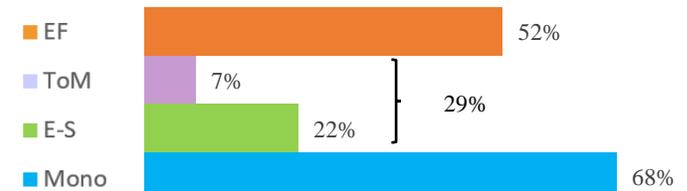
iv. Whole sample coding

The percentage distribution of the total number of units of coding relating to current experiences of school, made by all pupils during their pre-FAMe™ interviews (n=851), that were coded to autism theory in general (n=237) and to each theory node/s, was provided to demonstrate theory overlap (Fig. 25). For ease of comparison, these results are reproduced here (Fig. 29) in the same way as has been used to display the distribution of individual and between-group coding (Fig. 26-28).

Figure 29.

**Percentage of the total number of units of coding (n=871)
coded to 'Autism Theory' in general and the individual autism theory nodes**
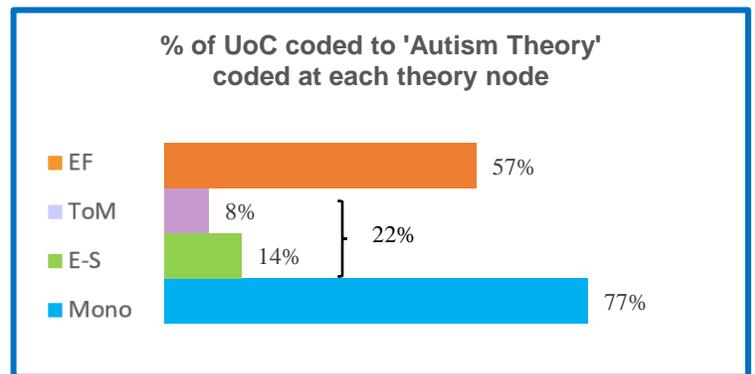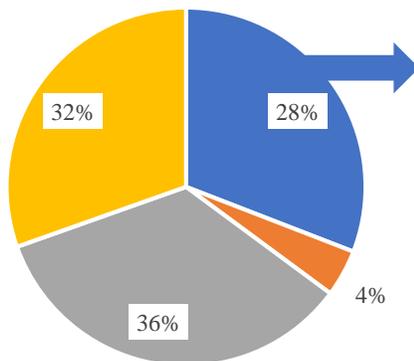
Overall, potential explanation was identified in autism theory for 28% of pupils' references. Of these, Monotropism theory was the most frequently coded theory, providing potential explanation for 77% of the total number of UoC coded to autism theory in general. Theory of Mind theory provided the least potential explanation, representing just 8% of the total references that were coded to a theory node.

Having completed the individual, between-group and whole group analyses, to establish the extent to which autism theory/ies provided potential explanation for the participating autistic pupils' school experiences, it was of interest to explore whether the identified distribution of references to autism theory nodes might have been impacted by pupils' attributing their experiences to either internal (i.e. a feature of themselves) or external (e.g. other people or the school environment) factors. In order to understand this, a repeat of the Level 2 analysis, exploring pupils' attribution of positive and negative school experiences to internal or external factors, was performed on Round 1b data (Coding Round 1b Extension).

Coding Round 1b Extension

i. Exploring the impact on the distribution of coding to autism theory nodes of pupils' attributing their school experiences to internal and external factors (Level 2 Coding)

This stage of the investigation was important, in order to ascertain whether the relatively low overall percentage of references (28%), coded to autism theory in

Coding Round 1b, might be explained by pupils' attribution of impact to external factors which autism theory does not attempt to explain.

The coding of pupils' interview data to the four deductive nodes: 'external negative'; 'external positive'; 'internal 'negative'; and 'internal positive/neutral', carried out in Round 1a Level 2 (UoC=812), was left in place, so the overall percentage distribution of references to these nodes (i.e.: 66% negative and 34% positive; 55% internal and 45% external) was therefore the same. However, when overlap with the Round 1b coding to autism theory/ies was explored, differences (from the Round 1a Level 2 analysis) were observed in the percentage distribution to the nodes of: 'Sensory'; 'Other Negative'; and 'Other Positive/Neutral'. This is accounted for in the following ways:

Some of the references (n=8) that were coded to 'DSM-5 B4. Hyper/hypo reactivity to sensory input' in Coding Round 1a are captured by 'Monotropism Theory' in Coding Round 1b, and therefore the number of references relating to sensory experiences is fewer. General and social anxiety were captured at the 'Criteria Implicit' and 'Literature Implicit' nodes in Coding Round 1a. However, no autism theory specifically attempts to offer explanation for anxiety and the majority of these references are therefore captured at 'Other Negative' in Round 1b accounting for the higher number of UoC shown coded at this node in Table 9 than in Table 7.

Table 9.

Overlap between negative and positive/neutral impact attributed by pupils to internal or external factors and cognitive autism theory
(Round 1b Coding)

Round 1b Node coded to	% of UoC where attributed impact is **Internal to the pupil** (n=456)		% of UoC where attributed impact is **External to the pupil** (n=370)		% of total units of coding in Round 1b Level 2 (n=826)
	Negative experience (n=265)	**Positive /Neutral experience** (n=191)	**Negative experience** (n=281)	**Positive /Neutral experience** (n=89)	
Executive Functioning theory	**27%** (n=72)	**0%**	**9%** (n=26)	**16%** (n=14)	**14%** (n=112)
Theory of Mind theory	**5%** (n=12)	**0%**	**1%** (n=3)	**0%**	**2%** (n=15)
Empathising-Systemising theory	**1%** (n=2)	**1%** (n=1)	**12%** (n=34)	**2%** (n=2)	**5%** (n=39)
Monotropism theory	**16%** (n=43)	**5%** (n=9)	**27%** (n=75)	**15%** (n=13)	**17%** (n=140)
Total coded to Autism Theory (Compound Node)	**32%** (n=86)*	**5%** (n=9)	**38%** (n=106)*	**27%** (n=24)*	**27%** (n=225)*
Sensory Related Experiences	**0%**	**0%**	**15%** (n=41)	**1%** (n=1)	**5%** (n=42)
Other negative	**68%** (n=179)	**0%**	**47%** (n=134)	**0%**	**38%** (n=313)
Other neutral/positive	**0%**	**95%** (n=182)	**0%**	**72%** (n=64)	**30%** (n=246)
Total not coded to autism theory	**68%** (n=179)	**95%** (n=182)	**62%** (n=175)	**73%** (n=65)	**68%** (n=601)
% of Total Internal or Total External	**58%** (n=265)	**42%** (n=191)	**76%** (n=281)	**24%** (n=89)	**Negative 66%** (n=546)
% of total UoC coded (n=826)	**32%** (n=265)	**23%** (n=191)	**34%** (n=281)	**11%** (n=89)	**Positive/ Neutral 34%** (n=280)
% of total UoC coded (n=826)	**55%** (n=456)		**45%** (n=370)		

(bracket marking Empathising-Systemising theory and Monotropism theory rows: **22%**)

*Theory overlap means that these numbers are smaller than the sum of the individual units of coding coded to the individual autism theory nodes

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It is evident, from this round of Level 2 coding, that it was not pupils' attribution of the cause of their school experiences to external factors that was responsible for the relatively low overall percentage of references coded to theory in Coding Round 1b, but rather that autism theory does not provide explanation for the majority of the experiences of school pupils discussed in their pre-FAMe™ interviews.

As was observed in Round 1a Level 2 Coding, there were more externally attributed negative experiences (n=106) which overlapped with autism theory than internally attributed ones (n=86). Considering that autism theory hypothesises the internal cognitive mechanisms behind autistic behaviour and experience this was surprising, and once again supports that idea that pupils frequently attributed their environment, or other people, to be the cause of the autism related difficulties they experienced at school. Overall, of the 225 individual references to 'Autism Theory' identified in this round of coding, the responsibility for the school experience described was externally attributed for 130 (58%).

Also evident from the Level 2 coding of Round 1b data, is the capacity of some theories to explain skills and strengths as well as difficulties, albeit to a relatively small extent (UoC=9). Examples of these included pupils' ability to concentrate on a topic of interest (Monotropism), and their enjoyment of subjects that involve activities where there are formulae and definitive right or wrong answers (Systemising).

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Section 2.

Exploring the Overlap Between Autism Theory and the Diagnostic Criteria for Autism

The autism theories under investigation in this study hypothesise the cognitive mechanisms underlying the outward presentation of autism which is defined in the diagnostic criteria (DSM-5, 2013). The various theories attempt to explain different aspects of the criteria, with their authors suggesting that it is the mechanism that underlies the one or more features of autism, addressed by their theory, that results in the presentation of the other features (Chown, 2017; Rajendran and Mitchell, 2007). For example, in Empathising-Systemising Theory (Baron-Cohen, 2009a), it is proposed that the narrow interests, repetitive behaviour, and resistance to change/need for sameness, explicit to autism (DSM-5, B2), derive from autistic individuals' tendency to systemise, while the explicit social and communication difficulties (DSM-5, A2; A3) are explained by a reduced ability to empathise (ibid). If this were the case it would be expected that overlap between coding to E-S theory and to the areas of the criteria it seeks to explain would be observed. The following section explores the overlap between coding to diagnostic criteria related nodes and to autism theory/ies.

i.   Criteria explicit

In order to better understand the relationship between autism criteria (description/definition of autism) and autism theory (hypothesised mechanisms

underlying autism), the percentage distribution of the units of coding, coded during round 1a to: a node relating to social communication and social interaction (i.e. DSM-5, 1, A1, A2 and A3) (n=98) (Fig. 30); or to restricted, repetitive patterns of behaviour, interests, or activities (i.e. DSM-5 2, B1, B2, B3, and B4) (n= 138) (Fig. 31) which were also coded during round 1b to autism theory node/s, were calculated. The percentage distribution of these to each autism theory node is shown in the adjacent bar chart. Theory overlap means the sum of these percentages can be >100 (this is the case for Figures 30-32).

Figure 30.

Percentage of the total UoC coded to DSM-5 Category 1 (Coding Round 1a) which overlap with coding to autism theory (Round 1b)
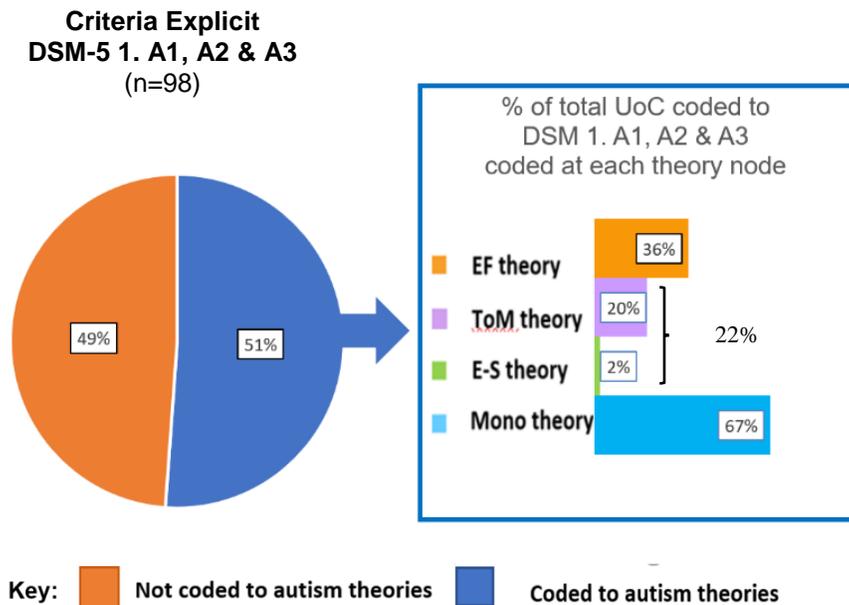
Just over half (51%) of the references made by pupils that were coded to a node relating to social communication and social interaction were also coded to an

autism theory node. Of these, two thirds (67%) had a potential explanation located in Monotropism theory, 36% in Executive (Dys)Functioning theory and 22% in Empathising-Systemising theory. Of these almost all were references to difficulties with ToM. This is in-line with the expectations for E-S theory set out by Baron-Cohen (2009), i.e. that the element of E-S theory relating to ToM difficulties will provide explanation for DSM-5 Category 1.

Figure 31.

Percentage of the total UoC coded to DSM-5 Category 2 (Coding Round 1a) which overlap with coding to autism theory (Round 1b)
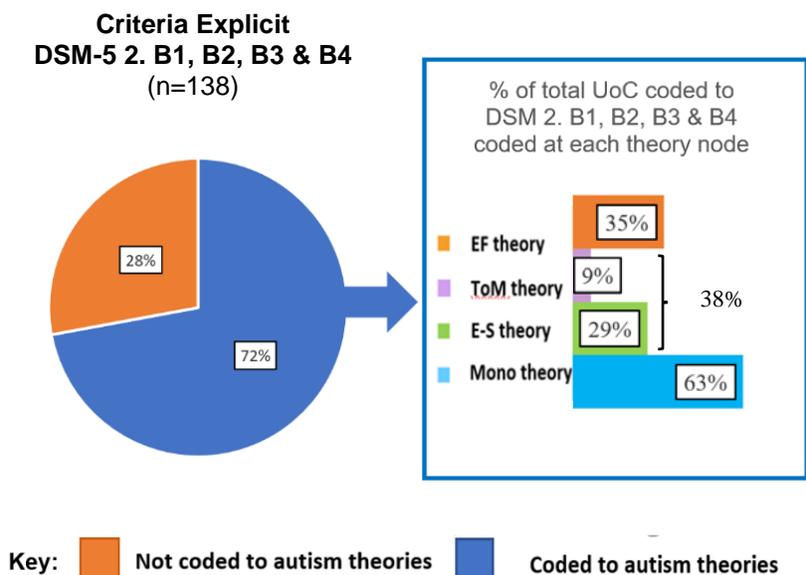
Nearly three quarters (72%) of all the units of coding coded to nodes relating to restricted, repetitive patterns of behaviour, interests, or activities were also coded to an autism theory node. Monotropism theory provided potential explanation for almost two thirds of these (63%), and explanation for 35% was identified in EF theory.

These percentages were very similar to those returned in the analysis of the DSM-5 1 (social communication and social interaction) nodes. Empathising-Systemising theory provided explanation for 38% of the total number of references coded to theory that were associated with DSM-5 Category 2 and of these, as Baron-Cohen (2009) hypothesised would be the case, it was the systemising component of the theory that was identified most frequently when exploring experiences related to restricted, repetitive patterns of behaviour, interests, or activities.

ii. Criteria implicit

The percentage distribution of the total number of units of coding coded during coding round 1a to the 'Criteria Implicit' feature of autism (n=78), which in this case referred almost exclusively to social anxiety and shyness, which were also coded to one of the autism theory nodes was calculated (Fig. 32).

Only 19% of the units of coding which referred to an implicit feature of autism (criteria and exemplars) had any potential explanation that could be located in one of the autism theories investigated. Of these, Executive (Dys)Functioning theory was the most frequently coded to, providing potential explanation for 60% of these references to school experiences.

Figure 32.

Percentage of the total UoC coded to Criteria Implicit (Coding Round 1a) which overlap with coding to autism theory (Round 1b)
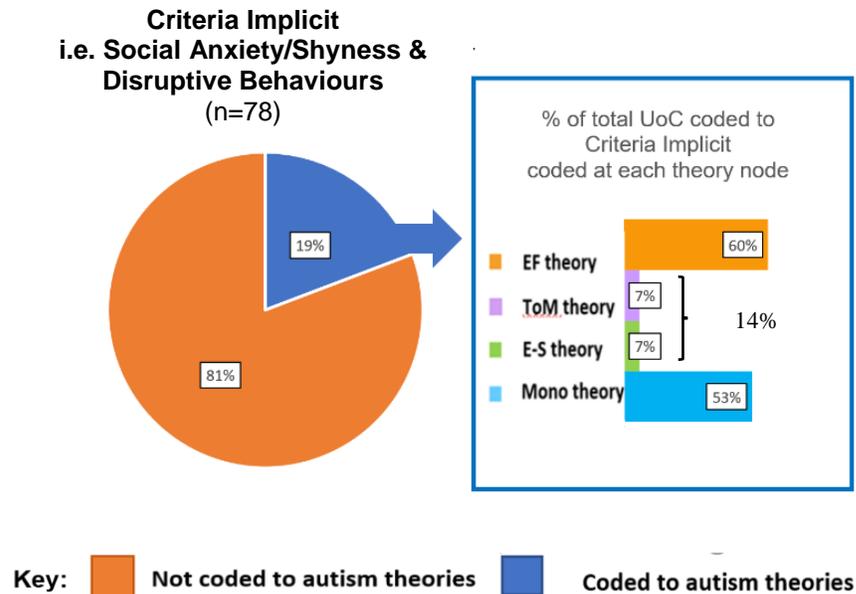
iii. **Criteria explicit and implicit features of autism combined (DSM-5 and Criteria Exemplars)**

The percentage of the total units of coding that were coded to all the diagnostic criteria nodes, i.e. relating to explicit *and* implicit features of autism (n=314), which were also coded to an autism theory node was calculated and is shown, together with the percentage of all units of coding that were not coded to a criteria related node but were coded to an autism theory (Fig. 33).

Figure 33.

Percentage of the total UoC coded to Criteria Explicit and Implicit nodes (Coding Round 1a) which overlap with coding to autism theory (Round 1b)

Total UoC coded to a Criteria Explicit or Implicit node (n=314)

Total UoC not coded to a Criteria Explicit or Implicit node (n=671)

Key: Not coded to autism theories — Coded to autism theories
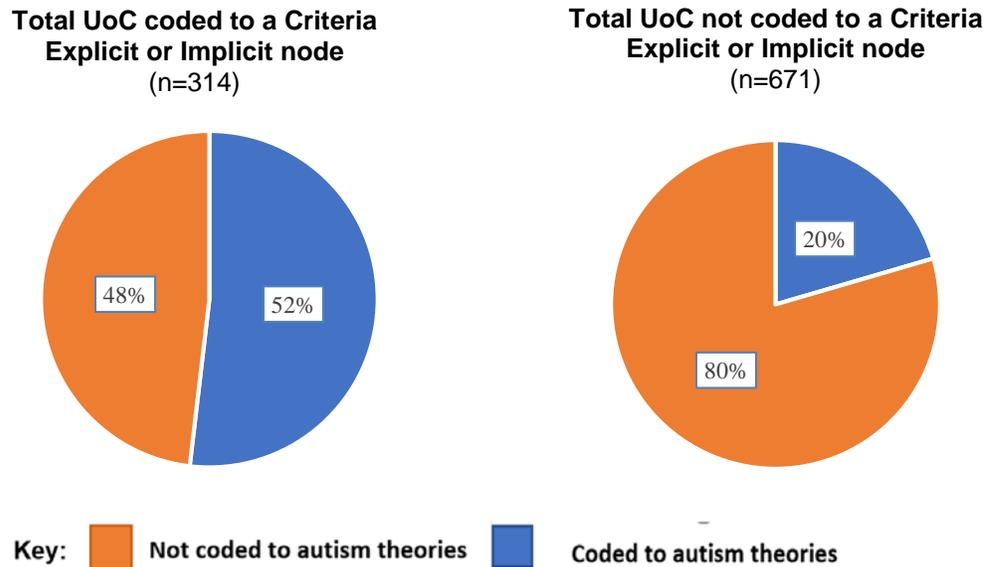
Potential explanation for just over half (52%) of the references made by pupils which could be associated with the diagnostic criteria (explicit and implicit) was located in at least one of the autism theories being investigated. For the references made that were not associated with the diagnostic criteria, i.e. coded to 'literature implicit' or 'other' (n=671), the percentage for which any explanation could be identified in an autism theory fell to 20%.

iv. Overview of coding rounds 1a and 1b including overlap

The percentage distribution of the total units of coding (n=985) which were coded at nodes related to: the diagnostic criteria; autism theory; both; or neither, is shown in Figure 34.

Figure 34.

Percentage of total UoC coded to Criteria Explicit/ Implicit (Coding Round 1a), Autism Theory (Round 1b), both (overlap) or neither

Total UoC
(n=985)

Key:

- Coded to diagnostic criteria explicit/implicit only
- Coded to autism theory only
- Coded to both diagnostic criteria explicit/implicit and autism theory
- Not Coded to either diagnostic criteria or autism theory
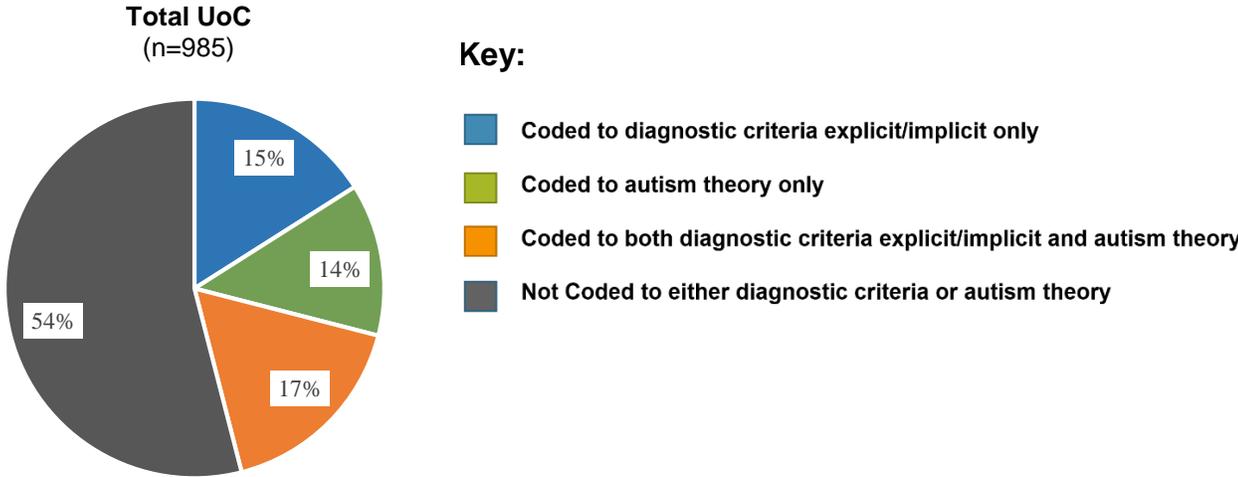
More than half (54%) of the total units of coding relating to participating pupils' current experiences of school were not coded at any of the criteria or theory nodes. This means that there was nothing in the pupils' narrative account of these experiences that could be located either in the diagnostic criteria as explicitly or implicitly related to autism, or which had a potential explanation that could be identified in one of the main cognitive autism theories being investigated. The implications of these findings are considered in the Discussion chapter.

v. Uncoded references

In order to provide a complete picture of the coded transcripts, Table 10 shows the number of units of coding made that were coded as: unrelated to current school experiences; were about past experiences of school; or were made in response to my clarification/a question about a point already coded. These UoC are not included in any of the analyses reported thus far.

Table 10.

Units of coding excluded from the analysis (n=387)

% of pupils (n=21) making references coded at these nodes	Node coded to	Number of units of coding coded at these nodes
82%	**Past**	85
100%	**Not related to school**	173
100%	**Clarification statement**	129
Total number of references made at these nodes		**387**

Section 3.

The Impact of Teachers' Behaviour and/or Practice on Pupils' Classroom Experiences

This section reports the findings of a further round of coding (Round 2), in which pupils' pre-FAMe™ interview transcripts were coded to three new nodes, in order to explore the impact of teachers' classroom behaviour and/or practice on the autistic pupils' experiences of school. The first two new nodes captured references in which any positive or negative impact on a pupil was attributed to teachers' classroom behaviour and/or practice, i.e.: (1) Teachers' behaviour and/or practice has a negative impact on pupil/s; (2) Teachers' behaviour and/or practice has a positive impact on pupil/s. In addition, a third node, (3) 'Desired Change' was created, to which explicit suggestions, made by pupils about what they would like teachers to do differently, were coded. The aim of this round of coding was to address research question 3, i.e.:

When engaging autistic pupils in research focusing on their experiences of school:

a. *What can be learned about autism/autistic pupils' school support needs from their descriptions of their school experiences?*

b. *Are autistic pupils able to identify and communicate positive and/or negative classroom experiences and, if so, how can these be used to inform teaching practice?*

Whole sample and between-group analyses were conducted to explore whether any relationship existed between a pupil's gender or anxiety level and their experience of teachers' behaviour and/or changes to classroom practice they believed would be most helpful to them. Findings are provided as the percentage of the whole sample/within-sample group who made at least one reference coded to a particular node, together with the average number of references made per pupil (Table 11). This allows between-group comparisons to be drawn despite the groups containing different numbers of pupils.

Table 11.

**The percentage of the total number of pupils in each group
who made at least one reference coded to each of the three nodes relating to
the impact of teacher behaviour**

Node coded to	Whole Sample n=21	Male Pupils n=15	Female Pupils n=6	Average anxiety group n=11	Above average anxiety group n=9
Teacher behaviour has negative impact	90% (n=19) Average refs/pupil =4.7	86% (n=13) Average refs/pupil =3.7	100% (n=6) Average refs/pupil =7	82% (n=9) Average refs/pupil =4.7	100% (n=9) Average refs/pupil =5.3
Teacher behaviour has positive impact	76% (n=16) Average refs/pupil =2	73% (n=11) Average refs/pupil =1.9	83% (n=5) Average refs/pupil =2.4	73% (n=8) Average refs/pupil =2.5	66% (n=6) Average refs/pupil =2.2
Desired change	100% (n=21) Average refs/pupil =8.3	100% (n=15) Average refs/pupil =7.6	100% (n=6) Average refs/pupil =9.8	100% (n=11) Average refs/pupil =6.3	100% (n=9) Average refs/pupil =11.4

From Table 11, it can be seen that the majority (90%) of all pupils described at least one experience of school in which teachers' classroom behaviour and/or practice had impacted negatively on them (average number of references made per pupil = 4.7). The percentage of pupils referring to teachers' negative impact ranged from 82% of those with average anxiety to 100% of those with above average anxiety levels. A higher percentage of girls referred to teachers impacting negatively on them than did boys (100% and 86% respectively) and made almost twice the number of references on average per pupil (girls = 7: boys = 3.7).

A lower percentage, but still the majority (76%), of pupils also referred to experiences of school which were positively impacted on by teaching practice and/or teachers' behaviour. The percentage of pupils making reference to positive teacher impact varied between groups with a higher percentage of female (83%) than male (73%) pupils, and a lower percentage of pupils in the above average anxiety level group (66%) than those in the average anxiety level group (73%) describing these experiences.

All 21 pupils made reference to changes they would like teachers to make to their classroom practice, to either start or stop doing in future, that they believed would benefit them in some way. There were considerably more references on average per pupil to ways in which they would like their teachers to change their behaviour made by pupils with above average anxiety levels (11.4 refs/pupil) than were made by pupils in the average anxiety level group (6.3 refs/pupil).

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Examples of references included at 'desired change':

- **Site 3, Pupil 06:** *I'm not a fan of that* [teachers leaning over him to look at his work]. *I would rather they asked if they could look at my work if they said, "X can I look at your work?" and I hand them the book – I would like them to do that*

- **Site 1, Pupil 03:** *I need them* [teachers] *to reassure me and just help me if I need help. I do sometimes have these things to help me calm down – I have them before the test happens which does sort of make me calm down in a way – I take these rescue remedies they help me sort of calm down but I would like as I say just help with the questions so I don't need it, ask if I'm OK, just reassure me – I may have just a blank moment sometimes.*

- **Site 2, Pupil 2:** *…if, once they'd explained everything, they came to me and asked if I was OK with that first – I think that would be quite good*

Sub-node coding for nodes

In order to capture the complete data set in as much detail as possible, sub-nodes were developed inductively during the coding process for each of the three new parent nodes.

i. <u>Teacher behaviour and/or practice having a negative impact on pupil</u>

In total there were nine sub-nodes to which all the references to teacher behaviours and/or practice that had a negative impact on pupils' experiences could

be coded. The percentages of the whole pupil sample making at least one reference to a sub-node ranged from 10%-57% (Fig. 35).

Figure 35.

Percentage of all pupils (n=21) making at least one reference coded to a sub-node under: 'Teacher behaviour has negative impact'
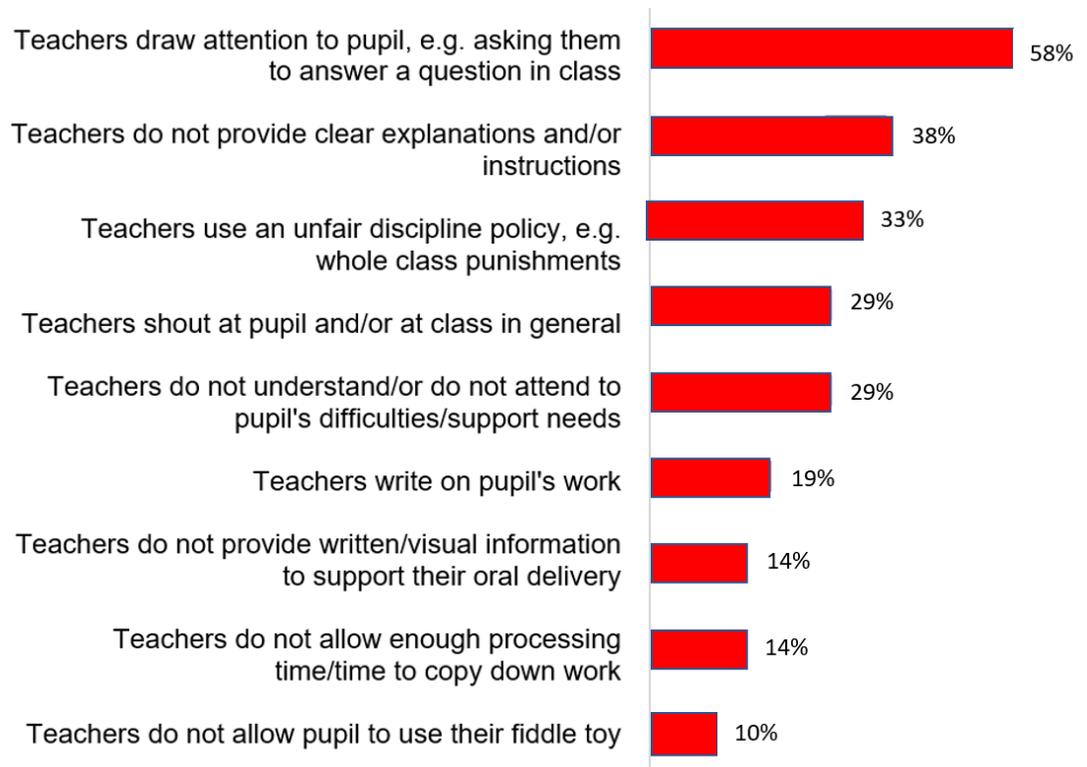
The teacher behaviour referred to by the highest number of pupils as having a negative impact on them was drawing attention to them in class e.g. asking them to answer a question when they hadn't volunteered/put their hand up. Other frequently reported difficulties were teachers' explanations/instructions not being clear enough to be understood (38%) and giving whole-class punishments, which pupils found difficult to accept when they had not been involved in the punishable pupil behaviour (reported by 33%).

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ii. Teacher behaviour and/or practice having a positive impact on pupil

In total there were nine sub-nodes to which all the references to teacher behaviours and/or practice which had a positive impact on pupils' experiences could be coded. The percentages of the whole pupil sample making at least one reference to a sub-node ranged from 5%-29% (Fig. 36). References coded to the same three sub-nodes were made by over a quarter (29%) of all pupils. These sub-nodes related to teachers: providing written/visual information/instructions about class and homework; providing clear unambiguous instructions; and being flexible about pupils' classroom behaviour, e.g. allowing them to listen to music during lessons.

Figure 36.

Percentage of all pupils (n=21) making at least one reference coded to a sub-node under: 'Teacher behaviour has positive impact'
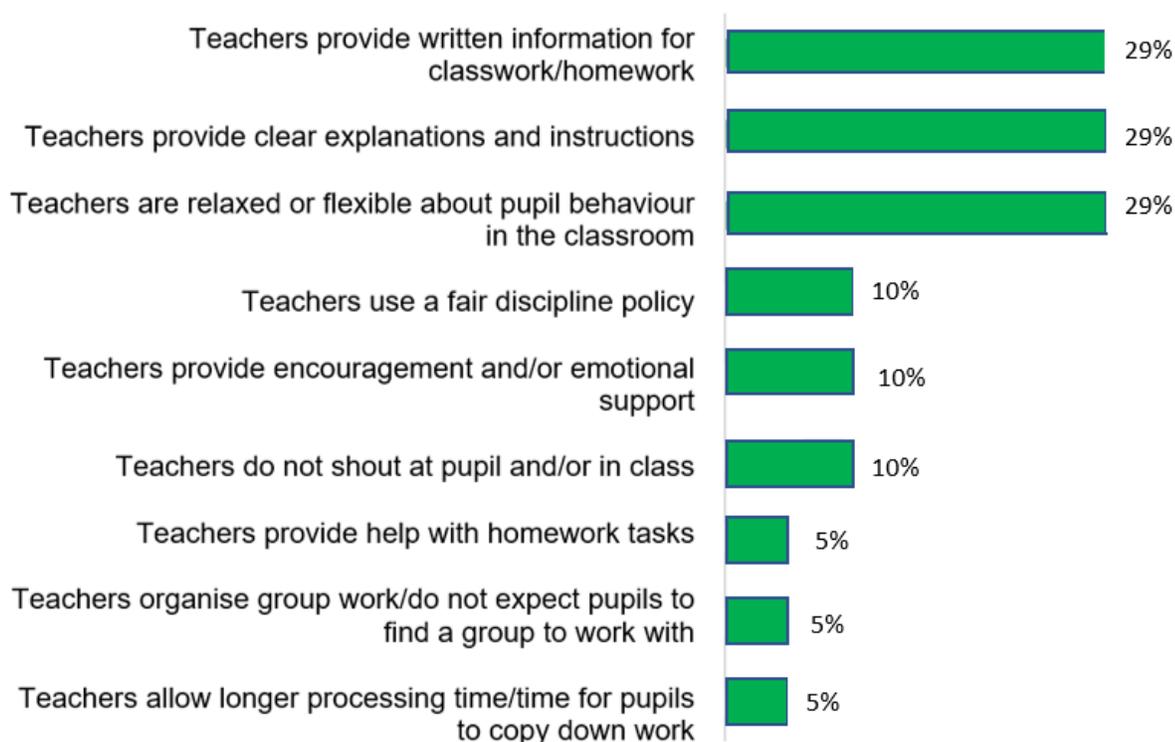
iii. <u>Desired change</u>

There were 17 sub-nodes developed during the coding of references to the 'Desired Change' node, i.e. changes to teachers' behaviour/teaching practice that pupils felt would have a positive impact on their classroom experience (Fig. 37). Seven of these were referred to by over a quarter of the pupil sample (range 29%-57%). Those that were referred to by the highest percentage of pupils related to teachers stopping drawing attention to them, and checking their understanding of tasks (57%). Being able to choose their own seat in the classroom, or having a designated seating plan that remained constant, was something 52% of pupils referred to at least once as something they felt would benefit them. Other frequently desired changes related to: the presentation and quality of instructions; the organisation of group-work tasks so that pupils were not left to find people to work with; and the provision of more emotional support/having a better understanding of mental health needs.

Figure 37.

The percentage of the pupil sample (n=21) reporting that they would like teachers to change their behaviour and/or practice in the manner described

I would like my teachers to:

Stop drawing attention to me in class	57%
Check my understanding of tasks	57%
Enable me to sit in a certain place/avoid seating plan issues	48%
Provide better explanations/concrete examples/break down instructions	38%
Organise the groups for group work/not expect me to find my own group	38%
Provide visual instructions/write instructions down for me	33%
Offer emotional support/be more understanding about my anxiety needs	29%
Let me leave the classroom/escape other pupils	24%
Give me more preparation/advanced warning of changes to planned events	24%
Keep the class quiet/under control	19%
Not invade my personal space/not lean over me	19%
Not write on my work	19%
Recognise my need to fiddle/tap	19%
Stop using whole class punishments/be more fair	14%
Allow me more time to process information/copy down work	10%
Give me less homework/offer more help with homework	10%
Stop picking on me/be nicer to me	5%

Pupils' FAMe™ Statements

The discussion of the desired teacher behaviours typically informed and/or coincided with the writing of pupils' FAMe™ Statements, i.e. the information pupils most wanted their teachers to know about them which was to be made available through the new FAMe™ System.

A 'FAMe™ statement' parent node was made and pupils' statements were collated and inductively coded to as many sub-nodes as were needed to capture the complete data set. The pupil who was withdrawn from the research because he was unable to engage with the interview process was able to write FAMe™ Statements, with my support, which were used by his teachers. These are included in this data set.

In total 27 sub-nodes were created, out of a potential 66 (i.e. 3 x statement per pupil), demonstrating that themes existed around which some FAMe™ Statements were clustered. However, 12 statements were unique to individual pupils. The percentage of pupils whose FAMe™ Statements were coded to the 14 themed sub-nodes are shown in Figure 38. The 12 unique FAMe™ Statements are displayed in Figure 39.

Discrepancies between the percentage of pupils referring to a desired future change, e.g. a preferred seating arrangement (48%, Fig. 37) and the percentage of pupils writing a FAMe™ statement relating to this (14%, Fig. 38), evidence that the FAMe™ statement writing process was one of prioritising the most salient issues for

each pupil, i.e. whilst almost half of the pupils talked about how having a particular seating plan would positively impact their classroom experience, they did not rank it in the top 3 things they would like teachers to know about/do for them. Not being asked to answer questions in front of the class/not having attention drawn to them was the most frequently referred to desired change and the most frequently requested FAMe™ statement, written by 59% of the pupils (n=13). Clarity and presentation of instructions/information and helping pupils find groups to work with were also relatively common FAMe™ statement themes, prioritised by 32% of the pupil sample (n=7).

Figure 38.

The percentage of pupils (n=22) with a FAMe™ Statement coded to each of the following sub-nodes

Do not ask me questions if I haven't put my hand up / Do not draw attention to me/ do not ask me anything in front of my peers	**59%**
Provide me with clear specific instructions or break instructions into smaller chunks	**32%**
Help me to find a group to work with / put me in groups with hard working motivated sensible pupils / or people I know / my friends	**32%**
Write my homework down for me / provide me with a homework sheet	**27%**
Check I have understood instructions before I begin a task	**27%**
Allow me to leave class without challenging me	**18%**
Minimise note-taking / writing is difficult for me	**14%**
Allow me to use my fiddle toy when stressed / to help me to concentrate	**14%**
Allow me to sit at the front / back / in a certain place	**14%**
Prepare me in advance for any change	**9%**
Do not write comments on my work – write them underneath or on a separate sheet	**9%**
Do not use sarcasm or metaphor when talking to me / the class	**9%**
Do not lean over me to look at my work - ask me to pass it to you	**9%**
Allow me to work on my own – I do not like group work	**9%**

Figure 39.

Unique FAMe™ Statements

1. Please do not shout at me

2. I like doing good work and am motivated to please

3. I need challenging interesting work rather than continued repetition of the same thing

4. If I zone out I am struggling with sensory overload - allow me to self-regulate then check my understanding of the task

5. Please check that I am OK and reassure me when we have tests

6. Never touch me or attempt to move me physically

7. Please prepare me in advance for change

8. Please check how I am as I enter the classroom/at the beginning of a lesson and help me if I am upset

9. If I have my hand half way up I need individual help/if I put it straight up I am volunteering to answer a question

10. Please walk away from me and disengage if I am arguing with you

11. Please allow me to listen to music while I work

12. Please check that everyone has finished copying work from the board before wiping it off.

Pupils' FAMe™ Statements coded to Explicit and Implicit Features of Autism as Defined in the Diagnostic Criteria

In order to determine whether the specific difficulties that pupils identified as being the most important areas for additional support/where they wanted teachers to do something differently (i.e. those prioritised and selected as FAMe™ Statements) were related to the explicit features of autism defined in the diagnostic criteria (DSM-5) or listed in the criteria exemplars (Carpenter, 2013), FAMe™ Statements were coded according to the Diagnostic Criteria Coding Strategy (Appendix 1B). Figure 40 displays the percentage of pupils' FAMe™ Statements (n=66) that were coded to each Criteria Explicit/Implicit node.

Figure 40.

The percentage of FAMe™ Statements (n=66) made by the whole pupil sample (n=22) in which the difficulty expressed was associated with an explicit/implicit feature of autism

Whole Pupils Sample's FAMe™ Statements n=66

Key:

- **DSM-5 A1.** Deficits in social-emotional reciprocity
- **DSM-5 A2.** Deficits in non-verbal communication behaviours used for social interaction
- **DSM-5 A3.** Deficits in developing, maintaining, and understanding relationships
- **DSM-5 B2.** Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour
- **DSM-5 B3.** Highly restricted, fixated interests that are abnormal in intensity or focus
- **DSM-5 B4.** Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment
- Criteria Implicit
- Literature Implicit
- Other Negative
- Other Positive or Neutral

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What is evident from Figure 40 is that, when pupils were specifically selecting areas of difficulty in school where they felt they would benefit from support/would like their teachers to do something differently, the majority of these (93%) were related to an explicit or implicit (social anxiety/shyness) feature of autism.

The FAMe™ statement that was coded at 'Other Positive' was, *'I like doing good work and am motivated to please'*. This pupil wanted his teachers to know that he was always trying his best, even if he didn't achieve in line with their expectations. Over half (54%) of the FAMe™ Statements were related to pupils' difficulties in areas related to DSM-5 Category B, i.e. experiencing: distress at small changes; difficulties with transitions; having rigid thinking patterns; having an inability to understand nonliteral aspects of speech (e.g. humour and sarcasm); and having/exhibiting rigid, inflexible or rule bound behaviour or thought (APA, 2013). Difficulties with executive functioning skills, such as organisation and following instructions are coded at this node.

Almost a quarter of the statements (22%) related to wanting to reduce feelings of social anxiety and shyness, e.g. *'Please **don't draw any attention to me** – good or bad'*, and, *'Please **only ask me to speak in front of the class if I put my hand up** to show I am happy to do so'*. Whereas only 10% of the whole samples' references to experiences of school in general (n=985) had been coded to nodes taken from DSM-5 Category A, i.e. social communication difficulties (Fig. 19), 18% of the FAMe™ Statements specifically targeted this area.

Coding of FAMe™ Statements to criteria nodes by gender

To explore whether there were any between gender-group differences, in the explicit/implicit features of autism that were associated with the difficulties pupils had prioritised for intervention, FAMe™ Statements made by the male and female puils were analysed separately (Figure 41).

Figure 41

The percentage of the FAMe™ Statements made by male (n=16) and female (n=6) pupils in which the difficulty expressed was associated with an explicit/implicit feature of autism

Male Pupils' FAMe™ Statements
n=48

Female Pupils' FAMe™ Statements
n=18

Key:

- **DSM-5 A1.** Deficits in social-emotional reciprocity
- **DSM-5 A2.** Deficits in non-verbal communication behaviours used for social interaction
- **DSM-5 A3.** Deficits in developing, maintaining, and understanding relationships
- **DSM-5 B2.** Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour
- **DSM-5 B3.** Highly restricted, fixated interests that are abnormal in intensity or focus
- **DSM-5 B4.** Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment
- Criteria Implicit
- Literature Implicit
- Other Negative
- Other Positive or Neutral

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There were several between gender-group differences in the areas related to explicit features of autism that pupils prioritised for extra support. A higher percentage of the girls' FAMe™ Statements (17%) related to needing support with issues relating to social-emotional reciprocity (DSM-5, A1) than did boys' (10%), e.g. *'Please check if I have understood instructions / if I am OK - **I find it difficult to initiate interactions / ask for help** but often need teacher input / reassurance'*, and, *'Please **help me find a group to work with** and check that I am comfortable / feel I will be allowed to contribute ideas - please don't ask me to work with X'*.

Girls also prioritised factors relating to feelings of social anxiety, e.g. *'Please take me out of the classroom if you want to check if I am OK / ask me how I am - **do not ask me anything in front of my peers'**; 'Please **don't draw ANY attention to me** – good or bad'*; and, *'Please **only ask me to speak in front of the class if I put my hand up** to show I am happy to do so'*. Conversely, boys prioritised sensory issues more frequently (i.e. those relating to DSM-5, B4) as a target for teacher change, i.e. 27% of their FAMe™ Statements compared to 11% of the statements written by the girls.

Coding of FAMe™ Statements to criteria nodes by anxiety group

To explore whether there were any between anxiety-group differences, in the explicit/implicit features of autism that were associated with the difficulties pupils had prioritised for intervention, FAMe™ Statements made by pupils with average levels of anxiety (i.e. BYI-A score of t<55) and and those with above average anxiety levels

(i.e. BYI-A score of t≥55) were analysed separately (Figure 42). The statements of the two pupils who did not complete the self-report measures were removed from this analysis.

Figure 42

The percentage of FAMe™ Statements made by pupils with average (n=10) and above average (n=10) levels of anxiety in which the difficulty expressed was associated with an explicit/implicit feature of autism

Average Anxiety Level Group's FAMe™ Statements n=30

Above Average Anxiety Level Group's FAMe™ Statements n=30

Key:

- DSM-5 A1. Deficits in social-emotional reciprocity
- DSM-5 A2. Deficits in non-verbal communication behaviours used for social interaction
- DSM-5 A3. Deficits in developing, maintaining, and understanding relationships
- DSM-5 B2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal/nonverbal behaviour
- DSM-5 B3. Highly restricted, fixated interests that are abnormal in intensity or focus
- DSM-5 B4. Hyper or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment
- Criteria Implicit
- Literature Implicit
- Other Negative
- Other Positive or Neutral

Differences in the areas chosen to be targeted for teacher change/intervention were less pronounced between the anxiety groups than they were between the genders. However, pupils who had above average levels of anxiety pre-FAMe™ had more statements aimed at general anxiety reduction (Literature Implicit). The proportion of FAMe™ Statements that related to DSM-5 Category B2 was also higher in the above average anxiety group, e.g. difficulties associated with resistance to change, executive functioning and transitioning between tasks. Conversly, pupils who fell into the average anxiety level group had a higher percentage of FAMe™ Statements which were associated with social-emotional reciprocity (DSM-5, A1).

Pupils' FAMe™ Statements coded to Cognitive Autism Theories

In order to determine whether the specific difficulties that pupils identified as being the most important areas for additional support/where they wanted teachers to do something differently (i.e. those prioritised and selected as FAMe™ Statements) could be explained using autism theory, FAMe™ Statements were coded according to the Autism Theory Coding Strategy (Appendix 1E). Figure 43 displays the percentage of pupils' FAMe™ Statements (n=66) that were coded to autism theory in general and, of these, the percentage that was coded at each individual theory node.

Figure 43

The percentage FAMe™ Statements (n=66) made by the whole pupil sample (n=22) where the difficulty expressed could be explained by autism theory
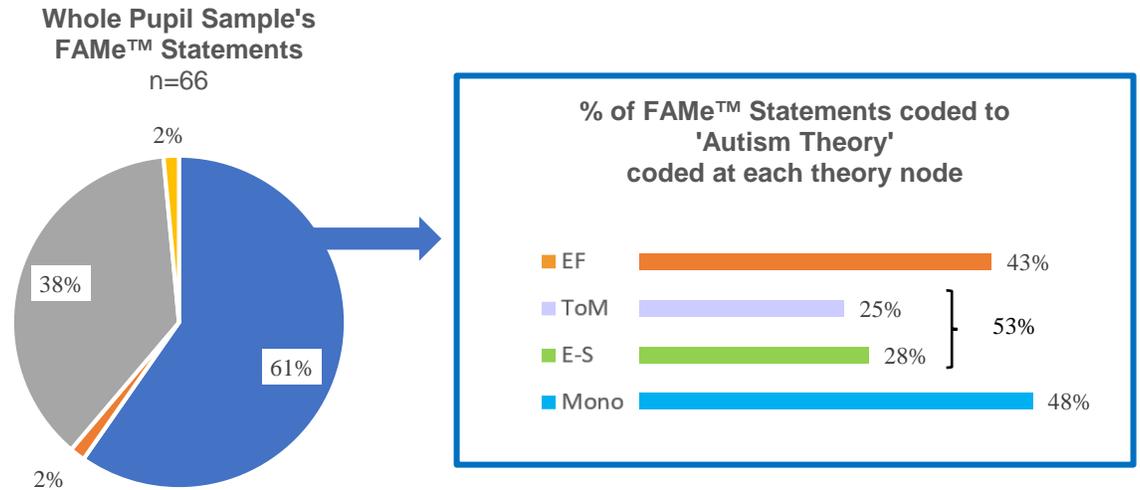
What Figure 43 evidences is that, as with the diagnostic criteria nodes, when pupils were specifically selecting areas of difficulty in school where they felt they would benefit from additional support/would like their teachers to do something differently, a higher percentage of these (61%) had a potential explanation that could be located in autism theory than had their references to experiences of school in general (28%, Fig. 29).

For the first time in this analysis the Empathising-Systemising theory leads here, with the highest precentage of pupils' references coded to it (53%). This

increased representation of E-S theory in Pupils' FAMe™ Statements relates to their specific selection of areas for in-class support which target difficulties with social interactions, e.g. '**I find working in groups difficult**', and, '**Please only ask me to work with pupils I get on with** and who like to work hard'.

The majority of the FAMe™ Statements for which no explanation was related to autism theory were associated with pupils' wanting teachers' to change practice in order to target feelings of social and general anxiety. None of the autism theories selected for analysis explicitly attempt to explain symptoms of anxiety.

Monotropism and Executive Functioning Theory were less well represented in pupils' FAMe™ Statements (48% and 43% respectively) than they were in pupils' references to their school experiences in general (77% and 57%). There was a high level of overlap between these two theories (i.e. both theories offer potential explanation for the same difficulty) when applied to pupils' FAMe™ Statements. e.g. *'Please **give me clear instructions and prepare me in advance** for change - I need to know what is happening'*, and, *'Please **write my homework in my planner for me**/check I have taken it down correctly/provide it on a homework sheet'* (coded to both Monotropism and EF theory).

Coding of FAMe™ Statements to autism theory nodes by gender

To explore whether there were any between gender-group differences, in the proportion of FAMe™ Statements in which the difficulty being targeted for

intervention could potentially be explained using autism theory, FAMe™ Statements

made by the male and female puils were analysed separately (Figure 44).

Figure 44

The percentage of the FAMe™ Statements made by male (n=16) and female (n=6) pupils in which potential explanation for the difficulty expressed could be located in autism theory
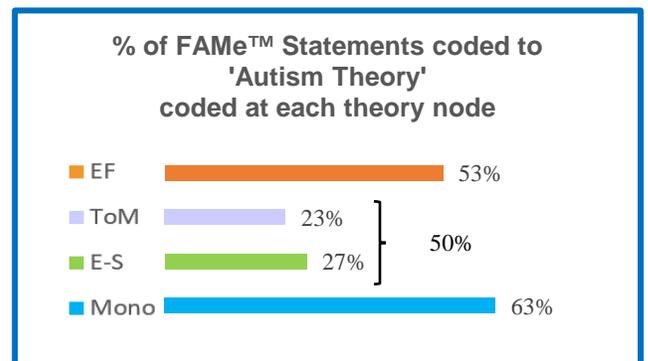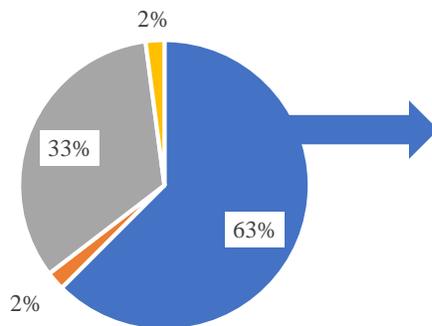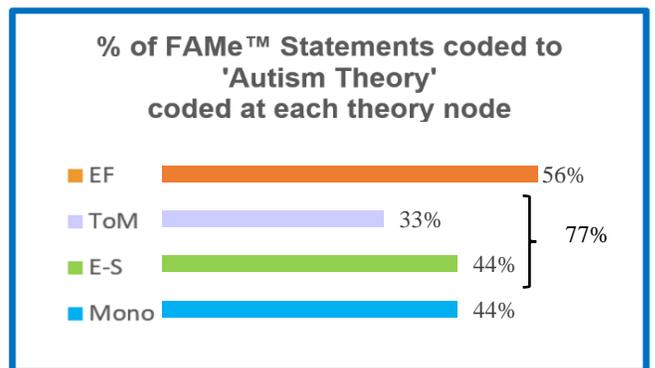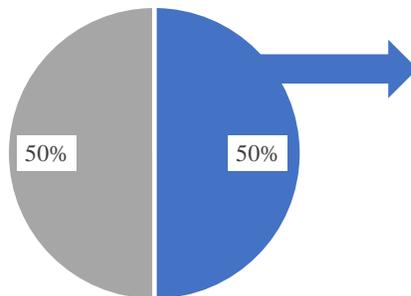
The overall distribution of the percentages of the FAMe™ Statements that could be explained by autism theory differed across gender groups, with a greater percentage of the difficulties targeted for change and described in male pupils' FAMe™ Statements having a potential expalantion in theory (63%), than those written by female pupils (50%). Differences also existed in the proportion of these which were coded to each individual theory, with a higher percentage of girls' FAMe™ Statements (77%) potentially being explained by Empathising-Systemising theory than those of the boys (50%), whilst boys had a higher percentage of FAMe™ Statements that could potentially be explained by Monotropism Theory.

Coding of FAMe™ Statements to autism theory nodes by anxiety group

To explore whether there were any between anxiety-group differences, in the percentage of FAMe™ Statements that could potentially be explained using autism theory, FAMe™ Statements made by pupils with average levels of anxiety (i.e. BYI-A score of t<55) and and those with above average anxiety levels (i.e. BYI-A score of t≥55) were analysed separately (Figure 45). The statements of the two pupils who did not complete the self-report measures were removed from this analysis.

From Figure 45 it can be seen that a higher percentage of the FAMe™ Statements written by the group of pupils with average anxiety levels had an explanation that could be located in autism theory than did the FAMe™ Statements written by pupils with above average anxiety levels (60% and 53% respectively). This

is largely due to the pupils with above average anxiety levels writing FAMe™ Statements targeted at rediucing anxiety, as anxiety is not specifically explained by any of the cognitive autism theories (although the causes of it might be).

Figure 45

The percentage of FAMe™ Statements made by pupils with average (n=10) and above average (n=10) levels of anxiety in which the difficulty expressed had a potential explanation located in autism theory
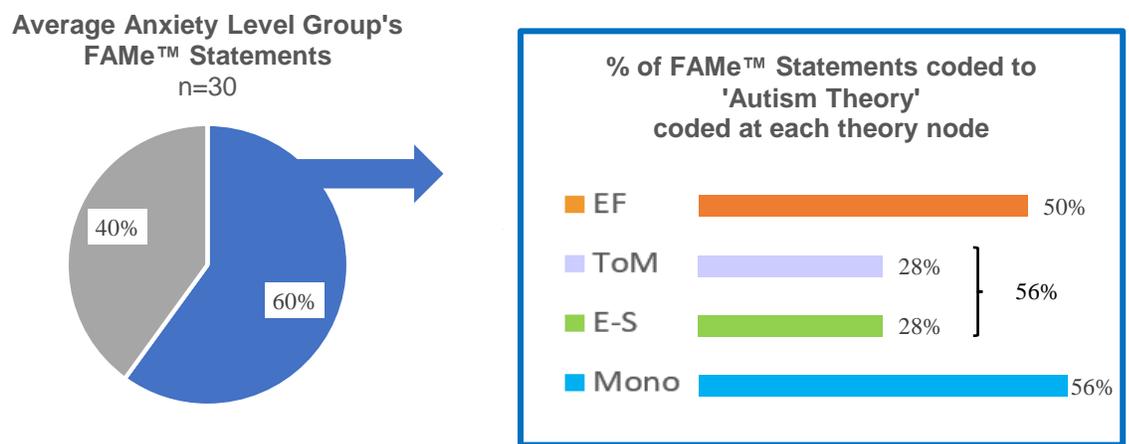
Average Anxiety Level Group's
FAMe™ Statements
n=30
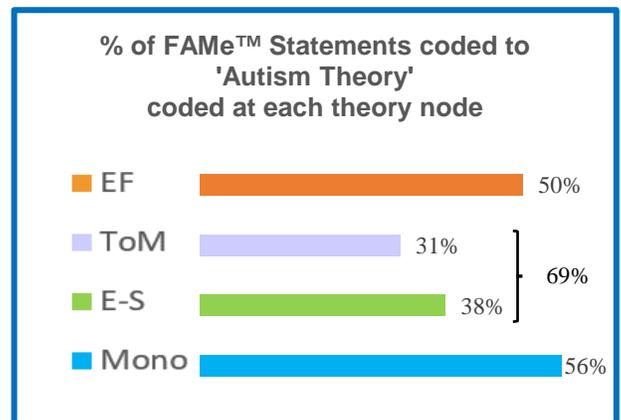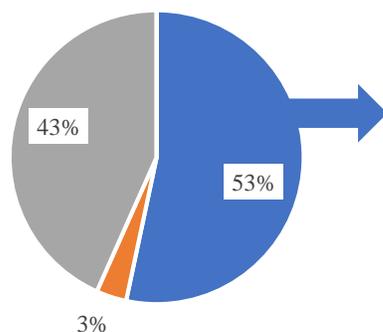
% of FAMe™ Statements coded to 'Autism Theory'
coded at each theory node

EF 50%
ToM 28%
E-S 28%   56%
Mono 56%

Above Average Anxiety Level Group's
FAMe™ Statements
n=30

% of FAMe™ Statements coded to 'Autism Theory'
coded at each theory node

EF 50%
ToM 31%
E-S 38%   69%
Mono 56%

Key:

Difficulties potentially explained by Autism Theories

Other Negative

Difficulties potentially explained by Sensory Differences
(for which potential explanation could not be found
in Monotropism theory)

Other Positive or Neutral

Of the FAMe™ Statements where an explanation of the issue to be targeted could be located in theory, Empathising-Systemising theory explained a greater proportion of the issues prioritised by the above average anxiety (69%) group than of those by the average anxiety goup (56%). There was no difference in the percentage of FAMe™ Statements coded to Monotropism or E-F theory across the gender groups. Once again E-S theory provided the highest percentage of potential explanations of all the theories when applied to specific difficulties (unlike when it had been applied to more general autistic school experiences). The implications of these findings will be considered in the Discussion chapter.

Section 4.

FAMe™ System Evaluation

Previous research has reported that for many autistic pupils their experience of school leaves them vulnerable to a range of negative outcomes related to their mental health and wellbeing (Fleury et al., 2014; Howlin and Moss, 2012; Keen et al., 2016; Levy and Perry, 2011), and that teachers' lack of knowledge and understanding, of autism in general and of their pupils' individual classroom support needs, contributes to this (Charman et al., 2011; Morewood et al., 2011; Osborne and Reed, 2011). The FAMe™ System was designed as a tool to facilitate improved teacher understanding of their individual autistic pupils and how they would like to be supported. It was expected that teachers would use this knowledge to adjust their

classroom practice, and that pupils' school experiences would be more positive as a result.

Whilst it is not possible to definitively attribute any positive impact on pupil well-being over the course of the FAMe™ project to teachers' FAMe™ System use, it was assumed that any significant positive change, from pre- to post FAMe™ in pupils' self-report scores, would indicate that this was potentially the case.

A comparative analysis of pupils' pre-and post-FAMe™ self-report scores was therefore conducted and the findings of this are reported (Part A). In order to identify qualitiative evidence to either support and/or refute the assumption that it was teachers' use of the FAMe™ System that had effected any change in pupils' self-reported well-being, pupils' post-FAMe™ interview data was coded according to a series of nodes relating to their perceptions of classroom practice change and its impact (Part B). The aim of the analyses reported in this section was to address Research Question 4, i.e.:

When information about individual autistic pupils is made easily accessible to their teachers:

   a. *In what way does teachers' behaviour and/or practice towards individual autistic pupils change?*

   b. *What impact is there on autistic pupils' educational experiences and quality of life (QoL) related outcomes?*

Part A.

Pupils' Post-FAMe™ Quantitative Data

Pupils repeated the same self-report measures as had been used to measure their pre-FAMe™ wellbeing during their post-FAMe™ interviews i.e.: the Beck Youth Inventory Anxiety Scale (BYI-A); the Beck Youth Inventory Depression Scale (BYI-D); and the Myself as a Learner Scale (MALS) (see Section 1, Part A). The same process of converting raw scores to T-scores was carried out, and pupil scores were grouped by category, i.e. average and above/below average scores. Above average anxiety and depression scores were considered to be negative mental health indicators. An above average MALS score signifies higher than average academic self-esteem (i.e. is positive) whilst a below average MALs score is considered negative.

The pupil who chose not to complete the self-report measures pre-FAMe™ was attending a work experience placement at the time of the post-FAMe™ interviews and did not respond to an invitation to attend. In addition, during the course of the FAMe™ Project, one pupil moved to another school and one started attending after-school sessions only, as a result of information that came to light during her pre-FAMe™ interview. Both of these pupils scores on the BYI-A pre-FAMe™ placed them in the 'above average' anxiety group. Their data has been removed from Table 12, and all subsequent pre-post FAMe™ comparative analysis, so as not to risk exaggerating the impact of FAMe™ on pupil well-being (this explains

the difference between the pre-FAMe™ findings shown in Table 4, Section 1, Part A and those displayed in Table 12).

It is evident from Table 12 that there was a change in the number of pupils whose self-report scores fell into each self-report category from pre- to post-FAMe™, and movement down the symptom severity scale within the above average anxiety and depression groups. No pupil's score on any of the 3 self-report measures crossed a cut-off boundary in a negative direction from pre-to post-FAMe™.

In order to ascertain the possible significance of these findings, mean whole sample anxiety, depression, and academic self-esteem scores, collected during the pre- and post-FAMe™ interviews (n=18), were compared using paired 2-tailed t-test analyses in which the variance was assumed to be unequal. The findings are displayed in Table 13.

Table 12.

The percentage of pupils (n=18) whose post-FAMe™ self-report scores fell into each category

Self-Report Category	Pre-FAMe™ % of pupil sample in each category (n=18)	Post-FAMe™ % of pupil sample in each category (n=18)	Pre-FAMe™ % of pupil sample with average or above average BYI scores (n=18)	Post-FAMe™ % of pupil sample with average or above average BYI scores (n=18)
Average Anxiety Levels	61% (n=11)	78% (n=14)	61% (n=11)	78% (n=14)
Mildly Elevated Anxiety Levels	0%	11% (n=2)	39% (n=7)	22% (n=4)
Moderately Elevated Anxiety Levels	0%	11% (n=2)		
Extremely Elevated Anxiety Levels	39% (n=7)	0%		
Average Depression Levels	56% (n=10)	83% (n=15)	56% (n=10)	83% (n=15)
Mildly Elevated Depression Levels	0%	6% (n=1)	44% (n=8)	17% (n=3)
Moderately Elevated Depression Levels	17% (n=3)	6% (n=1)		
Extremely Elevated Depression Levels	27% (n=5)	6% (n=1)		
Above Average MALS Score	22% (n=4)	56% (n=10)	**Key:**	
Average MALS Score	72% (n=13)	39% (n=7)	Green indicates positive well-being scores	
Below Average MALS Score	6% (n=1)	6% (n=1)	Red indicates negative well-being scores	

Table 13.

The statistical significance of the change in pupils' anxiety, depression, and academic self-esteem scores from pre- to post-FAMe™

Pupil sample (n=19)	t value	p value (i.e. significance level)
Anxiety mean T-scores Pre-FAMe™ = 57.68 Post-FAMe™ = 46.26	-7.638236	p ≤ 0.01
Depression mean T-scores Pre-FAMe™ = 55 Post-FAMe™ = 46.32	-3.958354	p ≤ 0.01
Academic self-esteem mean scores Pre-FAMe™ = 72.94 Post-FAMe™ = 78.79	3.095031	p ≤ 0.01

The difference in the pupil group's mean scores, from pre- to post-FAMe™ on each of the self-report measures, was significant at the level p ≤ 0.01, indicating that the post-FAMe™ change observed was unlikely to have occurred as a result of chance.

At an individual level, a decrease in anxiety scores, as measured on the BYI-A, was observed for 100% of the pupil sample (Fig. 46) and a decrease in depression scores (BYI-D) was observed for 83% of pupils (Fig. 47).

Figure 46.

Individual pupil's pre- and post-FAMe™ anxiety T-scores
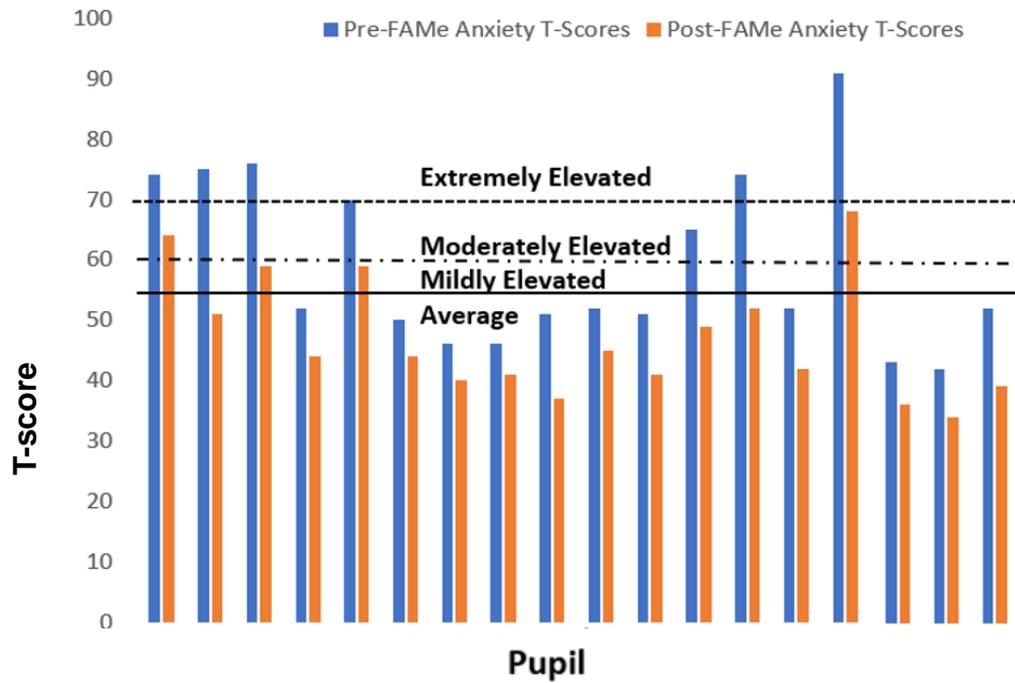
Figure 47.

Individual pupil's pre- and post-FAMe™ depression T-scores
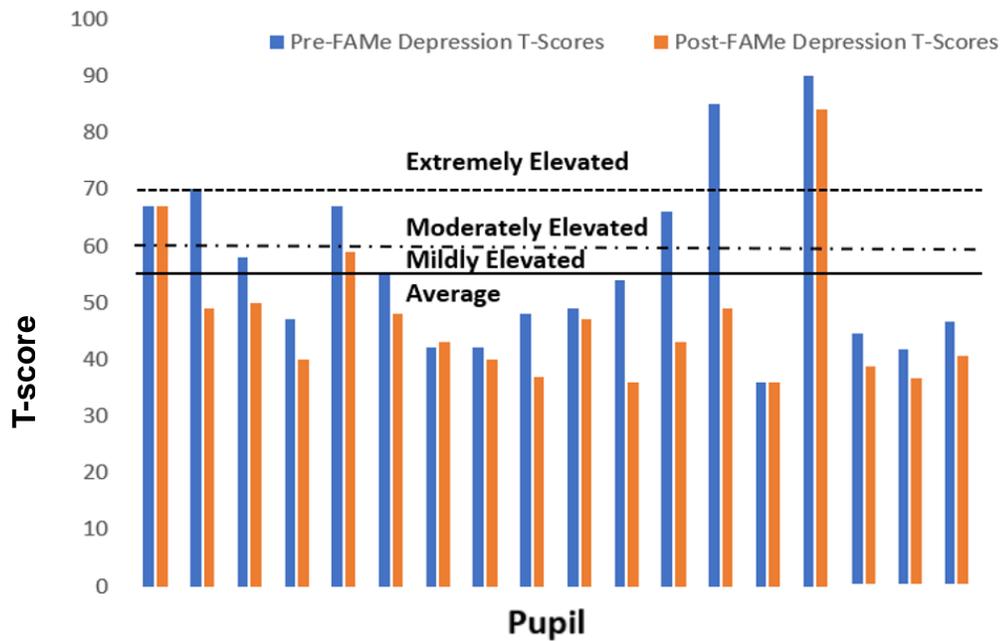
Eleven pupils' (61%) academic self-esteem scores (MALS) went up from pre- to post-FAMe™, 4 (22%) pupils' MALS scores remained constant and 3 (17%) of the pupils' scores fell but remained within the above average range (Fig. 48).

Figure 48.

Individual pupil's pre- and post-FAMe™ academic self-esteem scores
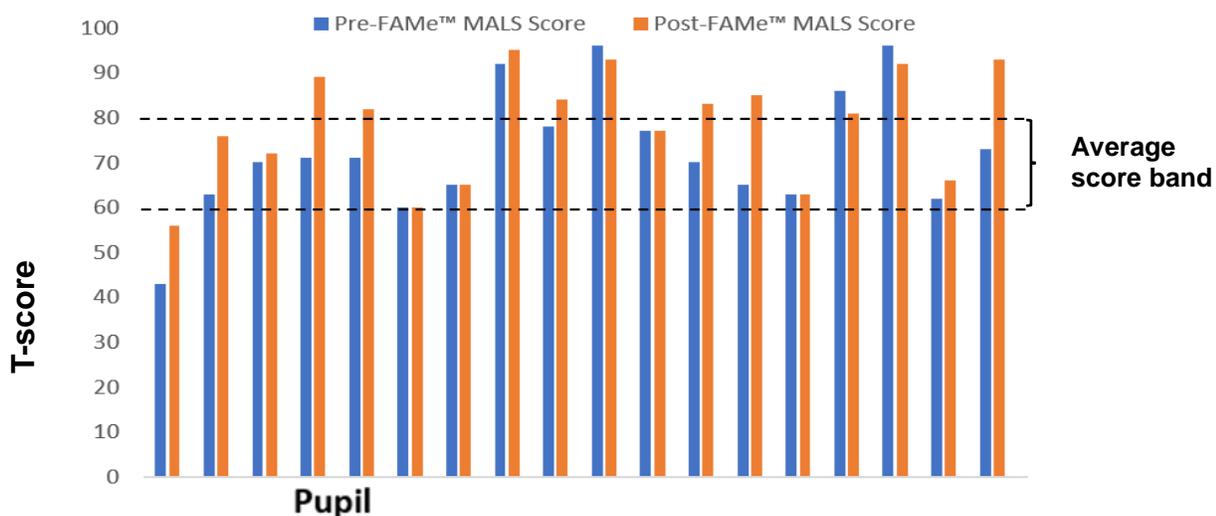
Pupils also repeated the 'How I feel at School' questionnaire during their post-FAMe™ interview and rated their answers to each of the questions about how they had felt in the week prior to interview as: 'very'; 'a bit/quite'; or 'not at all'. The findings are displayed in Figure 49, where pupils' pre-FAMe™ ratings are included for comparison. The bars have been stacked to read from positive (left) to negative (right). Where no data label exists the number of pupils was 0.

Figure 49.

The percentage of pupils (n=18) rating how they felt in class over the past week as, 'Very', 'A bit/quite', and 'Not at all' when assessed pre- and post-FAMe™
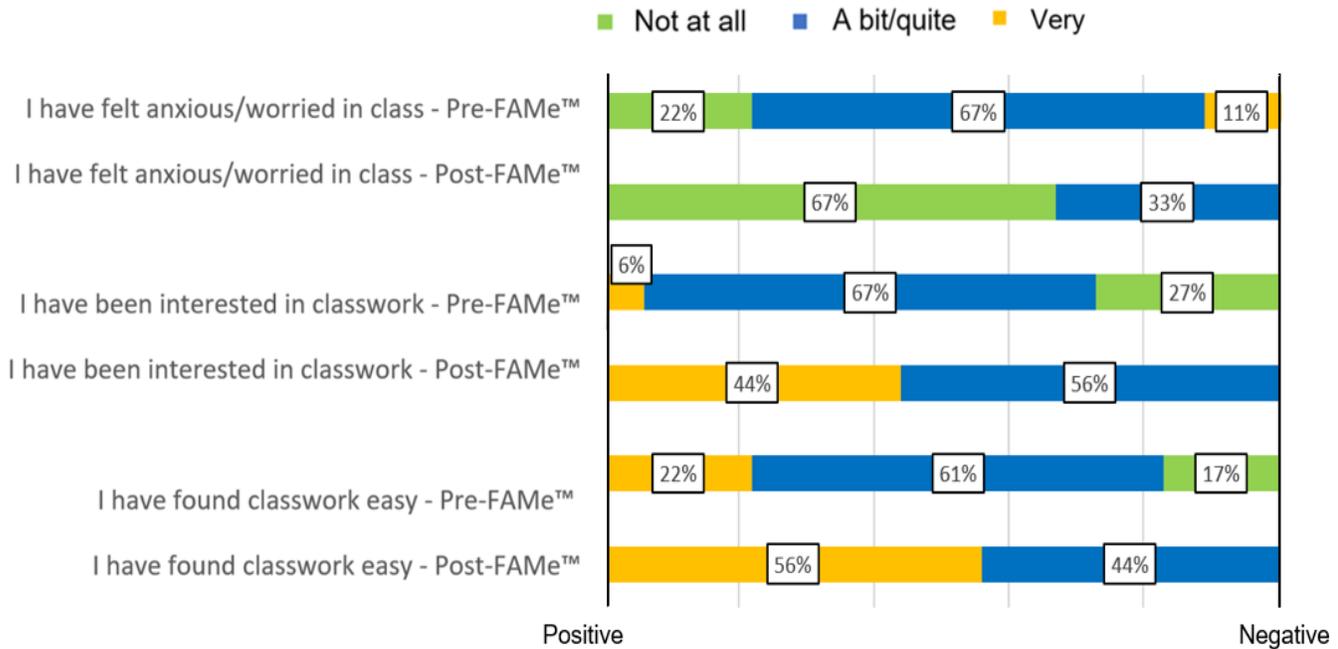
The percentage of pupils reporting no feelings of in-class worry/anxiety in the week prior to interview went up from 22% pre-FAMe™ to 67% post-FAMe™, with no pupils reporting feeling very worried/anxious in class post-FAMe™.

The percentage of pupils reporting being very interested in their classwork increased from 6% to 44%, and the percentage of those finding their classwork very easy went from 22% to 56%, from pre- to post-FAMe™. No pupils reported being not at all interested in classwork or not finding it at all easy post-FAMe™.

The post-FAMe™ version of this questionnaire also included an additional rating scale for each question asking: 'How has this changed since the FAMe™ Project started?' Pupils rated their answer as either:

1. 'I don't feel as anxious/as bored/that the work is hard as I did before FAMe™'
2. 'This has stayed about the same as it was before FAMe™'
3. 'I feel more anxious/more bored/that the work is harder than I did before FAMe™'

Figure 50 shows the percentage of pupils who rated their in-class anxiety levels, and interest in and ease of classwork, in the week prior to the post-FAMe™ interview as 'about the same' (i.e. rating 2) or more positively (i.e. rating 1) than they remember it being before FAMe™ was introduced. The majority (83-89%) of pupils felt that there had been a change in a positive direction in relation to all three questions. No pupil reported a negative change from pre- to post-FAMe™ (i.e. rating 3) for any of the issues being explored.

Figure 50.

Percentage of pupils (n=18) reporting a change in their classroom experiences from pre- to post-FAMe™

□ There has been change in a positive direction
□ Things have stayed about the same

Anxious/worried in class: 17% | 83%
Interested in classwork: 17% | 83%
Found classwork easy to understand: 11% | 89%
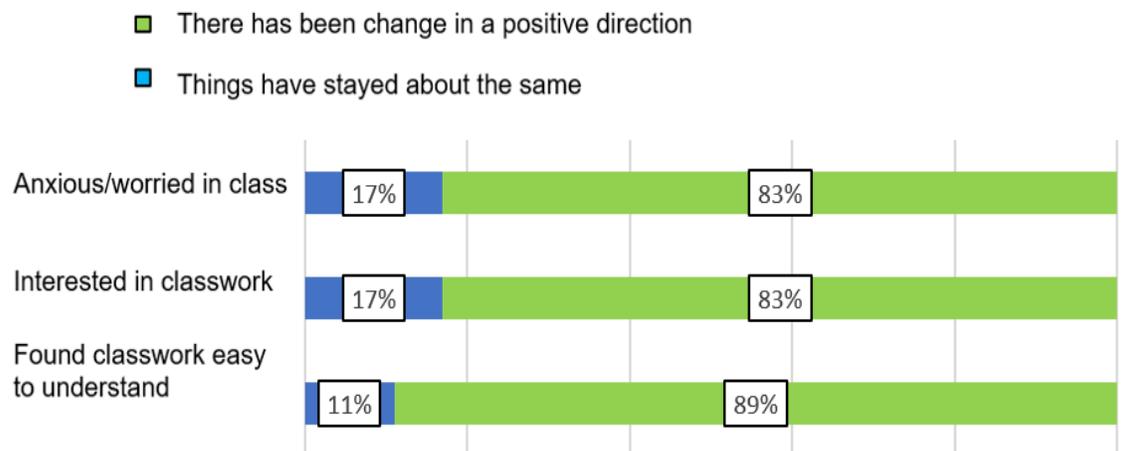
The implications of these quantitative findings are considered in the Discussion chapter.

Part B.

Pupils' Post-FAMe™ Qualitative Data: Pupil Perceptions of Teacher Change

Pupils' post-FAMe™ interviews focused on their school experiences in general, since the implementation of the FAMe™ System, and specifically on their perceptions of teacher change and the difference they felt this had made. Their thoughts about the pre-FAMe™ interview, pupil information packs, and the project in general were also sought and are reported at the end of this chapter.

Coding Round 2

Nodes

Pupils' perceptions about the impact of the FAMe™ System on teacher behaviour and of this on their classroom experiences were investigated by coding pupils' post-FAMe™ transcripts to three deductive nodes:

i. *Pupils reporting desired change in teacher behaviour and/or practice*

Coded to this node were specific references demonstrating that: pupils thought teachers had read their FAMe™ Statements and acted on them; pupils

believed teachers were more aware of their difficulties than they were pre-FAMe™;

and pupils reported examples of positive change in teaching practice and/or teachers'

behaviour towards them since the FAMe™ System was introduced.

Examples of references coded to this node:

- **Site 1, Pupil 04:** *Like when I ask a question they always help me and…*
  Qu: more than they did before?
  …yeah definitely more than they did before because they are more aware of my difficulties they can take them into consideration now

- **Site 02. Pupil 05:** *There are some classrooms...teachers who you can clearly see know* [about FAMe™] *they have changed*

- **Site 1, Pupil 01:** *Probably the writing in my homework has happened…if I'm in a rush to write it down I can't read it when I get home, but now the teacher says before he tells everybody else, he writes it down for me*

- **Site 1, Pupil 05:** *They have come and asked me if I'm Ok quite a bit which is on there* [i.e. a FAMe statement]

- **Qu:** and do you not think they would have done that before? [teachers have noticed when she is stressed and offered her the chance to do an alternative task]
  Site 1, Pupil 04: *I don't think they would have done that before. I don't think they would have been aware that I was getting stressed for a certain reason they might have just thought I was going crazy or something*

- **Site 1, Pupil 07:** *They have genuinely tried like not made me do stuff I don't want to do, that kind of thing...so I've been allowed to decide...put my hand up if I want to talk, that kind of thing*

ii. Pupils reporting a lack of change in teacher behaviour and/or practice

Coded to this node were specific references demonstrating that pupils believed that one teacher, or their teachers in general, had not read and/or not acted on their FAMe™ Statements.

Examples of references coded at this node:

- **Qu:** how's things been going?
  Site 3, Pupil 05: *literally hasn't changed at all*
- **Qu:** [shows pupil his FAMe™ Statement information] Has any of this been attended to?
  Site 1, Pupil 03: *No, I don't…I haven't seen any of those happening really at all in class*

- **Site 1, Pupil 03:** *I think that there are things that teachers need to work on and they need to have a look at it* [his FAMe™ information] *really. I think ALL teachers should take it on board really cos some teachers just ignore it*

- **Site 2, Pupil 05:** *If you see my teacher in science how she behaves around me how she talks to me it's pretty obvious that it seems that she actually hasn't read this* [his FAMe™ information]

- **Site 3, Pupil 06:** *…but some of them have completely ignored the facts* [FAMe™ Statements] *because like they don't really think that I may have the disabilities that I do have*

iii. Pupils reporting an overall positive impact which they attribute to FAMe™

This node was split inductively into:

a) Pupils reporting positive emotional impact

Coded to this node were specific references to feelings which demonstrate that pupils believed they: had experienced a reduction in anxiety/stress; feel 'better'; are happier; are more confident in class; enjoy school more; feel that teachers care about them/are helping them more, than they were pre-FAMe™.

Examples of references coded to this sub-node:

- **Qu:** and what difference does it make to you when teachers don't do these things [things FAMe™ Statements asked teachers to stop doing] ...when they help you?
  Site 1, Pupil 02: *I feel happier*

- **Site 3, Pupil 06:** *For me it's made school a lot nicer, I've been bored a lot less, I've actually enjoyed some of my lessons that I didn't like before*

- **Qu:** so, the ones [teachers] who have been doing things differently, what difference has that made to how you feel?
  Site 1, Pupil 04: *It's made school less stressful and easier and more enjoyable*
- **Site 1, Pupil 05:** *I don't mind asking for help as much, especially in D&T. Now* [since teachers have had her FAMe™ information] *I just think if I can't do it I don't stress, and I just go straight to the teacher and say I can't do this…*

- **Site 1, Pupil 05:** *It's made me feel more confident, especially because I knew that they knew what my problems were and that has changed like the way I react to things and how I feel in class it's made me think if anything happens they are going to know that I am stressed and that I am anxious and...*

- **Site 1, Pupil 07:** *It kind of like reassures you, like if you think they are going to pick on someone for an example ...but now I know they are not going to pick me it's like, 'oh that's great', that's a lot of stress off me like it just makes you feel more comfortable in class*

- **Qu:** does it change how you feel in class? [teachers having access to his FAMe™ Statements]
  Site 3, Pupil 02: *Yeah*
  Qu: can you tell me a bit about that?
  It makes me a bit more confident in class

b) Pupils reporting positive change in ability to learn and/or academic achievement

Coded to this node were specific references demonstrating that pupils believed they had: an increased ability to concentrate in class; a greater understanding of tasks; found following instructions easier; the capacity to do more work; achieved higher grades/marks

Examples of references coded to this node:

- **Qu:** Has anything changed in terms of your results or the amount of work you are doing? Do you think your teachers would notice that anything has changed?
  Site 1, Pupil 07: *Yeah, my teachers have said, "You are doing a bit more work"*

- **Site 1, Pupil 01:** *I understand the homework if I need to do any extra thing, so it has helped me, and I've been better in classes*

- **Site 2, Pupil 05:** *The lessons where it seems that they* [teachers] *have* [used FAMe™] *...I'm now having a clear interest in that* [classwork]

- **Qu:** And what difference has it [FAMe™] made for you? Has it made any difference?
  Site 2, Pupil 02: *Oh well in science I was a bit more higher grade - I got a 5a which was actually that means I was the highest grade out of my whole class*
  Qu: And do you think that has got something to do with this [FAMe™]?
  Yeah

- **Site 3, Pupil 01:** *I can concentrate a lot more*

- **Site 3, Pupil 03:** *I'm actually really enjoying lessons now*

- **Site 2, Pupil 02:** *It means I can work at the same pace as everybody else cos sometimes I'd get left behind and they'd be doing a group task and I'd be asking...”What question is this?” and they'd be, “We did this five minutes ago”...and that's not happening so much now*

- **Site 3, Pupil 02:** *In my Maths test I got the highest scores in Maths*
  Qu: Is that unusual for you?
  That's very unusual for me. I never normally finish tests before the end of the lesson, but I finished nearly first and spent the rest of the lesson drawing. It was awesome. I came top so that was cool

c) Pupils reporting positive impact - other (i.e. no specific reference to emotional or learning related change)

Coded to this node were references demonstrating that pupils believed there had been a positive impact on them, from their teachers' use of the FAMe™ System, but not making a specific reference that could be coded at nodes 3a or 3b. Some pupils gave very short, sometimes one-word answers, indicating positive impact but not providing evidence that enabled the reference to be coded to a more specific node.

Examples of references coded to this node:

- **Qu:** And has that been helpful?
  Site 1, Pupil 02: *Yes*

- **Site 1, Pupil 05:** *It's got better*

- **Site 3, Pupil 01:** *It's been helpful*

- **Site 1, Pupil 05:** *X* [friend] *has tried to help me...a lot of things have been a lot better*

- **Site 2, Pupil 03:** *…because I'm now working with people I know, and I know the school a little bit better, I think it's* [FAMe™] *really helped me*

Coding Strategy and Rules

Units of coding differed in length and were separated when: a pupil finished speaking; if they changed what they were speaking about during a sentence/answer; or if the node that could be coded to changed during their answer. One unit of coding could span an interruption/question from the interviewer. For example, these references were split in the following ways:

1. **Site 1, Pupil 04:** *They have not asked me as many questions in front of the class or they have asked me easy ones…* **- reference split here and coded to 1. 'Pupils reporting desired change in teacher behaviour and/or practice' -** *…so that is better -* **coded to 3c. 'Pupils reporting positive impact – other'.**

2. **Site 1, Pupil 07:** *They don't use my work as an example if I don't want them to - they ask, "Do you mind if we use your work", first…-* **reference split here and coded to 1. 'Pupils reporting desired change in teacher behaviour**

and/or practice' - *…it's just made class life a lot easier* - **coded to 3c.** '**Pupils reporting positive impact – other'.**

3. **Site 2, Pupil 05:** *I believe most of my teachers have read it and understand it and they are now helping me…-* **reference split here and coded to 1.** '**Pupils reporting desired change in teacher behaviour and/or practice' -** *…it makes me feel happier - that's really all I can say - I feel a lot better* **- coded to**

Coding Rules

1. References (Units of Coding) *must not* be coded to more than one node

2. References (Units of Coding) that cannot be coded to nodes 1-3a-c *must* be coded at 'Other' to be explored in the further rounds of coding

3. Repeat references/answers to questions asked for clarification purposes *must* be coded to 'Clarification'.

References that were coded to 'Other' or 'Clarification' were excluded from the following calculations and are not shown in any figures and/or tables unless specifically referred to.

Findings of Coding Round 2:
Pupils' Perceptions of Teacher Practice Change

The percentage of the post-FAMe™ pupil sample (n=18) making at least one reference/unit of coding (UoC) coded to each node was calculated and is shown in Figure 51. The average number of units of coding made (per pupil) is also shown, to indicate how frequently pupils tended to make reference to each theme.

Figure 51.

The percentage of pupils (n=18) with at least one reference coded to each of the nodes relating to teachers' post-FAMe™ practice change
(includes the average number of references made per pupil at each node)
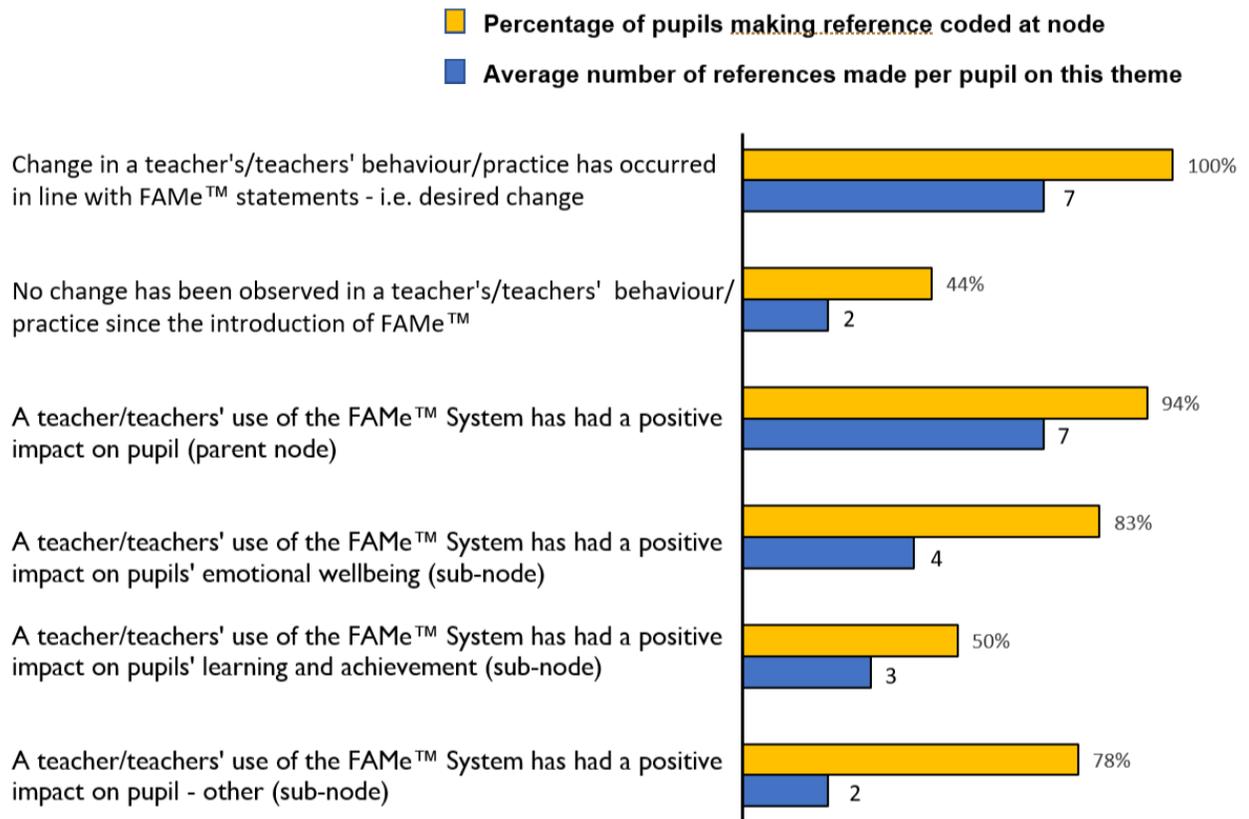
A greater percentage of pupils (100%) made at least one reference to teachers changing their behaviour and/or practice in line with their FAMe™ Statements than not (44%), and, on average, each pupil referred to desired teacher change having occurred on 7 separate occasions within their interview. This compares to an average of 2 references per pupil to teachers not altering their behaviour in line with pupils' FAMe™ Statements. All 18 pupils reported that they felt teachers' use of the FAMe™ system had impacted on their school experiences in a positive way.

A higher percentage of pupils reported that teachers' changed behaviour and/or practice had had a positive impact on factors related to their emotional wellbeing (83%), e.g. decreased stress and being happier, than their learning and/or achievement (50%), e.g. ability to concentrate and higher grades. Nevertheless, this suggests that half the sample attributed an increased ability to learn/success at school to teachers' use of the FAMe™ System, with each of these pupils making reference to this phenomenon 3 times on average. The implications of these findings are considered in the Discussion chapter.

Section 5.

Teachers

In this section, findings from the teachers' pre- and post-FAMe™ online surveys are presented, together with their thoughts about and experiences of using the FAMe™ System, and their suggestions for its future development.

1. Teachers' Pre-FAMe™ Survey Data

In order to establish a baseline understanding of teachers' autism training; knowledge of their individual autistic pupils; confidence in teaching these pupils; and how the FAMe™ System might be received, teachers in the three participating schools were invited to complete a pre-FAMe™ online survey, distributed to them through their school SENDCO via email.

Fifty-three teachers submitted responses. However, not all of the surveys were complete. The minimum response rate to any question was 46 (87% of the total sample). Reported percentages throughout this section were calculated according to the number of teachers responding to each specific question. The number of teachers who did not respond to each question is also shown. Following some of the questions, teachers were invited to provide more information to explain their response. Where teachers did this, a synopsis of their answers is provided following each table and examples of their written responses are provided in Appendix 17.

i.   Time spent teaching and amount of autism training received

The first question related to the length of time teachers had taught, post-qualification, and the extent of the autism-specific training they had received to-date. The findings are shown in Tables 12 and 13.

Table 12.

Time spent teaching since qualification training

Length of time as a qualified teacher	% of teachers who responded (n=41)
NQT	2%
0-5 years	21%
6-10 years	23%
11+ years	55%

Table 13.

Hours of autism-specific received

Hours of autism training received	% of teachers who responded (n=41)
0-2 hrs	83%
3-5 hrs	2%
5 hrs+	15%
Did not answer this question	12

The additional information provided by teachers highlighted the disparity of autism specific training that had been received. For example, one teacher reported receiving two hours of autism training over 11 years of teaching and another said they had attended a half hour session 10 years ago delivered by a parent of an autistic pupil. At the other end of the training spectrum, one of the teachers had previously worked in a specialist autism resource and stated that they had had 'many hours' of autism-related training in addition to attending 'more general SEND INSET

days'. Several teachers had received general SEND training on in service training (INSET) days which had contained some 'basic autism training', whilst others reported having had no additional autism training since completing their initial teacher training degree, although for one teacher that had included two days of autism-specific training.

ii.   Ease of access to pupil-specific information

Teachers were next asked: whether they knew which of the pupils they teach are autistic; about the information they received relating to individual pupils; and about the access they had to pupil-specific information. The percentages of teachers responding with either, 'Yes', or, 'No', to each question are summarised in Table 14 together with the number of teachers who answered each question.

Those teachers who provided additional information described having access to 'Pupil Profile' sheets and 'Pupil Passports' containing pupil-specific information which was typically available via a separate drive on the school computer system. When responding to the question about access to this information, it was evident that the process was not always straightforward, e.g. *'You have to load a webpage, click through some options, find the document, search for the pupil's name. It's a convoluted process'.* Teachers' responses to these questions reflected what I had been told by my own children's teachers, i.e. that pupil-specific information is available but not quick or easy to access. It was this that had initially prompted the development of the FAMe™ System.

Table 14.

Teachers' responses to questions relating to the pupil-specific information available to them pre-FAMe™

Question	% of teachers responding 'Yes'	% of teachers responding 'No'	No. teachers who did not respond
Are you aware which of the pupils you teach have a diagnosis of autism?	**98%** (n=52)	**2%** (n=1)	0
Have you been given/read specific information relating to your autistic pupil's individual needs?	**96%** (n=48)	**4%** (n=2)	3
Do you know how to access information about individual autistic pupil's learning/ classroom support needs?	**90%** (n=47)	**10%** (n=5)	1
Is this pupil-specific information easy for you to access?	**78%** (n=38)	**22%** (n=11)	4

iii. Frequency of accessing pupil-specific information

Teachers were next asked how often they typically accessed the pupil-specific information that was available to them pre-FAMe™, and also whether they would access this information more often if it was easier to access or contained more concise/specific information. Their responses to these questions are summarised in Tables 15 and 16.

Table 15.

**How often teachers accessed/read individual autistic pupil's
learning/classroom support information after the first reading pre-FAMe™**

Frequency	% of teachers giving this response (n=49)
More often than once a week	4%
At least once a month	8%
At least once a half-term	12%
At least once a term	16%
At least once during the academic year	20%
I don't access/read it after the first reading	12%
It depends on the individual pupil	28%

As can be seen in Table 15, almost a third (32%) of teachers reported that they do not access pupil-specific information as often as once a term, and only 20% accessed it more frequently than once a half-term. However, if pupil information was more concise and/or easier to access the majority (66-79%) of those who responded (n=47-48) indicated that they would access it more often (Table 16).

Table 16.

**Teachers' responses to questions about what would make them
access pupil information more often**

Do you think you would access autistic pupil's individual support information more often if:	% of teachers responding 'Yes'	% of teachers responding 'No'	Number of teachers who did not respond
It was easier to access?	**66%** (n=32)	**34%** (n=16)	6
It contained more concise/specific information?	**79%** (n=38)	**21%** (n=10)	5

iv. Confidence in ability to meet autistic pupils' classroom support needs

Teachers were next asked to rate their level of confidence about whether they understand, and feel able to meet, the learning and support needs of their autistic pupils. Their responses are summarised in Table 17, followed by a summary of their additional written comments. Two thirds of teachers indicated that they felt 'quite confident' about their understanding of and ability to support their autistic pupils. Fewer teachers felt confident (13%) than not at all confident (21%) that they were able to support their autistic pupils appropriately in the classroom.

Table 17.

Teachers' pre-FAMe™ levels of confidence in their ability to understand and meet the learning/classroom support needs of their individual autistic pupils

Please indicate how confident you are that you currently:	Not at all confident	Quite confident	Confident	Did not respond
Understand the learning/ classroom support needs of the individual autistic pupils you teach	**15%** (n=7)	**69%** (n=33)	**16%** (n=8)	5
Are able to meet the learning/ classroom support needs of the individual autistic pupils you teach	**21%** (n=10)	**66%** (n=31)	**13%** (n=6)	6

Teachers' additional comments revealed a variety of factors impacting on their confidence in their ability to meet autistic pupils' classroom support needs. These reflected the issues reported in autism education literature and described in the Literature Review chapter of this thesis and included: class size and the number of children with SEND within each class; time limitations; and the heterogeneity of the autistic population. One teacher described how they would like more specialist support, from a qualified TA in the classroom and from a SEND specialist to review their schemes of work. Another teacher's feedback demonstrated that within the current system they were finding it impossible to attend to the needs of all their pupils:

We all want to do more, we all know that in an ideal world there is so much more we could and should do. There are too many demands on our time and I'm afraid it is impossible to provide the differentiated support that is necessary for all the students that we teach. Even working more than three times the hours we are paid to work is not enough to plan lessons and mark the work, give constructive feedback etc. let alone differentiate all that sufficiently for the vast array of SEN we would like to better address

v.   Responses to the FAMe™ System concept

Teachers were next introduced to the concept of the FAMe™ System and asked whether they believed having access to such a system would impact on: how often they accessed pupil's individual information; their confidence about teaching their autistic pupils; their teaching practice; and their ability to meet the needs of their autistic pupils. Their responses to these questions are summarised in Table 18.

Almost half (49%) of teachers indicated that they would access pupil information at least once a week if it were provided to them through the register. This compared with only 4% who had indicated that they were currently doing this (Table 15). The vast majority (98%) of teachers indicated that they believed having easy access to pupil-specific information would increase their confidence about teaching autistic pupils at least a little, with almost a quarter (24%) believing their confidence would increase 'very much'. Around two thirds (64% and 66%) of the teachers who responded felt that having better access to pupil-specific information would effect 'quite a lot' or 'very much' change in their teaching practice, and ability to meet pupils' support needs, with only one teacher not anticipating that such change would occur.

Table 18.

The percentage of teachers who provided each response to questions relating to the impact they thought the FAMe™ System might have

How likely do you think it is that the new FAMe™ register-based reminder, with an easy-access link to key individualised pupil information, will:	Not at all/ less than once a half-term	A little/ at least once a half-term	Quite a lot/ at least once a week	Very much/ every lesson	Number of teachers that did not respond
Be accessed/read by you?	**4%** (n=2)	**47%** (n=22)	**30%** (n=14)	**19%** (n=9)	6
Increase your confidence regarding teaching autistic pupils?	**2%** (n=1)	**33%** (n=15)	**41%** (n=19)	**24%** (n=11)	7
Effect change in your autism practice?	**2%** (n=1)	**34%** (n=16)	**36%** (n=17)	**28%** (n=13)	6
Enable you to better meet the needs of your individual autistic pupils?	**2%** (n=1)	**30%** (n=14)	**32%** (n=15)	**36%** (n=17)	6

vi. Perceived barriers to FAMe™ System use

The final question of the pre-FAMe™ survey asked whether teachers anticipated any barriers which might prevent them from using the FAMe™ System and, if so, what these were. Ten teachers, 22% of the 45 that responded to this question, felt barriers might exist including existing time pressures and forgetting the information was there. Other teachers indicated their support for such a system, e.g.:

I think it sounds absolutely brilliant and we have talked about this for years as something that would be so useful for the classroom teachers and also those unfortunate times when cover lessons happen for various reasons, it will give the Cover Supervisor an instant idea of how to manage a pupil, if the register is available to them

vii.   Additional information

The pre-FAMe™ teacher survey ended with the following invitation:

If there is anything more you can tell me about your experience of teaching autistic pupils, for example about issues/difficulties you have encountered or successes you have had, please write about them here.

Responses indicated that difficulties were encountered when teachers were expected to intuit individual pupil's classroom needs and the appropriate strategies to support them from generic autism-related guidelines such as, 'use of techniques to aid ASD would help'.

Several teachers reported that the current information available to them was not sufficiently personalised to reflect the heterogeneity of the autistic pupil population and thus they were not able to avoid individual pupil's anxiety triggers. The need for patience, and an understanding that is was inappropriate to have the same expectations of all autistic pupils, or as of non-autistic pupils, in terms of their learning styles or output, were also reported.

2. Teachers' Post-FAMe™ Survey Data

Following one term of having access to the FAMe™ System via their registers, teachers were invited, by email via their school SENDCO, to take part in a post-FAMe™ online survey exploring their experience of, and thoughts about, using the FAMe™ System. Sixty-five teachers submitted survey responses, although not all submissions were complete. The minimum response rate to any question was 60 (92% of the total sample).

Teachers were asked to respond to 10 statements by indicating one of the following: 'Yes, or I agree'; 'Somewhat'; or 'No, or I disagree' and had the option to comment in more detail to explain their answers. An additional question, requesting information about what typically prompted teachers to access pupils' FAMe™ Statements, was also included.

As both pre- and post-FAMe™ teacher surveys were anonymous, it was not possible to compare teacher change at an individual level. Findings are therefore presented as percentages of the number of teachers responding to each question (range 60-65) and the number of respondents is shown throughout. Where additional qualitative information/feedback was given by teachers, the general theme of these comments is provided in each table. Examples of teachers written answers are provided, with their response, i.e.: 'Yes or I agree'; 'Somewhat'; or, 'No or I disagree' shown in parentheses, in Appendix 18. A summary, of the quantitative data reported in Figure 52, is shown in Table 19.

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Figure 52.

Teachers' responses to the first 10 survey questions of the post-FAMe™ online survey

Question 1 (n=65)	Yes or I agree	Somewhat	No or I disagree
The FAMe™ System alerted me to the presence of autistic pupils attending my lessons	**60%** (n=39)	**15%** (n=10)	**25%** (n=16)
Most frequently given reason/typical theme of answer	Dot in register by pupil's name highlighted pupil to teacher	System acted as a reminder/will be useful in future	Already knew which pupils are autistic/ system not necessary for this

Question 2 (n=64)	Yes or I agree	Somewhat	No or I disagree
The FAMe™ System gave me easy access to pupils' FAMe™ Statements	**58%** (n=37)	**26%** (n=17)	**16%** (n=10)
Most frequently given reason/typical theme of answer	Speed of access & concise information	Needed to be shown how to use it to begin with	No additional comments

Question 3 (n=62)	Yes or I agree	Somewhat	No or I disagree
The FAMe™ System was quick and/or straightforward to use	**61%** (n=38)	**28%** (n=17)	**11%** (n=7)
Most frequently given reason/typical theme of answer	Better than previous access to information, e.g. via pupil passport	Needed help to set it up	No access to electronic register (e.g. PE teachers)

Question 4 (n=61)	Yes or I agree	Somewhat	No or I disagree
I accessed pupils' FAMe™ Statements every time I taught them	**4%** (n=2)	**34%** (n=21)	**62%** (n=38)
Most frequently given reason/typical theme of answer	No additional comments	Used as a reminder that pupil needs extra support	Not necessary every lesson but checked frequently

Question 5 (n=61)	Yes or I agree	Somewhat	No or I disagree
The FAMe™ Statements provided me with information about individual autistic pupils that I did not already know	**40%** (n=24)	**34%** (n=21)	**26%** (n=16)
Most frequently given reason/typical theme of answer	Individualised info. that came from pupil helpful	No additional comments	Already had information about pupil

Question 6 (n=61)	Yes or I agree	Somewhat	No or I disagree
The FAMe™ Statements informed my classroom practice and/or changed the way I supported individual autistic pupils	**33%** (n=20)	**34%** (n=21)	**33%** (n=20)
Most frequently given reason/typical theme of answer	Teacher able to plan instruction to meet pupil's needs	Not all pupil requests could be met, e.g. seating plans	Started too late in year/ strategies already developed

Question 7 (n=61)	Yes or I agree	Somewhat	No or I disagree
The FAMe™ System changed the confidence I have in my ability to meet the learning and/or support needs of individual autistic pupils	25% (n=15)	42% (n=26)	33% (n=20)
Most frequently given reason/typical theme of answer	No additional comments	Good to have reassurance that teaching methods suited pupil	No additional comments

Question 8 (n=60)	Yes or I agree	Somewhat	No or I disagree
I have noticed a change in FAMe™ pupils' engagement and/or behaviour and/or learning since the FAMe™ project began	8% (n=8)	58% (n=34)	34% (n=18)
Most frequently given reason/typical theme of answer	No additional comments	Not enough detail provided	Not enough detail provided

Question 9 (n=60)	Yes or I agree	Somewhat	No or I disagree
There has been a change in FAMe™ pupils' academic outcomes and/or output since the FAMe™ project began	8% (n=5)	59% (n=35)	33% (n=20)
Most frequently given reason/typical theme of answer	More work produced	Some improvement seen	No additional comments

Question 10 (n=60)	Yes or I agree	Somewhat	No or I disagree
I would welcome updates to SIMs software that optimise the functioning of the FAMe™ System	80% (n=48)	15% (n=9)	5% (n=3)
Most frequently given reason/typical theme of answer	Speed/ease of access and pupil-specific info.	No additional comments	No additional comments

Table 19.

Summary of teachers' responses to questions 1-10 of the post-FAMe™ survey.

Question	Number of teachers responding to this question	Yes or I agree	Somewhat	No or I disagree
1. The FAMe™ System alerted me to the presence of autistic pupils attending my lessons	n=65	60% (n=39)	15% (n=10)	25% (n=16)
2. The FAMe™ System gave me easy access to pupils' FAMe™ Statements	n=64	58% (n=37)	26% (n=17)	16% (n=10)
3. The FAMe™ System was quick and/or straightforward to use	n=62	61% (n=38)	28% (n=17)	11% (n=7)
4. I accessed pupils' FAMe™ Statements every time I taught them	n=61	4% (n=2)	34% (n=21)	62% (n=38)
5. The FAMe™ Statements provided me with information about individual autistic pupils that I did not already know	n=61	40% (n=24)	34% (n=21)	26% (n=16)
6. The FAMe™ Statements informed my classroom practice and/or changed the way I supported individual autistic pupils	n=61	33% (n=20)	34% (n=21)	33% (n=20)
7. The FAMe™ System changed the confidence I have in my ability to meet the learning and/or support needs of individual autistic pupils	n=61	25% (n=15)	42% (n=26)	33% (n=20)
8. I have noticed a change in FAMe™ pupils' engagement and/or behaviour and/or learning since the FAMe™ project began	n=60	8% (n=8)	58% (n=34)	34% (n=18)
9. There has been a change in FAMe™ pupils' academic outcomes and/or output since the FAMe™ project began	n=60	8% (n=5)	59% (n=35)	33% (n=20)
10. I would welcome updates to SIMs software that optimise the functioning of the FAMe™ System	n=60	80% (n=48)	15% (n=9)	5% (n=3)

What can be understood from Figure 52 and Table 19 is that, on the whole, teachers' response to the trial of the FAMe™ System was positive. The majority of teachers (range 75-89%) responded with 'yes' or 'somewhat' to the questions about the FAMe™ System which related to it having: alerted them to the presence of autistic pupils in their lessons; provided easy access to pupil-specific information; and been easy and straightforward to use.

Additional information provided by teachers (Appendix 18) suggested that they valued the contribution by pupils to their own FAMe™ Statements and found these useful and interesting. However, most teachers did not feel the need to access pupils' information at the start of every lesson (66%). Qualitative feedback to this question suggested that information was remembered between lessons by teachers and that the FAMe™ System was used when they felt they needed to be reminded of a pupil's support needs.

Almost three quarters (74%) of teachers' responses indicated that FAMe™ Statements contained information about their autistic pupils' classroom support needs that they were not already aware of, and two thirds (67%) reported that their classroom practice and/or the support they offered to pupils in lessons had changed as a result of reading this new information.

Two thirds of teachers (67%) also reported that their confidence, in their ability to meet the classroom support needs of individual autistic pupils had increased, as a consequence of having access to pupils' FAMe™ Statements.

At least some change in pupil behaviour (i.e. 'yes' or 'somewhat'), and improvement in their academic learning and achievement, since the beginning of the FAMe™ Project, was reported by 66% of teachers. Finally, 95% of teachers indicated that they would welcome an optimally functioning FAMe™ System for use in the future.

Teachers were next asked to indicate what had typically prompted them to access an individual pupil's FAMe™ information. Their responses are summarised in Table 20.

Table 20.

The factors that typically prompted teachers to access pupils' FAMe™ Statements from the class register

What typically prompted you to access a pupil's FAMe™ information?	Percentage of teachers responding with this answer (n=60)
Saw pupil name highlighted in register	**55%** (n=33)
Staff briefing information and/or email reminder	**31%** (n=19)
Pupil factors (behaviour etc.)	**3%** (n=2)
Other	**11%** (n=6)

The heightened visibility on the class register of pupil specific information via their FAMe™ Statements appeared to act as a reminder/prompt to for more than half of the teachers who responded to this question (55%).

Further comments

Teachers were invited to provide any further comments about the FAMe™ System. Apart from one negative comment, i.e.

> *I felt that on the whole the FAMe system didn't provide any extra benefit to me when teaching autistic students. As a member of staff, I access the pupil IEP's regularly and I felt that the information provided by FAMe was simply a repetition of information is already readily available to teaching staff in school*

teachers' additional comments about the FAMe™ System concept and its use were positive. They reported that it had been useful, easy and quick to access, and had helped frame their lesson planning for autistic pupils. All suggestions for change/improvements to the system were about issues that had already been established as sub-optimum at the beginning of the project, but had to be accepted for logistical reasons, i.e. the necessary use of existing SIMS columns within the school register for the FAMe™ System trial. These issues have since been resolved in consultation with Capita (see p. 133). Examples of teachers' comments are provided in Appendix 18.

Section 6.

Post-FAMe™ SENDCO Survey

In addition to teachers, the SENDCOs of the three participating schools were also asked to complete an online post-FAMe™ survey. This focused on their overall impression of the FAMe™ System's efficacy, and the impact taking part in the project had had on them/within their school. They were first asked to indicate whether they agreed or disagreed with each of six statements and invited to explain their responses.

Table 21 shows the questions asked and the SENDCOs' responses to each. Where further written support for an answer was provided, this is included within the table. All three SENCDOs indicated that they had learned new information about their individual autistic pupils as a result of the FAMe™ Project and that this had informed/changed the support that was offered to these pupils in school. In addition, FAMe™ project information led to at least one outside agency referral in one school and a change in provision for two pupils, one to a specialist school and one from full-time education to twilight sessions only.

The three SENDCOs valued the contribution that information from the pupil self-report measures had on their understanding of pupils' needs, and all endorsed the continued collection of this information as part of the FAMe™ System package.

All three SENDCOs wished to continue to use the FAMe™ System in their schools

after the completion of the project.

Table 21.

SENDCO's responses to the post FAMe™ survey

Question	Number of SENDCOs giving this response	
	Yes	No
As a result of their participation in the FAMe™ project, I found out new information about FAMe™ pupils' support needs	3	0
SENDCO Site 2: *It is always useful for a pupil to have a 1:1 about their needs/ what will help, and this proved very useful for the pupils involved. We are always striving to improve pupil voice - this was a good help*		
Information gathered for the FAMe™ project informed the support I offered participants, and/or the support/provision arranged for them in school	3	0
SENDCO Site 2: *We put the info on our data base*		
Receiving additional information about autistic pupils' anxiety and depression scores was useful and should remain part of the FAMe™ package	3	0
SENDCO Site 2: *Absolutely. All background hopefully will help us to help our pupils*		
Information gathered for the FAMe™ project led to at least one pupil referral to an outside agency and/or professional for additional support	1	2
SENDCO Site 2: *Yes, and it has provided more information to be discussed with other agencies where referrals have already been made*		
Information gathered for the FAMe™ project led to a change in provision and/or placement for at least one pupil	1	2
SENDCO Site 2: *I am sure it improved the approach by staff* **SENDCO Site 3:** *One pupil has had a change in provision (now attending twilight sessions only)*		
If the functioning of the FAMe™ System becomes fully optimised in SIMs, I will be keen for our school to use it	3	0
SENDCO Site 2: *We just need the system sorted centrally and then it will be of immense benefit*		

SENDCOs were asked who they felt would be best placed to carry out FAMe™ pupil interviews if FAMe™ becomes available to other schools in the future. Two SENDCOs felt that they were the person within school best placed to do this in future (i.e. the school SENDCO should take on this role), and one SENDCO indicated they felt that this could be carried out by another member of school staff.

None of the SENDCOs thought an outside agency and/or other autism professional was needed to gather pupils' FAMe™ statement information, e.g.:

We have a corporate approach to this. It would be the person with the best relationship with the pupil from the Inclusion Team. We try to give pupils the choice of who - sometimes they even choose me!!

SENDCO Site 2.

Finally, SENDCOs were invited to provide any further comments about the FAMe™ System?

Their responses were:

- **SENDCO Site 1:** *Thank you for including us in project!*

- **SENDCO Site 2:** *Many thanks Julia. I am always wary of being involved in projects if they don`t seem to benefit our pupils. This will definitely do so.*

- **SENDCO Site 3:** *The benefits of being involved in this project have gone way beyond easier access to vital information.*

Section 7.

Pupils' experience of the FAMe™ interview process

During the post-FAMe™ interview, pupils were asked about their experiences of the pre-FAMe™ interviews, and pre-interview information. I was interested to understand whether there was anything I could have done differently to improve my research practice.

i.   Pre-FAMe™ interview and information pack

All 18 pupils made positive comments about their experience of the interview. No pupils reported that they had been upset, had needed anything they hadn't had access to, or any additional support from school staff, following our meeting.

Examples of pupils' references relating to the pre-FAMe™ interview and information pack include:

- **Qu:** In terms of how you felt after we met and talked...was there anything I could have done differently?
  Site 1, Pupil 03: *No, it was fine actually the way you did it there was nothing I could see wrong with what you were doing*

- **Site 2, Pupil 05:** *When I walked through here* [to come for post-FAMe™ interview] one of those times happened where, just for a brief moment, I liked myself
  Qu: Because you were coming to see me?
  Site 2, Pupil 05: *'Well...it was fun last time!*

- **Qu:** So, the things I said, the questions I asked, the things I brought with me...it was all OK?
  Site 1, Pupil 05: *Yes, it's all really good and helpful, especially because you're not really someone I know which is a good thing, because you don't really know much about me which is sort of good because I think the more people know about me already the less confident I feel telling them stuff so yes, I think it worked really well*

- **Qu:** … if we think about the way that I have done the project and the interview that I did with you last time...all the stuff I sent to you, having the video doing the interview, was there anything that made you uncomfortable or that you would have liked me to do differently?
  Site 1, Pupil 06: *No, it was fine*
  Qu: Was it helpful to have stuff upfront?
  Site 1, Pupil 06: *Yes...cos then like sometimes if you have a picture of someone in your mind and they are not how you expected then you get worried so...*

However, three pupils did make suggestions for future change they thought would improve the interview experience. These were:

- **Secret recording**

  Site 1, Pupil 02: *First of all, when you are recording the conversations, I think it would be nice if people didn't really know you were recording so maybe you could hide the iPhone [so he can forget it] that's better hidden from view, so I don't have to look at it*

- **Information about how long to expect the interview to take**

  Site 3, Pupil 04: *I was nearly late for a lesson and I left my bag and I didn't expect it to be that long*

- **More/better explanation of what was involved in the interview session**

  Site 1, Pupil 01: *I think that if someone else like had told me beforehand and explained what I was going to do and what was going to happen that would have helped…there was a link on the letter… but - I can't remember*

Qu: So, nothing that happened last time upset you, but if you had had it explained to you better beforehand you would have liked that...by someone in school?
Site 1, Pupil 01: *Yeah probably someone in school, yeah*

ii.   Pupils' thoughts about the FAMe™ Project (Coding Round 3)

In order to explore what pupils' thought about the FAMe™ project in general, and whether they would like the FAMe™ System to continue to be used in school when they returned in September for the new academic year, a third round of coding was performed. References made during the post-FAMe™ interview were coded to the following 3 nodes:

a) Pupils want FAMe™ System use to continue in school

Examples of references coded to this node:

- **Qu:** and if school are willing to, would you like them [FAMe™ Statements] to stay for next year?
  Site 3, Pupil 06: *Yeah definitely especially for new teachers*
- **Qu:** If school can carry on using this next year, would you like your new teachers to be able to see this information?
  Site 1, Pupil 03: *Yeah it would be really good if I come in to the first lesson with them if they read that, or if they read it before, before they actually meet me, that would be absolutely great*

- **Qu:** Would you like your new teachers to read this about you?
  Site 2, Pupil 03: *Mm* [yes] *will this happen next year?*
  Qu: Would you like it to? would you like this information still to be there on the register?
  Site 2, Pupil 03: *Yes*

- **Qu:** I don't know if the project is going to carry on, if school are going to leave the system running, but if they are do you want your information to stay on there?
  Site 3, Pupil 04: *Oh definitely*

b) Pupils thoughts about and experiences of taking part in the FAMe™ project – Positive

Examples of References coded to this node:

- **Qu:** Do you feel like the project has been worth taking part in?
  Site 3, Pupil 04: *Yes, definitely*

- **Qu:** And how do you feel about it [the FAMe™ Project] now?
  Site 1, Pupil 07: *I feel it's worked pretty well, they are like subtle changes that you don't really notice until you think about it*

- **Qu:** I'm quite astonished really at how much of a transformation I am seeing because everything about you seems so much better and it's difficult for me to know whether any of it is because of FAMe™, or whether it would have all happened anyway…
  Site 1, Pupil 05: *I don't think it would have all happened anyway*

- **Site 1, Pupil 05:** *I think it just made everyone more aware, even people who haven't read the facts have become more aware because a lot of people have asked where did I go on that day* [other pupils asking about the pre-FAMe™ interview] *what was I doing…and I explained why I was there and so a lot of people have become more aware and more considerate as well and a lot of my friends have been a lot nicer and things have just sorted themselves out*

- **Site 3, Pupil 04:** *In all honesty, I didn't think it would work this well*

- **Site 2, Pupil 05:** *If the FAMe™ project wasn't here then...I think I actually would have gone crazy*
  Qu: Wow, so you really think it's [FAMe™] protected you in some way?
  Yes, oh yes

- **Qu**: if the aim of my project was to make things better for you at school by telling your teachers information about you has it worked?
  Site 2, Pupil 04: *YES!* [shouts]

c) Pupils thoughts about and experiences of taking part in the FAMe™ project - Negative

Five pupils reported negative experiences related to taking part in the FAMe™ project. All but one of these pupils also made positive comments. Negative references tended to be related to individual teachers' use of the system, rather than the system itself, e.g. some teachers put the register on the interactive white board (despite having been instructed not to do so).

All references coded to this node:

- **Site 1, Pupil 06:** *Putting it* [the register] *on the board or something…usually if we have a supply teacher it's on the board*
- **Qu:** [Pupil has said some teachers don't look at FAMe™ Statements] So, if you were going to criticise the project, or the system, it's more about the fact that teachers don't use it than this not being a good idea?
  Site 3, Pupil 05: *Yes*

- **Site 3, Pupil 04:** *People started to think I've got like c3s [detentions] like every day* [because his name is highlighted in red on the register and this was also the 'on-report' indicator at his school, n.b. teachers were explicitly told that FAMe™ pupils were not on detention/report but sometimes other pupils saw the register and made comments about it]

- **Site 1, Pupil 03:** *Nothing negative has come out of it apart from that* [teacher put register on white board in front of whole class] *- it wasn't just one teacher that put it on the white board...it's not good*

- **Site 3, Pupil 03:** *Some of the teachers don't have access to the project - like the PE teachers - because the iPads don't have access to it*

  Qu: And would you like them to be able to see your statements?

  Site 3, Pupil 03: *Yes*

Round 3 Coding Findings

The percentage of the post-FAMe™ pupil sample (n=18) who made at least one reference that was coded to each node is shown in Table 22. The average number of references per pupil at each node is also shown, to indicate how many times pupils tended to make separate reference to each theme.

Table 22.

The percentage of pupils (n=18) with at least one reference coded to each node related to their thoughts about the FAMe™ System

Node	Percentage of pupils making at least one reference coded at this node (n=18)	Average number of references made per pupil on this theme
Want FAMe System use to continue next academic year	**100%** (n=18)	**2**
Positive thoughts about and experiences of taking part in the Fame™ Project	**83%** (n=15)	**3**
Negative thoughts about and experiences of taking part in the Fame™ Project	**28%** (n=5)	**1**

As can be seen from Table 22, all 18 pupils stated that they wanted their FAMe™ Statements to remain connected to the register, and for their teachers to

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continue to have access to them through the FAMe™ System. The majority (83%) specifically reported feeling positive about having taken part in the project and, on average, referred to this on 3 separate occasions. The 5 references made by 28% (n=5) of pupils to negative thoughts or experiences of the FAMe™ project are all provided in the examples given for Node C above. The implications of these findings will be discussed in the Discussion chapter which follows the summary of key findings.

Summary of Key Findings

The following section summarises the key findings from the two inter-related strands of the inquiry. First, findings from the analysis of the distribution of references, coded according to their association with autism diagnostic criteria definitions and descriptors (Coding Round 1a) and autism theories (Coding Round 1b), are presented. These evidenced the extent to which autism criteria and theory were able to provide explanation for pupils' general experiences of school and for the areas of difficulty they prioritised for additional teacher support and/or teacher practice change. This is followed by a summary of the findings obtained from analysis of the quantitative data, relating to pupil well-being scores, and how these indicated the occurrence of pre- to post- FAMe™ change. Finally, key findings relating to pupil and teacher impressions of the efficacy of the FAMe™ System, as a tool to effect change in pupils' educational experiences and outcomes, and teachers' confidence and ability to meet their autistic pupils' classroom support needs, are provided.

i. Diagnostic Criteria and Theory

- There existed a wide range of individual difference in factors underlying pupils' school behaviour and experience, of which only 33% were potentially related to the explicit/implicit features of autism taken from the DSM-5 (with a between-individual range of 8-56%)

- No internally attributed positive experiences of school were associated with explicit features of autism, evidencing the exclusive deficit-focus of the DSM-5

- Sixteen percent of all pupils' references to current school experiences were related to feelings of social or general anxiety evidencing its salience in this pupil population

- There existed a wide range of individual difference in the extent to which pupils' school related experiences could be explained by autism theory (with a between-individual range of 7-80%) with only 28% of all the references to school experiences described by participating pupils having a potential explanation that could be located in cognitive autism theory

- Of the five theories investigated, only Monotropism theory appeared to be universal across all participating autistic pupils. However, when applying Monotropism theory alone, as a means to understand the school experiences of the participating autistic pupils, the majority of the references made (79%) remained unexplained

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- More than half (58%) of all references relating to current experiences of school could not be coded to any diagnostic criteria or autism theory nodes, due, in part, to their weak ability to explain positive autistic experience and the presence of skills and strengths

- More than two thirds of the negative school experiences described that were not related to the diagnostic criteria, were attributed to the behaviour of other pupils (28%) or teachers (40%)

- 93% of pupils' FAMe™ Statements, in which they prioritised the most important areas to target for in-class support and/or teacher change, related to explicit or implicit features of autism

- The difficulties targeted for intervention in 61% of pupils' FAMe™ Statements could be explained by at least one of the autism theories still being investigated

ii.   Pupil Well-Being

- Almost half (45%) of the participating pupils had above average anxiety and half (50%) had above average depression levels pre-FAMe™, with scores in the extremely elevated range for anxiety and depression being recorded by 40% and 25% of pupils respectively

- Of all the references made by participating pupils which referred to their current experiences of school, two thirds related to there being a negative impact on the pupil

- When negative school experiences were linked to an explicit feature of autism, a higher percentage were externally than internally attributed, suggesting that the environment is an important factor in determining the impact of autism on autistic individuals

- A small minority (3%) of the references that were linked to the explicit features of autism (inherently negative) were related to externally attributed positive experiences, suggesting that it is possible for environmental factors to negate some of the difficulties associated with being autistic

- Pupils pre-FAMe™ anxiety and depression scores fell, and academic self-esteem scores rose, significantly ($p \leq 0.01$) over the course of the project. No pupil scored in the extremely elevated anxiety range post-FAMe™, this compared to 8 pupils pre-FAMe™

- The majority (79-81%) of pupils reported that they perceived an improvement in their in-class experiences (related to anxiety/interest in and ease of work) from pre- to post-FAMe™

iii. The FAMe™ System

(i) Pre-FAMe™

- All pupils were able to identify aspects of teachers' behaviour and practice which impacted on them either positively or negatively

- All pupils were able to provide FAMe™ Statements

(ii) Post-FAMe™

- All pupils wanted their school to continue to use the FAMe™ system following the completion of the project

- The majority (90%) of pupils felt their teachers' use of the FAMe™ System had impacted on their school experiences and general well-being in a positive way

- Almost half (47%) of pupils felt that teachers' use of the FAMe™ System had had a positive impact on their academic achievements ability to learn

- Two thirds of teachers (67%) reported that their teaching practice and/or the support offered to autistic pupils changed at least 'somewhat' as a result of the FAMe™ System

- Two thirds of teachers (67%) reported that their confidence in their ability to meet the needs of their autistic pupils increased as a result of using the FAMe™ System

- Two thirds of teachers reported at least some positive change in their autistic pupils' classroom behaviour and/or learning and academic outcomes as a result of their use of the FAMe™ System

- Almost all (95%) teachers reported that they would welcome an optimised version of the FAMe™ System for future use

Chapter Five: Discussion

Chapter Overview

In this Discussion chapter, the potential implications of both discrete and synthesised findings, from the different inter-related inquiries, are discussed, with specific reference to each of the four research questions. Feedback from pupils about the methodological process and my experience of this are considered, as are the limitations of this research and possible directions for future study.

The discussion is divided into subsections, reflecting the presentation of the earlier chapters. For ease of reading, unless specifically detailed to the contrary, all discussion of pupils' 'references' refers to those made during the pre-FAMe™ interviews, i.e. those that related to participating pupils' current school behaviours and experiences. Examples of pupils' transcript material is used throughout, both to illustrate the points made, and to ensure their voices are genuinely represented in this research discussion, which would not have been possible without their engagement and input.

Part 1 considers the implications the differences in coding distributions identified between individuals, and between gender and anxiety groups, in relation to diagnostic criteria and autism theory, might have for the understanding of autism and autistic experience and for the continued development of educational interventions. Autism theory overlap, and the claims made by the authors of the more recently developed theories (i.e. Baron-Cohen, 2009; Murray et al., 2005), that their

theories are positioned to extend or replace the three 'mainstream' cognitive theories (Rajendran and Mitchell, 2007), are also considered, in relation to the distribution of coding to each of the theories. Pupils' attribution of their positive and negative experiences of school to either internal or external factors and what these suggest about the impact of the environment on autistic experiences, and thus about the efficacy of the diagnostic criteria descriptors (which make no reference to these) to explain autism, are also discussed.

Based on the findings of this research, a new bio-psychosocial definition of autism is proposed. This definition utilises non-pejorative, non-medical language to construct autism as a distinct, qualitatively different (from the non-autistic) neurological type. It acknowledges autistic strengths as well as difficulties and reflects the impact of environmental factors on autistic functioning.

In Part 2, the coding of pupils' references to 'Other' nodes during Coding Round 1a, which identified teachers' behaviour/classroom practice as being the biggest single factor impacting on pupils' positive and negative experiences of school, is discussed. The focus is on these experiences and pupils' suggestions for teacher practice change that they felt would be beneficial to their psychological well-being and/or academic outcomes. In addition, the capacity of the diagnostic criteria definitions and descriptors, and the selected cognitive autism theories, to explain the specific areas of difficulty pupils prioritised for additional classroom support/teacher change (i.e. pupils' FAMe™ Statements), rather than their general school experiences, are discussed. Implications of these findings for teacher training, and

the benefits of engaging with individual pupils to ascertain their classroom support needs, are considered.

Part 3 focuses on pupils' perceptions of the teacher-practice change that occurred as a result of teachers' having access to their FAMe™ statements. Findings of the analyses of pupils' quantitative data, collected using repeated pre- and post-FAMe™ self-report measures, is discussed, in terms of the potential of the FAMe™ System to effect positive impact on pupils' educational outcomes and psychological well-being. Pupils' qualitative interview data is used to illustrate and validate points made.

In Part 4 the focus is on participating teachers and school SENDCOs. Teachers' levels of pre-FAMe™ autism training, their access to pupil-specific information, and their perceptions of their own ability to understand and meet the classroom support needs of their autistic pupils are discussed. Post-FAMe™ survey findings regarding teacher and SENDCO experiences of taking part in the project, and their perceptions of the efficacy of the FAMe™ System, as a tool to enable them to better understand and support their autistic pupils are considered, in relation to the future potential of the FAMe™ System to improve autism-related teaching practice. Suggestions for future teacher/school staff autism information/training are also provided.

The Discussion chapter finishes with Parts 5 and 6 which include a reflection on the methods and materials used to facilitate pupil participation and data collection.

It is suggested that these might be used to facilitate engagement with autistic pupils, both in school provision-planning consultation meetings and future research projects. The identified limitations of the FAMe™ Project findings are discussed, and I suggest the potential directions future study might take to develop this research further. These sections are followed by the thesis conclusion.

Part 1.

Diagnostic criteria and autism theory

Analysing pupils' interview transcripts, which had been coded according to whether they referred specifically to features associated with: the diagnostic criteria for and descriptors of autism; cognitive autism theory; autism literature; or none of these, demonstrated that there exists a wide range of individual difference in the internally and externally attributed factors underlying autistic pupils' school-related positive and negative experiences. This evidenced the heterogeneity of the autistic population (Attwood, 2008; Beardon, 2012; Fleury et al., 2014; Guldberg et al., 2011; Rosqvist, 2012; Sarrett, 2012) and supports previous claims (Parsons et al., 2011; Ravet, 2011) that practitioners and policy developers should view autistic pupils as individuals, rather than a homogenous group, when planning for and addressing their support needs in school.

i. The efficacy of the diagnostic criteria for autism as a means to understand the school experiences of autistic pupils: implications of the findings

Research Question One asked:

Are the explicit and implicit features of autism, specified in the diagnostic criteria of autism and autism literature, reflected in autistic pupils' descriptions of their lived experiences of school and, if so, to what extent?

It is important to note that this stage of the analysis was not intended to investigate the level of pupils' autistic *'symptoms',* i.e. *how* 'autistic' they are, a concept to which I do not subscribe. Rather, what was of interest was the salience of the explicit features of autism, outlined in the diagnostic criteria, to autistic pupils' experience of school, and thus whether knowledge of the diagnostic criteria can help explain or aid understanding of these experiences.

Exploration of the relationship between autistic pupils' school experiences and the explicit and implicit features of autism, defined in the most recently revised diagnostic criteria (explicit) (DSM-5, 2013) and its exemplars (implicit) (Carpenter, 2013), found that only one third of the total number of references pupils made were associated with these (explicit 24%; implicit 8%). Although all 21 pupils made some references in which the experience being discussed could be associated with one of the explicit features of autism (DSM-5), no specific feature was identified as having universal impact across the entire participant sample.

One explanation for the lack of evidence of explicit features of autism in the majority of pupils' descriptions of their school experiences might be that, overall, much of autistic pupils' experience is not specifically autism related, i.e. it is a reflection of pupil-life rather than of a particular neurological type. For example, many of the experiences described were passive, i.e. experienced as a result of the behaviour of others, and the autistic pupils' responses were either not atypical (anyone might be expected to experience this reaction regardless of their neurology), or at least was not evidenced to be so in their description. In addition, it is plausible that, as autism is neurological and only explicitly affects certain areas of functioning, descriptions of experiences that fall outside those areas, or do not require the specific application of the affected areas of cognition, will not necessarily evidence autism.

The following references are examples of pupils' descriptions of school experiences that were not considered to reflect autism:

they [other pupils] mainly do it when the teachers aren't around - the second the teacher steps out the room it's full on screaming and shouting.

(Site 1, Pupil 07)

the teacher actually shouts at the people to be quiet but they carry on so I don't know if there is anything they can do to help that – they'll carry on and do what they want really – they [teachers] *just keep shouting and shouting and no one stops and then they just end up sending people out and shouting and shouting and shouting at them and I'm writing and writing and writing and they are shouting and shouting at the person*

(Site 2, Pupil 03)

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a lot of people spread rumours around classrooms erm which is quite difficult to deal with when it's about me in particular

(Site 1, Pupil 05)

I used to not mind reading my work out - but everyone just randomly thinks that she [the teacher] *likes me so I don't put my hand up much anymore. Literally everyone - like I just have to pretend that I don't like the lesson cos everyone just says 'you're the favourite' when I'm not*

(Site 1, Pupil 06)

In terms of the references to school experiences that could be considered autism related, the explicit features of autism most frequently referred to, were insistence on sameness and adherence to routines (DSM-5, B2), and hyper/hypo-reactivity to sensory input (DSM-5, B4). DSM-5, B2 encompasses areas of difficulty associated with higher-level (executive) skills, e.g.: planning; organisation; making transitions; and following complex instructions, i.e. skills which are typically expected of pupils and likely inherent to achieving success in a mainstream secondary school. It was therefore not surprising to find difficulties in this area of functioning to be relatively well represented in autistic pupils' descriptions of their negative school experiences.

Several educational interventions/strategies currently exist which are specifically designed to support pupils who experience difficulties in these areas. These include: visual timetables (Mesibov and Howley, 2003); reorganising the furniture; labelling areas and equipment; providing a dedicated work area; and

teaching the children strategies with which to interpret and respond to demands as they arise (Jones, 2006).

During the pre-FAMe™ interviews participating pupils were shown photographs of visual timetables and mood-recognition boards (see Appendix 9), and we discussed their use of these, and other commonly used autism-related planning/learning aids, in school. It was stated by almost all of the pupils that, although these or similar tools had been available to them and used at primary school, none of them had been given access to or were using such strategies to support them in their current secondary school classrooms.

It is conceivable that secondary school staff are not aware of the executive functioning difficulties explicit to autism, or that it is assumed that pupils with such difficulties would bring any learning support aids with them on transition from junior school if they were still necessary. Perhaps by secondary age, pupils are generally expected (by school staff) to have developed compensatory skills, and/or to have outgrown the tools typically offered in infant and junior schools to overcome EF difficulties. Indeed, there is some evidence that that some of the EF difficulties observed in cognitively able autistic children do improve with age (Pellicano, 2010a). However, although the types of support tools designed to compensate for poor EF skills might seem less appropriate in secondary education, it was evident, both from the interviews, and the FAMe™ Statements made by pupils, that, for many, planning, organisation, following instructions and transitioning between tasks, *were* still areas of difficulty for them, and that (discrete) strategies designed to support them to

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overcome issues related to these would be welcomed. For example (from a pupil interview):

> *I need slow instructions – like if there's lots of instructions I just prefer to take it step by step…because there's like classes where they may say, "Do this and this and this…", and I'd like them to sort of explain it in slow steady progress of what to do instead of just like, "Do this this and this", and you have to do it. I'd rather it was like, "do this…" done it, "do this", done it – do you know what I mean?*

(Site 1, Pupil 03)

And from FAMe™ Statements:

- 'Please write my homework down for me / provide me with a homework sheet'
- 'Please check I have understood instructions before I begin a task'
- 'Please prepare me in advance for change'

Developing a range of secondary school age-appropriate strategies and tools, to better enable autistic pupils to plan, organise and complete tasks, would therefore appear to be a worthwhile endeavour and is an area where future research would likely benefit autistic pupils. Collaboration with pupils in such research, to ensure that the strategies developed accommodate their educational needs, both academically and in terms of their social anxieties about being singled out and teased for their differences, will be essential.

Sensory related difficulties (DSM-5, B4) were described by the highest number of pupils, had the widest range, and accounted for one quarter of all references coded to the explicit features of autism. This demonstrates the relative

significance of hyper- and hypo-reactivity to sensory input to autistic pupils' experience of school, and evidences that the re-inclusion of this feature of autism in the revised diagnostic criteria (DSM-5, 2013) was appropriate. Pupils felt that being able to leave the classroom when overwhelmed, specify a particular seat in a place they felt comfortable, and sit away from noisy others and/or close to like-minded hardworking peers, would help overcome some of the issues they experienced due to the sensory/physical environments of their classrooms. Such accommodations are relatively simple to put into practice, if teachers are aware of a pupil's individual requirements, and several pupils wrote FAMe™ Statements which included these requests.

Between-group and between-individual differences were found, both in the range of references relating to the criteria overall and the distribution of references to each specific criteria category. The most sizeable between gender-group difference related to social communication difficulties (DSM-5, Category A). Almost twice the percentage of the total number of references made by girls (14% of total references made to school experiences) than boys (8%) were associated with these factors.

Before assuming that girls necessarily have more difficulties with social communication than boys per se, it is important to consider the possibility that this between gender group difference might reflect the relative importance the different genders appeared to place on social relationships and friendships in general. For example, during interview, friendship difficulties, and the upset caused by these,

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were talked about at greater length and more frequently by the female pupils, and thus there were more references to social interactions overall.

Specific questions about friendships were not included in the interview schedule and male pupils tended to make only fleeting references to friends, such as that they liked to be put in groups with their friends/sit with them when working in class. Two of the female pupils (Site 1, Pupils 04 and 05), on the other hand, volunteered information about their social relationships with peers, which totalled over a quarter of the references they made overall, e.g.:

I have a few close friends, but I usually get into quite a few arguments with them because they are all telling me off for like copying them and things which I don't like

(Site 1, Pupil 04)

I always say to people I am a nice person and I wouldn't do this to myself - but obviously other people would - so a lot of people don't seem to like me and find me annoying if I try to explain why I'm annoying they get annoyed at me

(Site 1, Pupil 05)

Conversely, a higher percentage of references relating to DSM-5 Category B (i.e. restricted interests and repetitive behaviours) were made by male (16% of the total number of references they made about their school experiences) than female pupils (9%).

A similar proportion of both gender-groups' references were coded to the 'Criteria Implicit' node which related almost exclusively to social anxiety and shyness. Exploration of these references revealed that the majority described pupils' dislike of having attention drawn to them in class, rather than experiencing anxiety about social relationships in general, for example when teachers asked them to answer a question when they hadn't raised their hand to volunteer:

> *I've experienced it once or twice a few times before when I don't really want to speak in a way like in Maths and I find it a bit hard and I'm not entirely sure of an answer and I don't really want to be asked if I don't know an answer I feel a bit embarrassed if you know what I mean if I don't know the answer and another pupil might seem to think it's an easy question whereas I don't find it easy, so I prefer not for teachers to ask me, just for me to put my hand up if I know what I want to say*

> (Site 1, Pupil 03)

> *It's really stressful, cos like you never know if they* [teachers] *are going to ask you and then everyone will be laughing at you if you don't know*

> (Site 1, Pupil 06)

The small sample size, and thus the capacity of a single pupil's perseverance on a particular topic (e.g. friendship difficulties) to impact on group and whole sample percentage distribution of coding to individual nodes, means that caution must be exercised when drawing conclusions from these findings. However, it does appear that, in this sample population, discrete differences did exist in the explicit features of autism reflected in the school experiences of the gender groups, with girls being more affected and concerned by social factors and boys by non-social factors, such as having restricted interests and being resistant to change. This supports the

position of authors who suggest that autism manifests differently between the genders (e.g. Gould, 2017; Gould and Ashton-Smith, 2011; Halladay et al., 2015).

Overall, a slightly higher percentage of girls' references, than of those made by boys, were coded to the diagnostic criteria (DSM-5) nodes in combination. This does not reflect the claim that the criteria itself better supports the diagnosis of boys, as has been suggested (NAS, 2018b), although, if specifically asked about friendships/social issues, as would be likely during a diagnostic assessment, it is possible that boys would demonstrate equal levels of difficulty in that criteria area (DSM-5, Category A) to the girls, and thus would have made more criteria related references overall. Nevertheless, what the findings of this study do suggest is that there is potential benefit to the accuracy of the diagnostic process in reminding/making diagnosticians aware that a gender-specific prominence of certain autistic features might exist and that these should be considered when meeting individuals for assessment. Further exploration, of the way in which the explicit features of autism impact on the different gender groups, with a larger sample size would be a useful exercise in order to better understand the potential significance of these between gender-group findings.

Between anxiety-group differences existed in the number of references associated to the explicit features of autism, with a higher percentage of experiences described by pupils with above average anxiety levels being associated with the DSM-5 criteria nodes in general (i.e. 28% vs 20% of the total number of references made). The greatest between anxiety group differences were related to developing,

maintaining, and understanding relationships (DSM-5, A3), and insistence on sameness and adherence to routines (DSM-5, B2), with the more anxious pupils having a higher percentage of their references coded to these two explicit features of autism.

Although it is not possible to establish a causal relationship between anxiety and a greater tendency towards difficulties in these two areas of functioning, it seems reasonable to hypothesise the possibility of a bi-directional relationship, in which increased levels of anxiety contribute to relationship difficulties and a greater reliance on routine and vice-versa. For example, it is generally understood that elevated anxiety can result in increased attempts to, and reliance on being able to, control aspects of the environment (Neil, Olsson and Pellicano, 2016; Sinha et al., 2014), theorised by Beardon (2017a) to be an attempt to achieve and/or maintain the levels of global stability essential to positive well-being (Chown 2016). Conversely, pupils for whom dependence on routine, predictability and sameness is a salient feature of their autistic presentation, or who have difficulties with executive skills such as organisation and planning, are inherently pre-disposed to find the typically transition-filled, unpredictable nature of the secondary school environment challenging, thus potentially contributing to raised anxiety levels (Bolic-Baric et al., 2016; Charman et al., 2011; Keen et al., 2016; Osbourne and Reed, 2011; Ravet, 2011).

Pupils with higher than average levels of anxiety also made considerably fewer references to positive/neutral experiences (18%) which included references to personal strengths and skills and enjoyment of school, than those with average

anxiety levels (32%). Again, a greater sense of negativity and lack of recognition and/or discussion of personal strengths, could be a feature of being anxious/depressed (in all but one case the same pupils who had heightened anxiety levels also scored in the clinically significant range for depression), or it could be a contributing factor to pupils' heightened anxiety levels.

It was not possible to establish whether the above average anxiety group actually lack some of the strengths and skills that the pupils with average anxiety levels possess, or whether being anxious prevents pupils from engaging in activities that would enable them to use and recognise their underlying skills. This would be an area worthy of future investigation, especially as improving mental health outcomes for autistic children and young people is currently a priority area for reform (NAS, 2018c).

Regardless of the clinical anxiety group to which pupils belonged, the percentage of references made to feelings of worry, stress, and anxiety at school, both in relation to social anxiety (Criteria Implicit) and general anxiety (Literature Implicit) were very similar. These references accounted for 16% (average anxiety levels group) and 19% (above average anxiety levels group) of the total number of references each group made, demonstrating the salience of feelings of worry and stress across the participating autistic pupil population. Further investigation to establish whether certain internal or external protective factors exist, in the lives of individuals who maintain clinically insignificant levels of anxiety despite these experiences of stress/worry (i.e. those pupils in the average anxiety levels group),

will be an important area for future study. Exploring the descriptions of the positive experiences and skills provided by autistic individuals with average anxiety levels would likely be a good place to start.

It was found the one third of the references relating to social and general anxiety were externally attributed, i.e. the pupil felt that the cause of their feeling was attributable to someone (e.g. an angry teacher) or something (e.g. the environment of school) other than being a feature of themselves, e.g.:

> **School is the thing that makes me stressed** *I'm really calm when I'm at home like there's no problem when I'm at home but put me in a school environment and I hate it and I get like stressed*

> (Site 3, Pupil 08)

> *I think at the time I hadn't even done anything wrong. It was this one person who said something, and **our teacher got really angry because of this one person and whenever that happens I just get really panicked** thinking 'what did I do?'. I didn't do anything, and I get really stressed out thinking that I have done something when I haven't, and I feel like it's kind of my fault because I wasn't fully listening, or I was daydreaming at the time and I think, 'Oh no I've done something wrong', but...I know I haven't*

> (Site 1, Pupil 05)

Further examination of the attribution by pupils to internal and external factors, which impacted on both their positive/neutral and negative experiences of school provided some interesting insights. For instance, despite sensory sensitivities being an internal feature of the autistic profile (DSM-5, B4), sensory difficulties were

exclusively attributed by pupils to external/environmental factors, almost all of which had a negative impact. For example, the seven pupils who used a fiddle toy to aid concentration/reduce anxiety (sensory-seeking behaviour (internal) related to DSM-5, B4) did not consider this to be problematic in itself, however negative impact was felt when teachers removed/disallowed access to it in class (external).

The most frequently reported sensory difficulty, talked about by the highest number of pupils (n=12), related to the noise, heat, brightness, and business of the classrooms. This supports findings of previous research (Ashburner et al., 2008; Bogdashina, 2016; Murray et al., 2005) which has promoted the development of autism-friendly learning environments. Pupils in this study reported being frustrated because they found it hard to concentrate and described feelings of overwhelm and needing to escape, e.g.:

> *…just loudness in a way, I just want to concentrate on what I'm doing it might be the few people beside me who are messing about, and I also find that distracting as well when I am trying to learn*

<div align="right">(Site 1, Pupil 03)</div>

> *I am always concentrating unless it's really loud and then I have to sit there like that* [puts hands over ears] *because I can't concentrate, I get overwhelmed*

<div align="right">(Site 1, Pupil 04)</div>

Twelve pupils described teachers leaning over them to look at their work as intrusive and uncomfortable, and seven of these independently suggested that being allowed to hand their work to their teachers would be preferable, e.g.:

Teachers get really close, like not just when they are talking to you. I just don't like anybody in the immediate vicinity around me. I don't like big people hovering over me it makes me feel a bit uncomfortable

(Site 1, Pupil 09)

I don't like it when teachers are like leaning over me…
they could just ask me to come to the front and leave my book there

(Site 3, Pupil 05)

When pupils had been allowed to take steps to reduce the negative impact of the classroom environment, e.g. sit near an open window (Site 3, Pupil 02), or work in the learning centre (Site 3, Pupil 08), they felt the impact of this on them was positive. This suggests that it *is* possible to ameliorate the negative impact of sensory processing differences through environmental adaptation. However, as such a wide range of individual difference was demonstrated, in terms of which and to what extent pupils found aspects of the school environment stressful, engaging with pupils, to determine the most beneficial accommodations to meet their individual needs, will be essential to the success of the environmental/sensory adaptation provision-planning process.

Although overall there were twice as many references to negative experiences, than those having a positive/neutral impact on pupils, positive and neutral experiences accounted for a third of the total references made, two thirds of which were internally attributed (i.e. related to a pupil's own strengths and skills or to the specific absence of an autism related difficulty), e.g.:

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My favourite subject is Maths - I adore Maths - I am already like doing some A level Maths, I'm just like really god at it

(Site 2, Pupil 05)

I've never had trouble [working in groups] …*people I actually work with in groups are actually like me, they always try to participate in the group, so I never have trouble and I quite like working in pairs actually because it allows us to kind of join our ideas together to create something even better*

(Site 3, Pupil 04)

These references, to enjoyment of school and academic abilities, were unrelated to any of the explicit features of autism described in the diagnostic criteria as this focuses exclusively on *'deficits'* and *'significant impairment'* (DSM-5, 2013). Use of the DSM-5 definition alone, as a means to understand autism, is therefore likely to result in a lack of awareness, or recognition, of the existence of autistic skills and strengths, and missed opportunities to understand and thus potentially augment positive autistic experience.

Importantly, just over half of the references made which related to experiences that had a negative impact on pupils were attributed to external factors suggesting they would be amenable to environmental change/adjustments and, of these the majority were related to the behaviour/classroom practice of teachers and the behaviour of other pupils. Positive impact resulting from teachers' behaviour/practice was also demonstrated but to a much lesser extent. A thematic analysis of these references was carried out, to gain further insight into pupils'

perceptions of the positive and negative aspects of teaching practice, the findings of which are discussed in Part 2 of this chapter.

Interestingly, there existed more overlap between experiences associated with the explicit features of autism (criteria-related) and externally attributed locus of impact (than internally attributed factors), the vast majority of which were negative. This supports Beardon's claim, that 'Autism + Environment = Outcome' (2017a, p.11), in which it is proposed that it is not the explicit features of autism per se, but the interaction between these and external factors (the environment), that determines how and to what extent an autistic individual will be affected and/or is disadvantaged/or advantaged by being autistic. This is important in the context of education, where pupils are entitled to 'reasonable adjustments' (Equality Act, 2010; Children and Families Act, 2014). If successful, appropriate adjustments which concentrate on ensuring that the physical and sensory environment and teaching practice meet the specific needs of the pupil, should reduce the difficulties/disabilities associated with the interaction between an autistic pupil's neurology and the environment in which they are educated (Humphrey and Lewis, 2008; Lindsay, 2007; Mandy et al., 2016; Morewood and Glew, 2011). The facilitation of such personalised and appropriate educational adjustments was the main aim of the FAMe™ System.

That the extent of an individual's difficulties is affected by external factors, is not reflected in the diagnostic criteria medical model definition of autism (DSM-5). The findings of this project therefore supported the development of a more holistic definition, to better reflect autistic reality. When considering how to construct this

definition it was recognised that, as almost half of the criteria-related references to negative experiences made by pupils *were* attributed to internal features of themselves and/or their behaviours, the development of a new strictly social model definition (Oliver, 2004), which would inherently deny any individual/internal locus of disabling factors (Barnes, 2012; Mertens, 2010), would be inappropriate. Instead I took an interactionist view (Goodley, 2011; Bickenbach, 2011), and developed a definition rooted in bio-psychosocial model thinking (Shakespeare, 2014), to reflect what I already understood about autism (through: years of academic study; the writing of autistic authors; my own autistic children; and my personal insights as an autistic individual), and what I have learned and been able to evidence through my engagement with the autistic pupil involved in this project, i.e. that autism is associated with internally located skills (evidenced in pupils' interviews), as well as disabling factors (necessarily defined in the DSM-5 diagnostic criteria and also evidenced by pupils), the effects of which are impacted by external social/environmental circumstances.

The aim of this definition is to highlight, to those wanting to better understand autism, the complexity and heterogeneity of the autistic presentation and thus that there is more to being autistic than can be understood from knowledge of the current diagnostic criteria alone.

New bio-psychosocial definition of autism reflecting the findings of this research:

> *Autistic individuals share a neurological type, which is qualitatively different from that of non-autistics, and which will necessarily impact, both positively and negatively, on: aspects of their thinking and learning; sensory processing; social relational experiences; and communicative style, abilities, and preferences. An autistic person's experience of and ability to be successful in the world, will be dependent on the closeness of compatibility between their individual profile of skills and difficulties and their physical and social environment. Levels of sensitivity to environmental factors vary between individuals, and within the same individual over time, so that the presentation of autism is ever changing. A person's neurological type, however, remains constant, and being autistic is a lifelong identity.*

This definition has been well-received by colleagues and members of research groups to which I belong. Dr Beardon has adopted it in his teaching to students of autism (2017b) and Dr Chown has proposed that it be used by a collaborating group of independent researchers exploring autistic student support in University and college settings, and in an upcoming project investigating autistic well-being.

ii. **The efficacy of mainstream cognitive autism theory as a means to understand the school experiences of autistic pupils: implications of the findings**

The second research question, which asked:

To what extent can the school experiences of the autistic pupils participating in the FAMe™ Project be explained by cognitive autism theory?

was concerned with ascertaining whether understanding autism theory might aid non-autistic individuals to develop a better understanding of autism, and specifically of autistic school experiences, and/or might enable autistic individuals to better understand themselves (e.g. Chown and Beardon, 2017a; Chown, 2017). Discussion of the findings relating to this question are split into three sub-sections.

a. What the findings suggest about the potential value of the different autism theories as explanations of autism

Analysis of the coding of pupil transcripts found that potential explanation, in any of the autism theories being investigated, could only be identified for 28% of the total number of references made by pupils which related to their current experiences of school and that, as was the case for the diagnostic criteria, extensive between-pupil differences existed in the capacity of theory to explain their school experiences (range 7%-68%).

As discussed in relation to the diagnostic criteria (Coding Round 1a), during interview pupils made many references to experiences in which they were passive observers/recipients of the behaviour of others. Whilst their responses to these experiences might have had explanation in autism theory, when these responses were not explicitly discussed by pupils in interview they could not be coded. It was therefore hypothesised that the relatively low percentage of experiences associated with autism theory, which aims to explain the underlying neurological mechanisms behind autistic behaviours, might, in part, be reflective of this.

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In order to test this hypothesis, overlap between the references identified as being associated to explicit features of autism (i.e. those coded as criteria-related) and those coded to autism theory was explored in isolation. This analysis revealed that, although the percentage of references that could be coded to theory increased, even in synthesis current cognitive autism theory did not have the capacity to explain all of the explicit features of autism (as defined in the DSM-5 (2013)) evidenced in pupils' descriptions of their school experiences and almost half (48%) were left with no theoretical explanation. This finding supports both Rajendran and Mitchell's suggestion that, 'theoreticians may have to rein in any grand claims about accounts that seek to explain autism in its entirety' (2007, p.247) and Pellicano's (2010a) recommendation, that theorists should adopt a multiple-deficits model which views autism as the manifestation of several core underlying atypicalities.

What autism theory was able to do however, was provide explanation for some of the skills and strengths described by pupils and ignored by the deficit-focused diagnostic criteria. Examples included pupils' ability to concentrate on topics of interest (explained by Monotropism theory), and their enjoyment of subjects, such as Maths, which involve activities where there are formulae and definitive right or wrong answers (explained by the Systemising element of E-S theory). In combination then, it was found that explanation for almost half (46%) of all the references to school experiences described by the autistic pupils' in this study, could be located in either the current main cognitive autism theories and/or the most recently revised diagnostic criteria (DSM-5, 2013), with each offering some explanation that was not identified in the other.

b. What the findings suggest about the quality of the different autism theories in relation to Rajendran and Mitchell's (2007) criteria for 'good' autism theory

No explanation for pupils' school experiences using the theory of Weak Central Coherence could be identified. The possibility that this was due to my misunderstanding this particular theory was considered but rejected, on the grounds that neither Dr Beardon nor Dr Chown identified any missed examples of CC theory explanation during the validation of coding process.

It would thus appear that, for this sample of pupils, the theory of Weak Central Coherence could offer no explanation of the experiences of school they shared during interview. This supports the move made by Happé and Frith (2006) to reform/downgrade their original hypothesis, and the suggestion that weak central coherence should no longer be considered a theory that seeks to explain all aspects of autism (Chown, 2017; Rajendran and Mitchell, 2007). Instead central coherence should be regarded as an alternative information processing style (Chown, 2017; Happé and Frith, 2006), involving a bias towards detail but with the ability to extract overall meaning with effort (Happé and Frith, 2006), that is not universal to the autistic population (Chown, 2017). It might be useful for those seeking to understand autism, if the revised status of CC theory is made more explicit in future autism literature. Rather than continuing to describe it as a 'mainstream' autism theory (Rajendran and Mitchell, 2007), documenting its historical contribution to the

understanding of autism and to more recent theoretical developments would be more appropriate.

There existed considerable overlap between the remaining theories, with Monotropism theory providing explanation for two thirds of the references for which potential explanation was also identified in the other theories (of Executive (Dys)Functioning, Theory of Mind, and Weak Empathising-Strong Systemising) and for more than three quarters of the total number coded to autism theory overall (n=237). In addition, Monotropism theory accounted for at least a quarter of the references that were coded to theory for all 21 pupils (evidencing universality), and for almost three-quarters (between 70% and 100%) of all the references coded to theory for 81% of pupils, suggesting it was also close to achieving 'specificity' (Rajendran and Mitchell, 2007, p.224). Executive (Dys)Functioning theory came close to achieving 'universality' (ibid), being identified in the references made by 90% of the pupil sample and was found to provide potential explanation for more than half of the references coded to theory made by 12 pupils, with an overall range of 0-80%.

Empathising-Systemising theory provided explanation of more references to school experiences than did Theory of Mind theory, suggesting that the development by Baron-Cohen of E-S theory (2007), to subsume and extend his original ToM theory, has, as suggested (ibid), increased its capacity to explain autism. However, as E-S theory was only identified in the references to school experiences of nine of the pupils interviewed (43%), it remains a long way from meeting the 'universality' criteria (Rajendran and Mitchell, 2007, p.224). In addition, E-S theory provided potential

explanation for less than a quarter of all references coded to theory overall (which was 6% of the total number of references made), and so its potential to achieve 'specificity' (i.e. it's capacity to explain the full spectrum of autistic experience), which Baron-Cohen himself said was an essential feature of any 'good' autism theory (2008), was also not evidenced in this analysis.

When interpreting these findings, it should be recognised that the way E-S theory was coded to might have negatively impacted the percentage of references identified and coded to it. There were 30 additional references which could potentially have been explained by the systemising component of E-S theory, but which were excluded from the coded dataset at this node. This is because those pupils making these references demonstrated no evidence of empathy difficulties/described no experiences that could be explained by ToM theory at any point during their interview. I accept however that these pupils might have had difficulties relating to ToM that were not evidenced during our discussions.

To minimise any potential criticism, that my method of coding to E-S theory negatively impacted on the percentage of references coded to it, I reincluded the discounted references in order to report both sets of findings for comparison. When the additional excluded references were added into the analysis, the percentage of references coded to E-S theory rose to 25% of all references coded to autism theory as a compound node, and 8% of all references made. This demonstrated that, even when taking into account the total number of references to a pupils' tendency to systemise, regardless of evidence of any concurrent weakness in empathising skills,

the conclusion I had drawn, in relation to E-S theory's inability to claim uniqueness or specificity in relation to autism, was upheld. As neither ToM difficulties or a tendency towards systemising are unique to autism in isolation, i.e. Baron-Cohen's theory rests on the hypothesis that it is to co-occurrence of these two cognitive mechanisms which is unique to the autistic cognitive profile (2009a: 2009b), the reintroduction of the additional systemising-related references (made by pupils who did not demonstrate a weakness related to ToM) cannot be seen to improve the theory's value in relation to the 'uniqueness' criteria either.

Furthermore, whilst theory overlap did exist, between E-S theory and the other cognitive autism theories under investigation, only 38 (16%) of the 237 references coded to all theories could also be explained by E-S theory, whilst *all* references explained by E-S theory were found to have alternative theoretical explanations. Overlap between E-S and E-F theory only accounted for 5% of the total number of references which were associated with pupils' executive functioning skills, and which could be explained by EF theory. This suggests that the introduction of E-S theory has not impacted the status of E-F theory or, as Baron-Cohen claimed, rendered it superfluous. Baron-Cohen's assertion (2009a; 2009b), that E-S theory can explain all aspects of autism and is therefore positioned to make earlier cognitive theories redundant, was not justified by the findings of this project. In fact, the only one of the three 'mainstream' theories (Chown, 2017; Rajendran and Mitchell, 2007) apparently made redundant by E-S theory is Baron-Cohen's original theory of ToM. ToM theory is not discussed again during the interpretation of findings provided here.

In contrast to the findings relating to E-S theory, those relating to Monotropism theory were very different. More than three quarters of the total number of references coded to theory overall were coded to Monotropism. Furthermore, when pupils' references to school experiences that were associated with the social and non-social features of autism (i.e. DSM-5, Categories A and B) were examined separately, it was evident that Monotropism theory retained the same capacity to explain both categories (i.e. two thirds of the total number of references coded to DSM-5 categories A and B respectively). These findings further support my earlier assertion that Monotropism theory was the closest to achieving specificity, being able as it is to explain the highest proportion of references to criteria-related experiences overall, and those related to each criteria category to the same extent. It therefore appears, at least in relation to the pupils participating in this project, that Monotropism theory is better placed than E-S theory to assume the position of the new 'mainstream' autism theory.

Executive (Dys)Functioning theory also retained the same capacity to explain experiences across the spectrum of autistic difficulty, providing potential explanation for a third of the pupils' experiences associated with each diagnostic criteria category.

In combination, it was found that Monotropism and E-F theory could be used to explain 98% of the total number of pupils' references to their school experiences that were able to be coded to theory. It is possible, therefore, that a synthesis of these two autism theories might provide the most accurate theoretical explanation of autistic cognition currently available.

c. What the findings suggest about the potential of the different autism theories to aid understanding of the school experiences of particular groupings of autistic pupils

The coding distribution to 'Autism Theory', as a collective node, across the gender and anxiety groups was almost identical, with less than one third of the total units of coding made by all groups (range 29-31%), which was 52% of all references associated with explicit features of autism, being coded to an autism theory node.

However, between-gender and between-anxiety-group differences, in the particular theories which explained pupils' experiences, reflected those found when coding to the diagnostic criteria nodes, i.e. to the explicit features of autism. For example, male pupils had more of their references coded to EF theory than did girls. EF theory offers explanation for individuals experiencing difficulty when, for example: there is a lack of structure in the task given; they need to make a choice; they are trying to concentrate; they are processing information; or there is a need to transition between tasks. As boys were found to make more references that were associated with DSM-5 Category B2, i.e. 'insistence on sameness and inflexible adherence to routines', which captures difficulties with executive skills, it was not surprising to find a higher percentage of their references coded to EF theory than those made by girls.

Empathising-Systemising theory provided explanation for more than twice the percentage of references made by pupils with above average anxiety levels (29%) than of those with average anxiety levels (13%). This finding can be attributed to the

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relationship between the systemising component of E-S theory and the autism-explicit features of insistence on sameness (need for predictability), and the association between empathising (in terms of not being sure what other people are thinking/their intentions) and misunderstanding social relationships. These experiences were both more frequently identified in the references of the more anxious pupils (i.e. coded to DSM-5, A3 and B2) and included descriptions of difficulties with: unexpected change; unclear instructions/ explanations; or someone not doing what they say they will and/or breaking rules. Many of these experiences were also explained by EF theory (i.e. theory overlap occurred).

It is possible that Baron-Cohen's claims, that autism involves a specific cognitive style in which there is a dissociation between 'deficits' in empathising and an intact or even superior systemising drive (2009a; 2009b) is most applicable to a particular subset of autistic individuals, i.e. those who have clinically significant levels of anxiety. However, whilst Baron-Cohen positions systemising as an autistic strength, it appears that, when in an environment where systems cannot be relied upon, e.g. timetables change, or unpredictable events occur, a strong drive towards systemising can become a disadvantage. Again, this fits with Beardon's hypothesis that 'Autism + Environment = Outcome' (2017a, p.11).

The capacity of the diagnostic criteria and autism theory to explain the specific difficulties autistic pupils prioritised for intervention was significantly different to that reported here in relation to general school experiences. These are discussed in Part 2.

Part 2.

Teaching practice and pupils' suggestions for future change

The majority of pupils (90%) described at least one experience of school pre-FAMe™ in which teachers' classroom behaviour and/or practice had impacted negatively on them, and three quarters of the sample described an experience where the impact had been positive. All 21 pupils made reference to ways in which they would like their teachers to change in order to lessen the negative/increase the positive impact of their behaviour, with the above average anxiety group providing the most suggestions (11.4 per pupil on average) about how they would like their teachers to change their behaviour/classroom practice.

Exploring these references to teaching practice provided valuable insight, not only into the ways in which autistic pupils' school experiences are affected by their teachers, but also into their ability to identify and clearly express their support needs, which is not always recognised (Goode, 2007; Humphrey and Lewis, 2008; Mortier et al., 2011; Pivik et al., 2002; Sciutto et al., 2012). The wide variety of factors which were identified by pupils, as having both positive and negative impact on their school experiences, demonstrates the value of engaging with and listening to individual pupils rather than making assumptions based on their diagnostic label alone. Findings from this stage of the analysis provided answers to Research Question 3a:

What can be learned about autistic pupils' school support needs from their descriptions of their school experiences?

Coding evidenced that themes existed, around which pupils' references to the classroom behaviours of teachers that impacted on them either positively or negatively were clustered. In many cases, unsurprisingly, positive or negative impact depended on a teacher doing or not doing something related to the same theme. Themes related to teachers: drawing unwanted attention to pupils in front of their peers (negative); the quality/clarity and speed of the presentation of instructions, including those provided for homework tasks (positive or negative); discipline policies which were inconsistent between teachers or seemed illogical/unfair (negative), or fair discipline policies (positive); understanding/attending to or ignoring pupils' support needs, including allowing/not allowing them access to self-calming/concentration aids like fiddle toys (positive or negative); keeping or not keeping the classroom quiet and other pupils' behaviour under control (positive or negative); and organising group work (positive) rather than expecting pupils to find their own group of peers to work with (negative). What was interesting about this last point is that, although several of the pupils in this study reported not liking group work, it was not for the reasons that might be expected.

Based on my own experience, and reports in autism literature (e.g. Rose and Howley, 2003), I had assumed that dislike of group work would be associated with communication and/or relationship difficulties, and that pupils would request not being required to work in groups at all, i.e. to be allowed to work by themselves. However, although this was the case for some (depending on the task), more pupils described how the difficulties they experienced with group work were actually associated with the act of getting into a group in the first place. Their anxiety about

approaching others and fear of rejection appeared to be more of an issue than actually working with others. In fact, several pupils recognised the mutually beneficial aspects of sharing ideas and collaborating with their peers, albeit with the caveat that the peers be like-minded individuals, or friends, who didn't just mess about or not contribute to the group's efforts, e.g.:

Well if we are put into groups I don't mind, but if we have to pick our groups I absolutely hate that

(Site 1, Pupil 03)

I'd rather be put in groups rather than having to choose my own

(Site 3, Pupil 05)

I don't really like working in groups it's a bit nerve-wracking like trying to find trying to put [myself] into groups – I like being put into groups automatically but I don't like choosing my own group because I don't really know who to go for

(Site 1, Pupil 02)

I prefer working in groups than independently. I prefer it when teachers put me in groups though because I know then already who I'm working with rather than me choosing who I am working with, I don't like doing that

(Site 3, Pupil 01)

I never had trouble working in groups when people I actually work with in group are actually like me and they try to participate in the group then I never have trouble and I quite like working in pairs actually because it allows us to kind of join our ideas together to create something even better

(Site 3, Pupil 05)

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I don't like working in groups unless I am put with people I can actually work with then that is perfectly fine [happy to engage in group work]

(Site 3, Pupil 06)

When references to desired future change to teachers' behaviour/practice were analysed, eight pupils advocated for their teachers organising group work in class and only two pupils requested that they should be allowed to opt out and work independently instead.

This evidences the benefit of exploring, with individual pupils, the underlying factors behind the difficulties they express. It would be all too easy to assume, based on a theoretical or criteria-based knowledge of autism, that a pupil's dislike of group work was related to difficulties with social interaction and communication per se. Understanding that, for some pupils it is the act of initiating contact and making a choice that presents a difficulty, could enable teachers to adjust their practice in this area and make a positive difference to these autistic pupils' experience of group work, which is an essential element of many secondary school lessons (National Curriculum, KS3/4, DfES, 2013).

The majority of the references to desired future change that pupils said they would like teachers to make to their behaviour/classroom practice, reflected the themes outlined above relating to positive and negative impact. Additional themes not previously identified, around which 'desired change' references were clustered, included: checking pupils' understanding of tasks once instructions have been given;

avoiding seating plan issues/allowing pupils to sit in their preferred place; enabling pupils to leave the classroom if necessary, or to move away from distracting peers; providing advanced preparation for any changes to planned activities/teacher absence; not invading pupils' personal space/not leaning over them; and not writing corrections directly onto pupils' work.

The discussion during interview, of the changes pupils would like teachers to make to improve their classroom experiences, typically informed and/or coincided with the writing of pupils' FAMe™ Statements, i.e. the three key pieces of information pupils most wanted their teachers to know about them which were to be made available through the new FAMe™ System. This process required pupils to prioritise the issues that they felt most impacted on their classroom experiences, including for example, their anxiety levels, ability to learn/processing style and sensory processing difficulties, and select the three that they felt it would be most helpful for teachers to know and attend to, and provided the answer to Research Question 3b:

Are autistic pupils able to identify and communicate positive and/or negative classroom experiences and, if so, how can these be used to inform teaching practice?

Again, many of the 66 statements produced clustered around the themes already identified. However, there were some new themes, such as requests to use unambiguous language and avoid sarcasm, and 12 unique statements, demonstrating once more the importance of engaging with individual pupils. It was interesting that some of the issues, such as wanting to sit in a particular place, which

was mentioned by almost half of the pupils when talking about desired change, was only chosen as a FAMe™ statement by three pupils. This evidences how seriously pupils took the process of priortising their needs. It was clear during the interviews, and from the statements produced, that pupils were keen to ensure they identified the things that they felt would make the *most* positive difference to them on a day-to-day basis.

The most frequent theme amongst the FAMe™ Statements was a request for teachers to stop drawing attention to pupils in class, including: not asking them to show their work (even if it was as an example of excellence); not asking them to answer a question if they had not put their hand up; and not commenting on their mood. This is not to say that pupils wanted to be ignored. There were many examples in the FAMe™ Statements of desired interactions between pupils and teachers, such as for teachers to: provide additional instruction; check pupils' understanding of tasks; and check whether they were feeling anxious and offer reassurance/support, but pupils wanted their teachers to approach them individually, rather than making them the centre of attention by speaking to them in front of others.

When the coding strategies for diagnostic criteria related nodes (i.e. explicit and implicit features of autism) and autism theory (Appendix 1, parts A and E) were applied to the pupils' FAMe™ Statements, the analysis produced some interesting findings. Unlike when pupils had been discussing their school experiences in general (during their pre-FAMe™ interviews), where the majority of their experiences did not appear to be associated with explicit features of autism (DSM-5) and could not be

explained by autism theory, findings of the FAMe™ statement analysis was very different. Ninety-three percent of the FAMe™ Statements referred to difficulties that were associated with an explicit (71%) or implicit (i.e. social anxiety/shyness, 22%) feature of autism, and potential explanation for 61% could be located in at least one of the cognitive autism theories being investigated. In other words, when pupils were specifically selecting areas of difficulty experienced in school to target for intervention, i.e. where they felt a change in teacher behaviour/practice would be beneficial to them, these tended to be explicitly related to their autistic neurology.

Following the trend highlighted through the coding of the interview data, female pupils, more frequently than males, requested teacher change that would address difficulties related to social interactions, specifically social-emotional reciprocity (DSM-5, A1). For example, a higher percentage (23%) of female pupils' FAMe™ Statements involved asking teachers for support with getting into groups, or alerting teachers to the fact that they found initiating interactions more difficult, than did those of the male pupils (17%). The girls also more frequently than the boys prioritised factors relating to feelings of social anxiety (criteria implicit) such as: *'…do not ask me anything in front of my peers'*; *'Please don't draw ANY attention to me – good or bad'*; and, '*Please only ask me to speak in front of the class if I put my hand up*', with over a quarter of girls' FAMe™ Statements being related to this issue. Male pupils on the other hand prioritised sensory issues more frequently (27% of their FAMe™ Statements) than did the girls (11%). These findings suggest that it would benefit teachers to be aware of and expect between-gender-group differences when considering/planning how to meet the needs of the autistic pupils in their classrooms.

Unsurprisingly, pupils with above average levels of anxiety pre-FAMe™ had a higher percentage of FAMe™ Statements aimed at general anxiety reduction (Literature Implicit) than did pupils with average anxiety levels. The above average anxiety group also prioritised issues associated with resistance to change/adherence to routine and executive skills (DSM-5, B2) more frequently (a third of their FAMe™ Statements were related to reducing/addressing difficulties in this area) than did the less anxious pupils. However, despite between-group differences in frequency, this explicit feature of autism remained the most frequently prioritised issue to be targeted for intervention across all groups (31%). This evidences the significance of the negative impact difficulties with executive functioning skills, transitioning between tasks, reliance on rules and routines, and an insistence on sameness, have on autistic pupils' classroom experiences, and therefore, as previously discussed, that introducing strategies which can help overcome these difficulties in secondary mainstream classrooms might benefit a significant proportion of the autistic pupil population.

As the explicit feaures of autism were so strongly associated with the specific difficulties/areas pupils prioritised for teacher change, it is unsurprising that the explanatory potential of the cognitive autism theories, developed in order to explain the underlying mechanisms of these explicit features and already shown here to be related to the diagnostic criteria, also increased significantly when applied to pupils' FAMe™ Statements (61%) rather than to their school experiences in general (29%). The lack of capacity for any autism theory to explain anxiety however, limited their value somewhat, as over a quarter of the FAMe™ Statements written were requests

for teacher behaviour change aimed at reducing pupils' stress/anxiety levels in the classroom.

The high level of theory overlap remained, particularly between Monotropism and Executive (Dys)Functioning theory. However, whilst these two theories had shown a relatively high capacity to explain school experiences in general (77% and 57% of all coding to theory respectively), these percentages fell to 48% and 43% when these theories were applied to the specific issues/difficulties targeted for change, i.e. those selected for inclusion in pupils' FAMe™ Statements. The most noticeable difference in the representation of autism theories coded to FAMe™ Statements, rather than to school experiences in general, was seen for Empathising-Systemising theory which offered explanation for 53% of these, the highest proportion achieved by any theory This was a reflection of the 18% of FAMe™ Statements in which pupils specifically requested support that targeted difficulties with social interactions/interpretting other's behaviour/intentions, i.e. to difficulties that were associated with weak ToM. This difference in the explanatory potential of autism theory provides evidence that, whilst Monotropism theory is able to capture and explain a wider range of experience evidencing how it is to be autistic, E-S theory, like the diagnostic criteria itself, is more closely associated with autistic difficulties.

That the autistic pupils' FAMe™ Statements, i.e. what pupils most wanted teachers to know about them, and thus adjust their practice to accommodate, were so closely related to the explicit features of autism, suggests that teachers were not

(pre-FAMe™) meeting their autistic pupils' autism specific classroom/learning needs effectively. In this specific area, it appears that information about autism that can be understood from the diagnostic criteria (DSM-5, 2013), its exemplars, and autism theory (in particular E-S theory) could enable teachers to better understand the areas of likely difficulty and support needs of their autistic pupils. However, the variability, between individuals and between the gender and anxiety groups, in terms of the specific priorities for targeted in-class support, means that, as no teaching practices/teacher behaviours can meet *all* the needs of *all* the pupils, engaging with individual autistic pupils, to establish how their being autistic impacts their experiences of the classroom environment and learning, is essential.

Part 3.

Pupil Well-Being and the Impact of FAMe™

This part of the Discussion chapter addresses Research Question 4, i.e.:

When information about individual autistic pupils is made easily accessible to their teachers:

a. *In what way does teachers' behaviour and/or practice towards individual autistic pupils change?*

b. *What impact is there on autistic pupils' educational experiences and quality of life (QoL) related outcomes?*

i. Pupil well-being pre-FAMe™

Of all the references, made by participating pupils during their pre-FAMe™ interviews which referred to their current experiences of school, two thirds related to negative experiences/negative impact on the pupil. This supports existing literature which suggests that school is difficult for autistic young people (Fleury et al., 2014; Howlin and Moss, 2012; Keen et al., 2016; Levy and Perry, 2011). Participating pupils' pre-FAMe™ self-report measure scores demonstrated that almost half had above average anxiety (45%) and half had above average depression levels (50%). Scores were in the clinically significant 'extremely elevated' range for anxiety and depression (suggesting further assessment or intervention might be required (Beck et al., 2005)) for 40% and 25% of pupils respectively. In addition to pupils' self-reported anxiety levels measured using the BYI-A (Beck, 2005), analysis of pupils' responses to the 'How I feel at School Questionnaire', which was developed specifically for this project, indicated that the majority (80%) had felt at least 'a bit' anxious in class in the week prior to interview, with 15% reporting that they had felt 'very' anxious in the classroom.

These findings reflect those of previous research, which reports that anxiety is a common co-occurring issue for autistic young people (Ashburner et al., 2010; Bolic Baric et al., 2016; Charman et al., 2011; Keen et al., 2016; Osbourne and Reed, 2011; Ravet, 2011) and occurs in this population to a greater extent than is seen in the non-autistic one, where prevalence rates of anxiety are thought to be around 10% (NAS, 2010; Ashburner et al., 2010).

Interestingly, only one pupil demonstrated a level of academic self-esteem that was below average, and almost one third of the pupil sample had scores putting them in the above average category (as measured by the Myself as a Learner Scale, Burden, 1998). In addition, recognition of personal skills, strengths and abilities were evidenced in the qualitative interview data. Together these findings suggest that the high levels of general (as measured by the BYI-II) and in-class anxiety (reported on the 'How I feel at school' questionnaire), experienced by this group of pupils, were not related to concerns about their academic capabilities. What pupils did report were examples of feeling 'embarrassed' and anxious in class about what others think of them (8% of the total references made were related to shyness and social anxiety), e.g.:

> *I've experienced it once or twice a few times before when I don't really want to speak in a way like in Maths and I find it a bit hard and I'm not entirely sure of an answer and I don't really want to be asked if I don't know an answer I feel a bit embarrassed if you know what I mean if I don't know the answer and another pupil might seem to think it's an easy question whereas I don't find it easy so I prefer not for teachers to ask me, just for me to put my hand up if I know what I want to say*

<div align="right">(Site 1, Pupil 03)</div>

> *I don't like speaking out in class*
> **Qu:** Is there a reason for that?
> *It just makes me feel awkward and more self-conscious*

<div align="right">(Site 1, Pupil 07)</div>

> *This* [speaking out in class] *is one of the most negative things for me in school...I don't like the attention where like they are silently judging me or...something like that*
> **Qu:** And who do you think is silently judging you sometimes?
> *Well...sometimes when I get something wrong or if I act stupid for a few short seconds...I imagine..the first thing I imagine is that people*

<div align="center">380</div>

will look in my direction and just think...'Why???' Although I normally look around and nobody's looking at me, but it doesn't stop me from thinking that those people are judging me for what I do

(Site 2, Pupil 05)

Pupils also made the same number of references during interview (i.e. 8%) that related to feelings of general anxiety and worry in class, many of which were associated with their not having understood task instructions, e.g.:

Because I might get very worried on this question and don't know what to do and panicky as well – I get quite panicky about some questions if I don't know what to do

(Site 1, Pupil 03)

and getting worried about or during tests, e.g.:

I've done Ok but I tend to make a lot of silly errors maybe because I'm a bit panicky maybe and I tend to think, 'I've been really stupid there', I look at the tests afterwards and I realise, 'Why have I done that?' It's just annoying

(Site 1, Pupil 04)

Qu: So what sort of things make you stressed?
Erm being overwhelmed with work...too much pressure...that kind of thing...I don't really work well under limited time like in tests

(Site 1, Pupil 07)

It's like in the Maths test I really didn't understand it but the thing that made me angry and stressed about it the most was that I couldn't talk to the teacher about it

(Site 3, Pupil 05)

These causes of pupils' in-class anxiety were reflected in their references to 'desired future change' and in their FAMe™ Statements (reported in Part 2), the writing of which demonstrated that pupils possessed insight into both what made them feel stressed and what they thought teachers could do differently to relieve/remove some of the causes of their school-related anxieties.

ii.   Pupil well-being post-FAMe™

Following one term during which teachers had had access to pupils' FAMe™ Statements through their class registers, 18 pupils took part in a post-FAMe™ interview, during which the same self-report measures, as were used pre-FAMe™, were re-administered and completed. Comparative analysis of whole-group mean scores showed a statistically significant drop in anxiety and depression scores coupled with a rise in academic self-esteem levels (pre- to post-FAMe™ change in scores on all three repeated measures was significant at $p \leq 0.01$). These findings suggested that participating in the FAMe™ Project had had a positive impact on pupils' psychological well-being.

At an individual level, all 18 pupils' anxiety scores fell, indicating a reduction in symptom severity, and all but three pupils reported reduced levels of depression post-FAMe™. Of the seven pupils who had reported anxiety levels in the 'extremely elevated' range pre-FAMe™, two had post-FAMe™ scores that dropped through three classification cut-off boundaries into the average range (i.e. by at least 15 points), and all seven moved through at least one cut-off boundary in a positive

direction (e.g. from extremely to moderately, or from moderately to mildly elevated, or from mildly elevated to average). Five of the eight pupils who had pre-FAMe™ depression levels in the above average range reported a decrease in symptomology which placed them in the average depression range post-FAMe™. Eleven pupils' academic self-esteem scores increased over the course of the project. No pupil's score on any of the 3 self-report measures crossed a cut-off boundary in a negative direction from pre-to post-FAMe™.

In addition to the positive change evidenced through pupils' scores on the validated measures of well-being, the percentage of pupils reporting that they had not experienced any feelings of anxiety in class, during the week prior to interview, rose from 22% pre-FAMe™ to 67% post-FAMe, with no pupil reporting feeling very anxious in class post-FAMe™, compared with 11% pre-FAMe™. Similar improvements were seen in pupils' self-reported interest in and ability to do their classwork over the course of the project, with those reporting being 'very' interested increasing from 6% to 44%, and the percentage of those finding their classwork 'very' easy rising from 22% to 56%.

Without being aware of their pre- or post-FAMe™ self-report scores, the majority of pupils (83-89%) reported that they perceived an improvement in their in-class experiences (related to feelings of anxiety/stress, and their interest in and the ease of the work set) since the project began. No pupil reported perceptions of negative change from pre- to post-FAMe™ for any of the issues being explored.

These findings, relating to decreased in-class feelings of anxiety/stress, and improved interest in and ease of classwork from pre- to post-FAMe™, suggest that something had changed for pupils, within the classroom, over the course of the project. The following section considers whether pupils attributed this change to teachers' FAMe™ System use and a subsequent change in teaching practice.

iii. Pupils' perceptions of teacher change and the impact of FAMe™

In order to gain insight into the possible mechanisms behind these improved levels of pupil well-being, pupils' post-FAMe™ interviews, which focused on their school experiences in general since the implementation of the FAMe™ System and specifically on their perceptions of teacher change and the difference they felt this had made, were analysed.

All of the 18 pupils who remained in the project reported, during interview, that they believed their teachers had changed their classroom behaviour/practice in line with their individual FAMe™ Statements. Almost half of the pupils also reported occasions where individual teachers had not accommodated their needs in line with FAMe™, but the references made to this were less frequent (2 per pupil on average) than those made about positive teacher change (7 per pupil).

The majority of pupils (83%) described experiences related to improved positive well-being, e.g. *"I feel less stressed"*, and "*For me it's made school a lot nicer, I've been bored a lot less, I've actually enjoyed some of my lessons that I didn't like*

before", which they attributed to their teachers' changed practice, e.g. *"They have genuinely tried like not made me do stuff I don't want to do, that kind of thing...so I've been allowed to decide...put my hand up if I want to talk, that kind of thing",* and half of the pupils attributed an increased ability to learn, and/or higher levels of academic achievement, to teachers' use of FAMe™, e.g. *"It means I can work at the same pace as everybody else cos sometimes I'd get left behind and I'd be asking... "What question is this?" and they'd be, "We did this five minutes ago" ...and that's not happening so much now",* and*, "In my maths test I got the highest scores in maths…that's very unusual for me. I never normally finish tests before the end of the lesson, but I finished nearly first and spent the rest of the lesson drawing. It was awesome. I came top so that was cool".*

All 18 pupils advocated for the continuation of the FAMe™ System in their schools following completion of the project, and intimated that they thought it would be particularly beneficial for their new teachers as they moved into the next academic year group. Whilst it is not possible to conclusively evidence that it was teachers' use of pupils' FAMe™ Statements that effected the positive psychological and experiential change described by the pupils who took part in this project, further investigation of the FAMe™ System with a larger pupil sample is certainly warranted by these findings.

Other factors that might have had a positive impact on pupils' outcomes during their engagement with the FAMe™ Project

Bishton and Lindsay (2011) state that 'the act of asking the child their opinion is of less importance than the results of having that opinion heard' (p.171), and suggest that, if children are asked for their opinions, in order for positive impact to follow, they need to see the change that comes about as a result. That the teachers in this study engaged with the project and were perceived to change their practice in line with pupils' individually communicated support needs, means that the pupils witnessed first-hand the results of having their opinions heard, e.g. *"I had hopes for it* [FAMe] *but in all honesty I didn't think it would work this well"*. It is possible that this played a part in the overall positive impact of FAMe™.

Another factor possibly contributing to pupils' improved post-FAMe™ well-being was that, because details of the nine pupils whose self-reported anxiety and depression levels placed them in the 'extremely elevated' range pre-FAMe™ were communicated to the school SENDCOs (with pupils' knowledge/consent), these pupils might have subsequently been targeted for additional support in school that I was not made aware of. Changes I was informed of related to the placement/provision offered to two of these pupils which was adjusted, causing them to be withdrawn from the project, i.e. one moved school and one began attending twilight sessions only (n.b. pre-FAMe™ data from these pupils was not included in the analysis of pre- to post-FAMe™ change). One other pupil, who chose to remain in the project, disclosed suicidal ideation during his pre-FAMe™ interview, and was consequently referred to Child and Adolescent Mental Health Services (CAMHS) for

therapeutic support (although he was still on the waiting list at the time of the post-FAMe™ interview). This pupil attributed his improved emotional well-being to FAMe™, *"If the FAMe™ project wasn't here then...I think I actually would have gone crazy"*, Qu: "Wow, so you really think FAMe™ has protected you in some way?", *"Yes, oh yes".* However, it is likely that a combination of factors impacted on the lessening of his psychological distress, including a change in his home circumstances/living arrangements.

One unexpected finding, reported by three pupils during their post-FAMe™ interviews, was a change in their relationship with their parents. Pupils' FAMe™ Statements were sent home, via parental email, for pupils to make revisions/amendments before they were entered into the schools' register systems. Some parents took the opportunity to discuss their children's statements with them and heard, sometimes for the first time according to the pupils, about the issues underlying some of their children's difficulties at school. This resulted in parental interventions such as: creating homework planners and supporting with organisation of work to meet deadlines; setting up a meeting with school to discuss bullying issues; reminding teachers at parents' evening that there was information available about their child that they wanted them to know; and checking in regularly with their child about whether things were getting any better. All three of these pupils said they felt positive about this.

Part 4.

Teachers' and SENDCOs' experience
of the FAMe™ System and Project

i. Pre-FAMe™ experience of teaching autistic pupils and perceptions of the FAMe™ System concept

The majority of the 53 teachers completing the pre-FAMe™ teacher survey indicated that any specific autism training received had totalled fewer than two hours. This was despite the fact that over three quarters of those taking part had been qualified for over five years. In this respect, participating teachers' level of autism training reflected that described in previous autism education literature (Emam and Farrell, 2009; Witmer and Ferreri, 2014; Sprotson et al., 2017), in which it has been described as 'lacking' (NAS, 2016a). Qualitative responses evidenced between-teacher differences in training and experience ranging from, *'One hour, about 10 years ago, by a parent who came in after school to staff training'*, to, '*Many sessions, including working in a school for two years with an autistic unit'*.

With such a generally low level of autism-related training, it is not surprising that more teachers reported that they 'did not feel at all confident' than were 'confident' in their ability to meet the classroom support needs of their autistic pupils. Written comments identified a variety of barriers, perceived by teachers to negatively affect their ability to meet their autistic learners' needs, which included class size, time limitations and the heterogeneity of the autistic population.

Almost all teachers indicated that they knew which of their pupils were autistic and had received information about individual pupils' support needs. However, one third of teachers either did not know how to access this again after the first reading, or said that it was difficult to access, e.g. '*You have to load a webpage, click through some options, find the document, search for the pupil's name. It's a convoluted process'.* A minority (20%) of teachers accessed pupil-specific information more often than once a half term. However, a third stated that they did not access it again after the first reading or, if they did, only once at most during an academic year. It is possible that teachers' reliance on memory/lack of re-visiting pupil-specific information could have been negatively affecting the appropriateness of their pre-FAMe™ teaching strategies for individual autistic pupils. It appeared, from teachers' responses, that the lack of conciseness of the information available to them, and its (in)accessibility, played a part in the frequency with which it was read, as around three quarters of teachers stated that they would re-visit pupil information more often if these issues were improved.

The quality of the individualised pupil information available to teachers was also commented on by some, who felt they were in need of specific advice rather than generic information. For example, one teacher wrote, '*Sentences such as, "Use of techniques to aid ASD would help". What are these techniques? Is there a list somewhere? Is there a good website that will give me ideas? The training I have received hasn't given any practical advice on how to effectively support pupils with ASD'.* This reflects the difficulties, previously reported in autism education literature,

that teachers face when expected to intuit a pupil's needs from the wide array of subtle difficulties known to be experienced by individual autistic pupils (Leatherland and Beardon, 2016; Ravet, 2011; Singh and Elsabbagh, 2014), and thus to understand how to meet their classroom support needs without the information they need to do so (Emam and Farrell, 2009; Witmer and Ferreri, 2014; Sprotson et al., 2017). These difficulties were precisely what the FAMe™ System was designed to overcome.

The FAMe™ System concept was received favourably by the majority of teachers, with all but one indicating that they believed having easy access to pupil-specific information would increase the confidence they had in their ability to meet these pupils' needs at least 'a little', and a quarter believing their confidence would increase 'very much'. All but one teacher thought easy access to pupil information, through the class registers would effect at least some change on their teaching practice, with two thirds perceiving that their behaviour towards their autistic pupils would change 'quite a lot' or 'very much'.

Potential barriers to FAMe™ System use were suggested by almost a quarter of the teachers and included concerns about lack of time to access the information and forgetting that it was there. Ensuring pupils' FAMe™ Statements were as concise as possible (without losing their meaning) and the inclusion of the dot next to pupils' names in the register, to alert teachers both to a pupil's autism diagnosis and to the existence of their statements, were FAMe™ System design elements

purposefully incorporated, following the pre-FAMe™ teacher survey consultation, to address these specific concerns raised by teachers.

ii. Experience of using the FAMe™ System

Sixty-five teachers completed the post-FAMe™ survey after one term of having access to their autistic pupils' FAMe™ Statements through their class registers. Overall, teachers' response to the FAMe™ System was positive, with all but three teachers indicating that they would welcome an optimally functioning system to use in the future.

Three quarters of teachers said they found the dot next to a pupil's name in the class register helpful, either to alert them to or remind them that an individual pupil was autistic, and the majority of teachers (89%) thought the system was easy and straightforward to use. One unforeseen problem was that, in some subjects such as PE, teachers still rely on paper registers and so had no access to pupils' FAMe™ System information and the PE teacher who responded to the survey indicated that s/he felt s/he would have appreciated additional information about her/his autistic pupils. This will be an important issue to address moving forward, as PE was typically a lesson that the autistic pupils described as problematic. One possible solution to this would be to replace these teachers' paper registers with portable tablet computers, thus providing FAMe™ System access to those who do not work in a static classroom environment.

Additional qualitative information provided by teachers completing the post-FAMe™ survey suggested that they valued the contribution of pupils to their own FAMe™ Statements and found these useful and interesting. Three quarters of teachers' responses indicated that FAMe™ Statements contained information about their autistic pupils' classroom support needs that they were not already aware of, and two thirds reported that their classroom practice and/or the support they offered to pupils in lessons had changed as a result of reading this new information. Analysis of qualitative feedback identified that specific areas of change included: lesson planning; considering the accessibility of tasks and adapting instructions; approach to organising group work; seating arrangements; an end to a 'no hands up' policy for directing questions at pupils; focusing conversations with particular pupils around areas of need/checking that their support needs were being met; and providing more specific and directed positive feedback. This corroborates pupils' perceptions that their teachers had read and acted on their FAMe™ Statements.

Two thirds of teachers also reported that their confidence in their ability to meet the classroom support needs of individual autistic pupils had increased, as a consequence of having easy-to-access pupil-specific information through the FAMe™ System. In addition, at least some positive change in pupil behaviour and improvement in their academic learning and achievement, since the beginning of the FAMe™ Project, was also reported by 66% of teachers, supporting the comments made by pupils that they had found classwork easier and more engaging since the project began.

Barriers to/difficulties experienced with FAMe™ System use were typically related to the information provided having to be mixed in with other pupil information, e.g. when the gifted and talented column was used because a school was already using all the currently available columns in SIMS. This resulted in FAMe™ Statements not being as easy to identify as intended. These problems were recognised and acknowledged, but could not be remedied, before the project began. Following the positive project findings, they have since been resolved with the new marksheet design for FAMe™, agreed with Capita SIMS (see p.139-140), and the forthcoming addition of a new 'SEND' column, due to be rolled out to secondary schools by autumn 2018 (see Appendix 3).

iii.   Feedback from SENDCOs

All three SENDCOs responded positively to their school's involvement in this research project, e.g. '*The benefits of being involved in this project have gone way beyond easier access to vital information'.* They indicated that they valued having access to previously unknown information about their most vulnerable autistic pupils, learned as a result of feedback provided by me (with pupils'/parents' prior knowledge/consent), following pre-FAMe™ interviews. The sharing of this information was triggered by evidence of acute distress, obtained from the pupil self-report measures, and led to at least one outside agency referral for a pupil who disclosed suicidal ideation and a change in provision for two pupils, one to a specialist school and one from full-time education to twilight sessions only.

All three SENDCOs endorsed the continued collection of pupil well-being data as part of the FAMe™ System package. All other pupils' interview and self-report data remained confidential, unless individual pupils expressed the desire for me to share part or all of it, which some did. Regardless of how much additional information was shared, SENDCOs believed that the specific FAMe™ Statement content had informed/changed the support that was offered to *all* participating pupils in school as it had influenced teachers' practice.

All three SENDCOs expressed a desire to continue to use the FAMe™ System in their schools after the completion of the project. This was enabled through the updating of pupils' FAMe™ Statements, during their post-FAMe™ interviews, and making any necessary amendments to these within the schools' SIMS systems. School IT officers were subsequently sent information about how to optimise the FAMe™ System, following the post-FAMe™ consultation with Capita, and offered the opportunity to access advice about how to implement this if necessary.

Part 5.

This part of the Discussion chapter is a reflection on the methods and materials used to facilitate pupil participation and data collection.

i. Methods and materials

The pragmatic approach taken to this participatory-styled project justified the adoption of the range of methods employed to address the research questions (Morgan, 2007). Interviewing autistic pupils provided the opportunity to attend to and use their voices, both in the process of knowledge production (Beresford et al., 2004; Milton, 2014; Milton et al., 2014) and through communicating their self-identified support needs to effect positive change (Mertens, 2007). The collection of quantitative self-report and survey data evidenced the extent of the positive change pupils and teachers described and enabled validation through triangulation of the qualitative reports. Both data types were valuable in the evaluation of the efficacy of the FAMe™ System.

The development of interventions and/or strategies, with the capacity to reduce barriers to success and enhance positive outcomes for autistic young people, was highlighted as a research priority area by the autistic population (Pellicano et al., 2014) and is promoted as a 'desired end' (Johnson and Onwuegbuzie, 2004, p.16) by autistic advocates and researchers working in the field (e.g. Chown, 2017; Milton and Bracher, 2013; Ne'eman, 2011). At this stage, the FAMe™ System appears to

have real potential to facilitate improvement in this area. Evidence, from this study, that measurable positive change to autistic pupils' school experiences and well-being occurred, together with teachers' reports that the system was beneficial both to themselves and their pupils, provides an argument for a further extended FAMe™ System investigation to ascertain whether these findings can be replicated.

Of the 22 pupils who took part in the pre-FAMe™ interviews, all but two, both of whom were significantly less cognitively/academically able than the other participants (indicated by their presentation during interview and qualified through information provided in school performance/achievement target records and conversations with their SENDCOs), were able to engage fully with the process.

Of the two, with whom my task as interviewer/elicitor of information was more challenging, one appeared unable to reflect on the questions he was asked or demonstrate that he possessed insight relating to his differences and the difficulties he experienced as a result (which were described by his SENDCO as 'extensive'). In fact, this pupil displayed an attitude to life that appeared entirely positive. Despite the fact that several situations he described, particularly in relation to his treatment by other pupils, indicated to me that he was likely an object of amusement/a victim of teasing in school, his perception was that the actions of others, such as calling out his name in the corridor before pulling *"funny faces",* were examples of friendship which he indicated made him feel happy, e.g. *"I like it. Everyone knows me. Everyone is my friend".* He answered, "O*f course I am"* or, *"Of course I'm not",* to each of the self-report questions (depending on their positive or negative bias) and, when filling

in the 'What teachers do that I like/do not like' template sheets, copied the example sheets word for word.

The other of these 'more difficult to engage' pupils spent much of the interview session experimenting with the equipment in the room. Initially he responded to my questions using noises and gestures, although his verbal ability was evidenced through his telling of jokes. He talked about his special interests (finding out about how things work and visiting seaside resorts to collect key-rings) regardless of my attempts to direct his attention to the interview questions. He considered these to be *"work"* and therefore *"boring"*. He was given the opportunity to withdraw from the interview but chose not to, as long as I didn't make it last "*too long*". This pupil communicated the majority of his school-related answers via drawings to begin with and then provided further verbal explanation of these when prompted.

When I describe these pupils as 'difficult to engage', it is important to clarify that this was only in terms of the research element of this project, i.e. these two pupils contributed little data that was useful to me from a researcher perspective (in terms of the thematic analysis carried out to explore Research Questions 1 and 2). Indeed, the first pupil's data was withdrawn once it became clear he had not understood that he was involved in a research project and did not remember that he had consented (via completion of the consent form and verbally) to be a participant. Whilst the lack of useable qualitative data was frustrating for me as a researcher, it is important to stress that benefiting the pupils was the overarching goal of this project.

These two pupils *were* both able, with support, to create FAMe™ Statements, and appeared to understand that these were 'things that their teachers would get to know about them'. In addition, teachers specifically referred to these two boys in their post-FAMe™ survey feedback, giving examples of changes made to the support/strategies provided to them in the classroom as a result of their FAMe statement information. For the pupil who remained in the project, his post-FAMe™ interview indicated that these changes had been noticed and that he felt good about them, e.g.:

> *I don't have to sit at the front anymore*
> **Qu:** and what difference has that made?
> *I feel better, I do more work*

> (Site 2, Pupil 03)

Without the range of multi-media methods provided during interview, to facilitate pupil communication, I do not believe it would have been possible for me to establish this pupil's desire to be seated at the back of the room (which he drew onto the FAMe™ template sheet provided), or why this was important to him (i.e. he did not like knowing/feeling that *"all the eyes"* were looking at him when he was seated at the front). It is also possible that my experience, of talking/listening to autistic young people and adapting my communicative style to reflect and respect that of the individual, and/or our shared experiences and autistic neurology, enabled us to form connections (Milton, 2017) and to establish shared meanings (Cameron, 2011; Morgan, 2007; Hall, 2013) that might not otherwise have been identified. I was not fazed for example by having my hair and data collection materials blown about by

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the portable air conditioning unit, or the repeated attempts to unplug/switch off my phone (which was being used to record the interview). Having ascertained that these attempts were not because this particular pupil was uncomfortable with being recorded, but because he was enjoying testing my reactions, e.g. [laughing and aiming as if to throw phone] *"What will you do if I smash your phone? Will you be cross?".* I was able to engage him in a conversation about consequences and phone insurance before carrying on with the interview. I felt comfortable allowing him to lead me through his thoughts (many of which were coupled with what others might consider 'challenging behaviours'), until he was comfortable enough to allow me (a stranger) to lead him to mine.

What is essential to recognise about these two pupils is that, although they engaged with me in idiosyncratic ways, they *were* able to articulate their classroom support needs and, through having their voices attended to, both benefitted from being included in the project.

About half of the pupils used the writing materials to doodle whilst speaking (saying it helped them to concentrate/feel comfortable); make notes; or list possible FAMe™ Statements before prioritising their top three. Others asked me if I would write things down for them whilst some chose to communicate all their views verbally. This range of communication preferences, displayed by pupils during interview, supports the advocation for the provision of multiple data collection methods/tools when working with autistic individuals made by Nicolaidis et al. (2011).

Pupils were asked about their experiences of the project materials (e.g. the information packs (Appendix 5); introductory video (Appendix 6); examples/template sheets (Figures 7-10)) and of the interview itself, during our post-FAMe™ meetings. The majority of feedback was positive, e.g. *"It's all really good and helpful, especially because you're not really someone I know which is a good thing…I think the more people know about me already the less confident I feel telling them stuff so yes, I think it worked really well',* and*, "It was fine actually the way you did it there was nothing I could see wrong with what you were doing"* , with no pupil reporting that they had been upset by, or had needed anything they hadn't had access to during our meeting, or that they had wanted any additional support from school staff following their interview.

The introductory pre-FAMe™ video (https://youtu.be/IWZSaTZrO8U) was considered by pupils to have been a good way to reduce anxiety about meeting me and to prepare them for what to expect, e.g. *"Sometimes if you have a picture of someone in your mind and they are not how you expected then you get worried so..."*. However, one pupil could not remember whether he had seen this and said he would have liked more information before the interview about what was involved. Before engaging with autistic pupils in future FAMe™ research, it will be prudent to request that SENDCOs invite the pupils who have agreed to participate to watch the video in school, during the week prior to interview, to ensure they have seen it/remind them of what their participation will entail and reconfirm their consent to be involved.

When administering the self-report measures during the pre- and post-FAMe™ interviews, it was clear that, despite it being claimed by its authors (Beck et al., 2005) that the BYI is suitable for use with autistic children and young people, and its having been validated in previous research with autistic pupils (Ichikawa et al., 2013; Mandy et al., 2016), several of the questions required further explanation before the pupils in this study understood exactly what was being asked.

In addition, pupils found it difficult to 'plump' for one of the four options, i.e. 'never', 'sometimes', 'often' and 'always', and several requested to be allowed to circle more than one answer (I explained that this wasn't possible and that they should try to indicate the answer which best described the frequency they had experienced that specific thought/feeling during the previous two weeks).

My familiarity with the tendency of autistic indviduals towards the literal interpretation of language, including understanding how I might have interpreted the questions had I not had a background in psychology and mental health research, enabled me to reword and/or explain items that pupils found confusing. Using the terminology/language individual pupils had used during the preceding interview, I adapted/reworded questions (on demand) to reflect pupils' idiosyncratic language and their level of understanding of certain concepts. This process enabled me to be confident that the answers they subsequently provided reliably reflected their feelings about/experience of each item. Had pupils been required to answer these measures independently (for example if I had sent them out to them at home), I suspect pupils' misunderstanding of some questions would have led to my receiving

less reliable results relating to some individual's level of anxiety and depressive symptomology. This is an important point for future researchers to be aware of when choosing and deciding how to administer self-report measures to autistic pupils.

Negative references about taking part in the project tended to be related to individual teacher's use of the system, rather than the system itself, e.g. some teachers put the register on the interactive white board in front of the class (despite having been instructed not to do so) and pupils found the attention this attracted to them a source of embarrassment. All three schools already had a 'no whiteboard' policy for teachers when taking the register, i.e. teachers are expected to disconnect the link between their desktop computer and the main screen at this time, which they were reminded of by the SENDCOs before the beginning of the project and again after the half-term break. However, it was clear from pupils' comments that this did not always happen, especially when supply teachers were taking lessons, and that this is an ongoing issue which not only relates to FAMe™. Many types of sensitive data are communicated to teachers through the class register, often linked to specific vulnerabilities (e.g. parental discord/custody issues), and a number of pupils reported being asked questions by peers when this was displayed which made them feel uncomfortable. This issue needs addressing at a whole school level, regardless of whether a pupil is participating in FAMe™, to protect pupils' confidential data from being exposed to their peer group.

As with all research involving interviewing and encouraging emotionally vulnerable individuals to share their experiences, it was important that I was aware

of the possibility that pupils might become upset or disclose sensitive information that I would have a duty to report, and that I be both capable of dealing with this in the moment and know what to do about it following the interview. My duty to share such information was made explicit in the pre-FAMe™ information packs and at the beginning of each interview and was repeated to children who began to disclose.

Several of the pupils told me that they had, "*never talked about things like this before",* when they discussed experiences of bullying at school or difficulties with particular teachers. Three asked for my support to speak to their SENDCO following the pre-FAMe™ interview, to discuss worries/issues that they now felt they could better explain and potentially resolve with intervention from school staff. One pupil disclosed feelings of suicidal ideation and revealed aspects of his life both in and out of school that could not be kept confidential:

> **Qu:** [pupil pondering about how to answer a question on the BYI-II] So have you thought that [that he wishes he was dead] in the last two weeks?
> *Might be a shocking answer but I have thought about it a lot – a lot*
> **Qu:** And have you told anybody?
> *No. I just tell people what I feel like they want to hear, and I don't tell people the dark thoughts in my mind.*
> <div align="right">(pupil details protected)</div>

We discussed my duty to share this information and he acknowledged that he understood and gave permission:

> *I feel like it's like been for a really long time and nobody knows anything about this dark side of myself, I think it's time to let it get out there. I feel like there's lots of dark thoughts …if the score* [on the BYI-II

subscales] *does turn out really high, you know like a lot higher than other people, then I would want the problem to be resolved* [hoping that school staff will be able to help/support him]*.*

(pupil details protected)

He chose for me to communicate the contents of his disclosure to the SENDCO without him being present and acknowledged that he understood she would want to speak to him afterwards. Once the interview with this pupil was over he needed time to recover emotionally from his disclosure and we drew mazes and recited the periodic table together until he felt composed and ready to return to his lesson. For any interviewer engaging in research with autistic individuals, the importance of knowing/asking what strategies they have for self-calming/how they would like you to behave should they become distressed cannot be overestimated.

It has been suggested that the approach, methods and materials developed and used in the FAMe™ Project and described here, which continually informed pupils about what was involved at each stage of the research process, facilitated their participation in and accommodated their communication styles during interviews, and sought to protect them from harm at all stages, have the potential to be used as a framework, for thinking about research design, measurement and analysis, for researchers working with autistic pupils in the future (Chown, personal communication, 18/04/2018). In this sense, the FAMe™ Project would become a case study, or a 'paradigmatic example' (Morgan, 2007, p.56) to be used as an 'exemplar of a research model' (ibid) for future autism studies.

Dissemination of findings

The significant findings of the FAMe™ System evaluation will be fed back to participating pupils, parents and schools through the production of group-specific reports (in progress). These will be emailed to parents and SENDCOs with a request to share with pupils/school staff respectively. In addition, local NHS services, whose staff have been made aware of the project by some of the participating pupils, have made contact to request that findings relevant to their service be made available to them following project completion. For example, the leader of Sheffield's Community Physiotherapy & Occupational Therapy team has requested information regarding pupils' self-described school-related sensory sensitivities, and a member of the Sheffield Autism Strategy Group, who are developing methods to gain feedback from autistic children and young people regarding the services they receive, are interested in learning more about the materials devised for this project.

Suggestions for future teacher training

Data, gathered from the teachers taking part in this project, supported that of earlier studies which report that initial teacher training (ITT) and INSET is an insufficient source of autism specific information and does not enable teachers to appropriately adjust their autism pedagogy to meet the needs of their individual autistic pupils (Falkmer, Parsons and Granlund, 2012; Reed, Osborne and Waddington, 2012; Hebron and Humphrey, 2014). Whilst the FAMe™ System was designed in response to this situation, autism-specific SEND training for teachers and school staff will still have an important role to play in terms of continuing

professional development.   Using the information provided by the autistic pupil participants during interview, I have developed a series of slides that could be used as part of teacher education sessions (Appendix 19). It is hoped that the information provided will enhance teachers' understanding of autism in general and provide a back-drop to their having access to the FAMe™ System.

ii.   Limitations of this research and potential for future study

There were several limitations of this project that must be taken into account when considering the potential significance of the findings. These are discussed here, together with suggestions for how future FAMe™ research could be conducted differently to lessen their impact.

Firstly, the relatively small pupil sample, despite being reflective of qualitative research (Adler and Adler, 2014; Bryman, 2012b), means that caution must be employed when considering the implications of these findings. As expected, wide between-pupil variation existed in terms of the themes referenced, evidencing the heterogeneity of the autistic population (Attwood, 2008; Beardon, 2012; Guldberg et al., 2011). With a limited sample size, such as this one, there is an increased potential for such heterogeneity to impact on the between-group findings in particular, as participant numbers are necessarily diluted further. A follow-up study, to include pupils from more schools would be worthwhile to establish whether the findings of this project are replicated with a larger sample.

Another limitation related to the comparison of pre- and post-FAMe™ teacher survey data. Teachers' responses were provided anonymously and, as such, individual change from pre- to post-FAMe™, and an understanding of whether the FAMe™ System met teachers' expectations, could not be established. Findings are indicative of the general perceptions of those who completed each survey at each measurement point only. This was adequate for this project, as the pre-FAMe™ survey was used to inform the development of the system, and post-FAMe™ findings provided an indication of its efficacy and potential for positive impact. However, being able to ascertain whether the same teachers were involved in both stages of the research would serve to strengthen the validity of post-FAMe™ findings. One way this could be achieved in future would be to assign teachers a number, when they complete the anonymous pre-FAMe™ survey, and request that they record this on their post-FAMe™ submission, so the two can be brought together during analysis.

Data regarding such issues as pupil attainment-tracking, attendance levels and school requests for input from the local Autism Team, was not collected and/or analysed in this research. Also, as this project ran over the course of one term only, identifying significant positive change in pupils' academic attainment would have been difficult to establish. As these are areas which have implications for school performance tables and budgets (DfE, 2015), establishing whether the introduction and use of the FAMe™ System in schools achieves positive impact on them could be an important step towards encouraging Local Education Authorities to endorse its adoption. A further FAMe™ study, over the course of a full academic year, in

which pupil progress and attendance is also monitored and compared to expectations, based on previous years' results, would be a way to achieve this.

Whilst it is accepted that these findings should not be generalised to the wider autistic pupil population, much was learnt about the pupils taking part in this project which enabled their teachers to meet their learning and psychological support needs more successfully in school. In addition, findings from the pre-FAMe™ data corroborated those of previous research in this area (e.g. Charman et al., 2011; Falkmer et al., 2012; Mandy et al., 2016; Morewood et al., 2011), which suggests that autistic pupils find secondary school challenging and that teachers lack autism training and would like more pupil-specific information (Emam and Farrell, 2009; Lindsay et al., 2013; Reed et al., 2012). The extent of the positive change in pupils' self-reported well-being (which was universal and significant), and the endorsement of the FAMe™ System by those teachers who had access to it, indicates that further wide-scale investigation, using the optimised FAMe™ System, is warranted.

Teacher and pupil feedback suggested that introducing the FAMe™ System at the beginning of an academic year, rather than in the final term, as the timings of this PhD research necessitated, would be likely to produce even more significant results in terms of system impact. Initial conversations with my local council have indicated that a city-wide roll out, for the academic year 2018/19, might be achievable.

Analysis of pupils' interview data provided insights into the relative (in)ability of the diagnostic criteria and autism theory to aid understanding of their general school-related experiences. It is possible that, had the research focus been on other areas of life outside of school, or if the pupils had been posed other questions, a greater reflection of the explicit features of autism, or those that can be explained by theory, would have been evidenced in their responses. Further research, exploring other areas of autistic lived-experience using the same coding strategy, would be useful to understand whether these findings, i.e. that the capacity of the diagnostic criteria and autism theory to explain and aid understanding of autistic experience is limited, were context-specific or whether they apply to autistic experience more generally.

Chapter Summary

This Discussion chapter has provided an overview of the findings of the FAMe™ Project research and contextualised these, in relation to what was previously understood about the school experiences of autistic pupils and teachers' experiences of teaching them.

The investigation of research questions one and two, i.e.

1. *Are the explicit and implicit features of autism, specified in the diagnostic criteria of autism and autism literature, reflected in autistic pupils' descriptions of their lived experiences of school and, if so, to what extent?*

2.   To what extent can the school experiences of the autistic pupils participating

in the FAMe™ Project be explained using cognitive autism theory?

demonstrated deficiencies in the ability of both criteria descriptors and autism theory to account for: autistic strengths and abilities; individual's enjoyment of school and positive experiences; and the impact of environmental/external factors on autistic pupils' day-to-day functioning. Without providing explanation for these areas of a pupil's life, and instead only concentrating on difficulties and deficits, autism criteria and theory necessarily fail to enable a true understanding of how it is to be autistic.

Where criteria and theory were more useful/could provide a higher level of explanation, was in relation to pupils' prioritised classroom difficulties/areas specifically selected for intervention. In this regard, teachers' understanding of the explicit difficulties associated with autism might better enable them to adjust their general autism pedagogy to lessen the negative impact of their practice on autistic pupils. However, although the research findings from this study identified themes around which many of the participating pupils' prioritised difficulties were clustered, every pupil's FAMe™ Statements were unique. This demonstrates the importance of school staff engaging with individual pupils when planning their educational/classroom provision, rather than adopting a one-size-fits-all approach. The FAMe™ Project methods and materials would be suitable tools to facilitate such engagement in the future.

The FAMe™ System was able to meet the requests of teachers for easier access to pupil-specific information (Miller, 2002; Wilkinson and Twist, 2010) and teachers used this information to individualise their teaching practice according to the prioritised needs of their autistic learners. The impact of this change in teaching practice on pupils' psychological well-being was significant and both pupils and teachers reported an improvement in engagement with learning and in academic outcomes. These findings relate to research questions three and four, i.e.:

3.   *When engaging autistic pupils in research focusing on their experiences of school:*

   a) *What can be learned about autism/autistic pupils' school support needs from their descriptions of their school experiences?*

   b) *Are autistic pupils able to identify and communicate positive and/or negative classroom experiences and, if so, how can these be used to inform teaching practice?*

4.   *When information about individual autistic pupils is made easily accessible to their teachers:*

   a) *In what way does teacher behaviour/practice towards individual autistic pupils change?*

   b) *What impact is there on autistic pupils' educational experiences and quality of life related outcomes?*

Having established the success of the FAMe™ System to effect a change in autism-related teaching practice in the three participating schools, and consequently improve participating autistic pupils' school related experiences, I suggest that it has the potential to meet one of the priorities for new interventions, advocated for by members of the autistic population (Chown et al., 2017; Pellicano et al., 2014), i.e. to reduce barriers to success and/or enhance positive outcomes for autistic people. Continued research, to establish whether the findings of this project can be replicated in other schools, and potentially in other educational environments, such as colleges and Higher Education (HE) establishments, is therefore justified and worthwhile.

The conclusion which follows summarises the main points discussed here and highlights the original contribution to knowledge this research project has made. Implications for the future implementation of FAMe™ are outlined, including the need for the FAMe™ System to be considered part of a wider package, rather than being used in isolation.

Conclusion

National and international legislation and policy, (DfES, 2004b; HM Treasury/DfES, 2007; UN, 2006) enshrines the rights of disabled children to be consulted about 'their experience of daily life and about the services in place to support them' (Preece and Jordan, 2010, p11). Despite this, much engagement with members of the autistic population to date has been described as 'tokenistic' (Milton, 2014; Charman et al., 2011). This research has evidenced that by positioning autistic pupils as the true experts (Milton, 2014; Waltz, 2006) in their school experiences and attending to their voices, valuable insights into what and how it is to be autistic, and how best they can be supported in the classroom to achieve better educational outcomes, can be acquired.

There were several important conclusions which could be drawn from the FAMe™ Project research findings. These are presented here in relation to the four research questions posed.

Investigation of the first research question used thematic analysis techniques (Boyatzis, 1998; Crabtree and Miller, 1999; Elo and Kyngas, 2008) to establish the capacity of the diagnostic criteria definitions and descriptors to facilitate understanding of the experiences of school described by autistic pupils during interview. Findings demonstrated that many of the criteria-defined *'deficits'* in non-autistic functioning (DSM-5) were not reflected in autistic pupils' accounts of their school experiences in general and that, conversely, pupils' abilities and positive

experiences were not reflected in the deficit-focused diagnostic criteria. It was accepted that this was, in part, due to descriptions of school experiences in which pupils were passive observers rather than active participants, and that, had pupils described their responses to these experiences in more depth, further examples of the explicit features of autism (as defined by the diagnostic criteria) would likely have been identified. Nevertheless, one third of pupils' references related to their possessing skills, having positive experiences, or the specific lack of a criteria-related *'deficit',* and so it is concluded that the criteria definitions and descriptors are necessarily limited in their capacity to explain autism, or to promote understanding of how it is to be autistic within a mainstream school environment.

Also evidenced, through the coding of pupil attribution of cause to internal or external factors, was the extent to which pupils perceived that their environment, and/or the people within it, was responsible for both positive or negative impact, even when the experience itself was associated with an explicit feature of their autistic neurology. This provides the first research evidence in support of Beardon's theory, that there exists a 'Golden Equation' in which:

Autism + Environment = Outcome

(Beardon, 2017a, p11).

The hypothesis, that it is not autism per se that necessarily disadvantages/disables autistic individuals, but rather an interaction between explicit features of the autistic neurological profile and features of the environment in which the person in situated,

was supported both by pupils' attributional accounts and evidence of their improved educational outcomes, following the implementation of the FAMe™ System (discussed later in relation to Research Question four).

In relation to the second research question, thematic analysis of pupil interviews found cognitive autism theory to be similarly limited in its capacity to explain the majority of the participating pupils' general school experiences. Even when specifically applied to experiences that evidenced explicit features of autism, a synthesis of the cognitive autism theories under investigation (i.e. Theory of Mind theory, Executive (Dys)Functioning theory, Empathising-Systemising theory and Monotropism theory) still left half of such experiences without theoretical explanation. Consequently, it is suggested that claims by theoreticians (e.g. Baron-Cohen, 2009: 2009a) that their accounts 'explain autism in its entirety' (Rajendran and Mitchell, 2007, p.247) should be reconsidered. Instead it must be recognised that, although each has something to contribute to the understanding of 'the way autistic individuals process information and understand the world around them, and why certain behaviours are more evident in autism than in the non-autistic population' (Beardon, 2015, cited in Chown, 2017, p.8), there is more to being autistic than can be understood from knowledge of the current diagnostic criteria or cognitive autism theory, either independently or in combination.

Although no autism theory could explain all autistic school experiences, when exploring the references which *did* have a potential theoretical explanation, in contrast to the other theories investigated, Monotropism was shown to be universally

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applicable (Chown, 2017; Rajendran and Mitchell, 2007), i.e. it provided a potential explanation for a proportion of the references across the whole pupil group. Monotropism also provided explanation for the greatest number of pupils' experiences and so, of all the theories investigated, was the closest to reaching Rajendran and Mitchell's 'specificity' criteria for good autism theory (2007, p.224).

It was established that, in combination, the Monotropism and Executive-(Dys)Functioning theories provided potential explanation for 98% of the total number of pupils' references to their school experiences (that were able to be coded to any theory). It was therefore concluded that a synthesis of these two autism theories might provide the most accurate theoretical explanation of autistic cognition currently available.

These positive findings relating to Monotropism theory are significant as, to date, there has been no reported research investigating or establishing its relative value as a theory of autism. If adopted as a 'mainstream' autism theory (Rajendran and Mitchell, 2007), future researchers can begin to shift the paradigm lens away from autism as a collection of *deficits,* towards autism as a difference in cognitive processing style involving the distribution of scarce attention (Murray et al., 2005).

In contrast to the limited applicability of diagnostic criteria and theory to the general school experiences pupils described during their pre-FAMe™ interviews, when applied to the classroom issues prioritised for additional support and/or teacher practice change (i.e. pupils' FAMe™ Statements) the explanatory value of both

criteria and theory was significantly increased. Almost all (93%) of pupils' FAMe™ Statements were associated with autism-explicit difficulties (as described in the DSM-5) and two thirds had an explanation that could be identified in an autism theory. These findings suggest both that teachers' pre-FAMe™ teaching practice was not meeting the autism-specific classroom needs of their individual autistic pupils and that, although autism criteria and theory are limited in their capacity to offer explanation for autistic lived-experience, they might serve as useful tools for highlighting areas of potential difficulty where pupils are likely to benefit from additional support.

Of crucial importance when considering the implications of these findings was the evidence of heterogeneity, found in each stage of this research investigation, within the participating autistic pupil population. As extensive between-pupil differences existed, in terms of *which* explicit features of autism had the most impact on pupils' specific support needs (as well as their school experiences in general; the particular aspects of the school environment which could or could not be tolerated; and the identification of teaching practices that had either a positive or negative affect), continuing to base educational interventions on the categorical diagnosis of autism (Jones, 2006; Sarrett, 2012), rather than on pupils' individual profiles of needs and strengths, or to seek a 'best treatment' will be 'futile' (Schreibman, 2007, p.251).

Instead, as all the pupils in this project demonstrated that they were capable of identifying the teaching practices and environments that work best for them, I propose that exploring the views of individual autistic pupils, to determine their

individual support needs, should become the new standard. One way in which schools could facilitate the necessary pupil consultation would be to ensure the genuine inclusion of autistic pupils in their termly SEND reviews (a statutory requirement (DfE and DoH, 2015)). This will enable these pupils to contribute to their own provision-planning and, based on the findings of this project, is likely to enhance the success of any subsequent intervention. The prompt sheets and answer templates, developed for and used in this project to ascertain pupils' FAMe™ Statement information, would be suitable for this process.

Findings from previous studies, that autistic pupils are more vulnerable than their non-autistic peers to a range of negative psychosocial outcomes (Magiati et al., 2016; White et al., 2009; Selles et al., 2015; Steensel et al., 2011), were corroborated through the analysis, of the pre-FAMe™ interviews and pupil self-report measures, undertaken to answer research question three. However, it was also demonstrated that these outcomes are not necessarily inevitable or irreversible, and, as previously stated, that the pupils themselves were able to identify and articulate specific teaching strategies and environmental adaptations to ameliorate negative impact.

In answering research question four, it was found that communicating pupils' self-identified classroom support needs to teachers, through the FAMe™ System, had a positive impact on teachers' confidence to understand and meet individual pupils' classroom/learning support needs and led to changes in individualised teaching practice. As a consequence, a reduction in pupils' self-reported levels of

anxiety and depression and increase in their engagement with learning and enjoyment of school was observed.

With such positive preliminary findings over the course of one term, it is exciting to imagine what the introduction of an optimised longer-running FAMe™ System might achieve. Chown et al. (2017) suggest that, 'there is little point in researching autism unless the forces creating and sustaining the barriers to autistic people living fulfilling lives are tackled' (p.729). This research has demonstrated that, by providing a means to communicate the autistic pupil voice to teachers, the FAMe™ System has the potential to tackle some of the barriers to learning and positive well-being created by the lack of teacher autism-training, autism-knowledge, and autism-friendly educational provision, and thus better facilitate successful inclusion (Emam and Farrell, 2009; Witmer and Ferreri, 2014; Sprotson et al., 2017). Enhancing positive outcomes for autistic young people has been identified as a research priority by the autistic population (Pellicano et al., 2014). This project has established that engaging in research that prioritises this outcome is both achievable and worthwhile.

The design and efficacy of the methods used to engage with autistic pupils were vital to the success of this project. Pupils responded positively to the research information packs (Appendix 5) and video (Appendix 6) and made use of the various communication media available to them during interview (Figures 7-10). Photograph prompt sheets reduced the need for pupils to imagine situations and acted as an initial focus for discussion. Concrete examples of how their information might be

presented to and received by teachers proved useful, both in enabling pupils to construct and prioritise FAMe™ Statements, and in helping me establish that they understood how their information would be used and the purpose of the FAMe™ System. Feedback from pupils post-FAMe™ about their experiences of participating, suggest that it might be possible to conceptualise the FAMe™ Project as a 'model example' for carrying out research with autistic pupils (Chown, personal communication, 18/04/2018; Morgan, 2007, p.56).

Original Contribution to Knowledge

The findings of this project have made several original contributions to knowledge and have the potential to influence future autism practice.

Thematic analysis established the limited capacity of the autism diagnostic criteria and autism theory to explain autistic pupils' lived-experiences of school. This finding, in combination with pupils' identification of personal skills and strengths, not described in the diagnostic criteria definitions and descriptors, or explained by autism theories, and their attribution of positive and negative impact to their physical and social environment, led to the development of a new, holistic, bio-psychosocial definition of autism, to better reflect all aspects of autistic reality.

> *Autistic individuals share a neurological type, which is qualitatively different from that of non-autistics, and which will necessarily impact, both positively and negatively, on: aspects of their thinking and learning; sensory processing; social relational experiences; and communicative style, abilities, and preferences. An autistic person's experience of and ability to be successful in the world,*

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will be dependent on the closeness of compatibility between their individual profile of skills and difficulties and their physical and social environment. Levels of sensitivity to environmental factors vary between individuals, and within the same individual over time, so that the presentation of autism is ever changing. A person's neurological type, however, remains constant, and being autistic is a lifelong identity.

This definition has been adopted by Dr Luke Beardon in his teaching to new students of autism (Beardon, 2017b, Slide 10) and his conference presentations, thus giving it the potential to begin to change the conceptualisation of autism for future practitioners and researchers.

The universal applicability of Monotropism theory, to explain autistic experience across the participant population, was demonstrated and provided the first research evidence that this theory has the potential to contribute to a better understanding of autism. Monotropism theory appears to explain more aspects of autism than the long-standing dominant theories, which focus primarily on cognitive deficits, and thus is well-placed to supplement other relevant theory in this area.

Although there has been much research in recent years which has focused on the challenges faced by autistic pupils educated in mainstream schools (e.g. (Ashburner et al., 2008; 2010; Barnes and Harrison, 2017; Bolic-Baric et al., 2016; Charman et al., 2011; Keen et al., 2016; Hebron and Humphrey, 2014; Mandy et al., 2016; Morewood and Glew, 2011), very little qualitative information about how school is actually experienced by these pupils existed (Church et al., 2000). To the best of my knowledge, no previously reported study has specifically focused on

autistic pupils' perceptions of UK teaching practice in a mainstream learning environment or gained insight into specific factors that have positive or negative impact on pupils' psychological and academic outcomes. The direct link between a change in teaching practice and improved pupil well-being indicated in this study, suggests that further investigation in this area is justified.

The majority of pupils' FAMe™ Statements, which described their priorities for additional targeted support in the classroom (via teacher practice change), reflected difficulties in areas defined in the diagnostic criteria for autism. This provided evidence that the participating autistic pupils wanted their teachers to better understand their autism-specific classroom and/or learning support needs. However, despite being closely associated with the diagnostic criteria overall, wide between-pupil differences were observed, in terms of which and to what extent the explicit features of autism affected each pupil's classroom experience. This demonstrated the need for an individualised approach to pupil provision planning in schools.

Furthermore, engaging with autistic pupils established their ability to identify and articulate their own skills and difficulties and, through a variety of media, to define and communicate desired educational support practices to remove the barriers to their success. This is important evidence which supports the argument that provision planning should not only take into account the heterogeneity of the autistic pupil population, but that autistic pupils should be enabled to contribute to decisions made during the planning process. The findings from this project suggest

that the FAMe™ System has the potential to provide all schools with a low cost, straightforward method to achieve genuine pupil engagement and consultation.

The pupils working with me on this project demonstrated a considerable level of insight, not only relating to their own difficulties and the factors that contribute to these, but also into areas where they possess abilities and strengths. Although some researchers have already advocated that autistic pupils should be encouraged to participate in evaluating their educational environments (Pivik et al., 2002), and enabled to articulate what needs to be provided in mainstream schools that is currently not being offered (e.g. Bolic-Baric et al., 2016; Humphrey and Lewis, 2008; Mortier et al., 2011; Parsons et al., 2009; Reed et al., 2012; Sciutto et al., 2012; Simpson et al., 2007), I have been unable to locate any research demonstrating that a successful method of achieving this has been developed. In this respect the FAMe™ System itself can be considered a tool for enabling autistic pupils, individually and collectively, to make their own original contribution to knowledge in this area, with the potential to improve the evidence on which educational interventions are currently based, which has previously been described as contentious and ambiguous (Charman et al., 2011; Parsons et al., 2009). In addition, the project methods and materials, developed, and used successfully, to engage with pupils and collect their data FAMe™ Statement data, contribute to the limited resources available to researchers wanting to participate with autistic young people.

The FAMe™ Project and System

It cannot be identified, from the findings of this research, whether teachers' use of the FAMe™ System in isolation, or a combination of project-related factors, was responsible for pupils' enhanced experiences of school and their improved psychological well-being, which was evidenced through self-reported decreased symptomology of anxiety and depression and improved academic self-esteem. What is clear, however, is that participation in this project had some degree of beneficial effect for all the pupils involved.

The FAMe™ Project itself was a process in which the pupils were involved as active participants. For example, as a result of their participation, pupils were listened to and their self-identified needs were recognised and responded to. They were made aware that their experiences were considered important enough to be researched and that their teachers were keen to learn more about them and to offer appropriate support. The FAMe™ Project interview, whilst designed for research purposes, proved to be a fundamental element in the construction of pupils' FAMe™ Statements and provided, for some, their first experience of articulating what school was really like for them.

In addition, the use of self-report scales, during pre-FAMe™ interviews, provided the opportunity for pupils to talk about and reflect on their emotional state and enabled the identification of pupils considered to have 'clinically significant' levels of anxiety and depression, who would potentially benefit from therapeutic input.

School SENDCOs reported this information was useful in planning additional pastoral time for these pupils and, where appropriate, it prompted referrals to outside agencies for additional support.

It is likely that engagement with this process as a whole, rather than purely the implementation of the FAMe™ System, contributed to the overall positive impact reported by pupils. Future implementation of the FAMe™ System in schools should thus continue to involve active engagement with pupils. The methods of FAMe™ Statement generation must not be reduced to a template-filling exercise, but instead continue to utilise a genuine form of consultation, which reflects individual pupils' preferred methods of communication, in terms of how, where, and with whom they share their experiences and prioritise issues for change.

It was evidenced that FAMe™ Statements acted as valuable instruction for teachers, and the FAMe™ System as an effective means to communicate these. To ensure maximum benefit to autistic pupils however, the FAMe™ System should be considered as an integral element of a wider FAMe™ package, which retains all the individual elements/stages of engagement used in this project.

It is not clear whether my involvement in the pupil data collection, as a person external to the school, facilitated more open communication with pupils than might have been elicited by a member of school staff. One pupil specifically commented that she liked the fact that I was an 'outsider', as it made her feel more relaxed about sharing her school-specific experiences, especially in relation to individual teachers.

As an autistic individual and a parent of autistic children, I also felt and displayed genuine empathy for the pupils. I could relate intuitively to their school experiences and it is possible that this created a more open 'safe' dialogue in which the pupils felt that I understood their difficulties and was not judging them. I cannot know whether the interviews would have progressed differently had I not had 'insider insight' into how it is to be autistic.

In terms of who in school should conduct the FAMe™ interview/FAMe™ Statement collection in future, my experience of the interview process suggested that a good understanding of different autistic communicative styles and an ability to adapt one's own language/terminology to reflect that of the individual pupils, will be essential to the building of rapport and the facilitation of free-flowing conversation. In addition, it is necessary to understand the need to be flexible throughout, about how the interview is conducted, e.g. allowing pupils to move around the room, eat and drink and/or do whatever they need to feel most comfortable. The three SENDCOs in this project felt that they would be best placed to carry out future FAMe™ Statement collection. I propose that whoever takes on this responsibility should have a good working knowledge of autism and communicating with autistic young people. If this is to be someone from within school, asking the pupil who they would feel most comfortable talking to about their support needs would be the ideal.

The FAMe™ System itself was designed to work within the CAPITA School Management Information System (SIMS), as this is the software used throughout Sheffield schools. CAPITA hold 80% of the market share across all primary and

secondary schools in the UK (Unknown Author, *Education Investor*, 2013). This bodes well for an extended roll-out of the FAMe™ System, but liaison with other SIMS providers will be necessary to ensure autistic pupils in counties, such as Oxfordshire, who use RM Education software, are not disadvantaged through lack of access.

In designing and deciding to evaluate the FAMe™ System, I began this project with transformative aspirations (Mertens, 2010; Shannon-Baker, 2016). My hope was to facilitate the more successful inclusion of autistic pupils in mainstream schools by developing an intervention that, rather than targeting pupils for change, would enable them to communicate their support needs in order that individualised adaptations/reasonable adjustments could be made to their learning environment. System success was reliant on the participating pupils' ability to identify and express their difficulties and teachers' willingness to accept and utilise the information they were provided. Both participant groups responded positively to the FAMe™ System, as a concept and in practice, and the findings of this collaborative effort met the transformative aspirations I held for this project.

Up until now, many educational interventions and strategies have been based on modifying the theorised cognitive mechanisms underlying autistic pupils' supposed *deficits* (which may or may not even be experienced by or create difficulties for an individual (Sarret, 2012). More recently there has been a call to focus autism training on the practical, realistic elements of living with autism, rather than this theoretical approach more often taken (NAP, 2018). In the future, using the

methods developed for FAMe™, school staff should be able to engage with autistic pupils, through whichever means are best suited to their communication style and preference, to determine how their support needs can best be met through a combination of external adaptations and building on their existing areas of strength. Such engagement is not only more respectful of their human dignity (Groundwater-Smith and Mockler, 2007; Hill et al., 2004) but, according to the findings of this research project, is also more likely to achieve positive results.

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Appendices

Appendix 1

A. <u>Development of the Coding Nodes and Strategy for Coding</u>

Explicit and Implicit Features of Autism Nodes

The diagnostic criteria for autism (DSM-5, 2013 and ICD-10, 2010), contain reference to both explicit features (considered necessary, in various combinations and across multiple contexts, to receive a diagnosis) and implicit features (a range of other nonspecific problems [sic]) of autism. In her work based on the project carried out by Rice et al. (2013) outlining criteria exemplars, Carpenter (2013) cites additional implicit features of autism that are not captured by the diagnostic criteria. Taken in combination, the explicit and implicit features of autism, outlined in the diagnostic manuals and exemplars, were selected to create the first set of deductive nodes ('Criteria Explicit' and 'Criteria Implicit').

Other features/behaviours, commonly recognised in the autism literature as prevalent in the autistic population, and thus implicit to autism, and understood to have a negative impact on autistic experience (Beardon, 2017; Gibson and Kendall, 2010; Humphrey & Lewis, 2008; Osborne & Reed, 2011), but not necessarily captured by the diagnostic criteria, include: generalised anxiety (Ashburner et al., 2010; Bolic Baric et al., 2016; Charman et al., 2011); and masking/camouflaging, i.e. behaviours performed to compensate for/hide autistic difficulties (Attwood, 2007; Beardon, 2017; Gould and Ashton-Smith, 2011). In order to assess the significance of these, in relation to autistic pupils' experiences of school, their behavioural presentation/symptoms were included in at an additional 'implicit' node ('Literature Implicit').

Autism Theory Nodes

When referring to 'autism theory' throughout this thesis, I am explicitly discussing those cognitive theories, developed in an attempt to 'explain' the internal mechanisms (thought to be different to those of the PNT), that result in the observable behaviours/ presentation of autism and the experiences that autistic pupils have.

These nodes were selected according to what are generally accepted to be the main/most 'respected' (Lequia, 2011, p.408) autism theories (Chown, 2017; Murray et al., 2005), which attempt to provide 'cognitive explanations' of the 'core cognitive deficits [*sic*] that are autism' (Russell, 2002, cited in Murray et al., p.140), i.e. Executive (dys)Functioning; Weak Central Coherence; and Theory of Mind. In addition, two other, more recent theories were also selected for coding, i.e. Empathising-Systemising (E-S) theory (Baron-Cohen, 2002; 2009), and Monotropism theory (Murray et al., 2005). These theories were included because they are purported to extend and/or subsume existing theory and offer explanation, not only of the social difficulties experienced by autistic individuals, but also of restricted interests and repetitive behaviours, understood to be an explicit feature of autism (DSM-5), but left largely ignored by earlier autism theory (Baron-Cohen, 2009; Murray et al., 2005). A more detailed description of each theory, and the rationale for including them in the coding scheme is provided in the literature review chapter.

It is accepted that there exists 'overlap' between cognitive autism theories (Chown, 2017) as, essentially, they are efforts to hypothesise the mechanisms underlying the same thing, i.e. the behavioural presentation of autism. The coding

scheme takes potential theory overlap into account, by allowing coding to more than one theory node where appropriate.

No 'main' cognitive autism theory exists that specifically seeks to explain the range of sensory processing differences now made explicit in the revised diagnostic criteria (DSM-5, 2013, Category B4. 'Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of environment'), although some responses to sensory stimuli are explained by Monotropism theory (Murray et al., 2005). In order to reflect the salient nature of sensory processing differences within the autistic population, and capture those without any explanation in theory, a separate node ('Sensory Differences') was created.

Units of coding:

The units of coding (UoC) taken from pupil interviews differed in length and were separated when: a pupil finished speaking; if they changed what they were speaking about during a sentence/answer; or if the criteria or theory that can be used to explain the experience described in their sentence/answer changed. If appropriate a unit of coding spans an interruption/question from the interviewer and, in the case of autism theory, could be coded to more than one theory node. Units of coding are also referred to as 'references' throughout the results section. I use these terms interchangeably for ease of reading/improved sentence flow.

The following is an example of how a reference was split into units of coding for autism theory:

'My favourite subject is Maths - I adore maths - I am already like doing some A level maths and just as a quick joke thing...do you know pi? I've memorised about 100 digits of that I can memorise a LOT of stuff... **- Split here and first part coded at 'Other-Positive/Neutral'** (example of skills/enjoyment of learning) **-** *I can memorise well...a lot but after a couple of hundred things I need to remember my mind just sort of stops - it stops like screeches to a halt. I don't know what's going on anymore and I just kind of have - well like my mind goes blank a few seconds...I don't know what is anything really…there was this one case at school where I was like - I don't know - just thinking about a lot of maths and then after a few quick seconds I just thought like, 'Who are these people? Who am I?', and then it went back to normal - but I have those things, if I memorise too much, or if everything is just too much for me, that happens'*

Qu: and how do you feel when that happens?

'It's like...for me it's like...I don't know if this is a good description but it's like a mini few second coma where I'm just like, 'What is stuff' **– end of reference – coded at 'Executive Functioning'** (because it is an example of a difficulty caused by too much information/difficulties with working memory) **and 'Monotropism'** (because it is an example of extreme focus on one interest interfering with ability to perform).

This method of defining units of coding was used throughout the coding strategy for all nodes at all levels.

B. Identifying pupils' experiences of school which reflect explicit or implicit features of autism

Examples of the sort of difficulties a pupil might describe, in order for a unit of coding to be coded to an 'explicit' or 'implicit' feature of autism node, are provided throughout the following section for clarity. These were derived from my understanding of the autism diagnostic criteria, descriptions given in the criteria exemplars (Carpenter, 2013), and my knowledge of the data, gained during the transcription process. Extracts from pupil transcripts, coded to each node, are included to aid transparency and rigour and enable to reader to judge the quality of my coding. My Director of Studies, Dr Luke Beardon (EdD), and my colleague, Dr Nick Chown (PhD), both of whom are specialists in the field of autism, examined the pupil extracts provided here as examples and confirmed that, in their opinion, the nodes they are coded to are appropriate. In addition, Dr Nick Chown independently coded one pupil interview using this coding strategy. Our coding agreement for criteria nodes was 98%.

Coding a reference to an explicit or implicit feature of autism node required evidence that the experience being described could be attributed to an aspect of the following:

Explicit features of autism (Criteria Explicit)

The following nodes were developed from the **DSM-5, A:** 'Persistent deficits in social communication and social interaction' (reflected in **ICD-10, a & b:** 'Characteristic type of abnormal functioning in reciprocal social interaction and communication').

i.   Deficits in social-emotional reciprocity (DSM-5, A1)

For example, 'abnormal social approach and failure of normal back-and-forth conversation; reduced sharing of interests, emotions, or affect; failure to initiate or respond to social interactions; and lack of pleasure from social interactions' (APA, 2013).

Included at this node are references to pupils experiencing difficulty when:

- **they were expected to join/choose a group to work with, e.g. initiate a social interaction with a peer**
  e.g.

  Site 1. Pupil 05: *well if we are put into groups I don't mind, but if we have to pick our groups I absolutely hate that*

  Site 3. Pupil 01: *I prefer it when teachers put me in groups because I know already who I'm working with rather than me choosing who I am working with*

- **they needed/wanted to gain the teacher's attention to receive help with a task and/or initiate an interaction with a teacher**
  e.g.

  Site 1. Pupil 04: *I think that would be good* [teachers asking if she is OK] *because if they come up to me I can usually talk to them – I just can't actually approach them*

  Site 1. Pupil 03: *They don't check me – I may be at the back of the class and they don't check me…I need them to check me because I don't put my hand up…I don't know why*

- **they wanted to let someone know they were upset**

  e.g.

  Site 1. Pupil 04: *I couldn't ask to leave – I would leave if they* [teachers] *knew that I just could* [and didn't challenge her as she left the classroom]

- **they are expected/required to socialise/engage with other pupils, e.g. lunchtimes/unstructured times**

e.g.

Qu: [following pupil talking about feeling stressed in class]…if you are stressed in class...what kind of thing makes you stressed?
Site 1. Pupil 09: *It would be usually um group environments that's pretty stressful usually or um - trying to think...just probably group environments and just being asked to socialise a lot that's something that I struggle with quite a bit*

ii. <u>Deficits in nonverbal communicative behaviours used for social interaction</u> (DSM-5, A2)

For example, 'poorly integrated verbal and nonverbal communication; abnormalities in eye contact and body language, or deficits in understanding and use of gestures; a lack of facial expressions and nonverbal communication; and limited communication of own affect (inability to express emotions with words, expressions, gestures, tone of voice)' (APA, 2013).

Included at this node are references to pupils experiencing difficulty when:

- **they are trying to interpret others' body language**

e.g.

Site 2. Pupil 02: *I can't ever read that* [body language]*. If my teacher was just standing looking at me I would have thought they were looking at someone else because I'm not good with like eye coordination and all of that*

- **they are expected to make eye contact**

e.g.

Site 1. Pupil 09: *it's a little bit stressful because everyone will just be looking at you and just be like ...all those eyes...you know what I mean...*

- **others communicate nonverbally - e.g. through tone of voice, facial expression, gesture**
e.g.

    Site 1. Pupil 04: *…that teacher was just staring at me waiting for me to say 'sorry'. Everyone was looking at me cos she stopped the whole class for about three minutes and then she was like, 'X we are all waiting for you to say sorry', and I was like, 'but I didn't know that you wanted me to say sorry', I didn't say that though';*

    Site 2. Pupil 03: *I can't really tell if my English teacher is cross because she's really kind and gentle so I can't really tell*

- **they are unable to communicate their emotional state to others**

    e.g.

    Sit**e 1. Pupil 03:** *A few times before a Maths test I'm like, I get really, really upset and I can't say it*

iii. <u>Deficits in developing, maintaining, and understanding relationships (DSM-5, A3)</u>

For example, 'difficulties adjusting behaviour to suit various social contexts; difficulties in sharing imaginative play or in making friends; absence of interest in peers; not trying to establish friendships or not having preferred friends; having an interest in friendship but lacking understanding of the conventions of social interaction; and having a limited recognition of social emotions' (APA, 2013).

Included at this node are references to pupils experiencing difficulty when:

- **they want to form/have a positive relationship/friendship with a peer/ teacher**
e.g.

    Site 1. Pupil 05: *a lot of people don't seem to like me and find me annoying if I try to explain why I'm annoying they get annoyed at me*

Site 1. Pupil 05: *I have a few close friends, but I usually get into quite a few arguments with them because they are all telling me off for like copying them and things which I don't like*

Site 1. Pupil 04*: there was this girl that was like, 'Everyone act like X is not there', and I like pushed her and said like, 'I'm here', and I didn't do it to be aggressive*

Site 1. Pupil 05: *I need somebody to find me a new best friend pretty much,* [someone] *that will kind of understand my personality, won't go off with someone and doesn't have a group of friends who always talk about modern things - I wouldn't mind if they had a group of friends if the group of friends were nice*

- **they have to work in groups with other pupils**

  e.g.

  Site 3. Pupil 8: *I like doing stuff on my own so I can actually get it done and if I'm going to work in a pair I'm going to do the work myself and just say that you have done it so there is no point putting me in groups I will still do it by myself – I'm not going to let anyone do anything anyway so nobody wants to work with me anyway*

- **they do not adjust their behaviour to take account of school/classroom rules**

  e.g.

  Site 1. Pupil 01: *I shout out a lot in class – especially when I'm not supposed to – just comments and stuff that gets me into trouble – not like rude things just like stupid stuff really*

The following nodes were developed from the **DSM-5, B:** 'Restricted, repetitive patterns of behaviour, interests, or activities' (reflected in the **ICD-10, c:** 'Characteristic type of abnormal functioning in restricted, stereotyped, repetitive behaviour'):

iv. **Stereotyped or repetitive motor movements, use of objects, or speech (DSM-5, B1)**.

For example, 'exhibiting simple motor stereotypies; lining up toys or flipping objects; use of echolalia; use of idiosyncratic phrases; lining up objects; and repetitive action/play/behaviour' (APA, 2013).

No implicit references to stereotyped or repetitive motor movements, use of objects, or speech were identified in pupils' narrative accounts of their school experiences. Pupils demonstration of these behaviours during interview were observed but not recorded, as coding focused on pupils' perceived difficulties/behaviours or thinking affecting their experiences of school, and not their actual behaviours per se.

v. **Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (DSM-5, B2)**

For example, 'exhibiting extreme distress at small changes; experiencing difficulties with transitions; having rigid thinking patterns; performing greeting rituals; needing to take the same route, or eat the same food every day; compulsions; having an inability to understand nonliteral aspects of speech (e.g. humour and sarcasm); and having/exhibiting rigid, inflexible or rule bound behaviour or thought' (APA, 2013)

Included at this node are references to pupils experiencing difficulty when:

- **they are not prepared for change to their school routine in advance**

  e.g.

  Site 1. Pupil 04: *We have seating plans which usually don't change – I don't like it when they change but they usually don't so that's fine. It doesn't matter where I sit, as long as I stay in the same place*

  Site 1. Pupil 08: *there's nothing that I really mind - but I do like to know where I sit beforehand - if it's the start of a new lesson I like to know where I'm going to sit so it wouldn't be much of a fuss - if that makes sense?*

- **are expected to alter the way they do something**

  e.g.

  Site 1. Pupil 03: *I might want to do it THE certain way and it might take me a long time – it may take me longer and it may be because I want to do it quite good, I want to do it really good, it may sometimes take me more like twice as more as it's supposed to do maybe three times more. I think, 'I should do this', or 'oh no I should do this'…I don't really just want to stop after 20 minutes* [the time allotted for the task]

- **they have to cope with staff absence e.g. there is a supply teacher/ unexpected change of teacher**

  e.g.

  Site 3. Pupil 08: *I don't like not knowing stuff as well, I don't like surprises, so if a teacher is not here I don't like not knowing - in the morning my form tutor will tell me which teachers are and are not here …I like my routine and if there's going to be a change in routine I need like at least a week to get used to it*

- **they are transitioning back into school after a weekend/holiday/absence**

  e.g.

  Site 1. Pupil 1: [doesn't like Mondays]…*once we're at Tuesday or Wednesday, that's fine cos I've got back into the routine. After the holidays that's the worst I think because we have had such a long time away from school so it's bad (coming back) but I quite like school sometimes*

- **someone uses sarcasm or irony or implies, rather than is specific about, what they mean/want the pupil to do**

e.g.

Site 3. Pupil 08: *I need very specific instructions*

Site 1. Pupil 09: *Not being direct – I mean I get really frustrated if someone just says, 'Expand on this', I'm like, 'Tell me exactly what I need to do'. If they just tell me to expand on this…put more into this…I don't know what to do – how do I do that?*

vi. <u>Highly restricted, fixated interests that are abnormal in intensity or focus (DSM-5, B3)</u>

For example, 'having a strong attachment to or preoccupation with unusual objects; having an excessively circumscribed or perseverative interest; being overly perfectionistic; and having unusual fears' (APA, 2013).

Examples of units of coding at this node are:

Site 2. Pupil 05: *I wouldn't want like many people to know that I got stuck, because in things like maths I always strive to be the best student*

Site 1. Pupil 03: M*y mum's like, 'Just get it done…just get it done and out of the way', but I want it to be good and I generally just don't want to do homework really but if I'm going to do it I want to do it properly*

vii. <u>Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment</u> (DSM-5 B4)

For example, 'having an apparent indifference to pain/temperature; having an adverse/unusual response to sensory input; engaging in excessive smelling or

touching of objects; having a visual fascination with lights or movement; and exhibiting

tactile defensiveness' (APA, 2013).

Included at this node are references to pupils experiencing difficulty when:

- **their personal space is invaded**

  e.g.

  Site 3. Pupil 04: *I don't like them leaning over my body it makes me kind of uncomfortable like if they just stand behind me like what I mean is they like reading over my shoulder and getting really close like if this was my shoulder then getting close like that – I don't like that – I can be fine with them standing behind me and reading what I am doing I just don't like them getting really close*

- **they are prevented from fiddling/tapping in the classroom (sensory seeking behaviour used to aid emotional self-regulation/concentration)**

  e.g.

  Qu: some people have a fiddle toy

  Site 1. Pupil 01: *I've got one of them – I fiddle with it in class – I have this thing with coils on it – I have this box of things – I have a thing I can squeeze - but my teachers ask me to put it away…I think better when I've got it*

- **they are exposed to loud noise/unexpected noises and/or distracted by noise**

  e.g.

  Site 1. Pupil 04: *I am always concentrating unless it's really loud and then I have to sit there like that* [puts hands over ears] *because I can't concentrate, I get overwhelmed*

  Site 1. Pupil 04: *If I'm upset or anything that's when I then start noticing the lights, or when people are talking, or when people are making sounds…*

  Site 2. Pupil 03: *It's things like Maths and Science that I go out in because I really need to focus on them and I get distracted because I can hear them turning their pages and I can hear them writing and it's really bright in there and stuff*

- **they are in a classroom that they find too hot/too cold/dirty/smelly**

  e.g.

  Site 1. Pupil 01: *…when it gets too hot or there are too many people in there I get really, I feel really – I don't know how to describe it but I'll get quite angry because I'm not in a good place so that's how I feel*

  Site 3. Pupil 04: *the classrooms themselves a lot of the time they are like really hot and stuffy and I really don't like being warm cos I don't when I'm in those classrooms I don't sweat, but I feel like I'm about to sweat, so it just everything becomes really frictiony on my hands and sometimes it's even hard to get the lid off my pen because it's just slipping off so it's just like really warm really stuffy - it's just really annoying*

Implicit features of autism taken from DSM-5, ICD-10 and Criteria Exemplars (Criteria Implicit)

The following nodes were developed from the references to implicit features of autism made in the **DSM-5** (2013) and **ICD-10** (2010), **and in** the Guidelines and **Criteria Exemplars** (Rice et al., 2013) adapted by Carpenter (2013):

i. **Sleeping and eating disturbances** (DSM-5/ICD-10)

Included at this node are references to pupils experiencing difficulty when:

- **they are trying to get to sleep/have difficulty staying asleep**

  e.g.

  Site 3. Pupil 06: *My PE session was period 2, that teacher for that day is quite strict and I only got 4 hours sleep which to be completely fair that does make me quite aggravated when I don't get enough sleep so I can completely understand* [why got told off]

ii. Meltdowns/behavioural difficulties and temper tantrums (DSM-5/ICD-10/ Criteria Exemplars)

Included at this node are references to pupils:

- **hurting others at school**

  e.g.

  Site 3. Pupil 02: *I got a suspension on Friday for punching someone on the nose on Friday, that meant I didn't come to school on Monday*

  Site 3. Pupil 02: *Say if my idea was the one that would work and they* [other pupils] *took it and then they said, 'I've got it let's do this', and then they stole my idea - that can get a kick*

- **engaging in disruptive classroom behaviour**

  e.g.

  Site 1. Pupil 01: *I talk quite a lot in class*

  Site 3. Pupil 04: I'm always messing about with something in class most of the time just pulling faces

iii. Shyness/social anxiety (Criteria Exemplars)

Included at this node are references to pupils:

- **feeling embarrassed to do something publicly/in front of their peers**

  e.g.

  Site 1. Pupil 03: *I've experienced it once or twice a few times before when I don't really want to speak in a way - like in Maths and I find it a bit hard and I'm not entirely sure of an answer and I don't really want to be asked if I don't know an answer. I feel a bit embarrassed if you know what I mean if I don't know the answer and another pupil might seem to think it's an easy question whereas I don't find it easy - so I prefer not for teachers to ask me, just for me to put my hand up if I know what I want to say*

> **Site 1. Pupil 05:** *I wouldn't want to be singled out because I might get teased for it or I might get a little embarrassed*

- **being concerned about what others might think of them**

  e.g.

  > **Site 3. Pupil 05:** *I don't want to feel like I am special and I need different…yeah – I just want to be like everyone else'* … [teachers asking if he needed any help in class]…*'that would be nice but would that cause more like things happening like everyone thinking I'm special? Oooh oh God*

- **not liking to have attention drawn to them**

  e.g.

  > **Site 1. Pupil 04:** *I just said 'sorry', and everyone was staring at me and I just wanted to cry I felt awful…she was just staring at me like this…and I hate it when people look at me and the whole class was like looking at me and it was awful*

  > **Site 3. Pupil 06:** *that's OK* [teachers showing his work to the class] *as long as they are looking at me and I know why, but if they are looking at me and I don't know then I just I forget everything*

No references were found in the pupils' narrative accounts of their school experiences that could be coded to the following nodes:

iv. **Fears/phobias (DSM-5/ICD-10)**

v. **Self-directed aggression/self-injury (DSM-5/ICD-10)**

vi. **Lacking spontaneity, initiative and creativity in the organisation of their leisure time (DSM-5/ICD-10)**

vii. **Difficulty applying conceptualisations in decision-making in work (even when the tasks themselves are well within their capacity) (DSM-5/ICD-10)**

viii. **Problems with play/imagination (Criteria Exemplars)**

ix. **Language and developmental delays (Criteria Exemplars)**

x. **Poor imitation skills (Criteria Exemplars)**

Implicit features of autism taken from the autism literature (Literature Implicit)

The following nodes were developed due to their accepted salience within the experiences of the autistic population, as evidenced in autism literature (e.g. Ashburner et al., 2010; Beardon, 2017; Bolic Baric et al., 2016; Charman et al., 2011) and their inclusion in the autism descriptors written by the National Autistic Society (NAS, 2017).

xi. General Anxiety/Worry

Included at this node are references to pupils feeling:

- **worried or stressed** – when not specifically attributed to the social environment/ socialising/having attention drawn to them (coded to Criteria Exemplar, 'Shyness/social anxiety'), or perfectionistic tendencies (coded to DSM-5, B3, 'Highly restricted, fixated interests)

  e.g.

  Site 1. Pupil 05: *..there's pressure to keep the grades up and pressure's a big deal and they mention GCSEs and it would be good if they just know I get stressed and find it difficult to listen to them going on and on about the next tests and stuff like that*

  Site 1. Pupil 05: *There have been lessons when I have gone in shaking and stuff because things have been so stressful and then that makes the lesson even more stressful - I just get really stressed out*

- **symptoms of anxiety that are related to learning but not considered 'perfectionistic'**

  e.g.

  Site 1. Pupil 03: *I've done OK but I tend to make a lot of silly errors maybe because I'm a bit panicky maybe and I tend to think, 'I've been really stupid there', I look at the tests afterwards and I realise, 'Why have I done that?', it's just annoying*

Site 1. Pupil 03: *I might get very worried on this question and don't know what to do and panicky as well – I get quite panicky about some questions if I don't know what to do*

xii. <u>Masking Behaviours</u>

Included at this node are references to pupils:

- **purposefully hiding their feelings from others** (not because they are unable to express them - coded at DSM-5, A2, 'Deficits in nonverbal communicative behaviours used for social interaction')

  e.g.

  Site 1. Pupil 03: *I try and keep it contained, try and keep calm when there is tests, so teachers don't know*

  Site 2. Pupil 05: *I just tell people what I feel like they want to hear and I don't tell people the dark thoughts in my mind*

- **attempting to cover up their difficulties**

  e.g.

  Site 2. Pupil 04: *I don't know if this is a stupid example but it's like the matrix where everybody is like normal and they get on with their lives and …I'm this weird kind of out of place person that maybe doesn't even belong in this world…I feel like it's been for a really long time and nobody knows anything about [me]*

- **attempting to change in order to fit in with peers/align their behaviours with non-autistic peers' behavior**

  e.g.

  Site 1. Pupil 05: *I do have a friend who has been very nice who kind of knows about the issues and has been friends with me but they are quite aggressive...they always fight with boys and get quite angry very easily and so I have to always be careful about what I say and I can't be like the humorous fun person that I am and I kind of struggle fitting into her friendship group because it's not a friendship group I would choose to hang out with*

  Site 2. Pupil 05: *I don't want to complain and say 'oh this is awful' or 'I don't like that...cos everybody is doing it so I should just follow...*

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xiii.   **Other Negative**

Any negative school experience/experience that the pupil indicates they don't like/causes them difficulty, that cannot be coded at the 'Criteria Explicit', 'Criteria Implicit' or 'Literature Implicit' nodes.

Examples of units of coding at this node are:

- **Site 3. Pupil 03:** *I find it really hard like I was marking a test this week in maths and I had to write loads of things in from …just copying is so difficult I do everything my own way really like it's kind of, I mean I'm very good at copying skateboarding tricks but not anything paper wise*

- **Site 1. Pupil 05:** *There's a lot of things that happen - if I could always deal with them it would make me focus more - if there was nothing happening life wouldn't be interesting, but it would be good if there were less things happening*

- **Site 2. Pupil 02:** *I think it happens with most people who have dyslexia and that* [need teachers to check they have understood] *cos the words get jumbled up in your head*

- **Site 3. Pupil 02:** *I feel like I have some terrible guilt issues – sometimes I feel guilty for things that aren't even my fault – but to be honest I treat others the way that I have been treated*

xiv.   **Other Positive/Neutral**

Any positive school experience/experience that the pupil indicates they enjoy/like, any experience that pupils do not indicate presents a difficulty to them at school, or a reference to not experiencing an explicit/implicit feature of autism/related difficulty (e.g. expressing that they understand sarcasm or body language), that cannot be coded at the 'Criteria Explicit', 'Criteria Implicit' or 'Literature Implicit' nodes.

Examples of units of coding at this node are:

- **Site 1. Pupil 01:** *I think I'm quite good - like I know if someone is cross and I get sarcasm – and I do it quite a bit*

- **Site 1. Pupil 05:** *That would be all right - in science it's basically like sharing a microscope or getting out the chemicals or something like that, so I wouldn't really mind being put into groups for that*

- **Site 3. Pupil 04:** *I don't struggle with anything on there* [facial expressions/body language/sarcasm]

C. Explicit and Implicit Features of Autism Coding Rules

The following rules must be followed throughout the coding process to ensure that all pupil interviews are coded in the same way.

1. When coding to explicit and implicit features of autism nodes use the descriptions and examples given in the coding strategy for guidance. If *any* potential explanation for a behaviour and/or school experience can be identified in the diagnostic criteria, code accordingly. Do **not** make assumptions about whether experiences that might be considered typical of all pupils e.g. arguing with friends or not liking being shouted at, are/are not autism related, i.e. code *all* references to school experiences assuming the experience *is* autism-related.

2. Units of coding that relate to current experiences of school ***must not*** be coded to more than one explicit/implicit node – i.e. coding overlap is ***not*** permitted**.**

3. Units of coding which refer to experiences that happen outside school, and where an impact of these on school experiences is not made explicit, ***must*** be coded to 'Unrelated to school'. For example, 5 pupils reported sleep disturbances (implicit taken from DSM-5/ICD-10), however, only 1 pupil described this as causing a difficulty at school - the remaining references to sleep disturbances were coded at 'Unrelated to school'.

4. Units of coding to past experiences at school are first coded to the appropriate 'explicit' or 'implicit' node and then ***must*** also be double-coded to 'Past'. For example, the one reference that did refer to sleep issues impacting on school was coded to 'Past' as it had happened once and was not ongoing.

5. Repeat references, made for clarification purposes, ***must*** be coded at 'Clarification'

n.b. Units of coding that are coded at 'Unrelated to school', 'Past' or 'Clarification', are excluded from all data analysis. Calculations/totals are not included in the results section unless specifically referred to.

D. **Explicit and Implicit Features of Autism Hierarchical Coding Strategy**

For units of coding relating to current experiences of school the following steps must be completed in order:

1. Units of coding *must* be coded to an explicit feature of autism ('Criteria Explicit') node if possible

2. Units of coding that cannot be coded to an 'Criteria Explicit' node, *must* be coded to a 'Criteria Implicit' feature of autism node if possible (i.e. taken from the DSM-5/ICD-10/criteria exemplars)

3. Units of coding *must* be coded to an implicit node taken from the autism literature ('Literature Implicit') if possible, but only if coding to DSM-5/ICD-10/Criteria Exemplars ('Criteria Implicit') is not possible

4. Units of coding *must* only be coded to 'Other Negative' or 'Other Positive/Neutral' if they cannot be coded to an explicit or implicit feature of autism

E. Identifying pupils' experiences of school for which potential explanation exists in autism theory

Examples of the sort of difficulties a pupil might describe, in order for a unit of coding to be coded to one or more of the autism theory nodes, are provided throughout the following section for clarity. Extracts from pupil transcripts, coded to each node, are included to aid transparency and rigour and enable to reader to judge the quality of my coding. My Director of Studies, Dr Luke Beardon (EdD), and my colleague, Dr Nick Chown (PhD), both of whom are specialists in the field of autism, examined the pupil extracts provided here as examples and confirmed that, in their opinion, the theory nodes they are coded to are appropriate. In addition, Dr Nick Chown independently coded one pupil interview using this coding strategy. Our coding agreement for autism theory nodes was 94%.

Coding a reference to an autism theory node required evidence that the pupil attributed their experience to something for which a potential cognitive mechanism is hypothesised in autism theory, i.e:

a. <u>Difficulties caused by executive (dys)functioning</u>

Executive functioning (EF) refers to the ability to maintain an appropriate problem-solving strategy in order to attain a future goal (Milton, 2012), and includes the ability to prepare and engage in complex organised behaviour (Chown, 2017). It is generally considered to involve 'higher level' skills (Chown, 2017, p.178), which 'enable an individual to adapt and thrive in complex psychosocial environments' (Delis, 2012, p.14). Abilities such as the formation of abstract concepts; planning; focusing and sustaining attention; shifting focus; problem solving; cognitive estimation and working

memory are examples of 'executive' functions (Chown, 2017, p.176-177). Corbett et al. (2009, p.210) refers to executive function as, 'an overarching term that refers to mental control processes that enable physical, cognitive and emotional self-control'.

As executive functioning skills are related to learning, and in managing/coping with the demands of school (a complex psychosocial environment), it is of interest, both theoretical and in order to better understand autism, to explore whether executive (dys)functioning is implicit in pupils' narrative descriptions of their school experiences.

Included at this node are pupils' references to experiencing difficulty when:

- **there is a lack of structure in the task given / having unclear instructions**

  e.g.

  Site 3. Pupil 08: *'I need very specific instructions'*

  Site 1. Pupil 08: *'I need exact instructions I'd probably say without abstract language.'*

- **they need to make a choice, e.g. about how much work to do**

  e.g.

  Site 1. Pupil 04: *'I usually explain things in quite a lot of detail when I am answering questions [teachers say she hasn't done enough work/progressed through far enough] I don't know when to stop writing…or how to do something and I don't want to ask'*

- **they are trying to concentrate, e.g. needing to fiddle or tap to maintain focus/prevent daydreaming**

  e.g.

  Site 1. Pupil 09: *'I'm usually tapping I'm always tapping – either on things or on a drum kit and that's my way of concentrating'*
  Site 1. Pupil 05: *'I think if I'm having a stressful time I daydream - or if I'm bored because some of the lessons I can't understand some of the words they are saying - I just daydream and I don't even really know what I daydream about'*

- **they are processing information, e.g. instructions are given too fast**

  e.g.

  Site 1. Pupil 03: *'I need slow instructions – like if there's lots of instructions I just prefer to take it step by step and also there's like classes where they may say, 'Do this and this and this…', and I'd like them to sort of explain it in slow steady progress of what to do.'*

  Site 2. Pupil 05: *'this is the main reason that I sometimes get stuck at something - I need to understand what the teacher is saying but if they go faster or if something gets a bit more complicated I just totally think 'what's going on?'*

- **they have a preference for particular/additional presentation of information, e.g. verbal and/or visual**
  e.g.

  Site 1. Pupil 03: *'Sometimes basically instead of saying…if they are saying 'write this down in your books' and they like just say it…but if it's written down and I can copy it – I'm better with stuff like that instead of verbally'*

- **there is a need to transition between tasks/lessons/activities**

  e.g.

  Site 1. Pupil 03: *'I don't really just want to stop after 20 minutes'* [how long it's supposed to take]

- **they are unable to control their behaviour/act impulsively e.g. swearing in class/kicking a peer**
  e.g.

  Site 1. Pupil 01: *'I shout out a lot in class – especially when I'm not supposed to – just comments and stuff that gets me into trouble – not like rude things just like stupid stuff really'*

b. **Difficulties caused by weak central coherence**

Central Coherence (CC) refers to an ability to derive overall meaning from the constituent parts of a whole i.e. to perceive the gist of something (Chown, 2017). Weak central coherence results in difficulties accounting for overall contextual meanings,

whilst simultaneously having advantages in processing details or parts of an overall context (Happe, 1994).

No references to experiences relating to central coherence difficulties were identified in pupils' narrative accounts of their school experiences.

c. <u>**Difficulties caused by an under-developed theory of mind**</u>

Theory of Mind (ToM) relates to an individual's ability to attribute mental states, e.g. beliefs; intents; desires; pretending; and knowledge, to oneself and others, and to understand that others have beliefs; desires; intentions; and perspectives, that are different from one's own (Baron-Cohen, 2001; Chown, 2017).

Crucial to successful social interaction, an absence of age-appropriate ToM skills is considered to place an individual at a disadvantage in a social world where instant judgments must be made, and action taken (Baron-Cohen, 1995). In the school environment, which is inherently social, difficulties associated with ToM would theoretically be expected to have a significant impact on a pupil's experience.

Included at this node are references to pupils experiencing difficulty when:

- they are expected to understand non-verbal cues e.g. a teacher waiting for them to provide an answer/stop a behavior

- they misunderstand/fail to recognise sarcasm e.g. peers' use of sarcasm as humour

- they don't recognise that they are being teased e.g. are gullible and believe that people always mean what they say

- they fall out with/argue with peers because they misunderstand/don't recognise their point of view

- they don't know why someone is upset with them

Examples of units of coding at this node are:

- **Site 2. Pupil 05:** *'Sometimes when I get something wrong or if I act stupid for a few short seconds...I imagine…the first thing I imagine is that people will look in my direction and just think...Why???' although I normally look around and nobody's looking at me but it doesn't stop me from thinking that those people are judging me for what I do'*

- **Site 3. Pupil 02:** *'Say if a teacher was annoyed and I said, 'Do you want me to hand this in to you Miss?' and she said, 'No I want you to put it in the bin' – I would go and put it in the bin'*

- **Site 2. Pupil 02:** *'I don't know* [what teachers are thinking] *cos I don't really – I'm not exactly a mind reader really'*

- **Site 3. Pupil 05:** *'…it was just the beginning of the term and it was like really cool in Y8 but then from the beginning of term two he* [friend] *just went to hating me*
  Qu: and you don't know why?
  'No'

d. <u>**Difficulties caused by strong-systemising/weak-empathising**</u>

Empathising-Systemising (E-S) theory relates to a drive to analyse and construct systems, defined by rules that govern them, in order to predict how they will behave (Baron-Cohen, 2009; Chown, 2017; Milton, 2012) and an attempt to apply these rules to situations, rather than to rely on empathising and intuition which,

according to Baron-Cohen (2009), is deficient in autistic individuals. As E-S theory involves dual/opposite constructs (ibid), in order for references to be coded to the E-S node, evidence of a tendency towards systemising in itself is not enough. Unless both constructs are apparent in the same reference, a pupil's interview transcript must also contain references that can be explained by a weakness in empathy skills.

In order to capture all references appropriate for coding at the E-S node, all references to experiences that can be explained by a pupil's tendency to systemise will initially be coded to the E-S node, but only those made by pupils who also make references during their interview that are associated with ToM/empathy difficulties will be retained in the analysis.

School life is necessarily governed by (often complex) rules with many aspects that are characteristically predictable. However, the typical school day will also demand pupils to manage unexpected adjustments e.g. timetable changes and staff absences. As strong-systemisers typically lack the ability to generalise between situations (Baron-Cohen, 2009), according to E-S theory autistic pupils might be expected to struggle when faced with having to manage any such fluctuations to their routines. It is, therefore of interest, both theoretical and in order to better understand autism, to explore whether difficulties relating to strong-systemising and weak-empathising are implicit in pupils' narrative descriptions of their school experiences.

Included at this node are references to pupils experiencing difficulty when:

- they are faced with an unexpected change/ not given advanced preparation, e.g. there is a supply teacher in class/ have a test that they were not told about

- they are presented with unclear instructions/explanations, e.g. 'expand your argument'

- they experience someone not doing what they say they will, e.g. a teacher saying they will bring something into school/teach something in a lesson and then not doing so

And they have at least one reference coded to the ToM node.

Examples of units of coding at this node are:

- **Site 1. Pupil 03:** *'I need to know exactly what they want, what they are expecting, how much they are expecting …cos they may say, 'Write an essay about such and such', and I'm like, 'How much do I do?', and also clear instructions about what to revise for a test - sometimes they may not be quite clear what they want, and especially when you've got supply teachers and they say, 'You've got a test and you have to do such and such', but don't say what to revise'* **(would need additional evidencing of weak empathising/ToM)**

- **Site 3. Pupil 02:** *'She's* [teacher] *not forgotten, she's just not doing it! And you know when...have you ever done it where say you categorise a group of people? So, like say, 'Oh I don't like those people'…because that teacher lied to me* [didn't do what she said she would]*, I now believe that all teachers will lie to me - so my trust can be easily taken away'*

e. Difficulties caused by monotropism

Monotropism relates to an atypical strategy being employed in the distribution of attention (Murray et al., 2005). The amount of attention available to an individual at any one time is necessarily limited. Individuals with a monotropic cognitive style typically concentrate their attention on a small number of 'interests'. It is suggested (ibid.) that social interactions, the use of language, and the shifting of the object of attention, are all tasks that require broadly distributed attention

(rather than a monotropic focus) and that monotropism results in large areas of potential information not being registered.

Included at this node are references to pupils experiencing difficulty when:

- they do not see the point of a task/understand the goal, e.g. can't understand why they are expected to continue to practise a skill they already possess

- sensory stimuli distracts their attention from a task, i.e. disrupted concentration

- they do not value the point of a task/ are not motivated by it, e.g. feel they will never utilise the skill they are expected to learn

- they cannot understand how to perform a task/ do not understand precisely what a task it is/what steps must be taken to carry it out, e.g. when a teacher does not provide explicit instructions

- they do not know how to take the identified steps to complete a task, e.g. selecting the appropriate resources

- they are required to shift their attention, e.g. transitioning between tasks

- they are expected to do more than one thing at once e.g. taking down/listening to homework instructions whilst packing away their belongings

- they experience unexpected sensory stimuli, e.g. are startled by loud noise

- they do not attend to social stimuli, e.g. do not pick up on cues from tone of voice, gestures, facial expressions

- they cannot make sense of the continuous flux of social discourse, e.g. when they are expected to engage in group work/socialise during unstructured time

- they are expected to follow complex lists of instructions, e.g. when a teacher presents a task without breaking it down into smaller chunks of information

Examples of units of coding at this node are:

- **Site 1. Pupil 04:** *'When there's more people it's hard to follow because I listen to one person and another person starts talking - but if I'm talking to just one person I can usually keep up'*

- **Site 1. Pupil 09:** *'If I'm looking at you then it means that I am NOT listening so don't assume somebody's not listening just because they are not seeming to be paying attention'*

- **Site 1. Pupil 03:** *'I need them to make sure I have short clear instructions of what the task is and make sure I've got everything I need to know for the homework* [providing written homework] *would be helpful- also speak slowly so I can completely understand what it is…'*

- **Site 1. Pupil 04:** *'I am always concentrating unless it's really loud and then I have to sit there like that* [puts hands over ears] *because I can't concentrate, I get overwhelmed'*

f. **Difficulties caused by different sensory processing**

Difficulties processing everyday sensory information are experienced by many autistic people (NAS, 2017). Any of the senses may be over-sensitive (hypersensitive) or under-sensitive (hyposensitive), or both, at different times (Lawson, 2014). Difficulty with processing sensory information can lead to feelings of overload and overwhelm; dislike of touch or sound etc.; or engaging in sensory seeking behaviour.

n.b. Difficulties with sensory processing that can be attributed to monotropism are **NOT** included at the 'Different Sensory Processing' node as the coding strategy is hierarchical (see p. 35).

Included at this node are references to pupils experiencing difficulty when:

- they are exposed to noisy environments, e.g. the school dining hall/corridors

- their personal space is invaded

Examples of units of coding at this node are:

- **Site 1. Pupil 04:** *'I have my hands over my ears, that's when it's loud, but it's when I'm upset or anything, that's when I then start noticing the lights or when people are talking or when people are making sounds…if I'm just kind of not doing anything* [is a sign of feeling overwhelmed] *I wring my hands – I'd like to have a pass so I can get out'*

- **Site 1. Pupil 07:** *'There's nowhere you can really sit to get away from it - it's that loud - and I can't stand that'*

- **Site 3. Pupil 06:** *'For some reason, I don't like it if anyone touches my back so…when teachers lean over me…I don't like it'*

- **Site 3. Pupil 08:** *'When they come and read your work – I absolutely hate that. If they wanted to read it I'd be fine with it* [handing them work book], *but it's just when they come and lean over you I absolutely hate it'*

g. <u>Other Negative</u>

Difficulties at school that cannot be coded at an autism theory node or at 'Different Sensory Processing'

Included at this node are references to pupils experiencing difficulty when:

- other pupils are misbehaving in class, e.g. shouting out/ignoring the teacher

- relationships with other pupils are upsetting, e.g. bullying/teasing/falling out

- teachers' behaviour/teaching practice is upsetting, e.g. shouting/criticising work/behavior

- they receive unwanted attention/are made the centre of attention e.g. asked to answer a question in front of the class

- they feel pressure to perform, e.g. discussion about the future importance of doing well at school

Examples of units of coding at this node are:

- **Site 2. Pupil 02:** *'Sometimes it does get a little bit awkward - cos if I say I don't know the answer and they like say 'well give me your best or something' and then that makes it worse cos there's like more pressure to get it right…'*

- **Site 2. Pupil 03:** *'some of my teachers ask me questions without me putting my hand up and ask for answers and I don't like that because I think they might pick on me and make me answer it'*

- **Site 1. Pupil 04:** *'I just feel like she really doesn't like me because she's always – she never like smiles at me or anything and she never says anything nice - she just shouts at me she tells me off quite a lot more* [than other people get told off]*'*

h. <u>Other Positive or Neutral</u>

Reference to the specific absence of a difficulty, or possession of academic skills/abilities; enjoying school; and liking learning.

Examples of units of coding at this node are:

- **Site 1. Pupil 01:** *'I like my Science teachers because we do fun practicals and we get to interact with our work and we have to think a bit - that's why I like Science and Maths definitely'*

- **Site 1. Pupil 02:** *'I don't really worry when I'm at school - I worry sometimes I did worry a bit about my homework because I was in a bit of a tight fix - but I managed to sort that out'*

- **Site 1. Pupil 05:** *'I feel good going to school, I feel good that I am learning things and becoming more confident'*

- **Site 1. Pupil 04:** *'It could be that I've finished as I tend to finish very quickly…then I'd like more work to do'*

F. <u>Autism Theory Coding Rules</u>

The following rules were followed throughout the coding process to ensure that all pupil interviews were coded in the same way.

When coding to autism theory nodes use the descriptions and examples given in the coding strategy for guidance. If *any* potential explanation for a behaviour and/or school experience can be identified in an autism theory code accordingly. Do not make assumptions about whether experiences that might be considered typical of all pupils e.g. arguing with friends or not liking being shouted at, are autism related, i.e. code *all* references to school experiences assuming the experience *is* autism-related.

G. <u>Autism Theory Hierarchical Coding Strategy</u>

1. Units of coding which refer to experiences that happen outside school, with no reference to their impacting on school experiences, ***must*** be coded at 'Unrelated to school'.

For units of coding relating to experiences of school:

2. Units of coding which refer to current school experiences ***must*** be coded to more than one autism theory node if appropriate, to identify theory overlap

3. Autism theory nodes ***must*** take precedence over 'Sensory Processing' if possible

4. Units of coding coded to one or more autism theory node/s ***must not*** also be coded at 'Different Sensory Processing' or 'Other'

5. Units of coding which refer to past experiences at school ***must*** be double-coded to 'Past' to identify the time being referred to

6. Units of coding ***must only*** be coded to 'Other Negative' - examples of difficulties at school - or 'Other Positive' - example of skills/abilities/enjoyment of school/not an example of a difficulty - if they cannot be coded to an autism theory node, or to 'Different Sensory Processing'

7. Repeat references, made for clarification purposes, ***must*** be coded at 'Clarification' n.b. Units of coding that are coded at 'Unrelated to school',

'Clarification' and 'Past' are excluded from any calculations/totals and are not shown in the results unless specifically referred to.

Appendix 2

Sheffield Hallam University

APPLICATION FOR RESEARCH ETHICS APPROVAL (SHUREC2A)

SECTION A

Important Note - If you have already written a research proposal (e.g. for a funder) that answers the methodology questions in this section please include a copy of the proposal and leave those questions blank. You **MUST** however complete **ALL** of Section B and C (risk assessment).

1. **Name of principal investigator:** Julia Leatherland

    Faculty: Development and Society

    Email address: removed

2. **Title of research:** Communicating Autistic Pupil Voice: Does FAMe™ affect Autism Pedagogy and Pupil Outcomes?

3. **Supervisors**: Luke Beardon and Bronwen Maxwell

    Email address: removed **and** removed

4. **Proposal Tracking number (applicable for externally funded research):** N/A

5. **Other investigators (within or outside SHU)**

Title	Name	Post	Division	Organisation

6. **Proposed duration of project**

Start date: 01/10/2014   End Date: 30/09/2017

7. Location of research if outside SHU: Secondary schools from the SHU research engaged schools network

8. **Main purpose of research:**

Educational
qualification | X |

Publicly
funded
research
Staff
research
project
Other (Please supply details)

9. **Background to the study and scientific rationale** (500 words approx.)

Background: In the current UK secondary education system, where learning is viewed as the attainment of measurable skills by a set of normative criteria (Milton and Lyte, 2012), mainstream teachers are challenged to provide appropriate support to autistic pupils (typically with a diagnosis of Asperger Syndrome) without necessarily having an understanding of the types of difficulties these young people frequently present with, or of their individual support needs (e.g. Barnard et al., 2000; Brewin et al., 2008; Sciutto et al., 2012). These pupils are often wrongly labelled as lazy, defiant and difficult (Humphrey and Lewis, 2008) because teachers fail to understand their autistic perspective (Beardon et al., 2009; Milton, 2012).

Autistic pupils in mainstream schools have been identified as particularly 'vulnerable' and a 'difficult group to include' (House of Commons Education & Skills Committee, 2006), even when compared to other groups with special educational needs and disabilities (SEND), and their inclusion and how to make it successful has become a focus of much enquiry. In a survey of teacher beliefs about meeting the needs of autistic learners, 76% felt more autism-specific information would enable them to help these pupils have a more positive experience of school (Macbeath et al., 2011). Similar findings are reported throughout the 'autism and inclusion' literature (e.g. Morewood, Humphrey and Symes, 2011; Charman et al., 2011), where it has been suggested that, in order to develop inclusive pedagogy, teachers require *specific information* about individual pupil's SEND profiles (Barnard et al., 2000) as well as more generalised autism training (Sciutto et al., 2012).

Unfortunately, in the current mainstream school system, individual pupil information is often not available, accessible or up to date - despite having been identified by teachers as a necessary requirement for good autism practice (Hebron and Humphrey, 2014). This gap in teacher knowledge, of autism and its affect on individuals, is reported to be a major risk factor contributing to a range of negative outcomes affecting autistic pupils' quality of life (QoL) (Hebron and Humphrey, 2014), academic achievement (Charman et al., 2011) and their long-term mental health (Macbeath et al., 2006).

In response to teachers' requests for more accurate and accessible information about the needs of their autistic learners (e.g. Miller, 2002; Wilkinson and Twist, 2010), and the suggestion that their having this information might have a positive impact on pupil outcomes (Charman et al., 2011; Macbeth et al., 2011), I have designed a (technological) system to provide teachers with one-click access to pupil generated information about their own learning and classroom support needs (to be accessed by teachers at any time but preferably immediately before each lesson).

The Change Environment

External Domain

External Source of Information or Stimulus

Personal Domain

Domain of Practice

Knowledge Beliefs And Attitude

Professional Experimentation

Salient Outcomes

Domain of Consequence

→ Enactment

- - ▶ Reflection
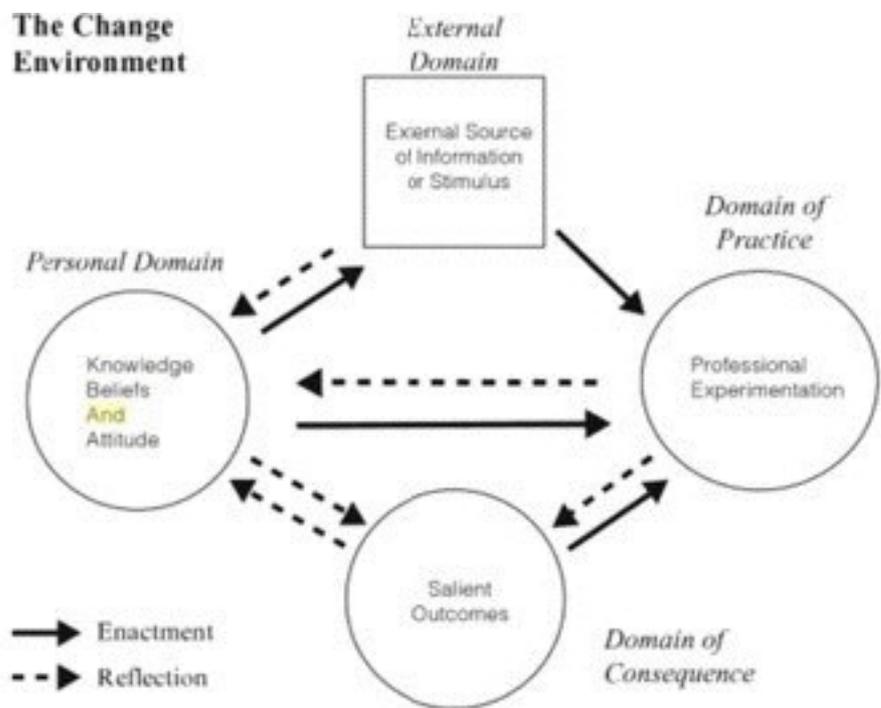
Figure 9-1. The interconnected model of teacher professional growth (Clarke & Hollingsworth, 2002, p.951).

Using the interconnected model of teacher professional growth (Clarke and Hollingsworth, 2002) to frame my thinking, my expectation is that engagement with a system that provides direct and accessible communication of pupil-need, (external stimulus), will inform/effect change in both the 'personal domain' and the 'domain of practice' of mainstream secondary school teachers who engage with it, (in relation to autistic pupils), and that this change will impact on pupil outcomes.

The domains of 'personal' and 'practice', used in Clarke and Hollingsworth's model, correspond to my understanding of 'pedagogy' - as teacher thinking and teacher doing, which has been informed by Westbrook et al. (2013). According to these authors, pedagogy is considered 'effective' when it has a 'visible, observable and measurable [desired] impact' on learners (p.8). This (effecting measurable positive impact on autistic learners) is the ultimate aim of the new system and I hypothesise that it will be achieved by increasing the 'effectiveness' of their teachers' autism pedagogy.

Theory / Hypothesis

Task 1.
Develop a system

Task 2.
Evaluate it
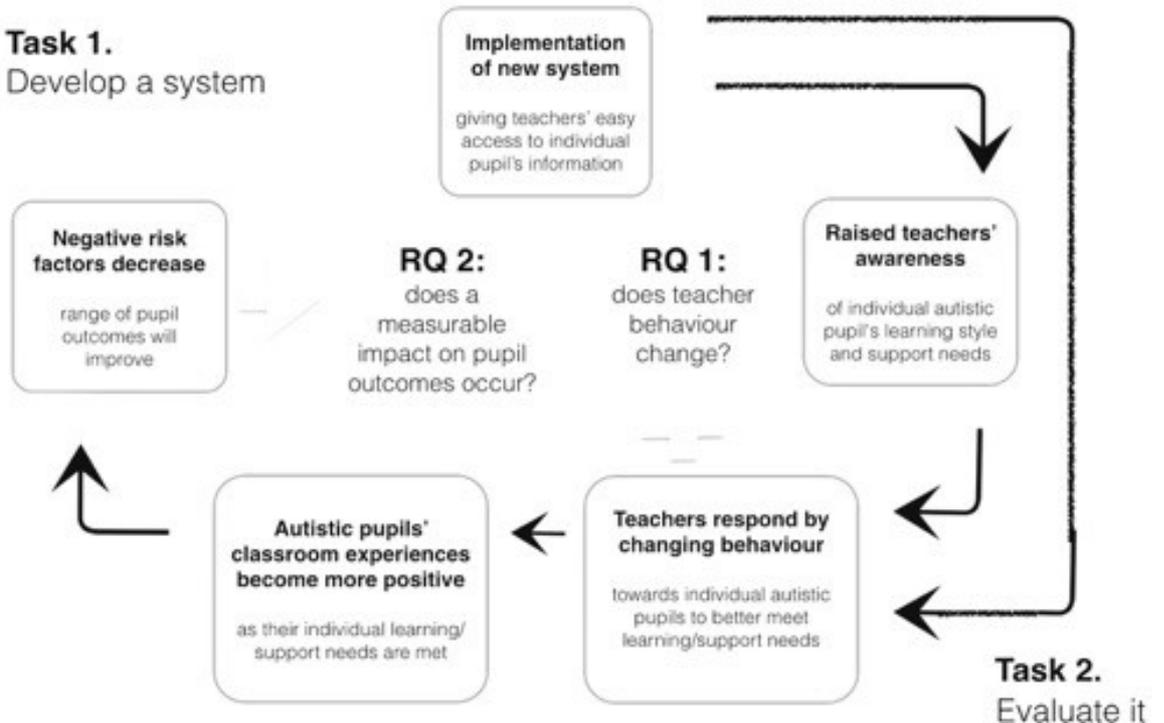
The new system - Progress to date:

The new pupil-teacher communication system will utilise the existing computerised school register software used throughout Sheffield (Capita SIMs).

The logistics of adding pupil-generated information (to be called 'Facts About Me' - FAMe™ info.) to the existing system have been discussed with Sheffield City Council's IT officers, who have confirmed the process will be straightforward and that there will be no financial implications for participating schools.

There will be a cost, in terms of staff time collecting and entering the new data into the system if it is used in the future, which is acknowledged. However, during the evaluation stage (this project) I will be collecting the information and overseeing the data entry myself.

Future data collection - SEN review meetings are now termly and are expected to include the voice of the pupil involved (SEND Code of Practice (CoP), 2014). This creates a potential opportunity for school SEND coordinators (SENCos) to collect new and/or review existing pupil information as necessary and keep the FAME™ system up to date.

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10.   Has the scientific / scholarly basis of this research been approved? (For example by Research Degrees Subcommittee or an external funding body

Yes ✔ (RF1)
No - to be submitted
Currently undergoing an approval process
Irrelevant (e.g. there is no relevant committee governing this work)

11.   Main research questions

The main research question to be addressed is:

How does making information about individual autistic pupils easily accessible to their teachers impact on the educational outcomes of this group?

a.   In what way does teacher behaviour/practice towards individual autistic pupils change?

b.   What visible, observable, measurable impacts on pupil outcomes occur? **(Primary focus)**

12.   Summary of methods including proposed data analyses

A mixed methods approach will be taken to measure the impact of the FAMe™ system on pupil outcomes and to explore the processes involved.

<u>Stage 1</u> **- System development** (Autumn term 1 & 2. Sept-Dec 2015)

As teacher acceptance and use of the system is key to the success of this project, it is essential to ascertain what teachers/those who understand teacher development think about the potential of the proposed system before finalising its development. Stage 1 therefore requires engagement with teaching staff **-** and those with expertise in the field of teacher learning and professional development - to ascertain whether they recognise potential in the new system in relation to enhancing / changing autism pedagogy and classroom practice and to identify potential barriers to its use.

Method:

A brief description of the project, followed by questions eliciting their response to it, will be sent via email / Qualtrics to a random sample of 10 teachers from one of SHU's research engaged schools. Participants will be invited to make contact with me via email should they wish to discuss/share their views in more detail.

In addition, conversations/informal interviews will be held (in person, by email or telephone) with members of SHU staff who have agreed to share their ideas (following meeting at conferences/ interest groups etc.) and who have expertise in teacher training / learning and professional development. Written notes will be made during / following these conversations.

Responses via qualtrics, email and verbal conversations will be collated and analysed according to salient themes.

Outcome: Key points raised will then be used to inform / finalise system development.

Recruitment of participants - outlined in detail in 'Section 3'.

Stage 2 - **Fieldwork** (Spring Term 1. Jan - Feb half-term 2016)

a). engage with individual autistic learners.

Verbally and visually introduce participants to the FAMe™ system - how it works/ what it is for/ how it will be used etc. Explain that the FAMe™ information is the *only* information that will be communicated to teachers (all other interview material will remain confidential).

Method:
Individual pupils will be asked to provide three pieces of information about themselves (FAMe™) that they would like their teachers to know. A semi-structured interview schedule will be designed around the generation of this FAMe™ information. The interview will contain questions relating to *why* the particular FAMe™ information was chosen/prioritised over other possibilities; *what difficulties*/issues are experienced - as a result of teachers not having access to this information at present*; and *what difference* they expect/hope teachers having access to this information will have**. Participants will be given the opportunity to share whatever information they choose / feel is important within the boundaries of these questions (expected time < 30 minutes).

*Participants will be asked to rate their current classroom experience (pre-system) at this stage of the interview on the following scale:

How OK have you felt in class over the last week?

I have felt completely OK -   I have
not felt OK at all - not at all anxious

                                                                                                        very

anxious
or worried   and
worried


```
        1           2           3           4           5
        ●  ━  ━  ━  ━  ━  ━  ━  ━  ━  ━  ●
```

**Participants will be asked to rate their predicted post-system classroom experience (when teachers have access to their FAMe™ information) at this stage of the interview on the following scale:

How OK do you think you will feel in class when teachers have your FAMe™ information?

I will feel completely OK -   I will not feel
OK at all -
not at all anxious   very
anxious
or worried   and
worried


```
        1           2           3           4           5
        ●  ━  ━  ━  ━  ━  ━  ━  ━  ━  ━  ●
```
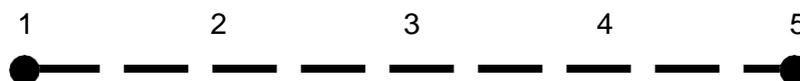
Additional materials - Example FAMe™ information; emoticons; photographs of classrooms/ teachers/ pupils; and paper and pencils for pupils to draw/ scribble on will all be available to facilitate communication and aid expression of ideas.

Interviews will be audiotaped and written field notes will be made post-interview to capture nonverbal communication / behaviours. Salient themes will be drawn from the audio data and particularly illuminating quotations will be transcribed for use in the discussion. Field notes and anything 'produced' by pupils using the additional materials will be used to enrich the audio data.

Short break if necessary.

a. Collect quantitative pre-intervention data from participant self-report measures:
- Myself as a Learner Scale (MALs) - (Burden, 1998)
- Beck Youth Inventory 2nd ed. (BYI-II) Anxiety and Depression sub-scales - (Beck et al., 2005)

b. **Run a training session with teachers.** Introduce all teachers of the participants to the FAMe™ system. Explain/demonstrate how it works, what I am asking of them - i.e. check if FAMe™ information is available for a class prior to the start of a lesson and to read it if it is.

c. **Check out with pupil participants that:**
  - they are satisfied that the FAMe™ information produced
  - it is an accurate reflection of the information they provided about themselves •
    they are happy for it to be entered into the system.

This will be done via parental email address with an option to meet and discuss if desired.

d. **Collection of school tracking and Local Authority Autism Team (LAAT) data** for Autumn half-term 2 and Spring half-term 1 (Oct. 15 - Feb. 16) — i.e. data concerned with pupil behaviour, attendance, attainment, progress and exclusions will be collected for each participant.

Stage 3 (February 1/2 term - 2016)

Engage with participating school IT personnel to input the pupil FAMe™ data and implement FAMe™ system (to run until end of Summer half-term 2)

Stage 4 (Summer half-term 2 - 2016)

a). re-engage with autistic participants.

- Semi-structured interview repeating the administration of the first rating scale i.e.

**How OK have you felt in class over the last week?**

I have felt completely OK -   I have
not felt OK at all - not at all anxious

          very

anxious
or worried   and
worried

    1   2   3   4   5

●— — — — — — — — —●
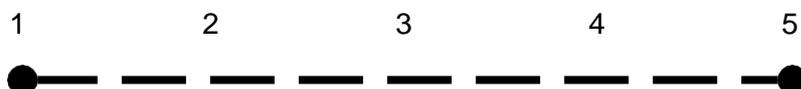
as the main point for discussion:

- Have you noticed *any difference* in the way your teachers' behave towards you since the FAMe™ system was introduced?
- Has this helped you? In what way/s?

Additional materials - emoticons; photographs of classrooms/ teachers/ pupils; and paper and pencils for pupils to draw/ scribble on will all be available to facilitate communication and aid expression of ideas.

The same protocol for recording/analysing data will be used as at Stage 2.

Short break if necessary.

Collect quantitative post-intervention data from participant self-report measures:

- Myself as a Learner Scale (MALs) - (Burden, 1998)
- Beck Youth Inventory 2nd ed. (BYI-II) Anxiety and Depression sub-scales - (Beck et al., 2005)

b). engage with teachers

Recruit a group of teachers from those who had access to the FAMe™ system and hold a focus group (n=5):

- Did you engage with the system?
- How easy was it to use?
- Are there any improvements that could be made?
- Were there any barriers to your using it? - What were they?
- In what way do you think your behaviour changed as a result of having access to the FAMe™ information?
- Do you think that changes in your behaviour have had an impact on your autistic pupils? In what ways?

Audiotape record the session and draw out salient themes for analysis.

Send survey via email/ Qualtrics to *all* the teachers who had a access to the FAMe™ system to establish how many teachers engaged with the FAMe™ system and whether they considered the pupil-specific information to be useful to them.

1. Did you use the FAMe™ System? Y/N (delete as appropriate)
2. Did you use it everyday? Y/N
3. Do you think it had an impact on your autism practice? Y/N
4. Would you continue to use it if it were available? Y/N

   Any comments about the system (ease of use/ usefulness etc.)?

c). Collection of school tracking and LAAT data (for Spring half-term 2 & Summer half-term 1. Feb - June 2016) i.e. data concerned with pupil behaviour, attendance, attainment, progress and exclusions will be collected for each participant.

Realistic Evaluation

- What was it about the FAMe™ system that worked for whom in what contexts?

  i.e. **Mechanism + Context = Outcome** (Pawson ad Tilley, 1997)

Programme hypothesis testing:

SPSS t-test analysis will be used to identify any significant differences in pupil self-report scores and school tracking/ LAAT data collected pre- and post-implementation off the FAMe™ system

Significantly different pre/post FAMe™ results will suggest evidence of impact. Programme hypothesis testing (Pawson and Tilley, 1997) will then be utilised to explore connections between this quantitative data and any salient themes drawn from the qualitative interview, focus group and survey data to explore the possible mechanisms and contexts involved in the change process.

This is important information for decision makers to have available, in order to target future populations who may benefit from the FAMe™ system (should it prove to have a positive impact on pupil outcomes).

References:

Burden, R.L. (1998) 'Assessing children's perceptions of themselves as learners and problem solvers. The construction of the Myself-As-a-Learner Scale'. School Psychology International 19 (4), 291-305.

Beck, J.S., Beck, A.T., Jolly, J.B., & Steer, R.A. (2005). Beck Youth Inventories Second Edition for Children and Adolescents manual. San Antonio, TX: PsychCorp

Pawson, R. and Tilley, N. (1997). Realistic Evaluation. Sage: London

SECTION B

1.   Describe the arrangements for selecting/sampling and briefing

potential participants. Stage 1.

Members of Sheffield Hallam teaching staff who have expertise in the area of teacher learning, fellow postgraduate students who are also teachers, and secondary school teachers/ SENCos from SHUIoE Research Engaged Schools Network will be contacted via email (see Appendix 1).

Stage 2.

Two/three secondary schools from the SHU research engaged network will be selected, based on their proximity to researcher / travel links for ease of access and the number of children with autism on roll. The average number of mainstream autistic pupils on roll at Sheffield secondary schools is 14. The target number of participants for this project is 20.

School recruitment criteria:
- Must use the Capita SIMs software system
- Must have >10 pupils with a diagnosis of Asperger Syndrome on roll (Y7-11)
- Must not have an autism specialist integrated resource within the school

- Must make commitment to engage* for duration Jan-July 2016

n.b. Schools with an autism specialist integrated resource will be excluded from the selection sample, as autism practice in those schools is unlikely to represent the majority of schools who do not typically have staff with high levels of autism expertise.

***School engagement will involve**:
- Making a commitment that ALL teachers of the autistic learners who have provided FAMe™ information will use the FAMe™ system
- Facilitating pupil interviews - providing a suitable room and possibly a member of staff SENCo if the interviews are to be held at school
- Authorising school IT staff to work with me to input the FAMe™ data into the system
- Facilitating teacher participation by allowing them time to attend the focus group
- The Headteacher will be contacted in the first instance to establish interest in being involved/ commitment to full-engagement and to obtain permission to discuss the project with the SENCo.

Once participating schools have been recruited:
I will meet with the school SENCo / members of the inclusion team to discuss the project and what is involved. Recruitment materials will be distributed to potential participants and their parents via the school SENCo who will remain the point of contact for potential participants and their parents until they a). choose to contact me for further information or b). informed consent has been obtained (see appendices 2-5 for information and consent forms).

2. **What is the potential for participants to benefit from participation in the research?**

Stage 1.

Teachers - no immediate benefit to teachers but potential long-term benefit if project objectives are met and system gets rolled out. **Pupils** - not involved at this stage

Stage 2.

Pupils:
- The potential benefit to pupils comes from their teachers having access to information that *they* have chosen to share. The process of obtaining the FAMe™ information from the pupils has the potential to make them feel valued and listened to as does the knowledge that their school has committed to a project aimed at facilitating teachers to better meet their learning and classroom support needs.

- If teachers' response to the pupil information is to better accommodate their classroom support needs then this has the **potential to improve pupil experiences and outcomes**.

Teachers:
- One **potential benefit** to teachers of being provided easy access to pupil-generated FAMe™ information is that, by accommodating/meeting the learning/support needs of autistic pupils, **pupil outcomes will potentially improve** - short-term outcomes, such as a reduction in challenging classroom behaviour and barriers to academic progress, and long- term outcomes, such as enhanced QoL and higher levels of academic achievement, have the potential to benefit **teachers** who are **accountable**

for the progress and attainment of their pupils.

- It is possible that teacher confidence in and satisfaction from teaching autistic pupils will increases a result of having a better understanding of their needs and being able to meet them this is not a focus of the research but may be a theme found within the data

3. **Describe any possible negative consequences of participation in the research along with the ways in which these consequences will be limited.**

Stage 1.

Teachers - are being asked to give up their time for no personal benefit - limited consequences as participation voluntary

Pupils - not involved at this stage

Stage 2.

Teachers:

- Are expected to do something in addition to their already busy workload - the FAMe™ system has been designed to be as easy and time efficient as possible

Pupils/parents:

- might feel pressured into participating and/or fear that they will be disadvantaged by not taking part - it will be made clear in the information and consent forms that participation is voluntary, that they are free to withdraw at any time and that non-participation will not affect their current relationships with school

Pupils:

- Might feel anxious about taking part and meeting a new person - as much information and communication as is needed to allay any anxieties will be provided. Pupils/parents will have the chance to email/telephone me, during the decision to consent phase, in order to discuss any issues of concern. Pupils may bring their parent/s or ask for a member of staff to be present throughout their interview. Alternatively interviews can be held at home if pupils feel more comfortable with that option.

- Might have expectations of the project that exceed what it actually achieves and feel disappointed by the lack of positive change in their school experiences - ensure pupils understand that this is a trial and it might not work.

- Might find the experience of talking about their experiences at school upsetting (especially if they have been negative) - It will be ensured that the member of school staff and/or parent, who usually provides the pupil with emotional support is available should they need to spend time with them following the interview - the interview can be paused/stopped immediately that a participant indicates that they are becoming distressed.

- Might find fitting interview time into an existing routine distressing - provide as much flexibility as possible about time and place of interview and plenty of notice with reminders leading up to it.

- Might be anxious about the interview itself and worry about what they will be expected to talk about - provide a copy of the interview schedule and details about how long it is expected to take.

4.   Describe the arrangements for obtaining participants' consent.

a). Schools - Headteachers of SHU Research Engaged Network schools will be approached via email and informed of the project (Appendix 2), its aims and what is involved. They will be encouraged to contact me by email or phone to discuss the project further. If they are interested in being involved in the project, permission will be sought to make email / telephone contact with the SENCo to establish their agreement to be the main point of contact between myself and the participants (autistic pupils and their parents) during the early stages (util informed consent is given).

b). Consent to participate will be requested from **parents and pupils.** Lack of either parental or pupil consent will result in a pupil not participating. SENCos will be given information/ consent packs to distribute to the parents of all pupils with a diagnosis of Asperger Syndrome on school role in both paper and email format. Information packs will include a link to a youtube video of me explaining the project and what is involved (see Appendices 2-5).

5.   Describe how participants will be made aware of their right to withdraw from the research.

Opt-in rather than opt-out recruitment method used - if potential participants do not respond then no further contact with them will be made - parents to be provided with my contact details for further information/ to discuss concerns. Their right to withdraw at any time will be made clear at each stage of the project as will their option to withdraw their child's data from the analysis - which will remain until the end of fieldwork in July 2016.

6.   If your project requires that you work with vulnerable participants describe how you will implement safeguarding procedures during data collection.

- School's safeguarding code of practice will be adhered to at all times.

- Participants will be given the option to have a familiar/preferred adult with them at all times during their contact with me.

- Confidentiality contracts will be dawn up between myself and the participants - it will be made clear that all information provided will be confidential (except the FAMe™ info which is designed to be shared) but that should anything be disclosed that makes me believe the participant or any one else is in danger/at risk, I have a duty to report that to the relevant authority (in this case the school Headteacher/SENCo) who will follow the statutory process for dealing with such issues.

- Participants will be told if I am going to report what they have told me and will be encouraged/ supported to share it with school/their parents themselves.

7.   If Disclosure and Barring Service (DBS) checks are required, please supply details

    • SHU DBS check request been made - process under way

8.   **Describe the arrangements for debriefing the participants.**

•   Following the Stage 2 pupil interviews, participating pupils will each receive a copy of their FAMe™ information before it is entered into the system. They will have the opportunity to amend the information if they feel it does not correctly reflect their classroom support needs. It will be explained that this is the ONLY information their teachers will be given and that no other information that was discussed during the interview will be shared.

•   Following Stage 4, when pupils have completed their post-intervention self-report measures details of their scores, whether they have changed since Stage 2, and what they might indicate about them as an individual with be shared with them and their parents.

9.   **Describe the arrangements for ensuring participant confidentiality.**

• Audio data will be collected using an iPod touch secured with password protection. This data will then be will the be transferred (using WebDAV) and stored securely on the SHU servers, following SHU guidance.

• Any written notes taken will be kept in a notebook which will be stored securely.

• Typed notes will be stored locally on a laptop computer, using password protection, and will also be transferred to the SHU servers. This will ensure that no data is accessible to anyone other than myself.

• Data will be anonymised (participants given numbers) and participant names and their corresponding numbers will be stored separately to ensure that, as far as possible, participants are not identifiable to anyone except me.

• Every effort will be made to preserve confidentiality, except in cases where a child protection issue arises. In these cases I will discuss this with the individual involved and support them to approach the child protection officer in their school. Should this not be appropriate, I will inform the pupil concerned of my intentions and approach the child protection officer myself.

• No data will be used where the individual concerned is identifiable except the FAMe™ information which is to be entered into the school SIMs software system and accessed by teachers.

10.   **Are there any conflicts of interest in you undertaking this research?**

• No conflicts of interest have been identified

11.   **What are the expected outcomes, impacts and benefits**

of the research? It is expected that this research:

• will enable teachers to better meet the classroom support needs of individual autistic pupils
• will have a positive impact on a range of outcomes for autistic pupils
• will identify conditions/mechanisms within the process that facilitate/restrict positive impact
• will identify characteristics of pupils, for whom impact was significant, which are shared by other vulnerable groups (e.g. high levels of anxiety/depression) enabling effective targeting of the system in the future

- will positively impact on teachers' confidence and sense of agency when working with autistic pupils

12.   Please give details of any plans for dissemination of the results of the research

It is expected that results of this research:

- will be written up for publication in academic and practitioner journals
- will be shared with the schools involved
- will be shared with Sheffield City Council
- will be presented to audiences at academic and practitioner conferences

SECTION C

RISK ASSESSMENT FOR THE RESEARCHER

1.   Will the proposed data collection take place on campus?

~~Yes   (Please answer questions 4, 6 and 7)~~
No   (Please complete all questions)

2.   Where will the data collection take place?
(Tick as many as apply if data collection will take place in multiple venues)

Location -- Please specify		
Researcher's Residence		
Participant's Residence	✔	pupil choice
Education Establishment	✔	pupil choice
Other		

3.   How will you travel to and from the data collection venue?

On foot   By car ✔   Public Transport

Please outline how you will ensure your personal safety when travelling to and from the data collection venue

I will make sure I know the route beforehand and leave plenty of time to avoid stress.

4.   How will you ensure your own personal safety whilst at the research venue?

If the interviews/ data collection takes place on school premises I will ensure I am aware of the emergency evacuation protocols and procedures. I will ensure that I sign myself in and that a member of school staff knows who I am with, what I am doing and where.

Interview sessions with participants in school or in their home will be audiotaped for data collection. If in a participant's home I will request that a parent is present during the interview. The audiotaped material will provide a record of any incidents for evidence should a complaint occur/ need to be made.

5. **If you are carrying out research off-campus, you must ensure that each time you go out to collect data you ensure that someone you trust knows where you are going (without breaching the confidentiality of your participants), how you are getting there (preferably including your travel route), when you expect to get back, and what to do should you not return at the specified time. (See Lone Working Guidelines). Please outline here the procedure you propose using to do this.**

I will share my travel plans/ itinerary with my husband and keep my mobile phone available at all times (this is hands-free in the car).

6. **Are there any potential risks to your health and wellbeing associated with either (a) the venue where the research will take place and/or (b) the research topic itself?**

> **None that I am aware of**
> ~~Yes (Please outline below)~~

7. **Does this research project require a health and safety risk analysis for the procedures to be used?**

> ~~Yes~~
> **No**

Adherence to SHU policy and procedures

Personal statement
I con8irm that: • this research will conform to the principles outlined in the Shef8ield Hallam University Research Ethics policy • this application is accurate to the best of my knowledge

Principal Investigator	--	Julia Leatherland
Signature		JML
Date		02/07/2015
Supervisors	--	Dr Luke Beardon & Dr Bronwen Maxwell
Signature		Luke Beardon
Date		15.08.15
Other signature		
Signature		Bronwen Maxwell
Date		13/7/15

Appendix 3

Communication with Capita about FAMe™ System Development

From: Neal, Phil (SIMS8 Business Readiness) – email address removed
Sent: 09 September 2016 12:19
To: Julia Leatherland – email address removed
Subject: RE: SIMS idea

Hi Julia

I've had a discussion with Lucy about your suggestions. Here's what she has said:

The change request that Julia is asking for, is already implemented in SIMS Primary! We have called it Learning Strategies, which is something that lots of schools liked the idea of when I went round researching SEN a few years ago. I am hoping that by surfacing it on the pupil log and class log, this will actually solve the problem that Julia is trying to solve. Most SENCOs feel that the reminder of what all students need, not only students on the autistic spectrum, is incredibly valuable to teachers. Once Julia has proof of how it is working with the mark sheets, it will be great to try and create a case study.

SIMS Primary is our next generation of software which starts being rolled out in April 17 but it will take a while to get all schools over to it! The secondary version will start to roll out late 2018.

I hope this helps and many thanks for making contact; it's really helpful to get feedback like this.

Best wishes

Phil

Appendix 4

PhD Project Participation Opportunity - Invitation to take part.

…'Communicating the Autistic Pupil Voice' [1]

Dear SENDCO,

I am writing to invite you to take part in an exciting project trialing a new pupil-to-teacher communication system in your school.

Previous research has highlighted the vulnerability of autistic pupils to a range of negative outcomes and the need for teachers to be better informed about the individual support requirements of these pupils.

The aim of this project is to give teachers easy access to information about individual autistic pupil's classroom support needs at the beginning of *every* lesson.

It is hoped that by increasing teacher awareness of the classroom support needs of their individual autistic pupils, teachers' behaviour will change to accommodate these, and autistic pupils will feel less anxious and more able to engage with their learning. Outcomes relating to pupil well-being and academic achievement will be monitored and used as a measure of system success/impact.

The system is called FAMe™ (which stands for Facts About Me) and has been designed to sit within the existing school SIMs software. It will:

- **contain information provided by the individual pupils themselves** (i.e. pupil's answers to, 'What would you most like your teachers to know about you/ do/ not do when you are in their lessons?')

- **give teachers one-click access to 3 FAMe™ statements with a photo** of each autistic pupil attending the lesson about to be taught

- **be easily updatable** so that pupil support needs can be reviewed as often as necessary and the system updated to reflect this

- **have no financial cost** to implement.

This project has been granted full ethical approval by Sheffield Hallam University's Research Ethics Committee.

What will taking part involve?

If your school would like to take part in this research project you, as SENDCO, will be my main point of contact.

---

[1] Autistic is used to refer to any pupil with a diagnosis considered part of the autistic spectrum. Currently, in mainstream secondary schools, the majority of pupils with an autism diagnosis will be diagnosed with Asperger Syndrome.

I will provide you with project information and consent packs to be sent to all autistic pupils on roll (years 7-10) and their parents. Once I have received the completed consent documentation:

- **I will hold semi-structured interviews** with all participating pupils at the place of their choice
  i.e. In school / at home / or via email

n.b. pupils will be given the option of having a member of staff or their parent present during the interview if it is to be held face-to-face.

Pupil interviews will be based around the generation of their three FAMe™ statements. During the interviews pupils will also be asked to complete some self-report questionnaires, exploring issues such as their engagement with school and their emotional well-being. Interviews will be conducted before the system is in use within school, and at the end of the trial (July 2016).

- **I will work with your school's IT department to set up the FAMe™ area** of the SIMs register page and input pupil information (FAMe™ system design has been completed in collaboration with Sheffield City Council IT officers to ensure compatibility with SIMs).

- **I will run a short training session with teachers to introduce them to the FAMe™ system** and how to use it - i.e:

  - At the start of a lesson click on the FAMe™ symbol next to the register
  - If a participating pupil is in that lesson their FAMe™ information will be viewable
  - If there are no participating pupils in that lesson this area will remain empty
  - Please read the FAMe™ information, ensure you know which pupil it relates to, and use it to help you provide the appropriate classroom support for that individual.

An example of what might be held in the FAMe™ area is:

Isabel Smith

1. Please don't draw attention to me or ask me questions in front of the class
2. It helps me if you can check I have understood a task before I begin working on it
3. I fiddle with things like blu tac to help me to concentrate

Joe Roberts

1. I find it hard to organise my work
2. I will take what you say literally – I might appear rude but it is not my intention
3. If I am not working it means I have not understood what you want me to do – please break down my instructions into smaller tasks

n.b. all teachers in a participating school should be encouraged to engage with the FAMe™ system for the duration of the project.

- **In July 2016 all teachers in a participating school will be contacted** via email and asked to complete the following and return it to me:

- Did you use the FAMe™ System? Y/N (delete as appropriate)
- Did you use it everyday? Y/N Before every lesson? Y/N
- Do you think it had an impact on your autism practice? Y/N
- Would you continue to use it if it were available? Y/N
- Any comments about the system (ease of use/ usefulness etc.)?

- **I will also be seeking to recruit a focus group of teachers (between 5 and 10)** to discuss their experiences of using, and opinion of, the FAMe™ system.

What do you need to do now?

If you are interested in finding out more about this project, or would like to sign your school up to take part, please contact me at julia.leatherland@student.shu.ac.uk to arrange a meeting or telephone discussion. All information and consent documentation is available on request.

I look forward to hearing from you,

best wishes,

Julia Leatherland
Doctoral Research Student
Sheffield Institute of Education

A bit about me.

- I am a mother of five children diagnosed with Asperger Syndrome.
- I have a first degree in Psychology, a Post Graduate Certificate in Asperger Syndrome, and a Masters Degree in Autism.
- I have experience of working with autistic individuals.
- I have experience of administering self-report measures.
- I am fully DBS checked.

I am committed to carrying out research that meets the current priorities of the autistic population - that is - research that can respond to the needs of autistic individuals and has the potential to effect immediate positive change within their lives. Listening to and sharing the voice of autistic individuals and the adoption of inclusive, participatory research methods are at the centre of my research practice.

Welcome to the FAMe™ Project

This pack contains information about the project

This link is to a five minute animation explaining the project
https://youtu.be/IWZSaTZrO8U

It would be great if you could take the time to watch it with your child

Pack Contents:

1. Parent Information - Short Form

A summary of the project for you to read first

2. Detailed Information for Parents

Includes information about my use of terminology; the background to the research; what will be involved for your child if you give permission for them to take part; project timings; contact details; and information about data security and storage

3. Pupil Information - Short Form

A summary of the project for your child to read first

4. Detailed Information for Pupils

Includes information about my use of terminology; the background to the research; what will be involved for your child if they take part; project timings; contact details; and information about data security and storage

5. Consent Forms

One to be completed and signed by you (parent/carer consent) One to be completed and signed by your child (pupil consent)

Appendix 5b

For animated video presentation please go to https://youtu.be/IWZSaTZrO8U

Hi,

My name is Julia Leatherland. I am a PhD student at Hallam University and I am doing a research project at your child's school.

My special research interest is autism - this interest started when I discovered that my own children are autistic.

Because your child has a diagnosis of an autism spectrum condition - which you might know as autism, Asperger syndrome, PDA or ASD - they are being invited to take part in my project.

There is research which suggests that autistic pupils find school more difficult than pupils who are not autistic. Some researchers think that this is partly because teachers don't really 'get' autism or understand what their autistic pupils need to help them learn better in the classroom.

I want to find out more about whether this is true. I have designed a system to remind your child's teachers about what support your child needs from them. I need your child's help to see if my system makes a difference to how well they learn and how they feel about school.

The system is called FAMe™. This stands for **F**acts **A**bout **M**e. Teachers will be able to see a list of 3 facts about your child (things your child has decided they want their teachers to know) when they take the register at the start of each lesson. These facts can be anything about your child that your child would like their teachers to know, or ways they would like their teachers to support them.

For example, one of my own children wants their teachers to know that they fiddle with blu-tac to help them to think, and need to be allowed to do it without the teacher commenting on it; another doesn't want to be asked to speak out in front of the class and finds it hard to work in groups of more than 3; and another needs their teachers to make sure they have written their homework down and understood the instructions before they leave the classroom. These are all things that they would put in their FAMe™ information.

It can be hard for teachers to remember all these things about all their different pupils all of the time. Especially at secondary school when they teach lots of classes and might only see your child for a few hours a week. The FAMe™ system has been designed to remind them.

If you consent to your child taking part in the project they will:

Meet me to talk about the information they would like their teachers to know about them. Together we will work out the 3 things that they think would be most helpful to remind their teachers of at the start of every lesson (their FAMe™ information).

n.b. FAMe™ information will be seen by teachers on their computer screens when they take the register - it will not be shown to anyone else.

I will talk to your child about their FAMe™ information because I would like to understand:

Why they feel that these particular things are important for their teachers to know

What difficulties/issues they currently experience in class, if any

What difference they think it will make to them when their teachers know and use their FAMe™ information in lessons

I will also ask your child to complete some questionnaires. I can read the questions to them and fill in the answers they give me, or they can fill them in by themself - whichever suits them better. I will be there to answer any questions they have. The questionnaires will give me an idea about how your child feels about themself and how much they like school. No one else will see the answers they give.

There are no right or wrong answers to any of the questions I ask your child. There are no tests. This project is about finding out if there is a way to help teachers enable their autistic pupils to feel more positive at school and not about how good your child is at answering questions.

I will give both you and your child my email address. This is so that if you - or they - want to tell me about anything that has happened at school, for example if one of your child's teachers has done something differently that was helpful to them - or if something less good has happened - you/they can let me know. I will not be able to comment or give you advice. I will only send you a 'thank you' response, so that you know I have received your message. It will be like you/your child is keeping a diary about school that only I can see. Any information you write and tell me about will help me with the research, but you don't have to tell me anything if you don't want to.

After about 4 months - before the end of the summer term - I will ask to meet your child again. We will talk about whether anything has changed for them at school and I will ask them to fill in the same questionnaires again. This is so I can compare their answers with the ones they gave at our first meeting and see whether their feelings about school and themself have changed since the start of the FAMe™ project.

If you would like to ask me any questions about the FAMe™ project you can email me at: address removed

If you think you would like your child to take part in the FAMe™ project, I need you to complete a consent form. I can't meet or talk to your child without your permission. I have also included more detailed information about the project in the 'Detailed Parent Information Sheet' for you to read. This sheet tells you things like who my supervisor at university is, what happens to the information you give to me, and lets you know that you can decide that you don't want your child to take part anymore if they don't like being in the project.

I have also made a video animation outlining the same information as is written here (see https://youtu.be/IWZSaTZrO8U). This is because people are different - some find it easier to understand information when they read it to themselves and others like to hear it read to them and see it in small amounts at a time. I am trying to make the information about my project as easy as possible for as many people as possible to understand.

I really hope you decide that you would like your child to help me trial the FAMe™ system in their school and that you say 'Yes' to them being in the FAMe™ Project.

I look forward to meeting them if you do,

best wishes,

Julia Leatherland

Appendix 5c

Detailed Information for Parents

Key points are highlighted in bold

**Please read this information about my PhD research project…**

You can also go to https://youtu.be/IWZSaTZrO8U to hear me talking about the project.

> **I want to find out whether autistic pupils have a more positive experience at school when their teachers are reminded about: 1). the support that they need in the classroom 2). what helps them feel comfortable and 3). what helps them to learn.**

The Research Project
A note about my use of language:

I use 'autistic' to describe individuals with any condition considered to be part of the autism spectrum. Recent changes to the diagnostic labelling system have seen Autism Spectrum Disorder (ASD) and autism become the new umbrella labels used to refer to all of the different autistic spectrum conditions - an umbrella label is a label that covers all the others and can be used to refer any of them. e.g.
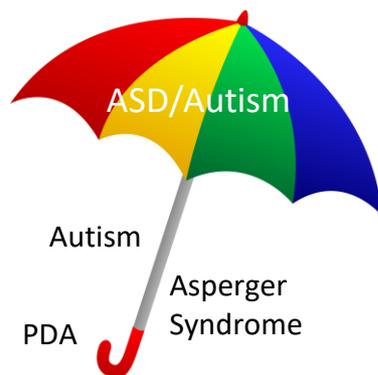
ASD/Autism
now used to refer to

all/any autistic spectrum conditions
Asperger Syndrome/Autism/PDA

I don't like the term 'disorder', because it suggests that something is wrong, so I don't ever use ASD. **I choose to use 'autism' and 'autistic'** instead.

> **Your child has a diagnosis of autism and attends a school that has links to Sheffield Hallam University's (SHU) Institute of Education, through a Research Engaged Schools Network. I am a PhD student at SHU working with supervisors from The Autism Centre (TAC) and The Sheffield Institute of Education (SIoE). Your child's school has agreed to take part in this project but, in order for your child to be involved, I need your permission and your child's permission too.**

Why have I sent this information pack to you?

Official Project Title

Autism Pedagogy and Pupil Outcomes: Communicating the Autistic Pupil Voice

> **Research has suggested that school can be particularly tough for autistic pupils and that they often experience more negative outcomes than pupils who are not autistic.**

Rationale

Some researchers think that the experiences and school outcomes of these autistic pupils would be more positive if teachers understood their individual classroom support needs better.

I think this is probably true and I also believe that **researchers should ask the pupils themselves** what they think and what support they would like in the classroom.

> **I have developed a new communication system to provide teachers with easy access to key facts about the learning and support needs of their individual autistic pupils. The key facts will be provided by the pupils involved and are known as 'Facts About Me' (FAMe). The system is called the FAMe™ system.**

The following information should enable you to decide whether you are happy for your child to take part in this trial of the FAMe™ system.

I have also made a video explaining the project which can be accessed via the following link **https://youtu.be/2x9ZFpD3y-k**

> **The project's aim is to find out whether the FAMe™ system enables teachers to better meet the classroom support needs of their autistic pupils, and whether this in turn leads to improved school outcomes for the pupils who take part. I need pupils with a diagnosis of autism to help me trial the system and see whether their teachers using it makes any difference to them.**

About the project

The system will be considered successful if a measurable positive impact is observed on a range of outcomes for the pupils who take part. I am interested in measuring whether there is an impact on outcomes such as self-esteem, anxiety levels, and educational engagement/attainment.

What will be involved for your child

> **a). Your child will meet me** to discuss what key information about them they would like their teachers to know/what information they think would help their teacher to support them.
>
> **Together we will write three statements of information** - their 'Facts About Me' (FAMe™ information).

This **FAMe information will be accessed by teachers**, before each lesson that your child attends, **to remind them of your child's support needs.**

An example of what your child's FAMe information might look like is:

• I fiddle with blu-tac when I am listening and it helps me to concentrate

• Please don't make me speak out in front of the class it makes me anxious

• I find it hard to work in groups and prefer working on my own or in pairs

Every child's **FAMe information** will be different as it **will represent** their **individual needs**.

I will talk with your child about the FAMe information they provide because I would like to understand:

1. **Why** they feel **these particular things are important** for their teachers to know

2. **What** difficulties/**issues they currently experience** in class if any

3. **What difference they think it will make** to them when their teachers know and use their   FAMe information

When I am talking to your child **our discussion (interview) will be audiotaped**. The recording will be heard only by me and possibly by my supervisor and PhD examiner (although they won't have met your child and the recording will have been anonymised).

I will be able to **identify issues that are particularly important to your child**. I will also explore whether themes exist across the experiences of all the autistic pupils taking part - within individual schools and across schools. Uncovering themes, if they exist, will enable me to provide more general feedback to schools at the end of the project to improve their understanding of the issues facing this group of pupils and inform their ongoing inclusive practice.

After approximately **four months** of the system being available to and used by teachers, **your child will be asked to meet me again** to discuss whether they feel the system has made any difference to their classroom experiences and what this has meant for them.

I anticipate that the interviews will last no more than 20 minutes each.

<u>Where the project will take place</u>

I understand that your child might feel anxious about talking to me and I would like to help them to feel as comfortable as possible. **The preference is for interviews to take place at school but** if it would make your child feel more relaxed **I can arrange to see him/her at home**. **You can be present if you or your child wishes** and you are especially welcome if you feel that you will be able to help your child identify and articulate their needs.

If the interview is to take place in school and you do not wish/are not able to be present, your child will be asked whether they would like a familiar/supportive member of staff to attend with them.

Every effort will be made to ensure that your child is prepared for and comfortable with what they are going to be doing with me.

I do not wish any child to be excluded from the project because the methods being used to collect data do not suit their preferred communication style. In the event that your child wishes to take part, but does not feel able to meet me face-to-face, **it is possible for me to carry out an email interview** in order to collect their information. Any contact I have with your child via email will be at a time which has been pre-arranged with you. I will not send or reply to emails from your child without your knowledge and agreement.

I have a range of visual materials/prompts (emoticons, photos of classrooms etc.) which will be made available to all pupil participants during the interview sessions to aid the production of ideas and to facilitate communication and identification of emotions. Your child will be given the choice about whether they wish to use them.

There will be opportunities for you and/or your child to meet, phone or email me before taking part in the interview, to discuss how best to meet their communication needs during the project.

> **b).** **As well as taking part in an interview your child will be asked to complete two self-report measures on which they will indicate which answer most represents the way they are feeling/what they think about themselves.**
>
> **These measures provide an indication of your child's levels of anxiety and depression and how they feel about themselves as a learner (academic**

Your child will be asked to complete these measures before their teachers have had access to their FAMe information and after approximately four months of it having been available to and used by teachers.

Results of these self-report scales will be used as a measure of system impact, with improved post-system scores (e.g. lower levels of anxiety) indicating system success.

These **self-report measures will take between 10-20 minutes for your child to complete** depending on their comprehension and whether they require the items to be read to them and/or their answers to be scribed. Again, every effort will be made to allow your child to engage with the self-report measures in the way that they are most comfortable with.

> **c). I will give your child my email address.** **This is so that if they want to tell me about anything that has happened at school, for example if one of their teachers has done something differently that was helpful to them - or if something less good has happened - they can let me know.**

I will not be able to comment on their emails or give them advice. I will only send you a 'thank you' response, so that they know I have received their message. It will be like they are keeping a diary about school that I can see.

Any information they write and tell me about will help me with the research, but **they don't have to tell me anything if they don't want to**.

> **d). In addition to collecting the above information from your child, I would like your permission to examine your child's school-tracking data** (e.g. behaviour points, achievement, attendance, exclusions etc. which is held on their record at school). **I will not access this information without your permission**. Analysing whether these factors change over the course of the FAMe™ project will help me to work out whether the system is helpful in reducing stress for autistic pupils.

When the project will take place

I will be interviewing pupils in January/February 2016 and during the last half term of the academic year (July 2016). Teachers will have access to and will be encouraged to use the FAMe™ system between these times.

Debriefing

I will be available in person, over the phone or by email should you or your child have any questions/concerns following taking part in any stage of this project.

Individual teachers will not have access to any of the information provided to me by you/ your child, except the FAMe™ information which is to be entered into the system.

However, **if your child shares information with me that I think it would be beneficial for certain school staff to know**/ enable them to better meet your child's needs (e.g. the school SENCo), **I will discuss this with your child**. Any ongoing **issues** that are **causing your child distress will need to be passed on to the relevant safeguarding staff**.

I will only share information about your child if I believe it is in their best interests for me to do so and I will not share information about your child without their knowledge.

I will not discuss your child with anyone outside school.

N.B. **If a child safeguarding issue arises**, and I believe your child or another is at risk of harm, **I have a duty to inform the member of school staff responsible for pupil protection** and safeguarding.

Who will be responsible for the information your child has given me when this study is over?

I am responsible for making sure the information your child gives me is kept safe and destroyed when it is no longer needed. Because I am a student I have a supervisor whose job it is to ensure I keep all the project information safe.

What will happen to the information your child has given me when this study is over?

It will be stored in the secure archives at Sheffield Hallam University.

I hope to write articles which will be published in journals so that other professionals can learn from the results. The publishers of journals require researchers to keep their data for a certain period of time so that they can prove that their findings were real and not just made up. **It will not be possible for anyone to identify your child** from the data as they will be given a unique number when they enter the project and only this will be stored with their information. When I am sure that I will not need to access the data again I will remove it from the archive and destroy it.

Who will have access to the information your child has given me when this study is over?

The **information your child gives me will be anonymised** and placed into a secure archive at Sheffield Hallam University where **only myself and my supervisor** (and possibly my PhD examiner) **will ever be given access to it**. It is anonymised so that my supervisor and the examiner will not be able to connect any information to your child – this means that your child will be allocated a unique number and all their information will be stored under that number. No record of their name will be kept with the information I collect from them.

What will happen to the results at the end of the project?

Once the project is complete **I will write up my findings in a 'Report for Pupils' and a 'Report for Parents'**, as well as in articles, to be submitted to academic and practitioner journals, and as a thesis to be submitted for the award of PhD.

You and your child will receive copies of these reports and be notified of any publications that follow. No one will know which information came from your child and which came from other pupils. **No one will know that your child was involved in the project unless you choose to tell them.**

How I will ensure your child's confidentiality is protected

When your child becomes a participant in this project they will be **assigned a unique reference number** (code). This unique number will be used to identify all of the data provided by/ collected about them. The information that links your child's name to their number will not be stored on the same device as their data. All information will be stored on password protected machines and no person will have access to it except for me (my supervisor and external examiner might ask to see anonymised examples of data). When reports are written about this project and its findings, **no identifying material will be used that will connect any data to your child.**

Participation is voluntary and you are free to withdraw

There is no obligation for you to give your permission for your child to take part in this project.

If you give permission and then change your mind **you are free to withdraw from the project at any time** (before July 2016) and any information already provided by your child will be removed from the project database.

Once analysis of data has begun (July 2016) withdrawal of their data will no longer be possible. You can however request that no further contact is made with you/your child.

Please contact me if you have any questions about this project

Via email in the first instance **email address removed**

It will then be possible to arrange to meet in person or talk over the telephone should you prefer.

You are also able to contact my supervisor Dr Luke Beardon

Dr Luke Beardon,

Contact Details Removed

Dr Beardon is a Senior Lecturer at The Autism Centre Sheffield Hallam University. You should contact him if you have any questions, concerns or complaints about anything that happens during the course of this project.

What I need you to do now

1. If you would like your child to be involved in this project, **please complete and return the consent form which is included in this pack**.

2. **Please show your child the 'pupil information' sheet and/or video**, talk them through what is involved and ask them whether they would like to take part.

3. **Please ask your child to complete the pupil consent form** if they would like to participate.

4. **Please return both consent forms in the stamped addressed envelope provided**.

Thank you so much for your time

I look forward to meeting you and your child if you decide to take part

Appendix 5d

For animated video presentation please go to https://youtu.be/IWZSaTZrO8U

Hi,

My name is Julia Leatherland. I am a PhD student at Hallam University and I am doing a research project at your school.

My special research interest is autism - this interest started when I discovered that my own children are autistic.

Because you have a diagnosis of an autism spectrum condition - which you might know as autism, Asperger syndrome, PDA or ASD - you are being invited to take part in my project.

There is research which suggests that autistic pupils find school more difficult than pupils who are not autistic. Some researchers think that this is partly because teachers don't really 'get' autism or understand what their autistic pupils need to help them learn better in the classroom.

I want to find out more about whether this is true. I have designed a system to remind your teachers about what support you need from them. I need your help to see if my system makes a difference to how well you learn and how you feel about school.

The new system is called FAMe™. This stands for **F**acts **A**bout **M**e. Teachers will be able to see a list of 3 facts about you (things you have decided you want your teachers to know) when they take the register at the start of each lesson. These facts can be anything about you that you would like your teachers to know, or ways you would like your teachers to support you.

For example, one of my own children wants their teachers to know that they fiddle with blu-tac to help them to think, and need to be allowed to do it without the teacher commenting on it; another doesn't want to be asked to speak out in front of the class and finds it hard to work in groups of more than 3; and another needs their teachers to make sure they have written their homework down and understood the instructions before they leave the classroom. These are all things that they would put in their FAMe™ information.

It can be hard for teachers to remember all these things about all their different pupils all of the time. Especially at secondary school when they teach lots of classes and might only see you for a few hours a week. The FAMe™ system has been designed to remind them.

If you decide you would like to take part in the project you will:

Meet me to talk about the information you would like your teachers to know about you. Together we will work out the 3 things that you think would be most helpful to remind your teachers of at the start of every lesson (your FAMe™ information).

n.b. your FAMe™ information will be seen by teachers on their computer screens when they take the register

I will talk to you about your FAMe™ information because I would like to understand:

Why you feel that these particular things are important for your teachers to know

What difficulties/issues you currently experience in class, if any

What difference you think it will make to you when your teachers know and use your FAMe™ information in lessons

I will also ask you to complete some questionnaires. I can read the questions to you and fill in the answers you give me, or you can fill them in by yourself - whichever suits you better. I will be there to answer any questions you have. The questionnaires will give me an idea about how you feel about yourself and how much you like school. No one else will see the answers you give.

There are no right or wrong answers to any of the questions I ask you. There are no tests. This project is about finding out if there is a way to help teachers enable their autistic pupils to feel more positive at school and not about how good you are at answering questions.

I will give you my email address. This is so that if you want to tell me about anything that has happened at school, for example if one of your teachers has done something differently that was helpful to you - or if something less good happens - you can let me know. I will not be able to comment or give you advice. I will only send you a 'thank you' response, so that you know I have received your message. It will be like you are keeping a diary about school that I can see. Any information you write and tell me about will help me with the research, but you don't have to tell me anything if you don't want to.

After about 4 months - before the end of the summer term - I will ask to meet you again. We will talk about whether anything has changed for you at school and I will ask you to fill in the same questionnaires again. This is so I can compare your answers with the ones you gave at our first meeting and see whether your feelings about school and yourself have changed since the start of the FAMe™ project.

If you would like to ask me any questions about the FAMe™ project you can email me at: email address removed.

If you think you would like to take part in the FAMe™ project, I need you and your parent or carer to complete a consent form. I can't meet or talk to you without your parent/carer's permission. I have also included more detailed information about the project in the 'Detailed Information for Pupils' sheets for you to read. This tells you things like who my supervisor at university is, what happens to the information you give to me, and lets you know that you can decide that you don't want to take part anymore if you don't like being in the project.

I have also made a video animation outlining the same information as is written here (go to https://youtu.be/IWZSaTZrO8U). This is because people are different - some find it easier to understand information when they read it to themselves and others like to hear it read to them and see it in small amounts at a time. I am trying to make the information about my project as easy as possible for as many people as possible to understand.

I really hope you decide that you would like to help me trial the FAMe™ system in your school and that you say 'Yes' to being in the FAMe™ Project.

I look forward to meeting you if you do,

best wishes,

Julia Leatherland

Appendix 5e

Detailed Information for Pupils

Key points are highlighted in bold

Please read this information about my PhD research project…

You can also go to https://youtu.be/IWZSaTZrO8U to hear me talking about this project.

> **I want to find out whether autistic pupils have a more positive experience at school when their teachers are reminded about the support that they need in the classroom, what helps them feel comfortable and what helps them to learn.**
>
> **I have designed a new system to remind teachers about these things at the beginning of every lesson and this project is about testing whether**

The Research Project

Why I use the word 'autistic' instead of one of the other labels you might have heard.

I use 'autistic' to describe individuals with any condition considered to be part of the autism spectrum. You might have a diagnostic label of Asperger Syndrome, Autism or PDA, or you might have heard people say you have an 'Autism Spectrum Disorder (ASD). Autism and ASD are the new umbrella labels used to refer to all of these different autistic spectrum conditions - an umbrella label is a label that covers all the others and can be used to refer to them all. e.g.

ASD/Autism

Autism

PDA
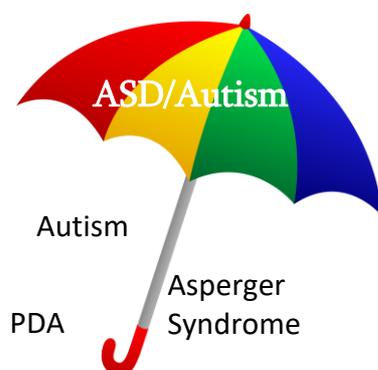
Asperger
Syndrome

ASD/Autism
now used to refer to

All autistic spectrum conditions
Asperger Syndrome/Autism/PDA

I don't like the label 'disorder', because it suggests that something is wrong, so I don't ever use ASD. I choose to use 'autism' and 'autistic' instead.

> **Research has suggested that school can be particularly tough for autistic pupils and that they often experience more negative outcomes than pupils who are not autistic.**

Why do we need a new system?

Some researchers think that the experiences and school outcomes of these autistic pupils would be more positive if teachers understood their individual classroom support needs better.

I think this is probably true and I believe that **researchers (like me) should ask pupils (like you)** what you think and what you would like.

The new system should enable these things to happen and **I am asking for your help** to see if it works.

Official Project Title

Autism Pedagogy and Pupil Outcomes: Communicating the Autistic Pupil Voice

What the title means for you:

a) If your teachers read some key facts about you before each lesson does it change the   way they behave towards you in the classroom?

b) If teachers' behaviour towards you in the classroom changes, does this make your
experience of school better and improve your outcomes?

About the project

The FAMe™ System
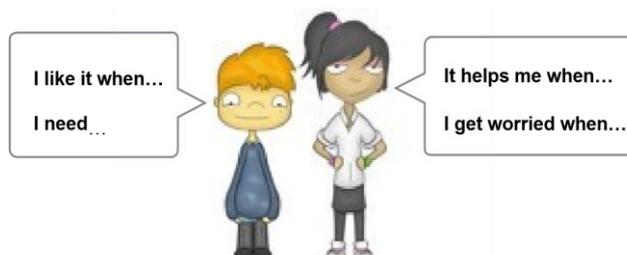
1. Autistic pupils provide 'Facts about Me' (FAMe™) information (things they think it would be useful for their teacher to know about them)

2. Teachers read the FAMe™ information before each lesson to remind them what each autistic pupil needs/ wants them to know

The project **aim is to** find out whether the FAMe™ system **help**s **teachers** to **meet** the classroom support **needs of their autistic pupils.**

The **system will be considered successful if** the **pupils** who take part **tell me that things have got better** for them in the classroom **and/or** if their **outcomes improve**.

Why I am asking you

> **I am looking for young people who have a diagnosis of autism to try out the system. Your school has agreed to take part in the project but I can't ask you anything or give your teachers information about you unless you and your parents or carers say it is OK for me to do so.**

What I am asking you to do

> **a). You will meet me…**
>
>
>
> - **Julia Leatherland**
> - **Phd Research Student at Sheffield Hallam University**
> - **Mum of 5 autistic children**
>
> **to talk about what *you* would like your teachers to know about *you*.**
> **We will work out what information you think would help your teachers to support you in the classroom.**

Together **we will write three statements** of information which will be **called your 'Facts About Me' (FAMe™).** This FAMe™ information will be read by your teachers, before each lesson, to remind them of your support needs. **FAMe™** will be on the teacher's computer and they will access it through the register**.**

Here are some examples of what FAMe™ information might look like

Every pupil's information can be different

- I fiddle with blu-tac when I am listening and it helps me to concentrate

- Please don't make me speak out in front of the class it makes me anxious

- I find it hard to work in groups - I prefer working on my own or in pairs

We will talk about your FAMe™ information because **I would like to understand:**

1. **Why** you feel **these** particular things **are important** for your teachers to know

2. **What difficulties**/issues **you** currently **experience** in class if any

3. **What difference** you think **it will make** to you when your teachers know and use your FAMe™ information

I would like to understand these things because it will help me to explain why the system works (if it does) and to persuade more schools to use it.

When we are talking, **our voices will be recorded**. The recording will only be listened to by me. It will help me to remember what you said and compare your answers to those of other autistic pupils who are also taking part in this project. The only things your teachers will find out about from what you tell me is the information we put into your FAMe™ statements.

After about four months of the system being used by teachers, **I will ask you to meet me again** (or email me) to talk about whether the system has made any difference to your classroom experiences and how this has made you feel. I will record this meeting/ interview as well.

How long will the interviews take and where will they happen?

Interviews should last no more than 20 minutes each. I know it can be tricky to meet someone you don't know and talk to them about how you feel. **I am happy for you to meet, phone or email me before taking part**, to discuss how to make you feel most relaxed and able to talk in our meetings.

You can bring a parent/ carer - or someone who supports you at school - to all our meetings if you would like to. **I want you to feel as comfortable as possible when you meet me** so, if you would like it better, and your parents don't mind, I can arrange to come to your house to interview you there.

If you really don't want to meet me face-to-face, but you would like to take part in the FAMe™ project, I can arrange for you to do your interviews via email. This must be agreed with your school and parents and we will only be able to contact each other via email at times that have been arranged in advance.

During the interview I will be showing you some rating scales and I will ask you to tell me on a scale of 1-5 how you feel about some things at school. There are no right or wrong answers to any of the questions I ask you. There are no

tests. **This project is about finding out if there is a way to help teachers make autistic pupils feel more positive at school** and not about how good you are at answering questions.

> **b).** **As well as talking to me about what you would like your teachers to know, I would like you to complete two self-report measures** (questionnaires).

You can read these to yourself or I can read them to you. You can check with me what the questions on them mean if you are not sure. **The questionnaires will tell me something about the way you are feeling and what you think about yourself**. It is important that I collect this information before your teachers start using your FAMe™ information and after about four months, so that I can tell if the system makes a difference to your overall mood and how you feel at school.

These questionnaires will take between 10-20 minutes to fill in. **No one** apart from me **will see the answers you have given**.

> **c). I will give you my email address. This is so that if you want to tell me about anything that has happened at school, for example if one of your teachers has done something differently that was helpful to you - or if something less good has happened - you can let me know.**

I will not be able to comment or give you advice. I will only send you a 'thank you' response, so that you know I have received your message. It will be like you are keeping a diary about school that I can see. Any information you write and tell me about will help me with the research, but **you don't have to tell me anything if you don't want to**.

When the project will take place

We will meet in **January or February 2016 and** some time in **June or July 2016**. Teachers will be encouraged to use the FAMe™ system between our meetings.

Every effort will be made to make sure that you understand and are happy with what you are going to be doing with me before we start.

Debriefing / answering your questions

I will be available in person, over the phone or by email **to answer any questions** or worries you have about taking part in any stage of this project.

Individual teachers will not have access to any of the information you give me, except your FAMe™ information which will be entered into the FAMe™ system. **Other members of school staff** - like your SENCo - **might need to be made aware of issues** you share with me. This will depend on what it is you tell me. **I will always tell you if I need to share something you have said** with someone else. **I will not discuss you with anyone without your knowledge.**

If a child safeguarding issue arises and I believe you or someone else is at risk of harm, I have a duty to inform the member of school staff responsible for pupil protection and safeguarding.

Who will be responsible for the information you have given me when this study is over?

I am responsible for making sure the information you give me is kept safe and destroyed when it is no longer needed. Because I am a student I have a supervisor whose job it is to ensure I keep all the project information safe.

What will happen to the information you give me when this study is over?

Your information will be stored in the secure archives at Sheffield Hallam University. Only myself and my supervisor will ever be given access to it. I hope to write articles about my findings for journals, so that other professionals can learn from the results. The publishers of journals require researchers to keep their data for a certain period of time so that they can prove that their findings are real and not just made up. When I am sure that I will not need to access the data again I will remove it from the archive and destroy it. When I write about this project no one will know that that you were one of the pupils taking part. I will not use any names – not even of schools.

What will happen to the results at the end of the project?

Once the project is complete **I will write up my findings in a 'Report for Pupils' and a 'Report for Parents'**, as well as in articles, to be submitted to academic and practitioner journals, and as a thesis to be submitted for the award of PhD.

You and your parent/carer will receive copies of these reports and be notified of any publications that follow. No one will know which information came from you and which came from other pupils. If you would like to tell

other people what you said then that is fine but they won't know from reading the report and I will never tell them.

How I will ensure your confidentiality is protected / that no one knows who you are

When you become a participant in this project you will be assigned a number (code). This unique number will be used to identify all of the information provided by/collected about you. The information that links your name to your number will not be stored on the same device as your data. All information will be stored on password protected machines and no person will have access to it except for me and my supervisor.
When reports are written about this project and its findings, **nothing will be used that will connect your information to you.**

Participation is voluntary and you are free to withdraw

You do not have to take part in this project - **participation is entirely voluntary**- that means **it is your choice.**

If you agree to be involved and then change your mind **you are free to withdraw** from the project at any time (before July 2016) and any **information** already provided by you **will be removed** from the project database.
Once analysis of data has begun (July 2016) withdrawal of your data will no longer be possible.

Please contact me if you have any questions about this project

Via email in the first instance **email address removed**

It will then be possible to arrange to meet in person or talk over the telephone should you prefer.

My supervisor is:
Dr Luke Beardon
Contact Details Removed

You or your parents can contact him if you have any questions about me or the project or if you are not happy about something I do.

What I need you to do now

- If you would like to be involved in this project, **please complete and sign the consent form** which is included with this letter

- **Your parent/ carer will also need to give permission** for you to be involved and have their own information sheet and consent form to complete

- **Please return all consent forms** to me in the stamped addressed envelope provided

Thank you so much for your time

I look forward to meeting you if you decide to take part.

Appendix 5f

Pupil Consent Form

TITLE OF RESEARCH STUDY: The FAMe™ Project

Autism Pedagogy and Pupil Outcomes: Communicating the Autistic Pupil Voice

Please answer the following questions by PUTTING A CIRCLE around the response that applies

1. I have read the Information Sheet for this study, watched the video – see link **https:// youtu.be/IWZSaTZrO8U** - and/or have had details of the study explained to me.

   YES   NO

2. I understand that I may ask the researcher (Julia) questions at any point during this study.

   YES   NO

3. I understand that I can stop taking part in the study at any time - until July 2016, without giving a reason. I know I can say I don't want to answer any particular questions in
the study and that that is OK.

   YES   NO

4. I understand that no one other than Julia Leatherland and her supervisor will see/hear the information I provide and no one will know who I am because Julia will always use a number instead of my name (make my information anonymous).

   YES   NO

5. I understand that if I tell Julia Leatherland something and she thinks someone at my school should know, because I need help or someone is in danger, she will share the information with the school SENCo. Julia will tell me she is going to do this.

   YES   NO

6. Would you like to take part in the FAMe™ project described in the information sheet?

   YES   NO

Pupil's name ……………………………………   **Date………………………..**

Pupil's signature…………………………….   **Pupil's email address…………………**

Researcher: Julia Leatherland

Contact Details Removed

Director of Studies: Dr Luke Beardon

Contact Details Removed

Parent Consent Form

TITLE OF RESEARCH STUDY: The FAMe™ Project

Autism Pedagogy and Pupil Outcomes: Communicating the Autistic Pupil
Voice

Please answer the following questions by PUTTING A CIRCLE around the responses that apply

1. I have read the Information Sheet for this study, watched the video – see link **https:// youtu.be/IWZSaTZrO8U -** and/or have had details of the study explained to me.

                                                                                    YES   NO

2. I understand that I may ask the researcher (Julia) questions at any point during this study.

                                                                                    YES   NO

3. I understand that I can ask that my child stop taking part in the study at any time - until July 2016, without giving a reason. I know I can say I don't want my child to answer any particular questions in the study and that that is OK.
                                                                                    YES   NO

4. I understand that no one other than Julia Leatherland and her supervisor will see/hear the information my child provides and no one will know who my child is because Julia will always use a number instead of my child's name.
                                                                                    YES   NO

5. I understand that if my child tells Julia Leatherland something and she thinks someone at my school should know, because my child needs help/support or someone is in danger, she will share the information with the school SENCo. Julia will tell my child if she is going to do this.

                                                                                    YES   NO

6. I give permission for Julia Leatherland to access my child's school tracking data

                                                                                    YES   NO

7. Do you give permission for your child to take part in the research project described in the information sheets provided?
                                                                                    YES   NO

Pupil's name ……………………………   **Date………………………..**

Parent's signature……………………………   **Parent's email**
address………………………..

Contact: <u>Julia Leatherland</u>

Contact Details Removed

Contact: Dr Luke Beardon

Contact Details Removed

Appendix 6

The pupil information video can be viewed by following this link:

https://www.youtube.com/cards?video_referrer=watch&v=lWZSaTZrO8U

The contents of each slide was narrated by me. Transcript is provided beneath a slide where additional words were also spoken.
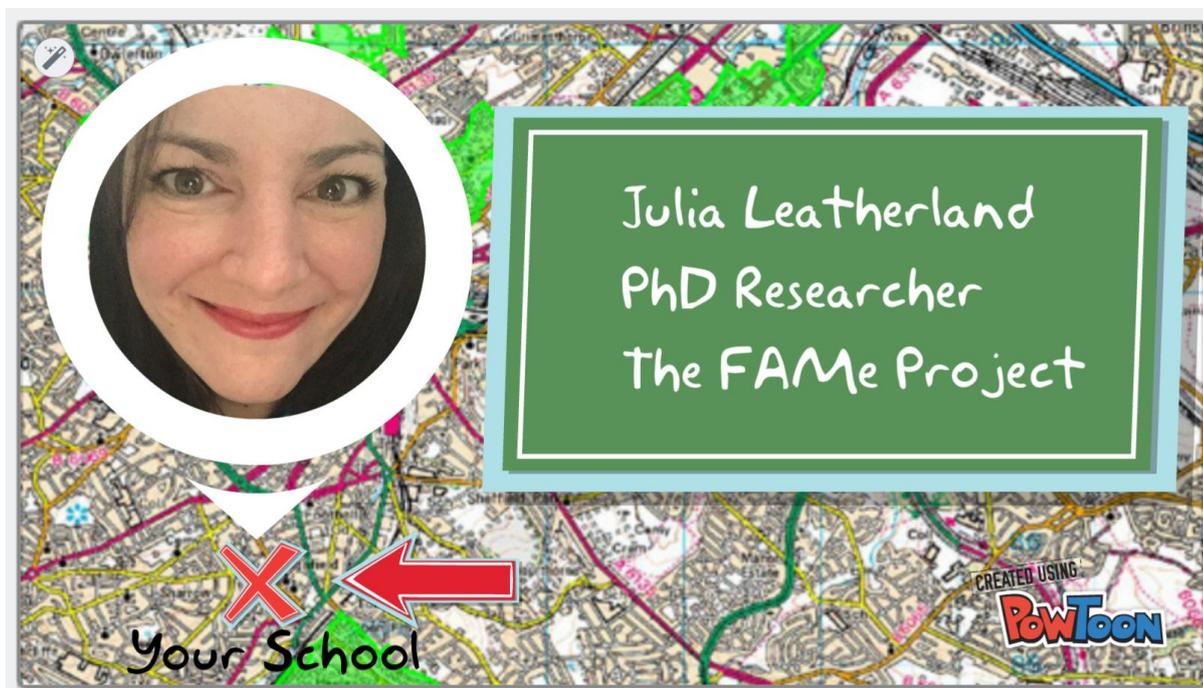
Hi, my name is Julia and I am doing a research project at your school

My special research interest is autism. I started being interested in autism when I

found out that my own children are autistic
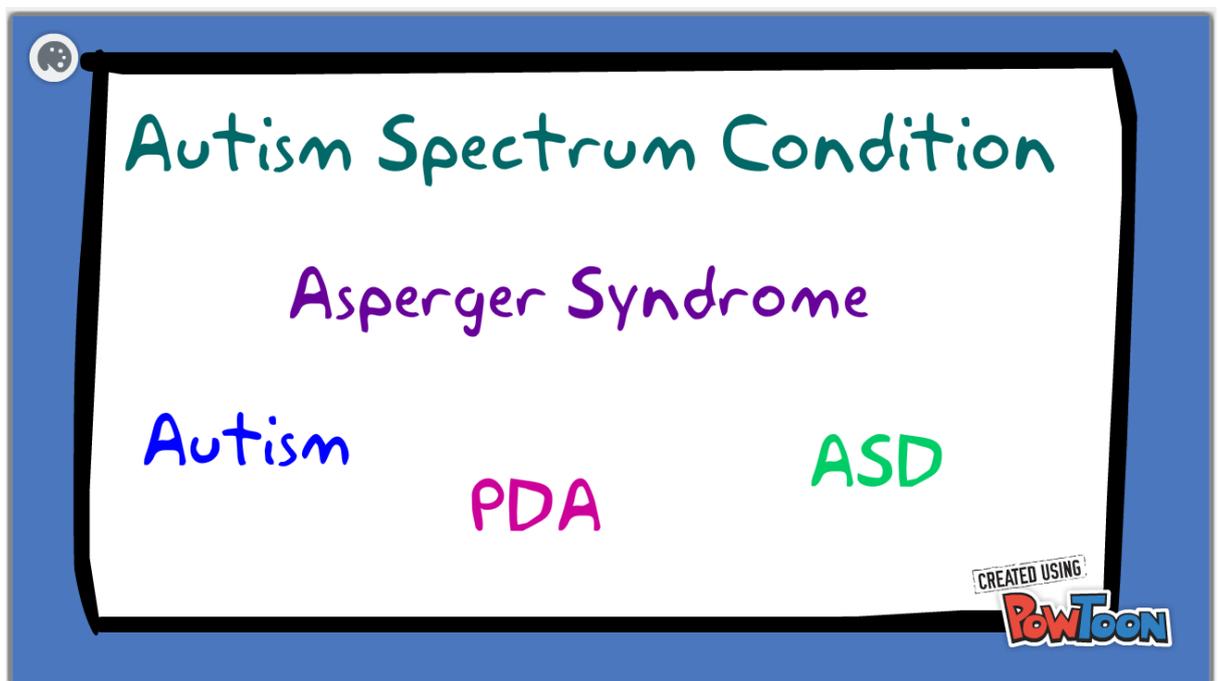
Because you have a diagnosis of an autism spectrum condition…
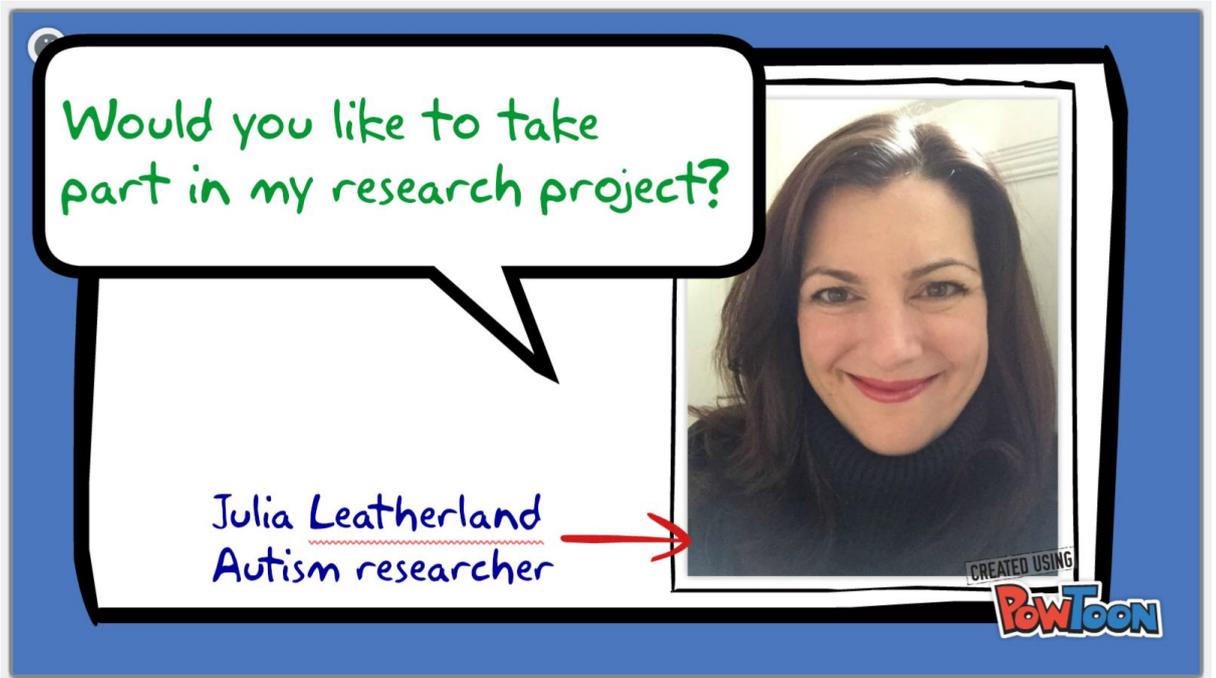
…I am inviting you to take part in my research project
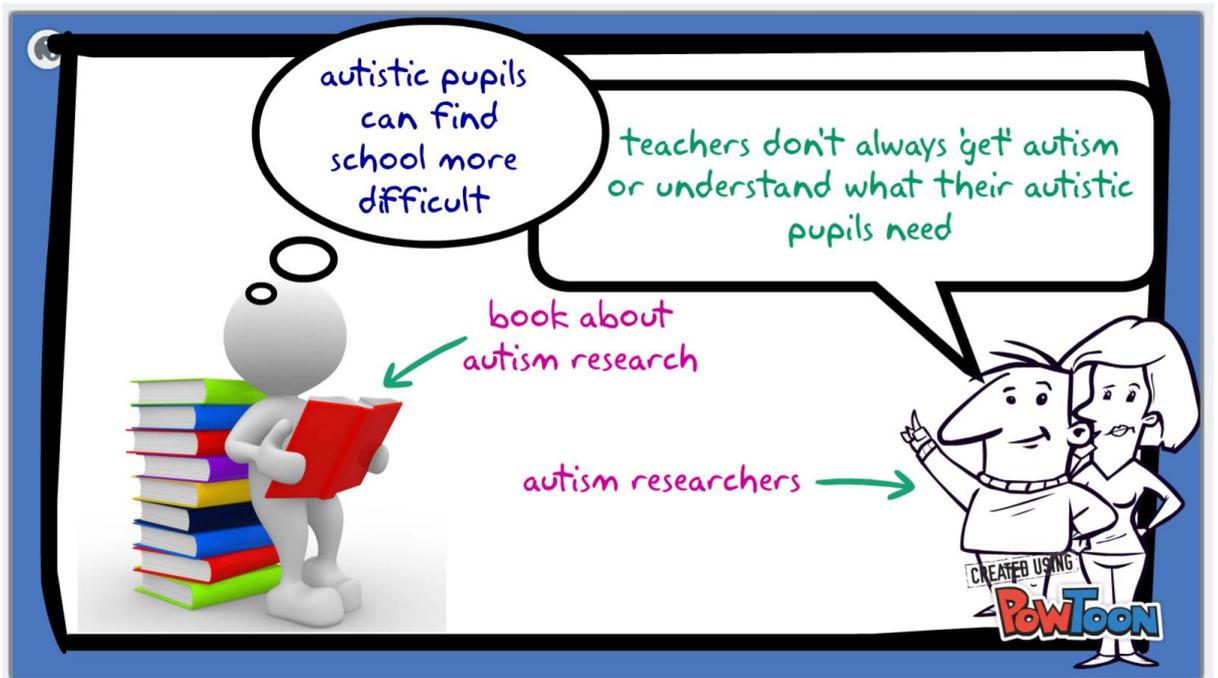
There has been some research which suggests that autistic pupils can find school more difficult than pupils who are not autistic. Some researchers think this is because teachers don't always get autism, or understand what their autsitic pupils need

Often teachers are given information about you at the beginning of the year

at the same time as they get information about other pupils who also need additional or different support in the classroom

The problem is...

Even when teachers know a lot about autism...or have taught autistic pupils before

they won't necessarily know what you need because all autisic people are different

They can sometimes forget what it is that you need them to do

And I've had an idea
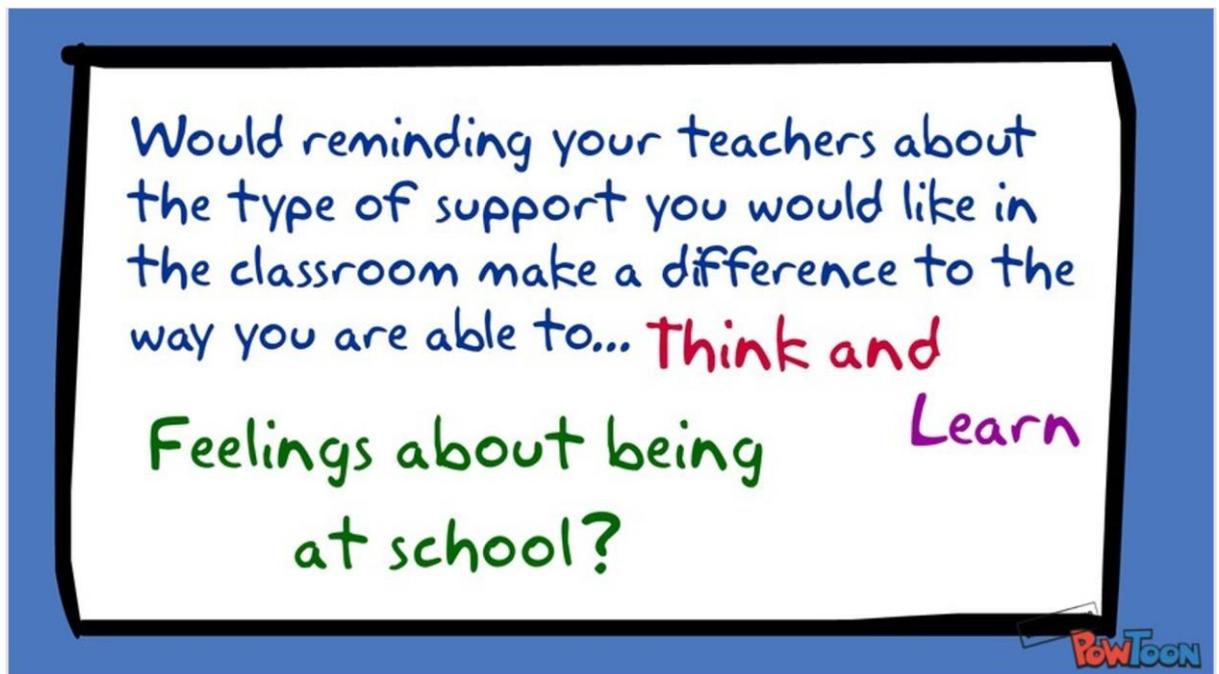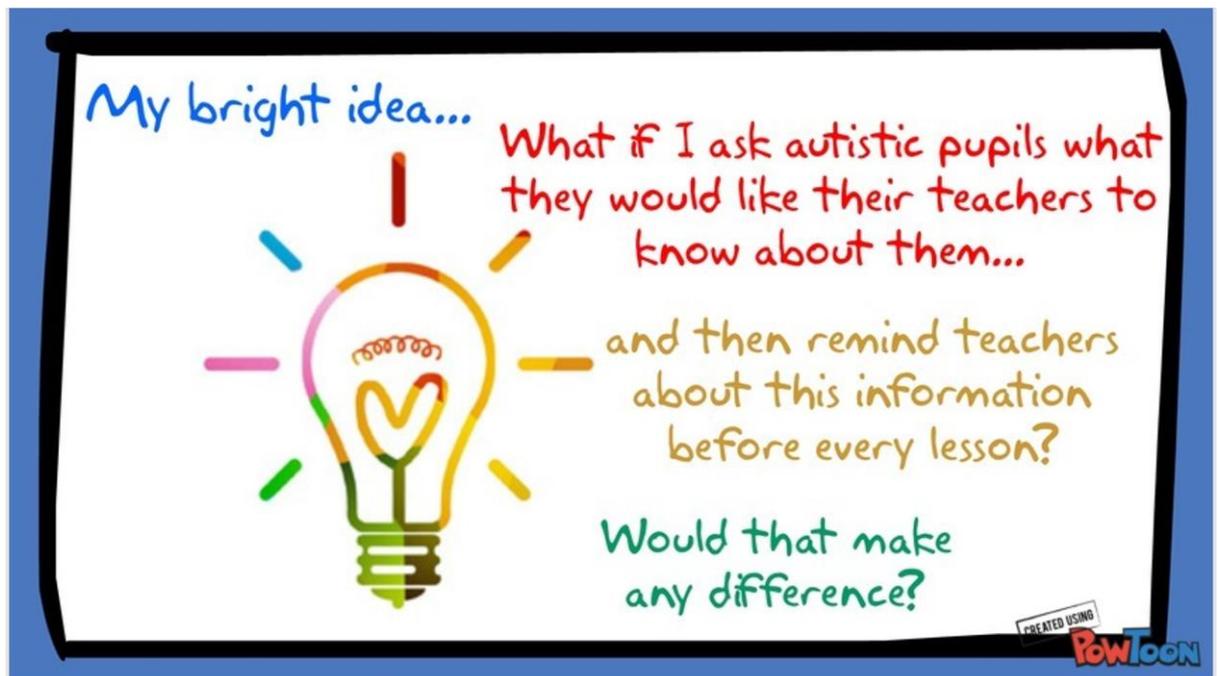
For example, would reminding your teachers about the type of support you would like in the classroom make a difference to the way you are able to think and learn or change the feelings you have about being at school?
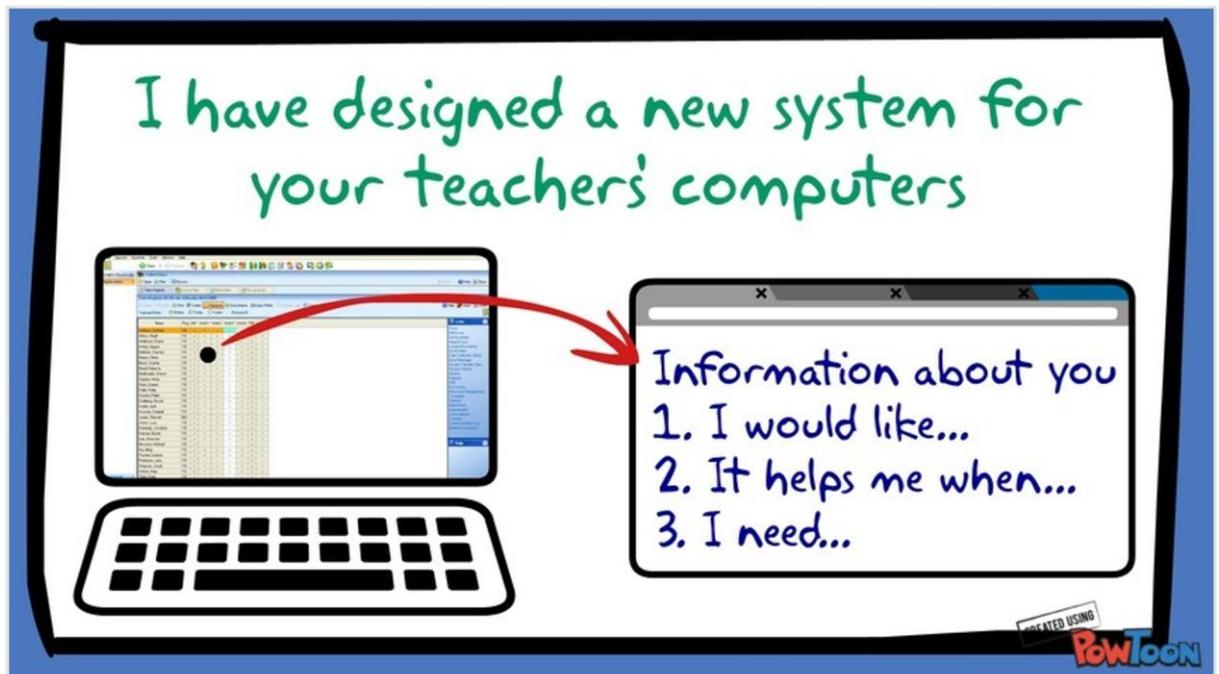
I have designed a new system for your teachers' computers. If they see a dot next to your name in the register, it will remind them that you have left some information about how you would like them to be with you in the classroom, and what support you would like to help you to learn
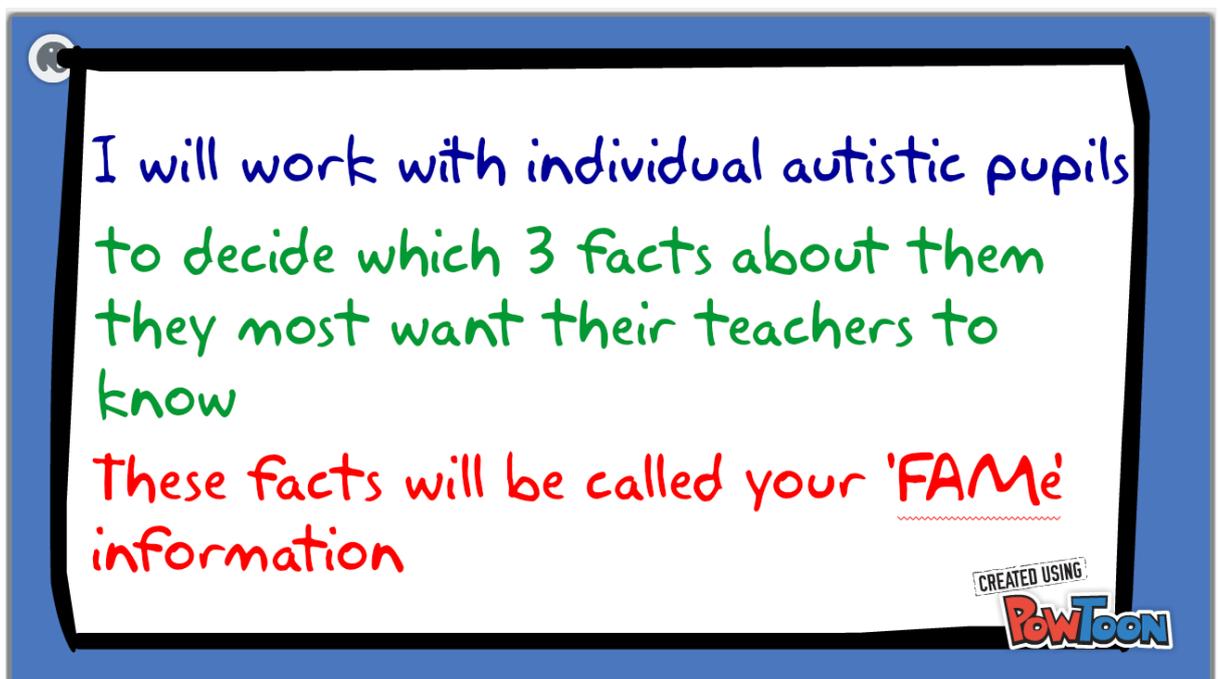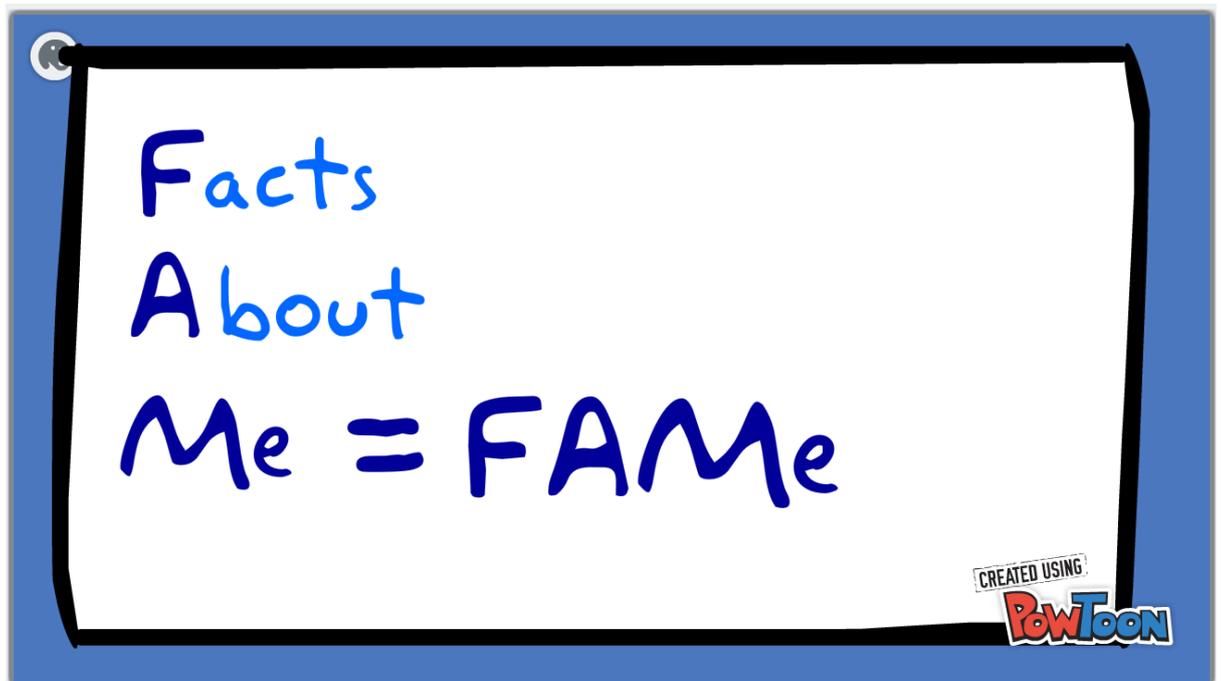
FAMe™ stands for Facts About Me, and this is…
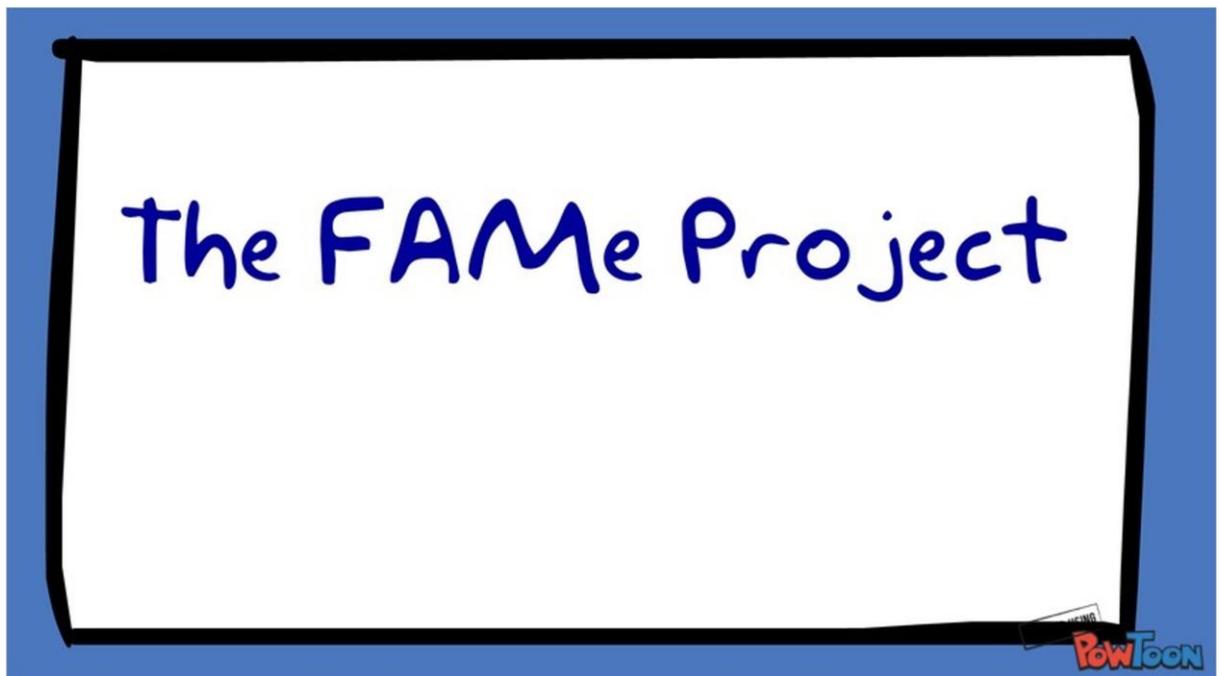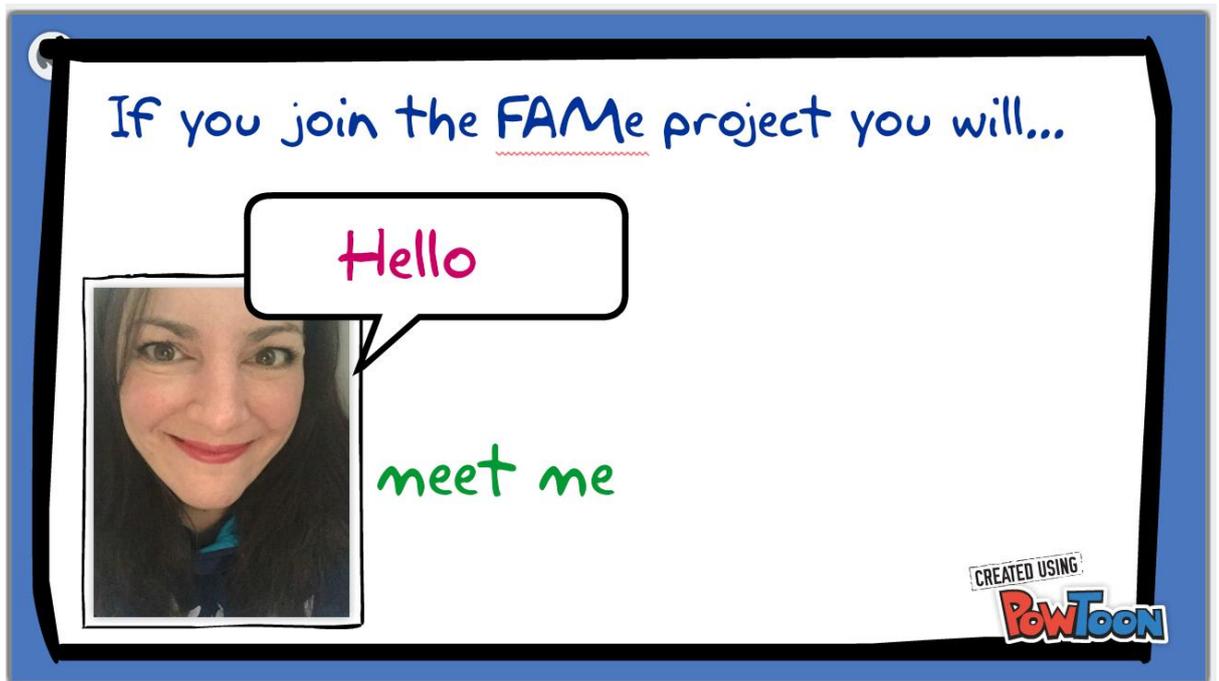
If you join the FAMe™ project, you will meet me…
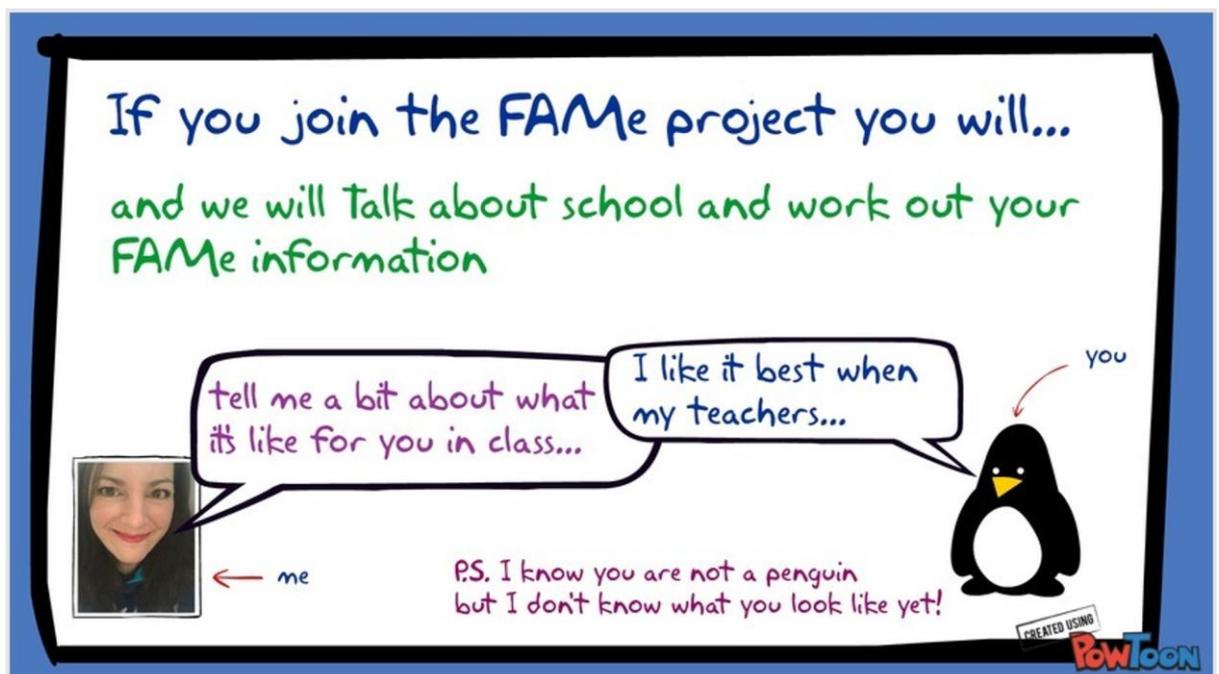
…and we will talk about school and work out your FAMe™ information. I will ask you

a bit about what it is like for you in class and you can tell me what your teachers do

that you find helpful and if there are any things that make being in class difficult for

you

I will also need you to fill in some questionnaires. These will tell me more about how you feel in general and how you feel about learning

Or you can complete the questions by yourself. I will be there in case you need help with any of the questions
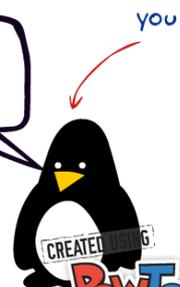
This is so that I can see if the way you feel about yourself and school changes when teachers read your FAMe information before each lesson

Meeting 1. compared to **Meeting 2.**

How you feel now → How you feel after your teachers have been using FAMe

I will give you my email address

This is so that if you want to tell me about anything that has happened at school, for example if one of your teachers has done something differently that was helpful to you – or if something less good has happened – you can let me know
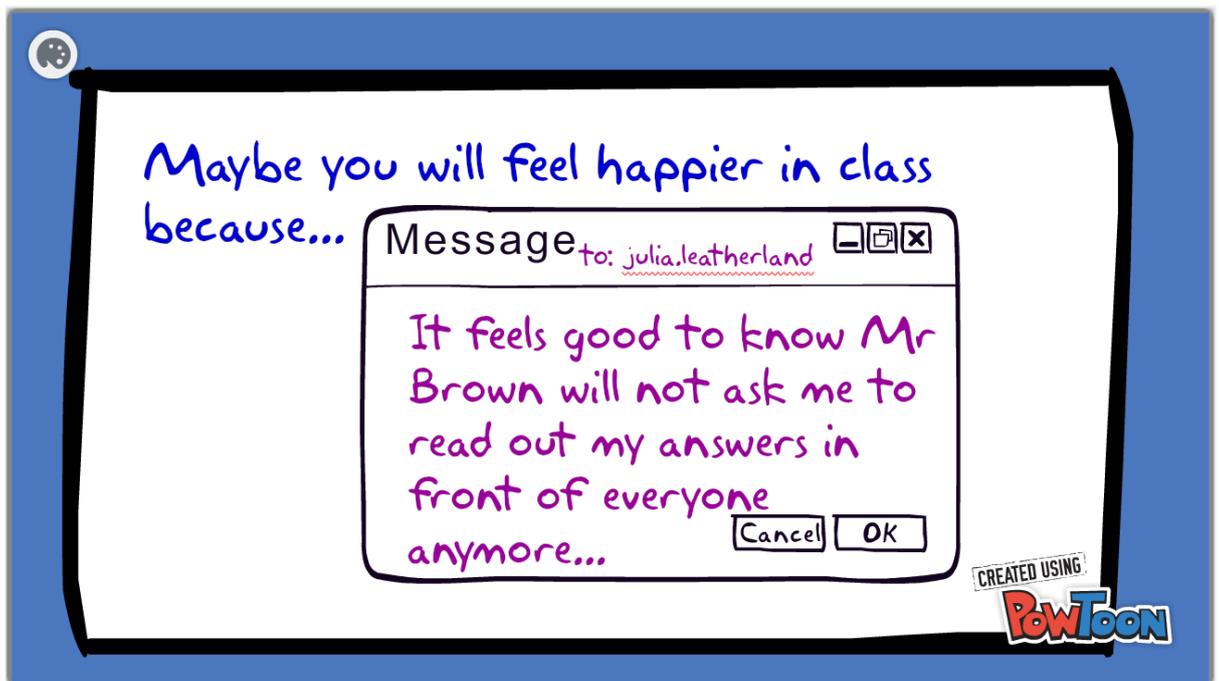
Maybe you will feel happier in class because, after reading your FAMe™ information, one of your teachers has stopped asking you to read your answers out in front of everyone
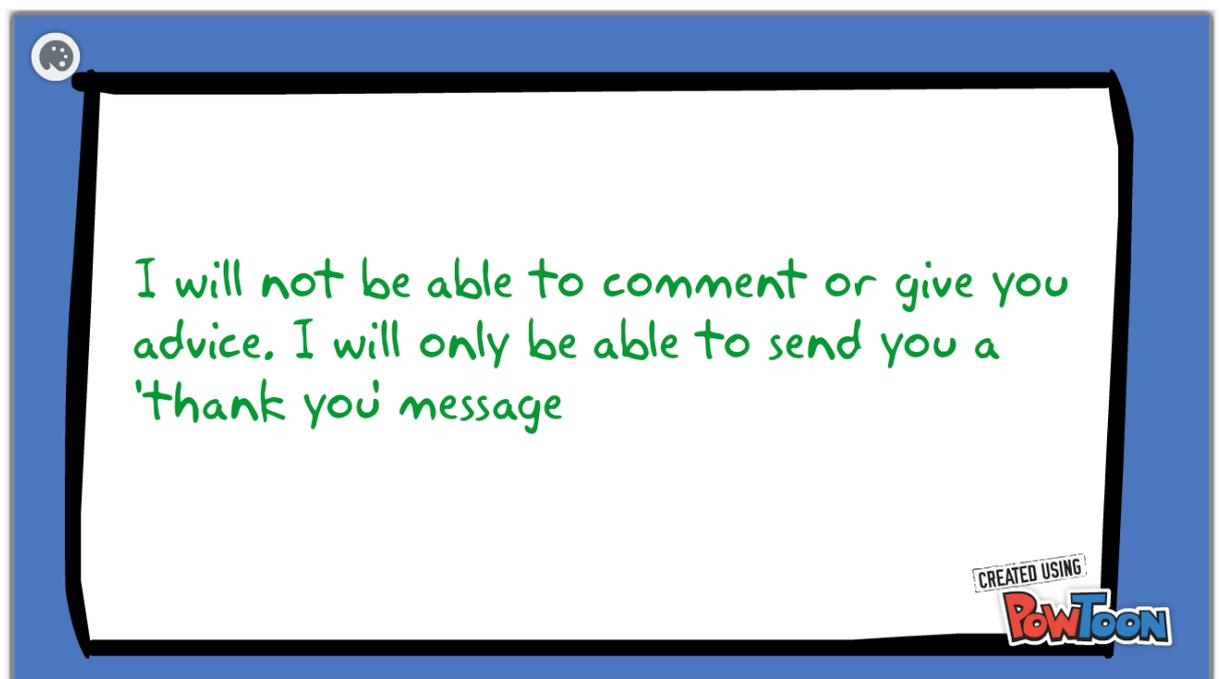
I will only be able to send you a thank you message but anything you tell me will help with my research
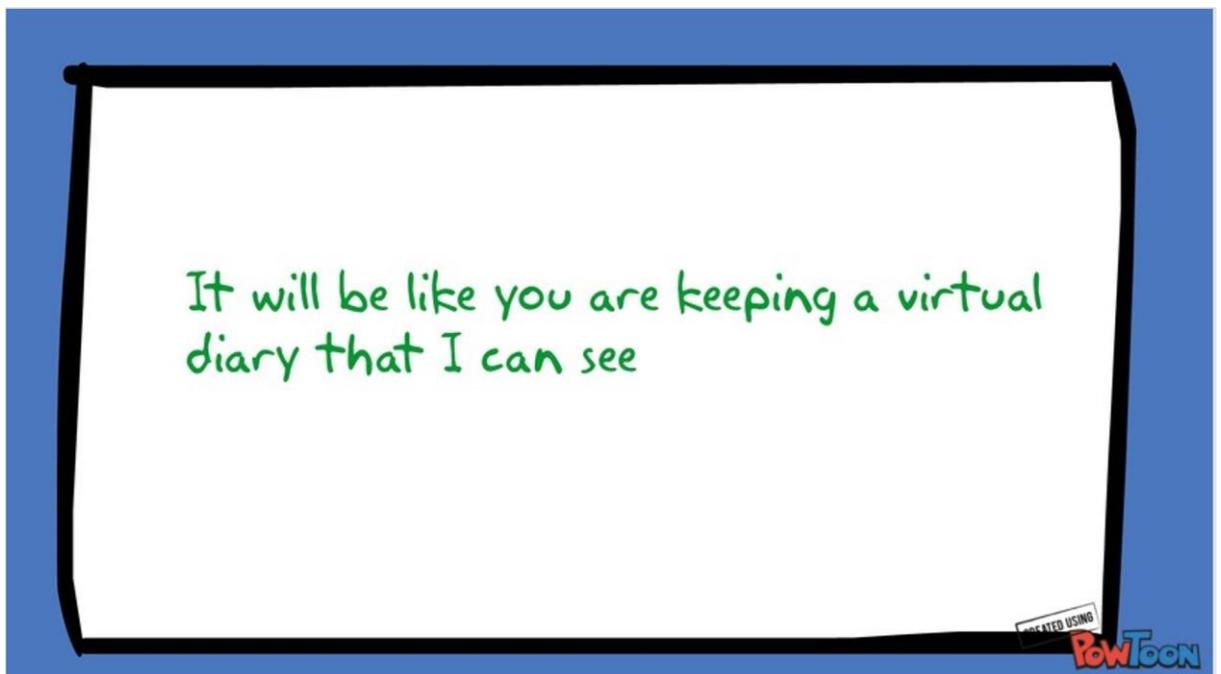
Here are some things I think you need to know…
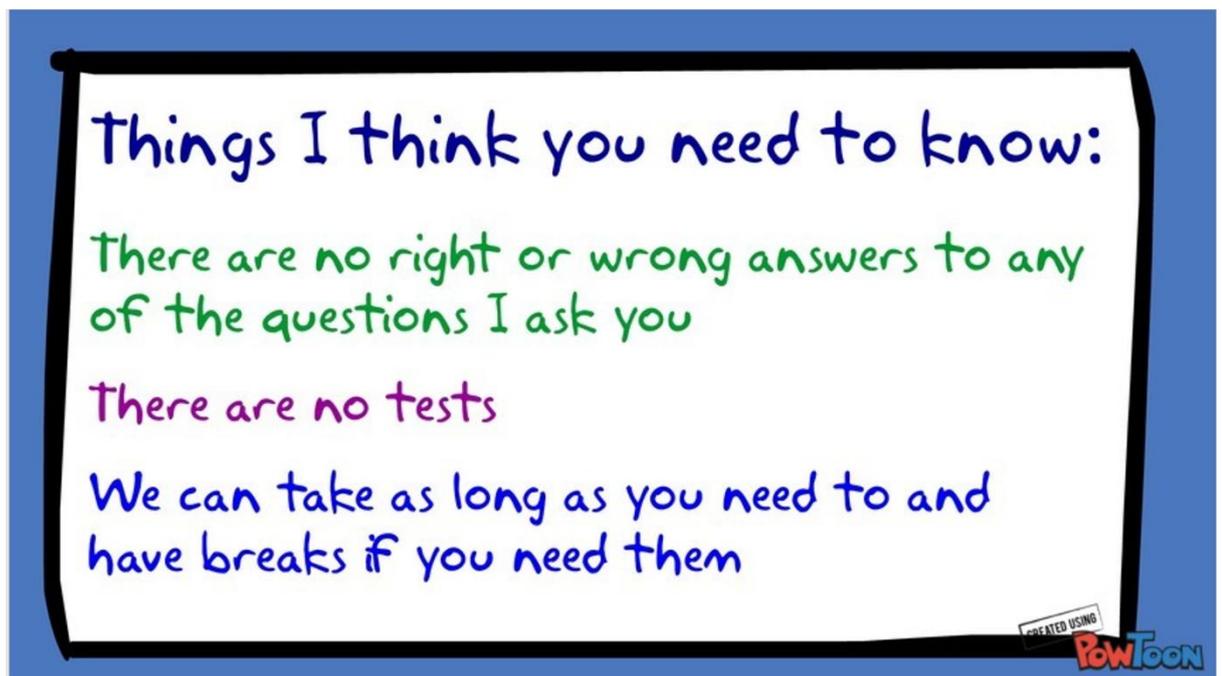
What you tell me and write on your questionnaires is confidential

- that means no one else will see or hear it unless you choose to share it

However if you tell me something that I think an adult at school needs to know about

- if you need help, or someone else is in danger -

I have to share this with your SENCo

I will tell you if I need to do this

and see if you would like to come and talk to them with me

If you would like to be in the FAMe project you need to:

1. Read the 'Pupil Information Sheet'

2. Ask your parent or carer to read the 'Parent Information Sheet'

3. Sign the consent forms

Both of you need to sign the consent forms

Appendix 7

Pre-Interview Script read to all pupils

Hello / Introduction / Thanks

Overview

I am going to be asking you some questions about school and what it is like for you in the classroom - I am using this question sheet to make sure that I ask all the pupils taking part the same things - without it I might forget something.

I am interested to hear about:

- What aspects of learning/being in the classroom are difficult for you
- What things your teachers do/could do that you find/think you would find helpful

We will use the information you tell me to create 3 key facts about you for your teachers to read before each lesson

I hope that giving teachers this information about you will make it easier for them to help you in the classroom - the information might be about anything e.g.

- where you sit
- how teachers present you with instructions
- the way that teachers speak to you
- whether you need a fiddle toy
- whether you need to take breaks

Each individual pupil will have their own list of things they find helpful

I have made sheets of photos which will help us think about being in the classroom and what you do and don't like teachers to do

I expect that this stage of our meeting will take about 20 minutes. It depends how much you want to tell me.

Our meeting will be recorded on an iPhone. This is so that I can listen to it later and make notes. I will not play the recording to anyone else

When we have written your FAMe™ information we will have a short break

After the break you will be filling in 3 questionnaires. These are not tests.

Appendix 8

Pre-FAMe™ Pupil Interview Schedule

We are going to start by talking about how you feel about school in general

Do you like school?
How do you feel about coming to school?

Please will you tell me a bit more about why that is?

Let's think about being in the classrooms at school

Is there anything about the classrooms themselves that you particularly like or don't like?

Please will you tell me a bit more about this?

Now let's talk about your teachers

Let's look through these prompt sheets and see if there are any things happening to the pupils in the photos that bother you when you are in class

Feel free just to talk to me about what your teachers do that make it easier or harder for you to learn in class, you don't need to wait for me to ask a specific question - just talk about what matters to you

(if they need prompting) for example…
Do they let you sit where you feel most comfortable? Do you understand their instructions?
Do you feel anxious about certain things?

We can fill in these sheets to get us thinking…(teacher behaviour I like/don't like) - use coloured pens - show example sheets -

Do you think your teachers understand you and what support you need to help you feel OK and able to learn?

What makes you think that?

Is there anything that happens in class that makes it difficult for you to learn?

What could be different to make it easier?

Is there anything that happens in class that makes you feel worried/anxious?

What could be different to stop you feeling that way?

It's time to write your FAMe™ information

Get the FAMe™ sheet out

Thinking about what we have been talking about…the things your teachers do that you like and things that you don't like…what helps you to learn…what makes you anxious etc…

Let us start writing things on this sheet - things you would like your teachers to know about you

Are there any specific things you wish your teachers knew or understood about you?

What difference do you think it would make if your teachers knew these things/acted differently?

How do you think that would make you feel?

We need to come up with 3 things - the things you most want teachers to know right now.

We can change this information again next term but right now let's decide on the 3 things that you think would make the most difference to you - that would make you feel more able to learn or more comfortable in the classroom

Appendix 9

Pupil Prompt Sheets for Pre-FAMe™ Interview

Some pupils like working as part of a group

Some pupils like to work in pairs

Some pupils do not mind when people lean over them

Some pupils do not like it when teachers write on their work

Some pupils find facial expressions easy to read

Some pupils find body language difficult to interpret

Some pupils don't 'get' sarcasm and are confused by it

Others find it easy to understand

YOU DON'T SAY?

Sarcasm

Because beating the crap out of people is illegal

Some pupils need to fiddle with something in order to listen and concentrate

Some pupils need space to be alone sometimes

Some pupils find it difficult to recognise how they are feeling and need help
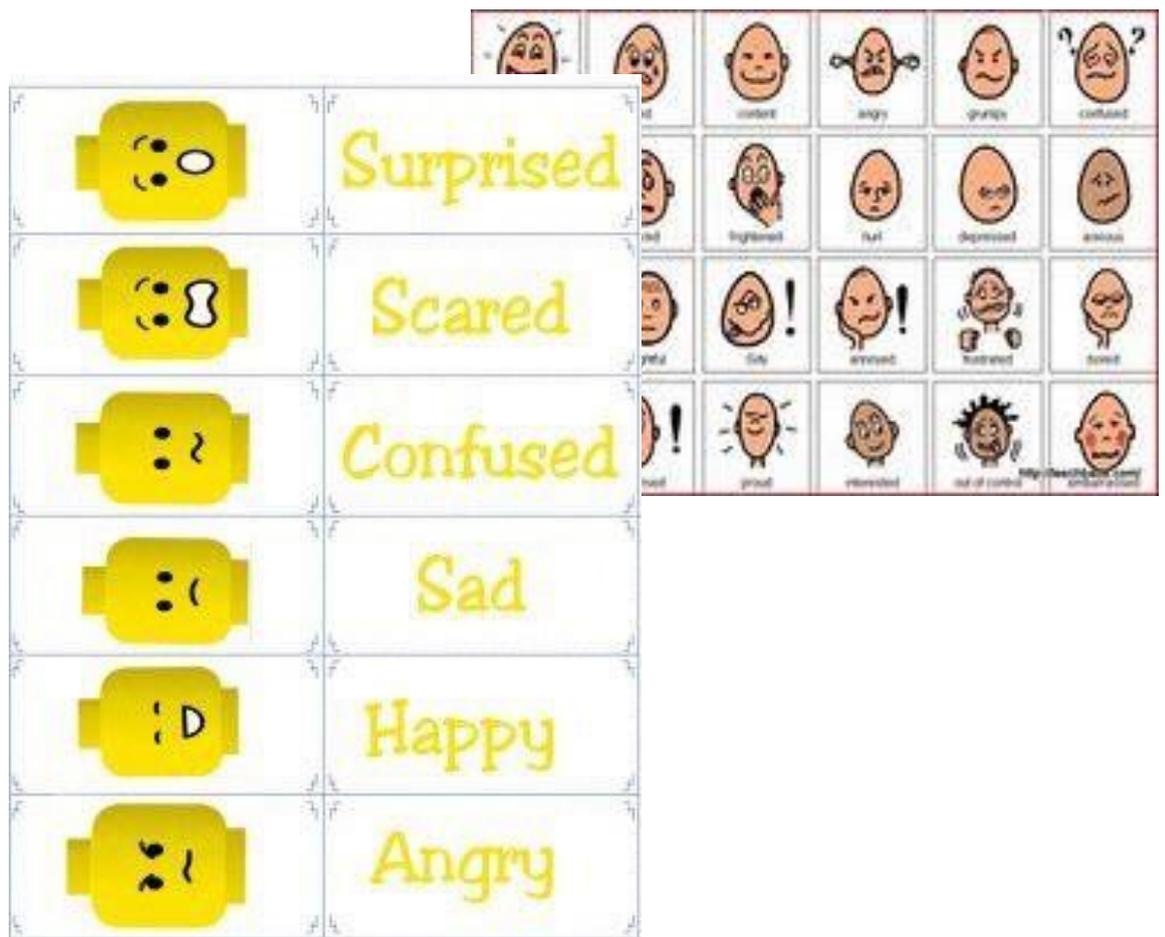
Some pupils use a card to let their teacher know they are getting stressed

I need a break

Some pupils are happy to put their hand up

Some pupils like to speak out in class

Some pupils do not like it when everyone is looking at them

Some pupils enjoy demonstrating their work to the class
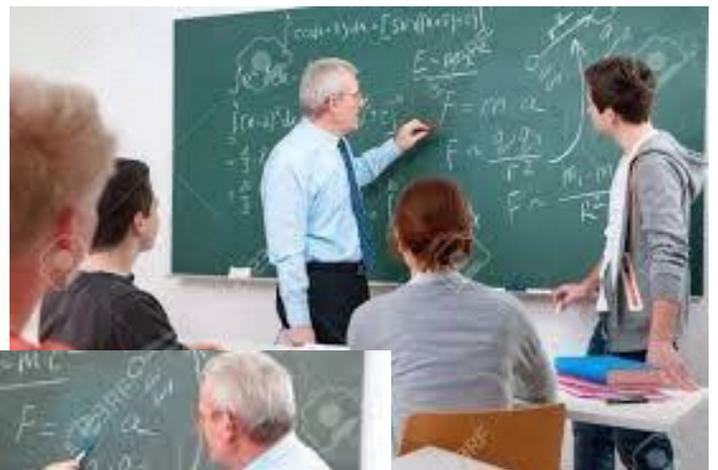
Pupil Interview Schedule Post-Fame™

We are going to talk about how things have been for you at school since we last met.

1. **Let's start by having a look at the information you gave me to give to your teachers**

If we take these things one at a time…

- **Do you think your teachers have read the information about you?**
- What makes you think that?

- **What things if any have teachers done differently?**
- What difference has this made to you?

- **Have any of your teachers talked to you about your FAMe™ statements and/or you being in the project?**

2. **I would like to know a little bit about how you felt after we last met.**

Do not worry about being polite – I really want to know…

- **Did you feel hopeful that things would change as a result of you being in the project?**

- **How do you feel about it now?**

- **Did you feel OK about having spoken to me?**
  Were you upset afterwards?
  Did it help you share how you were feeling with anyone else?

- **Was there anything I could have done differently to make our meeting better for you?**

3. **If you were going to write your FAMe™ statements again today would they be different?**

4. **Is there anything else you would like to tell me about school? / about FAMe™?**

Break

Questionnaires

Appendix 11

Julia Leatherland
PhD Student
Institute of Education
Sheffield Hallam University

Invitation to Participate

The following is a link to a questionnaire. The questionnaire can be completed online and should take no more than 5-10 minutes
*** link went here****

Dear teacher,

Your SENCo has agreed that your school take part in a PhD research project which involves trialling a new computerised method of communicating the individual needs of autistic pupils to their teachers.

In previous research…

Autistic pupils have reported:

That, when their teachers have understood and attended to their individual support needs, they experience

- increased positive engagement with school and learning
- improved relationships with peers
- an improved sense of well-being in areas related to quality of life - such as a decrease in symptoms of anxiety and depression

Teachers have reported:

- a need for more autism training
- the desire to have a better understanding of their autistic pupils
- a lack of information about their autistic pupils presented in a way that is useful to them

The system being trialled has been developed in an attempt to find a solution to some of these issues.

The System

Autistic pupils will be supported (by me) to generate three facts about themselves that they would like you/all their teachers to know. They will be encouraged to generate statements that relate to factors they believe will support their engagement in lessons and/or learning e.g:

- Please check I have understood the learning task correctly
- Fiddling with blu-tac helps me to concentrate and listen
- I don't work well in groups of more than 3 people

These facts will be entered into the SIMs system, in a new area that will be titled **FAMe™** (Facts About Me = FAMe™).

The 'quick note' column of SIMs will need to be activated to remain permanently visible on all teachers' register screens. A dot in the 'quick note' column tells you there is something about that pupil that you need to be aware of - as it does now.

However, during the trial, the word **FAMe™** will appear first, when you hover over the dot, for any autistic pupil who is taking part. One click from the register page will then take you to the FAMe™ area where that pupil's three FAMe™ statements will be visible.

The Trial

This trial is an evaluation of the FAMe™ system. The existing SIMs software has been manipulated to include it. During the trial FAMe™ information will still not be as easily accessible as would be ideal - i.e. once prompted you still have to click to see it.

I will use any evidence - that teachers having easy access to such individual pupil information has a positive effect on autistic pupils' outcomes - to petition CAPITA - the makers of SIMs. If, as hypothesised, access to FAMe™ statements does enable teachers to more effectively support autistic pupils, I will argue for space to made for it within SIMs. The addition of a FAMe™ column would allow FAMe™ information to be visible to all teachers without having to leave the register page.

Potential benefits of the FAMe™ system over what currently exists.

- Teachers will be alerted to the presence of an autistic pupil on a lesson by lesson basis and prompted to read their FAMe™ information

- FAMe™ information will remind teachers about individual pupil's particular support needs / teachers will no longer have rely on their memories
- Teachers will not necessarily need an understanding of autism to be able to include their autistic pupils more effectively
- FAMe™ information is easy to update to take account of the changing needs of autistic pupils

The questionnaire

In order to evaluate the impact of FAMe™ I need to collect pre and post-system data from autistic pupils and their teachers.

I am particularly interested in the views of teachers, like you, who will have access to autistic pupils' FAMe™ information for the duration of the trial.

I would like to understand such issues as:

- whether you are currently aware of which of your pupils is autistic
- whether you currently feel you have any difficulty remembering and meeting the individual needs of the autistic pupils you teach
- what difference having easy access to pupil specific information might make to the classroom support you offer these pupils
- what potential barriers to FAMe™ system use you can foresee

I also need to collect some demographic data, such as your gender, subject area and number of years as a teacher, in order that I can explore whether similarities/differences exist between the experiences of teachers belonging to these different groups.
I understand the pressures on teachers' time and have designed the online questionnaire to capture the information I need from you in as short a time as possible.

Your participation in this project is entirely voluntary.

If you are willing to share your experiences and views with me please follow this link to the questionnaire ***link went here***

Thank you very much for your time.

Appendix 12

Teacher Pre-FAMe™ Survey

Please complete the following demographic information

The FAMe™ Project

Your answers will enable me to better understand the current experiences of mainstream secondary school teachers who teach autistic pupils.

I am also interested in the perceived usefulness of the newly designed FAMe™ information communication system.

Please answer all the questions and give as much detail as you feel happy to share.

NQT/years as a teacher following NQT induction period

○ NQT

○ 0-5

○ 6-10

○ 11+

Do you have any additional responsibilities, e.g. are you a Head of Department or hold a senior leadership position?

Please provide details here

_____

If you have received any autism specific training please describe it here?

Please include how long it lasted - e.g. 1 hour; 1 session; 1 day - by whom it was delivered and whether it was part of a more general SEND training programme.

_____

_____

_____

_____

_____

These next questions relate to your current experience

Are you aware which of the pupils you teach have a diagnosis of autism?

(n.b. 'autism' is used to refer to *any* diagnosis considered to be part of the autism spectrum)

○ Yes

○ Don't know/not sure

○ No

Have you been given/read specific information relating to your autistic pupil's individual needs? (n.b. 'autistic pupil' is used to refer to *any* pupil with a diagnosis of autism)

○ Yes - please describe _____

○ No

Do you know how to access information about individual autistic pupil's learning/ classroom support needs?

○ Yes

○ No - please go to next page

Is this pupil-specific information easy for you to access?

○ Yes

○ No - please explain why not _____

How often do you typically access/read autistic pupils' learning/ classroom support information after the first reading?

If it depends on the individual pupil, please say something about this in the box provided

○ every lesson

○ at least every day

○ at least once a week

○ at least once a month

○ at least once a half-term

○ at least once a term

○ at least once during the academic year

○ I don't access/ read it after the first reading

○ It depends on the individual pupil _____

Do you think you would access autistic pupil's individual support information more often

	Yes	No
If it was easier to access?	○	○
If it contained more concise/specific information?	○	○

Please indicate how confident you are that you currently:

	Not at all confident	Quite confident	Confident
Understand the learning/classroom support needs of the individual autistic pupils you teach	○	○	○
Are able to meet the learning/support needs of the individual autistic pupils you teach	○	○	○

Please provide some detail to help me understand your answers

_____

_____

_____

_____

_____

These questions relate to how you might engage with a new system - FAMe™

FAMe™ is a new information communication system that will sit within 'Quick Note' (QN)

Once activated the QN column will remain alongside the register at all times.

Autistic pupils participating in the FAMe™ system trial will be flagged to you through the QN column.

The FAMe™ symbol will act as a prompt for you to access three statements about these pupil's individual learning/classroom support needs.

The statements will have been generated by the pupils themselves and will contain the key information *they* most want *you* to know about them.

Examples of FAMe™ statements are:

> Please ensure I have understood the instructions before I start a task
> I fiddle with blu-tac to aid concentration and listening
> I do not work well in groups of more than three

The idea is that the register-linked 'FAMe™' prompt will remind you which pupils are autistic.

It is hoped that by then providing one-click access to key pupil information, the FAMe™ system will enable teachers to better understand and meet autistic pupils' learning/ classroom support needs.

How likely do you think it is that the new FAMe™ register based-reminder, with an easy-access link to key individualised pupil information will:

	not at all/less than once a half-term	a little/at least once a half-term	quite a lot/at least once a week	very much/every lesson
Be accessed/read by you	○	○	○	○
Increase your confidence regarding teaching autistic pupils	○	○	○	○
Effect change in your autism practice	○	○	○	○
Enable you to better meet the needs of your individual autistic pupils	○	○	○	○

Do you anticipate any barriers that might prevent you from using the FAMe™ system?

If yes, please explain your answer

○ Yes _____

○ No

This area is for you to include any further information you would like to share

If there is anything more you can tell me about your experience of teaching autistic pupils, for example about issues/difficulties you have encountered or successes you have had, please write about them here.

_____

_____

_____

_____

_____

Appendix 13

Teacher Information sent out when FAMe™ System was activated on registers

The FAMe™ Project

Facts About Me

How I would like to be supported as an autistic learner

A new system to give teachers easy access to information about individual autistic pupil's support needs

Do you teach these pupils?

Pupil Photographs were included

| Name of pupil | Name of pupil | Name of pupil |

| Name of pupil | Name of pupil |
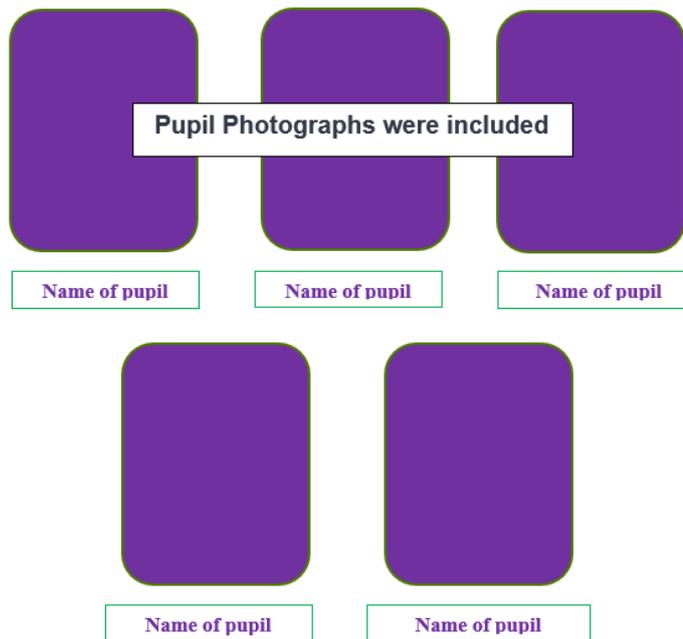
They have provided information about themselves that they would like you to know

Look out for their names highlighted in **RED** in the register

They are **NOT on REPORT**

Hover over the ● to see their FAMe™ information – These are the 3 facts about themselves that they most want you to know

More detailed FAMe™ information is included in SEN Section 11

The FAMe™ Project

Facts About Me

How I would like to be supported as an autistic learner

Do you teach these pupils?

They have provided information about themselves that they would like you to know

A new system to give teachers easy access to information about individual autistic pupil's support needs

Year 7 -

Year 8 -

Pupils' names removed

Year 9 -

Year 10 -

Look out for their names in the register – There is important information in QUICKNOTE

Hover over the ● **to see their FAMe™ information - these are the 3 facts about themselves that they most want you to know**

More detailed FAMe™ information is included in SEN Section 11

Appendix 14

Teacher Post-FAMe™ Project Feedback Survey

Please read the following:

The FAMe™ Project - Collecting Teachers' Views

This term your school has been trialing The FAMe™ System
 - designed to give teachers easier access to autistic pupils' SEND information

 The following short survey asks about your experience of using it
  - your views will be used to inform the FAMe™ System's continued development

You are not asked for your name and your answers will be treated in confidence
- reports of study findings will not identify the schools involved.

Results/feedback provided to schools will not identify individual pupils or members of staff - staff roles (e.g. SENDCO) might be referred to for clarity

_____

Completion of this questionnaire is taken as consent for your views to be used in the evaluation of FAMe™

Thank you in advance if you decide to take part

Julia Leatherland
PhD Student / Principal Researcher The
FAMe™ Project
Institute of Education, Sheffield Hallam
University

Dr Luke Beardon
Senior Lecturer Autism / Director of Studies (FAMe™)
The Autism Centre, Sheffield Hallam University

Please provide the following information about your school

Which school do you teach at?

◯ Site 1

◯ Site 2

◯ Site 3

FAMe™ = Facts About Me

The FAMe™ System is designed to:

1. **Alert teachers via the register to the presence of any autistic pupils attending a lesson**

2. **Provide teachers with one-click access from the autistic pupil's name to their FAMe™ Statements**

NB. FAMe™ Statements provide concise information about a pupil's classroom support needs and are generated in consultation with individual pupils

One aim of this evaluation is to determine whether updates to SIMs - to fully optimise the functioning of FAMe™ - would be welcomed by teachers

----

Based on your experience of using the FAMe™ System - and considering its purpose - **please highlight your level of agreement with the following 10 statements**

Text boxes are provided should you wish to explain your responses

Any feedback you give will be gratefully received

----

1. The FAMe™ System alerted me to the presence of autistic pupils attending my lessons

○ Yes / I agree

○ Somewhat

○ No / I disagree

2. The FAMe™ System gave me easy access to pupils' FAMe™ statements

○ Yes / I agree

○ Somewhat

○ No / I disagree

3. The FAMe™ System was quick and/or straightforward to use

○ Yes / I agree

○ Somewhat

○ No / I disagree

4. I accessed FAMe™ pupils' FAMe™ Statements every time I taught them

○ Yes / I agree

○ Somewhat

○ No / I disagree

5. The FAMe™ Statements provided me with information about individual autistic pupils that I did not already know

○ Yes / I agree

○ Somewhat

○ No / I disagree

6. The FAMe™ Statements informed my classroom practice and/or changed the way I supported individual autistic pupils

○ Yes / I agree

○ Somewhat

○ No / I disagree

7. The FAMe™ System changed the confidence I have in my ability to meet the learning and/or support needs of individual autistic pupils

○ Yes / I agree

○ Somewhat / I neither agree or disagree

○ No / I disagree

8. I have noticed a change in FAMe™ pupils' engagement and/or behaviour and/or learning since the FAMe™ project began

○ Yes / I agree

○ Somewhat

○ No / I disagree

9. There has been a change in FAMe™ pupils' academic outcomes and/or output since the FAMe™ project began

○ Yes / I agree

○ Somewhat

○ No / I disagree

10. I would welcome updates to SIMs software that optimise the functioning of the FAMe™ System

○ Yes / I agree

○ Somewhat

○ No / I disagree

And finally...

What typically prompted you to access a pupil's FAMe™ information?

○ Saw pupil name highlighted in register

○ Staff briefing information and/or email reminder

○ Pupil factors (behaviour etc.)

○ Other

Are any further comments you would like to make about the FAMe™ System?

_____

_____

_____

_____

_____

If you are willing to discuss your opinion and/or experience of the FAMe™ System in more detail, please provide your name and email address

_____

_____

Appendix 15

SENDCO Post-FAMe™ Project Feedback Survey

The FAMe™ Project
Collecting SENDCOs' Views

Dear SENDCO

Thank you for agreeing to trial The FAMe™ System in your school this term

The following short survey asks for your feedback
  - your views will be used to inform the FAMe™ System's continued development

Your answers will be treated in confidence
- reports of study findings will not identify the schools involved. Results/feedback provided to schools will not identify individual pupils or members of staff - however, staff roles (e.g. SENDCo) might be referred to for clarity

Completion of this questionnaire is taken as consent for your views to be used in the evaluation of FAMe™

Thank you in advance if you decide to take part

Julia Leatherland
PhD Student / Principal Researcher
The FAMe™ Project
Contact details removed

Dr Luke Beardon
Senior Lecturer Autism / Director of Studies (FAMe™)
Contact details removed

Please provide the following information about yourself:

At which school are you the SENDCo (or equivalent)?

○ Site 1

○ Site 2

○ Site 3

FAMe™ = Facts About Me

The FAMe™ System is designed to:

1. **Alert teachers via the register to the presence of any autistic pupils attending a lesson**

2. **Provide teachers with one-click access from the autistic pupil's name to their FAMe™ Statements**

NB. FAMe™ Statements provide concise information about a pupil's classroom support needs and are generated in consultation with individual pupils

One aim of the evaluation is to understand whether there have been any benefits to you, as school SENDCo, from the implementation of the FAMe™ System in your school

---

Based on your experience of trialing the FAMe™ System - and considering its purpose **please highlight your level of agreement with the following 6 statements**

Text boxes are provided for you to explain your responses

Any feedback you give will be gratefully received and help with the evaluation of FAMe™

1. As a result of their participation in the FAMe™ project, I found out new information about FAMe™ pupils' support needs

○ Yes / I agree

○ Somewhat

○ No / I disagree

2. Information gathered for the FAMe™ project informed the support I offered participants, and/or the support/provision arranged for them in school

○ Yes / I agree

○ Somewhat

○ No / I disagree

3. Receiving additional information about autistic pupils' anxiety and depression scores was useful and should remain part of the FAMe™ package

○ Yes / I agree

○ Somewhat

○ No / I disagree

4. Information gathered for the FAMe™ project led to at least one pupil referral to an outside agency and/or professional for additional support

○ Yes / I agree

○ Somewhat

○ No / I disagree

5. Information gathered for the FAMe™ project led to a change in provision and/or placement for at least one pupil

○ Yes / I agree

○ Somewhat

○ No / I disagree

6. If the functioning of the FAMe™ System becomes fully optimised in SIMs, I will be keen for our school to use it

○ Yes / I agree

○ Somewhat

○ No / I disagree

If FAMe™ becomes available to schools in the future - who do you think is best placed to carry out the pupil interviews?

Please explain your answer

○ School SENDCo

○ Other member of school staff

○ Outside professional / Autism professional

And finally...

This area is for you to include any further information you would like to share

**Are there any further comments you would like to make about the FAMe™ System?**

_____

_____

Appendix 16

Copy of signed confidentiality document

Julia Leatherland PhD confidentiality clause:

As a colleague of Julia Leatherland, who has knowledge of autism and autism theory, I agree that I am appropriately qualified to verify the coding of her qualitative data for reliability/triangulation purposes.

I hereby confirm that I will not share the contents of the data sent to me for this purpose with anyone and understand that it is confidential.

Signed:
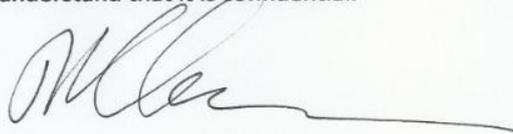
Name: Nicholas Chown

Dated: 01-03-2017

Nicholas Chown professional profile:

Nick Chown is an independent autism advocate, mentor, researcher, and trainer. He has undertaken research on barriers to learning for students with autism in further and higher education, autism awareness in the UK police service, viva protocols for doctoral students with autism, and diagnostic pathways for autistic adults. His doctoral thesis focused on language methods and the applicability of Wittgenstein's language game concept in autism. He is a member of the editorial board of the Journal of Autism and Developmental Disorders, and a reviewer for various other journals. In addition to leading the Higher Achievers project investigating support for autistic students in UK HE, Nick was involved in the LSBU project mentoring autistic adults both as mentor and a member of the advisory board. Nick's book 'Understanding and Evaluating Autism Theory' was published in 2016. Prior to working in autism Nick was in corporate risk management.

Appendix 17

Teachers' Pre-FAMe™ survey data:

Examples of additional written responses

The following are examples of the information provided by teachers about the autism training they had received:

- *Over the past 11 years I have received 2 hours of specialist training on autism*

- *General session on SEN there was generic information given on autism as well as some specific example for specific pupils (at previous school) about 30mins*

- *One hour, about 10 years ago, by a parent who came in after school to staff training*

- *Relatively little, despite years of service. Occasional sessions as part of inset days*

- *Over course of career, probably about three half day sessions at different schools*

- *One hour at university*

- *Many sessions, including working in a school for two years with an autistic unit. Also, generalised SEND ones*

- *2 days whilst training*

Have you been given/read specific information relating to your autistic pupil's individual needs?

- *Yes - Information Sheets on J drive. Student profile sheets*

- *Pupils have a 'passport' which explains what makes them anxious/stressed and what teachers can do to help*

- *Some notes on how they respond to certain things, good ways to work with them etc.*

- *Yes - we receive SEN profiles with details of the needs of each student and strategies that support them in the learning. This is personalised for each student*

- *Yes, a document provided by our SENCO on how to deal with students with Autism plus a personal profile of each child and their individual needs*

- *Each student has information on the inclusion register which I have read. I have also spoken with pupils' key workers where there is a significant impact on their ability to access lessons*

Is this pupil-specific information easy for you to access?

- *No - Several folders to navigate through on J drive*

- *Not sure where it is under new system*

- *It is once you have identified a student on SIMS and you search them and go to their linked documents. It would be useful if this was updated - instead of scrolling back through e-mails, etc.*

- *I have to find where the whole school document is saved on the MLE or in my inbox which takes a while*

- *You have to load a webpage, click through some options, find the document, search for the pupil's name. It's a convoluted process*

- *Fairly but how to access it can be forgotten if visits to the files are infrequent*

Comments relating to teachers' pre-FAMe™ levels of confidence in their ability to understand and meet the learning/classroom support needs of their individual autistic pupils

- *With any student, I strive to enable them to learn in the best way possible. With autistic students, I do wonder if there may be something I've missed that would help them more*

- *I would like more trained TA support. Would like more admin support to produce special paper-work. I would like a trained SEN teacher to review my schemes of work*

- *I will have read the information about an individual but because of the numbers of students I teach, some I know less well. I need to have experience with a student to really understand them better*

- *I feel that, especially in Y7, the class sizes are now bigger and with more pupils with additional needs in those classes it is very hard to support everyone fully when I have 27 pupils and 15+ have additional needs. I know what I need to do in order to support them, but am finding it almost impossible to execute it*

- *Time is the limiting factor. We all want to do more, we all know that in an ideal world there is so much more we could and should do. There are too many demands on our time and I'm afraid it is impossible to provide the differentiated support that is necessary for all the students that we teach. Even working more than three times the hours we are paid to work is not enough to plan lessons and mark the work, give constructive feedback etc. let alone differentiate all that sufficiently for the vast array of SEN we would like to better address*

- *There is such a wide variety of needs within our autistic pupils that I'm not sure I always precisely do what each child needs. I do the basics, plus a few specifics for those with complex needs, but if I had more time I know I could do more*

- *Teaching so many different groups (the whole of key stage 3) sometimes I may unknowingly let information slip from my head. And sometimes there are not enough hours in the day to be on top of all students' needs*

- *I feel relatively confident when I have built relationships with individual students and know their needs, less confident when I first meet them*

- *I am always open to finding out more so that I can meet their needs better as each individual has such specific triggers etc. I welcome anything that makes that process happen easier!*

- *I am aware of which students are diagnosed ASD, and I employ various strategies to help them learn. It isn't a one size fits all though, so there are always ways to improve and tailor your teaching*

Perceived barriers to FAMe™ System use

- *Time available in a busy work schedule* (barrier)

- *Incorporating this into systems we already have to use each lesson such as SIMS. Being forgetful...*(barrier)

- *Time pressures!* (barrier)

- *I think it sounds absolutely brilliant and we have talked about this for years as something that would be so useful for the classroom teachers and also those unfortunate times when cover lessons happen for various reasons, it will give the Cover Supervisor an instant idea of how to manage a pupil, if the register is available to them*

- *I think it will remind people really easily to revisit the needs of the autistic pupil simply and quickly so no barriers as far as I can see*

Additional information

The pre-FAMe™ teacher survey ended with the following invitation:

If there is anything more you can tell me about your experience of teaching autistic pupils, for example about issues/difficulties you have encountered or successes you have had, please write about them here.

- The following responses were provided:

- *What works one week might not work the next, and staff need to understand that all lessons need to be a fresh start*

- *Needs patience and understanding – I am still not generating sufficient work from pupil*

- *Knowing anxiety triggers or not knowing the signs when a pupil is getting overly anxious because it is not included in their notes. Sentences such as 'use of techniques to aid ASD would help'. What are these techniques? Is there a list somewhere? Is there a good website that will give me ideas? The training I have received hasn't given any practical advice on how to effectively support pupils with ASD*

- *I wish to reiterate that I feel very well supported to meet the needs of the autistic students I teach*

- *Each has needs that are specific to them as an individual. It's not easy to generalise re. autism...*

- *Inadvertently causing a student distress because I didn't know that they would have an issue with me doing a certain thing (negative). Putting in place a successful support package to enable a student to engage (positive)*

- *It is frankly nonsense that we are expected as teachers to be almost proficient at clinical psychologist level without having had any training at all. I probably got a few hours training on Autism on a PGCE over fifteen years ago and the rest I've picked up on the fly. If the government want us to be able to teach SEND students properly and understand their needs then teacher training will need to become more like medical training and we would have to spend an additional 3-4 years at University doing a science based course; then they would have to increase wages in the profession and this is never going to happen. Am I supposed to teach myself about SEND? I have a SEND child myself at home, so I am interested and keen to learn in this area. Do a few bullet points on an IEP really help me? Does some INSET training when I'm tired really help me? Am I just guessing at what the child really needs to make progress? Will I ever receive adequate training from the education sector? Difficult questions all. I think as teachers we are sometimes scared of giving the flexibility Autistic pupils sometimes need, not trying to force them into my idea of the perfect lesson/pupil is really important to me and having infinite patience! I have grown to not fear letting the pupils with Autism lead their own learning but balancing that with routines and boundaries that all teenagers need is sometimes hard. I do think though it's just an endless learning curve but a really rewarding and interesting one*

Appendix 18

Teachers Post-FAMe™ Survey Data

Examples of additional written responses

The FAMe™ System alerted me to the presence of autistic pupils attending my lessons

- *Yes, it was a straight forward simple way of highlighting this* (Yes)

- *I already knew this particular pupil was autistic, but it may have been useful if I had not* (Somewhat)

- *Already aware of autistic students in my classes, but will be useful with new classes next year* (Somewhat)

- *I already was aware of this because information that school provides for us* (No)

The FAMe™ System gave me easy access to pupils' FAMe™ statements

- *I think the FAMe project is an excellent idea for these targeted children. It allows us to have quick look at their specific needs and what exactly they want from us as teachers* (Yes)

- *It's installed and easy to use with helpful info, quick to get to it too. I like it!* (Yes)

- *It means that information is easily accessible and provides a good reminder when teaching individual classes* (Yes)

- *It was a bit tricky to set up but once I got the hang of it, fine* (Somewhat)

The FAMe™ System was quick and/or straightforward to use

- *This is much better than searching for IEP's* (Yes)

- *I think it is a good, easy, and effective way to quickly get information that otherwise might not be too forthcoming especially from students who are shy Also, better to do it this way and save time than have meetings to go through it* (Yes)

I accessed pupils' FAMe™ statements every time I taught them

- *I don't have time to be able to do this every lesson, but the dot next to her name does remind me/alert me that there are extra things I need to be aware of* (Somewhat)

- *I didn't need to access the information every time as I knew what the statements said. I did check from time to time to see whether anything had changed* (No)

The FAMe™ statements provided me with information about individual autistic pupils that I did not already know

- *The 3 things that the student said were really helpful. This is particularly useful when teaching someone for the first time* (Yes)

- *I have clicked on to see what X's preferences/requests are, which make total sense* (Yes)

- *Good that the 3 things are from the pupil as it makes more sense and I now know that the three things will help that pupil (*Yes)

- *It is a good source of information as it gives the information which students feel is best for teachers to know. For example, X is sat at the front, but this is the first time I have known that he feels uncomfortable answering questions as*

I generally have a no hands up policy in class and direct questions [at pupils] (Yes)

- *Internal systems already alerted me to this information* (No)

The FAMe™ statements informed my classroom practice and/or changed the way I supported individual autistic pupils

- *Helped inform my specific seating plan with that student* (Yes)

- *I think the scheme is a really good idea in order to know more about the pupils I teach. Their likes and dislikes will assist in the planning of lessons and help foster positive relationships with all pupils involved* (Yes)

- *It's helped me to tailor my conversations with these particular students and focus on where I can help them* (Yes)

- *The FAMe notes are very useful in terms of knowing how X would like to work – I will call on her randomly less often and will change her into a different working group with her preferred partner. Thanks for these useful pointers – these would be great to have for the other SEND students in my classes* (Yes)

- *Reminded me to ensure that the environment and tasks were suitable and easy to access for pupils* (Yes)

- *It was interesting to see this from a pupil's perspective … As I am sure you can appreciate, it is difficult to arrange a seating plan to ensure ALL pupils are satisfied with the person they are sitting next to. A more specific focus on preferred learning methods or their particular interests in a subject area may be more helpful* (Somewhat)

- *Started too late in the year, already established strategies with the students* (No)

The FAMe™ System changed the confidence I have in my ability to meet the learning and/or support needs of individual autistic pupils

- *They certainly helped* (Somewhat)

- *Did not necessarily change my confidence but acted as a reassurance* (Somewhat)

I have noticed a change in FAMe™ pupils' engagement and/or behaviour and/or learning since the FAMe™ project began

- *I have not noticed any remarkable differences, but pupils seem settled* (Somewhat)

- *Some changes* (Somewhat)

- *No change - student still hardworking, happy, engaged... However, I can see how it could have an impact* (No)

There has been a change in FAMe™ pupils' academic outcomes and/or output since the FAMe™ project began

- *As a result of the statements, I make sure I check learning and praise constantly and the pupil seems more willing to produce work* (Yes)

- *Some improvement in assessments* (Somewhat)

- *Work in class is still of similar ability but homework tasks have been completed on time* (Somewhat)

- *Yes, but can't separate this from expected progress throughout the duration of an academic year* (Somewhat)

I would welcome updates to SIMs software that optimise the functioning of the FAMe™ System

- *It's a simple, accessible way to get information on students. It's also a very helpful reminder on strategies to use. However highlighting pupils in red (same as a detention) makes it awkward if the register is on the whiteboard* (Yes)

- *So much easier to access information than before* (Yes)

- *Useful as a fast way to have fingertip access in one place to SEN information* (Yes)

Further comments

Teachers were invited to provide any further comments about the FAMe™ System.

<u>Positive comments</u>

- *I feel that it is an extremely useful tool, particularly with a new class*

- *Like all these types of systems/info it has helped frame how I approach the planning and teaching of the pupil and how I will consider individuals and groups in the future*

- *I found it quick and useful to have that instant reminder*

- *It is a great idea and staff now need to be more aware of its benefits through SIMs etc...*

- *As on any system, it needs to be easy to use and time saving. I think this system should be rolled out so that you can access all individual needs of pupils*

- *This is a good idea in principle and would have been particularly helpful earlier on in the year when I did not know my students as well. By the time it was introduced I already knew the needs of my students*

Difficulties/suggestions for system improvements

- *FAMe™ information is currently linked to the Gifted and Talented column, so some students who are not autistic or part of the project have their name highlighted too. This can be misleading*

- *I am sure this is a really good system, and I am sorry I have had to answer this survey so negatively. In PE, we have worked on paper registers all year so we as a department have been largely unaware of this system whatsoever*

- *There was too much other information which appeared by the numerous black dots which were unrelated to the FAMe system because it is used for other things. The vast majority of these dots just said things like 'Dad's mobile number invalid' or similar. This led to me often ignoring the black dots when busy*

- *One issue with it was that it highlighted students' names in red which is the same as when a student got detention. One of the girls in my form noticed this one day and became very upset that she was being associated with naughty students just for her learning needs. I would suggest a different colour is used to highlight autistic students, but the idea is a good one in principle as you look at your register every lesson, so it is a constant reminder*

Negative Comment

- *I felt that on the whole the FAMe system didn't provide any extra benefit to me when teaching autistic students. As a member of staff, I access the pupil IEP's regularly and I felt that the information provided by FAMe was simply a repetition of information is already readily available to teaching staff in school*

Appendix 19.

Supporting Autistic Pupils in the Classroom

- Every autistic pupil will have **specific individual support** needs

However

- As a group autistic pupils are likely to **share areas of strength and weakness**

    Knowing what these might be is important in order to better enable you to:

    - Create an **autism-friendly** classroom environment
    - **Reduce barriers** to pupil-engagement and learning
    - Facilitate **successful inclusion**

The information in the following slides was provided by a group of 22 autistic secondary school pupils who took part in the FAMe™ Project

The FAMe™ Project involved interviewing autistic pupils to find out more about how they experience school.

Participating pupils identified:

- Areas of **strength/ability/skill**
- Areas of **weakness/ barriers to learning**/sources of **stress**
- Aspects of **teaching practice**/teacher behaviour that they **found helpful**
- Aspects of **teaching practice**/teacher behaviour **that** was unhelpful/**caused anxiety**

Common Areas of Strength and Ability amongst Autistic Pupils

Many of the pupils said that they:

Cognition and Learning

- Have a **desire to do well** / perform to best of their ability
- Enjoy **following rules** (as long as they are logical, fair and understood)
- Enjoy engaging in **practical tasks**
- Like to **see a project** through **to completion**
- Enjoy **problem solving**
- Have a keen **eye for detail**

Social

- **Value** positive **relationships** with school staff/peers

Common Areas where Autistic Pupils might experience difficulty

Many of the pupils said that they:

Cognition and Learning

- Find it **difficult to follow**/remember **instructions** (especially when presented verbally)
- Find it **difficult to organise** the **equipment** needed for a task/lesson/school
- Find it **hard to concentrate when** the classroom is **noisy**/other pupils are 'messing around'
- Find it **difficult to begin** a task **if** they **do not understand** the **goal**/reason it is important
- Find **abstract concepts**/instructions confusing/**difficult** to grasp

Social

- **Do not know how to**/get stressed when they need to **initiate interactions** with others
- Often **misinterpret** the **communication**/motivation/intentions of others

Many of the pupils said that they feel anxious in class when:

- Their physical/**sensory environment** is:
  - **Busy**/crowded
  - **Noisy**
  - **Unpredictable**/not well controlled (especially relating to the behaviour of other pupils)
  - **Messy**/dirty/cluttered

- They are **made** the **centre of attention** (even if the attention is positive)
- They are **required to initiate an interaction**, e.g. ask for help; get into a group
- Their **communication**/motivation/intention is **misunderstood** by others
- They **do not understand** the **task instructions**/instructions are given too quickly/too much information is presented at once
- They are **not allowed to**/attention is drawn to them when they **engage in self-regulatory activities**, e.g. fiddling; tapping; humming

Teaching practice that was identified as unhelpful and/or caused stress **i.e. created barriers to learning:**	• Not appearing to understand/**not attending to** pupils' individual **support needs** • **Drawing attention to pupil** - including asking them to answer a question when they haven't put their hand up • **Not providing clear**/explicit **explanations** and/**or instructions** • **Not providing visual**/written **instructions** to support oral delivery • **Not providing enough processing time**/time to copy down instructions • **Shouting** at individual pupil or at whole class • **Not keeping behaviour** of class **under control**/allowing class to get noisy • Using **unfair discipline policies**, e.g. whole-class punishments • **Not allowing** use of fiddle toy/**self-regulatory activity** • **Writing on** pupils' **work** (rather than underneath/in the margin/on a separate piece of paper)

Teaching practice that was identified as helpful and/or reduced stress

i.e. removed barriers to learning:
_____

- **Not drawing class attention to** autistic **pupil** for any reason unless they have their hand up

- **Organising group work** rather than expecting pupils to find a group to work with

- **Providing clear**/explicit explanations and **task instructions**

- **Approaching individual** autistic pupil before start of task **to ensure understanding** of instructions

- **Providing written information** for classwork/homework

- Being relaxed and **flexible about certain behaviours**, e.g. use of fiddle toys, having headphones in

- **Using a fair discipline policy**, i.e. don't punish whole class for behaviour of a few pupils

- **Providing emotional** encouragement and **support**

- **Keeping class behaviour**/noise levels **under control**

- **Not shouting** at/embarrassing/belittling pupils

Key points to remember

- **Every autistic pupil's** classroom support **needs will be different**

- Engaging with and **asking the pupil is** the **best method to establish** the help that they **need**

But:

- The positive **teaching practices highlighted** in this presentation have been identified by a group of 22 autistic pupils and are **thus likely to represent good autism-friendly classroom practice**